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Julie says the portrait was “for people to see who I am.” Special thanks to Community Living Trent Highlands.

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Attainable Dreams and Harsh Realities: Housing for Individuals With Intellectual and Developmental Disabilities

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Abstract

Individuals with intellectual and developmental disabilities (IDD) and their families are often faced with little to no choice regarding where and with whom the individual can live, and many remain living in the family home well into adulthood, despite this not being the desired arrangement for the individual or his or her ageing parents. To address this significant gap in access to housing, a research team interviewed individuals with IDD, family members, service providers, researchers, policy makers, students, and educators to determine what they saw as the most pressing and impactful concerns regarding the state of housing, and where to go in the future to ensure fair and accessible housing for this chronically undervalued population. Results indicate that significant positive change in the housing landscape could result from separating support from housing, including housing for individuals with IDD in the broader housing discussion, and increasing individualized funding opportunities to facilitate the development of personalized housing.

Despite concerted efforts toward community integration, individuals with intellectual and developmental disabilities (IDD) remain marginalized and disadvantaged (Ditchman, Kosyluk, Lee, & Jones, 2016). One of the key barriers to true integration is access to housing, ranging from the most basic concern of homelessness (Mercier & Picard, 2011), to the more nuanced influences that housing can have on one's quality of life, including access to community and relationships (Gjermestad, Luteberget, Midjo, & Witsø, 2017). Historically, individuals with IDD were often sequestered to segregated large-scale living institutions (Brown & Radford, 2015). Societies in the global north are now moving away from mass institutions and are focusing on small cluster group-home models that are meant to provide more integrated and community-based housing. Although group homes are an improvement over large institutions, they too face criticism due to a lack of choice regarding where and with whom an individual will live (Gjermestad et al., 2017).

While research indicates that Canadian adults with IDD often want to live independently (Canada Mortgage and Housing Corporation, 2006), 50 to 60% live with family members for various reasons (Weeks, Nilsson, Bryanton, & Kozma; 2009). Strain on residential services is increasing at a rate that is untenable; the Auditor General of Ontario found that from 2009 to 2014 there was a 50% increase in the number of individuals awaiting residential services, while the number of individuals served increased by only 1% (Ministry of

Community and Social Services, 2016). Despite efforts toward deinstitutionalization, some individuals with IDD end up "institutionalized by default" because of a lack of available housing and support options (Dube, 2016). Increasingly, individuals, families and service agencies are looking to support semi-independent living options. While semi-independent living is a phrase that is open to interpretation, it is generally framed as an individual residing in their own dwelling, alone or with roommates of their choosing, and receiving drop-in support from one or more community agencies throughout the week.

The purpose of this study was to gain a better understanding of the current state of housing for individuals with IDD and to provide direction for potential policy changes in the move toward true community integration. This study was part of a larger housing innovation study conducted by developmental services faculty and researchers from Centennial College and staff from Community Living Toronto, a large urban social service agency (Atack et al., 2019). Interviews took place between 2016 and 2017.

Materials and Methods

The study was approved by the participating organizations' research ethics review committees and all participants provided informed consent. A qualitative design using semi-structured interviews was conducted with stakeholders including people with IDD and those who had direct experience in researching, managing, supporting, or living in housing with people with IDD. The conceptual framework for the study was the Appreciative Inquiry approach (Whitney, Trosten-Bloom & Cooperrider, 2003). This approach explores community action and development from a capacity-building perspective. Key concepts from the Appreciative Inquiry approach were applied when developing the research design and interview questions and included: ownership, collaboration, access and control. Appreciative Inquiry is now regarded as best practice in conducting research with marginalized populations and communities.

Key informant groups were identified and included: individuals with IDD, families, educators, researchers, service providers, and policy makers who were recruited using purposive, snowball and convenience sampling from within the IDD sector. The number of participants was not fixed at the start of the study; our goal was to interview until the team felt that data saturation across the stakeholder groups had been achieved. Criteria for data saturation included: no new coding or themes emerged, the data was deemed 'rich' and sufficient information had been obtained so that the study could be replicated (Fusch & Ness, 2015). The study included 29 participants across a range of different roles including educators, service providers, policy makers, researchers, family members, and individuals with IDD (Table 1). Most interviews took place between the interviewee and the interviewer, although some individuals with IDD had a family member present to facilitate communication. Interviews lasted anywhere between 20 minutes to two hours. Most participants resided in Ontario, Canada.

Table 1. Stakeholder Role

Role	*n*
Educator	5
Service Provider	10
Policymaker/Analyst/Researcher	3
Family Member	7
Person With Intellectual Disability	4

The interviews were conducted by a researcher with extensive experience working with individuals with IDD. Participants were asked to describe their experience with different housing models and the benefits and limitations of those models. Questions were shortened and provided in a plain language format for individuals with IDD when necessary or desired.

All interviews were recorded and transcribed and an editing analysis approach was used for data analysis (Loiselle & Profetto-McGrath, 2011). Major interview questions were used to structure the initial analysis template. Five transcripts were read and coded. Some key messages that arose repeatedly became subthemes and the template was revised accordingly. All transcripts were then reviewed using the template, and the template was revised as necessary. All transcripts were coded by one researcher with a sampling of interviews coded by a second researcher to validate coding and themes. Major findings were reviewed by the extended research team which included developmental service educators and community agency staff. Stakeholder meetings were held in the community where the results from the study were presented. Twenty stakeholders attended the meetings, including people with IDD, parents, representatives from community organizations and policy makers. Those attending were invited to discuss the results; there was strong agreement regarding the findings.

Results

There was considerable consensus across responses; however, where groups or individuals differed, that was noted. Results and subsequent themes identified were guided by interview questions (Table 2).

Table 2. Interviews: Major Themes

- Optimal housing models
- Family decision making and housing
  - Availability
  - Securing and peace of mind
  - Affordability
- Benefits and challenges: Current group housing models
- Future alternative models
- New directions for policy
  - Normalize housing
  - Separate support from housing
  - Increase overall funding

Optimal Housing Models

Across participants, consensus was that the ideal housing model is one that is flexible, individualized, sustainable, and open to the changing needs and desires of the individual in question. As one participant noted, ideally a person with IDD would have a "whole smorgasbord and you just take what you want."

Individuals with IDD reported that it was important to live somewhere where they could "make new friends," and preferably to live with a friend they already knew. This was echoed among family members who indicated that it was very important to ensure that the individual with IDD was matched with a friend or someone who could become a friend in their housing arrangement. Family members felt the individual should not live with someone selected at random.

Individuals with IDD were keen to move out of their parents' homes and expressed their readiness for autonomy. This was balanced by a desire to feel safe and secure in their home and to have people around to help in case of emergencies. Individuals with IDD also reported that it was important to have good access to public transportation and to live near family, work and leisure activities.

Decision Making Regarding Housing

Three major factors affected decisions regarding housing: availability, security, and resources.

Availability. Availability was the primary issue voiced by educators and family members, and a major issue among other groups as well. Family members noted that a lack of available options forced them to "choose" whatever housing was available.

Educators reported that since quality housing (i.e., housing that is safe, secure, personalized and where living companions are chosen by the individual and family) is rarely available, housing decisions are based on desperation and taking what is available. They explained that housing scarcity is due to a lack of funding and limited funding flexibility. Educators further described how funding is typically directed to group-based residences and funnelled through community service agencies, meaning that there is little available for establishing alternative or semi-independent living arrangements. Families reported being placed on wait lists and ultimately feeling obliged to choose from options that are funded, like group homes, rather than establishing an alternative housing model. Moreover, some families reported that some community agencies are chronically underfunded; shared living spaces have little room for innovation or personalization.

Security and peace of mind. All participants agreed that security, both in terms of personal safety and housing stability, is an essential element of housing. However, the majority noted that there was tension between families wanting the most secure, stable environment possible and the person with IDD's desire for independence. One parent noted, "Safety and security are the top priorities for the families but for the individuals it's being able to live with friends. Being able to do things without your mom and dad over your shoulder." This was reflected in the interviews with individuals with IDD, who mentioned the importance of feeling safe, but also said that they wanted to move out of the family home to meet new people and become more independent. Family members, educators, policy makers, and service providers suggested that the need for present and future security pushed families to favour group living arrangements.

Affordability. Across stakeholder groups, many participants stated that finances played a major role in determining housing. In Ontario, individuals with IDD generally receive their primary source of funding via the Ontario Disability Support Program (ODSP), where the maximum shelter allowance for a single person receiving ODSP is $479 per month (MCSS, 2016).

Family members with sufficient personal finances reported being able to provide their own alternative housing arrangements. One educator stated, "Placement is simply based on availability, perceived need; the models are almost irrelevant in terms of considering what might work for someone. The exception is when the family has the skill or resources to negotiate something better." These points were exemplified by three family members who had set up their own housing arrangements for their family members with IDD. They were able to invest in housing, which allowed them to create more flexible and suitable arrangements. One of the parents remarked, "We're fortunate enough to be able to afford to see our son have good living accommodation. Many, many people aren't."

Benefits and Challenges of Current Group Housing Models

Several participants reported that current group housing models were useful in terms of the stability they provided. Two family members said that group housing provided support to the family as well as a degree of independence to the person who might otherwise be living at home with their parents. Group homes were also viewed as beneficial in that they provided long-term security and were sustainable over time, which was necessary since health, family support and disability are not constants.

By contrast, several educators and family members mentioned that group housing made having "normal" relationships very difficult; they noted that there is a dehumanizing aspect of forming relationships exclusively with paid staff or having to live with individuals one would not normally choose. Moreover, they believed that living in such a housing situation emphasized a person's segregation from the rest of the community, making it more difficult to become socially integrated.

Movement Toward Future Housing Options: Alternative Housing Models

Families and service providers reflected upon the growing movement away from traditional group homes and the growth of new models. Driven by families, these "pockets of innovation" were born out of need, creativity, or sometimes, desperation. Families and service providers shared several examples of housing innovation to which they were connected. For example, two individuals with IDD renting a home together and sharing caregiver costs; individuals with IDD who live with students who provide informal support; a duplex, in which individuals with IDD resided in one unit with supportive neighbours; a single-family home where two individuals with IDD resided with two "family facilitators" who provided care and lived rent-free thanks to a private family foundation; and a neighbourly co-op apartment building housing a typical mix of residents including people with IDD.

Overall, most service providers reported an excitement around future housing options, with one participant stating, "The government is just starting to think about the fact that people with intellectual disabilities have the same housing needs as everybody else, which bodes well for having access to subsidized and affordable housing outside traditional models." That said, some service providers also expressed concern that while innovation was developing, there remained financial pressures to return to congregated living arrangements. A number of family members, educators, and service agency members also articulated ideas regarding policy changes that they thought would lead to better and more varied housing opportunities for individuals with IDD.

Normalize housing. Some participants suggested that government and agencies needed to view housing for individuals with IDD as part of broader housing issues rather than as a developmental services-specific concern. This philosophical shift would result in viewing individuals with IDD as full and equal citizens not only in the eyes of the government, but, by extension, in greater society. Further, this position would open doors to greater linkages between service systems, including housing corporations, Habitat for Humanity and mortgage financing companies.

Separate support from housing. Further separation of funding for support from housing would allow families and individuals with IDD to find their own housing solutions and to obtain the level of support they require, rather than forcing them to accept any available premade housing solution with built-in support simply because it is funded. A researcher stated, "If you separate out housing and social care, I can live somewhere and if I don't like where I live I can move somewhere else, but I can take my social care staff with me and vice versa." One policy-maker recommended increasing funding for people who are trying to pursue alternate housing options, and providing more support for organizations who want to unbundle housing and support. Families noted that current policy focuses too much on oversight and not enough on individual empowerment.

Increase overall funding. Every family member reported that lack of funding and difficulty acquiring available funding was a major issue. One policy-maker and several family members argued that currently, many individuals with IDD are living below the poverty line, and are therefore unable to access a variety of housing options, particularly in large urban centres. Providing individuals with IDD with sufficient income to pay for their own housing through employment opportunities or increased financial supports could help ensure individuals would be able to live in a housing situation of their own choice.

Discussion

Not surprisingly, the bulk of discussion around concerns and directions for improvement in housing for individuals with IDD centred on finances. With rental, real estate and staff costs increasing every year, traditional funding platforms like ODSP and Passport do not offer enough to support creative options for housing for individuals with IDD. ODSP's shelter allowance of $479 per month makes it extremely difficult for individuals to afford clean, safe, suitable housing. Further, for individuals who need daily staff support, the financial strains can be amplified, with funding offered through Passport – which provides a maximum of $35,000 individualized funding a year for individuals with IDD (MCSS, 2014) – often falling short. Notably, Passport functions as a reimbursement system – families need to pay for services out of pocket and submit receipts to the Passport office for approval, making its successful use difficult, if not impossible, for families with limited financial reserves.

Current housing supports through the Ontario government remain in line with the initial movement from large-scale institutionalization, focusing on access to traditional housing models such as group homes, where housing and support are tied together. This conservative model of housing and support delivery continues despite evidence that suggests that semi-independent living options not only result in better social and quality of life outcomes but are also less expensive on an individual basis (Stancliffe & Keane, 2009). Separating housing from care would require not only major policy shifts, but changes in oversight and new accountability structures. Historically, there has been reluctance to make these changes, not only due to the large-scale organizational changes required, but also the need for a significant philosophical change, placing more power in individuals' hands. Yet, by providing a more robust funding platform and separating care and housing through policy reforms, the Ontario government could facilitate the development of housing options as unique and varied as the people with IDD who need them. All stakeholders agreed or implied that housing for individuals with IDD is currently insufficient and requires reform. However, it should not be misinterpreted that the goal of this project was simply to criticize group homes and group-based living options, or that all respondents viewed group homes in a negative light. To the contrary, the goal was to expand ideas of what different housing options might look like and how they can be accessed, providing more robust and varied options for housing that best fit the needs and desires of individuals with IDD. Rather than moving *away* from certain housing options, we should instead be moving *toward* a more varied housing palette and expanding individuals' opportunities to choose the type of housing that works for them. The goal should be empowerment and agency that allows individuals with IDD to choose where they want to live and with whom. This shift in housing options will require support services to adjust and change (Isaacson, Cocks, & Netto, 2014).

The need for greater social connection, community and friendship was another key message delivered by study participants. The majority of respondents viewed housing as a gateway to community integration, both in terms of where an individual lives, and with whom. This was particularly important from the perspective of individuals with IDD themselves, who frequently discussed the desire to live with friends, and near important personal landmarks. Strengthening personal networks was viewed as important not only for the individuals with IDD, but also for their family members, who often take on significant advocacy roles for their loved ones.

While the key messages conveyed by participants were remarkably consistent across groups, this study was limited in that it focused on a relatively small number of respondents who primarily lived in one particular geographic region; findings are applicable to some individuals, not intended to be generalized to every person in every region. Further research regarding a comparative analysis of funding and housing structures across several regions to determine best practices is needed.

Conclusion

Housing is an essential component of achieving self-realization and true social inclusion. Participants in this study indicated that progress has been made; however, significant policy change is needed to ensure the housing needs and goals of individuals with IDD are met.

Key Messages From This Article

People with disabilities. You deserve to be able to choose where you live, and with whom.

Professionals. Housing opportunities that promote greater social connection, community and friendship are needed.

Policymakers. Policy changes, including more funding and funding that does not tie support with housing, would help individuals with disabilities to have more choice in housing.

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A Curriculum of Caring for People With Developmental Disabilities in Medical Education

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developmental disability, medical education, program evaluation

Abstract

The Curriculum of Caring for People with Developmental Disabilities provides experiential learning to improve the capacity of healthcare professionals to deliver person/family-centred care to people who live with intellectual and/or developmental disabilities (ID/DD). The purpose of this project was to explore the impact of the curriculum on medical students' self-reported comfort, confidence, and competence in providing healthcare to the ID/DD population. The rationale for this study was to better understand how experiential learning (bringing people with lived experience into the medical school experience of trainees) might prepare future physicians to improve health care experiences for an underserved population.

A three-phase experiential learning model: (1) early exposure, (2) clinical skills training, and (3) application in clinic settings, was introduced to undergraduate medical students ($n = 28$*). (Phase 1 included 52 nursing students in an interdisciplinary half day program.) A pre-post survey was used to explore changes in self-reported comfort, confidence and competence on a five-point scale. A repeated measures ANOVA and subsequent post-hoc independent t-tests were used to analyze the data. Narrative comments complemented results at each phase.*

Participants' self-reported comfort, confidence, and competence increased significantly following Phase 1 ($p < .001$*) and Phase 2 (*$p < .001$*). Post Phase 3 responses, were not significant. Student narrative comments were analyzed inductively using open-coding and overarching themes were coupled with participant quotes to accompany the analysis in each phase.*

This study adds to the literature on ID/DD curricula in healthcare education. The Curriculum of Caring influenced students' perceived capacity to provide healthcare to the ID/DD population.

The Ministry of Community and Social Services (2008) defines a developmental disability (DD) as:

> significant limitations in cognitive functioning and adaptive functioning and those limitations originated before the person reached 18 years of age, are likely to be life-long in nature, and affect areas of major life activities such as personal care, language, skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity.

The American Psychiatric Association (2013) describes an intellectual disability (ID) as "a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains.” While definitions and diagnostic criteria are used for service eligibility, delivery, and research, there is recognition of heterogeneity of etiologies, presentations and needs that may change over the lifespan.

The Curriculum of Caring for People With Developmental Disabilities

Key Messages

Experience Matters

People with developmental disabilities can share their experiences to help health care students/ workers to do a better job of listening and caring for their needs.

Communication Counts

Health care students/workers can be taught how to Communicate CARE when they meet people with developmental disabilities.

Intellectual and developmental disabilities (ID/DD) can be associated with a range of medical and mental health conditions with potential dysfunction in multiple organ systems or functional realms: for example, sensory, neurological (Cooper, Melville, & Morrison, 2004; Prasher & Gomez, 2004; Van-Schrojenstein-Lantman-de-Valk, Metsemakers, Haveman, & Crebolder, 2000), gastrointestinal, metabolic (Bohmer, Klinkenberg-Knol, Niezen-de-Boer & Meuwissen, 2000; Melville, Hamilton, Hankey, Miller, & Boyle, 2007), and mobility (Cooper et al., 2004; Melville et al., 2007; Prasher & Gomez, 2004; Van-Schrojenstein-Lantman-de-Valk et al., 2000). People with ID/DD tend to have a higher prevalence of health problems than the general public (Cooper et al., 2004; Krahn, Hammond, & Turner, 2006), yet their health needs often go unrecognized and unmet (Cooper et al., 2004). An Ontario study highlights the urgency for adults with DD, who were more likely to frequent emergency rooms and less likely to access primary care (Centre for Addiction and Mental Health, 2013).

Barriers to identification of treatable conditions can be both patient and clinician related. Some patients with ID/DD may not fully appreciate the significance of their symptoms or be able to verbally describe them (Krahn et al., 2006; Van-Schrojenstein-Lantman-de-Valk, & Walsh, 2008). Healthcare providers report discomfort interacting clinically with patients who have an ID/DD, citing a lack of training and inexperience interviewing this population (Chew, Iacono, & Tracy, 2009). While medical professionals receive training in clinical and communication skills, teaching is generally focused on oral history taking without explicit emphasis on adaptations for people with ID/DD or other communication barriers. Medical education and ID/DD curricula can play a critical role in preparing physicians to adapt clinical approaches in order to meet the healthcare needs of patients with ID/DD and alternate communication styles (Minihan et al., 2004).

A report by the International Association for the Scientific Study of Intellectual and Developmental Disabilities and Inclusion International (2000) recommended that all nations ensure sufficient numbers of health professionals be trained in the care of individuals with ID/DD. In recent years, medical schools have used a variety of approaches to teach medical students about disabilities, including didactic lectures, small group interactions, and opportunities to shadow professionals who serve individuals with disabilities (Conill, 2008; Gosney, Storman, Geving, & Liu, 2009; Parkin & Stein, 2001; Voelker, 2002). Few Canadian and American medical schools report formally including specific ID/DD training as part of their curriculum, providing students with optional ID/DD training (Holder, Waldman, & Hood, 2009; Minihan et al., 2004). The Curriculum Assessment of Needs Project by The American Academy of Developmental Medicine and Dentistry (2004) indicated that 81% of medical students received less than three hours of formal DD education and 38% reported no formal training (Jurczyk & Kelly, 2009; Waldman, Fenton, Perlman, & Cinotti, 2005). Fifty-three percent of Deans who responded did not feel that their graduates were competent to treat people with ID upon graduation, and 56% of students did not feel competent to treat patients with an ID. There is recognition that most adult primary care physicians and subspecialists have not been clinically trained or operationally prepared to receive persons with significant developmental disabilities into their community practice settings (Jurczyk & Kelly, 2009).The challenge remains: how can students acquire adequate experience to feel capable of providing the necessary person-centred care to populations considered more challenging due to communication barriers and complex needs? There are programs designed to foster cultural competencies with other marginalized populations through exposure, longitudinal experiences, and mentorship (Huang & Malinow, 2010). Curriculum developers and planners have incorporated learning experiences into their programs that equip healthcare learners to become comfortable and better able to adapt healthcare to the needs of diverse patient populations (Kripalani, Bussey-Jones, Katz, & Genao, 2006; Long-Bellil, Robey, Graham, Minihan, Smeltzer, Kahn, & Alliance for Disability in Health Care Education, 2011; Woodard, Havercamp, Zwygart, & Perkins, 2012).

The Curriculum of Caring for People with Developmental Disabilities was developed by medical educators in partnership with developmental service providers and patient educators. In 2008, McMaster University, Michael G. DeGroote School of Medicine, and Niagara Regional Campus (NRC) partnered with Bethesda Services to provide students with opportunities to interact with people whose lives are affected by ID/DD. Brock University Health Sciences (Nursing and Department of Applied Disability Studies) joined as collaborators to further develop, implement and evaluate experiential learning interventions. Program evaluation (anonymous student feedback used to shape each phase of the Curriculum of Caring since the 2008 inception) was augmented by this preliminary study exploring the influence of the three phases of the Curriculum of Caring on undergraduate medical student self-reported comfort, confidence, and competence as healthcare providers to people with ID/DD.

Materials and Methods

Curriculum of Caring Overview

Phase 1: Early Exposure. Initial early exposure was designed as an interprofessional half-day for medical and nursing students in a community-based setting for children and adults with DD (Bethesda Services, Niagara region, Ontario). Medical (*n* = 28) and nursing (*n* = 51) students completed pre-session questionnaires. Faculty of medicine and nursing facilitators prompted small groups of eight to nine medical and nursing students to share experiences working with people with DD. The small groups then rotated among four 30-minute experiences: (1) three to four volunteer hosts from Bethesda's Adult Day Program discussed their lives and answered questions; (2) an interactive, introductory overview of ID/DD was

Table 1. Curriculum of Caring for People with Developmental Disabilities: Three Phases of Experiential Learning

Curriculum of Caring	*McMaster University Undergraduate Medical Education Program*	*Niagara Regional Campus Medical Students* n = *28*
Phase 1: Early Exposure in first year	• Interprofessional half day with nursing students	Pre-Post session questionnaires, narrative comments
Phase 2: Clinical Skills pre-clerkship	• Small group Intro to Communicate CARE & Interviews	Pre-Post session questionnaires, narrative comments
Phase 3: Clinical Application during psychiatry clerkship	• Student placement with preceptor working with interdisciplinary teams for youth and adults with ID/DD	Optional post questionnaire with narrative feedback

provided by a specialist physician and nurse; (3) a Community Networks of Specialized Care facilitator led a case-based discussion, introducing the Canadian Primary Care Practice Guidelines for ID/DD (Sullivan et al., 2011); and 4) a mother of a child with ID/DD shared family experiences (https://machealth.ca/programs/curriculum_of_caring/m/mediagallery/1867). All students participated in group reflective discussions followed by post-session questionnaires.

Phase 2: Clinical Skills Interviewing. Clinical skills training was provided for all NRC medical students (*n* = 28) prior to clerkship. Medical students visited a Bethesda Services clinic setting in groups (n = 7-8). A Curriculum of Caring clinical skills primer was presented, highlighting adaptations for interviews with persons with ID/DD: Communicate C.A.R.E. (Clearly, Attentively, Responsively, Engaging the person first and others as appropriate). For more information see Curriculum of Caring for People with Developmental Disabilities (n.d.). Students had opportunities to interact with four volunteer patients (two students per patient for approximately 20 minutes). The volunteers had varying cognitive, communication, and mental health profiles. Some had caregivers present. Students were instructed to interact with the volunteers/caregivers, learn about their particular health and/or mental health needs and make be prepared to discuss observations. These interviews were followed by facilitated group discussions with the clinical skills preceptor, focusing on the interviewer's experiences and what they learned from and about the people they interviewed.

Phase 3: Application. Application of "Communicate C.A.R.E." and clerkship level competencies took place in various clinic settings, with the most focused ID/DD experience during their psychiatry clerkship rotation. The psychiatry clerks (*n* = 28) worked with interprofessional teams at community-based clinics for children and adults with ID/DD and varied healthcare needs. The psychiatric preceptor provided clinical experiences that included opportunities to participate in interviews, patient care, and team discussions. Students encountered patients with ID/DD in other clinical settings such as a pediatric rehabilitation centre; however, these experiences were not formally tracked or evaluated. At the conclusion of clerkship, medical students (*n* = 14) volunteered to complete post-questionnaires with narrative comments.

Study Population

Undergraduate medical students (*n* = 28) participated in all three phases of the Curriculum of Caring. Senior nursing students (*n* = 51) participated in the initial phase (interprofessional half day). The same cohort of medical students participated in all three experiential learning interventions; however, due to anonymity of the survey responses, within-subject analyses could not be conducted. The Joint Research Ethics Board of McMaster University Faculty of Health Sciences, Hamilton Health Sciences and St. Joseph's Healthcare Hamilton approved this study (File #15-174).

Study Design

A pre-post study design was used to evaluate changes in participants' comfort, confidence and competence after exposure to the Curriculum of Caring program. Questionnaires were administered to participants pre and post Phases 1 and 2. Medical students were invited to complete a post questionnaire at the end of clerkship (Phase 3). Participants used a 5-point Likert Scale (1 = *strongly disagree* to 5 = *strongly agree*) to self-rate and comment on their level of comfort being with, confidence interviewing, and competence working with this population in a healthcare capacity.

Analyses

IBM SPSS Statistics for Windows Version 22.0 (IBM Corp., Armonk, NY, USA) was used for quantitative analyses. A 2 (pre vs. post) x 3 (comfort, confidence, competence) repeated measures ANOVA was conducted to examine changes in students self-reported measures of comfort, confidence and competence during Phase 1 and Phase 2. Subsequent post-hoc independent *t*-tests were used to analyze the data. Mean scores for comfort, confidence, and competence were reported for post-Phase 3.

Narrative comments by participants were analyzed inductively using open-coding, where codes were attributed to fragments of sentences. The codes were then grouped together, with analysis of similarity and differences reviewed among the researchers. Final overarching themes were coupled with participant quotes to accompany the analysis in each phase.

Results

Phase 1: Early Exposure

There was a statistically significant difference pre and post early exposure, $F(1, 78) = 82$, $p < .001$, partial $n^2 = 0.55$, where the mean scores were higher after the intervention ($\mu = 3.89$, $\sigma = 0.07$) than before ($\mu = 3.23$, $\sigma = 0.08$). There was also a statistically significant difference among scores relating to comfort, confidence, and competence, $F(2, 156) = 52$, $p < .001$, partial $n^2 = 0.39$. Subsequent *t*-tests show that comfort was always rated highest ($\mu = 3.94$, $\sigma = 0.60$), followed by confidence ($\mu = 3.47$, $\sigma = 0.60$), and competence ($\mu = 3.28$, $\sigma = 0.74$). Finally, there was a significant interaction between pre and post early exposure and comfort, confidence, and competence, $F(2, 156) = 20$, $p < .001$, partial $\eta^2 = 0.06$. While post intervention scores were always greater than pre scores, the shift was greatest for competence, $t(78) = 10.6$, followed by confidence, $t(78) = 7.1$, and smallest for comfort, $t(78)= 4.9$.

Narrative comments provided by students highlighted appreciation for the value of interacting with people with lived experience with ID/DD (patient educators), the powerful messages derived from the parent stories and the importance of interprofessional teamwork. Students describe this experience as *"eye opening"* and *"providing a way to understand what it means to humanize medicine."* One student expressed a shift to a person-oriented perspective with implications for improving practice:

> "Being able to interact with patients and see the programs, understand the patient stories, and understand how we can do a better job as healthcare providers."

Students described feeling more comfortable, confident and competent, but recognize exposure alone is insufficient:

> "There's a lot to learn and we need to gain more experience through practice."

Phase 2: Clinical Skills Interviewing

There was also a significant difference between pre and post clinical skills interviewing, $F(1, 27) = 57$, $p < .001$, partial $\eta^2 = 0.55$, where the mean scores were higher after this intervention ($\mu = 3.83$, $\sigma = 0.11$) than before ($\mu = 2.94$, $\sigma = 0.12$). There were significant differences among comfort, confidence, and competence, $F(2, 54) = 52$, $p < .001$, partial $n^2 = 0.41$. Subsequent *t*-tests showed that comfort was always rated highest ($\mu = 3.92$, $\sigma = 0.53$), followed by confidence ($\mu = 3.23$, $\sigma = 0.70$), and competence ($\mu = 3.01$, $\sigma = 0.61$). Finally, there was a statistically significant interaction between pre and post clinical skills interviewing and comfort, confidence, and competence, $F(2, 54) = 8$, $p = .001$, partial $\eta^2 = 0.03$. This interaction demonstrates pre and post differences that are significant for all three measures with the greatest shift for competence, $t(27) = 7.0$ and confidence, $t(27) = 7.0$, and smaller for comfort, $t(27) = 4.6$.

Narrative comments demonstrate the importance of clinical skills with communication adaptations when interviewing patients with ID/DD. Students described this intervention as helpful with interviewing volunteer patients with mild intellectual disabilities:

> "increasing [their] ability to simplify language and communicate."

A number of students described feeling apprehensive or nervous prior to these encounters but appreciation/enjoyment following the interactions. One student shared:

> "I feel much more at ease. It sounds silly, but there is nothing to be scared or nervous about."

Another medical student explained how this experience increased confidence:

> "Getting to speak to patients was helpful and rewarding. I was able to gain more confidence in speaking with people who have DD. I learned a lot!"

Phase 3: Application

Following the third, clinical application phase of the Curriculum of Caring, after medical students had completed their clinical clerkship, 14 of the 28 students who participated volunteered to complete the post-questionnaire. Questionnaires were not provided as each student completed their individual clinical clerkship placement to preserve anonymity. Mean scores are reported for post intervention: comfort ($\mu = 4.07$, $\sigma = 0.62$), confidence ($\mu = 4.07$, $\sigma = 0.83$), and competence ($\mu = 3.57$, $\sigma = 0.85$). Narratives highlighted the students' reflections on the cumulative influence of the Curriculum of Caring interventions. Some comments indicated increased comfort in speaking/interacting with people who have ID/DD and recognizing that they could *"understand them as people."* A medical student further explained the impact of this experience on future medical practice:

> We saw many children and adults with ID/DD and often many social factors complicating the picture. As a future family physician, this experience certainly impacted my ability to competently assess and acutely manage medical illness in patients with ID/DD. I feel that I now have a stepwise approach to new onset challenges in this patient population.

This description emphasizes how sequential experiences that include application of acquired learning in interprofessional settings can prepare medical students for future practices that include individuals with ID/DD. Although students generally felt more comfortable, confident, and competent, there were comments indicating more time and exposure to ID/DD healthcare across healthcare settings would be valuable.

Discussion

Undergraduate training plays a critical role in the development of professional attitudes and competencies among learners who will need to serve diverse populations and individual patients with complex needs (Kripalani et al., 2006; Long-Bellil et al., 2011; Woodard et al., 2012). Incorporation of ID/DD experiential learning provides opportunities to shift attitudes, foster cultural competencies (Huang & Malinow, 2010), and better prepare students to provide healthcare to special populations (Chew et al., 2009; Minihan et al., 2004; Woodard et al., 2012).

The Curriculum of Caring was designed to give students opportunities to learn from both patients and caregivers, develop skills interviewing people with varied cognitive and communication capabilities, and deliver relevant and timely healthcare. The inclusion of people who live with disabilities in all aspects of the curriculum is considered essential to promoting what people with disabilities say they want/need: person/family-centred care (Moores et al., 2015). Various approaches to teaching medical students about disabilities have been studied including: didactic lectures, small group interactions, and shadowing health professionals (Conill, 2008; Gosney et al., 2009; Parkin & Stein, 2001; Voelker, 2002). These studies have demonstrated positive results with development of skills, increased awareness (Conill, 2008; Gosney et al., 2009; Parkin & Stein, 2001), as well as changes in attitudes, values and beliefs around ID/DD (Parkin & Stein, 2001). The Curriculum of Caring has been distinguished by the three phase modular progression of ID/DD experiential learning throughout the undergraduate medical program. The curriculum has distinctly benefited from the involvement of patient educators in every phase.

These findings are similar to those of previous studies, (Conill, 2008; Gosney et al., 2009; Parkin & Stein, 2001; Voelker, 2002) as participants' self-reported comfort, confidence, and competence significantly increased during early exposure and clinical skills training. Following early exposure and clinical skills training, the largest shift was in competence, followed by confidence, then comfort. This smaller shift in comfort may be explained by students who started the program feeling more comfortable due to previous experiences (i.e., friends, family member, volunteering, previous work), yet not as confident or competent in interviewing or treating this population prior to clinical training. Future research could examine the impact of having previous experience with the ID/DD population and the influence of subsequent training. Narrative comments were a rich source of data for understanding the experiences and insights of students.

Limitations

Use of anonymous student questionnaires was considered efficient and feasible with limited available time. The approach built on program evaluation methods and accommodated the collection of qualitative data. However, the approach did not permit for the control of confounding variables such as previous training or the tracking of participant responses across time. A limitation of Phase 1 early exposure evaluation was blended data between medical and nursing students. Separately analyzing these two groups may have revealed differences in self-ratings of comfort, confidence and competence related to prior experience (senior nursing students clinical placements) or different narrative perspectives. A separate analysis could also have provided insight for future curriculum development specific to nursing. Another limitation was the inability to track individual medical student self-reports of comfort, confidence, competence and comments across interventions over time. Using unique identifiers could have improved the analysis, strengthened the results of this study, and provided more focused information for program refinement. Further, the use of self-assessment tools has the recognized limitation that people are generally poor assessors of their own performance or behaviour (Eva, Cunnington, Reiter, Keane, & Norman, 2004). Although students were observed by their preceptor during clinical skills and clerkship interactions, feedback was formative, and not part of the study. A final consideration is the small sample size at a regional campus, limiting generalizability of findings. Despite the limitations of the current study, it is hoped that merits of inclusion of patients/families of underserved populations in sequential training as a means of fostering cultural competencies is reinforced by the findings.

Conclusions

The Curriculum of Caring was designed as a progressive three-phase model of experiential learning to increase the capacity of future healthcare professionals to provide person/family-centred care to people affected by ID/DD. Study results show increases in comfort, confidence, and competence with a progression of experiences through medical school (early exposure to people who live with ID/DD, clinical communication skills training and opportunities for application in clinic settings.

This study adds to the literature on ID/DD curricula in medical education and supports the inclusion of patient educators in the experiential learning process. Introducing opportunities to meet with patients early in training, adapt interviews to accommodate exceptionalities, and practice with clinical teams appears to effectively shift comfort, confidence, and competence in learners and thereby increase capacity to address the needs of those with ID/DD. It is hoped that this educational initiative and preliminary study will inform the development of curricula aimed at equipping future generations of healthcare professionals with attitudes and skills that translate into the beneficial practice of person and family-centred care.

Key Messages From This Article

People with disabilities. Curriculum of Caring teaches medical students to listen to and learn from people who live with developmental disabilities. Students met with people who have lived experience with disabilities while they were in training. This helped them to feel they could do a better job when they graduate as doctors.

Professionals. Curriculum of Caring was developed to improve capacity to deliver person-centred care. Results show improved student-reported comfort, confidence, and competence in providing healthcare to this generally underserved population.

Policymakers. Healthcare education aimed at increasing capacity to care for this underserved population has the potential to improve satisfaction with healthcare services.

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La perception de la réalité sociale d'adolescents vivant présentant un trouble du spectre de l'autisme

Résumé

L'adolescence est peu étudiée chez la population ayant un trouble du spectre de l'autisme (TSA) alors qu'elle s'avère être une période importante dans le développement de l'identité, notamment par le biais des activités réalisées ainsi que par les relations avec les pairs. L'objectif de cet article est de présenter les résultats d'une étude exploratoire effectuée auprès de 14 adolescents ayant un TSA fréquentant une classe ordinaire. Des questions ont été posées dans le cadre d'une entrevue semi-structurée. Les thèmes abordés concernent les changements observés lors de leur entrée dans la puberté, leurs relations sociales ainsi que sur leurs loisirs. Bien que la plupart des répondants semblent être en mesure d'identifier les changements physiques et psychologiques vécus, ils ne sont pas tous en mesure de modifier leurs habitudes pour s'adapter aux changements générés par la puberté. Qui plus est, les adolescents rapportent tous des difficultés sur le plan des relations sociales, malgré leur fort désir d'entretenir des relations amicales. Il est alors observé que différents concepts, notamment ceux de l'amitié et de l'intimidation ne sont pas forcément bien intégrés pour ces jeunes adolescents présentant un TSA.

Social Reality: Perceptions of Adolescents Living With Autism Spectrum Disorder

Abstract

Adolescence is poorly studied for a population with autism spectrum disorder (ASD), although it is an important period for the development of identity, particularly through activities carried out as well as relationships with peers. The goal of this article is to present the findings of a study performed with 14 students with ASD who were integrated in a regular classroom. Though semi-structured interviews, questions about their puberty, social interaction as well as hobbies were asked. Many of them seemed more aware of their physical changes that were taking place than the psychological one. While this is true for all adolescents, it may prove more important for those with ASD as those changes may strongly impact their social relationships. Besides dealing with puberty-related changes, adolescents also face a new social reality. Although all participants reported difficulties on a social level, it is important to note their strong desire to cultivate and maintain friendships. Creating a bond may prove to be a challenge as the concepts of friendship and intimidation may not be well understood.

Habituellement diagnostiqué dans la petite enfance, le trouble du spectre de l'autisme (TSA) présente un tableau clinique dont les manifestations à l'adolescence sont souvent bien différentes de celles observées en bas âge (APA, 2013). Afin de poser un diagnostic, deux critères doivent être observés tels que décrits dans la cinquième version du *Manuel diagnostique et statistique des troubles mentaux* (DSM-5) (APA, 2013). D'abord, des difficultés persistantes et marquées sur le plan de la communication et de l'interaction sociale sont notées. La communication non verbale n'est pas toujours bien intégrée chez cette clientèle. Ainsi, les adolescents ayant un TSA peuvent interpréter de façon inadéquate les intentions d'autrui (D'Entremont & Yazbek, 2007). De plus, pour répondre aux critères diagnostiques, ils doivent présenter des caractéristiques qui ont trait aux comportements restreints. Ceux-ci peuvent être des obstacles importants à l'adolescence tant dans la création de liens sociaux que dans la limitation des intérêts pour des activités habituellement valorisées chez les adolescents.

Les dernières données sur la prévalence du TSA indiquent une augmentation importante (CDC, 2014), notamment au Québec (Diallo, Rochette, Pelletier, & Lesage, 2017). Incidemment, on observe une multiplication des études québécoises réalisées auprès de cette population. Toutefois, la majorité de ces études visent la petite enfance et les services spécialisés. Peu d'études québécoises ciblent les adolescents présentant un TSA, particulièrement ceux fréquentant une classe ordinaire. Aucune ne fait état sur leur perception face à leur développement de leur identité et leur affirmation de soi ainsi que sur leurs relations avec leurs pairs. Alors que l'adolescence et le passage de l'école primaire à l'école secondaire concordent bien souvent avec l'arrivée de la puberté et que ces deux événements peuvent générer des défis sur le plan des relations sociales, la présente étude amène donc un regard nouveau sur la réalité vécue par les adolescents ayant un TSA ainsi que sur la manière dont ils la perçoivent.

Cette étude vise à décrire la perception des adolescents sur les changements physiques et psychologiques vécus, leurs impressions sur leurs relations sociales ainsi que l'exploration de leurs loisirs alors qu'ils entrent dans la puberté, à l'aube de leur passage vers l'école secondaire.

Les changements physiques et psychologiques observés chez les adolescents

La puberté est un stade de développement durant lequel le corps vit des changements importants tels que l'apparition de la pilosité et l'augmentation de la sudation (Cloutier & Drapeau, 2008) de même qu'une augmentation rapide de la taille et de la masse corporelle (Pinyerd & Zipf, 2005). Ces changements, parfois drastiques, peuvent causer un inconfort physique et psychologique (Cloutier & Drapeau, 2008). Alors que les adolescents présentant un TSA font souvent preuve d'une résistance face aux changements (APA, 2013), ceux-ci peuvent être d'autant plus être importunés par l'arrivée de la puberté. Outre la rigidité pouvant être observée, il est possible qu'un accompagnement soit nécessaire pour soutenir l'adolescent, notamment en lien avec de l'hypo- ou de l'hypersensibilité de même que la compréhension de certaines normes sociales (Sicile-Kira, 2006).

En plus d'entrainer des changements physiques, les hormones sécrétées à la puberté peuvent aussi avoir une incidence sur le fonctionnement psychologique. La littérature scientifique fait état d'un plus grand risque de développer un trouble de santé mentale au début de l'adolescence chez les jeunes présentant un développement typique (Bélanger & Marcotte, 2011). Il en est de même pour les adolescents ayant un TSA alors que Leyfer et ses collaborateurs (2006) rapportent que leur échantillon (n = 109) dont les participants sont âgés de 5 et 17 ans présentent un haut taux de trouble psychiatrique associé à leur TSA.

Selon une méta-analyse réalisée auprès d'adolescents au développement typique, la prévalence d'un trouble de santé mentale serait de 13,4 % (Polanczky, Salum, Sugaya, Caye & Rohde, 2015). Les troubles les plus fréquents chez ces derniers sont le trouble anxieux (6,5 %), le trouble du déficit de l'attention avec ou sans hyperactivité (TDAH) (3,4 %) et les troubles de l'humeur (2,6 %). Chez les jeunes ayant un TSA, âgés de 10 à 14 ans, Simonoff et ses collaborateurs (2008) estiment que 70 % présentent au moins un trouble concomitant à leur TSA. D'ailleurs, selon cette étude, les troubles les plus communs chez ceux-ci seraient le trouble anxieux (29,2 %), le trouble du déficit de l'attention (28,2 %) et le trouble d'opposition avec provocation (28,1 %).

Les relations sociales à l'adolescence

Alors que le développement identitaire est fortement influencé par les pairs à l'adolescence, être accepté par ceux-ci et éviter le rejet sont des sources de préoccupations (Sebastian, Viding, Williams, & Blakemore 2010). Lors du passage vers le secondaire, le nombre d'élèves par classes et par école est beaucoup plus important. Ainsi, la possibilité de créer des liens d'amitié est grandissante. De par la nature des difficultés sociales inhérentes au TSA, force est de constater que les jeunes ont des difficultés à créer et à maintenir des relations amicales avec les autres élèves de leur âge (Laugeson, Frankel, Mogil, & Dillon, 2009). À cet effet, il est fréquent qu'à l'adolescence, les relations sociales se complexifient faisant vivre une plus grande exclusion aux adolescents présentant un TSA de la part de leurs pairs (Adreon & Stella, 2001) notamment lors des premières années du secondaire où les jeunes présentant un TSA peuvent être la cible de moqueries (Carrington, Papinczak &Templeton, 2003).

Cela s'explique en partie, par les défis sur le plan de la communication sociale qui comprennent notamment des difficultés à réguler leurs émotions (Schroerder, Cappadocia, Bebko, Pelper, & Weiss (2014) à communiquer efficacement avec autrui (Nabuzoka, 2013), à comprendre les intentions des autres ainsi qu'à se mettre à leur place (Baron-Cohen, 1989; Kaland, Callesen, Moller-Nielsen, Mortenson, & Smith, 2008).

Une étude réalisée auprès de parents de 40 adolescents ayant un TSA indique que le développement des habiletés sociales représente un des plus grands défis pour leur enfant, puisque ces derniers persistent à avoir des conversations unilatérales, engagent un minimum de conversations, adoptent des comportements inappropriés et immatures dans des situations sociales et comprennent peu les indices verbaux et non verbaux de la communication (Church, Alisanski, & Amanullah, 2000). L'étude de Orsmond, Krauss et Seltzer (2004) témoigne de l'isolement social que peuvent vivre les personnes ayant un TSA en attestant que 46 % des 235 adolescents et adultes de leur échantillon n'avaient pas d'amis. Lasgaard et ses collègues vont dans le même sens en concluant que 21 % des 39 des garçons présentant un TSA de leur étude rapportent se sentir toujours ou souvent seuls (Lasgaard, Nielsen, Eriksen, & Goossens, 2010). Dans leur étude, Poirier et Vallée-Ouimet (2015), retiennent que 12 des 17 adolescents ayant un TSA, auraient des amis et que ceux-ci auraient en moyenne de 2,79 amis. Parmi ces derniers, sept inviteraient des amis à la maison et six se feraient inviter.

Outre les difficultés liées aux relations interpersonnelles inhérentes aux adolescents ayant un TSA, l'intimidation fait également partie de la réalité du monde scolaire. Selon le ministère de l'Éducation et de l'Enseignement supérieur (MEES)[1] (2008), l'intimidation correspond à une agression qui peut se manifester par des attaques physiques, des propos humiliants, des menaces, de l'extorsion (taxage) ou une relation punitive qui consiste à ignorer la présence de l'autre, à refuser de communiquer avec lui ou à l'isoler socialement.

Bien que tous les élèves peuvent être à risque d'être victimes d'intimidation, les adolescents ayant un TSA peuvent être la cible des intimidateurs (Fisher & Taylor, 2016; Humphrey & Hebron, 2015; Van Schalkwyk, Smith, Silverman, & Volkmar, 2018) en raison de leurs habiletés sociales déficitaires et de leur cercle social restreint ou inexistant (Martlew & Hodson, 1991). D'ailleurs, Carrington, Papinczak et Templeton (2003) soulèvent que tous les participants de sexe masculin interrogés (n = 4) ont vécu des périodes où ils ont été victimes de moqueries lors des premières années du secondaire. Dans un contexte de transition scolaire, 22 participants sur 30 ont rapporté avoir vécu une situation d'intimidation (Fisher & Taylor, 2016). En raison de leurs difficultés liées à la communication sociale, les adolescents ayant un TSA ne s'expriment pas toujours sur cet événement ou ne comprennent pas nécessairement ce qu'ils vivent (Van Roekel, Scholte, & Didden, 2010). Cette prévalence pourrait atteindre 94 % selon la revue de littérature d'Humphrey et Hebron (2015). D'après cette recension des écrits, les facteurs de risque les plus importants chez la population ayant un TSA sont le fait d'avoir un diagnostic de syndrome d'Asperger (ou des déficits de compréhension sociale plus légers), le début de l'adolescence ainsi que le fait de fréquenter une école ordinaire et présenter des

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[1] À ce moment, le nom était le ministère de l'Éducation, du Loisir et du Sport (MELS)

problèmes de comportement associés au TSA. Plus récemment, Van Schalkwyk et ses collaborateurs (2018) se sont penchés sur l'intimidation que peuvent vivre 35 adolescents ayant un haut niveau de fonctionnement lors de la transition vers le collège. Selon leur étude, 51 % des participants rapportent avoir été victimes d'intimidation et le taux est estimé à 31 % selon leurs parents. La prévalence rapportée diffère d'une étude à l'autre selon le répondant questionné. En effet, une étude effectuée auprès d'enseignants indique que les gestes d'intimidation auprès des jeunes ayant un TSA seraient plus fréquents que ne le rapportent les élèves (Van Roekel et al., 2010). Il importe aussi de noter que la prévalence peut varier selon la définition retenue et que si la définition apprise de ce qu'est l'intimidation n'inclut que des gestes de violence physique, il est probable que les gestes de violence verbale ne soient pas rapportés par le jeune (Plimley & Bowen, 2006).

Les activités de loisirs

Au Québec, les élèves passent près de sept heures par jour à l'école incluant, les pauses et l'heure du diner. Bien que l'école et les tâches connexes occupent une grande partie de la journée des adolescents, il est intéressant de se questionner sur les activités réalisées en dehors du contexte scolaire. Les bienfaits de la pratique du sport ont grandement été démontrés sur les plans de la santé physique et mentale, en plus, il permet aussi d'établir des contacts sociaux.

Au Québec, Poirier et Vallée-Ouimet (2015) ont interrogé 17 parents d'adolescents présentant un TSA. Sur ce nombre, 13 avaient au moins une activité de loisir. Parmi celles-ci notons l'ordinateur (n = 4), les jeux vidéo (n = 4), la natation (n = 2), le vélo (n = 2), participer à un groupe de jeunes présentant un TSA (n = 2), la lecture (n = 2), nourrir et regarder les oiseaux (n = 2) ainsi que de participer à des activités organisées par un centre de répit (n = 1). Aux États-Unis, Orsmond et Kuo (2011) ont étudié les activités quotidiennes des adolescents et adultes présentant un TSA. Pour ce faire, 103 mères ont complété à deux reprises, un journal des occupations de leur enfant sur une période de 24 heures. Les chercheurs concluent que les participants passent plus de temps seuls et que la personne qu'ils côtoient le plus est leur mère. L'étude souligne que les adolescents ayant un TSA consacrent la majeure partie de leur temps à dormir, faire des activités personnelles, aller à l'école et maintenir une hygiène. Parmi les activités recensées, les auteurs notent : regarder la télévision, consacrer du temps à l'ordinateur, écouter de la musique, faire de l'activité physique et relaxer. À la lueur des données descriptives recueillies, il semble qu'ils privilégient les activités sédentaires et individuelles, comme regarder la télévision ou passer du temps à l'ordinateur. Il importe d'ailleurs de souligner que le manque d'habiletés sociales entrave le désir d'interagir avec les autres (Walker, Colvin, & Ramsey, 1995). Cela pourrait expliquer, en partie, pourquoi les adolescents ayant un TSA sont ainsi plus enclins à engager des activités solitaires et à passer moins de temps en interaction (Symes & Humphrey, 2010).

La méthode

Cette étude s'inscrit dans le cadre d'une recherche plus vaste portant sur la perception du passage du primaire au secondaire chez les adolescents ayant un TSA comparativement à celle de leurs pairs présentant un développement typique. Pour ce faire, un échantillon de convenance composé de 14 adolescents ayant un TSA fréquentant une classe ordinaire a été recruté pour participer à l'étude. Un entretien semi-structuré a été conduit et les questions ont porté sur les changements physiques et psychologiques ainsi que les relations sociales et les activités de loisirs. Les réponses des participants ont été extraites afin de faire un portrait détaillé de la réalité des adolescents présentant un TSA.

Les participants

Au total, 14 élèves (12 garçons et 2 filles) de 6^{e} année du primaire âgés en moyenne de 12,35 ans (ET = 5,43 mois) présentant un TSA[2] ont été recrutés pour l'étude. Ce nombre a été défini suivant une saturation des données. Tous les élèves fréquentent une classe ordinaire dans une école secondaire de la grande région de Montréal (Québec, Canada). Ils proviennent de 13 écoles de six commissions scolaires différentes.

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[2] Comme les participants ont reçu leur diagnostic avant l'arrivée du DSM-5, leurs diagnostics étaient : 1 Asperger; 2 autistes; 2 TSA; 3 TED-NS; 6 TED. Ils sont donc maintenant tous considérés comme ayant un trouble du spectre de l'autisme.

L'instrument de mesure

Les résultats présentés sont extraits d'une partie de l'entrevue semi-structurée élaborée en fonction des questions de recherche et de la littérature sur le sujet. Le schéma d'entretien est composé de questions ouvertes et fermées. Pour le présent article, 20 questions ont été retirées, analysées et divisées en trois sections : les changements vécus lors de l'adolescence, les relations sociales et les activités de loisir. Dans un premier temps, les participants ont été questionnés sur les changements physiques observés : « Tu deviens un adolescent, as-tu remarqué des changements physiques? Si oui, lesquels? ». Dans un deuxième temps, les participants devaient répondre en lien avec les changements psychologiques : « As-tu remarqué des changements dans tes émotions (humeur)? Si oui, lesquels? ». En troisième temps, les activités de loisirs et les relations sociales ont été explorées : « Quels sont tes loisirs favoris? » « Est-ce important pour toi d'avoir des amis? ».

L'analyse des données

La méthode qualitative de Miles et Huberman (2003) a d'abord été privilégiée dans le cadre de cette étude afin d'explorer en profondeur la perception des adolescents ayant un TSA tout en visant l'émergence de réponses issues de leur quotidien. Toutefois, compte tenu des réponses peu élaborées des participants, certaines informations recueillies lors des entrevues semi-structurées ont été regroupées sous forme de fréquences et de moyennes. Cette façon de faire a été privilégiée à l'analyse thématique initialement prévue compte tenu du contenu offert par les participants. Ainsi, chacun des verbatim a fait l'objet d'une écoute et d'une transcription ainsi que d'un accord interjuge. Chacun des thèmes nommés par les participants a été listé, puis comptabilisé en fréquences. La même procédure a été utilisée pour les informations pouvant faire l'objet de moyennes. Finalement, des verbatim ont été ajoutés aux fréquences et aux moyennes afin de contribuer à la compréhension des perceptions des participants et apporter une richesse supplémentaire à l'information recueillie.

Les résultats

Les résultats obtenus sont présentés selon les trois objectifs spécifiques, soit la description de la perception des changements physiques et psychologiques vécus lors de l'entrée à l'adolescence ainsi que leurs relations sociales et leurs activités de loisirs.

Les changements vécus lors de l'entrée à l'adolescence

La première section fait état des changements physiques et psychologiques rapportés par les participants. Tous les participants interrogés, à l'exception d'un sujet, ont perçu des changements sur le plan physique. De façon spontanée, la plupart d'entre eux disent avoir grandi (8/14), avoir constaté des changements dans la voix (5/14), avoir une pilosité émergente (3/14), observer une prise de masse plus rapide (3/14), transpirer plus (1/14) et avoir de l'acné (1/14). Une des deux filles constate une augmentation de sa poitrine.

La plupart des adolescents (8/14) appliquent du déodorant ou du parfum, mais quatre refusent de le faire. À ce sujet, deux participants mentionnent que leurs parents les obligent à en appliquer. Ainsi, la moitié des participants ne semblent pas bien comprendre les bienfaits d'une routine d'hygiène quotidienne : « Je me lave quand [je sens mauvais]. » Somme toute, bien que l'hygiène ne soit pas une préoccupation pour tous les participants, presque tous (13/14) remarquent les changements que leur corps subit.

Parmi les 14 répondants, neuf ont rapporté avoir vécu des changements d'humeur ou d'émotions. Quatre d'entre eux confient avoir plus de difficulté avec la gestion des émotions (se fâche plus rapidement, est plus irritable, a des sautes d'humeur plus fréquentes, est plus émotif). D'ailleurs, deux participants disent se sentir plus fatigués, ce qui aurait une incidence sur leur tempérament. Deux participants indiquent se sentir tristes et quatre d'entre eux notent avoir acquis de la maturité et donnent en exemple le fait d'avoir un meilleur contrôle sur leurs émotions.

Les relations sociales

Lorsque les adolescents participants à l'étude sont questionnés sur le nombre d'amis qu'ils ont, les participants répondent avoir en moyenne 7,1 amis (ÉT = 4,99). Un participant exprime bien son incompréhension de la notion d'amitié : « Je ne sais pas si j'en ai vraiment [des amis]. » La différence entre le concept d'amis et de compagnons de classe n'est d'ailleurs pas nécessairement maitrisée alors qu'un participant mentionne que : « Tout le monde dans ma classe *sont* mes amis. » La majorité des répondants (n = 9) ont indiqué qu'il est important d'avoir des amis. Un participant mentionne qu'il souhaite avoir des amis : « Sinon, je vais rester tout seul et c'est ennuyeux. Je m'ennuierais à mort. » Pour d'autres (2/14), il n'est pas important d'avoir des amis : « Ce n'est pas vraiment important, mais c'est bon d'avoir des amis. » Deux autres répondants indiquent qu'ils sont indifférents à l'égard du fait d'avoir des amis. Un seul participant rapporte ne pas avoir d'ami. Les participants affirment voir en moyenne 1,8 ami (ÉT = : 2,61) à l'extérieur du cadre scolaire.

Questionnés sur la notion d'intimidation, tous les participants incluent au moins un des termes suivants : « se faire achaler, se moquer et faire rire de soi ». Un peu plus de la moitié (8/14) des répondants mentionnent avoir été victimes de ce genre de comportements : « Je pensais que c'était drôle, mais quand j'ai appris c'était quoi, je n'ai pas aimé ça. » Pour certains, les moqueries ont cessé après l'intervention d'un membre du personnel de l'école alors que pour d'autres, le harcèlement a été présent pendant plus longtemps : « C'était une année, ça a duré toute l'année cette intimidation-là. » À l'inverse, six participants disent ne pas avoir subi de moqueries de la part des autres élèves. Toutefois, pour deux participants, il est particulièrement difficile de différencier l'intimidation des actes de moquerie isolés : « De ces temps-ci, il y a des choses que des gars que je connais très bien, mais qui ne sont pas du tout mes amis, font, mais que je ne suis jamais sûr si c'est de l'intimidation ou s'ils me taquinent. Je ne suis jamais sûr entre les deux. » Alors que pour d'autres, ce concept n'est pas clair : « Je ne sais pas comment qu'on [fait pour être] une victime d'intimidation. » Seulement un répondant parmi les neuf ayant répondu à la question avoue adopter le rôle de l'agresseur et ne pas vivre d'intimidation.

Les activités de loisirs

L'activité la plus prisée chez les adolescents interrogés est le sport. Plus de la moitié ont indiqué pratiquer un sport (8/14). Par contre, tous ont précisé faire des sports récréatifs individuels (tennis, vélo, natation, athlétisme, cross-country), alors qu'un seul fait partie d'une équipe sportive compétitive (hockey). La seconde activité privilégiée des adolescents s'avère être les jeux vidéo (7/14). Les autres activités sont de jouer dehors (3/14), écouter la télévision (2/14), faire de la lecture (2/14), jouer aux LEGO® (2/14), jouer de la musique (1/14) et faire du dessin (1/14).

Lorsqu'ils sont avec leurs pairs, les adolescents présentant un TSA jouent principalement aux jeux vidéo (7/14). Cette activité présente d'ailleurs un grand intérêt pour eux. Les jeux de guerre semblent être particulièrement appréciés comme l'indique un participant : « On ne se tanne pas [des jeux comme ça] ». D'autres jeunes vont s'adonner à un sport (6/14). Les sports pratiqués avec leurs amis sont majoritairement des activités pratiquées en individuel, comme le vélo et le tennis, et non des sports nécessitant une collaboration, à l'exception d'un participant qui fait partie d'une équipe de hockey.

La discussion

L'objectif de cette étude est de recueillir la perception des jeunes ayant un TSA quant aux changements physiques et psychologiques vécus, sur leurs relations sociales, ainsi que les activités qu'ils affectionnent lors de leur entrée dans la période de l'adolescence. Les données recueillies sont relativement semblables aux énoncés retrouvés dans la littérature scientifique sur le sujet.

Le premier constat de cette étude est que les changements physiques rapportés par les participants sont concordants avec ceux retrouvés dans la littérature (Cloutier & Drapeau, 2008; Pinyerd & Zipf, 2005). Malgré que les participants notent des transformations corporelles, certains d'entre eux ne sont pas sensibles au fait que l'entrée dans la puberté nécessite une nouvelle routine d'hygiène ou ne sont pas favorables à l'idée de modifier leurs habitudes actuelles. Ces données viennent corroborer les propos de Sicile-Kira (2006) qui soutient que certains adolescents ont besoin d'accompagnement dans cette sphère de leur quotidien. Notons qu'Hénault (2006) met l'emphase sur la pertinence de développer les connaissances sociosexuelles des adolescents ayant un TSA puisque cela pourrait s'avérer être un facteur de risque en lien avec l'intimidation.

Il n'est pas surprenant que les participants de l'étude aient plus aisément observé les changements physiques que les changements psychologiques, puisque ces transformations sont plus concrètes et que les capacités d'introspection peuvent être déficitaires chez cette clientèle (APA, 2013). Bien qu'aucune mesure standardisée n'ait été réalisée lors de la présente étude, les participants ont rapporté des changements sur le plan de l'humeur depuis le début de leur puberté, notamment une plus grande irritabilité ainsi que d'autres symptômes pouvant s'apparenter à des manifestations d'un trouble psychologique (APA, 2013) telles que des sautes d'humeur, une grande fatigue, des difficultés à se lever le matin. Ces propos auto rapportés s'apparentent à la présence d'irritabilité et la tendance au retrait social tel que le mentionnent Anderson, Maye et Lord (2011). Les changements psychologiques observés par les participants mettent en lumière l'importance d'évaluer leur adaptation, d'autant plus sachant que les adolescents ayant un TSA présentent fréquemment des troubles associés (Leyfer et al., 2006; Kerns, Renno, Kendall, Wood, & Storch, 2017; Kuusikko et al., 2008; Simonoff et al., 2008) et que la transition vers le secondaire s'avère être une période de vie particulièrement critique pour le développement de l'anxiété et de la dépression chez les jeunes adolescents ayant un développement typique (Bélanger & Marcotte, 2013). Cet aspect requiert une attention particulière de la part des cliniciens et du personnel en milieu scolaire puisque de telles manifestations influencent de façon négative les relations sociales à l'adolescence (Johnston & Iarocci, 2017).

De façon générale, les participants de l'étude semblent entretenir des relations plutôt positives avec leurs pairs. En effet, les répondants indiquent avoir un cercle social plus grand que ce qui est rapporté par plusieurs auteurs (Fisher & Taylor, 2016; Humphrey & Hebron, 2015). D'ailleurs, malgré la présence de difficultés rapportées, les adolescents affirment avoir en moyenne plus d'amis que ce qui est rapporté dans la littérature (Orsmond, Krauss & Seltzer, 2004; Poirier & Vallée-Ouimet, 2015). En effet, Orsmond et ses collaborateurs (2004) indiquent que près de la moitié des adolescents et des adultes présentant un TSA n'auraient pas d'amis, alors que seulement un participant de notre étude affirme ne pas en avoir. L'étude de Poirier et Vallée-Ouimet (2015), soulève que seulement la moitié d'entre eux voient leurs amis à l'extérieur de l'école, alors que dans la présente étude, environ un tiers des participants ne voient pas leurs amis à l'extérieur de l'école. Cependant, s'il est considéré que les amis sont les personnes fréquentées en dehors du cadre scolaire, le nombre moyen d'amis des participants chute et se rapproche plus des résultats de celui rapporté par Poirier et Vallée-Ouimet (2015). Un seul participant dit avoir une dizaine d'amis en dehors de l'école. Ceci peut s'expliquer par le fait qu'il participe à une activité parascolaire.

Malgré l'apparence de relations sociales positives, il n'en demeure pas moins que les lacunes sur le plan de la compréhension des normes sociales peuvent engendrer des difficultés sur les plans de l'adaptation et de l'acceptation auprès des autres jeunes de leur âge. Près de la moitié des répondants de l'étude confie vivre de l'intimidation, ce qui s'apparente au taux de 30 % rapporté par les adultes de l'étude de Van Roekel et de ses collaborateurs (2010). Le taux rapporté demeure tout de même moins élevé que les données rapportées dans la méta-analyse de Humphrey et Hebron (2015). Les auteurs indiquent que moins la théorie de l'esprit des participants est développée, plus ils sont enclins à mésinterpréter les situations d'intimidation. Considérant que les élèves de la présente étude avaient un niveau fonctionnement suffisamment élevé pour fréquenter une classe ordinaire, il est possible d'avancer que la majorité d'entre eux peuvent identifier correctement ce qu'est une situation d'intimidation, d'autant plus qu'ils ont tous été en mesure d'attribuer une définition valable de l'intimidation. Toutefois, comme l'indiquait un participant, lorsque confrontés à une situation d'intimidation, ceux-ci peuvent tout de même éprouver des difficultés de compréhension en lien avec les normes sociales. Par conséquent, même chez les participants de la présente étude, il existe un écart entre la capacité à définir une situation et reconnaître lorsqu'une telle situation est vécue. En outre, dans la majorité des cas, les participants ont rapporté un acte isolé, ce qui n'est pas considéré comme de l'intimidation au sens de la loi.

Il importe de souligner la sensibilisation réalisée par les milieux scolaires auprès des élèves sur l'intimidation en adoptant des politiques et des lois encadrant l'intimidation notamment avec le projet de loi 56 : Loi qui visant à combattre l'intimidation et la violence à l'école. Depuis le dépôt du projet de loi, tous les établissements d'enseignement du Québec doivent mettre en œuvre un plan de lutte contre l'intimidation et la violence à l'école. Une sensibilisation doit être faite auprès des adolescents présentant un TSA afin qu'ils puissent reconnaitre les gestes d'intimidation qu'ils peuvent subir ou poser. Ceux-ci doivent également être accompagnés, puisque comme en témoignent les enseignants dans l'étude de Van Rockel et al. (2010), ce ne sont pas tous les élèves qui sont capables de reconnaitre et de dénoncer les gestes d'intimidation.

Les loisirs rapportés par les répondants sont très semblables à ceux notés par Poirier et Vallée-Ouimet (2015) ainsi que par Orsmond et Kuo (2011). Les adolescents questionnés ont un grand intérêt, spécialement pour les jeux vidéo et le sport.

La présente recherche apporte un regard nouveau quant à la perception de 14 adolescents québécois ayant avec un TSA lors de leur entrée à l'adolescence alors que les écrits scientifiques concernant cette clientèle sont relativement pauvres. Cependant, certaines limites doivent être prises en considération. En effet, le nombre restreint de participants, la géolocalisation ainsi que l'échantillon de convenance, le niveau de sévérité du TSA ne permettent pas de transférer les résultats à l'ensemble des adolescents ayant un TSA. Les participants ciblés ne représentent pas non plus l'ensemble des adolescents en raison de la tranche d'âge ciblée. De plus, malgré leur niveau de fonctionnement adéquat, leurs réponses à l'entrevue semi-structurée demeurent brèves et peu élaborées.

Les recherches futures pourraient envisager l'utilisation de mesures validées ainsi que des entrevues cliniques afin de déterminer la présence ou l'absence d'un trouble de santé mentale en concomitance avec le TSA lors du passage vers l'école secondaire. Ce même genre de processus pourrait s'avérer pertinent pour les cliniciens afin de faire du dépistage et de la prévention auprès des élèves ayant un TSA. Toujours dans un contexte de prévention, les cliniciens bénéficieraient à faire alliance avec les familles et les partenaires externes afin de sensibiliser les adolescents aux changements physiques et psychologiques qu'ils s'apprêtent à vivre ainsi que les adaptations requises. Évidemment, il importe de poursuivre la lutte à l'intimidation et la violence à l'école. Alors que l'intimidation est une réalité sociale, que le gouvernement injecte des sommes importantes à cet effet, que les intervenants du milieu scolaire sont mobilisés et que les élèves sont de plus en plus sensibilisés, il serait pertinent de conduire une étude sur l'intimidation, particulièrement auprès d'une clientèle à besoins particuliers. Finalement, des activités de loisirs organisés pourraient être mises en place dans les milieux scolaires (club de lecture, club scientifique, club de sports, séances de jeux, etc.) afin de favoriser le sentiment d'appartenance et de permettre aux élèves ayant un TSA de rencontrer d'autres adolescents qui partagent des intérêts communs.

Messages clés de cet article

Personne ayant un trouble du spectre de l'autisme et les familles. La transition de l'école primaire au secondaire est une étape importante dans le cheminement scolaire de l'élève. Il importe de participer aux activités favorisant une bonne transition scolaire. Durant cette période, il peut être normal que l'adolescent requière du soutien pour s'adapter à cette nouvelle étape.

Professionnels et gestionnaires. La transition de l'école primaire au secondaire s'avère être une étape importante dans le cheminement des élèves ayant un TSA. Les activités de transition et la collaboration entre l'école primaire et l'école secondaire sont des pratiques gagnantes afin de mieux soutenir les élèves ayant un TSA, de faire de la sensibilisation, du dépistage et de la prévention.

Key Messages From This Article

Persons with disabilities and family. Transition from elementary school to high school is an important step in the student's academic progress. It is important to participate in activities to promote a good transition. During this time, it may be normal for the adolescent to require support to adapt to this new stage.

Professionals and decision makers. Transition from elementary school to high school is an important step in the journey for students with ASD. In order to support students with ASD, transition activities and collaboration between elementary school and high school are best practices that allow doing awareness, screening and prevention.

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Aucun conflit d'intérêt à signaler. Toute correspondance concernant cet article devrait être adressée à Ariane Leroux-Boudreault, Université du Québec à Montréal, C.P. 8888 succursale Centre-ville, Montréal (Québec). Téléphone : 514-796-9251. Télécopieur : 514-987-7953. Adresse électronique : ariane.leroux.boudreault@gmail.com

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Expectations of Youth With a Fetal Alcohol Spectrum Disorder in Adulthood: Caregiver Perspectives

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Abstract

There are limited data about adults who have fetal alcohol spectrum disorders (FASD). Caregivers of youth with FASD (N = 16) participated in telephone interviews that included the open-ended question, "What kind of adult life do you think they will have?" A total of 57 unique responses were made to the question. These responses were grouped together independently by participants. Grouping data were analyzed using multidimensional scaling and cluster analysis. It is noteworthy that as well as highlighting concerns, participants also highlighted youths' assets and hope for them as adults. Caregivers' concerns about the future needs of their youth mirrors the literature on needs and expectations of adults with FASD. This consistency reinforces the lack of research attention to adults' needs from caregiver perspectives. Participants also revealed deep concerns about their youth's futures. Despite being committed to caregiving, caregivers indicated that they will not be able to do it well enough or long enough to keep their adult children from having serious problems.

Fetal alcohol spectrum disorders (FASD) are a significant cause of compromised child and youth development (Bell et al., 2016). Canadian estimates of FASD range from 0.26 to 26.9% (Ospina & Dennett, 2013; Pei, Tremblay, McNeil, Poole & McFarlane, 2017). The most frequently used Canadian estimate is 9.1 per 1,000 births (Health Canada, 2006). Effects of prenatal exposure to alcohol range in type and severity but manifest as lifelong challenges. Modifications to living and learning environments increase the opportunities for optimal growth and functioning, but underlying conditions do not disappear.

There is limited knowledge about the issues faced by adults with FASD (Chudley, Kilgour, Cranston, & Edwards, 2007). Few diagnostic and intervention protocols or programs exist for them (Temple, Ives, & Lindsay, 2015). Yet with growing awareness, early identification and diagnostic services, the effects of prenatal exposure are more frequently identified. With this visibility it is increasingly important to meet the needs of youth as they mature into adults with FASD (Popova, Lange, Burd, & Rehm, 2015). The purpose of the present study is to identify anticipated service needs for adults with FASD from the perspectives of caregivers on youth.

Literature Review

Fetal alcohol spectrum disorder can be diagnosed in adults based on both medical and neurodevelopmental assessment (Cook et al., 2016). The medical assessment includes social and health history with a physical exam. In addition, confirmation of prenatal alcohol exposure is necessary unless all three facial features (distinctive shape and size of palpebral fissure, philtrum and upper lip) are present. A neurodevelopmental assessment indicating severe impairment in three domains is required. These domains include motor skills, neuroanatomy/physiology, cognition, language, achievement, memory, attention, executive functioning (impulse control and hyperactivity), emotion regulation, social skills and communication (Committee on Substance Abuse, & Committee on Children with Disabilities, 2000; Kodituwakku, 2007; Rangmar, Sandberg, Aronson, & Fahlke, 2015; Streissguth et al., 1991). Given the persistence of neurological deficits as well as behavioural and social challenges, youth often require ongoing support (Barr, et al., 2006). Developmental changes in early adulthood as well as the service gaps for adults with FASD and the emotional experience of planning for the child's future as an adult are described in the following three sections.

Developmental Changes

Transition-aged youth with FASD do not mature mentally, emotionally or socially at the same pace as they do physically (DeJoseph, 2011). As their bodies grow, others' expectations increase putting them in situations for which they are not prepared (Denys, Rasmussen, & Henneveld, 2011). Underlying challenges persist but manifest differently as differences from typically developing peers become more apparent (Brownell et al. 2013; Jirikowic, Gelo, & Astley, 2010). For example, communication problems are reflected in socio-behavioural challenges (Kelly, Day, & Streissguth, 2000; Kully-Martens et al., 2012) and acting "younger" than one's age (Åse et al., 2012; Kully-Martens et al., 2012;). Unsafe situations with "older" peers raise chances of perpetrating or being a victim of crime (Denys et al., 2011). Difficulties with impulse control may increase risk of problematic substance use or self-harm (O'Malley & Huggins, 2005). Finally, challenges associated with inattention or cause and effect reasoning are associated with learning and behavioural problems at school (Millians, 2015) as well as in a job (Kalberg et al., 2006).

In a large retrospective study of adults with FASD it was noted that 1 in 5 was raised by a biological parent and half had been confined within a justice or health care setting (Streissguth, et al., 2004). Substance abuse and depression were the most frequent mental health needs identified (Famy, Streissguth, & Unis, 1998; Chudley et al., 2007). Relative to adults without FASD, they were more likely to have been unemployed and in receipt of disability benefits.

Service Needs

Adults with alcohol-related disabilities require moderate to high levels of support (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004). As an adult, it is difficult to obtain a diagnosis. Barriers include the relative lack of diagnostic expertise, navigating the health system to find assistance, as well as doing paperwork and getting to appointments (Denys et al., 2011). Importantly, it is challenging to obtain information from a parent about prenatal alcohol exposure (Chudley et al., 2007). A comprehensive multidisciplinary assessment and diagnosis also identify the specific needs of each individual as well as services that are matched to meet those needs. The diagnosis is necessary to access services.

Most FASD programs are not equipped or funded to deliver services to adults (Petrenko Tahir, Mahoney, & Chin, 2014a). Adults with FASD who receive services often do so through generalist disability, health and justice systems. Professionals working with adults in these systems are less often FASD-sensitive (Petrenko et al., 2014b). Without specialized preparation many are legitimately uncomfortable working with FASD (Caley et al., 2008). As a result, adults rarely receive targeted intervention or support (Paley & O'Connor, 2009; Spohr & Steinhausen, 2008). Those without networks to help with general decision-making, residential support and direct assistance, such as obtaining medical and social services (Streissguth, Barr, Kogan, & Bookstein, 1996) will become isolated (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008).

Reliance on Caregivers

Plans for children when they became adults are important to caregivers. Many caregivers worry a great deal about what their adult lives may be like (Clark et al., 2008; Michaud & Temple, 2013; Watson, Hayes, Coons, & Radford-Paz, 2013). The process of determining what the youth could or would do, as well as what they are unable to do, as aging adults is very stressful (Jirikowic, Olson, & Astley, 2012; Paley, O'Connor, Frankel, & Marquardt, 2006). Many caregivers decide to remain on as service coordinators and advocates as well as sources of residential and personal support (Clark et al., 2008). Among those caregivers the prospect of open-ended and high levels of involvement and responsibility is substantial (Michaud & Temple, 2013; Mukherjee, Wray, Commers, Hollins, & Curfs, 2013).

Method

Concept mapping is an approach to the quantitative analysis of qualitative data. The main benefit of concept mapping compared to other qualitative approaches is that multiple participants organize the data and together determine the thematic structure. Concept mapping has been used in program development (Trochim & Kane, 2005), theory development (Rosas, 2005) and program evaluation (Markham, Mintzes, & Jones, 1994). It has also been used with different stakeholders in social work such as students (Chun & Poole, 2009), practitioners (Osmond & Darlington, 2005) and clients (Brown, 2007). In the present study, five steps for developing a concept map were followed including: (a) determination of the focal question and population from which sample was drawn, (b) collection of participants' responses to the focal question, (c) provision of all participants' responses to participants for grouping into concepts, (d) statistical analysis of participants' grouping of responses, and (e) construction of the concept map.

Focal Question and Sample

The study was conducted in partnership with a local clinic and community network of professionals and caregivers to children and youth with a FASD. The question was focused on service planning needs for youth and adults with FASD. Email advertisements were sent through the network with the request to share with any individuals who might be interested in participating. Interested individuals were asked to contact a member of the research team by telephone.

This study was focused on outcomes caregivers anticipated for their youth as adults with FASD. For this reason, individuals who had cared for a youth over the age of 10 years who had a diagnosis of FASD or was suspected to be affected, were invited to participate. Potential caregiver participants with a youth who was suspected of having FASD were screened prior to inclusion using the Neurodevelopmental Screening Tool (NST; Nash, Koren, & Rovet, 2009; Nash, et al., 2006). This instrument, based on preliminary findings in support of a behavioural phenotype for FASD, was used to score responses to several questions about a child's behaviour (https://ken.childrenshealthcarecanada.ca/xwiki/bin/download/FASDScreeningToolkit/A+Novel+Screening+Test+for+the+Behavioral+Phenotype+of+FASD/TheNeurobehaviouralScreeningToolRevised.pdf).

Participants' Responses to the Focal Question

When interested individuals contacted a member of the research team by telephone, each was provided an overview of the study and information about what their involvement would include. Following receipt of verbal consent, in accordance with the institutionally-approved research protocol, an interview was administered by telephone. The interview included several demographic questions. If a participant cared for a youth who was suspected of having FASD, the NST was administered. The interview also included several open-ended questions, of which the following was the focal question for the present study: "What kind of adult life do you think they will have?" Following the interview, the responses were scored using the NST and responses from participants below a minimum cutoff score were excluded from the analysis. Scores below the cutoff suggested that the child did not fit the behavioural phenotype. Data from participants who had not cared for at least one child who fit the phenotype were excluded.

In total, 16 participants had cared for a youth with a suspected or confirmed FASD who was over the age of 10 years. Together, participants cared for 24 youth. Seven youth were aged 10–14, 11 youth were 15–19, and 5 were 20 years or older at the time of interview. Participants included aunts, birth parents, grandparents, foster and adoptive parents. One male participated. Their average family incomes were evenly split between less and more than $50,000.

Grouping of All Responses Returned to Participants Into Concepts

Responses recorded by hand during the telephone interviews were assembled into a master list. The list of responses was independently reviewed by three researchers to identify any that were unclear or redundant (i.e., appeared more than once). The researchers' combined ratings for each response were reviewed and any that was identified by two reviewers as either unclear or redundant was discussed. Responses that were judged to be redundant were removed and any that were unclear were edited for clarity.

The final list of responses was printed for interested participants to group together. Each response was printed on a separate card. A complete set of cards was sent to each participant. Participants were asked to look at all responses and group them together in whatever way made sense to them. A member of the research team mailed out the package, confirmed receipt by telephone, followed up with a call to answer any questions and schedule a call to obtain the groupings over the telephone at a mutually agreeable time. A total of 15 participants returned their groupings.

Statistical Analysis of Grouping

The sorting data were analyzed by the Concept System Global MAX software (Concept Systems, 2019). Multidimensional scaling used the groupings provided by participants to organize responses spatially on an x-y axis with distances between the points reflecting the frequencies with which each was grouped together by participants with every other response (Kruscal & Wish, 1978). Responses close to each other on the map indicated that the participants had placed those particular responses into the same group often, while responses further apart indicated that participants had rarely placed those two responses together in the same group.

Cluster analysis was applied to the multidimensional scaling data to determine the underlying thematic structure. The analysis began with each response as its own concept. Each step of the analysis included the combining of two concepts until the point where all responses were within a single concept (Anderberg, 1973; Everitt, 1980). Bridging indices were generated for each response based on the frequency with which each was grouped together by participants with only those in the vicinity on the map, or with others in different regions of the map. A low bridging index (i.e., 0.25 or less) indicated that the response was grouped together only with those nearby on the map while a high bridging index (i.e., 0.75 or greater) indicated that the response was grouped together with other responses in areas of the map at greater distances. More detail on these procedures can be found at https://socialresearchmethods.net/mapping/mapping.htm.

Construction of the Concept Map

The final decision about the number of concepts and labels for each was made by two of the researchers. The determination about concepts utilized both qualitative and quantitative data. Responses were reviewed for similarities within and differences between concepts. Map solutions with concepts that had the greatest within concept homogeneity and between concept heterogeneity were favoured. Bridging index data was used to assist with the determination of the best number of concepts favouring maps with concepts reflecting lower average bridging indices. Concept maps of 12, 10, 6, 5, 4, and 3 were reviewed before determining that the four-concept solution fit the data best. Individual bridging indices were used to identify responses that were the most central to the content of each concept. These responses within each concept were used to guide the decision about appropriate labels. Labels provided by participants for their own groupings also informed the labels applied by the researchers.

Results

The resulting concept map (see Figure 1) was constructed based on the responses generated and grouped together by participants. There were 57 unique responses for the analysis (see Table 1). Responses were grouped together by 15 participants. A validity index, called the stress value, was calculated for the map. The value was 0.29 which was within an acceptable range (Rosas & Kane, 2012). The four concepts included: (a) have a purpose, (b) serious problems, (c) continuous challenges, and (d) always need support. Participants described positive qualities of their youth, as well as expectations for ongoing challenges their youth will face as adults such as housing issues, and finally, the need for ongoing support throughout their lives.

Have a Purpose

Responses in this concept centered on the youths' positive qualities and hopeful outlook for them as adults in several ways. In some cases, caregivers made plans for their future, such as "we have set up some resources for her" as well as made a commitment to remaining involved, so that "parents will help him be mentored." Participants were hopeful that their adult children will "find a purpose" and "find a career." With the recognition that "he is a hard worker," it was felt to be "possible he will get a job," perhaps "working part time" and in some cases, there is a "need to create a job." For some, their hopes included education. A goal could be to "get her high school diploma" or continue with the "occupational therapist is helping her to go to college." Participants were "hoping he will be financially independent" through employment or by "be on Disability Support

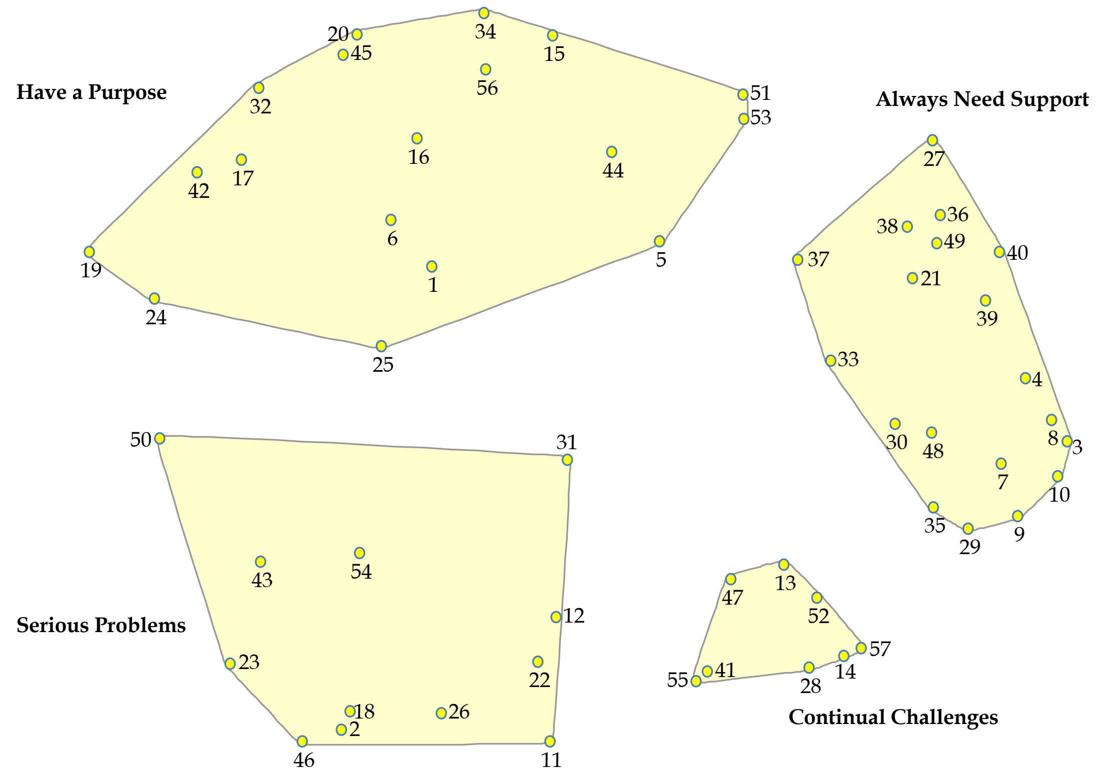

Figure 1. *Concept map of participants' responses. Numbers identify responses listed in Table 1. Distance between numbered responses indicate frequency with which participants placed them together in the same grouping. Nearby = more often grouped together. Far Apart = less often grouped together.*

Table 1. Participants' Responses Organized by Concept

Concept	*Response*	*Bridging Index*
Have a Purpose		**0.36**
44.	Parents will help him be mentored	0.19
15.	Find a career	0.19
53.	We have set up some resources for her	0.2
16.	Find a purpose	0.2
5.	Be on disability support program	0.2
1.	Need to create a job	0.25
51.	Take a special needs cooking class	0.27
56.	Working part time	0.27
20.	He is a hard worker	0.31
32.	Lives in a house independently	0.34
45.	Possible he will get a job	0.35
25.	Hoping they will find happiness	0.37
17.	Get her high school diploma	0.38
34.	Loyal, so if he finds the right person, he can have a good partner	0.4
6.	Being able to maintain structure and routine	0.4
42.	Occupational therapist is helping her to go to college	0.51
24.	Hoping he will be financially independent	0.67
19.	Have some friendships	1
Serious Problems		**0.34**
12.	Do as much as you can to prepare but don't know what will happen	0.13
31.	Live with us for most of his life	0.16
11.	Discouraging because work so hard to raise them	0.18
2.	Afraid he is going to end up in jail	0.19
22.	Hope she will not drink and do drugs	0.2
46.	Pregnant, uneducated, and in abusive relationship	0.22
26.	If we can't manage him, he will need to leave	0.24
18.	Getting into conflict with the law	0.32
54.	Will live with mother whole life	0.45
23.	Hope will not get kicked out of the house	0.47
43.	Only supervision strong enough is parental	0.68
50.	Stay in high school until she is 21	0.78

Legend

- Concept is a descriptive label given by researchers based on responses contained within given categories.
- Responses are words provided by participants in response to the focal question.
- Bridging index is a number between 0.00–1.00 indicating the degree to which a response was grouped together by participants with others near to it in a given category on the concept map (less than 0.25 = often grouped with others nearby; greater than 0.75 = often grouped with responses in other regions of the map).
- Concept average (bolded number) is the mean of all individual bridging indexes within each of the concepts.

continued on following page

Table 1. Participants' Responses Organized by Concept (continued)

Concept	*Response*	*Bridging Index*
Continual Challenges		**0.07**
14.	Fear that there will be a hard road	0.02
57.	Worry about lack of impulse control	0.04
13.	Don't know if he will be able to support himself	0.05
28.	It's a worry	0.05
52.	They will struggle	0.08
41.	Not very hopeful right now	0.09
47.	Safety will be a concern	0.09
55.	Won't have a normal life	0.11
Always Need Support		**0.07**
33.	Lowered expectations	0
38.	Needs help with money	0
21.	He is going to be closely supervised	0.04
36.	Need someone to help him financially	0.04
48.	She will never be able to handle own money	0.04
30.	Likely never earn his own living	0.04
35.	Maturity is not there	0.05
3.	Always need help with living tasks	0.06
39.	Needs personal hygiene reminders	0.07
4.	Always need someone to help with decisions	0.07
29.	Lack of boundaries	0.07
10.	Disability doesn't mature with them	0.07
9.	Cognitively can't have what she wants	0.08
7.	Can't be responsible for himself	0.08
37.	Need to be safe in the house	0.08
49.	Someone to cue him to help him regulate	0.1
40.	Needs someone to help with transportation	0.11
8.	Can't do typical jobs	0.14
27.	Involve as many people as possible to help him	0.22

Legend

- Concept is a descriptive label given by researchers based on responses contained within given categories.
- Responses are words provided by participants in response to the focal question.
- Bridging index is a number between 0.00–1.00 indicating the degree to which a response was grouped together by participants with others near to it in a given category on the concept map (less than 0.25 = often grouped with others nearby; greater than 0.75 = often grouped with responses in other regions of the map).
- Concept average (bolded number) is the mean of all individual bridging indexes within each of the concepts.

Program." Life skills included cooking for self after "take a special needs cooking class," as well as "being able to maintain structure and routine" in order to "lives in a house independently." Participants hoped that they would "have some friendships" and noted that a positive quality was being "loyal, so if he finds the right person, he can have a good partner." They were "hoping they will find happiness."

Continual Challenges

Participants were concerned about ongoing struggles for their youth as adults and that in general, they were "not very hopeful right now." They "fear that there will be a hard road" ahead for them and "don't know if he will be able to support himself." "It's a worry" for participants that "they will struggle" and "won't have a normal life." There was also "worry about lack of impulse control" and knowledge that their "safety will be a concern."

Serious Problems

In this concept, responses focused on difficulties participants anticipated for their youth as adults. They were aware that they would "do as much as you can to prepare but don't know what will happen." While it was anticipated that they "live with us for most of his life" because the "only supervision strong enough is parental" they knew that "if we can't manage him, he will need to leave." Sometimes, reunification with another parent was expected "will live with mother whole life," but that was also qualified with the response: "hope will not get kicked out of the house." Participants felt that it was "discouraging because work so hard to raise them" and they could not imagine a way they could prevent more potential problems from occurring. They wanted them to "stay in high school until she is 21." For that to happen, they also "hope she will not drink and do drugs" and their biggest fear that she could be "pregnant, uneducated, and in abusive relationship." Participants were concerned about their adult children "getting into conflict with the law" and "afraid he is going to end up in jail."

Always Need Support

Responses in this concept focused on the types of supports necessary for their youth throughout their lifetimes and to "involve as many people as possible to help him." They also had accepted that their futures have been largely predetermined by their disabilities in that the "disability doesn't mature with them" and that he will need "someone to cue him to help him regulate" because he "can't be responsible for himself." Because the "maturity is not there" and a "lack of boundaries" caregivers need "lowered expectations" and to help their youth recognize themselves that "cognitively can't have what she wants." As adults, they will "always need help with living tasks," consistently "needs personal hygiene reminders" and "needs someone to help with transportation." They suggested that they will "likely never earn his own living" because "can't do typical jobs" and "need someone to help him financially" because "she will never be able to handle own money." It will be important that "he is going to be closely supervised" because he will "always need someone to help with decisions" and "need to be safe in the house."

Discussion

Responses provided by participants in the four concepts were compared to the literature. Similarities and differences were found. Issues identified by participants that have been reported in the literature lent support to the concepts and constructs studied. Issues identified by participants that had not been reported in the literature suggested areas potentially worthy of exploration.

Have a Purpose

Connections between education and employment opportunities and how they were related to being included in one's community were identified by participants. There is literature about the benefits of such opportunities and their association with feeling connected to others and prevention of social isolation (Spohr & Steinhausen, 2008). The need for assistance in these areas was similarly identified by both participants and within existing literature (Clark et al., 2008; Streissguth et al., 1996).

However, we found no literature on the positive characteristics of youth and how these could extend into adulthood concerning their personal contentment or the relevance to them of having or being a good partner in an intimate relationship.

Continual Challenges

There has been considerable research on the pervasive and persistent challenges associated with neurological problems among youth with FASD (Streissguth et al., 1991) that are expected to continue throughout adulthood (Rangmar, Sandberg, Aronson, & Fahlke, 2015). These are consistent with participants' expectations for their youth into adulthood. There has been attention to the needs of caregivers of children and youth who are affected. However, neither the caregiving responsibilities – nature, extent, and impact – have been explored, nor the emotional toll of immediate, unanticipated and significant problems that caregivers face have been identified, as participants have done in the present study, within the literature. Additionally, there has been little attention to how the caregiving challenges vary according to the role and responsibilities of the caregiver in the lives of their youth as adults.

Serious Problems

There is a great deal of literature on the nature and extent of secondary disabilities (e.g., Barr et al., 2006). Such problems may include disrupted education, substance abuse and trouble with the law (Rangmar et al., 2015). Participants also mentioned that despite their best efforts to provide care for their youth, they worried about the development of secondary disabilities for them as adults who could be without such care should they be unable to continue to care for them. In the literature, consistent parenting and residence are known to have strong preventive effects against secondary disabilities (Streissguth et al., 1996).

Always Need Support

Responses in this concept overlapped considerably with the existing literature. Several references to the need for long-term caregiving support have been made (DeJoseph, 2011), given life skills and problem-solving challenges (Denys et al., 2011) affecting interpersonal relationships and residential stability (Åse et al., 2012; Kelly et al., 2000; Kully-Martens et al., 2012; Manji, Pei, Loomes, & Rasmussen, 2009). There is divergence between participants' views and what has been reported in the literature concerning on the absence of any support for the family to take on these responsibilities with their youth and view it as a lifetime commitment. There is some literature on the experiences of youth aging out of care and hoping to continue to rely on their foster parents (Burnside & Fuchs, 2013). However, caregivers in the present study reported that lifelong care would be necessary and if they were unable to provide it, they worried about who it would be provided by and how.

Conclusion

Despite all of the problem focus in the current literature, participants did highlight positive characteristics of their youth and the contributions they would make as adults. Caregivers noted that in the presence of necessary supports and services they could, as adults, live productive and full lives. However, the hopefulness evident within some responses was overshadowed by the realities of social barriers as well as absence of FASD-designated services for adults. The lack of social and professional support for adults who experience FASD-related impairments was evident in the literature and noted by participants.

Participants in the present study held a view about the futures of their youth as adults that placed ongoing caregiver support as necessary but insufficient. While they were cognizant of the need for support of the youth into adulthood, they did not envision a future within which they were enough of an influence to prevent negative outcomes. Indeed, they envisioned a future with continual challenges and insecurity about their own abilities as well as a lack of resources to provide the kind of support they expected would be needed.

Interestingly, participants did not identify any specific resources, other than provincial disabilities funding, to assist their youth as adults. This absence reflects a general absence of services that exist for adults with FASD. Additionally, the references to professionals who are knowledgeable about FASD, presumably with adults as well, that were prevalent in the literature were not identified by participants in the present study. The absence of professionals or agencies having a role in the lives of their youth as adults can be contrasted with their awareness of the potential for them to go to become involved in illegal activities and the justice system.

Implications

Participants' identification of strengths and optimism for their youth aging into adulthood was countered by a great deal of concern about their welfare. The impairments they know the youth have were expected to be increasingly exacerbated and frustrated as they grew older. Caregivers' concerns centered on the needs of their adult children potentially becoming more than what they could effectively support themselves. This combined with the lack of social inclusion, service access and knowledgeable professionals for adults in the community left them very worried. It is suggested that dedicated transitional support and services would be of great help for youth who have an FASD diagnosis to assist with planning for adulthood. Such planning should include housing and income support as well as education and employment. Arrangements for health care would also be necessary.

Key Messages From This Article

People with disabilities. You have a lot of positive qualities. You can do many things that other people do. You also need other people to help you sometimes.

Professionals. The challenges that accompany fetal alcohol spectrum disorder require environmental accommodation and lifelong support.

Policymakers. Fetal alcohol spectrum disorders should be formally recognized and targeted in services for adults with disabilities.

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Applying the HC-IDD Frailty Index to Developmental Services Agency Chart Data

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Abstract

Frailty is a common geriatric syndrome experienced by adults with intellectual and developmental disabilities (IDD) earlier than those without IDD. Measurement of frailty in this population is crucial to inform care planning aimed at preventing adverse outcomes. This study sought to determine whether frailty could be measured based on information documented in developmental services agency charts and how chart-derived scores performed compared to a validated frailty measure developed for adults with IDD who receive home care. Records from a developmental services agency were reviewed for the presence of deficits indicated in the Home Care – Intellectual and Developmental Disabilities Frailty Index (HC-IDD FI). Only 13 of the 42 HC-IDD FI deficits met the inclusion criteria to create a chart-derived score. In the developmental services sample (n = 170), the chart-derived score was associated with age, level of IDD, living arrangement, and hospitalization in the subsequent year, but not with sex. Poor agreement between the HC-IDD FI and scores derived from items captured in charts was observed in a sample of 106 home care recipients with IDD. Assessing frailty among aging adults with IDD using developmental services agency records requires the systematic recording of changes in function to account for the dynamic nature of frailty.

Frailty is an age-associated clinical syndrome characterized by elevated risk of adverse health outcomes, such as disability, institutionalization, morbidity and mortality (Evenhuis, Schoufour, & Echteld, 2013), increased care intensity, and health care costs (Schoufour, Evenhuis, & Echteld, 2014). There are two main approaches to measuring frailty: the phenotype approach (Fried et al., 2001) and the accumulation of deficits approach (Rockwood & Mitnitski, 2007). The phenotype approach identifies frailty as the presence of at least three of the following characteristics: weight loss, weakness, exhaustion, low physical activity, and slowness, while the accumulation of deficits approach considers the proportion of deficits (e.g., decline in function, medical diagnoses, social isolation) present, rather than specific symptoms. Regardless of the measurement approach, frailty has been shown to develop significantly earlier on average in individuals with intellectual and developmental disabilities (IDD) compared to the general population (Evenhuis et al., 2013; McKenzie, Ouellette-Kuntz, & Martin, 2017; Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2013). As a result of the increasing life expectancy among individuals with IDD (Thorpe, Davidson, & Janicki, 2000), frailty is predicted to become a major healthcare challenge in this population.

Thus far, four groups of researchers have developed frailty measures specifically for adults with IDD (McKenzie, Martin, & Ouellette-Kuntz, 2016). The Home Care-IDD Frailty Index (HC-IDD FI) was developed by McKenzie, Ouellette-Kuntz and Martin (2015) using an accumulation of deficits approach based on items reported in the RAI-Home Care assessment instrument (Morris et al., 2009), which is used as part of regular clinical practice across Ontario's home care sector. The HC-IDD FI includes 42 deficits that span five domains (i.e., physiological, psychological, cognitive, social, and service use), and is associated with age, health status (McKenzie et al., 2015), and admission to long-term care (McKenzie, Ouellette-Kuntz, & Martin, 2016). The score is calculated by dividing the number of deficits present by the number of deficits measured, and then categorized into non-frail (score < 0.21), pre-frail (score = 0.21–0.30), and frail (score > 0.30). Additional details on the development of the HC-IDD FI and categories is provided in McKenzie et al. (2015). The HC-IDD FI has also been shown to improve the ability to predict admission to long-term care or death among home care users with IDD (Ouellette-Kuntz, Stankiewicz, McIsaac, & Martin, 2018).

In Ontario, responsibility for supporting adults with IDD in the community (for example, through residential services, day programs, and employment supports) lies with the developmental services sector, not the health care sector. However, just as in the general population, adults with IDD may experience health conditions or health events that have an impact on their ability to remain in the community. In Ontario and elsewhere, a focus on aging in place has meant that home care services are used to assist individuals in their home through provision of nursing care, homemaking support, meal support, and therapies. Ontarians with IDD, whether they live in their own home, family home, or group home, are also eligible to receive home care services. As use of the RAI-HC assessment is restricted to those in home care, information on frailty calculated through the HC-IDD FI is available only for a subset of adults with IDD – those assessed for home care services. As assessment of frailty in the developmental services sector could contribute to enhanced care planning and better outcomes in this population, there is a need to measure frailty outside of the home care system. This study aims to do that by: (1) determining if the items from the HC-IDD FI are captured in developmental services sector agency files and produce a chart-derived score; (2) assessing the relationship between the resulting chart-derived score with sociodemographic factors known to be associated with frailty in this population (e.g., age, sex, level of IDD), as well as with hospital admission; and (3) testing the validity of the chart-derived measure through comparison with the HC-IDD FI score in a sample of home care users with IDD.

Method

Ethics approval for this study was provided by the Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board. All analyses were conducted using SPSS.

Samples

The study is based on a sample of 170 adults with IDD supported by a developmental services agency who were registered residential clients from 2016 to 2017 (i.e., to ensure hospitalization data was available for the subsequent year), and a sample of 106 home care recipients with IDD in Ontario assessed with the RAI-HC. The home care data are held on a secure server at the University of Waterloo and made available to the research team through a data-sharing agreement between the Ontario Ministry of Health and interRAI (i.e., through Dr. Lynn Martin as interRAI Fellow).

Presence of HC-IDD FI Items in Developmental Services Sector Agency Files

A chart review was conducted to identify the presence of the 42 deficits in the HC-IDD FI. Generally, if an item was not present in the chart, it was coded as "missing." Given the participating agency's reporting requirements and policies, missing items related to diagnoses, prescribed medications, hospitalizations, and falls were instead coded as "not present." More specifically, absence of the following were considered to be "not present" rather than "missing": hospital admission, dementia/Alzheimer Disease, diabetes, arthritis, hypertension, respiratory disease, fall frequency, osteoporosis, hearing impairment, cataract, antidepressant, medications, delirium, coronary artery disease, specific infection, stroke, and circulatory diseases. It was assumed that the absence of health conditions in chart data indicate that the individual was not diagnosed or reported to have the deficit.

As in the development of the HC-IDD FI, deficits had to meet the following inclusion criteria to be retained in the chart-derived measure: no more than 30% of the client files were missing information regarding the deficit, and the deficit was neither too prevalent (i.e., present in more than 80% of clients) nor too rare (present in less than 5% of clients) (Schoufour et al., 2013). A score was then calculated using deficits that met the inclusion criteria (see McKenzie et al., 2015).

Relationship Between the Chart-Derived Score, Sociodemographic Factors, and Hospital Admission

Using a cross-sectional study design, the chart-derived score was tested for its association with age (Spearman's rank correlation coefficient), sex (Mann Whitney U Test), living arrangement (i.e., group home vs. host family; Mann Whitney U Test), and level of IDD (Spearman's rank correlation coefficient and Kruskal Wallis Test).

A retrospective cohort approach was used to test the association between the chart-derived score and hospitalization in the subsequent year (Mann Whitney U Test).

Validity of the Chart-Derived Measure in a Sample of Home Care Users with IDD

The HC-IDD FI and chart-derived scores were both computed in the home care sample to determine the convergent validity (i.e., correlation) between the two scores, using the concordance correlation coefficient (Lin, 1989).

Results

Sample Characteristics

Of the 170 clients from the developmental services agency, the majority lived in a group home (77.6%) while the others lived with a host family. Clients' ages ranged between 19.8 and 86.4 years (*M* = 51.9 years), and 51.2% were men. Approximately a third had a mild to moderate level of IDD (32.9%) and 40.6% had a severe to profound level of IDD; the level of IDD was not indicated in 26.5% of the charts reviewed. Although not statistically significant, those living in host family settings were slightly younger (*M* = 48.8 years vs. 52.8 years in group homes, $p = .13$). There was an association between the type of living arrangement and level of IDD ($p < .001$) with half of adults living in group homes (50.8%) having a severe to profound level of IDD compared to only 5.3% of those living with a host family.

Presence of HC-IDD FI Items in Developmental Services Sector Agency Files

Only 13 of the 42 deficits in the HC-IDD FI met the inclusion criteria: hospital admission, dementia/Alzheimer disease, diabetes, arthritis, hypertension, respiratory disease, fall frequency, osteoporosis, hearing impairment, cataract, stamina, antidepressant use, and medication use (see Table 1 on the following page). Twenty-two deficits were excluded based on missing data, and seven were excluded as they were too rare (see Table 2 on p. 47). The scores derived from these 13 items, shown in Table 1, ranged from 0 to 0.58 (*M* = 0.19).

Relationship Between the Chart-Derived Score, Sociodemographic Factors, and Hospital Admission

There was a moderate positive correlation between the chart-derived score and age, $r(168) = 0.43$, $p < .001$, and a weak positive correlation with level of IDD, $r(168) = 0.22$, $p = .002$. Specifically, individuals with a severe/profound level of IDD had a significantly higher score compared to those with an unknown level of IDD (*Mdn* = 0.19 vs. *Mdn* = 0.12,

Table 1. Breakdown of Chart Abstraction Results for 13 Included Deficits in the Developmental Services Agency Sample (n = 170)

Included Deficits	*Present (percent)*
Medications (4 or more within the last 7 days)	70.6
Osteoporosis	29.4
Cataract	23.5
Antidepressant (use within the last 7 days)	18.8
Hearing Impairment	17.0
Hypertension	15.3
Arthritis	12.4
Fall Frequency (more than 1 fall in the last 90 days)	9.4
Diabetes	8.8
Respiratory Disease	7.6
Dementia/Alzheimer Disease	5.3
Hospital Admission (within the last 90 days)	5.3
Stamina (leaving the house less than 6 days a week)	5.3*

**Note: 5.9% of information was missing in the stamina category*

respectively; $p = 0.004$). Living in a group home (*Mdn = 0.19)* was associated with higher scores than living with a host family (*Mdn* = 0.12), $U = 1215.50$, $p < .001$). Scores did not differ by sex ($U = 3165.00$, $p = .163$).

Approximately 18.8% ($n = 32$) of the sample was hospitalized within the year following the measurement of the chart-derived frailty score, with a total of 48 recorded hospitalizations. Higher scores were significantly associated with hospitalization (*Mdn* = 0.19 vs. *Mdn* = 0.15 for not hospitalized, $p = .026$).

Validity of the Chart-Derived Measure in a Sample of Home Care Users With IDD

The sample of 106 home care recipients with IDD were on average 32.1 years old (with ages ranging from 20 to 63 years), which is almost 20 years younger than the average age for the agency sample reported above. As with the agency sample, the majority in the home care sample were men (59.4%). This sample consisted of individuals with varying levels of IDD, however, the level of severity was not reported in the RAI-HC instrument. The HC-IDD FI scores ranged from 0.02 to 0.52 ($M = 0.12$) and the chart-derived scores ranged from 0.00 to 0.37 ($M = 0.11$). There was poor agreement between scores ($r_c = 0.43$) (see Figure 1 on p. 48).

Discussion

This study revealed that most items in the HC-IDD FI were not systematically captured in developmental services agency records. Items excluded due to missing data mostly related to changes in function. Although attention to change in function is likely, there was no systematic approach to ensuring changes or stability in functioning (e.g., dressing ability) are documented in client charts. In the context of frailty assessment, it is important to capture and record small changes.

The deficits that were excluded because of rarity included diseases often associated with increasing age (e.g., delirium, coronary artery disease, stroke, and circulatory diseases). The relative rarity of these deficits could be explained by the fact that the study sample

Table 2. Breakdown of Chart Abstraction Results for 29 Excluded Deficits in the Developmental Services Agency Sample (n = 170)

Excluded Deficits	*Criteria for Exclusion*	
Changes (Decline/Worsening)	> 30% Missing (Percent)	Rare (< 5%) (Percent)
Social Activity (participation)		1.8
Continence	98.2	
Decision Making	97.1	
Communication	94.1	
Mood	91.2	
Overall Care Needs	88.8	
Hygiene/Bathing	82.4	
Toilet Use	79.4	
Dressing	78.8	
Eating	74.7	
Behaviour	68.2	
Unsteady Gait	48.8	
Mobility in Bed	44.1	
Stair Climbing	38.2	
Transfers	35.3	
Locomotion out of Home	32.4	
Diagnoses		
Circulatory Diseases		2.9
Stroke		0.6
Specific Infection		0.6
Coronary Artery Disease		0.4
Delirium		0.0
Other issues/symptoms		
Social Isolation (alone for long periods of time or all of the time)		0.6
Loneliness	100	
Fear of Falling	99.4	
Shortness of Breath	98.8	
Short-term Memory Problem	98.2	
Edema	95.3	
Pain Disruption (disrupts usual activities)	91.2	
Pain Frequency (any pain)	36.5	

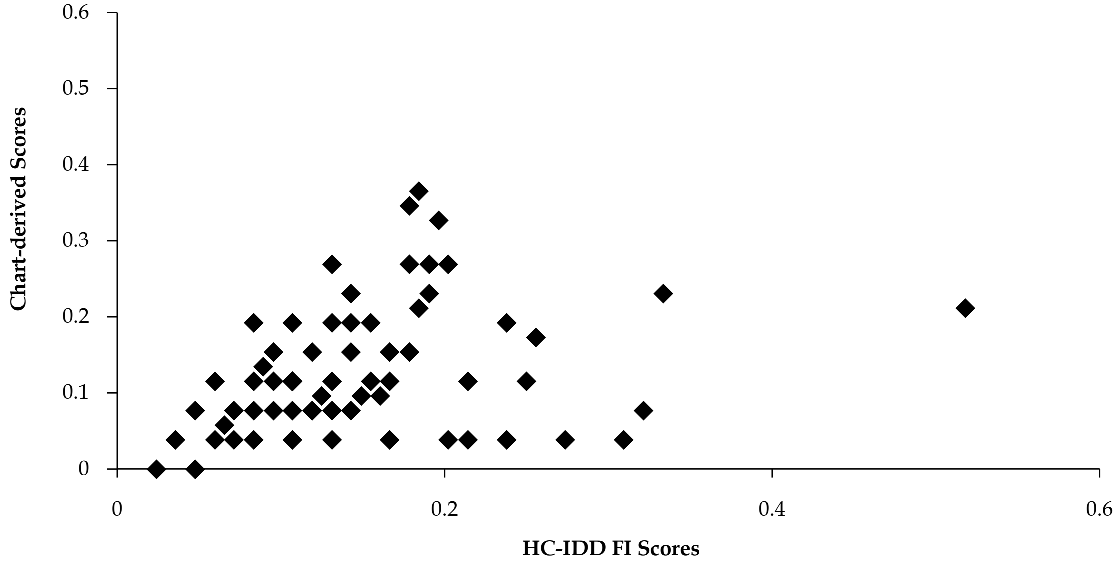

*Figure 1. HC-IDD FI and chart-derived scores concordance plot in the home care sample (n = 106)**

**Note: The chart-derived and HC-IDD FI scores are likely not concordant due in part to the insufficient number of deficits included in the chart-derived score and to the differing demographics in the developmental services and home care sample.*

was younger than the home care cohort used to develop the HC-IDD FI (mean age of 51.9 years compared to 56.2 years in home care) (McKenzie et al., 2015). Social isolation and changes in social activity were also rarely recorded in the charts; this may be unique to the sample where living arrangements (group home and host family) promote group activities and opportunities for socialization.

Despite the limited number of items that met the inclusion criteria, the resulting chart-derived score was associated with age, level of IDD, and living arrangement in the developmental services agency sample, but not with sex. These associations have been previously reported in the literature. Frailty has consistently been shown to increase with age (see, for example, Evenhuis Hermans, Hilgenkamp, Bastiaanse, & Echfeld, 2012), and to be more prevalent among those with more severe levels of IDD (Schoufour et al., 2013). For 26.5% of the developmental services agency sample, however, the level of IDD was not available through the chart review. The extent to which this information may be missing from client charts across the developmental services sector is unknown and the reason for missingness is unclear. A review of the documentation of level of IDD in developmental services agencies may be warranted. The lack of difference in frailty scores by sex has been previously reported by Schoufour and colleagues (2013). However, future research should continue to examine this sex difference and attempt to understand it. While the relationship between frailty and living arrangement has not been extensively explored, an Ontario study found that among a sample of home care users with IDD, those living in group homes were older, more frail, and had more severe levels of IDD than those living elsewhere in the community (Martin, Ouellette-Kuntz, & McKenzie, 2018). In the agency sample, half of the individuals living in group homes had a severe/profound level of IDD compared to around 5% in host family settings; it is therefore not surprising that those in group homes had higher scores. That said, there is a need to further investigate the cause and effect relationship between frailty, level of IDD, and living arrangement.

In the agency sample, the chart-derived score was predictive of hospitalization in the subsequent year. The limited literature in this area has produced contradictory results: some have reported that frailty is a significant predictor of hospitalization, with frail and pre-frail individuals having a higher risk of hospitalization (Kojima, 2016), though others have reported no significant relationship (Schoufour, Echteld, Bastiaanse, & Evenhuis, 2015).

The poor agreement between the chart-derived and HC-IDD FI scores in the home care sample can be mainly attributed to the paucity of deficits included in the chart-derived score. Previous research has recommended a minimum of 30 to 40 items for a reliable frailty index (Searle, Mitnitski, Gahbauer, Gill, & Rockwood, 2008); relying on only 13 items to measure frailty is therefore not recommended. Most retained deficits related to diagnoses rather than everyday function – as such, the 13-items may not be sensitive to change in status or capture the dynamic nature of frailty.

This study has a number of strengths including the evaluation of all residential clients within a developmental services agency, consisting of a diverse group of clients with a wide age range, and use of a validated frailty measure. Agency charts also had designated areas for documenting diagnoses and incidents (ex. falls and hospitalizations), which helped to clarify that the missingness of certain deficits indicated that they were not present rather than truly missing.

However, this study is not without limitations. The study was limited to a single agency, and additionally restricted to residential clients as they were thought to have more complete files (for example, compared to individuals supported in day programs only). Consequently, the chart-derived measure may not be generalizable to other agencies or other types of clients. Other agencies may also have different record keeping practices, which may result in identification of more or fewer frailty deficits. While it is thought that the discordance between the chart-derived and HC-IDD FI scores is mainly attributable to the small number of deficits contributing to the chart-derived score, inherent differences between the two samples may have also played a role. In particular, the home care sample had a younger mean age, and a greater proportion of males compared to the developmental services agency sample. It also was not possible to evaluate the level of IDD severity and living arrangements in the home care sample.

Based on the findings from this and previous studies (e.g., Searle et al., 2008), reliance on 13 items to measure frailty is not recommended. The dynamic nature of frailty necessitates the recording of deficits across multiple frailty domains, especially those related to functional changes. In order to understand the generalizability of the current study findings, the application of the HC-IDD FI to charts from other agencies is needed to ensure the HC-IDD FI is a measure of frailty that developmental services agencies can use. Other outcomes associated with frailty (for example, admission to long-term care, falls, and mortality) should also be considered when determining the predictive ability of the chart-derived measure in future studies.

Key Messages From This Article

People with disabilities. Many changes occur as you get older, especially in your health and abilities. Noting the smallest change in everyday ability can help others support you.

Professionals. Frailty predicts adverse outcomes and is more prevalent among adults with intellectual and developmental disabilities. Client charts should capture key information needed to measure frailty as knowledge of frailty status could improve care planning and facilitate personalized care.

Policymakers. Implementation of a frailty measure in developmental services requires detailed chart-data and will help support well-being and aging care among individuals with intellectual and developmental disabilities.

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Autism Spectrum Disorder Knowledge, Training and Experience: Ontario Physicians' Perspectives About What Helps and What Does Not

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Abstract

Background: *Many physicians experience barriers such as lack of time and expertise, as well as facilitators such as collaboration with other healthcare professionals, when providing care for individuals with autism spectrum disorder (ASD). This study aimed to identify barriers and facilitators that Ontario physicians encounter when providing care for individuals with ASD.*

Method: *Twenty-seven physicians practicing in Ontario participated in a two-phase study. During the first phase, participants completed a questionnaire regarding their demographic information as well as their knowledge, competency and experiences when providing care for individuals with ASD. During the second phase, five participants answered questions about their experiences when providing care for individuals with ASD.*

Results: *In this study, physicians expressed their needs for further education and training regarding ASD. Despite physicians' reported lack of comfort and expertise in diagnosing individuals with ASD, they identified working in an interdisciplinary team as a facilitator in helping them to provide care for this population. The findings also revealed that previous work experiences with individuals with ASD, and collaborating with parents of children with ASD enhance physicians' experiences when providing care for this population.*

Conclusions: *Findings have implications for raising awareness in healthcare and educational systems regarding the steps need to be taken to enhance Ontario physicians' experiences when providing care for individuals with ASD.*

Despite the high prevalence of autism spectrum disorder (ASD) – 1 in 66 children (Government of Canada, 2018) – many medical practitioners experience barriers (e.g., lack of education and training) in providing care for this population, especially in areas such as diagnosis and treatment (Daniels, Halladay, Shih, Elder, & Dawson, 2014; Fenikilé, Ellerbeck, Filippi, & Daley, 2015). In addition to challenges, researchers have also identified several facilitators (e.g., working in a multidisciplinary team) that enhance the diagnostic and treatment processes for both physicians as well as individuals with ASD (Major, Peacock, Ruben, Thomas, & Weitzman, 2013). Given the importance of physicians' roles in providing care for the ASD population, it is necessary to investigate their experiences, both positive and negative, in order to enhance healthcare management for individuals with ASD.

ASD is a pervasive neurodevelopmental disorder that is characterized by deficits in two developmental areas including social-communication as well as behavioural skills (American Psychiatric Association, 2013). Although caregivers often identify early symptoms of ASD (i.e., delay in language and social skills development) as early as 18 months of age, research shows that many children with ASD do not receive a diagnosis until the age of four or five (McMorris, Cox, Hudson, Liu, & Bebko, 2013; Warren, Stone, & Humberd, 2009). Additionally, the literature shows that parents of children with ASD have raised concerns regarding the delay in the diagnosis as well as the lack of direction and support they receive from healthcare professionals throughout this process (Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor, 2012; Glazaard & Overall, 2012). Even though the diagnosis of ASD often employs a multidisciplinary approach (i.e., collaboration among healthcare professionals as well as families of individuals with ASD), many parents feel left out, as their views are not sufficiently included in the process. These parents must often become self-reliant and gain knowledge regarding the diagnosis of their children on their own (Brookman-Frazee et al., 2012; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Glazzard & Overall, 2012). Research also shows that parents have raised concerns regarding the lengthy ASD diagnostic process, and that they often receive the diagnosis for their children after the fourth visit with a medical professional (Siklos & Kerns, 2007).

Challenges in Providing Care

Because physicians are the first healthcare professionals who interact with children suspected of having ASD, they play an important role in the early identification of ASD symptoms in the pediatric population (Self, Parham, & Rajagopalan, 2015). A growing body of research has revealed some of the barriers that medical practitioners experience when making a diagnosis of ASD. For instance, a study investigating physicians' experiences in terms of knowledge and preparedness in identification and diagnosis of ASD showed that medical practitioners expressed their need for further education and training regarding this matter (Fenikilé et al., 2015). Research shows that many physicians in the United States. have described the ASD diagnostic tools as time-consuming as well as demanding in terms of knowledge and expertise (Carbone, Behl, Azor, & Murphy, 2010; Fenikilé et al., 2015; Nah, Young, Brewer, & Berlingeri, 2014). In line with such findings, Finke, Drager and Ash (2010) investigated general pediatricians' experiences with regard to the diagnosis of ASD, using a qualitative interview methodology. Pediatricians reported a lack of ASD-specific training during medical school. Some pediatricians stated that developmental pediatricians receive more training about ASD, while other participants expressed their lack of comfort with the diagnostic process, and discussed referring individuals with a suspected diagnosis of ASD to more specialized professionals (i.e., developmental pediatricians and psychologists) (Finke et al., 2010). Research also shows that pediatricians in different regions of the United States report screening children for developmental delays, but only 8% screen for ASD (Dosreis, Weiner, Johnson, & Newschaffer, 2006). In the same study, most pediatricians referred children to other clinical specialists, and 20% used a wait-and-watch strategy for children younger than two years of age (Dosreis et al., 2006).

Facilitators

In addition to the barriers faced by physicians, recent studies have identified factors that enhance medical practitioners' experiences when providing care for individuals with ASD. For instance, Ritzema, Sladeczek, Ghosh, Karagiannakis, and Manay-Quian (2014) recommended collaboration among physicians and psychologists in order to facilitate the delivery of health care services for individuals with developmental disabilities including ASD. Through partnerships with other healthcare professionals, researchers have identified significant benefits for physicians (e.g., consulting with other healthcare professionals), children (e.g., receiving early diagnosis and treatment), and families of individuals with developmental disabilities (e.g., less frustration in terms of obtaining medical support for their children). Such collaborations ultimately promote optimal service delivery for individuals with ASD and other developmental disabilities (Ritzema et al., 2014; Zwaigenbaum et al., 2016).

Researchers in the United States, Australia, and United Kingdom have identified working experience with individuals with ASD and other developmental disabilities as imperative in improving medical practitioners' knowledge, skills, comfort levels and attitudes when providing care for this population (Havercamp et al., 2016; Woodard, Havercamp, Zwygart, & Perkins, 2012). Additionally, Ontario physicians who have been in practice for a longer period of time have reported higher comfort level when providing care for individuals with ASD compared to those who have been practicing, for example, for less than five years (Ghaderi & Watson, 2019). According to Havercamp and colleagues (2016), medical training that provides opportunities for medical students to gain hands-on experience working with individuals with ASD and developmental disabilities has been shown to be effective in enhancing practitioners' knowledge, competencies and attitudes. In other words, medical students who directly worked with patients with developmental disabilities indicated improvements in their knowledge, communication skills, self-efficacy, and attitudes when providing care for this population (Havercamp et al., 2016).

Despite a wealth of research based in the United States, United Kingdom, and Australia investigating the experiences of medical practitioners when providing care for the ASD population, there is little known about these matters in Ontario, Canada. Overall, research illustrates that there are obstacles (i.e., delay in diagnosis, medical practitioners' lack of knowledge and comfort level in providing care for individuals with ASD) and facilitators (i.e., collaboration with other healthcare professionals) that impact physicians' experiences when dealing with individuals with ASD. Furthermore, the results of the study by Ghaderi and Watson (2019), indicated that Ontario physicians reported lack of comfort in providing diagnosis and treatment for this population; therefore, there is a need to explore Ontario physicians' experiences when providing diagnosis and treatment for individuals with ASD. The present study was based on examination of data generated from the two-phase study previously described by Ghaderi and Watson (2019), but it focused on qualitative information pertaining to barriers and facilitators that Ontario physicians experience when providing care for the ASD population. Some data from this study have already been published (Ghaderi & Watson, 2019).

Methods

As explained by Ghaderi and Watson (2019), "participants in this study were accessed through snowball sampling, social media (e.g., Facebook), as well as conferences in health- and developmental-related areas" (p. 684). The Laurentian University Ethics Board approved this study, and informed consent was obtained from all participants at both phases of the study (i.e., quantitative and qualitative). Participants were assured that they had the freedom to withdraw from the study at any time. All participants are referred to by pseudonyms to protect their identities.

Participants

As explained by Ghaderi and Watson (2019), participants in this study were comprised of physicians who would encounter individuals with ASD (e.g., family physicians, pediatricians, and developmental pediatricians), and who practiced in the province of Ontario. Twenty seven participants completed a set of quantitative questionnaires, at the end of which they were invited to participate in a semi-structured interview. From 27 participants, five [family physician (n = 3), developmental pediatrician (n = 1), child and adolescent psychiatrist (n = 1)] volunteered to partake in a semi-structured interview. The age of participants (n = 27) ranged from 28 to 62, with a mean age of 43, and the majority were female (85%). Further information outlining participant demographics can be found in Ghaderi and Watson (2019).

Materials

For the purpose of this study, participants were first invited to participate in the survey and then some of whom participated in the semi-structured interviews.

Phase I. "In this phase, participants completed the Healthcare Professional Questionnaire, which was adapted from the Healthcare Student Questionnaire (Isaacs, Minnes, Burbidge, Loh, & Versnel, 2012; Minnes, Isaacs, Burbidge, Loh, & Versnel, 2012). The questionnaire was set up via REDCap, which is an online survey website hosted at Laurentian University. Participants also had the option of filling out a paper copy of the questionnaire. The initial section of the Healthcare Professional Questionnaire was designed to capture participants' demographic information such as age, gender, areas of speciality, years of practice, as well as the communities that they had practiced in (i.e., rural and urban)" (Ghaderi & Watson, 2019, p. 685).

In addition to the demographic information, the questionnaire was also designed to investigate participants' levels of education and training in regards to providing care (i.e., diagnosis and treatment) to individuals with developmental disabilities, throughout their undergraduate degrees, medical school, as well as professional training (e.g., pediatric residency). For example, participants were asked to rate their opinion about the usefulness of general undergraduate medical training in increasing their knowledge about developmental disabilities on a 3-point Likert scale (i.e., *"not helpful"* to *"very helpful")*.

Phase II. "At the end of the survey, the participants were invited to partake in a semi-structured interview. All the interviews took place over the phone" (Ghaderi & Watson, 2019, p. 685). The semi-structured interview consisted of approximately 14 questions, "which were intended to explore the participants' perceived levels of competency as well as their experiences when dealing with individuals with ASD" (p. 685). Sample interview questions included "What previous experience(s) do you have with people with intellectual or developmental disabilities? ASD?", "How have these previous experiences influenced your perceived self-efficacy (ability) to care for individuals with intellectual or developmental disabilities? ASD?"

Analysis

As discussed by Ghaderi and Watson (2019), "to analyze the questionnaire responses, data were coded in Statistical Package for the Social Sciences (SPSS; v22)" (p. 685). Using descriptive analyses, the demographic characteristics of the participants, as well as the frequency of their answers with regards to questions such as *"How competent do you feel collaborating with different healthcare providers, educators, and other professionals?"* were summarized.

As discussed by Ghaderi and Watson (2019), "in order to capture participants' experiences, this paper employed an integrated approach where the interview results that coincided with findings from the quantitative analyses were analyzed and presented here. Participants' responses to open-ended interview questions, such as *"Have you been exposed to ASD during your medical practice,"* were examined and analyzed using an inductive thematic analysis (Braun & Clarke, 2006). All interviews were digitally recorded and transcribed verbatim. Transcripts were read and reread in order for the researchers to become familiar with the data. Following repeated readings, the researchers gathered detailed notes, and comments were made in the margins of the transcript with regards to the thoughts and statements that were discussed by participants, as well as patterns that occurred in the data. Next, the initial codes were generated based on recurring patterns, and the data were collapsed into labels. Then the codes were combined to create themes that accurately represented the data. The themes were defined based on the aspects of the data that were being captured as well as their meaningfulness in the present study" (p. 686). For the purpose of this paper, the data that were gathered during the interview were integrated with the results of the quantitative analyses.

Results

These sub-sections are based on the main themes identified in the analysis of the interviews and are supported by the questionnaire responses in an integrated approach.

"There was no particular focus on ASD": Barriers in Providing Care for Individuals With ASD

Participants stated that factors such as limited focus on ASD in medical school and professional trainings or workshops, as well as difficulties accessing resources or information about providing services to individuals with ASD, hinder their ability to provide care to individuals with ASD. The results of the questionnaire also revealed that most participants identified insufficient education and training throughout undergraduate medical education and unhelpfulness of resources available to them as barriers impeding their preparedness to meet the needs of patients with ASD.

Participants were asked to rate the usefulness of their general undergraduate training and professional or postgraduate training in increasing their knowledge about developmental disabilities on a 3-point Likert scale. Thirty-three percent of the participants rated their undergraduate training as *"not helpful,"* 37% rated it as *"moderately helpful,"* and 3.7% rated it as *"very helpful"* (see Figure 1). In addition, 53% of the participants rated their professional or postgraduate training as *"moderately helpful,"* and 42% rated it as *"very helpful"* (see Figure 2).

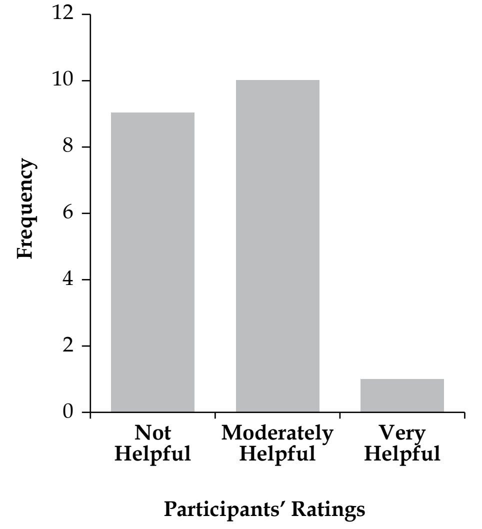

*Figure 1. Participants' ratings on usefulness of undergraduate training in increasing their knowledge regarding developmental disabilities**

**20 of 27 participants answered this question*

These results show that most participants did not feel that they received sufficient knowledge and training with regards to the diagnosis and treatment of developmental disabilities during their undergraduate medical education. Additionally, less than half the participants found their professional training on developmental disabilities as very helpful in providing them with knowledge and training regarding such matters. Similar to these findings, all participants who participated in the interview raised concerns with regard to the lack of education on ASD and developmental disabilities during their undergraduate and post-graduate medical education. For example, when asked about his medical education and training on ASD, Jason, a family physician, responded that "There was no particular focus on ASD." Monica, a psychiatrist, also stated "I imagine there would have been a lecture, but I can't remember; there would have been a … pediatric lecture." Other participants with pediatric or developmental psychiatry specialties claimed they obtained most of their education about the diagnosis and treatment of ASD during their professional training, as opposed to their undergraduate training. For instance, Monica, a developmental psychiatrist, stated "after psychiatry, I did an extended fellowship in child and adolescent psychiatry. It's been 20 years, I have been working in developmental disabilities with both children and adults." Based on these results, it appears that physicians who pursue professional or postgraduate medical education are more likely to gain knowledge and training regarding ASD in comparison to other physicians. Overall, all participants expressed the need for more extensive education about ASD throughout their medical education.

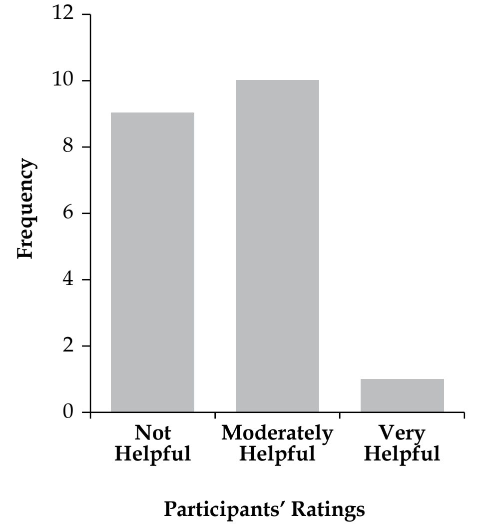

Figure 2. Participants' ratings on usefulness of professional/postgraduate training in increasing their knowledge regarding developmental disabilities

Although participants reported high rates of participation in professional trainings and workshops on ASD (85.2%), they did not report these trainings as being helpful in improving their knowledge about the diagnosis or treatment of autism. This lack of relationship between training and increased knowledge is demonstrated by Sharon, a developmental paediatrician, who when asked about the helpfulness of training sessions, stated "with conferences, yes and no, because sometimes they are very generalized; so, they discuss general things and not very specific like, OK, we have a kid with ASD, and this is what we should do." Therefore, it is likely that the educational content of the professional opportunities and workshops may not be judged as helpful in enhancing physicians' knowledge about ASD.

"I definitely see a lot of ASD in my practice": Facilitators in Providing Care for Individuals With ASD

When asked about factors that enhance their experience and perceived competency when providing care for individuals with ASD, participants reported that clinical exposure and working with this population as well as working as part of an interdisciplinary team facilitated their experiences and improved their perceived comfort level.

The interview analysis showed that participants who have worked with individuals with ASD reported higher knowledge regarding the diagnosis and treatment of autism. For example, Sharon, a developmental paediatrician, stated "I definitely see a lot of ASD in my practice. Prior to residency, not much exposure in medical school, but I definitely see a lot more in my private practice, a lot more diagnosis of ASD." Additionally, Nina, a family physician, stated "I think the more experience people have, especially in the training, and understanding of what's going, the easier it becomes, because we learn from our patients; every patient we encounter, we learn. So, one of the critical things to have is exposure as medical students and residents." These findings reveal that despite the desire for more education and training throughout their medical education, work experiences with this population enhanced their perceived knowledge about the diagnosis and treatment of ASD. The interview findings thus highlight the importance of hands on experience with the ASD population to enhance physicians' perceived knowledge about the diagnosis and treatment of ASD.

The literature has demonstrated that collaboration among healthcare professionals is one of the leading factors in enhancing the healthcare system for both physicians and individuals with ASD (Swiezy, Stuart, & Korzekwa, 2008). Descriptive analysis was performed in order to investigate the frequency of participants who have had experience working as part of an inter-professional team. The results showed that 89% of the participants (n = 24) have worked as part of a professional interdisciplinary team. The analysis of the interview transcripts also revealed that participants working in an interdisciplinary team reported higher levels of comfort and competence in providing care for individuals with ASD. For example, when Monica, a psychiatrist, was asked about her experience working with individuals with developmental disabilities and ASD, she stated

> I love it. It's extremely appealing and rewarding, and part of it is when you have the ability to work as an interdisciplinary team, and I think if you are trying to do it on your own as a healthcare provider, it is rather daunting and very very time consuming. I think, part of the joy is when you feel confident, they know you are gonna do your best to understand them and help them to have a better quality of life, they feel better and is best done in team settings.

These findings illustrate that working as part an interdisciplinary team contributes to physicians' enhanced experiences and perceived competence when providing care (i.e., making a diagnosis) for individuals with ASD.

Discussion

The present study was conducted to explore the barriers and facilitators physicians experience when providing care for individuals with ASD. Previous studies have shown that lack of education and training regarding ASD throughout medical education is a significant barrier medical practitioners experience when dealing with this population (Carbone et al., 2010; Fenikilé et al., 2015; Nah, Young, Brewer, & Berlingeri, 2014). In support of these findings, the results of this study also revealed that most participants rated the usefulness of undergraduate medical training as moderate in increasing their knowledge regarding developmental disabilities and

ASD. Furthermore, a handful of participants expressed their needs for further education and training regarding ASD in medical school. Most participants, who participated in the interviews, stated that they may have received only one lecture regarding ASD during their undergraduate medical education. Due to a perceived lack of ASD training throughout their medical education, participants felt the need to educate themselves by attending conferences, workshops, and training on their own time. While some participants reported such workshops and trainings helpful in providing them with knowledge and skills about dealing with individuals with ASD, other participants found such trainings to be too general and therefore unhelpful.

On the other hand, approximately half of the participants (i.e., 53%) rated the usefulness of postgraduate and professional training as very helpful in increasing their knowledge regarding such disabilities. Participants who obtained their degrees in more specialized programs regarding children and adolescents (e.g., developmental paediatrician and child and adolescent psychiatrist) received more training and education with regard to individuals with developmental disabilities and ASD, compared to family physicians, who felt they did not receive sufficient training with regard to this population, unless they participated in specialized workshops on developmental disabilities due to their personal interests. Overall, the results of this study are in line with previous findings with regards to medical practitioners' concerns about challenges they experience in terms of the time they must spend in order to educate themselves on the diagnosis and treatment of ASD (Carbone et al., 2010; Nah et al., 2014).

According to Havercamp and colleagues (2016), in order to improve the quality of care for individuals with ASD, there is a need for healthcare providers to receive ASD-specific training. However, the findings of this study revealed that participants often do not find the educational content helpful in increasing their knowledge regarding ASD in approaching the needs of this population. Specifically, professional trainings and workshops may focus on the general topic of developmental disabilities rather than being specific to ASD and its diagnostic and treatment approach. In line with previous research (e.g., Havercamp et al., 2016; Major et al., 2013), the findings of this study shed light on physicians' needs for more specific training, through which they learn about ASD, its symptomology, identification, diagnosis, and treatment, rather than education or workshops focused on the general topic of developmental disabilities. Therefore, it is imperative to implement ASD-specific training in medical curricula and residency programs in order to provide physicians with clinical exposure to the ASD population.

The findings of this study also identified a few facilitators reported by participants related to their training and experiences when providing care for this population. As discussed by Havercamp and colleagues (2016), clinical experience working with individuals with ASD improved medical students' attitudes, knowledge and skills in providing care for this population. Similar to such findings, participants in this study also identified hands-on clinical experience working with individuals with ASD as helpful in enhancing their knowledge and comfort level in meeting the needs of this population. Research shows, receiving education and training with regards to ASD has proven to be imperative in physicians' preparedness and comfort level providing care (i.e., diagnosis and treatment) for individuals with ASD (Finke et al., 2010). Therefore, implementing clinical placements and residency programs that are focused on ASD will provide physicians with opportunities to enhance their competency in meeting the needs of patients with ASD.

Finally, collaboration among healthcare professionals (e.g., physicians and psychologists) has demonstrated to enhance the ASD diagnostic process as well as medical practitioners' experiences when providing care for individuals with autism and developmental disabilities (Ritzema et al., 2014). In line with these findings, participants in this study reported higher comfort levels and perceived competence providing care for individuals with ASD when they work with other healthcare professionals. Therefore, promoting and improving communication and collaboration between medical practitioners and other health care professionals such as psychologists as well as speech and language pathologists is a critical step towards enhancing the primary care for individuals with ASD and their families.

Limitations

Even though this study addressed the gap in the literature with regards to Ontario medical practitioners' experiences when providing care for individuals with ASD, a number of limitations are present. This study investigated the experiences of medical practitioners in limited geographic areas in Ontario, and therefore results may not be generalized to other communities in this province. For the purpose of this study, information regarding physicians' past trainings (i.e., where and when they received trainings) were not gathered. This information may have better explained their perceptions of the trainings that they have had received. Furthermore, given the nature of the medical profession, physicians are often considered the busiest professionals (Cunningham et al., 2015; Flanigan & McFarlane, 2008). More than 50 participants, whose contact information was gathered through the College of Physicians and Surgeons of Ontario (CPSO) website, social media, and snowball sampling, were invited (i.e., via emails, phone calls, etc) to participate in the study, but only 27 participants filled out the questionnaires and five participated in the interviews. Consequently, the current participants may have different experiences working with individuals with ASD than practitioners practicing in other regions of Ontario due to their interest in terms of obtaining education and training in this area.

Finally, in order to facilitate medical practitioners' participation in this study, a significant number of participants were recruited at conferences (i.e., the Health and Wellbeing Conference and Child Development Update conference). These conferences were in the areas of physical and developmental disabilities, where participants were exposed to education and training about developmental disabilities. Therefore, due to the educational setting, the possibility exists that these participants may have had biased perceptions of their own knowledge and competency. Participants recruited at the conferences may have higher levels of interest in acquiring knowledge and training with regards to developmental disabilities, as well as ASD. In addition, due to the educational nature of the conferences, some participants may have experienced a heightened perception of their knowledge about the diagnosis and treatment of ASD, and therefore, may have rated their perceived knowledge higher in comparison to other developmental disabilities.

Conclusion and Implications

This study investigated the barriers and facilitators that Ontario physicians experience when providing care to individuals with ASD. The findings illustrate a number of challenges that physicians often encounter when dealing with individuals with ASD. Most participants expressed their needs for further ASD-specific education and training throughout their undergraduate medical education. Physicians would benefit from professional development opportunities that are focused specifically on ASD and would provide them with knowledge and hands-on experience with regard to providing care for the ASD population.

The current study supports the findings of existing research that those who have had clinical and experiential experience working with individuals with ASD reported higher levels of comfort and competence in meeting the needs of this population. Furthermore, the findings of this study revealed that collaboration among physicians and other healthcare professionals have been found to play a significant role in their knowledge and comfort level when dealing with this population.

In conclusion, the findings of this study point to the importance of increasing discussion of ASD in medical school curricula and professional development. In addition to providing more ASD education and training throughout medical education, it is imperative for medical students and practitioners to gain hands-on clinical experiences working with individuals with ASD throughout their medical education and residency programs. Finally, even though lack of education and training are identified as some of the significant barriers medical practitioners experience when dealing with this population, other facilitators such as collaboration with other healthcare professionals can be promoted in order to enhance the experiences and perceived competence of physicians, ultimately improving the care for patients with ASD and their families.

Key Messages From This Article

Professionals. Physicians have a desire to learn more about autism diagnosis and treatment of individual with ASD. However, they do not feel prepared to meet the needs of their patients with autism. Therefore, experience working with individuals who have autism increases the perceived competence of physicians working with this population. Additionally, working in an interdisciplinary team enhances physician competence when they have a patient with autism.

Policymakers. Policy to promote more extensive education and clinical trainings regarding ASD is crucial in medical schools, in order to better prepare future medical practitioners to feel competent to provide care for this population.

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Traditional and Cyber Bullying and Victimization Among Youth With Autism Spectrum Disorder: An Investigation of the Frequency, Characteristics, and Psychosocial Correlates

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Abstract

High rates of Internet use among youth with autism spectrum disorder (ASD) increases the likelihood for engagement in cyber bullying and experiences of cyber victimization, which subsequently increases risk for behavioural and mental health problems. The current study aimed to examine the frequencies, characteristics, and psychosocial correlates of traditional and cyber bullying and victimization among youth with ASD. Youth with ASD (n = 23, aged 10–17 years) completed an online questionnaire about their experiences of traditional and cyber bullying and victimization, technology use, social support, symptoms of anxiety and depression, and life satisfaction. Parents answered questions related to their children's general demographic characteristics (e.g., age, gender, cultural background) and autistic traits. Rates of traditional (60.9%) and cyber (73.9%) victimization exceeded rates for traditional (26.1%) and cyber (17.4%) bullying. Multiple regression analyses indicated that engagement in cyber bullying and experiences of cyber victimization were associated with increased symptoms of anxiety but not depression. Findings show the pervasiveness of bullying and victimization even amongst a small sample of youth with ASD, and demonstrate the importance of developing intervention strategies to help youth use effective coping strategies and to reduce the rates of traditional and cyber bullying and victimization in this population.

Bullying is a pervasive global problem that has a negative impact on youth development. Several meta-analyses suggest that traditional forms of peer-based bullying and victimization (i.e., physical, verbal, or relational) are bi-directionally associated with behavioural and mental health problems in adolescence (Casper & Card, 2017; Reijntjes, Kamphuis, Prinzie, & Telch, 2010; Reijntjes et al., 2011). Increased advancements and accessibility to technology have changed the landscape of social interactions and have coincided with the emergence of a new form of bullying called cyber bullying, or peer-based bullying through the use of technology. Cyber bullying is also associated with behavioural and mental health problems in typically developing youth (Holfeld & Mishna, 2019; Kowalski, Giumetti, Schroeder, & Lattanner, 2014). Despite similarities with traditional forms of bullying with regard to intent, repetition, and a power imbalance between the victim and perpetrator (Kowalski et al., 2014), cyber bullying appears to be a unique and distinct form of bullying (Dempsey, Sulkowski, Nichols, & Storch, 2009; Law, Shapka, Domene, & Gagne, 2012;

Wang, Iannotti, & Nansel, 2009). Although cyber bullying is reported less frequently than traditional forms of bullying (see Modecki, Minchin, Harbaugh, Guerra, & Runions, 2014), it may be more distressing because it can be perpetrated anonymously, involve an unlimited audience, and can leave youth susceptible to abuse day or night, at home or at school (Holfeld & Mishna, 2018).

Youth with developmental disabilities (DD) in general are at a heightened risk for peer-based bullying or victimization compared to typically developing youth (see Schroeder, Cappadocia, Bebko, Pepler, & Weiss, 2014) and high rates of Internet use in this group makes it highly probable that they will experience cyber victimization (e.g., been bullied through technology) and/or engage in cyber bullying behaviours (e.g., bullied others through technology) (Kuo, Orsmond, Coster, & Cohn, 2014). Youth with autism spectrum disorder (ASD) are particularly vulnerable because the characteristics of the disability itself include difficulties with social communication and interaction, and rigid, repetitive, and often unusual behaviours, making them particularly vulnerable and visible targets for bullying. Social communication issues such as lack of social insight and poor theory of mind (i.e., difficulty understanding others' perspectives) (Carter, 2009; Kowalski & Fedina, 2011; Twyman et al., 2010), and difficulties understanding non-literal speech (e.g., sarcasm, figures of speech) and social nuances of speech all increase the probability that youth with ASD may misunderstand communications or respond in socially inappropriate ways. Further, youth with ASD have a high risk for developing behavioural and mental health problems (Kowalski et al., 2014), and consequently, it is critical to understand and prevent further risk in this vulnerable group. In the current study, we report the frequencies, characteristics, and psychosocial correlates of traditional and cyber bullying and victimization among youth with ASD to facilitate a clearer picture of the problem.

Rates of traditional victimization (from being bullied) range from 44 to 75% across studies involving youth with ASD (Carter, 2009; Rose, Espelage, Aragon, & Elliot, 2011; Schroeder et al., 2014; Twyman et al., 2010; van Roekel, Scholte, & Didden, 2010). The rates for traditional victimization are generally high in disability groups (Kumpulainen, Rasanen, & Puura, 2001), and may be up to four times higher among youth with less severe autism (e.g., Asperger's Syndrome) than among typically developing youth (Little, 2001). Youth with ASD are particularly vulnerable to bullying because their typically developing peers often see them as odd and unusual (Cappadocia, Weiss, & Pepler, 2012; Kowalski & Fedina, 2011). They have difficulties interacting with others because they struggle to process and interpret emotional information and other social cues in the typical ways (Montgomery, Stoesz, & McCrimmon, 2012; Rigby, Stoesz, & Jakobson, 2015; 2018). This makes establishing friendships challenging, and may isolate youth with ASD from their peer group, thus leaving them highly vulnerable to additional social challenges. Furthermore, youth with ASD are more prone to aggressive behaviours, which may increase their risk for engaging in bullying behaviours (Gotham, Unruh, & Lord, 2015; McClintock, Hall, & Oliver, 2003). Both victimization and aggression towards others may be exacerbated by a lack of insight (see Frith, 1994) in social situations and impaired ability to accurately and efficiently process social and emotional information (Montgomery et al., 2012). For example, they may mimic the bullying behaviours that they see others demonstrating without understanding the social nuances and implications (Frith & Hill, 2004). Thus, youth with ASD may not be aware of or understand the consequences of their own behaviour.

Despite the growing concern surrounding traditional bullying and victimization among youth with ASD, less is known about this specific group's engagement in cyber bullying or experiences of cyber victimization. For example, rates of engagement in cyber bullying and experiences of cyber victimization were 6% and 21% respectively for a sample of 42 youth (aged 10-20 years) diagnosed with ADHD and/or Asperger's Syndrome; 38% reported engagement in traditional bullying and 57% experienced traditional victimization (Kowalski & Fedina, 2011). For youth with DD (n = 114, aged 12–19 years), 16% engaged in cyber bullying and 22% reported cyber victimization via the Internet at least once in the past month (Didden et al., 2009). However, research that has focused specifically on youth with ASD and their experiences with cyber bullying and victimization is limited.

Similar to typically developing peers, youth with ASD report increased mental health symptomatology when they are involved in traditional bullying (see Schroeder et al., 2014). For example, traditional victimization is positively associated with internalizing symptoms (e.g., anxiety and depression) whereas traditional bullying is negatively associated with emotional regulation challenges (Cappadocia et al., 2012; Rieffe, Camodeca, Pouw, Lange, & Stockman, 2012; Zablotsky, Bradshaw, Anderson, & Law, 2013). A similar trend was shown for youth with ADHD and/or Asperger's syndrome who were involved in cyber bullying (i.e., engaged in cyber bullying behaviours or had experiences of cyber victimization) and reported greater symptoms of anxiety and depression than for those reporting no involvement (Kowalski & Fedina, 2011). Likewise, in a longitudinal study of 113 youth aged 13 to 15 years with DD, Wright (2017) found that cyber victimization was associated with more symptoms of depression, however, this association was weakened when youth reported more support from parents or teachers (but not peers). Given the risk to youth with ASD, the specific aims of the current study were to: (1) determine the frequencies of both traditional and cyber bullying and victimization in a sample of youth with ASD; (2) extend past research to describe youths' unique experiences with traditional and cyber victimization; and (3) examine the psychosocial correlates (e.g., symptoms of anxiety and depression, life satisfaction, and social support) for cyber bullying and victimization.

Method

Participants and Procedure

Youth with ASD were recruited via word-of-mouth, social media advertising, through the Autism Spectrum Disorders Canadian-American Research Consortium (ASD-CARC; www.asdcarc.com), a research organization whose primary goal is to improve the "lives of those affected by ASD," and via newsletters distributed by community autism service agencies across Canada. One hundred parents and their children began the online survey, and recruitment was continuous over a 2-year period from 2013 to 2015. Data from 42 participants were excluded due to missing data patterns on at least 50% of the questions; in these cases, a parent started the survey but did not complete their portion. Because the data for the present study was collected via anonymous web-based survey, we paid particular attention to the pattern of responses of the 58 complete questionnaires that remained. We found strong evidence to suggest 35 cases of inattentive or careless responses (e.g., same responses on many or all items) on the portions of the survey that the adolescents were asked to complete. Thus, the final sample included 23 youth (18 boys, 5 girls) who scored 30+ on the adolescent version of the Autism-Spectrum Quotient (AQ-Adol; Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006) indicating increased severity of autistic traits (M = 36.0, SD = 4.4, *Range* = 30.0–45.0). Participants ranged in age from 10 to 17 years (M = 13.7 years, SD = 2.4), were in enrolled in grades four to 12 (M_{grade} = 8.4, SD = 2.4), and identified as Caucasian (91.3%), Asian (4.3%), or other (4.3%).

Parents interested in participating in the study clicked on the link that directed them to an online questionnaire created and delivered using Qualtrics (Qualtrics LLC, US). Parental consent and youth assent were required to initiate the online survey, and participants were prompted to print consent/assent forms for their records. The questionnaire took 30–90 minutes for participants to complete. Parents who provided an email address were eligible to win one of five Amazon gift cards worth $50. This study was approved by the Psychology/Sociology Research Ethics Review Board at the University of Manitoba, Winnipeg, Canada.

Measures

Measures completed by parents. Parents responded to questions about their child's general demographic characteristics (e.g., age, sex, grade, and cultural background) and severity of autistic traits.

Autism Spectrum Quotient. Parents' perceptions of the severity of autistic traits among their children were measured using a 50-item adolescent version of the AQ-Adol (Baron-Cohen et al., 2006). The AQ-Adol assesses five areas of functioning, social skills, attention switching, attention to detail, communication, and imagination, using 10 questions for each area. Items are rated on a 4-point Likert-type scale ranging from 1 (*definitely agree*) to 4 (*definitely disagree*). Each response is coded as either a "0" or "1" to represent the absence or presence of each symptom, respectively. A total AQ-Adol score was created by summing the coded responses; higher scores represented a greater severity of autistic traits (α = .97). Subscale scores were computed by summing the responses to 10 questions for each scale. Previous work has shown that 90% of adolescents with increased severity of autistic traits met the cut-score, (i.e., scored 30+ on the total AQ-Adol), but controls did not meet the cut-score (Baron-Cohen et al., 2006). Thus, for the present study, we analyzed the data from youth scoring at or above the cut-score of 30 to help ensure that the experiences of youth with ASD were being described.

Measures completed by youth. Youth completed questions about their involvement in traditional and cyber bullying and victimization, technology access and use, symptoms of anxiety and depression, social support, and life satisfaction.

Technology access and use. Youth were asked whether they owned a cell phone and the amount of time they spent using it during the week and on the weekend. They were also asked how many computers were in the household, and the amount of time they spent on it during the week and on the weekend. Time spent using cell phones and computers were each rated on a 5-point Likert scale (1 = *less than 1 hour*, 2 = *1–2 hours*, 3 = *2–3 hours*, 4 = *3–4 hours*, 5 = *more than 4 hours*). Week and weekend responses for cell phone and computer use were summed to create a technology use score.

Traditional bullying behaviours and victimization experiences. We adapted the Revised Olweus Bully/Victim Questionnaire (Olweus, 1996), a widely used instrument to assess bullying (Solberg & Olweus, 2003). Youth were provided with a definition of traditional bullying:

> A student is being bullied when a student or group of students do any of the following: say mean or hurtful things to him/her or tease him/her in a hurtful way; spread false rumours about him/her; hit, kick, or push around him/her; or intentionally leave them out of the group. These things happen repeatedly over time and it is hard for the student being bullied to defend him/herself. It is not bullying when these things are done in a friendly or playful way or when two students of about the same strength argue or fight.

Youth then reported their involvement for discrete traditional bullying (i.e., "How often have you bullied others?") and victimization (i.e., "How often have you been bullied?") events in the past two to three months on a 4-point Likert-type scale (0 = *never*, 1 = *once or twice*, 2 = *a few times*, 3 = *many times*, 4 = *every day*). Follow-up questions asked youth about their most recent victimization experience such as: why they thought they were targeted, how long the situation lasted, the severity of the experience, the identity of the bully and the strongest emotion they experienced. Youth were also asked about their responses to the experience and the perceived effectiveness of the response(s) in reducing the bullying and distress.

Cyber bullying behaviours and victimization experiences. Involvement in cyber bullying was assessed using a behavioural index of cyber bullying offending and victimization (adapted from Patchin & Hinduja, 2010). Over the last decade (Hinduja & Patchin, 2015), strong psychometric properties have been reported for these measures across a range of studies. Five-items asked youth about their engagement in cyber bullying behaviours (e.g., "Took a picture of someone and posted it online without their permission") and 9-items asked about their cyber victimization experiences (e.g., "Something posted online that you did not want others to see") in the past two to three months. Items were rated on a 5-point Likert-type scale, ranging from 0 (*never*) to 4 (*every day*). Two indices of cyber bullying involvement were computed by summing the ratings for each scale; higher scores represented greater engagement in cyber bullying (α = .99) and greater cyber victimization (α = .99). Similar to traditional victimization in the previous measure, we asked youth to share details about their most recent cyber victimization experience.

Perceived social support. Adolescents' perceived level of social support was assessed using the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988). Strong psychometric properties (e.g., reliability and validity) of the MSPSS have been reported in past research (Zimet, Powell, Farley, Werkman, & Berkoff, 1990). In the current study, we assessed perceived social support from friends (4-items; e.g., "I can count on my friends when things go wrong") and family (4-items; e.g., "My family really tries to help me"). Youth rated each item on a 7-point Likert-type scale that ranged from 1 (*very strongly disagree)* to 7 (*very strongly agree*). Items on each scale were summed with higher scores representing greater perceived support from friends (α = .96) and family (α = .92).

Symptoms of anxiety and depression. Youths' self-reported symptoms of anxiety and depression were measured using the shortened 21-item version of the Depression, Anxiety, and Stress Scale (DASS-21; Lovibond & Lovibond, 1995). Although originally developed for adult populations (Henry & Crawford, 2005), strong psychometric properties for the DASS-21 have been found in adolescent samples (Campbell, Slee, Spears, Butler, & Kift, 2013; Szabó, 2010) Participants rated their symptoms of anxiety (7-items; e.g., "I felt I was close to panic") and depression (7-items; e.g., "I felt that I had nothing to look forward to") in the past week on a 4-point Likert-type scale, ranging from 0 (*did not apply to me at all*) to 3 (*applied to me very much* or *most of the time*). Scores from each subscale were summed with higher scores representing higher levels of anxiety (α = .94) and depression (α = .97).

Satisfaction with life. Youths' subjective well-being and satisfaction with life was assessed using the 5-item Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffith, 1985). Past research demonstrates the reliability and validity of the SWLS across different age groups (Pavot & Diener, 2008; Pavot, Diener, Colvin, & Sandvik, 1991). Youth rated each item (e.g., "I am satisfied with my life") on a 7-point Likert-type scale, ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Overall life satisfaction scores were created by summing the responses for each item so that higher scores represented greater levels of life satisfaction (α = .94).

Data Analyses

Descriptive statistics and zero-order correlations were used to examine the associations between all study variables. Descriptive statistics were also used to assess the frequency of traditional and cyber bullying and victimization, as well as the characteristics of youth's most recent experience with traditional and cyber victimization. Two multiple regression analyses were conducted to examine the relation between traditional and cyber victimization and anxiety and depression. Due to our small sample size, we limited the number of predictor variables to three (i.e., cyber bullying, cyber victimization, and satisfaction with life). We chose the standard 'enter' method because it is the most conservative and recommended for smaller sample sizes (Brace, Kemp, & Snelgar, 2006). Thus, the three selected predictor variables were added simultaneously in one block/step. All variables were examined for normality, outliers, skew, and kurtosis; results suggested that the scores were normally distributed. All analyses were conducted using SPSS version 25.0.

Results

Descriptive Statistics and Zero-Order Correlations

Descriptive statistics and zero-order correlations between variables are presented in Table 1. Overall, symptoms of anxiety were positively associated with symptoms of depression and engagement in cyber bullying behaviours, and negatively correlated with satisfaction with life. Symptoms of depression were negatively correlated with satisfaction with life but not with engagement in cyber bullying behaviours. Cyber victimization experiences were positively associated with both traditional bullying behaviours and traditional victimization experiences, but not related to engagement in cyber bullying behaviours.

Technology Access and Use

More than half of the youth (60.9%) did not own a cell phone. Of the nine that did, six reported that they received a cell phone at the average age of 12 years (*SD* = 2.3; *Range* = 10–15 years). Cell phones were used primarily for sending and receiving text messages (44.4%) and social networking (33.3%). However, all youth reported access to a computer (and/or iPad) in their homes, and most had access to three or

Table 1. Descriptive Statistics and Zero-Order Correlations

Variable	*M*	*(SD)*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*
1. Anxiety	3.83	(3.08)	—								
2. Depression	3.87	(3.67)	.58**	—							
3. Technology use	8.87	(3.49)	.29	.34	—						
4. Traditional bullying	0.26	(.45)	.17	-.12	-.30	—					
5. Traditional victimization	1.17	(1.15)	.39	.09	-.07	.44*	—				
6. Cyber bullying	0.52	(1.28)	.58**	.32	.26	.07	.21	—			
7. Cyber victimization	3.43	(3.27)	.31	.24	.03	.45*	.56**	-.19	—		
8. Family support	24.57	(3.76)	-.17	-.34	.04	.12	.44*	-.34	.18	—	
9. Peer support	21.09	(4.63)	-.11	-.13	.07	.14	-.39	.08	-.07	-.30	—
10. Satisfaction with life	24.17	(7.20)	-.55**	-.75***	-.21	-.13	-.18	-.15	-.23	.26	.33

Note: *$p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

more computers (73.9%). Nearly 69.6% of youth used a computer in an open area in the home, whereas 30.4% used a computer in their bedrooms. The majority of youth primarily used a computer to play online games (34.8%) or watch videos online (21.7%). The mean technology use score for cell phones and computers was 8.9 (*SD* = 3.5; *Range* 3–19).

Frequency and Characteristics of Bullying and Victimization

Traditional bullying. Youth were less likely to report engaging in bullying behaviours (26.1%) than experiencing victimization (60.9%) in the past two to three months. When recalling their most recent victimization experience, youth felt the bullying occurred for no particular reason (40.0%), for having a disability (35.0%), or for their physical appearance (15.0%). These experiences often lasted less than a week (50.0%) with many of them ending within one day (30.0%). For others, the experience lasted a few months or longer (30.0%). The majority of youth rated their victimization experience as moderate (63.3%) or severe (15.8%), and reported feeling upset (35.0%), frustrated (30.0%), angry (20.0%), or helpless (10.0%) as a result. Approximately 5% of youth reported that they were not bothered by the experience. In the majority of cases (90.0%), youth knew the identity of their harasser. Youth first responded to their experience by using an active response (25.8%; e.g., telling an adult), a reactive response (21.5%; e.g., confronting their harasser), or a passive response (17.2%; e.g., trying to ignore it). The first response was rated as at least somewhat effective for 26.5% of youth in reducing the bullying, and 47.4% of youth in making them feel better. Responding by telling a peer was at least somewhat effective for 29.4% of youth in reducing the bullying and 37.6% of youth in making them feel better. Responding by telling a parent was at least somewhat effective for 55.6% of youth in reducing the bullying and 62.6% of youth in making them feel better.

Cyber bullying. Table 2 includes the percentages of youth engaged in various cyber bullying behaviours or victimization experiences at least once in the past two to three months. Similar to the pattern seen with traditional bullying, youth were less likely to report engaging in cyber bullying behaviours (17.4%) than experiencing cyber victimization (73.9%). However, when asked to report on specific, discrete cyber bulling behaviours, engagement in cyber bullying ranged from 4.3% to 17.4% (two behaviours were not endorsed), and experiences of cyber victimization ranged from 4.3% to 30.4%. The most common cyber bullying behaviour was "posting something online about someone else to make others laugh." The most common cyber

Table 2. Percentage of Youth Engaged in Cyber Bullying Behaviours and Victimization Experiences at Least Once within the Past 2-3 months

Cyber bullying behaviours	%
Posted something online about someone else to make others laugh	17.4
Sent someone a text message to make that person angry or to make fun of that person	4.5
Sent someone an email to make that person angry or to make fun of that person	0
Posted something on someone's social networking profile (e.g., Facebook) to make that person angry or to make fun of that person	0
Taken a picture of someone and posted it online without that person's permission	4.3
Cyber victimization experiences	%
Made fun of in a chat room	13.0
Received an email from someone you know that made you really mad	13.0
Received an email from someone you didn't know that made you really mad	4.3
Someone posted something on your social networking profile (e.g., Facebook) that made you upset or uncomfortable	17.4
Someone posted something on another web page that made you upset or uncomfortable	30.4
Received an instant message that made you upset or uncomfortable	27.3
Been bullied or picked on by another person while online	30.4
Have you been afraid to go on the computer	8.7
Anyone posted anything about you online that you didn't want others to see	17.4

victimization experience was "someone posting something on another web page that made you upset or uncomfortable."

When asked about their most recent cyber victimization experience, most youth reported that they did not know why they were harassed (66.7%) but some indicated they were victimized because of their physical appearance (11.1%) or disability (11.1%). These experiences often lasted less than a week (66.7%) with most situations lasting just a day (55.6%). One-third of situations lasted a week or two. The majority of youth rated the severity of the experience as moderate (77.8%) and knew the identity of their harasser (66.7%). Youth reported that their strongest emotion from the experience was feeling upset (44.4%), followed by feeling sad (22.2%), angry (22.2%), or frustrated (11.1%).

Youth first responded to the experience using an active response (33.3%; e.g., telling an adult); a reactive response (33.3%; e.g., confronting their harasser); or a passive response (11.1%; e.g., trying to ignore it). Overall, the first response was rated as at least somewhat effective for 77.7% of youth in reducing the bullying, and 77.8% of youth in making them feel better. Responding by telling a peer was at least somewhat effective for 37.5% of youth in reducing the bullying and 66.6% of youth in making them feel better. Responding by telling a parent was at least somewhat effective for 77.8% of youth in reducing the bullying, yet 100% of youth indicated it made them feel better.

Psychosocial Correlates of Anxiety and Depression for Cyber Bullying and Victimization

In the first analysis (see Table 3 on the following page), a significant model emerged, $F(3,19) = 11.76$, $p < .001$, explaining 65.0% of the variance in anxiety. Engagement in cyber bullying behaviours ($\beta = .58$, $p = .001$) and experiences

Table 3. Standardized Regression Coefficients for Predicting Anxiety and Depression

	Anxiety			*Depression*		
Predictors	*B (95% CI)*	*SE*	β	*B (95% CI)*	*SE*	β
Satisfaction with life	-.17 (-.29, -.04)	.06	-.40*	-.35 (-.51, -.19)	.08	-.69***
Cyber bullying	1.41 (.69, 2.12)	.34	.58**	.68 (-.21, 1.57)	.42	.24
Cyber victimization	.31 (.02, .59)	.14	.32*	.14 (-.22, .49)	.17	.12

*Note: CI = confidence interval. *p < 0.05, ** p < 0.01, *** p < 0.001.*

of cyber victimization (β = .32, p = .04) were associated with greater anxiety symptoms, whereas satisfaction with life (β = -.40, p = .01) was associated with fewer symptoms of anxiety. In the second analysis (see Table 3), a significant model also emerged, $F(3, 19) = 10.27$, $p < .001$, explaining 61.8% of the variance in depression. Greater satisfaction with life (β = -.69, $p < .001$) was associated with fewer symptoms of depression; however, engagement in cyber bullying behaviours or experiences of cyber victimization was not associated with level of depressive symptoms.

Discussion

In the new technological world, youth have an endless number of tools (e.g., social media, text messaging, discussion boards, and chat rooms) at their disposal to socialize and communicate with strangers, friends, and family all over the world (Holfeld & Leadbeater, 2015). Digital technology can be a powerful tool for establishing friendships, especially for youth with ASD who often have difficulties interacting socially with others in face-to-face situations. However, their social naiveté in combination with a greater frequency of online access and use may leave them susceptible to bullying in the digital world (Zweers, Scholte, & Didden, 2017). In the current study, our objectives were to calculate the frequencies of traditional and cyber bullying and victimization among a sample of youth with ASD; describe the unique characteristics of youths' experiences of traditional and cyber victimization; and examine the relationships between psychosocial variables and cyber bullying behaviours and victimization experiences to understand risk level and inform prevention opportunities.

In our small sample of youth with ASD, we found that the self-reported rates of traditional and cyber bullying were 26% and 17%, respectively. These rates support past research examining the frequency of traditional bullying behaviour in youth with ASD (e.g., 26.9%, Campbell et al., 2017; range of 15% to 46% across informants, van Roekel et al., 2010) and typical youth (35%, see meta-analysis by Modecki et al., 2014). However, the rates of engagement in cyber bullying behaviours was higher than past research in youth with ASD and intellectual and developmental disabilities combined (e.g., 7.7%; Campbell et al., 2017; 6%, Kowalski & Fedina, 2011), but consistent with the pattern found with typical youth (e.g., range of 5% to 33%, see review by Holfeld & Leadbeater, 2015; 15%, see meta-analysis by Modecki et al., 2014). As seen with typically developing youth (Patchin & Hinduja, 2012), engagement in bullying behaviours was lower than those reported for traditional and cyber victimization experiences (61% and 74%).

The high rates of traditional victimization are consistent with past research among youth with DD (44–75%, Carter, 2009; Rose et al., 2011; Schroeder et al., 2014; Twyman et al., 2010; van Roekel et al., 2010); however, the rates of cyber victimization are again higher than in past research using a similar sample (see Campbell et al., 2017; Didden et al., 2009; Kowalski & Fedina, 2011). When considering the frequency of each type of cyber victimization experience, rates ranged from 4.3% to 30.4%, which is comparable to past research of youth with DD (Campbell et al., 2017; Kowalski & Fedina, 2011) and typically developing youth (Holfeld & Leadbeater, 2015).

Indeed, one reason for differences between studies is that we asked participants about their direct experiences with different types of cyber bullying behaviours or victimization experiences without mention of cyber bullying or cyber victimization. This approach has been shown to result in higher estimates of the frequency of cyber bullying or victimization than more conservative global assessments (Ybarra, Boyd, Korchmaros, & Oppenheim, 2012), and thus may provide a more accurate account of youth's actual online experiences. Using a direct approach is particularly important when surveying (or otherwise communicating with) children and youth with ASD (Hagner & Cooney, 2005; Wetherby, Prizant, & Schuler, 2000), as some researchers have argued that they may not interpret bullying and victimization in the same way as their typical peers (Schroeder et al., 2014; van Roekel et al., 2010).

Results such as these suggest that odd or unusual behaviours and the inability to perceive and accurately process social cues (Montgomery et al., 2012; Rigby et al., 2015; 2018) in youth with ASD increase the challenge of developing positive peer relationships and friendships. Specifically, peers may view youth with ASD as awkward, making those with ASD vulnerable to bullying. Because of their difficulties in understanding others' facial expressions, feelings, and intentions (Montgomery et al., 2012; Rigby et al., 2015; 2018), youth with ASD may inadvertently engage in more bullying behaviours or experience victimization more often (see Zweers et al., 2017). Given the importance of social and emotional processing in this context, an important avenue for future research would be to examine the emotional intelligence, social perception, and processing abilities of youth with ASD to further understand how this relates to bullying behaviours and victimization experiences. Although this study was limited to questionnaire items, using videos or scenarios depicting traditional and cyber bullying and victimization may facilitate an understanding of the nature of impairments that may be more closely related to everyday experiences. Further, it may be helpful to examine the aspects of the scenarios that children and youth with ASD pay attention to and how they interpret the situations, which may be useful for developing interventions to help youth with ASD to cope with or avoid cyber victimization experiences.

Our findings highlight similarities and differences between our samples' most recent experiences with traditional or cyber victimization. Youth with ASD felt that they were more likely to experience traditional victimization than cyber victimization because of their disability. When recalling their most recent victimization experience, youth felt the bullying occurred for no particular reason (40% for traditional victimization and 67% for cyber victimization). This is not surprising given that youth with ASD often struggle in face-to-face social interactions, lack social insight, and report poor theory of mind. In the online world with an absence of social or visual cues, it may be even more difficult for youth with ASD to recognize other's intentions.

Experiences of traditional victimization tended to last longer than those of cyber victimization. For example, two-thirds of situations involving cyber victimization ended in less than a week compared to half of the situations involving traditional victimization. One-third of traditional victimization experiences lasted at least a few months, but none of the cyber victimization experiences lasted that long. Despite a shorter duration, it has been suggested that the characteristics of online world (e.g., potentially unlimited audience, permanency of online content, and the potential anonymity of the perpetrator) can make experiences of cyber victimization (from being bullied) more distressing than traditional forms of victimization (Holfeld & Mishna, 2018). In our study, both traditional and cyber victimization were rated as very serious as nearly 80% of youth rated the severity of their experience as moderate or severe. In both types of victimization situations, youth reported a range of emotions but (understandably) were most likely to feel upset from the experience. Accurately recognizing one's own and others' emotions is important for successful social interactions and increased social interactions facilitate skills improvement. However, individuals with ASD often find social interactions stressful, and thus may avoid them and consequently miss opportunities for improvement.

Youth were most likely to respond to traditional or cyber victimization by using active responses such as telling someone (e.g., friend or adult) or reactive responses such as confronting their harasser or getting revenge. Passive responses (e.g., doing nothing or trying to ignore it) were less likely to be endorsed. Overall, youth reported greater effectiveness in dealing with cyber victimization than traditional victimization. Specifically, the first response(s) to cyber victimization were perceived to be more effective at reducing the bullying and distress associated with it, whereas the first response(s) to traditional victimization were perceived as less effective. Moreover, youth were more likely to receive the help they needed to reduce the bullying and distress when they told a friend or adult in situations involving cyber victimization compared to traditional victimization. Past research with typically developing youth has found that victims often did not receive the help they needed to reduce the bullying or distress when reporting their experience to a friend or an adult (Holfeld & Grabe, 2012). Similarly, youth with ASD may not use parents as a support in these instances (Bitsika & Sharpley, 2014; Humphrey & Symes, 2010a; 2010b). In contrast, youth in the current study indicated both friends and adults were particularly helpful when reporting cyber victimization; other recent research reported that teen girls with ASD indicated parent support was crucial in navigating bullying (Ward, 2016). It is possible that youth with ASD receive a significant amount of family support, and thus may have strong and positive relationships with their parents and siblings (Hutton & Caron, 2005; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004). However, given mixed findings in this area, more research is required to fully understand this. Alternatively, given that all of our youth accessed computers located in open spaces in the home, it is possible that they were more comfortable with their parents about their technology experiences and any internet activity would provide observable opportunities for parent supervision and intervention. We did not collect information about specific child-parent interactions in our sample, but examining child-parent relationships in the ASD population and how that influences the tendency for youth with ASD to report cyber bullying behaviours or victimization experiences to their parents is an important area to understand further.

Past research shows that engagement in cyber bullying is more likely to be related to externalizing problems, whereas experiences of cyber victimization are more likely to be associated with internalizing symptoms (Nixon, 2014). Surprisingly, both engagement in cyber bullying behaviours and experiences of cyber victimization were related to greater symptoms of anxiety, but not depression. In the traditional bullying literature, anxiety and depression are typically combined to form a measure of internalizing symptoms; however, while they often co-exist and overlap, they are distinct constructs (Beck & Clark, 1988; Cummings, Caporino, & Kendall, 2014) with different diagnostic criteria (American Psychiatric Association, 2013). In addition, even adolescents who have both anxiety and depression demonstrate different coping strategies, depending on whether the primary diagnosis is anxiety or depression (Garnefski & Kraajj, 2018), suggesting a strong case to assess these disorders separately. Further, there is some evidence to suggest that these constructs are differentially associated with cyber victimization. For example, in a sample of typically developing youth, Rose and Tynes (2015) found that cyber victimization predicted anxiety whereas depression predicted cyber victimization across three assessment points. While both anxiety and depression impact emotion recognition (e.g., in faces), depressed adolescents demonstrate more severe impairments (Demenescu, Kortekaas, den Boer, & Aleman, 2010) and also show poorer ability to accurately discriminate emotional vocalizations Y/N, while anxious teens showed no impairment (Morningstar, Dirks, Rappaport, Pine, & Nelson, 2019).

Engagement in cyber bullying behaviours also predicted anxiety. However, this result is not surprising as the relation between cyber bullying and victimization appears to be more cyclical than the pattern seen with traditional bullying and victimization (Den Hamer, Konijn, & Keijer, 2014; Holfeld & Mishna, 2018). Specifically, youth who engage in cyber bullying are also more likely to experience cyber victimization. In fact, these roles have been also found to predict more cyber witnessing, which in turn, predicts greater engagement in cyber bullying and experiences of cyber victimization in typically developing youth (Holfeld & Mishna, 2018). It is important for future research to consider how youth with ASD who witness cyber bullying may be impacted by the experience and how this may be exacerbated by involvement in other roles of cyber bullying.

Limitations

Concerns over participant response patterns (e.g., same responses on many or all items) considerably reduced the amount of usable data. Careless responding may result from survey length, environmental distraction, lack of respondent interest, and lack of social contact between participants and researchers (Meade & Craig, 2012). Moreover, an official clinical diagnosis of ASD was not made in the present study, although the AQ was used to validate the presence or absence of autistic traits as has been done in previous research (Rigby et al., 2015; 2018). A limitation of the Total AQ-Adol scores, however, is that these scores do not distinguish between individuals with ASD who require support, substantial support, and very substantial support, or identify the presence of an intellectual disability. Because we opted to conduct an online study, ensuring that an official diagnosis was provided by a qualified practitioner was not possible.

Some have questioned the ability of people with ASD to accurately self-report their experiences given that their symptoms may preclude sophisticated awareness of self and others. Although this is an appropriate consideration in contextualizing the responses of those with ASD, several research studies indicate that youth with ASD do provide accurate self-report (Keith, Jamieson, & Bennetto, 2019; Mazefsky, Borue, Day, & Minshew 2014; Ozsivadjian, Hibberd, & Hollocks, 2014) that are consistent with their autonomic arousal recordings (Keith et al., 2019) and parent-report (Ozsivadjian et al., 2014). Under-reporting rather than over-reporting experiences and/or symptoms may be more of a concern for some youth with ASD. Montgomery et al. (2012) found that youth (aged 16 to 21 years) under-reported the severity of experiences and/or symptoms, or scored high on positive impression validity scales, suggesting reporting better outcomes (although still in the impaired range) than was really the case. Despite slight differences between studies, there is sufficient evidence to demonstrate that self-reports from youth with ASD are indeed appropriate and provide meaningful self-perception/symptom report information for this population.

Participation self-selection, rather than random selection, may have also limited the generalizability of the findings. Access to technology and youths' ability to independently complete the survey (i.e., ASD symptom severity level) may have contributed to a self-selection bias. We also acknowledge that parents and/or youth with ASD with bullying and victimization experiences may have been drawn to participate in our study because it was online and anonymous. Compared to individuals without ASD, individuals with ASD often prefer communication via computers because the messages are easier to control, allows for greater comprehension, and provides a safer way to communicate to others about their true selves and experiences (Gillespie-Lynch, Kapp, Shane-Simpson, Smith, & Hutman, 2014). While providing a sense of safety and security for some individuals, the anonymous online environment could inflate the frequencies of all types of bullying behaviour and victimization. As described above, however, inflation of frequencies of traditional and cyber bullying behaviours and victimization experiences in our study is unlikely as our estimates were consistent with previous reports with larger samples and in paper-based survey research conducted during class time in schools (e.g., Campbell et al., 2017; Carter, 2009; Rose et al., 2011; Schroeder et al., 2014; Twyman et al., 2010; van Roekel et al., 2010).

Because of the limited sample size of our study, the results from the multiple regression analyses should be interpreted with caution as the calculated effect sizes could be strongly influenced by possible sampling error as described above. A small sample size prevented us from controlling for traditional forms of bullying and victimization in multiple regression models. A small sample size also limited our ability to examine how perceived support from family and friends may serve as a protective factor (particularly over the long-term) and reduce the effects of bullying on the development of anxiety and depression in youth with ASD. There is some evidence to suggest that parent and teacher support provide a buffer against symptoms of depression associated with cyber victimization in youth with DD (Wright, 2017). A strong support network has also been found to be protective against traditional victimization for youth with ASD (Gray, 2004). Research with typically developing youth shows that more positive perceptions of support is associated with less traditional victimization (Conners-Burrow et al., 2009; Jenkins & Demaray, 2012; Wang et al., 2009; Yeung Thompson & Leadbeater, 2013) and cyber victimization (Smokowski, Evans, & Cotter, 2014). Future work could determine whether gender differences in social support received exist, and how this affects psychosocial outcomes in those who experience traditional or cyber victimization.

Conclusion

Our findings demonstrate the pervasiveness of bullying and victimization among youth with ASD. The majority of youth reported at least some experience with traditional and cyber victimization. Compared to their typical developing peers, youth with ASD reported much higher rates of peer victimization. Youth reported greater effectiveness in dealing with experiences of cyber victimization (e.g., reducing the bullying and distress) compared to traditional victimization. Greater engagement in cyber bullying and more cyber victimization experiences was also associated with more anxiety, but not depression. The findings from this study may influence the development of intervention strategies to help youth with ASD to acquire and utilize effective coping strategies and to further develop home and school programming to reduce the rates of traditional and cyber bullying and victimization in this clinical population.

Key Messages From This Article

People with disabilities. We hope that this project will help your family and teachers to understand that having a disability makes it more likely that you will be bullied online or offline, so that you can learn what to do to feel safe.

Professionals. Both engagement in cyber bullying and experiences of cyber victimization are more likely to happen to and relate to greater anxiety in youth with ASD. Intervention strategies appropriate for youth with ASD must be developed and implemented so they can acquire and utilize coping strategies.

Policymakers. Efforts to create safe and supportive school environments must be inclusive for all youth to effectively reduce rates of bullying and victimization.

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Welcome On Board

Journal on Developmental Disabilities French Language Editor

Journal on Developmental Disabilities (JODD) welcomes Dr. Mélina Rivard to the JODD Chief Editorial Board as French Language Editor. Dr. Rivard (PhD, PsyD) is Professor, Department of Psychology in the University of Quebec at Montreal, and Researcher at the University Institute for Mental Health of Montreal and the University Institute in Intellectual Disabilities and Autism Spectrum Disorders. As Research Scholar (junior 1) of the Fond de Recherche Québécois en Santé (FRQS), she has set up a funded laboratory called *ÉPAULARD* (Étude des Problématiques comportementales en AUtisme et Les Autres Retards de Développement/Study of Behavioural Issues in Autism and Other Developmental Delays). This laboratory currently trains more than 30 students, including 12 at the doctoral level, as well as other clinical and research trainees. In the last five years, she has published more than 30 scientific articles in international journals, made more than 100 presentations at conventions or knowledge transfer activities and obtained grants from various provincial and national research funds (e.g., Conseil de recherches en sciences humaines du Canada – CRSH); FRQS; Fonds de recherche du Québec – Société et culture (FRQSC), and the Quebec Ministry of Health and Social Services and Foundations (e.g., Miriam, Butters, Bouchard) as the principal investigator.

Chair, Ontario Association on Developmental Disabilities Publication Committee

JODD welcomes Dr. Sue VanDeVelde-Coke as Chair of the Ontario Association on Developmental Disabilities (OADD) Publication Committee. Dr. VanDeVelde-Coke (RN, MBA, PhD) is the President and CEO of Kerry's Place Autism Services. She has served as Executive Vice President and Chief Professions/Nursing Executive at Sunnybrook Health Sciences Centre, Vice President at VON National Canada, Senior Vice President at Winnipeg Health Sciences Centre, and Executive Director of CARE, Centre for Internationally Educated Nurses. Dr. Coke has served on numerous federal, provincial and local task forces and committees namely, the Canadian Nurses Association, the Academy of Canadian Executive Nurses, and the VON National Board of Directors. She is currently a Director on the Habitat for Humanity GTA and the Canadian Nurses Foundation Board of Directors, and is a certified Health Executive.[1]

Reviewers of JODD Articles During 2019

Having a reliable panel of expert reviewers is key to the provision of constructive feedback to authors of articles submitted to the JODD for publication and to the selection of the top paper for the annual JODD Student Publication Prize. Many thanks to the individuals listed below who provided helpful feedback during 2019. Special thanks to Donato Tarulli, Frances Owen and Dorothy Griffiths for mounting the special issue, "Transition Aged Youth" in 2019.

Reviewers During 2019

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[1] Kerry's Place Autism Services. (2019). *Our senior staff*. Retrieved from https://www.kerrysplace.org/about-us/our-senior-staff/

The 2018 Brown and Percy

JODD Student Publication Prize

The Brown and Percy JODD Student Publication Prize… is intended to… encourage student contribution to the journal. The prize (cash award of $500 and an inscribed plaque) will be awarded to an author of what is judged to be the most outstanding student contribution published in a calendar year. In the event of a tie, each winner will receive $250 and an inscribed plaque. A student contribution is deemed to be a paper that has been successfully peer-reviewed and published in the *Journal on Developmental Disabilities* based on research or ideas of someone who is currently a student, or of someone reporting work completed while he or she was a student (e.g., a thesis). Normally, an eligible author for this award is first author of the paper.

ELISA RICHER is the winner of the prize for 2018. Her paper is "He's on the Streets, and Stealing, and Perpetuating the Cycle… and I'm Helpless: Families' Perspectives on Criminality in Adults Prenatally Exposed to Alcohol" by Elisa Richer and Shelley L. Watson. *Journal on Developmental Disabilities, 23*(3), 90–104.

The award to Elisa was announced at the Annual Research Special Interest Group Seminar Day held at the Marriot on Falls Inn, Niagara Falls, Ontario, April 11, 2019.