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Women With Intellectual and Developmental Disabilities: Their Perceptions of Others' Attitudes Toward Their Pregnancy

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Objectives

Historically, childbearing among women with intellectual and developmental disabilities (IDD) was discouraged to the point of involuntary sterilization. There has been a shift in the last 40 years which recognizes all women's rights to retain their fertility and found a family. More women with IDD are now having children, however continue to face negative attitudes around childbearing. Women with IDD are a high-risk maternity population and require supportive prenatal care; their perceptions of others' attitudes may impact their likelihood to seek care, thus influencing their prenatal health. Our study aims to (1) describe how mothers with IDD perceive the attitudes of others toward their pregnancy, and (2) explore any perceived differences in attitudes of informal and formal support persons.

Methods

We used a descriptive case study approach. All transcripts of English-speaking participants (n = 2) from a larger qualitative study were analysed. Participants had IDD (as reported by developmental service agency staff), were older than 18 years at the time of the interview, had given birth in the last five years, and had sufficient verbal capabilities and memory recall to engage in an interview. Data were collected through semi-structured interviews. The interview included socio-demographic and pregnancy-related questions, a Social Circles Task to quantify formal and informal supports, and an adapted version of the Social Support Self-Report to describe perceptions of the quality of this support. We employed a content analysis framework to conduct an in-depth description of the two cases. Interviews and transcripts were reviewed in detail. Transcripts were then coded line by line in NVivo, using an open coding style. Matrices were used to extract relevant data.

Results

Preliminary results demonstrate two important findings. Firstly, both women perceived positive and negative attitudes from their informal and formal support persons. Reactions to the announcement of pregnancy were perceived as mostly positive and congratulatory from family and partners. Negative attitudes expressed by nurses were experienced in hospital before or after childbirth. Secondly, other personal characteristics of the women, separate from their disability, appeared to contribute to others' attitudes. One woman described her history with mental illness as the possible foundation of nurses' concerns. The other woman attributed her likeability and willingness to learn as explanation for why people in the community and service agency may have reacted so positively to her pregnancy.

Discussion/Conclusions

In this exploratory study, two women with IDD experienced largely positive attitudes from support persons. Personal characteristics other than their disability appeared to underlie others' attitudes. However, this was a case study, and both participants were part of the same developmental service agency; therefore, findings may not be representative of the experience of all women with IDD. Moreover, our data were originally collected for another purpose and therefore may not capture all the nuances of experienced attitudes. Nonetheless, this is one of the first studies to investigate the perceptions of women with IDD about others' attitudes. Our results suggest avenues for future research which could ultimately lead to improvements in service provider education and program delivery.

Understanding the Experiences of Parents and Children With ASD Who Attend the "Program to Assist Social Thinking" (PAST)

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Objectives

Positive youth development (PYD) is a strengths-based perspective focused on fostering the following positive outcomes among youth: *Competence* (i.e., holding a positive view of one's actions within specific domains), *Confidence* (i.e., an internal sense of overall self-worth and self-efficacy), *Connection* (i.e., positive bonds with people and institutions), *Character* (i.e., respect for societal and cultural rules), *Compassion (Caring)* (i.e., showing sympathy and empathy), and *Contribution* (i.e., helping family, community members, and self) (Lerner, 2005). This resilience-based framework has been a model in interventions for typically developing youth, particularly in the United States (Catalano et al., 2004), although it has yet to be applied to programs for youth with autism spectrum disorder (ASD). The purpose of the current research is to understand the experiences of parents and children ages 8 to 12 years old with high functioning ASD who attend a novel school-based social-emotional intervention, the Program to Assist Social Thinking (PAST), from a PYD framework.

Methods

A total of 18 Year 3 PAST students and parents participated in our study. We conducted two focus groups with the children (*n* = 6 and *n* = 4). Focus groups involved: (1) a group discussion about PAST and (2) a drawing activity in which children were asked to draw their experiences of PAST. We conducted individual in-depth interviews with parents (*n* = 8) who described their experiences of the program. All interviews were audio-recorded and transcribed verbatim.

Results

Transcripts and drawings are being analyzed using thematic analysis (Braun & Clarke, 2006). Findings from our analysis will reveal themes highlighting the experiences of children with high functioning ASD who attend PAST and their parents.

Discussion/Conclusions

Our findings will underscore the importance of understanding the perspectives of children with high functioning ASD who attend PAST and their parents. The findings may have practice implications on the delivery of future iterations of the program and may inform the development of similar school-based social-emotional interventions for youth with ASD.

Fitness Trainer Perceptions of Disbility Changed Through Exercising With Adults With Autism Spectrum Disorder and an Intellectual Disability

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Objectives

Sociological theory suggests that prevailing assumptions of disability can be altered when exposed to individuals with disability acting in ways that challenge common perceptions. Given the lower levels of physical activity and fitness, and higher levels of obesity among individuals with autism spectrum disorder (ASD), participation in physical exercise by these individuals may exemplify one such behaviour that challenges dominant beliefs regarding abilities of people with ASD. In order to explore this avenue for social change, this study qualitatively examined the impact of volunteering as a personal fitness trainer for an adapted physical exercise (APEX) program designed for adults with ASD and an intellectual disability (ID).

Methods

Nine volunteers (undergraduate students from the Department of Kinesiology) of an APEX program completed one-on-one semi-structured interviews related to their experience as a personal fitness trainer for an adult with ASD-ID. Personal fitness trainers attended the APEX program two times per week, for a total of 12 weeks, with each session being 90 minutes in duration. Responsibilities included training APEX participants in a traditional exercise regimen which involved cardiovascular training on a stationary bike, strength training using weight machines and free weights, as well as coordinating sports and games participation. Verbatim transcripts of audio-recorded, semi-structured interviews were analyzed using inductive content analysis, and a constant comparison method was employed to organize common features between meaning units.

Results

The impact of volunteering as a personal fitness trainer for an APEX program was depicted through two broad categories: (1) challenging personal perceptions, and (2) shaping an inclusive future. Subcategories within "challenging personal perceptions" included *knowing the individual* and *emphasizing the capacity for growth*. Volunteers recognized that individuals with ASD-ID have unique personalities that are not defined by their diagnoses, a realization that challenged previous misconceptions. Additionally, through time spent with the APEX program, volunteers recognized the capacity of these individuals to learn new skills and complete activities that are typically set outside imaginable possibilities for people with disabilities. The second broad category entitled "shaping an inclusive future" included *building skills* and *creating a ripple effect*. Volunteers recognized that skills (e.g., patience, humbleness) learnt through supporting participants in the APEX program would benefit their future careers and volunteer positions pursued within the field of disability studies, aiding the development of an inclusive community. Moreover, APEX volunteers saw themselves as ambassadors of social change as they exposed other gym members to the abilities of individuals with ASD-ID. Through this exposure, volunteers noted reduced stigma toward individuals with ASD-ID within the gym setting, creating a ripple effect regarding the impact the APEX program has on shaping an inclusive community.

Discussion/Conclusions

Quality time spent engaging with individuals diagnosed with ASD-ID in an exercise setting had a positive effect on perceptions of disability by emphasizing the uniqueness and potential of the whole person with ASD-ID. It is through the development of personal qualities and skills suitable for interacting with individuals with disability, and positive exposure to people with ASD-ID that we can foster social change and create inclusive communities.

"The Larger Experience of Being a Sib Has Really Coloured and Influenced Who I Am": The Experiences of Individuals With Siblings

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Objectives

Sibling relationships foster social competence, overall adjustment and peer acceptance by providing a model for cooperation, and managing conflict. However, individuals who have siblings with autism spectrum disorder (ASD) are not frequently investigated within family research. When siblings are studied, maternal accounts about sibling interactions are often provided, which have shown discordance with sibling reports. Research also yields mixed findings. Potential risks of emotional and prosocial behaviour problems have been found in siblings of children with ASD, while other studies have found positive effects such as greater affection and lower levels of quarrelling. Thus, this study developed a balanced investigation of sibling interactions through first-hand accounts that can explain the nature of the relationship when one sibling has ASD.

Methods

Participants included 18 individuals who have a sibling with ASD. Participants ranged in age (6–54) and the majority were female. A mixed-methods approach consisted of two questionnaires and an in-depth interview. The Sibling Inventory of Behaviour Scale (SIBS) and The Sibling Daily Hassles and Uplifts Scale (SDHUS), both reliable and valid measures, assisted in quantifying problematic challenges or uplifts experienced by siblings. The qualitative component of the study, semi-structured interviews, were informed by a basic interpretive approach (Merriam, 2000) and captured the unique perspectives and personal accounts that can sometimes be lost in objective measures.

Results

Interpretative Phenomenology Analysis of interview transcripts yielded five themes across all interviews. Siblings in the sample "move through phases," experiencing prominent challenges such as problematic behaviour. However, only four participants described direct physical conduct, such as biting, slapping and/or kicking. "Coping Mechanisms" consisting of external networks and self-calming behaviours helped participants cope with difficult aspects, such as tantrums. While a majority of participants reported family and friends as support systems, very few participants accessed sibling support groups. "Shared Interests" was a recurrent theme, as it assisted participants in overcoming hassles and embracing more positive experiences with their sibling. A majority of siblings also voiced a new sense of "Growth" through feeling a greater sense of compassion and understanding of difference as a direct result of having a sibling with ASD. A commonality across all participants included a "Concern about the Future," where they discussed whether the same degree of care provided by parents could be given in later life. All siblings questioned the availability of resources and balancing their own responsibilities with caregiving roles. Quantitative data obtained through questionnaires was used to triangulate and further inform themes. An integration of qualitative and quantitative data is presented to provide a complete conceptualization of the sibling experience.

Discussion/Conclusions

Participants discussed both positive and negative sides to having a sibling with ASD, yielding a fuller understanding of what this experience is really like. Results consistently showed that siblings are concerned about the future caregiving for their brother or sister, especially due to a lack of available resources and familial discussion. With deinstitutionalization, many individuals with ASD are living with their families and most siblings are expecting to provide supports to their siblings once their parents can no longer provide care.

The study contributes to existing family literature by addressing paucities in our knowledge of siblings. Particularly, the results address the transition from a sibling role to that of caregiver, in order to inform tailored support programs for these individuals.

"It Seems Like a Pretty Reasonable Scenario, a Well Put Together Story": Using Vignettes as a Data Collection Tool With Health Care Students

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Objectives

Vignettes can be employed in research in a number of ways, including as hypothetical scenarios which are used to prompt responses to interview questions or to elicit an understanding of a participants' knowledge, attitudes, or opinions, based on their response to how they would behave in a hypothetical scenario. Vignettes have traditionally been employed as a data collection tool for quantitative research (e.g., Reiss, Levitan, & Szyszko, 1982; Reiss & Szyszko, 1983) or as a form of presenting the findings of qualitative, interview research (e.g., Blodgett, Schinke, Smith, Peltier, & Pheasant, 2011). However, vignettes can also be uniquely used as a tool to *collect* research data, especially in conjunction with other data collection methods (e.g., qualitative, semi-structured interviews). As part of a larger, mixed methods study examining health care students' knowledge, attitudes, and self-efficacy regarding fetal alcohol spectrum disorder (FASD), health care students participated in one of three, scenario-based vignettes.

Methods

Modeled after vignettes created by Reiss and colleagues, and informed by previous findings from research with families raising children with FASD, three scenario-based vignettes were developed describing different scenarios regarding alcohol consumption during pregnancy. The vignettes include a number of differing characteristics, such as the age of the pregnant woman, the location in Ontario (e.g., rural, urban, Northern, Southern), the current trimester of pregnancy, the type, amount, and frequency of alcohol consumed (e.g., "low" drinking exposure, binge drinking episode), and the amount of social support available to the pregnant woman. Health care students (n = 18) responded to one of the three vignettes, which were rotated between interviews.

Results

The experience of using scenario-based vignettes as a data collection tool for understanding health care students' knowledge and self-efficacy regarding FASD will be discussed. The vignettes allowed the researchers to collect information regarding how students would behave in potential "real life" situations, based on the manipulation of variables that would not necessarily be possible in other types of research studies, such as observational research. In addition to interviewing students about their *perceived* knowledge and self-efficacy regarding FASD, the use of vignettes allowed students to demonstrate their perceived level of knowledge through a clinical application exercise. The vignettes were instrumental in understanding health care students' existing beliefs and prejudices about FASD, as well as their perceived selfefficacy and ability in applying their knowledge to practical, clinical situations.

Discussion/Conclusions

The use of vignettes to collect qualitative data is a creative and unique approach to data collection. By including scenario-based vignettes, there is a potential for knowledge mobilization to occur immediately, as the vignettes may be used as a case-based teaching tool. The need for case-based learning and training has previously been suggested as a key component in reducing the knowledge and application gap in clinical practice for FASD.

The F-Words in Childhood Disability: Embracing Opportunities for Knowledge Translation

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Objectives

In 2012, two *CanChild* researchers published: *"The 'F-words' in childhood disability: I swear this is how we should think!"* Building on the WHO's International Classification of Functioning, Disability and Health (ICF) framework, the article featured key strengths-based ICF themes – Function, Family, Fitness, Fun, Friends, and Future. This poster reports how the Diffusion of Innovation (DOI) theory has been used in the knowledge translation (KT) journey we have been on over the last four years to move the F-words ideas into practice.

Methods

DOI theory aims to explain *how* and *why* an innovation (or an idea) is adopted. It identifies four key factors that influence the adoption process: time, social networks, communication channels and the innovation itself. Our integrated team has used various communication channels (websites, social media, webinars, publications, presentations) to spread awareness of the F-words to multiple social networks, including international audiences. We have embraced opportunities presented to us for KT and learned about the importance of partnerships. All of our KT activities are performed in partnership with the knowledge users (i.e., parents and clinicians). Researchers, clinicians and families have found common ground in the F-words, and we believe by working together we can move these ideas into practice.

Results

To date, the article has had 6,395 downloads; there have been over 60 local, national, and international presentations; and the video has received over 2,000 views. There have also been multiple Facebook posts, tweets, online news articles (n = 8) and online blogs (n = 6), written by health researchers, physiotherapists, occupational therapists, and parents. Recently, we held a webinar on the F-words through the Canadian Association of Paediatric Health Centres (CAPHC), which attracted an international audience of mainly healthcare professionals. Subsequently, health care organizations in Ontario have been contacting us to run interprofessional workshops on the F-words and collaborative practice. This is an example of the power of communication channels and social networks, and the importance of recognizing and seizing opportunities as they arise.

Discussion/Conclusions

Knowledge translation is a process that takes time and commitment. We have come a long way from when the paper was initially published in July 2012, but still have a ways to go before the F-words are fully integrated into practice. We hope to continue to foster partnerships and to build opportunities for knowledge brokering. In order to reach a wider audience, our next step is to develop and evaluate the impact of an online F-words Knowledge Hub for families and service providers.

References and Resources

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CanChild "F-words" Knowledge Hub: www.canchild.ca/f-words

Digital Technology Use in Art Therapy With Adults With Developmental Disabilities

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Objectives

Researchers have commenced examining the use of digital technology as communication devices with children and youth with developmental disabilities. Results from these studies have been mostly positive. This phenomenological art-based study on the other hand, explored the use of digital technology as an art medium and clinical intervention tool for adults with autism spectrum disorders and other developmental disabilities. The study explored the following two research questions: (1) How do adults with developmental disabilities experience digital technology as an art medium and a clinical intervention tool in art therapy? and (2) Which image making and creative activity applications are most suited for adults with developmental disabilities? It is critical to explore and evaluate how digital technology can be used as a viable creative and cost-effective device with this population in clinical settings.

Methods

Five male and three female adults (*N* = 8) between the ages of 24 and 49 participated in the study. Participants were diagnosed with a variety of disabilities, including autism spectrum disorders (*n* = 4), Down syndrome (*n* = 2), and a developmental disability not otherwise specified (*n* = 2). Participants attended five one-hour individual art therapy sessions during which they created on a Lenovo Yoga 13.3-inch Windows 8 Convertible Ultrabook™ and a Samsung 7-inch Galaxy Tab 3 Android touch tablet. At the end of each session, participants were asked the following question: "What did you like about the image making and creative activity application used today? Sessions were geared towards each individual's level of cognitive and physical ability and encompassed the following three segments: warm-up activity, art-based intervention, and closure activity. Artworks and session field-notes were the raw research data. Thematic analysis was utilized to determine common themes and patterns.

Results

Study results revealed the following six themes: a simple and mess-free digital canvas, independence, interplay of digital art and music, computer skills and cognitive development, voice and vision, and digital art directives. Participants with tactile sensitivity favoured creating art on the texture-free touchscreen devices. The three most favoured imagemaking applications among participants were Fresh Paint, Coloring Mandalas, and Sand Draw, while the two most preferred creative activity applications were PuzzleTouch and Sticker Tales.

Discussion/Conclusions

Adults with developmental disabilities are creative and imaginative individuals. Thus, it is important for clinicians to design and implement safe and innovative therapeutic settings for adults with developmental disabilities to express their thoughts and feelings verbally and non-verbally through the creative process. The benefits of digital technology in art therapy include portability, a multimedia communication platform to access photos and music from the Internet, and multiple image printing capacities. Future research with individuals of all ages with developmental disabilities is recommended in order to continue investigating the opportunities and challenges of digital devices as image making and creative activity tools in clinical settings.

My Life as an Epic Win: Self-Determination in Individuals With ASD

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Objectives

The transition into adulthood can be a difficult time for any young person. For individuals with autism spectrum disorder (ASD) who have challenges in communication, social interactions and executive functioning (DSM 5, 2013), this transition could be extremely difficult. Lower rates of post secondary school education and employment amongst young adults with ASD demonstrate the need for more programs to assist during this transitional period (Shattuck et al., 2012). The concept of "self-determination" has been central to research on understanding and improving outcomes for young adults with disabilities (Wehmeyer, Shogren, Zager, Smith & Simpson, 2010). Research has shown that higher rates of self-determination in teens with and without disabilities are associated with many positive outcomes in adulthood (Cobb et al., 2009; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015).For young adults with HFASD, there is little evidence for the effectiveness of teaching self determination on their adult outcomes (Wehmeyer et al., 2010; Shogren et al., 2015). To address this concern, in the winter of 2014, a 10-week course called *My Life as an Epic Win,* designed to teach self-determined behaviours (i.e., goal setting, action planning, actions attainment, and problem-solving) was delivered and evaluated for eight older teens and young adults with HFASD and their parents.

Methods

This study used a comparative case study design involving descriptive, interpretive analysis to describe the engagement of participants with protocols relating to self-determination. Specifically, qualitative within and across participant analyses of pre- and post-course measures of self-determination were used to explore the impact of the course on self-determination for three of the eight young adults with high functioning ASD who participated in the *My Life as an Epic Win* course. Two measures of self-determination were used (1) the Arc's Self-Determination Scale (SDS; Wehmeyer & Kelchner, 1995), and (2) Visioning and Action Questionnaire (VAQ), a self-report questionnaire exploring the participants' use of the self-determined behaviours taught in course.

Results

Analyses of these three case studies were useful in two ways. First, the analyses showed how these individuals with high functioning ASD already demonstrated self-determination prior to the course. Secondly, the analyses provided insight into how self-determined behaviours were enhanced through training for these participants. Separate from the case study analysis, procedural analysis provided guidance as to how the course could be improved to enhance future participants' acquisition of self-determined behaviours. As well, this procedural analysis identified ways to improve the research protocol to ensure the collection of complete and meaningful data for all participants.

Discussion/Conclusions

This study allowed us to evaluate the effectiveness of the course across three participants and helped us to develop further research questions that will be tested in future Epic Win research groups. Future directions of this research will be discussed. In conclusion, a course such as this can promote a "growth attitude," by encouraging participants to continue learning and experiencing situations that may be outside their comfort zone; leading them closer to their goals and ultimately, an *Epic Life*.

Self-Compassion and Psychological Outcomes in Parents of Adults With Intellectual and Other Developmental Disabilities

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Objectives

The purpose of this research is to explore the relationship between selfcompassion and psychological outcomes in parents of adults with intellectual and other developmental disabilities (IDD). Specifically, we sought to determine whether being selfcompassionate is related to negative psychological outcomes such as stress and depression, and positive psychological outcomes such as mindfulness and empowerment. We hypothesized that self-compassion would be negatively associated with stress and depression, and positively associated with mindfulness, mindful parenting and empowerment. In other words, we expected that parents of adults with IDD who are more self-compassionate would experience lower levels of psychological distress.

Methods

The sample consisted of 59 parents of adults or adolescents with IDD. Mean parent age was 56.51 (*SD* = 8.74), and mean child age was 22.94 (*SD* = 5.84). Of the 59 parents, 24 had a child with autism spectrum disorder, seven had a child with a genetic syndrome and six had a child with a comorbid psychiatric disorder. Parents filled out five separate questionnaires in either an online or paper format. Self-compassion was assessed using the Self Compassion Scale – Short form (SCS-SF; Neff, 2003), a 12-item self-reported measure. Depression and stress were assessed using the 7-item stress subscale and the 7-item depression subscale of the short-form Depression Anxiety Stress Scale (DASS-21; Henry & Crawford, 2005). The Bangor Mindful Parenting Scale (BMPS; Jones et al., 2014), a 15-item self-report measure, and the Five Facet Mindfulness Questionnaire (Baer, Smith, Hopkins, Krietemeyer & Toney, 2006), a 39-item self-report questionnaire, were adopted to assess mindful parenting, and mindfulness respectively.

Empowerment was assessed using the family subscale of the Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992). The relationship between Self-compassion and psychological outcome variables was assessed using Pearson's correlation coefficients.

Results

Self-compassion was found to be negatively associated with stress ($r(57) = -.38$, $p = .003$), and depression ($r(57) = -.31$, $p = .021$). Additionally, self-compassion was found to be positively associated with mindful parenting ($r(55) = .59$, $p < .001$), mindfulness ($r(47) = .61$, $p < .001$) and family empowerment ($r(52) = .44$, $p = .001$).

Discussion/Conclusions

This study is the only one to date that has explored self-compassion in older parents of adults with IDD. Results supporting the relationship between self-compassion and psychological outcomes suggest that self-compassion is an important target of future intervention in this population. Older parents of adults with IDD face unique hardships as their children transition into adulthood, such as changes in service needs, limited service availability, and parents having their own health issues due to aging. An important target of future research would therefore be to examine whether interventions aimed at teaching and understanding selfcompassion can help parents in this population achieve better outcomes.

Teaching Categorizing Strategies to Children With Autism Spectrum Disorders to Assist Recall

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Objectives

The emergence and development of memory strategies are essential components of memory development and cognitive abilities (Schneider & Bjorklund, 1998; Schneider & Pressley, 1997). Memory strategies allow individuals to remember more information, by reducing the memory load. The majority of studies on memory strategies have focused on typically developing children and often on simple strategies such as rehearsal.

Very few studies have looked at the use of more complex memory strategies such as categorization and organization in individuals with autism spectrum disorder (ASD). Children with ASD are less likely to spontaneously use memory strategies, and they often do not use them effectively (Bebko & Ricciuti, 2000). Although strategies can be taught, children with ASD rarely maintain them over time (Cheung et al., 2010).

We explored effective methods of teaching categorization and organization strategies to children with ASD, and how to provide skills that are maintainable and generalizable across different cognitive tasks. We hypothesized that children with ASD could be trained to use these strategies, but our main focus was on what would be required for maintenance and generalization of them over time.

Methods

Nine children (age: 7–13) with ASD (Verbal Mental Age ≥ 4 years to ensure they could understand and complete the tasks) were divided into two groups in a multiple baseline design (group A and B). After baseline, all participants took part in two 45-minute training sessions per week for three consecutive weeks and a follow-up session three weeks later. During each of the training session participants were first assessed on a memory task in which they were presented with 12 cards from four categories (foods, animals) randomly arranged, and were told they could do anything they wanted with the cards to help remember them. The number of cards recalled and the strategy

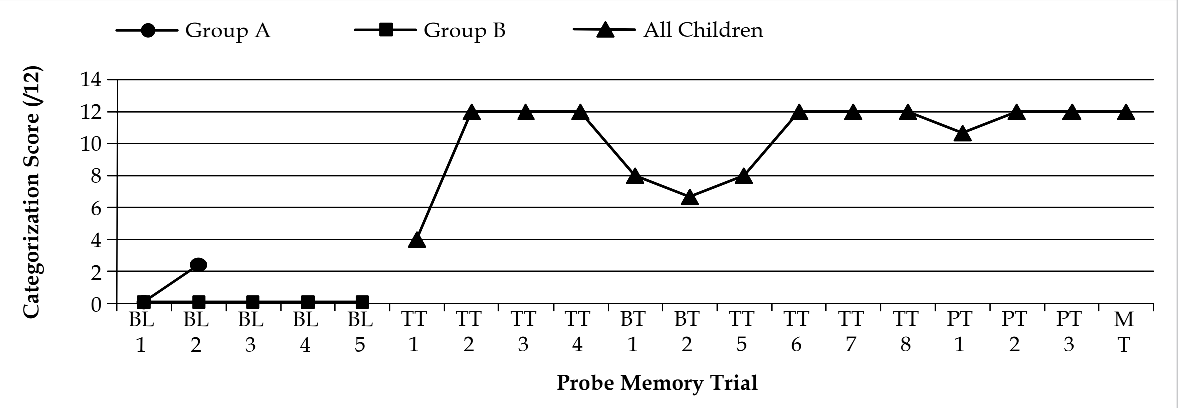

Figure 1. Average categorization scores

used by the child were recorded. The rest of the sessions involved strategy training where participants were carefully taught to use categorization and organizational memory strategies. Different games that benefitted from the use of memory strategies were used to test for generalization of skills.

Results

As seen in the Figure, during baseline (BL), no spontaneous categorization/organizational strategy use was observed. After one set of training trails (TT1-4), all the children used categorization successfully, but half did not maintain the skills in the between training sessions (BT trials). With only one more set of training trails (TT6-8), all the children used categorization successfully, maintained it on post-test follow-up trials (PT1-3) and when re-assessed three weeks later (MT).

Discussion/Conclusions

Organizational memory strategies can be readily taught to children with ASD using a carefully controlled procedure, leading to improved performance in learning situations. With these procedures, maintenance and generalization to new situations can occur. These methods can be easily adapted to educational settings for children with ASD. Being able to teach memory strategies to children with ASD in an efficient manner can help these children improve their recall and clustering capabilities which in turn can positively impact memory capacities and cognitive functioning.

When Did It Hurt the Most? Respite Providers' Perceptions of Painful Experiences in Children With Intellectual Disabilities

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Objectives

Children with intellectual disabilities (ID) often struggle to provide accurate, consistent pain self-reports due to limited verbal communication abilities (Breau & Camfield, 2011; Dubois et al., 2010; Stallard et al., 2001). Thus, these children may rely on caregivers to assess and manage their pain (Breau et al., 2003). Little research has examined non-healthcare secondary caregivers' (e.g., respite workers [RW]) understanding of pain in children with ID. Our aim was to examine RW perceptions of pain intensity experienced by a child with ID in a number of painrelated situations. These perceptions could speak to RW ability to assess pain (understand pain communication and contextual factors) and is likely related to subsequent pain management decisions.

Methods

As part of a larger study on pain-related beliefs and care decisions for children with ID, 54 RW (45 female; Mean$_{age}$: 33.8 years; range: 18–67): (1) completed a series of demographic questions, (2) read four vignettes about a 10-year-old child with ID experiencing pain [pain related to headaches, arthritis, a fall, and an unknown source of pain; Genik et al., 2015], and (3) described when they believed the child experienced the highest level of pain intensity. Following the development of coding schemes and training, two research assistants coded participants' responses. Interrater reliability was calculated using Cohen's Kappa and frequency analyses were used to describe participants' responses.

Results

Cohen's Kappa ranged from 0.80–0.95, indicating substantial to almost perfect agreement. Across vignettes, participants believed that the most pain occurred during either (1) a single behavioural cue, e.g., screaming [range: 1.9%–50.0%], (2) a general event, e.g., when playing [range: 16.7%–79.6%], (3) a pain-related event, e.g., during headache [range: 0.0%–7.4%], or (4) when multiple indicators were present, e.g., squinches eyes and whimpers [range: 7.4%–16.7%]. Some participants did not believe or were unsure if the child had experienced pain (range: 1.9%–9.3%). When the pain was accidental, participants depended most on a general event to determine when the child experienced the most pain (e.g., "during the fall," 79.6% for fall vignette). However, when pain was chronic, participants depended most on specific aspects of the child's behaviour as a cue for when the child was experiencing the most pain (e.g., "when the child winced," 50% for arthritis vignette).

Discussion/Conclusions

Participants believed different cues and events could indicate when a child was experiencing the most pain. These ideas varied depending on the type of pain and scenario. For example, participants focused more on the general event leading to the pain for accidental pain, but more on the child's for chronic pain. The results demonstrate the need for RW to be flexible and vigilant with respect to the various cues they pay attention to when assessing pain. Investigation into how caregivers' perceptions of pain intensity in children with ID impacts pain assessment and subsequent management is warranted.

Improving Pain Assessment and Management Knowledge of Children's Respite Workers: Development and Preliminary Effectiveness of the "Let's Talk About Pain" Training Program

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Objectives

For children with intellectual disabilities (C/ID), pain is common, and understanding pain expression can be complex (Breau et al., 2003; Breau et al., 2007; Stallard et al., 2001). Efforts to improve pain assessment among caregivers of C/ID have focused largely on primary caregivers and health-care professionals. However, C/ID spend significant time with other secondary caregivers, such as respite workers (RW; Shelton & Witt, 2011). Standardized painrelated education for these caregivers has not been developed.

This presentation will discuss a two-phase study which first explored perceived pain training needs and format preferences of RW and managers using exploratory analyses. Second, a pain training program was developed and piloted. It was hypothesized that following completion of the training program, RW would demonstrate increased pain-related knowledge, improved perceptions of the feasibility of and confidence and skill in pain assessment and management, and also rate the program favourably.

Methods

For phase one, participants (n = 22; 19 female; M_{age}: 37.10; age range: 20–59 years) engaged in an interview or a focus group related to participants' experiences with pain in C/ID, perceived pain-related training needs, and program format preferences. Content and thematic analyses were used. Fifty RW participated in phase two (46 female; M_{age}: 33.20; age range: 20–59). Prior to the training, participants completed demographics, two knowledge measures (one adapted, one newly created) and provided self-reports of their perceived feasibility of and their confidence and skill in pain assessment and management for C/ID. Following the training, participants completed the same knowledge measures and ratings as well as a program evaluation questionnaire. Descriptive/frequency analyses and t-tests were used.

Results

In phase one, variable ideas about pain in C/ID were expressed, and participants rated their interest in and perceived value of a pain training program highly (range: 8.82–9.59 out of 10; 10 = Strongly Agree/Extremely Important). Informed by phase one, an in-person, half-day, interactive training program was developed. The program focused on what pain is, as well as pain expression, assessment and management in the context of C/ID and respite settings. In phase two, participants demonstrated significant increases in pain-related knowledge on both measures following completion of the pain training program (r = .81–.88). Participants' ratings of the feasibility of and their confidence and skill in pain assessment and management related to C/ID also increased (r = .41–.70). The training program was rated favourably overall (range: 8.61–9.15 out of 10).

Discussion/Conclusions

Participants' pain training needs and preferences were generally consistent with previous research literature (e.g., group-based training, Moreland & Myaskovsky, 2000; active learning, Prince, 2004). The created program showed promising results in terms of increased knowledge, confidence and skill. Strengths, limitations and future research directions (e.g., formal evaluation of the effectiveness of this training program through a randomized controlled trial) will be discussed.

Treatment of Problem Behaviours in Children and Youth With ASD and/or ID

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Objectives

Often, people with ASD and/or ID have "dual diagnoses," meaning co-occurring behavioural and/or mental health problems. Various treatment methods may be used which may or may not be evidence-based. In situations of behavioural crisis, youth may be taken to the Emergency Department as a last resort (e.g., Weiss, Slusarczyk, & Lunsky, 2011). The aim of the current research was twofold. First, we examined the presence and frequency of three problem behaviours (aggression, self-injurious behaviour (SIB), and mental health concerns) and whether/how they were treated. We expected that the more frequent the behaviour, the more likely it would be to receive treatment, more types of treatment, and more evidence-based treatment methods. Second, we examined the relationship between use of the Emergency Department and the different types of treatment methods used, for low and high frequency problem behaviours for each of the three behaviours.

Methods

Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) was a multi-year research project examining the health, wellbeing and social inclusion of children with severe DD. The current study uses information from 435 children and youth between the ages of 4 and 20 years (*M* = 11.43, *SD* = 3.87) whose parent completed the GO4KIDDS Basic Survey. We categorized frequency of problem behaviours into never, less frequent, and more frequent over the past 2 months. For each behaviour, parents were asked if the following treatments were provided: medication, formal behavioural program, informal behavioural/teaching strategies, OT/PT, diet/supplements, and expressive therapies.

Results

Preliminary analyses show that 56% of our sample display some degree of aggression, but only 45% of those are receiving one or more treatment(s) for it; 40% display SIB and 31% of those are receiving treatment; and 58% display mental health concerns and 41% of those are receiving treatment. Informal behavioural/teaching strategies was the most common type of "treatment" for all behaviours. In almost all cases, there is no relationship between the frequency of problem behaviour and either the type of treatment or the number of treatments. Other analyses are ongoing.

Discussion/Conclusions

A substantial number of children and youth display aggression, SIB, and or mental health problems. In each case, less than half of those are receiving treatment of any kind. Of those that are receiving "treatment," it is most often informal and not evidence based. There appears to be no relationship between the frequency of the behaviour and the number or type(s) of treatments used. In this poster we will discuss several possible explanations for these rather unexpected findings and their implications for clinical practice.

Sibling Relationships in Families of Children With Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder, and Down Syndrome: A Comparison Study

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Objectives

Studies have shown that it is often a sibling who takes on the support and caregiving role in the life of a person with a developmental disability (DD) when the parent is no longer able to (Griffiths & Unger, 1994). However, very little research has examined how siblings adapt to their brother or sister with DD. To date there is also limited examination in regards to siblings of children with specific disabilities such as autism spectrum disorder (ASD) and Down syndrome (DS), and to the researcher's knowledge, no current studies investigating siblings of children with fetal alcohol spectrum disorder (FASD). Differences in the behavioural challenges posed by children with ASD, DS, and FASD are critical and to the extent that those difficulties vary across diagnoses, differences in sibling reactions are possible. It is important to make clear why siblings' experiences would be expected to differ as a function of their sibling's diagnosis, and if researchers can determine where siblings of children with specific disabilities struggle and where they are doing well, supports can be tailored to help lighten their experiences.

Methods

As part of a larger mixed methods research project examining the experiences of families raising children with ASD, FASD, and DS, this study will involve collecting, analyzing, and integrating both qualitative and quantitative data in one single study (Teddlie & Tashakkori, 2009). A total of 39 siblings participated; 15 siblings of children with FASD, 13 siblings of a brother or sister with ASD, and 11 siblings of individuals with DS. In-depth, semi-structured interviews were conducted, which were informed by a basic interpretive approach (BIA; Merriam, 2002). Participants also completed two quantitative questionnaires, the Sibling Daily Hassles and Uplifts Scale (SDHUS; Giallo & Gavidia-Payne, 2002, 2006) and the Sibling Inventory of Behaviour Scale (SIBS; Schaefer & Edgerton, 1981; Hetherington, Henderson & Reiss, 1999)

Results

Interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009) was used to analyze interview transcripts. Five main themes were identified: positive transformational outcomes, sibling challenges, caregiving roles, awareness of disabilities, and formal supports. Questionnaire responses were also integrated to triangulate themes. Comparison findings between sibling groups from these questionnaires will be analyzed and discussed here.

Discussion/Conclusions

The results of this study provide a preliminary understanding of the lived experiences of siblings living with brothers and sisters who have been diagnosed with ASD, FASD, and DS. Results of this study will be helpful in developing and implementing appropriate supports for siblings of children with DD (e.g., sibling support groups, respite services) which may differ based on sibling diagnosis. Limitations and directions for research will be discussed.

Systematic Review of Mindfulness Interventions and Mindfulness Measures Used With the Autism Population

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Objectives

There is a growing body of research exploring the application and assessment of mindfulness in individuals with autism spectrum disorder (ASD). This poster presents an ongoing review of the literature on the evaluation of mindfulness within the ASD population. Specifically, we wish to understand how mindfulness is being qualified (i.e., how mindfulness is defined) and quantified (i.e., how mindfulness is being assessed), and examine how it is being used in interventions for individuals with ASD.

Methods

A review was conducted in accordance with the guidelines described by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009). A comprehensive list of search terms was developed by reviewing applicable literature and the thesaurus banks of each of the search drives for alternate but related terms used most frequently within each bank. The final list of search terms included mindfulness [mindful*, meditation, acceptance, (acceptance and commitment therapy), (dialectical behaviour therapy), buddhis*, Vipassana, Theravada, zen] and autism [autis*, (asperger syndrome), (pervasive developmental disorder), (developmental disabilit*), (autistic disorder)]. Articles were reviewed and included based on the following criteria: (1) the target population included individuals with a diagnosis of ASD, and (2) the intervention provided to the target population included a mindfulness component and/or mindfulness was assessed in the target population. Articles were excluded if they were: (1) not data-based (e.g., books, theoretical papers, or secondary reviews), (2) unpublished dissertations or theses, (3) not published in English, (4) examined populations that did not explicitly identify as having a diagnosis of ASD, or (5) reviews or meta-analyses of articles.

Results

An initial search of the databases using the search terms listed above yielded 1360 articles. A total of 12 articles out of the original 1,360 met inclusion criteria and are currently being examined for: (1) any measures reported to assess mindfulness, and (2) any interventions reported to include mindfulness-based therapy strategies. There were few studies that either used a mindfulness measure or mindfulness based intervention with the ASD population, and a preliminary review suggests few mindfulness measures are used.

Discussion/Conclusions

This poster will elaborate on these preliminary findings and discuss how mindfulness is currently being used and measured with the ASD population. Focus will be placed on the conceptualization of mindfulness and how it is related to the current use of mindfulness strategies and measures. Finally, an evaluation of the studies will be presented. Each of these topics will inform potential directions for future research in mindfulness with this population.

Treatment Adherence in ABA: Practices and Opinions of Behaviour Analysts

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Introduction and Objectives

Treatment adherence in Applied Behaviour Analysis (ABA), has been found to be positively related to treatment effectiveness (Fryling, Wallace, & Yassine, 2012). Yet studies such as Moore and Symons (2011) have reported that just under 25% of parents in their sample did not implement behavioural and/or medical intervention plans that they had been asked to follow for their child. Treatment integrity in general is not commonly reported in ABA research (McIntyre, Gresham, DiGennaro & Reed, 2007), Adherence to treatment recommendations by natural care providers in non-clinical settings is less frequently monitored and reported (Allen & Warzak, 2000). The purpose of this study was to begin address the dearth of research examining treatment adherence in practice by examining behaviour analysts self-report on their practices and opinions regarding treatment integrity and adherence.

Methods

Specifically an on-line survey was designed to collect information on behaviour analysts' practices when working families, staff, and educators of individuals with Intellectual and Developmental Disabilities, and to determine the extent to which the behaviour consultants were following best practices (treatment integrity), monitoring mediator treatment adherence. Further questions related to their opinions about the importance of treatment adherence and integrity in research and practice. This international survey was completed by 160 behaviour analysts with a wide range of educational backgrounds, years of experience, and differing certification levels.

Results

This study revealed some significant gaps between best practices and reported practices of behaviour analysts with respect to assessment methods, mediator training approaches on treatment plan, and objective monitoring of treatment adherence in practice. Despite these gaps, most analysts described their treatments as relatively effective in decreasing challenging behaviour and/or increasing replacement skills. Research has found that different treatment errors produce different impact on behavioural outcomes (St Peter Pipken, Vollmer & Sloman, 2010). The most common perceived barriers to treatment adherence in practice were focused on caregivers including burnout, lack of training and/or knowledge, and their prior learning history. This was interesting given that caregiver training and knowledge relating to intervention should be the responsibility of the behaviour analyst providing the intervention.

Discussion/Conclusions

This study reveals a training need for behaviour analysts and further research into the relationship between treatment adherence and outcomes in practice.

Sibling Experiences in Families of a Child With a Disability: Down Syndrome, Cystic Fibrosis, and Cerebral Palsy

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Objectives

Raising a child with a disability can be stressful for parents and caregivers, but the experiences of the child's brother or sister is often overlooked (Stoneman, 2007). Siblings are emotionally influenced by each other during childhood, and this reciprocal influence continues into adulthood (Wennström, Isberg, Wirtberg, & Rydén, 2011). Down syndrome is a genetic condition that results in cognitive impairments and health conditions such as heart defects. Generally, siblings of individuals with Down syndrome describe their experiences as very positive, have lower levels of depressive symptoms compared to siblings of individuals with other disabilities, and perceive themselves as being better people because of their siblings with Down syndrome (Skotko, Levine, & Goldstein, 2011). Cystic fibrosis is a fatal genetic condition that causes a build-up of mucus in the lungs (Cystic Fibrosis Canada, 2014). Siblings of those with cystic fibrosis express positive feelings about their experiences, with the exception of feeling neglected due to their parents' focus on the child with cystic fibrosis (Havermans et al., 2010). Cerebral palsy is a permanent and non-changing disability that is seen in individuals with brain damage and results in motor impairment (Miller, 2005). Siblings of individuals with cerebral palsy often report having a number of responsibilities, such as being a secondary caregiver and teacher for their brother or sister, particularly into adulthood (Dew, Llewellyn & Balandin, 2014). This mixed methods study allows siblings to describe their experiences, including the hardships, rewards, and coping methods employed when having a sibling with Down syndrome, cystic fibrosis, and cerebral palsy.

Methods

Participants for this study will include 10 siblings to an individual with Down syndrome, 10 siblings to an individual with cystic fibrosis, and 10 siblings to an individual with cerebral palsy. Participants will be recruited through disability support and health organizations and word of mouth. Both biological and adoptive siblings are invited to participate. This study will employ a mixed methods approach (Johnson & Onwuegbuzie, 2004), consisting of a semi-structured interview and two questionnaires, the Sibling Inventory of Behaviour Scale (Schaefer & Edgerton, 1981) and the Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2006). Responses on specific items and subscales will triangulate qualitative results to further understand the siblings' experiences. Interviews will be analyzed using Interpretive Phenomenological Analysis (Smith & Osborn, 2008).

Results

Data collection is currently ongoing. It is anticipated that siblings in the three groups will report similar stressors and uplifts as measured by the questionnaires, but there will be unique challenges as described in interviews. Preliminary analysis suggests that siblings of individuals with Down syndrome describe their experiences as positive and are willing to act as a future caregiver. It is expected that siblings of individuals with cystic fibrosis will see their brother or sister as if they did not have a disability, but may feel resentment because of the parents' focus on the child with cystic fibrosis. Finally, we anticipate that siblings of individuals with cerebral palsy will describe more demands compared to the other sibling groups and may reluctantly take on the role as caregiver.

Discussion/Conclusions

The results of this study will provide a better understanding of the experiences of individuals who have a sibling with a disability, and will fill the gaps within the literature, particularly adding to the limited research on siblings of individuals with cerebral palsy. Finally, this study will assist clinicians and disability service providers to develop appropriate services and supports for siblings of those with disabilities.