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Published in: Developmental Neurorehabilitation

Citation: Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer & the QUALA group (2015) Are you doing what you want to do? Leisure preferences of adolescents with cerebral palsy, Developmental Neurorehabilitation, 18:4, 234-240, DOI:

10.3109/17518423.2013.794166 To link to this article:

<http://dx.doi.org/10.3109/17518423.2013.794166>

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doi: 10.3109/17518423.2013.794166

<http://dx.doi.org/10.3109/17518423.2013.794166>

Are you doing what you want to do? Leisure preferences of adolescents with cerebral palsy

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To cite this article: Keiko Shikako-Thomas, Michael Shevell, Lucyna Lach, Mary Law, Norbert Schmitz, Chantal Poulin, Annette Majnemer & the QUALA group (2015) Are you doing what you want to do? Leisure preferences of adolescents with cerebral palsy, *Developmental Neurorehabilitation*, 18:4, 234-240, DOI: 10.3109/17518423.2013.794166 To link to this article: <http://dx.doi.org/10.3109/17518423.2013.794166>

Introduction

Participation in leisure activities by children with disabilities is a concept that has received growing interest, particularly since it has been brought to the forefront by the World Health Organization (WHO) in their International Classification of Functioning, Disability and Health (ICF [1]).

Involvement in certain activities and preferences for those activities are likely to be related, however, literature shows that they are distinct concepts [2, 3]. The ability to partake in preferred leisure activities may have an influence on an individual's overall quality of life, especially during adolescence when exploring and asserting one's interests is developmentally important [4–6]. Moreover, it is known that preference for certain types of activities contributes to more engagement in those activities [7, 8].

Studies on participation have largely focused on school-age children with cerebral palsy (CP) [8, 9] with few studies examining specific participation characteristics of adolescents [10, 11]. Studies to date reveal that adolescents with CP may experience decreased participation in leisure activities; however, existing evidence has not focused on specific leisure preferences and the characteristics that may define these preferences. It is conceivable that several factors such as gender, severity of disability, and family factors may contribute to shaping preferences [12, 13]. Understanding of specific preferences and the factors related to preferences for certain activities can contribute to the development of client-centred interventions that may ultimately contribute to greater engagement in leisure activities for this high-risk population.

The objective of this study was to describe leisure activity preferences of adolescents with CP and their relationship to actual levels of participation and to identify factors associated with greater interest in particular leisure activities.

Methods

Participants

Adolescents 12–20 years of age with a diagnosis of CP were recruited for a study describing factors influencing their leisure participation and quality of life (QUALA study). A sample of children (6–12 years) who had participated in a previous study [9] was contacted for participation in this study. Another sample was recruited from specialty clinics in schools, rehabilitation centres, and community programs across the province of Quebec who were initially contacted by a health care professional.

Procedures

A cross-sectional design was used. Ethical approval was obtained from the Montreal Children's Hospital, the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR), and the Agence de la santé et des services sociaux de Montréal (ASSS). Once consent (parent) and assent (adolescent) were obtained, an appointment was made with the participant and the parent (mother or father) to complete evaluations at one of the assessment sites or as a home visit. The adolescents who were able to complete the Preferences for Activities of Children (PAC [3]) were interviewed by an occupational therapist or a psychologist. Parents were invited to provide minimal assistance if necessary. The evaluator administered the Children's Assessment of Participation and Enjoyment with the adolescent and proxy help if necessary (CAPE [3]) and the Vineland Adaptive Behaviour Scale (VABS [14]) with parents. Parents completed a sociodemographic information questionnaire and self-completed questionnaires: the Family Environment Scale (FES [15]), Strengths and Difficulties Questionnaire (behavior: SDQ [16]). Adolescents completed the Dimensions of Mastery Questionnaire (mastery motivation: DMQ [17]) and the Self-Perception Profile for Adolescents (SPPA [18]) with minimal parental assistance if necessary.

An occupational therapist (OT) or a physical therapist (PT) classified participant's gross motor function and manual ability using the Gross Motor Function Classification System (GMFCS [19]) and the Manual Ability Classification System (MACS [20]) and a neurologist confirmed the CP diagnosis and assigned a subtype of motor impairment.

Outcome measure

The PAC is a questionnaire that measures preferences for leisure activities. It is meant to be completed by the child, with proxy- help if needed. Fifty-five leisure activities are rated by the respondent on a 3-point scale according to the prompt: "if you could do anything in the world, how much would you like to be doing this specific activity": (1) Would not like to do it at all; (2) Would sort of like to do it; (3) Would love to do it. Activities are grouped into five subdomains (recreational, social, active-physical, skill-based, and self-improvement) for which continuous mean scores are derived. A higher PAC mean score indicates a higher preference for the activity type. Reliability has been tested, Cronbach's alpha range from 0.67 to 0.77 for the five subdomain scales for internal consistency [3].

The CAPE contains the same 55 leisure activities that are then rated as "yes" or "no" if they have been performed in the past 4 months. If performed, there is a numbered scale for intensity of participation, from 1 (1 time in the past 4 months) to 7 (once a day or more). For the purposes of this study scores were derived for intensity (how often) for each of the five domains. Final scores are expressed on a continuous scale. Test-retest reliability ranges from 0.65 to 0.75 on overall participation, and face validity is assured by extensive literature review and on the basis of the ICF.

Statistical analysis

Descriptive statistics were conducted to characterize leisure preferences of adolescents with CP, and participants' personal and environmental characteristics. Scores of preferences in the five different domains (recreational, active-physical, social, skill-based, and self-improvement) were obtained. The Pearson product moment correlations were used to determine associations between preferences for activities (PAC) and intensity of participation (CAPE) in the five domains. Student's T-tests were carried out to compare gender and age differences in the PAC. Chi-square tests were performed to test the differences between preferences for activity and intensity of involvement in each activity (recoded into three categories: 1: once a month, 2–3 times in the past 4 months or once in the past 4 months, 2: every two weeks or once a week, and 3: 2–3 times a week or once a day or more). Simple and multiple linear regressions were carried out to identify models of predictors of leisure preferences in each of the five participation subdomains.

We established a conceptual model of preferences for activities based on previous studies on preferences for younger children with physical disabilities [8, 9] and preferences for activities in adolescents without disabilities [2]. We initially used a hierarchical regression approach and compared the best predictive models generated in this approach to those generated in our initial conceptual modeling.

Results

Participants' characteristics

A total of 128 participants completed the PAC. Mean age was 15.4 years (± 2.1) and 59% were male. Participants were primarily ambulatory, with 72% in GMFCS levels I or II and had good manual function (67% MACS I and II). Half of the participants presented with difficulties in activities of daily living, 37% had difficulties in communication and 31% in socialization domains as measured by the Vineland Adaptive Behavior Scale-II (abnormal scores < 78) and 60% were in special schools or in special resource classes within regular schools. The sociodemographic characteristics of participants and comparison between participants and non-participants are presented in Table I.

Table I. Participant's characteristics.

	PAC completed (<i>N</i> = 128)	PAC not completed (<i>N</i> = 44)
Age (mean; SD)	15.3; 2.1	15.5; 2.7
Gender	60% male	64% male
VABS (% Abnormal)		
<i>Communication</i>	37%	97%
<i>Socialization</i>	31%	95%
<i>Daily living skills</i>	50%	97%
GMFCS		
I	40%	3%

	PAC completed (<i>N</i> = 128)	PAC not completed (<i>N</i> = 44)
II	32%	10%
III	7%	10%
IV	11%	10%
V	10%	67%
MACS		
I	37%	3%
II	30%	10%
III	19%	13%
IV	10%	10%
V	4%	64%
School type		
<i>Special</i>	32%	70%
<i>Regular with special resources</i>	28%	7%
<i>Regular</i>	40%	11%

Description of preferences

Social and active-physical activities were most preferred (social mean score = 2.53; SD = 0.38; active physical mean score = 2.10; SD = 0.42), and self-improvement activities were the least preferred (self-improvement mean score = 1.93; SD = 0.49). Adolescents presented a very low level of participation in skill-based activities regardless of high preferences in this activity domain (skill-base mean score = 2.04; SD = 0.51). Playing computer or videogame (recreational), going to the movies (social), doing snow sports (active-physical), playing a musical instrument (skill-based) and shopping (self-improvement) were the top preferred activities in each of the five domains. Table II shows the five most preferred activities in each domain.

Table II. Top 5 activity preferences per domain.

Activity	"I would love to do it" (%)
<i>Recreational</i>	
Computer or videogame	81

Watching TV or rented movie	74
Listening to music	70
Taking care of a pet	52
Playing board or card games	45
<i>Social</i>	
Going to the movies	78
Hanging out	74
Going to a live event	65
Going to a party	64
Making food	56
<i>Active-physical</i>	
Snow sports	64
Doing a paid job	63
Water sports	63
Doing team sports	58
Playing games	54
<i>Skill-based</i>	
Playing a musical instrument	56
Swimming	53
Dancing	48
Taking music lessons	45
Horseback riding	42
<i>Self-improvement</i>	
Shopping	60
Reading	48
Doing a volunteer work	38

Going to the public library	37
Getting extra help for schoolwork from a tutor	35
Writing letters (or email)	35

Girls and boys had different preferences. While girls would prefer to do more skill-based and self-improvement activities, boys had higher mean preference for active-physical activities, but contrary to gender expectations, the difference was not statistically significant for this latter activity subdomain (Table III). There were no significant differences in activity preferences between younger (15 years and younger) and older adolescents (16 years and older).

Table III. Differences in gender.

Girls = 52 Boys = 76	PAC (mean, SD)	<i>t</i> (df), sig
Recreational	Girls (2.22, ± 0.39) Boys (2.04, ± 0.39)	2.58 (129), $p < 0.05$
Active-physical	Girls (2.11, ± 0.44) Boys (2.12, ± 0.39)	-0.16 (129), $p = 0.90$
Social	Girls (2.62, ± 0.34) Boys (2.47, ± 0.39)	2.3 (129), $p < 0.05$
Skill-based	Girls (2.23, ± 0.43) Boys (1.91, ± 0.50)	3.73 (129), $p < 0.001$
Self-improvement	Girls (2.11, ± 0.42) Boys (1.80, ± 0.51)	3.54 (129), $p < 0.001$

A low positive relationship between age and preferences was noted only for social activities ($r = 0.18$; $p < 0.05$). Mastery motivation, as rated by parents was positively associated ($p < 0.05$) with interest in recreational ($r = 0.25$) and active-physical ($r = 0.31$) activities. However, correlations with adolescent-completed DMQ questionnaires showed a significant relationship between the adolescents' total persistence and all the five PAC leisure domains. Different aspects of self-perception were related to participation ($p < 0.05$): feeling good about performance in sport activities was related to high preferences for social activities ($r = 0.29$) and romantic appeal was related to preferences for self-improvement activities. Interestingly, a higher general sense of self-worth was negatively related ($p < 0.05$) to preferences for skill-based activities ($r = -0.24$). Family active-recreational orientation was related to preference for active-physical ($r = 0.25$) and self-improvement ($r = 0.20$) activities. Higher functioning levels (VABS-II) was related ($p < 0.05$) to less preferences in recreational ($r = -0.37$), skill-based ($r = -0.26$) and self-improvement ($r = -0.37$) activities. The impact (distress and social impairment) of negative behavior (SDQ) had a fair positive association ($p < 0.05$) with preferences in recreational ($r = 0.31$), skill-based ($r = 0.18$) and self-improvement ($r = 0.21$) activities.

Table IV shows the best predictive models for leisure activities preferences. When controlling for activity limitations, boys had less preference for skill-based and self-improvement activities. A higher sense of mastery motivation, as perceived by the adolescents, accounted for more preferences for active-physical and self-improvement activities while an increased negative reaction to failure had a modest negative relationship with preferences in these same domains in addition to skill-based activities ($p < 0.05$ in all subdomains). Other family and environmental characteristics such as family activity orientation (families that tend to engage in or value recreational and intellectual/cultural activities) and family expressiveness (the extent to which members of the family can express their feelings) were not significant individually, but contributed to the total explained variance in the models. In general, our models explained 14% of the variance in preferences for social activities, but explained up to 40% of the variance in preferences for self-improvement activities.

Table IV. Best predictive models of preferences for leisure participation.

Outcome (<i>N</i> = 88)										
	Recreational		Physical		Social		Skill-based		Self-improvement	
	β	<i>p</i> Value	β	<i>p</i> Value	β	<i>p</i> Value	β	<i>p</i> Value	β	<i>p</i> Value
Model R^2 *, <i>p</i> value	0.26; 0.04		0.20; 0.20		0.14; 0.58		0.26; 0.04		0.40; <0.001	
Gender	-0.08	0.39	0.07	0.47	-0.04	0.68	-0.25	0.04	-0.31	0.00
Total motivation	0.14	0.07	0.22	0.01	0.05	0.49	0.08	0.39	0.18	0.03
Negative reaction to failure	-0.01	0.84	-0.06	0.31	-0.05	0.40	0.02	0.79	-0.06	0.35
Prosocial behavior	0.02	0.31	-0.03	0.16	0.00	0.74	-0.00	0.74	-0.02	0.26
Family activity orientation	0.00	0.68	0.00	0.17	-0.00	0.52	0.00	0.11	0.00	0.06
Family expresiveness	0.00	0.41	0.00	0.50	0.00	0.33	-0.00	0.62	-0.00	0.89
Family income	-0.08	0.34	-0.00	0.92	0.04	0.61	-0.19	0.09	-0.00	0.94
School type	-0.10	0.33	-0.22	0.04	-0.20	0.07	-0.13	0.32	-0.17	0.14

Bold values indicate a significant beta ($p < 0.05$). DMQ (C/P) – Dimensions of Mastery Questionnaire Child/Parent; FES – Family Environment Scale; GMFM-66 – Gross Motor Function Measure; MACS – Manual Ability Classification System; VABS – Vineland Adaptive Behavior Scale.*Models included GMFM-66, MACS, VABS (communication, socialization), Age.

Relationship between preferences and actual involvement in leisure activities

The level of participation in leisure activities and the preferences for those activities were modestly correlated for the five participation sub-domains (r range 0.24; skill-based activities -0.58 ; recreational activities, $p < 0.01$). Comparing the frequency (how often) of participation and preference for each of the 55 activities, we could see that adolescents engage more often (once a week or more) in activities they prefer when these activities are more home-based and less structured such as listening to music and watching TV or a rented movie (i.e. 82% and 79% of adolescents who did it once a week or more also rated these activity as “I would love to do it”). Conversely, activities that are not necessarily freely chosen but yet happen in higher frequencies such as doing chores and homework were rated as “would not like to do it at all” by 42% and 52%, respectively, of adolescents who engaged in these activities at least once a week. Activities that commonly require more structure, planning or people out of the family circle such as going to a party or going to the movies were performed rarely regardless of higher preference for them (i.e. 87% and 78% of adolescents “would love to” go to the movies or to go to a party, but did it less than once a month). Leisure preferences and actual involvement (Chi-square test) for activities are presented in Table V.

Table V. participation frequency and preferences.

Activity	Total number who performed once a week or more (total N who preferred this activity)	p Value (Chi-square)
Bicycling	13 (44)	0.33
Computer or videogame	82 (116)	0.00
Crafts	21 (69)	0.78
Hanging out	34 (88)	2.45
Individual physical act	15 (39)	0.01
Non-team sports	7 (21)	0.08
Paid job	8 (28)	0.90
Talking on the phone	34 (97)	0.18
Playing games	27 (77)	0.04
Playing with pets	45 (76)	0.00
Pretend or imaginary play	7 (35)	0.79
Reading	43 (81)	0.00
School club	5 (21)	0.84
Taking care pet	19 (53)	0.46

Activity	Total number who performed once a week or more (total <i>N</i> who preferred this activity)	<i>p</i> Value (Chi-square)
Watching TV	81 (120)	0.00
Writing letters	15 (59)	0.10
Writing stories	11 (28)	0.91
Listening to music	75 (108)	0.00
Activity	Total number who participated once a week or more (total <i>n</i> who preferred this activity)	<i>p</i> -Value (Chi-square)
Doing a chore	22 (90)	0.21
Participating in community organizations	9 (29)	0.44
Doing homework	38 (92)	0.36
Playing a musical instrument	10 (31)	0.40
Activity	Total number who participated once a month or less (total <i>n</i> who preferred this activity)	<i>p</i> -Value (Chi-square)
Fishing	7 (13)	0.59
Full day out	32 (60)	0.28
Gardening	5 (16)	0.64
Live event	35 (57)	0.78
Going to the movies	61 (92)	0.82
Going to a party	55 (86)	0.05

Discussion

This study demonstrated that adolescents with CP have preferences for a variety of activities, but especially in the social and active-physical domain. Girls had more preferences than boys in all activity domains, except in active-physical activities. There were no differences for preferences between younger and older adolescents. Adolescents' persistence in completing a challenging task, negative reaction to failure, negative behavior and different aspects of self-perception such as athletic competence and romantic appeal were adolescent-related factors that contributed to preferences for certain types of activities. Family orientation towards leisure and moral-religious orientation were the family factors that predicted preference for activities. Preferences for certain activities and actual engagement and enjoyment in these activities were modestly correlated.

No studies to our knowledge have explored predictors of preferences for adolescents with disabilities. The PAC reflects what an adolescent would like to do in an “ideal” situation, in the absence of constraints of all kinds, to include environmental barriers, lack of resources, and disability itself. Previous qualitative studies completed by our group showed that in contrast to their parents, adolescents do not perceive disability as a barrier to participation; one of the main barriers perceived is the lack of opportunities to make individual choices [21]. Intensity of participation in each of the five domains was only modestly correlated with preferences, except for recreational activities, showing that there is a discrepancy between what an adolescent would like to do and what they actually do in real life. However, if we look at the activities that have higher discrepancies, we can conclude that activities that adolescents would really like to partake in, but do so with least frequency, are the ones that may present with the greatest physical, attitudinal, or socioeconomic (i.e., environmental) barriers such as going to the movies, going to a party, or participating in a full-day outing. Conversely, most activities that are done with higher intensity and are highly preferred, are passive and home-based in nature, naturally present with few or no barriers to participation, such as listening to music, playing computer or videogames, and watching TV. These findings resonate with a previous study that found as children grew older, they tend to spend more time at home and less in the community [11].

While we could logically attribute much of these discrepancies between preferences and participation to disability-related aspects, similar findings were reported by Garton and Pratt [2] in describing leisure preferences of typically developing adolescents. Recent studies reported differences in levels of participation between adolescents with and without disabilities [11, 22], with less participation being consistently attributed to adolescents with physical disabilities, however, these studies did not report participants’ preferences. In Garton and Pratt’s study, social activities were most preferred by typically developing adolescents, and the most common reasons cited for not engaging in preferred activities were the lack of facilities for the preferred activity, lack of time and opportunities, or feelings of poor physical ability to engage in the activity. Their conclusion was that personal interest precedes participation, which may lead to a belief that in the absence of ability and environmental barriers, adolescents would participate in activities of their choosing. Similarly, recent studies of predictors of participation of youth with disabilities have demonstrated that enjoyment of activities is a predictor for involvement in these activities [10, 23, 24] as well as availability of environmental resources that facilitate the engagement in preferred activities [25]. While this study approximates the preferences of adolescents with and without disabilities, it also proposes a challenge for clinicians and researchers, that is to understand what influences preferences for certain activities on valuing preferences of clients on rehabilitation programs.

Studies have reported a trend for decreased participation as children with disabilities grow older [8, 9, 11, 23]. However, no studies have compared the development of preferences in this population during adolescence. Our group has previously reported preferences for leisure activities in school-age children (6–12 years) with CP [26]. Mean scores of preference in the five domains were consistently lower than this age group for adolescents, although not dramatically different. However, adolescent’s enjoyment of participation and preferences for recreational activities and self-improvement activities are significantly less related in adolescents (school-age/adolescents enjoyment vs. preferences r : recreational 0.46/0.24; self-improvement 0.82/0.60; skill-based 0.44/0.24), except for active-physical activities, in which adolescents preference and engagement was higher (school-age/adolescents r = 0.20/0.35). This preliminary comparison suggests that adolescents may not enjoy engaging in activities that they previously enjoyed, in spite of their on-going involvement and they may be participating in less skill-based activities such as swimming or horseback-riding, in spite of higher preferences for these activities.

Nonetheless, the higher correlation between preference for active-physical activities and actual involvement in this type of activity may be a good indicator of the importance of maintaining programs and opportunities for this type of activity, in spite of the general higher preferences in the adolescent groups for passive, electronic, and computer-based activities.

Consideration of the adolescent-related factors that predicted preferences for certain types of activities is important in the development of intervention strategies and programs. While a simple question to be included in intervention plans, goal setting, and programs is: “what would you like to do?” – a more complex question is what are the factors that may shape your preferences and more specifically, how to support personal choices that promote physical and psychosocial health and well-being. Interventions could be developed targeting aspects of mastery motivation such as negative reaction to failure and strategies that will facilitate the ability to persist in tasks that are challenging or difficult. Behaviour problems tend to persist as children grow older and should be addressed [27]. Aspects of self-perception that may influence preferences for certain activities must also be integrated into interventions. Interestingly, feeling competent in sports activities was associated with interest in social activities, which contributes to our understanding of secondary benefits that adolescents may experience when engaging in active-physical activities. This may be explained by the fact that physical activities include team sports and other opportunities for social interaction, which has also been observed in studies of adolescents without disabilities [28].

Family activity orientation demonstrated importance in explaining preferences for different types of leisure activities. Although one may think that adolescents’ preferences may be predominantly dictated by peers, it is acknowledged that family has an important influence on the decision-making and activities chosen by adolescents with or without disabilities [25, 29, 30]. Moreover, family activity orientation has an influence on the actual levels of involvement in leisure for adolescents with disabilities, who are more likely to partake in activities with their family than with their peers [10, 11]. Interventions targeted at improving participation for this population should consider a family-centered approach where families’ values, expectations, and preferences are taken into consideration, in addition to that of the adolescent. However, it is important to note that differentiating from their parents and acquiring personal autonomy in decision-making are important developmental competencies that should be acquired during adolescence and intervention should promote opportunities for adolescents to develop social competencies outside the family context. Community programs that are universally accessible should be created, In addition to the benefits of integration of adolescents with different abilities, this would allow adolescents with disabilities to circulate in the public spaces and participate with more autonomy from their families [31].

Study limitations

One limitation of this study is the inclusion of only adolescents who could self-report or required minimal parental help to indicate their leisure preferences. Although the participants represented adolescents across all the spectrum of CP severity, as expected, these adolescents had higher levels of language and cognitive functioning than those who did not complete the PAC. It is a constant challenge trying to understand the most subjective needs of adolescents who present with more severe ability. Moreover, multivariate models did not explain a large percentage of the variance in preferences in some activity domains, showing this is a complex construct likely influenced by other variables that were not accounted in our models.

Conclusions

Rehabilitation interventions should consider adolescents' preferences and family dynamics, target mastery motivation, and address behavioral and self-perception difficulties to help adolescents shape their preferences and engage in leisure activities of their choosing. Health promotion programs for adolescents with disabilities should also facilitate accessibility and the pursuit of adolescents' interests and preferences and therefore promote more fulfilling life styles.

Acknowledgements

We would like to thank the adolescents and families that participated in this study. We wish to thank our research coordinator, Anna Radzioch and research assistants Joey Waknin and Christopher Saunders. We would also like to acknowledge the contributions of the professionals who assessed participants in the study: OTs: Noemi Dahan-Oliel, Rena Birnbaum and Claudia de Luca/PTs: Melissa Turner, Shannon McShane/Psychologists: Lisa Steinbach, Mafalda Porporino, Chantal Martel, Catherine Zygmuntowicz, Sarah-Jane Renaud/Neurologists: Dr Shevell, Dr Poulin, Dr Moore, Dr Rosenblatt, Dr Srouf, Dr Tremblay, Dr Oskoui.

This paper was presented (poster) at the Canadian Association of Occupational Therapy Annual Meeting in Quebec, QC, June 2012.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

This study was funded by the Canadian Institutes of Health Research (CIHR). In addition, we were benefited from research infrastructure provided by the Montreal Children's Hospital Research Institute and the Centre for Interdisciplinary Research in Rehabilitation of the Greater Montreal (CRIR); both funded by FRSQ. K.S.-T. was supported by a doctoral award provided by the Canadian Child Health Clinician Scientist Program (CCHCSP), NeuroDevNet, and the Montreal Children's Hospital Research Institute/Foundation of Stars.

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