



Person-reported perspectives on support availability for people with disabilities during the COVID-19 pandemic in Quebec

Alena Valderrama^{1,2} · Xanthy Lajoie³ · Mylène Armstrong¹ · Alexei Luizar-Obregon⁴ · Olaf Kraus de Camargo⁵

Received: 3 September 2021 / Accepted: 29 June 2022

© The Author(s) under exclusive license to The Canadian Public Health Association 2022

Abstract

Objectives To identify the perception of the availability of community support and the support needs of autistic people and people with disabilities, from their own perspectives and from those of their caregivers at the time of the COVID-19 pandemic in Quebec, to assess the association between the available support and the perceived stress levels to evaluate the role of perceived social support as a potential buffer of this association.

Methods A total of 315 respondents participated in a 4-min online survey across the province of Quebec by snowball sampling. Community support was defined as availability of adapted healthcare, adapted information, adapted educational services and community services.

Results The community support and services during the COVID-19 pandemic were not available or were not sufficiently adapted to their needs. About 40% of autistic people or people with disabilities and 44% of their caregivers perceived their days as being quite stressful or extremely stressful. This is twice the rate of that of the general population in non-pandemic time. Nevertheless, social supports can play a mediating role in attenuating the effects of the absence of adapted services on the stress level of this vulnerable population.

Conclusion The non-availability of adapted services was related to an increase in the stress level in this population. Our study adds that other than social support, adapted healthcare/tele-healthcare and in-home support services could reduce the impact of the pandemic on the stress level of autistic people and people with disabilities. Adapted educational services and necessary equipment for online education for people without resources could reduce the impact on the stress level in caregivers. People with disabilities and their caregivers are one of the most vulnerable groups in our society. Public health measures of containment and mitigation need to consider more their specific needs.

✉ Alena Valderrama
alena.valderrama.med@ssss.gouv.qc.ca

¹ Department of Social and Preventive Medicine, School of Public Health, Université de Montréal, Montreal, QC, Canada

² Sainte-Justine University Hospital and Research Centre of the Sainte-Justine University Hospital, 3175 Chem. de la Côte-Sainte-Catherine, Montreal, QC H3T 1C5, Canada

³ Department of Psychology, Université de Montréal, Montreal, QC, Canada

⁴ Department of Economics, Universidade Federal Fluminense, Rio de Janeiro, Brazil

⁵ McMaster University - Ron Joyce Children's Health Centre, Hamilton, ON, Canada

Résumé

Objectif Identifier la perception de la disponibilité du soutien communautaire et les besoins de soutien des personnes autistes et des personnes en situation de handicap, de leurs perspectives mêmes et de celles de leurs aidants durant la pandémie de COVID-19 au Québec, et évaluer l'association entre le soutien disponible et les niveaux de stress perçus afin d'évaluer le rôle du soutien social perçu comme un médiateur de cette association.

Méthode Un total de 315 répondants ont participé à un sondage en ligne de 4 minutes à travers la province de Québec par échantillonnage en boule de neige. Le soutien communautaire a été défini comme la disponibilité de soins de santé, d'informations, et de services éducatifs et communautaires adaptés à leurs besoins.

Résultats Le soutien communautaire, et les services disponibles pendant la pandémie de la COVID-19, n'étaient pas disponibles ou étaient insuffisamment adaptés à leurs besoins. Environ 40 % des personnes autistes ou en situation de handicap et 44 % de leurs proches aidants perçoivent leurs journées comme assez ou extrêmement stressantes. C'est deux fois plus que le taux dans la population générale en période non pandémique. Néanmoins, le soutien social peut jouer un rôle médiateur en atténuant les effets de l'absence de services adaptés sur le niveau de stress de ces populations vulnérables.

Conclusion La non-disponibilité de services adaptés augmente le niveau de stress de cette population. Notre étude ajoute que, outre le soutien social, les soins de santé adaptés, les services de soutien à domicile et les soins de santé à distance pourraient réduire l'impact de la pandémie sur le niveau de stress des personnes autistes et en situation de handicap et que les services éducatifs adaptés et l'aide à l'éducation à distance pourraient réduire l'impact sur le niveau de stress des proches aidants. Les personnes en situation de handicap et leurs proches aidants constituent l'un des groupes les plus vulnérables de notre société. Les mesures de santé publique d'atténuation de la pandémie doivent tenir compte de leurs besoins.

Keywords Disability · Autism · COVID-19 · Public health

Mots-clés Handicap · autisme · COVID-19 · santé publique

Introduction

In Quebec, 9.6% of the population, 15 years old and above, have a disability. Of these, 74.6% require assistance to complete at least one activity of daily living (ADL). Only 26.7% live independently and 36.7% have an income of less than \$15,000 a year (OPHQ, 2019). Approximately 1 in 66 children and youth in Canada are diagnosed with autism spectrum disorder (ASD) (Ofner et al., 2018), and they will experience significant social inequities. As a result, they have a higher prevalence of mental and physical illnesses compared to the general population (Diallo et al., 2017). As well, autistic people experience mental issues and daily stress which affect their quality of life (Park et al., 2019).

Caregivers of people with disabilities experience more mental health problems compared to the general population. For example, the lived experience of parents of autistic children is marked by higher rates of emotional stress and strain as compared to that of parents of typically developing children, with about 50% of parents reporting stress in their daily lives (Papadopoulos et al., 2019). People with disabilities and their caregivers are one of the most vulnerable groups in our society.

Little has been compiled on how people with disabilities, autistic people and their caregivers are being affected and are facing the pandemic (Armitage & Nellums, 2020; Schiariti, 2020). The COVID-19 pandemic compromised support services and caused drastic changes of circumstances and routines for many autistic people and people with disabilities

(Colizzi et al., 2020), with potentially serious consequences for their mental health and well-being (Pellicano & Stears, 2020). The question arises whether the COVID-19 outbreak has resulted in an increase in difficulties among this population and their caregivers and in increasing social health inequities (Chakraborty, 2021).

Within the framework of the International Classification of Functioning, Disability and Health (ICF), this translates into identifying barriers and developing facilitators with the goal to enable participation (WHO, 2001). Therefore, it is important to know the level of support received by these vulnerable populations during the pandemic and to understand the impact that the level of support may have on their stress, to address unmet support needs and find effective strategies to better respond to these needs. Based on what is known, we wanted to study the situation in Quebec, from the perspective of people with disabilities themselves.

The main goal of this research was to assess the perception of the availability of community support and the support needs of autistic people and people with disabilities at the time of the COVID-19 pandemic in Quebec, from their own perspectives and from those of their caregivers. Community support was defined as availability of adapted healthcare, adapted information, adapted educational services and community services. A second objective was to assess the association between the available support and the perceived stress levels and to assess the role of perceived social support as a potential buffer of this association. Social support was defined as a

mediator between the stressful event and the person's health with several dimensions: tangible, instrumental or material help; informational support for problem-solving; emotional support; and support for acceptance, self-esteem and belonging (Caron & Guay, 2006). In this research, we were interested in instrumental, informational and emotional support because they were the ones most at risk of being cut off during the pandemic.

Methods

Design and data collection

An online 4-min survey in French was developed and study data were collected and managed using REDCap electronic data capture tools hosted at *CanChild, McMaster University* (Harris et al., 2009, 2019). It was available for 4 weeks in September 2020, resulting in a convenience sample of participants across the province of Quebec. Our recruitment strategy used convenience and snowball sampling by broadcasting the opportunity for participation on social media, *CHU Sainte-Justine* online networks and our collaborators' network, such as autistic persons associations, parents' associations and *Fédération Québécoise de l'autisme*.

Outcomes

This study focused on available support during the COVID-19 pandemic for autistic people and people with disabilities in terms of (1) available adapted healthcare; (2) available adapted information; (3) adapted educational services; and (4) community services, from the perspective of (a) autistic people or people with disabilities over 18 years of age and (b) caregivers of autistic people or people with disabilities of any age. Inspired by Caron and Guay (2006), we also asked about perceived social support with two questions and one single-item stress level perception question (Eddy et al., 2019). We recruited people identified as autistic people or people with disabilities or their caregivers. There were no exclusion criteria. Two autistic people revised the questionnaire to ensure accessibility.

We asked everybody: "Thinking about the amount of stress in your life, would you say that most days are: not at all stressful; not very stressful; a bit stressful; quite a bit stressful; extremely stressful?" (Shields, 2006). They were also asked about perceived social support with two questions: "I have someone who I trust and who I can turn to in case of problems" and "There are people I can count on in case of emergency". For both, 6-point Likert scales were used (always-often-sometimes-rarely-never-I do not know). We chose these two questions because, according to the literature, it is the availability of social support that is most predictive of its

positive effects on reducing the experience of stress (Caron & Guay, 2006). In the last section of the questionnaire, the following demographic information was collected: "What area do you live in?" and "What country were you born in?". Finally, there was also one open question for everybody: "Do you have any other comments, questions or information you would like to share with us?". No response was mandatory.

Data analysis

The data were analyzed using IBM SPSS Statistics software (version 25) and R 4.1. Descriptive statistics were used to analyze participants' perspectives on available supports for autistic people and people with disabilities, as well as the perceived social support and perceived life stress by autistic people, people with disabilities and their caregivers. The chi-square test or the exact Fisher test was used for bivariate analyses between participants' perspective of available support and perceived life stress.

We constructed a continuous composite variable, the "social support level", for the two social support questions. We considered a rating as follows: "Always=6", "Often=5", "Sometimes=4", "Rarely=3", "Never=2" and "Don't know=1". Thus, a score was associated with each respondent for each question and the sum of the scores of the two questions resulted in the "social support level". The values could vary from a minimum of 2 to a maximum of 12. Next, we stratified the variable into two levels: level 1 of social support with people whose maximum score was 9 points and who constituted 50% of the sample (median), and level 2 of social support with people with a score above the median of 9.

We developed a second set of composite continuous variables, called "Accumulation of non-adapted services" or ANAS, using a partial cumulative procedure applied on the set of perception of unavailability of adapted services: we gave a value to each response as follows: no = 2, don't know = 0, yes but not enough = -1, yes = -2. These cumulative variables correspond to the sum of the contributions of each indicator variable. Thus, we originated different combinations of variables. We obtained several expressions of an accumulation of non-adapted services, i.e. non-adapted services plus non-adapted information, etc. For each combination, we calculated the respective ANAS which was the sum of the values of the variables that were part of the combination. With the ANAS obtained, we estimated the parameters of the ordinal logistic models. We retained just the combinations that had an increasing structure in the chain of combinations. Finally, we only retained the models in which the ANAS coefficient had p values lower than 0.10.

Finally, we considered "perceived life stress" as an ordinal dependent variable with three categories: (1) "not at all stressful" together with "a little stressful", (2) a bit stressful, and (3) "quite a bit stressful" together with "extremely stressful".

Afterwards, using ordinal logistic regression, we predicted the perceived life stress level by autistic people, people with disabilities and their caregivers according to the perception of adapted supports available in the community or in health services for autistic people or people with disabilities (continuous composite variable ANAS). At the same time, we also examined how life stress levels varied by perception of social support. Regressions were adjusted for the country of birth and area of residence. All results were described according to their confidence interval and *p* value.

Finally, a qualitative thematic analysis of the content of the verbatims of the open question was carried out by two researchers (AV, MA) using the NVivo 12 software.

The study obtained approval from the Research Ethics Board of the Sainte-Justine University Health Centre (CHU Sainte-Justine) project 2021-3050. Online informed consent was obtained from all the participants.

Description of the sample

A total of 315 respondents participated in the survey. Our sample consisted of 55 autistic people or people with disabilities and 279 caregivers. Nineteen of them were autistic people or people with disabilities and caregivers at the same time and they were analyzed as autistic people or people with disabilities. Most respondents live in large cities and in non-rural areas, 119 and 73, respectively. There were 200 participants who were born in Canada and 105 who were born outside of Canada (Table 1).

Results

No response was mandatory, and more than two thirds of the participants answered all questions, which is considered acceptable (Groves & Peytcheva, 2008). Tables 2 and 3 show the number of responses for each question. For descriptive and bivariate results from caregivers, the responses “No” and “Don’t know” were coded together. For descriptive and bivariate results for autistic persons or people with disabilities, we coded together “yes” with “yes but not enough” and “no” with “I don’t know”.

Expressed needs and perception of available support

Table 2 shows that 27 (61.4%) autistic people needed healthcare services, and 16 (59.3%) of them had telehealth services. There were 25 (58.1%) who needed home support, and 25 (55.6%) who answered needing delivery services. Most of them also answered not having adapted services or not knowing their existence, like adapted information about the pandemic from community organizations (27 or 60.0%).

Table 1 Characteristics of the sample

Characteristic	<i>N</i>
Autistic persons and people with disabilities	55
Only autistic persons	26
Only people with disabilities	7
Autistic persons with disabilities	3
Autistic persons or people with disabilities and caregivers	19
Caregivers of an autistic person or person with disabilities	279
What area do you live in (respondents=230)	
Large cities (Montreal-Quebec)	119
Other non-rural regions of Quebec	73
Rural regions	38
Country of birth (respondents=315)	
Canada	200
France	10
Other	105
Total respondents	315

Table 3 shows that 141 (61.3%) of caregivers perceived adapted health services as not available and that 142 (63.1%) of caregivers perceived information about the pandemic as not adapted for autistic people or people with disabilities. Furthermore, 185 (83.7%) of caregivers perceived the online education as non-adapted for students with special needs.

Self-reported social support and perceived life stress

Since the beginning of the pandemic, 28 (65.0%) autistic people or people with disabilities and 172 (78.5%) caregivers perceived their days as being quite stressful, stressful or extremely stressful. On the other hand, 8 (18.6%) autistic people or people with disabilities and 66 (33.1%) caregivers reported rarely or never having someone they trust and to whom they can turn for advice if they had problems. We performed bivariate analyses of the relation between social support and the perception of the life stress level for the two groups. Although we found a negative trend, it was not statistically significant (Table 4).

Association of stressful life with availability of adapted services

We found a positive trend between autistic respondents or people with disabilities reporting a lack of adapted services, such as healthcare or other services at home, or adapted information about the COVID-19 pandemic and their perception of daily stress levels. However, no association reached statistical significance at *p*<0.05. For caregivers, we also found a positive trend, but not significant, between the perception of not

Table 2 Descriptive perceived availability and needs of adapted services by autistic people and people with disabilities during the pandemic

Autistic people or people with disabilities				
Questions: during the pandemic	Response	Respondents	N	% *
Did you need healthcare?	Yes	44	27	61.4
	No		17	38.6
If yes, did you receive tele-health services?	Yes	27	16	59.3
	No		11	40.7
If you have been exposed to COVID-19 and needed care, were the services adapted?	Yes	42	6	13.3
	No		1	2.4
	Did not need it		35	83.3
Did you need home support?	Yes	43	25	58.1
	No		18	41.9
If yes, did you receive home support?	Yes	25	12	48.0
	No		13	52.0
Did you need delivery services? For example, for groceries or medication?	Yes	45	25	55.6
	No		20	44.4
If yes, did you receive delivery services? **	Yes	25	22	88.0
	No		3	12.0
Do health services provide you with adapted services?	Yes	45	19	42.2
	No		26	57.8
Do health services or organizations provide you with home support?	Yes	44	17	38.6
	No		27	61.4
Do community organizations provide you with information about COVID-19 adapted to your needs?	Yes	45	18	40.0
	No		27	60.0
Do health services provide you with information about COVID-19 that is tailored to your needs?	Yes	44	22	50.0
	No		22	50.0
Do education services provide you with adapted online education?	Yes	43	8	18.6
	No		10	23.3
	Not at school		25	58.1

N total 55 * The proportions were based on the number of respondents. "No" and "Don't know" were coded together. "Yes" and "Yes, but not enough" were coded together. ** We asked, "If yes, by whom were these services provided?" The responses were : community organization (2), family (1), CLSC (6), other (4), I must pay (3)

having available adapted services during the pandemic for their children and their perception of a stressful life.

Regression and bivariate analyses

We estimated ordinal regression models (Cumulative Link Models) for each group. As shown in model 4 of Table 5, for autistic people and people with disabilities, an increase in one unit in the ANAS 4 (non-adapted healthcare and no home delivery and no home support and no tele-healthcare) drives a 25% increase in the probability of change from "Not at all stressful/not very stressful" to "A bit stressful" (95% CI 1.02, 1.51, $p < 0.05$). With the same model 4, at perceived social support level 2, the odds of being more likely to change from "Not at all stressful/not very stressful" to "A bit stressful" decline by 17% (CI 0.04, 0.67, $p < 0.05$) (Table 5).

Table 6 shows the regression models for caregivers. For the four models, for every unit increase in ANAS the increased odds of being more likely to change from "Not at all stressful/not very stressful" to "A bit stressful" are significant. For instance, an increase in one unit in the ANAS 4 (non-adapted healthcare and no home support and no adapted school and no equipment for online education) drives a 7% increase in the probability of change from "Not at all stressful/not very stressful" to "A bit stressful" (CI 1.01, 1.14, $p < 0.05$). And at perceived social support level 2, the odds of being more likely to change from "Not at all stressful/not very stressful" to "A bit stressful" decline by 46% (CI 0.32, 0.90, $p < 0.05$) (Table 6).

For both caregivers and autistic people or people with disabilities, the four models indicate that the perceived social support component on the stress level is individually significant in reducing the probability of going from a lower stress level to a higher

Table 3 Descriptive perceived availability of adapted services by caregivers during the pandemic

In terms of support, do health services or community organizations offer:	Respondents	Caregivers		
		<i>N</i>	% *	
Adapted health services during the COVID-19 pandemic?	Yes	230	89	38.7
	No		141	61.3
Adapted facilities, if a person with autism or a disability has been exposed to COVID-19 and requires, e.g. isolation or care?	Yes	225	13	5.8
	No		212	94.2
Support at home?	Yes	226	37	16.4
	No		189	83.6
Delivery services (e.g. groceries, hygiene items, medication)?	Yes	225	102	45.3
	No		123	54.7
Adapted information on COVID-19 (e.g. sign language, captioning, plain language)?	Yes	225	83	36.9
	No		142	63.1
Adapted online education for children with special needs?	Yes	221	36	16.3
	No		185	83.7
Necessary equipment for online education for people without resources?	Yes	220	56	25.5
	No		164	74.5

N total 265. *The proportions were based on the number of respondents. “No” and “Don’t know” were coded together

one (Tables 5 and 6). We analyzed separately the 26 participants who identified as autistic persons and the results were similar.

Thematic analyses of responses to open question

There were many recurring themes during the analysis of the open question. Two main categories stood out: the sense of being

abandoned by the system, a fact that just got worse with the pandemic (obstacles, missing resources, inequities within the system), and the effects of the COVID-19 pandemic on daily life (disorganization, exhaustion, stress, and financial constraints).

Many parents of autistic children expressed the feeling of having been abandoned by the system even before the pandemic. Many expressed the feeling that their needs were not

Table 4 Descriptive perceived social support and level of stress in autistic people, people with disabilities and their caregivers

Questions	Autistic people or people with disabilities		Caregivers		Chi ² /Fisher	Freeman	
	Respondents	%*	Respondents	%**	<i>p</i> value	Thet-stat	
I have someone I trust and to whom I can turn for advice if I have problems	Always / Often	20	46.5	98	44.8	0.25	0.066
	Sometimes	14	32.6	53	24.2		
	Rarely / Never	8	18.6	66	30.1		
	I don’t know	1	2.3	2	0.9		
	Total respondents	43	100.0	219	100.0		
There are people I can count on in case of an emergency	Always / Often	25	58.1	96	43.8	0.12	0.079
	Sometimes	7	16.3	60	27.4		
	Rarely / Never	10	23.3	62	28.3		
	I don’t know	1	2.3	1	0.5		
	Total respondents	43	100.0	219	100.0		
Since the beginning of the pandemic, regarding the level of stress in your life, the majority of your days are:	Not at all stressful/Not very stressful	15	34.9	47	21.5	0.16	0.064
	A bit stressful	11	25.6	73	33.3		
	Quite a bit stressful/Extremely stressful	17	39.5	99	45.2		
	Total respondents	43	100.0	219	100.0		

N total 50. **N* total 265. **The proportions were based on the number of respondents

Table 5 Determinants for stress level increase for autistic people or with disabilities by best ordinal logistic regression models

Variables	Model 1		Model 2		Model 3		Model 4	
	Odds (95% CI)	Adjusted odds (95% CI)	Odds (95% CI)	Adjusted odds (95% CI)	Odds (95% CI)	Adjusted odds (95% CI)	Odds (95% CI)	Adjusted odds (95% CI)
Low social support level	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0
High social support level	0.20 (0.06, 0.69)	0.22 (0.06, 0.79)	0.18 (0.05, 0.62)	0.18 (0.05, 0.71)	0.19 (0.06, 0.66)	0.19 (0.05, 0.70)	0.20 (0.06, 0.68)	0.17 (0.04, 0.67)
ANAS 1*	<i>p</i> = 0.01	<i>p</i> = 0.02	<i>p</i> = 0.008	<i>p</i> = 0.015	<i>p</i> = 0.010	<i>p</i> = 0.014	<i>p</i> = 0.011	<i>p</i> = 0.012
ANAS 2**	1.72 (0.66, 4.44)	1.60 (0.59, 4.39)						
	<i>p</i> = 0.271	<i>p</i> = 0.356	1.27 (0.94, 1.70)	1.21 (0.89, 1.65)				
			<i>p</i> = 0.114	<i>p</i> = 0.232				
ANAS 3***					1.22 (1.00, 1.57)	1.23 (0.97, 1.57)		
ANAS 4****					<i>p</i> = 0.052	<i>p</i> = 0.081		
Not born in Canada	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Born in Canada		2.20 (0.35, 14.01)		2.44 (0.38, 15.33)		3.00 (0.47, 19.49)		3.63 (0.57, 23.10)
		<i>p</i> = 0.401		<i>p</i> = 0.347		<i>p</i> = 0.247		<i>p</i> = 0.174
Large city	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Non-rural		1.63 (0.36, 7.32)		1.55 (0.35, 6.82)		1.75 (0.39, 7.85)		1.79 (0.39, 8.17)
		<i>p</i> = 0.524		<i>p</i> = 0.558		<i>p</i> = 0.467		<i>p</i> = 0.455
Rural		1.42 (0.33, 6.17)		1.30 (0.30, 5.53)		1.23 (0.28, 5.42)		1.57 (0.35, 7.03)
		<i>p</i> = 0.637		<i>p</i> = 0.731		<i>p</i> = 0.782		<i>p</i> = 0.562
Log likelihood	-42.846	-40.959	-42.147	-40.644	-41.437	-39.756	-40.929	-38.833

Bold values denote statistical significance at the *p* < 0.05 level

¹ Dependent variable: 3 categories of stress level: not at all stressful/not very stressful, a bit stressful, quite a bit stressful/extremely stressful

*ANAS 1 = non-adapted healthcare

**ANAS 2 = non-adapted healthcare + no home delivery

***ANAS 3 = non-adapted healthcare + no home delivery + no home support

****ANAS 4 = non-adapted healthcare + no home delivery + no home support + no tele-healthcare

Table 6 Determinants for stress level increase for caregivers by best ordinal logistic regression models

Variables	Model 1		Model 2		Model 3		Model 4	
	Odds (95% CI)	Adjusted odds (95% CI)	Odds (95% CI)	Adjusted odds (95% CI)	Odds (95% CI)	Adjusted odds (95% CI)	Odds (95% CI)	Adjusted odds (95% CI)
Low level of social support	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0
High level of social support	0.52 (0.31, 0.88) <i>p</i> = 0.014	0.50 (0.29, 0.86) <i>p</i> = 0.014	0.54 (0.32, 0.91) <i>p</i> = 0.022	0.52 (0.30, 0.92) <i>p</i> = 0.025	0.56 (0.33, 0.5) <i>p</i> = 0.032	0.54 (0.30, 0.95) <i>p</i> = 0.032	0.54 (0.32, 0.90) <i>p</i> = 0.020	0.51 (0.29, 0.88) <i>p</i> = 0.017
ANAS 1*	1.19 (1.03, 1.36) <i>p</i> = 0.016	1.20 (1.04, 1.39) <i>p</i> = 0.013						
ANAS 2**			1.12 (1.01, 1.23) <i>p</i> = 0.027	1.13 (1.02, 1.25) <i>p</i> = 0.021				
ANAS 3***					1.11 (1.02, 1.0) <i>p</i> = 0.019	1.12 (1.02, 1.21) <i>p</i> = 0.015		
ANAS 4****							1.07 (1.01, 1.14) <i>p</i> = 0.032	1.07 (1.01, 1.15) <i>p</i> = 0.029
Not born in Canada	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Born in Canada		1.06 (0.46, 2.44) <i>p</i> = 0.891		1.05 (0.46, 2.41) <i>p</i> = 0.904		1.09 (0.48, 2.51) <i>p</i> = 0.826		1.12 (0.49, 2.56) <i>p</i> = 0.795
Large city	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Non-rural city		0.55 (0.31, 0.99) <i>p</i> = 0.048		0.55 (0.31, 0.99) <i>p</i> = 0.047		0.54 (0.30, 0.96) <i>p</i> = 0.037		0.55 (0.31, 0.98) <i>p</i> = 0.043
Rural area		0.66 (0.31, 1.40) <i>p</i> = 0.285		0.68 (0.32, 1.45) <i>p</i> = 0.318		0.70 (0.33, 1.51) <i>p</i> = 0.371		0.68 (0.32, 1.45) <i>p</i> = 0.324
Log likelihood	-223.768	-207.542	-224.268	-207.937	-223.908	-207.628	-224.399	-208.230

Bold values denote statistical significance at the *p* < 0.05 level

¹ Dependent variable: 3 categories of stress level: not at all stressful/not very stressful, a bit stressful, quite a bit stressful/extremely stressful

*ANAS 1 = non-adapted healthcare

**ANAS 2 = non-adapted healthcare + no home support

***ANAS 3 = non-adapted healthcare + no home support + no adapted school

****ANAS 4 = non-adapted healthcare + no home support + no adapted school + no equipment for online education

being heard. The situation did not get better once the first wave hit. They saw many of their already limited services being put on hold. They also felt that the services that did remain were not sufficient to meet their needs.

The services for intellectual disabilities were almost nonexistent before the pandemic. During the pandemic, we were left to fend for ourselves. Our child obviously lost a lot of what he had learned. There is no support from schools nor from the health system. Appalling.
– Parent of a person with a disability

COVID-19 did not just affect the services, it also greatly influenced daily life. Some autistic persons experienced a lot of disorganization in their routine, from lack of preparation to help them follow sanitary measures such as sneezing in the elbow, wearing a mask and washing their hands. Many reported the need to stop working as a consequence.

I have a lot of difficulty wearing a mask, it makes it excessively difficult to think, to concentrate, to work. [...] At work, the mask is also obligatory, I have not worked since mid-May because of this new rule. It's disabling not being able to work with a mask.
– Autistic person

Parents and caregivers expressed a lot of exhaustion and the feeling of being overworked.

We feel alone every day when we are parents of an autistic child. As soon as there is an external factor like a pandemic, it just adds to the fatigue already accumulated. – Parent of an autistic child

Nevertheless, a few respondents pointed out some positive outcomes such as the normalization of autistic traits, like wanting to stay home and being socially distant. This resulted in some experiencing less stress than before the pandemic.

Isolation has been for our totally Asperger family the best time of our lives. Returning to work/school is very stressful. – Autistic person and parent of an autistic person

Discussion

Our study shows that during the COVID-19 pandemic in the province of Quebec, from the perspective of autistic people or

people with other disabilities and their caregivers, the community support, defined as availability of adapted healthcare, adapted information, adapted educational services and community services, was not available, was not known, or was not sufficiently adapted to their needs. Endorsing our quantitative findings, the qualitative analysis of the open question answers shows the sense of abandonment and distress in which this vulnerable population finds itself, feelings that have been heightened by the pandemic. This situation increases the perceived stress level of this population. In addition, the accumulation of non-adapted healthcare, no home support services and no tele-healthcare increases the impact of the pandemic on the stress level of autistic people and people with disabilities. As well, other than no adapted healthcare and no home support, no adapted educational services and no assistance for tele-education increase the impact for stress level in caregivers. Nevertheless, perceived social supports can play a mediating role in attenuating the effects of the absence of adapted services on the perceived stress level of these vulnerable populations.

Even more stressful lives during the pandemic

About 50% of caregivers of children with disabilities have some stress in their daily lives in non-pandemic time (Papadopoulos et al., 2019). In Canada in 2019, 21% of Canadian people over 12 years old perceived most days as quite a bit or extremely stressful (Statistics Canada, 2019). In 2020, during the pandemic 28% of Canadians reported high stress levels (quite a bit stressful or extremely stressful) (Statistics Canada, 2020). In our study, 17 (39.5%) autistic people or with disabilities and 99 (44.2%) caregivers of autistic people and people with disabilities perceived their days as being quite stressful or extremely stressful. This is a significant increase of their stress levels during this pandemic, being twice that of the general population in non-pandemic time.

Widening an already existing lack of services but also promising avenues

Autistic people and people with disabilities are a population with difficulties to access services in general (OPHQ, 2019). While the direct impact of infection with SARS-COV-2 is major, such as a larger case fatality rate and higher morbidity in autistic children (Colizzi et al., 2020), this group also suffers more from the impact of non-inclusive COVID-19 pandemic mitigation measures (Amorim et al., 2020). As a result, as was revealed by Kent et al. (2020), outreach services that provide food and medication may have been disrupted, increasing the risk of food insecurity, or the exacerbation of chronic problems, and the disruption of support for daily living (Eshraghi et al., 2020; Smile, 2020). Nevertheless, according to our data, the absence of tele-healthcare contributes to

the increase of the stress level in autistic persons and persons with disabilities. So, as was already pointed out by other authors (McDevitt, 2021; Rao, 2020), it appears that tele-healthcare could be a particularly promising strategy to increase access to services for this population. For caregivers, what increased their stress levels, other than the absence of adapted health services and home support, was a lack of adapted educational services and a lack of educational assistance for tele-education. The impact of the lockdown on the development of children and adolescents with disabilities must be studied but also the opportunities that tele-education could have for autistic students and students with other disabilities.

What are the opportunities to protect this population in this crisis?

Around 12% and 15% of the Quebec population aged 12 and over has a low level of emotional and informational social support, respectively (MSSS, 2020). Even though they were not measured with the same indicator, our study shows that 8 (18.6%) autistic people or people with disabilities and 66 (33.1%) caregivers reported to rarely or never have someone to trust and to turn to for advice if they have problems. Social support is a well-known protective factor of mental health, and it could be a buffer between non-availability of adapted services and perceived stress levels. The unmet need for social support of parents of autistic children is acknowledged in non-pandemic times (Valderrama et al., 2020). The social support needs of these populations are not met during non-pandemic times nor during a pandemic when it is even more necessary to do so (Chen et al., 2020). Other researchers studying people with disabilities report similar data related to stress levels, the unavailability of adapted services and the need of social support for this vulnerable population (Amorim et al., 2020; Mumbardó-Adam et al., 2021). Therefore, beyond expanding remote services, we need to propose population-based measures to provide this population with social support.

Some autistic people or people with disabilities show lower perceived stress levels than other groups. It could be because some people find positive outcomes during the pandemic, but further research is needed.

Limitations

As this is a convenience sample, the results cannot be extrapolated to the general population. We did not ask about educational level or other economic status proxies, and our cohort is probably not the most vulnerable of the vulnerable, who might have shown even more severe impacts. We had about one third of nonresponses and we did not analyze the differences between the people who answered or not some questions. Other than perceived stress levels, we did not use

validated scales. We did not use a validated scale for measuring social support; instead we used two questions inspired from short scales (Kocalevent et al., 2018) to look for the available instrumental support. However, this study sample mainly consists of autistic people and their caregivers, populations that are hard to reach.

Conclusion

Disability as conceptualized in the ICF (WHO, 2001) refers to the interaction between individuals with a health condition (e.g. long-term physical, mental, intellectual or sensory impairments) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports). These environmental barriers may hinder their full and effective participation in society on an equal basis with others. Autistic people, people with disabilities and their caregivers were left unsupported during the COVID-19 pandemic and they report significant levels of stress. Within the concept of the ICF, environmental factors can also act as facilitators for participation. COVID-19 pandemic mitigation strategies must be inclusive to avoid widening existing disparities. Targeted measures are needed to improve adapted supports and to protect them from discrimination. Our study adds that other than social support, adapted healthcare, home support services and tele-healthcare could reduce the impact of the pandemic on the stress level of autistic people and with disabilities and that adapted educational services and necessary equipment for online education for people without resources could reduce the impact on the stress level in caregivers. These findings should be further explored in order to find interventions that better meet the needs of this population. Finally, it is necessary to raise awareness and show the reality of this population, and the need to prioritize them, to develop disability-inclusive public health responses and emergency preparedness, and to train health professionals about this reality.

Contributions to knowledge

What does this study add to existing knowledge?

- From the perspective of autistic people or people with other disabilities and their caregivers, the community support and the services during the COVID-19 pandemic were not available or were not sufficiently adapted to their needs.
- About 40% of autistic people or people with disabilities and 44% of their caregivers perceived their days as being quite stressful or extremely stressful. This is double the

rate of that of the general population in non-pandemic time.

- Public health measures of containment and mitigation need to consider the needs of people with disabilities.

What are the key implications for public health interventions, practice or policy?

- The social support needs of these populations are not met during non-pandemic times nor during a pandemic when it is even more necessary. Social support could be a buffer between non-availability of adapted services and perceived stress levels.
- For autistic persons or people with disabilities, the absence of adapted healthcare, home support services and telehealthcare significantly increased their perceived life stress. For caregivers, the absence of adapted health services and home support, a lack of necessary equipment for online education for people without resources, and a lack of adapted educational services significantly increased their perceived life stress.
- Targeted public health measures are needed to improve adapted supports and to protect this vulnerable population from discrimination.

Author contributions AV and OK designed the study, XL oversaw recruitment and data collection, and AV and MA carried out the qualitative data analysis. AL carried out the quantitative data analyses. AV wrote the first draft. All authors discussed the results and contributed toward the final version.

Data availability Dataverse UdeM Valderrama, Alena, 2021, "Données de réplication pour : Person-reported perspectives on support availability for people with disabilities during the COVID-19 pandemic in Quebec", Scholars Portal Dataverse, VERSION PROVISOIRE.

Code availability <https://dataverse.scholarsportal.info/privateurl.xhtml?token=388d7b84-58b2-4305-93de-157baa6f8dc8>

Declarations

Ethics approval and consent to participate The study obtained approval from the Research Ethics Board of the Sainte-Justine University Health Centre (CHU Sainte-Justine) project 2021-3050. Online informed consent was obtained from all the participants.

Consent for publication Not applicable.

Conflict of interest The authors declare no competing interests.

References

Amorim, R., Catarino, S., Miragaia, P., Ferreras, C., Viana, V., & Guardiano, M. (2020). The impact of COVID-19 on children with autism spectrum disorder. *Revista de Neurologia*, *71*(8), 285–291. <https://doi.org/10.33588/m.7108.2020381>

- Armitage, R., & Nellums, L. B. (2020). The COVID-19 response must be disability inclusive. *The Lancet Public Health*, *5*(5), e257. [https://doi.org/10.1016/S2468-2667\(20\)30076-1](https://doi.org/10.1016/S2468-2667(20)30076-1)
- Caron, J., & Guay, S. (2006). Soutien social et santé mentale : concept, mesures, recherches récentes et implications pour les cliniciens. *Santé Mentale au Québec*, *30*(2), 15–41. <https://doi.org/10.7202/012137ar>
- Chakraborty, J. (2021). Social inequities in the distribution of COVID-19: An intra-categorical analysis of people with disabilities in the U.S. *Disability and Health Journal*, *14*(1), 101007. <https://doi.org/10.1016/j.dhjo.2020.101007>
- Chen, S. Q., Chen, S. D., Li, X. K., & Ren, J. (2020). Mental health of parents of special needs children in China during the COVID-19 pandemic. *International Journal of Environmental Research and Public Health*, *17*(24), 9519. <https://doi.org/10.3390/ijerph17249519>
- Colizzi, M., Sironi, E., Antonini, F., Ciceri, M. L., Bovo, C., & Zocante, L. (2020). Psychosocial and behavioral impact of COVID-19 in autism spectrum disorder: An online parent survey. *Brain Sciences*, *10*(6), 341. <https://doi.org/10.3390/brainsci10060341>
- Diallo, F. B., Institut national de santé publique du Québec, & Bureau d'information et d'études en santé des populations. (2017). *Surveillance du trouble du spectre de l'autisme au Québec*. <http://collections.banq.qc.ca/ark:/52327/3200497>
- Eddy, C. L., Herman, K. C., & Reinke, W. M. (2019). Single-item teacher stress and coping measures: Concurrent and predictive validity and sensitivity to change. *Journal of School Psychology*, *76*(October), 17–32. <https://doi.org/10.1016/j.jsp.2019.05.001>
- Eshraghi, A. A., Li, C., Alessandri, M., Messinger, D. S., Eshraghi, R. S., Mittal, R., & Armstrong, F. D. (2020). COVID-19: Overcoming the challenges faced by individuals with autism and their families. *The Lancet Psychiatry*, *7*(6), 481–483. [https://doi.org/10.1016/S2215-0366\(20\)30197-8](https://doi.org/10.1016/S2215-0366(20)30197-8)
- Groves, R. M., & Peytcheva, E. (2008). The impact of nonresponse rates on nonresponse bias: A meta-analysis. *Public Opinion Quarterly*, *72*(2), 167–189. <https://doi.org/10.1093/poq/nfn011>
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support [Research Support, N.I.H., Extramural]. *Journal of Biomedical Informatics*, *42*(2), 377–381. <https://doi.org/10.1016/j.jbi.2008.08.010>
- Harris, P. A., Taylor, R., Minor, B. L., Elliott, V., Fernandez, M., O'Neal, L., McLeod, L., Delacqua, G., Delacqua, F., Kirby, J., Duda, S. N., & Consortium, R. E. (2019). The REDCap consortium: Building an international community of software platformpartners. *Journal of Biomedical Informatics*, *95*, 103208. <https://doi.org/10.1016/j.jbi.2019.103208>
- Kent, K., Murray, S., Penrose, B., Auckland, S., Visentin, D., Godrich, S., & Lester, E. (2020). Prevalence and socio-demographic predictors of food insecurity in Australia during the COVID-19 pandemic. *Nutrients*, *12*(9). <https://doi.org/10.3390/nu12092682>
- Kocalevent, R. D., Berg, L., Beutel, M. E., Hinz, A., Zenger, M., Härter, M., Nater, U., & Brähler, E. (2018). Social support in the general population: Standardization of the Oslo social support scale (OSSS-3). *BMC Psychology*, *6*(1), 31. <https://doi.org/10.1186/s40359-018-0249-9>
- McDevitt, S. E. (2021). While quarantined: An online parent education and training model for families of children with autism in China. *Research in Developmental Disabilities*, *109*(February), 103851. <https://doi.org/10.1016/j.ridd.2020.103851>
- Mumbardó-Adam, C., Barnet-López, S., & Balboni, G. (2021). How have youth with autism spectrum disorder managed quarantine derived from COVID-19 pandemic? An approach to families

- perspectives. *Research in Developmental Disabilities*, 110(March), 103860. <https://doi.org/10.1016/j.ridd.2021.103860>
- Office des personnes handicapées du Québec. (2019). Aperçu statistique des personnes handicapées au Québec. 2019. <https://www.ophq.gouv.qc.ca/publications/statistiques/les-personnes-handicapees-au-quebec-en-chiffres/aperçu-statistique-des-personnes-handicapees-au-quebec.html#c28362> Accessed 20 August 2021.
- Papadopoulos, C., Lodder, A., Constantinou, G., & Randhawa, G. (2019). Systematic review of the relationship between autism stigma and informal caregiver mental health. *Journal of Autism and Developmental Disorders*, 49(4), 1665–1685. <https://doi.org/10.1007/s10803-018-3835-z>
- Park, S. H., Song, Y. J. C., Demetriou, E. A., Pepper, K. L., Norton, A., Thomas, E. E., Hickie, I. B., Hermens, D. F., Glozier, N., & Guastella, A. J. (2019). Disability, functioning, and quality of life among treatment-seeking young autistic adults and its relation to depression, anxiety, and stress. *Autism: The International Journal of Research and Practice*, 23(7), 1675–1686. <https://doi.org/10.1177/1362361318823925>
- Pellicano, E., & Stears, M. (2020). The hidden inequalities of COVID-19. *Autism*, 24(6), 1309–1310. <https://doi.org/10.1177/1362361320927590>
- Rao, P. T. (2020). A paradigm shift in the delivery of physical therapy services for children with disabilities in the time of the COVID-19 pandemic. *Physical Therapy*, October. <https://doi.org/10.1093/ptj/pzaa192>
- Schiariti, V. (2020). The human rights of children with disabilities during health emergencies: The challenge of COVID-19. *Developmental Medicine and Child Neurology*, 62(6), 661. <https://doi.org/10.1111/dmcn.14526>
- Shields, M. (2006). Stress and depression in the employed population. *Health Reports*, 17(4), 11–29.
- Smile, S. C. (2020). Supporting children with autism spectrum disorder in the face of the COVID-19 pandemic. *CMAJ*, 192(21), E587. <https://doi.org/10.1503/cmaj.75399>
- Statistics Canada. (2019). Table 13-10-0096-04 perceived life stress, by age group. 2019. <https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310009604>
- Statistics Canada. (2020, mai 27). The Daily—Canadians' mental health during the COVID-19 pandemic. <https://www150.statcan.gc.ca/n1/daily-quotidien/200527/dq200527b-eng.htm>
- Valderrama, A., Courcy, I., Weis-Heitner, L., & Forgeot d'Arc, B. (2020). Les enjeux de littératie dans la communication aux parents du diagnostic de trouble du spectre de l'autisme chez l'enfant. *Santé Mentale au Québec*, 45(1), 127–145. <https://doi.org/10.7202/1070244ar>
- World Health Organization. (2001). *International Classification of Functioning, Disability and Health: ICF*. World Health Organization.

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.