


Educational challenges for 22q11.2 deletion syndrome in Japan: Findings from a mixed methods survey

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Abstract

Background: The 22q11.2 deletion syndrome (22q11DS) is characterised by a changing pattern of overlapping intellectual, physical, and mental disabilities along the course of one's life. However, the impact of overlapping disorders (multimorbidity) on educational challenges remains unclear.

Method: A survey was conducted with 88 caregivers of individuals with 22q11DS. A quantitative analysis of educational challenges and support needs divided into age groups (7–12, 13–15, 16–18, and 19 years and over) and a qualitative analysis of the free-text items in the questionnaire was conducted.

Results: Caregivers were more interested in comprehensive developmental support when their children were younger, and the emphasis shifted to concerns regarding environments that matched individual characteristics at older ages. Furthermore, when there are multiple disabilities or disorders, support is concentrated on the more obvious disabilities, and the lack of support for the less superficially obvious disabilities associated with multiple difficulties, including mental health problems, can be a challenge for people with 22q11DS and their families.

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Conclusions: This study suggests a need for increased focus on multimorbidity and associated disabilities in school education that are difficult to observe because of their mildness or borderline levels if present alone.

KEYWORDS

22q11.2 deletion syndrome, educational challenges, multimorbidity, qualitative, quantitative, questionnaire

1 | BACKGROUND

The 22q11.2 deletion syndrome (22q11DS) is caused by the microdeletion of chromosome 22, with an incidence rate of 1/2000 to 6000 (McDonald-McGinn, 2018). Many individuals have resulting physical conditions, such as congenital heart diseases, characteristic facial features, and immunological problems. Individuals with 22q11DS often co-develop neurodevelopmental comorbidities, including attention deficit hyperactivity disorder (ADHD, 37.1%), autism spectrum disorder (ASD, 12.8%), and intellectual disability (45.9%) (Schneider et al., 2014; Swillen et al., 1997). Comorbid psychiatric disorders are also common, with anxiety disorders accounting for 35.6% in children and 33.9% in adolescents (Schneider et al., 2014). Schizophrenia, which typically occurs in adolescence, is estimated to occur in approximately 20%–25% of individuals with 22q11DS (Fiksinski et al., 2021; Qin et al., 2020; Schneider et al., 2014). It has been pointed out that these neuropsychiatric comorbidities can result in learning and behavioural challenges in school life for individuals with 22q11DS (Donna Cutler-Landsman, 2020). Thus, individuals with 22q11DS experience multimorbidity (Niarchou et al., 2017), and even if each is present at a mild or borderline level, their overlap is likely to cause a mismatch with the existing social structure, including educational services that are matched to the majority or those with a single disability.

Furthermore, the patterns of the co-presence of disorders attributed to 22q11DS change with the affected person's growth. In some individuals, congenital heart diseases or physical conditions, such as a cleft palate, may be alleviated through treatment or over time. In contrast, cognitive or mental difficulties may increase with age. Such comorbidities may cause educational challenges and support needs that change throughout different educational stages.

Previous studies on the educational challenges of 22q11DS have reported associated cognitive features. Cutler-Landsman (2020) suggested that cognitive and behavioural problems in children with 22q11DS, such as diminished attention and cognitive capacity, can pose difficulties in school life. For example, children with 22q11DS find it difficult to engage in visuospatial processing (Attout et al., 2017; Niklasson & Gillberg, 2010) and exhibit weak arithmetic skills (Carvalho et al., 2014).

Regarding cognitive issues, Tobia et al. (2018) examined educational attainment and verbal, non-verbal, and spatial abilities in 18 children and adolescents with 22q11DS at two time points, 5 years apart. This longitudinal study indicated that age-related decline in cognitive function may be the result of altered profiles of cognitive strengths and weaknesses in people with 22q11DS. Furthermore, it has become

clear that phenotypes of cognitive development tend to change and diverge with age (Swillen & McDonald-McGinn, 2015). In addition, 82 individuals with 22q11DS who developed psychotic symptoms had lower reading ability even before the emergence of symptoms and continued to demonstrate difficulties with cognitive flexibility compared to those without psychosis (Antshel et al., 2017). This highlights the need for a focus on the relationship between cognitive abilities and various co-developing symptoms.

Regarding psychobehavioral issues, examinations using the Child Behaviour Checklist (CBCL) have revealed that internalising problems tend to be particularly common among individuals with 22q11DS (Klaassen et al., 2013; Wray et al., 2013). This suggests that individuals with 22q11DS tend to have psychobehavioral issues that are internalised rather than externalised, thus making it challenging to understand their difficulties at the surface level.

Affected individuals and their families face various educational challenges and support needs (Cohen et al., 2017) because the characteristics of symptoms and disabilities associated with 22q11DS differ greatly depending on the individual. However, the educational challenges and support needs due to overlapping disorders and illnesses remain unclear.

One reason for this may be related to the state of special needs education in Japan. In addition to individual support in regular classrooms, special support education in elementary schools (generally for ages 7–12) and junior high schools (generally for ages 13–15) in Japan includes instruction in schools for special needs education, special classes, and special support classrooms/resource rooms. Special support schools are divided into five disability categories: intellectual, physical, health, visual, and hearing disabilities. Special classes include those for language disorders and autism/emotional disorders in addition to the above five categories. Children with severe multiple disabilities attend classes focused on multiple disabilities. Furthermore, children with intellectual disabilities are typically not included in the instructions provided by special support classrooms/resource rooms. In addition to regular classes and special-needs schools, correspondence high schools and night high schools are available as school options for high school students (generally aged 16–18). Correspondence schooling is a type of high school in which students study primarily at home and earn credits through correctional instruction, schooling, and examinations.

While this situation allows children to choose the school or class according to their condition, it also creates a situation in which children are forced to choose the school or class they attend according to their primary disability as well as their intellectual and adaptive functions. Consequently, children with multiple albeit mild disabilities

often struggle to choose schools and classes, and some do not receive the support and guidance they truly need.

In Japan, education for children with various special educational needs is promoted according to the severity, overlap, and diversification of disabilities, and individual educational support and instruction plans are created, where necessary, for children and students enrolled in regular classes. However, in the case of children or students with 22q11DS who display multimorbidity, it is difficult to discern their educational challenges and support needs and thereby provide support or guidance tailored to these needs.

Therefore, in this study, we clarified the impact of overlapping disorders, which is a characteristic of 22q11DS, on educational challenges and support needs. In addition, it is necessary to note that the support status of special needs education in Japan differs among elementary, junior high, and high schools. Therefore, this study aimed to clarify the educational difficulties and support needs of four age groups of children according to their respective school life stages.

2 | METHODS

2.1 | Development and implementation of the survey

A detailed description of the methodology for our web-based survey is available from our previous studies (Morishima et al., 2021; Tamune et al., 2020). Briefly, an anonymous online questionnaire survey concerning the challenges and support needs related to medical care, education, and welfare services was developed based on previous literature and clinical guidance (e.g., Basset et al., 2011; Campbell et al., 2018; Fung et al., 2015; Habel et al., 2014) with inputs from the parents caring for an individual with 22q11DS. The final version of the survey questionnaire was divided into two main parts (Part A and Part B), which were subdivided into 10 domains as follows (Table S1): (1) Demographics of parents (Part A); (2) Demographics and lifetime diagnosis of comorbidities in an individual with 22q11DS (Part A); (3) Parental psychological distress and various challenges in medical, welfare, educational, and other areas (Part A); (4) Situation of notification of 22q11DS diagnosis, related impact, and required support in medical areas (Part B); (5) Information about disability certificates and required support in welfare areas (Part B); (6) Information about educational attainment and required support in educational areas (Part B); (7) Problems related to transition (Part B); (8) Sibling issues (Part B); (9) Research needs (Part B); and (10) Positive and negative changes in parents' lives (Part B). The items in Part A were mandatory, whereas those in Part B were optional.

The response period was from March 20 to November 8, 2019. The web questionnaire was accessed through our research team's web page ('22q-pedia'; <https://22q-pedia.net/>). The survey was publicised to patients' families through e-mail and/or letters, with the help of a Japanese 22q11DS family association (the 22 Heart Club) and the Association for the Protection of Children with Heart Disease, along with other people involved in the medical care of 22q11DS. Therefore, the recruited population was unclear and the response rate could

not be calculated. A paper-based questionnaire with the same content as the web-based questionnaire was sent by mail upon request to the participants who found it difficult to answer the web questionnaire. Of the 125 valid responses, four were paper-based.

In the current study, demographic and clinical information (Part A, #1 and #2), quantitative responses to questions about educational challenges (Part A, #3), and quantitative and qualitative responses to questions about educational attainment and required support in educational areas (Part B, #6) were used.

2.2 | Participants

Although valid responses were provided by 125 caregivers, we used the responses from 88 caregivers (81 of whom were mothers) caring for children of elementary school age or older to focus on children who had or had received education in school (7 years old or older) for #1, #2, and #3 (Part A). There were 69 responses to #6 (Part B). Of the 125 valid responses, 37 were excluded because they were caregivers of preschoolers who had not yet experienced school education.

The responses were analysed to identify the respective educational challenges in elementary school, middle school, high school, and beyond by dividing the respondents according to the age groups of the children they were caring for (7–12 years old, $N = 36$; 13–15 years old, $N = 11$; 16–18 years old, $N = 12$; 19 years or older, $N = 29$) (Tables 1 and 2). Caregivers of children aged ≥ 19 years responded retrospectively.

This study was approved by the Ethics Committee of the Faculty of Medicine, University of Tokyo (Approval No. 2018015NI). Participants expressed their consent to participate in the study by responding to the questionnaires. A prepaid card equivalent to 5000 yen (approximately 45 USD) was provided to each respondent as a reward.

2.3 | Data analysis

This was a mixed methods study that included both quantitative and qualitative analyses.

2.3.1 | Quantitative analysis

Quantitative data were collected using multiple-choice questions. Items related to individuals' backgrounds included questions about age, gender, IQ (IQ results obtained by parents when diagnosing a disability in a hospital or obtaining a certificate), co-existing illnesses, and type of school or class they were enrolled in (Tables 1 and 2). Respondents were instructed to respond with a 'Yes/No' response to each item of the questionnaire to indicate the existence of each educational challenge or support need (Table 3). One-way analysis of variance (ANOVA) and descriptive statistics were analysed using SPSS (version 25.0; IBM, Tokyo, Japan) for multiple-choice questions in the survey. Statistical significance was set at $p < .05$.

TABLE 1 Demographics and school characteristics of individuals with 22q11.2 deletion syndrome ($N = 88$).

Demographic information	7-12 ($N = 36$)	SD or %	13-15 ($N = 11$)	SD or %	16-18 ($N = 12$)	SD or %	19- ($N = 29$)	SD or %
Age (average years)	9.3	1.8	13.7	0.6	17.3	0.7	22.6	4.4
Gender (male/female)	16/20	male, 44.4	6/5	54.5	7/5	58.3	14/15	48.3
IQ score (average)*	68.9 ($N = 27$)	9.5	68.1 ($N = 8$)	19.3	66.6 ($N = 9$)	17.0	57.7 ($N = 24$)	17.3
Elementary school								
Regular classes	10	27.7	-	-	-	-	-	-
Special support classroom/ resource rooms (speech and language classes, etc.)	4	11.1	-	-	-	-	-	-
Special classes	15	41.7	-	-	-	-	-	-
Schools for special needs education	4	11.1	-	-	-	-	-	-
No response/others	9	25.0	-	-	-	-	-	-
Junior high school								
Regular classes	1	2.8	3	27.3	-	-	-	-
Special support classroom/ resource rooms (speech and language classes, etc.)	-	-	2	18.2	-	-	-	-
Special classes	-	-	4	36.4	-	-	-	-
Schools for special needs education	-	-	2	18.2	-	-	-	-
No response/others	-	-	2	18.2	-	-	-	-
High school								
Full-time (all-day) high school	-	-	-	-	1	8.3	-	-
Correspondence high school	-	-	-	-	1	8.3	1	3.4
Part-time (evening) high school	-	-	-	-	0	0.0	1	3.4
Schools for special needs education	-	-	-	-	6	50.0	-	-
No response/others	-	-	-	-	3	25.0	-	-
School/employment								
Technical school/university	-	-	-	-	-	-	2	6.9
Regular employment	-	-	-	-	-	-	2	6.9
Employment of the disabled	-	-	-	-	-	-	7	24
Community workshop	-	-	-	-	-	-	6	21
No response/others	-	-	-	-	-	-	10	34

*One-way ANOVA, $F[3,64] = 2.64$, $p = 0.057$.

2.3.2 | Qualitative analysis

For free-text responses ($N = 69$) to the questions in the evaluation form, a theme analysis was conducted in three steps (Tables 4 and 5). The first question was related to educational challenges: 'Please feel free to describe any difficulties you have encountered in using schools or other educational institutions because of your child's overlapping disorders or disability'. The second question was related to educational support needs: 'Please feel free to describe what kind of support you think is necessary for individuals with 22q11DS and their parents in schools and other educational institutions'. The first author independently coded all transcripts according to their

content and meaning. Next, the data were divided into categories, and each category was named. In addition, themes were identified and names were defined among the different units. To ensure reliability, the code content was determined and reviewed for all analyses through multiple discussions among the three researchers, including the first author. The first author (MT) was a licensed clinical psychologist and held a Ph.D. Of the two non-primary authors who conducted the analysis, one researcher (AK) was a Psychiatric Social Worker, and the other was a Ph.D., trained in qualitative analysis. The other staff member (NN) was a licensed clinical psychologist and a Ph.D. In cases where opinions differed, repeated discussions were held on all code contents to reach a consensus. We

TABLE 2 Comorbidities in individuals with 22q11.2 deletion syndrome ($N = 88$).

	7-12 ($N = 36$)	(%)	13-15 ($N = 11$)	(%)	16-18 ($N = 12$)	(%)	19- ($N = 29$)	(%)
Physical disorders	36	100.0	11	100	12	100	29	100
Congenital heart disease	30	83.3	9	81.8	9	75	25	86.2
Immune system disorder	10	27.8	3	27.3	3	25	14	48.3
Endocrine disorder	12	33.3	5	45.5	5	41.7	15	51.7
Gastrointestinal disease	11	30.6	5	45.5	4	33.3	15	51.7
Otorhinolaryngology/maxillofacial disease	31	86.1	8	72.7	6	50	26	89.7
Orthopaedic disease	10	27.8	8	72.7	6	50	14	48.3
Other physical disorders	9	25	1	9.1	1	8.3	12	41.4
Growth/developmental disorders	34	94.4	10	90.9	12	100	28	96.6
Intellectual disability	28	77.8	8	72.7	10	83.3	24	82.8
Autism spectrum disorder	4	11.1	2	18.2	2	16.7	4	13.8
Attention deficit hyperactivity disorder	3	8.3	1	9.1	2	16.7	2	6.9
Oppositional defiant disorder	1	2.8	0	0.0	0	0.0	0	0.0
Learning disability	9	25.0	2	18.2	2	16.7	8	27.6
Speech delay	23	63.9	4	36.4	7	58.3	15	51.7
Selective mutism	0	0.0	1	9.1	1	8.3	4	13.8
Delayed motor development	16	44.4	3	27.3	3	25.0	10	34.5
Growth disorder/short stature	11	30.6	3	27.3	2	16.7	10	34.5
Other growth/developmental disorders	3	8.3	1	9.1	0	0.0	1	3.4
Psychiatric/neurological disorders	6	16.7	1	9.1	4	33.3	21	72.4
Schizophrenia	0	0.0	0	0.0	0	0.0	8	27.6
Major depression	0	0.0	0	0.0	0	0.0	1	3.4
Bipolar disorder	0	0.0	0	0.0	0	0.0	2	6.9
Anxiety disorder	0	0.0	0	0.0	3	25.0	10	34.5
Panic disorder	0	0.0	0	0.0	0	0.0	2	6.9
Obsessive-compulsive disorder	0	0.0	0	0.0	1	8.3	3	10.3
Epilepsy	6	16.7	1	9.1	1	8.3	8	27.6
Other neuropsychiatric disorders	2	5.6	0	0.0	1	8.3	3	10.3

believe that these tasks resolved the risk ambiguity in interpretation with the three researchers reaching a consensus. Finally, cross-checking and discussions were conducted by the research team, which included experienced psychiatrists, psychologists, and mental health workers. The research team agreed on the final coding framework, and we believe that discussions among the research team minimised bias and ensured reliability. Microsoft Excel was used to manage the qualitative data.

3 | RESULTS

3.1 | Quantitative data

3.1.1 | Background factors

The percentage of male patients in each group was approximately 50%. The average Full scale IQ was 68.9 in the 7-12 years age group,

68.1 in the 13-15 years age group, and 57.7 in the 19 years and older age group, however, there were no significant differences ($F_{3,64} = 2.63, p = .057$, one-way ANOVA; Tables 1).

The 7-12 years age group comprised children in elementary and middle schools, whereas children in the 13-15 years age group were in regular classes, resource rooms, special classes, and schools for special needs education. In contrast, high school-level schooling consisted of regular schooling, including correspondence schooling and part-time evening schools or schools for special needs education (Table 1).

All individuals with 22q11DS tended to have some form of co-existing physical disorder. Across all age groups, more than 70% were affected by congenital heart diseases, and more than 50% had co-existing otorhinolaryngology or craniofacial disorders (Table 2). Regardless of the age group, the co-existence of growth/developmental disorders was observed in more than 90% of individuals. Intellectual disabilities were observed in more than 70% of all groups, and the next most common issue was linguistic difficulties

TABLE 3 Responses to the questions of educational challenges and support needs.

Items related to educational challenges (N = 88)	7-12		13-15		16-18		19-	
	(N = 36)	(%)	(N = 11)	(%)	(N = 12)	(%)	(N = 29)	(%)
#1 Lack of information regarding school selection	9	25.0	1	9.1	1	8.3	1	3.4
#2 Lack of consultants or contacts regarding school selection	7	19.4	2	18.2	0	0.0	3	10.3
#3 No educational institutions suitable for the individual's characteristics/traits	12	33.3	3	27.3	1	8.3	3	10.3
#4 Lack of special classes/schools for special needs education	7	19.4	2	18.2	0	0.0	0	0.0
#5 Lack of institutions for higher education suitable for the individual could go to	5	13.9	4	36.4	2	16.7	4	13.8
#6 Lack of home/visiting educational services	1	2.8	0	0.0	1	8.3	2	6.9
#7 Regular classes teachers were unhelpful	5	13.9	0	0.0	1	8.3	0	0.0
#8 Special classes teachers were unhelpful	7	19.4	0	0.0	0	0.0	2	6.9
#9 Schools for special needs education teachers were unhelpful	0	0.0	1	9.1	0	0.0	2	6.9
#10 Cannot keep up with schoolwork	16	44.4	0	0.0	2	16.7	4	13.8
#11 Difficulty with participating in events such as field days and school festivals	3	8.3	2	18.2	0	0.0	3	10.3
#12 Difficulty making friends	8	22.2	2	18.2	1	8.3	8	27.6
#13 Refusal to attend school	3	8.3	0	0.0	2	16.7	3	10.3
#14 Being bullied	5	13.9	0	0.0	0	0.0	4	13.8
#15 How to spend time after school	9	25.0	3	27.3	5	41.7	1	3.4
#16 Participating in extracurricular lessons and activities	6	16.7	1	9.1	0	0.0	1	3.4
#17 Communicating with the home room teacher	7	19.4	0	0.0	2	16.7	4	13.8
#18 Homeroom teacher changed	5	13.9	0	0.0	1	8.3	0	0.0
#19 Lack of knowledge regarding 22q11.2 deletion syndrome on the part of staff (faculty, etc.)	22	61.1	6	54.5	4	33.3	7	24.1
#20 Lack of understanding on the part of school staff (faculty, etc.) of the fact that children with 22q11.2 deletion syndrome may need more consideration than children with ordinary physical or intellectual disabilities	14	38.9	6	54.5	3	25.0	8	27.6
#21 Cannot come to an agreement with the school regarding educational policy for the individual with 22q11.2 deletion syndrome	5	13.9	0	0.0	0	0.0	4	13.8
#22 You (the parent or guardian) or your family's anxiety or resistance to selecting a special classes or schools for special needs education	10	27.8	0	0.0	0	0.0	0	0.0
#23 Anxiety or resistance that the individual feels regarding selection of a special classes or schools for special needs education	3	8.3	0	0.0	0	0.0	0	0.0
#24 Other	2	5.6	2	18.2	2	16.7	6	20.7
Items related to educational support needs (N = 69)	7-12		13-15		16-18		19-	
	(N = 29)	(%)	(N = 7)	(%)	(N = 9)	(%)	(N = 24)	(%)
#1 Additional staff allocation system for daycare and kindergarten	9	31.0	3	42.9	1	11.1	2	8.3
#2 Hospital classroom	2	6.9	0	0.0	0	0.0	0	0.0
#3 Support from home room teacher	5	17.2	2	28.6	4	44.4	7	29.2
#4 Support from school nurse	4	13.8	2	28.6	3	33.3	5	20.8
#5 Psychological support from school counsellor	7	24.1	3	42.9	2	22.2	6	25.0
#6 Lifestyle support from a social worker	4	13.8	2	28.6	2	22.2	6	25.0
#7 Developmental support from special classes specialists or visiting tutors	10	34.5	3	42.9	2	22.2	4	16.7

(Continues)

TABLE 3 (Continued)

Items related to educational support needs (N = 69)	7-12 (N = 29)		13-15 (N = 7)		16-18 (N = 9)		19- (N = 24)	
		(%)		(%)		(%)		(%)
#8 Environmental considerations for hyperacusis	4	13.8	1	14.3	2	22.2	5	20.8
#9 Consideration for restrictions on physical activity	3	10.3	2	28.6	3	33.3	3	12.5
#10 Support for refusal to attend school	3	10.3	0	0.0	2	22.2	9	37.5
#11 Measures to address bullying and support	0	0.0	1	14.3	2	22.2	8	33.3
#12 Career and educational counselling	4	13.8	3	42.9	2	22.2	10	41.7
#13 Other	2	6.9	2	28.6	1	11.1	3	12.5

(Table 2). Neuropsychiatric disorders co-existed in 33.3% of the 16- to 18-year-old age group, but this percentage increased dramatically to 72.4% in the 19-year-or-older group (Table 2).

3.1.2 | Educational challenges at each age group

The most prevalent challenge in the 7-12 age group was '#19: Lack of knowledge regarding 22q11DS on the part of the school staff (faculty, etc.)' at 61.1%, followed by '#10: Cannot keep up with school-work' at 44.4%, and '#20: Lack of understanding on the part of the school staff (faculty, etc.) of the fact that children with 22q11DS may need more consideration than children with ordinary physical or intellectual disabilities' at 38.9% (Table 3).

In the 13-15 age group, both #19 and #20 were the highest at 54.5%, followed by '#5: Lack of institutions for higher education that the individual could attend' at 36.4%.

In the 16-18 age group, '#15: What to do after school' was the highest (41.7%), followed by #19 (33.3%), and #20 (25.0%).

In the 19 years and older age group, '#16: Difficulty making friends' and #20 were high, at 27.6%, followed by #19 at 24.1%.

3.1.3 | Educational support needs in each age group

Respondents were asked to answer 'Yes/No' to each question to indicate whether each support need existed (Table 3).

In the 7-12 age group, '#7: Developmental support from special education classroom specialists or visiting tutors' was highest at 34.5%, followed by '#1: Additional staff allocation system for daycare and kindergarten' at 31.0%.

In the 13-15 age group, '#1 and #5: Psychological support from the school counselor', '#7 and #12: Career and educational counselling' were the highest at 42.9%.

In the 16-18 age group, '#3: Support from homeroom teacher' was highest at 44.4%, followed by '#4: Support from school nurse' and '#9: Considerations for restrictions on physical activity' at 33.3%.

In the group of individuals aged 19 years and older, '#12: Career and educational counseling' was highest at 41.7%, followed by '#10: Support for refusal to attend school' at 37.5%.

3.2 | Qualitative data

3.2.1 | Educational challenges

In this study, respondents were asked to freely describe the educational challenges children face because of overlapping disorders and disabilities. We extracted 38 labels from the responses analysed. Using the extracted labels, we established Category 1 consisting of eight subcategories (a-h), Category 2 consisting of four subcategories (a-d), and Category 3 consisting of one subcategory (a) (Table 4).

To summarise, in Category 1, 'Educational challenges due to overlapping disorders/disabilities', were identified, such as the focus of support and guidance only on the more obvious disabilities, even when there are multiple disabilities or overlapping disorders. Difficulties such as not being able to receive the necessary support because of mild or borderline disabilities were also identified. In Category 2, 'Difficulties related to support and guidance', were identified with a lack of consideration for learning, as well as physical and mental health at school. In Category 3, 'Lack of understanding about the disability', was identified with teachers' lack of understanding of multiple disabilities.

3.2.2 | Educational support needs

In this study, we asked the respondents to freely describe their support needs when receiving education. We extracted 78 labels from the responses analysed. Using the extracted labels, we established Category 1 consisting of six subcategories (a-f), Category 2 consisting of six subcategories (a-f), and Category 3 consisting of five subcategories (a-e) (Table 5).

To summarise, in Category 1, 'Needs for support and guidance that considers multiple disabilities', we identified requests for individual consideration of complications that vary from child to child and for understanding the borderline nature of disabilities. In Category 2: 'Support and guidance needs', there were requests for support for children's mental health and learning difficulties. In Category 3, 'Needs for understanding the disability', there were requests for understanding the disability and disorder itself, and for cooperation between schools, families, and other professionals.

TABLE 4 Qualitative analysis of free-text responses to the questions regarding educational challenges.

Category	Excerpt from narrative
1. Educational challenges due to overlapping disorders/disabilities	
Difficulty in adapting to the typical model of education for the intellectually disabled due to the combination of intellectual and physical difficulties/extreme anxiety (education based on training style lacks consideration for the mental aspects associated with the multimorbidity, making adaptation difficult)	<p>If there were overlapping intellectual/physical disabilities and hypersensitivity, the special classes for intellectual disability did not lead to mental and physical relief.</p> <p>Due to his/her vulnerability to stress, my child closed his/her mind and was unable to keep up with children in special classes who had a lot of energy.</p> <p>The teacher cannot understand the distress of the student's inability to keep up with the pace of those around him/her.</p>
Difficulty in getting teachers to understand intellectual disabilities that are difficult to see due to the coexistence of physical and intellectual problems	<p>My child has a heart disease and an intellectual disability, so I struggled to figure out how to make the kids in the class understand each one, and in the end, I could only talk about the heart.</p> <p>There was consideration for heart diseases that are easy to see, but not for difficulties of mild intellectual disabilities and extreme anxiety.</p>
Lack of consideration for other disability categories due to the choice of schools and classes that emphasise one of the overlapping disorders	<p>Support for intellectual disabilities was provided in the special class, but there were difficulties in obtaining consideration for speaking and hearing difficulties.</p> <p>Since he/she had both intellectual and mental disabilities, he/she requested to use the special support classroom for mental disabilities but was told that it was not suitable for him/her if he/she had intellectual disabilities.</p>
Difficulties associated with the borderline nature of physical and intellectual disability levels	<p>Although my child has overlapping disorders, both physical and intellectual, his/her borderline disabilities make teachers think that he/she could do more.</p>
Difficulties with the fact that classes for children with multiple disabilities may not be able to accommodate them due to their mild disabilities	<p>I was told that if he/she had multiple disabilities, he/she should go to a special class for multiple disabilities, but I was perplexed because everyone in that class was in a wheelchair, and he/she had no problem walking.</p>
Complaints about teachers' attitude	<p>There was no willingness on the part of the teachers to learn about 22q11.2 deletion syndrome.</p> <p>The more I explained the symptoms, the more confused the teacher became.</p>
Parental conflict	<p>I did not tell the teacher everything because I believed in his/her potential for growth.</p>
Appreciation for flexible and personalised support	<p>He/she could not be placed in a group because of his/her selective mutism, but teachers provided him/her with a different curriculum with individualised instruction, which helped.</p> <p>When my child had psychosomatic symptoms and stopped attending school, there was no counsellor available at first, but they dispatched one on short notice.</p>
2. Difficulties related to support and guidance	
An environment that makes it difficult for the student to feel emotionally secure in school	<p>He/she complained of physical symptoms and had trouble attending school, but there was no support from the school.</p> <p>The change in environment caused psychological symptoms (obsessive-compulsive disorder, hair pulling, selective mutism, etc.) and prevented him/her from joining the group.</p>
Lack of teachers who can provide specialised and individualised services	<p>The educational system could not provide guidance from specialised teachers for speech and hearing disorders.</p> <p>He/she applied for regular classes but was told that he/she would have to be chaperoned.</p>
Lack of medical and physical consideration	<p>I would like to see consideration given to injuries and bleeding.</p>
Lack of learning support	<p>It was difficult to find an environment where he/she could get support for his/her learning, and he/she had to study on his/her own a lot, so it was hard to learn.</p>

(Continues)

TABLE 4 (Continued)

Category	Excerpt from narrative
3. Lack of understanding about disability	
Lack of understanding of the characteristics of illness and multiple disabilities in children with 22q11.2 deletion syndrome by school officials	In the regular class, there was no understanding of intellectual disabilities and the disorder. There is a lack of understanding and appropriate approach from teachers about multiple disabilities.

4 | DISCUSSION

This mixed methods study that included both quantitative and qualitative analyses indicated that caregivers' attention tends to be focused on the adaptation of individuals with 22q11DS to the school environment, along with providing developmental support for neurodevelopmental difficulties at younger ages. However, as individuals with 22q11DS get older, the emphasis of caregivers shifts toward seeking an environment that fits their characteristics associated with multimorbidity and multiple disabilities. We were able to clarify that even if each disorder was mild or borderline, their overlap created challenges and support needs that were difficult to observe, such as anxiety, susceptibility to fatigue, and borderline illnesses. To our knowledge, this is the first large scale investigation to reveal difficulties and support needs in school education for children with 22q11DS, with special attention paid to the mismatch between the school system and individuals' multimorbidity and associated disabilities.

4.1 | Difference by age group in educational challenges and support needs (quantitative analysis)

For families of individuals with 22q11DS, even mild or borderline symptoms of the disability or disorder can lead to educational challenges because of their overlap. In this study, we elucidated the educational challenges and support needs of individuals with 22q11DS in each age group, as well as the challenges and support needs that arise due to overlapping disorders and disabilities (Table 3).

The results of the quantitative analysis indicated that caregivers of children with 22q11DS felt that there was a lack of understanding and knowledge regarding 22q11DS among the school staff for all age groups. Previous studies have also highlighted this issue (Cohen et al., 2017; Lee et al., 2005; Reilly, 2012; Reilly, Murtagh, & Senior, 2015; Reilly, Senior, & Murtagh, 2015). Caregivers of individuals with 22q11DS aged 7–12 years were more likely to consider their children's academic delays as educational difficulties, and they had a great need for developmental support and allocation of additional staff. For 13- to 15-year-old, the level of support needed was about the same for all choices; thus, we believe that this is a time when various individual characteristics and environmental considerations are intermixed. In particular, the high proportion of developmental disorders, such as ADHD and ASD, at a young age (Fiksinski et al., 2018; Kates et al., 2019) suggests that neurodevelopmental difficulties affect learning. It is necessary to know what disorder and

disability individuals with 22q11DS have to adequately consider the educational needs and challenges they face at school.

For 16- to 18-year-old, there is a strong need for support from homeroom teachers and school nurses, as well as support needs that consider restrictions in physical activity. One of the challenges in Japanese high school education is the fragility of the support system. Compared to elementary and junior high schools, Japanese high schools provide insufficient educational plans and services to meet individual support as well as insufficient transition support from junior high school (Tabe, 2011). In Japan, students with various disorders/disabilities and their families often choose schools for special needs education or correspondence high schools when they consider entering high school. However, many full-time teachers and correspondence high schools lack an understanding of students with special support needs. This situation can be a serious detriment to education for children and families who may have multiple disabilities and disorders, such as individuals with 22q11DS. The caregivers of individuals with 22q11DS aged 19 or over, whose responses were retrospective, had a high need for career counselling and had difficulty finding employment and choosing a school. Previous studies have indicated the importance of daily life skills in individuals with 22q11DS as their adaptive function has been established to affect their employment status (Butcher et al., 2012; Mosheva et al., 2019). For families that include individuals with 22q11DS, even after the child has successfully graduated from school, the transition to employment can pose an issue.

This suggests that for individuals with 22q11DS, emphasis is placed right from a young age on adapting to the environment, such as the school site, with a need for developmental support regarding neurodevelopmental difficulties. However, in older age groups, the emphasis may be on finding an environment that better fits the child's personality and characteristics.

4.2 | Educational challenges and support needs (qualitative analysis)

Based on the open-ended responses provided by families, we extracted the challenges and support needs in an educational environment that could not be obtained through multiple-choice responses. The results of this survey revealed that support tends to be biased toward one disability when disabilities and disorders overlap and that there is a lack of consideration when the degree of severity of each disorder is mild or borderline, despite it being difficult for the patient.

TABLE 5 Qualitative analysis of free-text responses to the questions regarding educational support needs.

Category	Excerpt from narrative
1. Needs for support and guidance that considers multiple disabilities	
Support that considers the individuality of each child in dealing with various complications that vary from person to person, and hope for an education that values the individuality of each child	I would like teachers to search for the best solution for the child in front of them, not based on their past experiences. There are many differences between individuals, so I would like them to provide support that suits each individual.
In addition to the consideration of intellectual disabilities, there are also support needs for comorbid physical illness, extreme anxiety, hypersensitivity, etc.	There was support for the intellectual side, but I would like to see more understanding of the lack of physical strength and tardiness due to heart and internal disorders.
Consideration for the borderline nature of physical and intellectual disability levels	I want teachers to understand the characteristics of 22q11.2 deletion syndrome, such as his sensitivity and borderline disability. I would like teachers to understand that although he/she sometimes seems to be able to do everything, he gets tired easily and is mentally sensitive. I want teachers to treat him/her like any other child, but I do not want them to force him/her to do things because there are many things she cannot do.
Hope regarding the attitude of teachers so that they can face the children	I want teachers to learn more about the disability and think about it with us. I would like the whole school to understand that it is necessary to have people who can move according to their physical condition and to have flexibility in the classroom.
Hope that parents' conflicts will be taken into consideration	Please do not use words that encourage the separation of parents and children.
Appreciation for teachers' individualised and flexible approach	It was reassuring to know that when I handed the pamphlet of the family association to the teacher, she tried to understand it.
2. Support and guidance needs	
An environment where children with mental and sensory sensitivities, and communication difficulties can feel mentally secure and can spend time at their own pace and physical condition	I would like teachers to pay more attention to his/her sensitive senses (smells, sounds, etc.) and communication with his friends (he/she is not good at communication or behaving in a group). I would like to see an environment where the guidance is given warmly and unobtrusively, and at the student's own pace, rather than enthusiastically.
Availability of teachers and support staff who can provide professional and individualised support	I would like the school to provide mental support for my child, taking into consideration his or her physical and mental condition. It would be good if there were supporters with specialised knowledge. I'd like the school to provide a place where my child can stay individually with a teacher.
Academic guidance and support	Even if they sit quietly in class, they often do not understand the content, so I would like to see some support such as adding explanations. I would like the school to have support for education and classes.
Support on how to relate to and explain things to friends	I would like teachers to explain my child's strengths and weaknesses in an easy-to-understand manner to his/her friends in the same grade. I would like to have outside support and guidance on how to interact with other students.
Support for promoting the sharing of information about children with 22q11.2 deletion syndrome	I would like to see posters at school that say, Do you have this kind of disorder? I would like to see something to share information about the lifestyles of other children with the same disorders/disabilities, and about going on to higher education and employment.
Desired education system	(Because it was not possible in some areas) I would like to have the option to return to regular classes from special classes. I would like to see resource rooms placed in each school.

(Continues)

TABLE 5 (Continued)

Category	Excerpt from narrative
3. Needs for understanding the disability	
Understanding of the characteristics of multiple disabilities and disorders	I want you to understand disabilities and disorders. I want you to learn more about this disability.
Cooperation with families	I want you to share information closely with parents. I would like to see an exchange of information between homeroom teachers and parents.
Cooperation between medical care, schools, and education	I would like to see the medical field reach out to educational institutions. Parents should be able to know what they should explain to the school.
Cooperation to connect the community and society such as education, medical care, welfare, and family	I would like to see a consistent approach to therapy and education, with detailed coordination on how the child is doing at home. There were many things that were difficult to explain, so I would like to have people who can connect schools, families, hospitals, and society.
Cooperation regarding consultation and support for parents	Parents are desperately trying to cope with the difficulties their children are facing, but the mental and physical burdens are great, and I would like to see multifaceted support such as hospital visits, referrals to counsellors, and advice on transferring to another school, so that they do not have to experience alone.

For example, children with mild intellectual disability and borderline intelligence (IQ50-85) face challenges such as not fitting in at special support schools and regular classes (Bouck, 2014), which leads to problems with cognitive and adaptive skills (APA, 2013), as well as mental health challenges, and a high risk of developing mental illness (Kok et al., 2016; Koslowski et al., 2016) (Tables 4 and 5).

The results suggest that caregivers want schools to consider the fact that a child with high levels of anxiety and irritability, susceptibility to fatigue, internal disorders, and borderline illnesses is difficult to understand through external observation alone. It is extremely important that individuals with 22q11DS are provided psychological support, given the fact that they tend to have a high level of anxiety regardless of age group and have a high risk of developing mental illnesses in adolescence (Fiksinski et al., 2018; Kates et al., 2019). In fact, this study revealed that caregivers tended to be particularly concerned about their children's vulnerability to stress. In younger individuals with 22q11DS, studies using MRI brain structure analysis indicated a decrease in pituitary volume (Armando et al., 2018) involving reduced stress tolerance and vulnerability to psychiatric comorbidities found in daily life (Sandini et al., 2020). It is suggested that the freely written responses by caregivers, such as 'vulnerability to stress' and 'sensitivity', may stem from the fact that these biological factors of 22q11DS affect their mental difficulties. Previous studies have also pointed out that adults with 22q11DS have severe fatigue, which is associated with psychiatric vulnerabilities (Vergaelen et al., 2017). However, teachers in school may not understand the challenges that children with 22q11DS face that are less apparent on the surface, such as low-stress tolerance, high anxiety, and fatigue. The most important aspect of this study is that the wide variety of overlapping disorders and disabilities duals with 22q11DS and the lack of understanding of the challenges that are not apparent on the surface may be educational challenges for individuals with 22q11DS and their families. In fact, the results of this study revealed that the caregivers of

individuals with 22q11DS wanted that their children's schools consider them at their own pace, such as 'Understanding that although he/she sometimes seems to be able to do everything, he/she gets tired easily and is mentally sensitive' and 'An environment where the guidance is given warmly and unobtrusively, and at the student's own pace'. Teachers in schools need to understand and be aware that individuals with 22q11DS may face challenges that may not be apparent on the surface.

Although caregivers feel there is a need to consider educational challenges, it is difficult for them to propose concrete countermeasures that schools should take. We believe this is represented by the comments in which they expressed that educators should think alongside parents, with the desire to support staff with specialised knowledge, because the extent and details of symptoms and disorders vary between individuals. Although the families concerned have many support needs, it is unclear how many educators can realise that support. As this study was able to demonstrate that family members have a high need for collaboration between education and medical care or welfare, we must aim to visualise their individual needs and provide comprehensive support through collaborations between supporters involved in the child's life, such as school staff, regional administrative personnel, and medical care practitioners, rather than between parents alone.

4.3 | Limitations

First, there is an issue with the representativeness of the target participants. Information for the survey was disseminated through family associations and websites, and subjects with a variety of demographic and clinical characteristics were obtained from all of Japan. However, as the author's group is the only one in Japan that operates a specialised psychiatric outpatient clinic for 22q11DS, it is possible that

caregivers of individuals with greater difficulties and needs than those in Japan participated in the study. However, it can be argued that this made it possible to highlight the invisible needs of the syndrome. Second, it is unclear whether the study revealed difficulties and needs specific to this syndrome as it did not use other chromosomally induced syndromes as controls. However, it can be said that we were able to outline the educational challenges of a syndrome in which the overlap between physical, intellectual, and mental health changes dynamically with each stage of life. Third, the results may reflect the peculiarities of the Japanese school education system, and may not be generalizable to an international situation. However, the results may provide suggestions for a society and education system that includes syndromes with disabilities that are difficult to observe, such as 22q11DS. Fourth, the questionnaires were administered to family members, and the answers were primarily provided by mothers. Conducting questionnaire surveys on a large-scale is difficult because of intellectual limitations and high levels of anxiety and tension in interpersonal situations. However, it is important to capture the subjective challenges and needs that are difficult to express in words. For example, we may be able to conduct surveys with visual indicators (e.g., illustrations and photographs) by supporting staff with personnel whom individuals with 22q11DS trust. This viewpoint should be considered in future studies. Finally, there were limited questions on the educational difficulties and support needs of the caregivers of individuals with 22q11DS. Consequently, some details regarding difficulties in schools have not yet been clarified. However, this survey allowed us to gain an overview of the difficulties and support needs of individuals with 22q11DS and their families. We believe that this has helped us consider the nature of future support in school education.

5 | CONCLUSION

This mixed analysis of quantitative and qualitative data from 88 caregivers of individuals with 22q11DS suggested that for the school education of children with 22q11DS, more focus is required on multimorbidity and associated disabilities that are difficult to observe because of their mild or borderline levels if present alone. We hope that this study will contribute to the well-being of individuals with 22q11DS by providing an insight into the most important learning opportunities in the early stages of their lives, such as educational settings during childhood and adolescence, and that it will ultimately help guarantee their rights to education and social inclusion.

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CONFLICT OF INTEREST STATEMENT

None of the authors have any conflict of interest to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study may be available upon request after the approval of the ethical committee of the University of Tokyo. The data are not publicly available due to privacy or ethical restrictions.

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REFERENCES

- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
- Antshel, K. M., Fremont, W., Ramanathan, S., & Kates, W. R. (2017). Predicting cognition and psychosis in young adults with 22q11.2 deletion syndrome. *Schizophrenia Bulletin*, 43, 833–842.
- Armando, M., Sandini, C., Chambaz, M., Schaer, M., Schneider, M., & Eliez, S. (2018). Coping strategies mediate the effect of stressful life events on schizotypal traits and psychotic symptoms in 22q11.2 deletion syndrome. *Schizophrenia Bulletin*, 44, S525–S535.
- Attout, L., Noël, M. P., Vossius, L., & Rousselle, L. (2017). Evidence of the impact of visuo-spatial processing on magnitude representation in 22q11.2 microdeletion syndrome. *Neuropsychologia*, 99, 296–305.
- Bassett, A. S., McDonald-McGinn, D. M., Devriendt, K., Digilio, M. C., Goldenberg, P., Habel, A., Marino, B., Oskarsdottir, S., Philip, N., Sullivan, K., Swillen, A., Vorstman, J., & International 22q11.2 Deletion Syndrome Consortium. (2011). Practical guidelines for managing patients with 22q11.2 deletion syndrome. *The Journal of Pediatrics*, 159, 332–339.e1.
- Bouck, E. C. (2014). The postschool outcomes of students with mild intellectual disability: Does it get better with time? *Journal of Intellectual Disability Research*, 58, 534–548.
- Butcher, N. J., Chow, E. W., Costain, G., Karas, D., Ho, A., & Bassett, A. S. (2012). Functional outcomes of adults with 22q11.2 deletion syndrome. *Genetics in Medicine*, 14, 836–843.
- Campbell, I. M., Sheppard, S. E., Crowley, T. B., McGinn, D. E., Bailey, A., McGinn, M. J., Unolt, M., Homans, J. F., Chen, E. Y., Salmons, H. I., Gaynor, J. W., Goldmuntz, E., Jackson, O. A., Katz, L. E., Mascarenhas, M. R., Deeney, V. F. X., Castelein, R. M., Zur, K. B., Elden, L., ... McDonald-McGinn, D. M. (2018). What is new with 22q? An update from the 22q and you Center at the Children's Hospital of Philadelphia. *American Journal of Medical Genetics, Part A*, 176, 2058–2069.
- Carvalho, M. R., Vianna, G., Oliveira, L. e. F., Costa, A. J., Pinheiro-Chagas, P., & Sturzenacker, R. (2014). Are 22q11.2 distal deletions associated with math difficulties? *American Journal of Medical Genetics, Part A*, 164A, 2256–2262.
- Cohen, W., McCartney, E., & Crampin, L. (2017). 22q11 deletion syndrome: Parents' and children's experiences of educational and

- healthcare provision in the United Kingdom. *Journal of Child Health Care*, 21, 142–152.
- Cutler-Landsman, D. (2020). *Educating children with velo-cardio-facial syndrome, 22q11.2 deletion syndrome, and DiGeorge syndrome* (3rd ed.). Plural Publishing Inc.
- Fiksinski, A. M., Schneider, M., Murphy, C. M., Armando, M., Vicari, S., & Canyelles, J. M. (2018). Understanding the pediatric psychiatric phenotype of 22q11.2 deletion syndrome. *American Journal of Medical Genetics, Part A*, 176, 2182–2191.
- Fiksinski, A. M., Schneider, M., Zinkstok, J., Baribeau, D., Chawner, S. J. R. A., & Vorstman, J. A. S. (2021). Neurodevelopmental trajectories and psychiatric morbidity: Lessons learned from the 22q11.2 deletion syndrome. *Current Psychiatry Reports*, 23, 13.
- Fung, W. L., Butcher, N. J., Costain, G., Andrade, D. M., Boot, E., Chow, E. W., Chung, B., Cytrynbaum, C., Faghfoury, H., Fishman, L., García-Miñaur, S., George, S., Lang, A. E., Repetto, G., Shugar, A., Silversides, C., Swillen, A., van Amelsvoort, T., McDonald-McGinn, D. M., & Bassett, A. S. (2015). Practical guidelines for managing adults with 22q11.2 deletion syndrome. *Genetics in Medicine*, 17, 599–609.
- Habel, A., Herriot, R., Kumararatne, D., Allgrove, J., Baker, K., Baxendale, H., Bu'Lock, F., Firth, H., Gennery, A., Holland, A., Illingworth, C., Mercer, N., Pannebakker, M., Parry, A., Roberts, A., & Tsai-Goodman, B. (2014). Towards a safety net for management of 22q11.2 deletion syndrome: Guidelines for our times. *European Journal of Pediatrics*, 173, 757–765.
- Kates, W. R., Mariano, M. A., Antshel, K. M., Chandra, S., Gamble, H., & Giordano, M. (2019). Trajectories of psychiatric diagnoses and medication usage in youth with 22q11.2 deletion syndrome: A 9-year longitudinal study. *Psychological Medicine*, 49, 1914–1922.
- Klaassen, P., Duijff, S., Swanenburg de Veye, H., Vorstman, J., & Beemer, F. (2013). Behavior in preschool children with the 22q11.2 deletion syndrome. *American Journal of Medical Genetics, Part A*, 161A, 94–101.
- Kok, L., van der Waa, A., Klip, H., & Staal, W. (2016). The effectiveness of psychosocial interventions for children with a psychiatric disorder and mild intellectual disability to borderline intellectual functioning: A systematic literature review and meta-analysis. *Clinical Child Psychology and Psychiatry*, 21, 156–171.
- Koslowski, N., Klein, K., Arnold, K., Kösters, M., Schwohl, M., & Salize, H. J. (2016). Effectiveness of interventions for adults with mild to moderate intellectual disabilities and mental health problems: Systematic review and meta-analysis. *The British Journal of Psychiatry*, 209, 469–474.
- Lee, T. H., Blasey, C. M., Dyer-Friedman, J., Glaser, B., Reiss, A. L., & Eliez, S. (2005). From research to practice: Teacher and pediatrician awareness of phenotypic traits in neurogenetic syndromes. *American Journal of Mental Retardation*, 110, 100–106.
- McDonald-McGinn, D. M. (2018). 22q11.2 deletion syndrome: A tiny piece leading to a big picture. *American Journal of Medical Genetics, Part A*, 176, 2055–2057.
- Morishima, R., Kumakura, Y., Usami, S., Kanehara, A., Tanaka, M., Okochi, N., Nakajima, N., Hamada, J., Ogawa, T., Ando, S., Tamune, H., Nakahara, M., Jinde, S., Kano, Y., Tanaka, K., Hirata, Y., Oka, A., & Kasai, K. (2021). Medical, welfare, and educational challenges and psychological distress in parents caring for an individual with 22q11.2 deletion syndrome: A cross-sectional survey in Japan. *American Journal of Medical Genetics, Part A*, 188, 37–45.
- Mosheva, M., Pouillard, V., Fishman, Y., Dubourg, L., Sofrin-Frumer, D., & Serur, Y. (2019). Education and employment trajectories from childhood to adulthood in individuals with 22q11.2 deletion syndrome. *European Child & Adolescent Psychiatry*, 28, 31–42.
- Niarchou, M., Moore, T. M., Tang, S. X., Calkins, M. E., McDonald-McGuinn, D. M., & Zackai, E. (2017). The dimensional structure of psychopathology in 22q11.2 deletion syndrome. *Journal of Psychiatric Research*, 92, 124–131.
- Niklasson, L., & Gillberg, C. (2010). The neuropsychology of 22q11 deletion syndrome. A neuropsychiatric study of 100 individuals. *Research in Developmental Disabilities*, 31, 185–194.
- Qin, X., Chen, J., & Zhou, T. (2020). 22q11.2 deletion syndrome and schizophrenia. *Acta Biochim Biophys Sin (Shanghai)*, 52, 1181–1190.
- Reilly, C. (2012). Behavioural phenotypes and special educational needs: Is aetiology important in the classroom? *Journal of Intellectual Disability Research*, 56, 929–946.
- Reilly, C., Murtagh, L., & Senior, J. (2015). The impact on the family of four neurogenetic syndromes: A comparative study of parental views. *Journal of Genetic Counseling*, 24, 851–861.
- Reilly, C., Senior, J., & Murtagh, L. (2015). A comparative study of educational provision for children with neurogenetic syndromes: Parent and teacher survey. *Journal of Intellectual Disability Research*, 59, 1094–1107.
- Sandini, C., Chambaz, M., Schneider, M., Armando, M., Zöller, D., & Schaer, M. (2020). Pituitary dysmaturational affects psychopathology and neurodevelopment in 22q11.2 deletion syndrome. *Psychoneuroendocrinology*, 113, 104540.
- Schneider, M., Debbané, M., Bassett, A. S., Chow, E. W., Fung, W. L., & van den Bree, M. (2014). Psychiatric disorders from childhood to adulthood in 22q11.2 deletion syndrome: Results from the international consortium on brain and behavior in 22q11.2 deletion syndrome. *The American Journal of Psychiatry*, 171, 627–639.
- Swillen, A., Devriendt, K., Legius, E., Eyskens, B., Dumoulin, M., Gewilling, M., & Fryns, J. P. (1997). Intelligence and psychosocial adjustment in velocardiofacial syndrome: A study of 37 children and adolescents with VCFS. *Journal of Medical Genetics*, 34, 453–458.
- Swillen, A., & McDonald-McGinn, D. (2015). Developmental trajectories in 22q11.2 deletion. *American Journal of Medical Genetics, Part C, Seminars in Medical Genetics*, 169, 172–181.
- Tabé, A. (2011). Trends in special needs education in Japan's high schools: An examination of the current situation and recommendations for the future. *The Japanese Journal of Special Education*, 49, 317–329 (in Japanese).
- Tamune, H., Kumakura, Y., Morishima, R., Kanehara, A., Tanaka, M., & Okochi, N. (2020). Toward co-production of research in 22q11.2 deletion syndrome: Research needs from the caregiver's perspective. *Psychiatry and Clinical Neurosciences*, 74, 626–627.
- Tobia, V., Brigstocke, S., Hulme, C., & Snowling, M. J. (2018). Developmental changes in the cognitive and educational profiles of children and adolescents with 22q11.2 deletion syndrome. *Journal of Applied Research in Intellectual Disabilities*, 31, e177–e181.
- Vergaelen, E., Claes, S., Kempke, S., & Swillen, A. (2017). High prevalence of fatigue in adults with a 22q11.2 deletion syndrome. *American Journal of Medical Genetics, Part A*, 173, 858–867.
- Wray, E., Shashi, V., Schoch, K., Curtiss, K., & Hooper, S. R. (2013). Discrepancies in parent and teacher ratings of social-behavioral functioning of children with chromosome 22q11.2 deletion syndrome: Implications for assessment. *American Journal on Intellectual and Developmental Disabilities*, 118, 339–352.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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