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The Importance of School Leadership Support when Working with Students with Smith-Magenis Syndrome – A Q Methodology Study

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ABSTRACT

Smith-Magenis syndrome (SMS) is a rare genetic syndrome. Students with SMS have a neurobehavioural phenotype which has been characterised as challenging for both parents and teachers. Challenging behaviour often has a negative impact on the person's learning ability and is a hindrance in the learning environment. Challenging behaviour also impacts on teachers in terms of stress and burnout. The aim of this study was to explore what type of support the school staff needs in order to handle the challenging behaviour and academic development of students with SMS using Q methodology. Fourteen staff members working with students with SMS in Norway participated in the study by sorting 40 statements according to the Q methodology. The sorting was analysed based on the by-person factor analysis. Four viewpoints were identified as follows: 1) In control, 2) struggling, 3) Strugglers relying on parents, and 4) Support dependent. Several consensus statements were associated with the academic work of the students with SMS. The consensus statements regarding academic work showed that this is not a priority for these students. Support from the school's leadership and colleagues is imperative, in addition to cooperation from parents, to provide safe and productive school environments for children with SMS.

KEYWORDS

Challenging behaviours; handling behaviours; Q methodology; school staff; school; Smith-Magenis syndrome

Introduction

Managing students misbehaving is one issue that has the most impact on teachers in terms of stress and burnout, according to Kokkinos (2007)

Challenging behaviour in schools puts a great demand on the capacity of the staff, such as their competency, motivation, and values (Roland, Øverland, & Byrkjedal-Sørby, 2016). Further, working with challenging behaviour in schools demands special skills in the team, and it seems that in general, there is a lack of resources for dealing with students who display challenging behaviour (Roland et al., 2016). Addressing challenging behaviour in schools is also important regarding the schools duty to provide both staff and students with a safe setting (Michail, 2011; The Education Act, 1998).

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In a phenomenological study of the experiences of teachers teaching children with attention deficit hyperactivity disorder (ADHD), the main themes discovered were as follows: lack of information, resources, and support, disruptive child behaviour, and the burden of having the child in the class (Harazni & Alkaissi, 2016). Teachers in the study by Harazni and Alkaissi (2016) indicated that they knew that their practises towards students with ADHD were not suitable, but they did not have any other options. Rae, Murray, and McKenzie (2011) found that teaching staff had a relatively limited knowledge regarding the term challenging behaviour in relation to children with intellectual disabilities. In the same study (Rae et al., 2011) they found that the knowledge about the management of challenging behaviour in children with ID also was relatively low. This study also pointed out the limited research carried out in the educational setting in relation to children with ID and challenging behaviour (Rae et al., 2011).

Students with Smith-Magenis Syndrome

Smith-Magenis syndrome (SMS) is a rare, neurodevelopmental disorder caused by haploinsufficiency of the retinoic acid induced 1 (RAI1) gene due to either a deletion of chromosome 17 (17p11.2) or a mutation in RAI1 (Slager, Newton, Vlangos, Finucane, & Elsea, 2003; Smith et al., 1986). Common characteristics observed in children with SMS include cognitive impairment, sleep disturbance, self-injury, stereotypies, and aggressive behaviour (Greenberg et al., 1996; Smith, Dykens, & Greenberg, 1998). The incidence of SMS is estimated to be 1:15 000–1:25 000 births (Greenberg et al., 1991). In Norway, the Frambu Resource Centre for Rare Disorders has a record of approximately 40 persons with SMS. The disorder is underdiagnosed, and delayed diagnosis is fairly common (Gropman, Duncan, & Smith, 2006).

Students with SMS have a neurobehavioural phenotype which has been characterised as challenging for both parents and teachers. The educational functioning in students with SMS is significantly influenced by this phenotype based on physical, cognitive, and medical symptoms (Haas-Givler & Finucane, 2014). These problems include sleep disruption, behavioural and psychiatric symptoms, stereotypic behaviours, sensory integration issues, and variable levels of intellectual disabilities (ID) (De Leersnyder et al., 2001; Gropman et al., 2006; Laje et al., 2010; Madduri et al., 2006; Martin, Wolters, & Smith, 2006; Poisson et al., 2015). A number of persons with SMS also meet the criteria for Autism spectrum disorders (ASD) (Laje et al., 2010; Martin et al., 2006).

Recent research has reported a reversed gender difference in SMS and ASD, which favours females (Nag, Nordgren, Anderlid, & Naerland, 2018). Variable levels of cognitive impairment have also been observed in SMS, ranging from low to severe ID, while most of the patients have mild to moderate ID (Poisson et al., 2015). The substantially challenging behaviour and impaired adaptive functions lead to lower cognitive functioning in many individuals with SMS (Neira-Fresneda & Potocki, 2015). This may interfere disproportionately with learning and school performance and affect the overall educational performance of these students (Haas-Givler & Finucane, 2014). It has also been observed that individuals with SMS need more assistance than expected, based on their level of intellectual functioning (Udwin, Webber, & Horn, 2001).

Further, recent research has demonstrated that students with SMS display both challenging aggressive and self-injury behaviour and non-physically challenging behaviour in

school (Nag, Øverland, & Nærland, 2020). A study by Nag et al. (2020) also revealed that the school staff cope differently based on the type of behaviour that is considered problematic by them (for example, aggressive versus non-physical challenging behaviour).

Challenging behaviour often has a negative impact on the person's learning ability and also proves to be a hindrance in the learning environment (National Collaborating Centre for Mental Health (UK), 2015; Roland et al., 2016). According to Neira-Fresneda and Potocki (2015), both educational and behavioural intervention for students with SMS can be extremely challenging.

Aim of the Study

This study explores what type of support the school staff needs in order to handle the challenging behaviour and academic development of students with SMS.

Methods

This study follows the design of a study that was conducted previously, regarding the challenging behaviours associated with SMS and how the school staff copes with the same, and data for both the studies were collected simultaneously (Nag et al., 2020).

William Stephenson developed and introduced the Q methodology in 1935 (Stephenson, 1935). According to Stephenson (1953), a person's subjectivity is a set of communicative behaviours and is a factor that can be measured and studied. The Q methodology is designed to explore patterns of a person's viewpoint. A by-person factor analysis indicates the subjectivity by identifying unique viewpoints that are revealed as factor structures (Brown, 1986; Stephenson, 1953). Generally, five steps are used in Q studies: a) definition of concourse, b) developing the Q set, c) defining the participants, d) the Q sort and analysis, and e) interpretation (Van Exel & de Graaf, 2005).

Definition of Concourse

The concourse is defined as the universe of available communication regarding a specific topic (Brown, 1980; Thorsen & Allgood, 2010). The term comes from the Latin word, *concursus*, which implies, 'a running together', or a scenario where ideas run together in thought (Brown, 1993). The content of the concourse can be collected from different sources such as interviews, conversations, social media, magazines, or literature (Brown, 1980). Defining the concourse for this study was done by looking into research regarding SMS in general. In this Q study, various sources have been used to identify the concourse, such as data from open-ended and standardised assessment of functioning (Developmental Behaviour Checklist and Vineland Adaptive Behaviour Scales) that have been administered to parents of persons with SMS as a part of a larger study (Nag, Hoxmark, & Naerland, 2019; Nag & Naerland, 2020; Nag et al., 2018, 2020), and literature regarding SMS (Haas-Givler & Finucane, 2014; Neira-Fresneda & Potocki, 2015). The standardised assessments of functioning, the open-ended questionnaires filled in by the parents and the literature were used to identify statements regarding SMS and challenging behaviours.

Developing the Q set

The statements from the concourse have been systematically reduced from 150 to 40 by utilising the Fisher's balanced block design to create a balanced and structured set of statements (Fisher, 1960; Stephenson, 1953). Fisher's balanced block design is a two-dimensional model with effect on one side and levels on the other side (Fisher, 1960).

In this study, a 3 × 2 block design has been used. Three main dimensions (methods, cooperation, and guidance/knowledge) on the effect side of the block design and two main dimensions (behaviours and academic focus) on the level side, were used to ensure that a wide range of statements were included. An additional category of statements, 'school staff emotions' was added (Table 1). The statements were then reduced by categorising them into similar groups. From statements that address the same issue, a single statement was selected, or statements were combined. The statements were printed on separate cards and numbered arbitrarily. These generated statements are known as the Q set (Coogan & Herrington, 2011; Van Exel & de Graaf, 2005).

Participants (P set)

In this study, the P set constitutes school staff members who are working with a student with SMS. Principals of the 10 Norwegian schools (we know of only 10 students with SMS in grade school in Norway) were contacted and asked to distribute the Q sort to a maximum of three of their staff members who are working with a student with SMS. Approximately 50% (14) volunteered to participate in the study, and they completed and returned the Q sort. A reminder email was sent to the principals after one month. The 14 staff member represent six or seven students with SMS. Each staff member only works with one student with SMS (none of the schools have more than one student with SMS). Most participants (eleven) worked in regular education settings, while only three worked in special education schools. More than half of the participants (eight) did not have any special education training. None of the participants had worked with a student with SMS before starting to work with the students they are currently monitoring. Six participants had worked with the student with SMS for one to two years, five had worked with the student with SMS for four to five years, and one had worked with the student with SMS for seven years. Two of the participants did not specify how long have they worked with the student with SMS.

Q sorting

In Q methodology the participants sort the Q set of statements into a grid (Figure 1). In this study a distribution grid with eleven categories (from +5 to −5) has been created to fit 40 statement cards. The sort represents the participants' viewpoints. Face to face

Table 1. Fishers balanced block design, N = 40.

	Behaviours	Academic	School Staff Emotions
Methods	6 statements	6 statements	5 statements
Cooperation	5 statements	4 statements	
Guidance/Knowledge	7 statements	7 Statements	

-5	-4	-3	-2	-1	0	1	2	3	4	5

Figure 1. The grid used during Q sort.

interviews are usually recommended in the Q methodology (Van Exel & de Graaf, 2005), but as the students with SMS live across Norway, it was concluded that this would be rather ineffective and expensive. The Q sorts were sent in the mail and the participants sorted these themselves. The package also included information regarding the study and written instructions to sort the cards. Studies have indicated that Q sort sent through the mail or conducted using a computer has no difference in reliability or validity than an interview-based (face-to-face) Q sort (Reber, Kaufman, & Cropp, 2000b; Van Tubergen & Olins, 1979). The participants were instructed to sort the cards ranging from 'most like' to 'most unlike' based on their experience of working with the student with SMS. After they finished sorting the cards, the participants were instructed to write the numbers of the statements at the correct place in the grid (Figure 2). They were also asked to provide a rationale for the positioning of the two cards which they placed on the far right (+5) and far left (−5) side of the grid. A form was provided for this purpose.

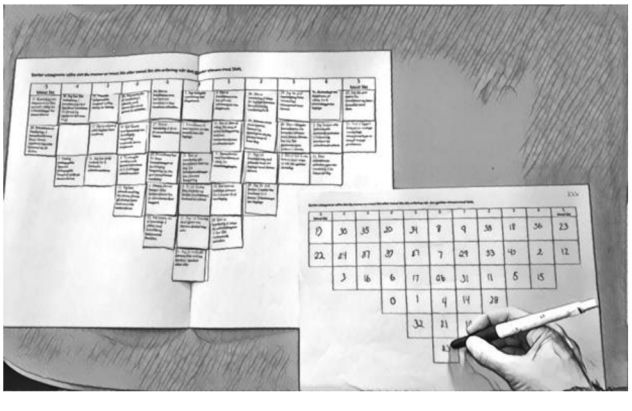

Figure 2. The participants writing down the numbers of the statements in the correct place in the grid.

Data Analysis and Interpretation

All the Q sorts were plotted and analysed using the PQMethod (Schmolck, 2002). During the process of analysis, the degree or level of dissimilarity and similarity of points between the individual sorters were calculated. Following that, a factor analysis was performed to examine how many groupings of similar Q sorts were made. The factors or views comprise persons with similar views (sorts) (Van Exel & de Graaf, 2005). Factor scores are essentially weighted z-scores for each statement in the Q sample. Furthermore, these scores can be converted into an array of scores (factor array) that correspond to the plus 5 to minus 5 values in the original Q sort continuum (McKeown & Thomas, 1988). The factors were interpreted based on the characteristic statements of each factor and the distinguishing and consensus statements. Additionally, written statements regarding why the participants placed the statements on either end of the scale were used to support the results.

Ethical Considerations

This study is part of a larger study regarding SMS. It was approved by the Norwegian Ethical Committee (2015/1026). The participants were asked to sign an informed consent form before taking part in the study.

Results

In the principal component analysis, the program calculated eight unrotated factors with eigenvalues from 7.29 to 0.36 and explained variances from 52 to 3%. Using varimax rotation, four factors were extracted. One Q sort was confounded, which means it loaded similar on more than one factor. Five participants loaded on factor 1, three on factor 2, three on factor 3, and two participants on the fourth factor (Table 2). Only two participants loaded on the fourth factor, however when the same was calculated with four factors, three distinct factors were identified (Table 2). In the principal component analysis, the fourth factor had an eigenvalue less than 1 (0.91) while in the investigation of the factors, factor 4 had some distinct differences in comparison with the three other factors and it was therefore decided that all four factors

Table 2. Factor loadings with an X indicating a defining Q sort.

Staff Code*	Factor 1	Factor 2	Factor 3	Factor 4
1SET F	0.0603	0.2158	0.7750X	0.4302
2TA M	0.8490X	0.0420	0.1349	0.1485
4SET M	0.4880	0.3829	0.3033	0.1459
3 U F	0.3449	0.8222X	0.0944	0.0151
5SET F	0.3449	0.2000	−0.0779	0.8450X
6 T F	0.2975	0.1581	0.4541	0.6755X
7TA F	−0.0516	0.8474X	0.2095	0.1941
8TA M	0.7099X	0.2096	0.2357	0.3610
9SET M	0.5238	0.3532	0.6378X	0.0377
10SET M	0.6391X	0.4363	0.3668	0.2837
11 U M	0.7408X	0.2674	0.1892	0.3456
12O M	0.2565	0.5779X	0.2173	0.3914
13O M	0.8595X	0.0797	0.1919	0.1495
14SET F	0.3803	0.1510	0.8238X	−0.0950

* SET: Special Education Teacher, T: Teacher, TA: Teacher Assistant, O: Other school education, U: Unknown profession, F: Female student with SMS, M: Male student with SMS

Table 3. Correlation among factors.

	Factor 1	Factor 2	Factor 3	Factor 4
Factor 1	-	r = 0.43	r = 0.59	r = 0.61
Factor 2		-	r = 0.48	r = 0.43
Factor 3			-	r = 0.38

should be presented. These four factors explained 28, 17, 17, and 14% variances, respectively. All four factors were correlated (Table 3), and this indicates an overlap between them. However, all these factors also have some distinct differences.

Table 4 gives an overview of the statements that loaded high and low on each of the four factors. The statements on the extreme ends of the sorting grid (+5, +4, −4, and −5) represent the factors and were used to interpret and understand the meaning of the factors.

Interpretation of Factors

Factor 1: In Control

This factor indicates that the staff has received guidance and information regarding SMS and handle the work well. They enjoy their work and feel safe even though the students display challenging behaviour. Two of the participants explained the placement of statement 25 (Table 5), I am afraid when the student gets angry and is screaming, kicking, or hitting as following:

> I have worked with this student for many years. I feel that I know him well. I think it is advantageous to know each other. He also knows my boundaries.

> I know how to react in different situations, and I mostly know what sets off the behaviour.

These staff members also work well with the parents. One of the participants commented on the cooperation with the parents as follows:

> Cooperation from the parents is instructive and good. They are grateful for the job we are doing, and they often tell us that. I feel that they are confident that we are taking good care of their child.

Factor 2: Struggling

This factor focuses on the perspective that it is hard to work with students with SMS because of their challenging behaviour. Furthermore, these staff members struggle as they need to do things a little differently as compared to other students. One participant described the placement of statement 20 on the most like side of the grid (Table 5), and states, I think it is hard to work with this student because of the behaviour, and further elaborates:

> The behaviour of these students is the most challenging aspect of working with them. A lot of planning and adaptation is required on a daily basis and even though a lot of effort is made, the child might still display challenging behaviour.

Furthermore, staff members find it difficult to communicate with parents about this behaviour as the parents could be sensitive. However, they work well with the parents. This group does not have support from the school leadership and from their colleagues.

Table 4. Characteristic statements and scores for the four viewpoints.

	Factor 1 – in control	Factor 2 – strugglers	Factor 3 – strugglers relying on parents	Factor 4 – support dependent
he positive side of the grid	30. I have been given guidance in how to handle this student's challenges and feel safe (+5) 33. I am looking forward to every day because of this student's charm, humour, and love (+5) 40. The most important knowledge on how to work with this student have I gotten through my own practise in the school (+4) 12. We may avoid many problems by being ahead of possible tricky situations (+4) 36. Knowledge about this disorder is important regarding the academic adaptation (+4) 31. Cooperation with the parents are important regarding the adaptation in the school (+3) 23. I get good support from the parents and like to talk with them (+3) 3. Regular pedagogical/special education tools work well with this student (+3)	12. We may avoid many problems by being ahead of possible tricky situations (+5) 14. It needs clear boundaries to be able to get any academically work done (+5) 20. I think it is hard to work with this student because if the behaviours (+4) 2. I often use individual support conversations before and after challenging behaviours (+4) 26. It is hard when the parents get upset regarding feedback about the student's act (+4) 36. Knowledge about this disorder is important regarding the academic adaptation (+3) 23. I get good support from the parents and like to talk with them (+3) 31. Cooperation with the parents are important regarding the adaptation in the school (+3)	12. We may avoid many problems by being ahead of possible tricky situations (+5) 23. I get good support from the parents and like to talk with them (+5) 31. Cooperation with the parents are important regarding the adaptation in the school (+4) 2. I often use individual support conversations before and after challenging behaviour (+4) 40. The most important knowledge on how to work with this student have I gotten through my own practise in the school (+4) 36. Knowledge about this disorder is important regarding the academic adaptation (+3) 15. It is the challenging behaviours that makes it difficult to have focus on the academic (+3) 33. I am looking forward to every day because of this student's charm, humour, and love (+3)	36. Knowledge about this disorder is important regarding the academic adaptation (+5) 30. I have been given guidance in how to handle this student's challenges and feel safe (+5) 12. We may avoid many problems by being ahead of possible tricky situations (+4) 18. I get a good follow-up after difficult situations with this student (+4) 28. I receive good support from the school leadership, so I can focus on the academic work (+4) 2. I often use individual support conversations before and after challenging behaviours (+3) 14. It needs clear boundaries to be able to get any academically work done (+3) 21. I know what I should do if the student self-injures (+3)

(*Continued*)

Table 4. (Continued).

	Factor 1 – in control	Factor 2 – strugglers	Factor 3 – strugglers relying on parents	Factor 4 – support dependent
The negative side of the grid	8. I lack training regarding this disorder (−3) 15. It is the challenging behaviours that makes it difficult to have focus on the academic (−3) 6. We are lacking a structure that could prevent challenging behaviours (−3) 22. The parents are difficult to cooperate with because the student behaves different at home and at the school (−4) 20. I think it is hard to work with this student because if the behaviours (−4) 1. This student does not need preparation before an activity to make it work (−4) 24. I think it is challenging to cooperate with the parents of this student (−5) 25. I am afraid when the student gets angry and is screaming, kicking, or hitting (−5)	6. We are lacking a structure that could prevent challenging behaviours (−3) 13. I can work academically with this student the same way I do with all other students (−3) 8. I lack training regarding this disorder (−3) 28. I receive good support from the school leadership, so I can focus on the academic work (−4) 24. I think it is challenging to cooperate with the parents of this student (−4) 29. It is not important to me that my colleagues and leadership at the school gives me praise and value my work (−4) 19. It is not important to have knowledge regarding this disorder in order make adaptation to this student (−5) 1.This student does not need preparation before an activity to make it work (−5)	1. This student does not need preparation before an activity to make it work (−3) 30. I have been given guidance in how to handle this student's challenges and feel safe (−3) 37. It is easy to put academic demands on this student (−3) 25. I am afraid when the student gets angry and is screaming, kicking, or hitting (−4) 17. The parents have too high expectations regarding the academic work and that makes the cooperation with them difficult (−4) 19. It is not important to have knowledge regarding this disorder in order make adaptation to this student (−4) 24. I think it is challenging to cooperate with the parents of this student (−5) 22. The parents are difficult to cooperate with because the student behaves different at home and at the school (−5)	20. I think it is hard to work with this student because if the behaviours (−3) 39. There is a lot of knowledge regarding this disorder and academic functioning (−3) 6. We are lacking a structure that could prevent challenging behaviours (−3) 19. It is not important to have knowledge regarding this disorder in order make adaptation to this student (−4) 1. This student does not need preparation before an activity to make it work (−4) 13. I can work academically with this student the same way I do with all other students (−4) 10. It is difficult to follow the recommendations we have been given regarding the behaviours (−5) 34. It is the parents that have taught us how to handle the behaviours (−5)

Factor 3: Strugglers Relying on the Parents

In this view the school staff have received information and guidance from parents but not much from the school leadership or from any other organisations (pedagogical centres for example). One of the participants described cooperation with the parents this way:

> I have valuable interactions with parents. They know their child the best. We can discuss the challenges faced and the solutions.

In this factor, the staff members struggle with academic focus due to the challenging behaviour, however, they enjoy working with these students.

> A lot of the time in school is used for breaks, rewards, acting out, repetition, slower progressions, and so on.

Factor 4: Support Dependent

In this view, they have received guidance and training regarding SMS and have support from the school leadership and colleagues.

> We are closely associated with the habilitation centre and receive guidance, and the centre regularly follows up. They are always available to address questions, extra visits, and so on when we need assistance because of an increase in the challenging behaviour.

These staff members have not received sufficient information from parents and do not work with a lot of parents. One of the participants explained the placement of statement 34 (Table 5), the parents have taught us how to handle the behaviour, on the least like side of the grid and further elaborates:

> The parents are exhausted and do not have the energy to contribute and help us in the school day.

Distinguishing Statements

Eighteen of the statements distinguish between the four different factor views. The scores on all statements and distinguishing statements are presented in Table 5.

Five of the statements were distinguishing for factor 1 (in control). Those holding this view believed that the challenging behaviour did not stop the students from having an academic inclination, and they, along with those holding factor 3 (strugglers relying on parents), were not afraid when the students gets angry, and clearly looked forward to their work days because of the students' charm, humour, and love. The school staff with this perspective believed that knowledge regarding SMS was not as important when planning adaptations for the students as compared to the school staff that represents the three other factor views. However, the staff in the former category believed that knowledge regarding SMS was important when planning academic adaptation.

Six of the statements were distinguishing for factor 2 (struggling). The school staff that holds this view believed that it was difficult to work with these students because of the challenging behaviour, they believed that it was hard when parents get upset because of

the feedback from the school, and they lacked support from colleagues and the leadership at the school and do not received sufficient follow up after bad episodes.

Seven of the statements were distinguishing for factor 3 (strugglers relying on parents). The school staff that holds this view believed that they received sufficient support from the parents and did not lack training related to SMS. However, they believed that they have not received any training on how to handle the challenging behaviour. Simultaneously, they did not get afraid when the students got angry.

Four statements distinguished factor 4 (support dependent) from the other factors. The staff members that hold this view believed that they got sufficient support after difficult episodes and did not have any problems in following the recommendations regarding the challenging behaviour. This group of staff members had not been trained by the parents and valued the cooperation of the parents less than the other staff.

Consensus Statements

Fourteen statements did not distinguish between any of the factors (Table 5). In all the factors, the staff agreed that preparation for the student ahead of the activities and to be prepared for difficult situations were important for dealing with students with SMS. They also agreed that they did have a structure that helped in preventing challenging behaviour. Several of the consensus statements were related to academic work with the students with SMS and had been scored in the middle (+2 to −2). It seemed that they agree that academic work was not a priority for these students.

Differences Based on the Gender of Students and the Role of the School Staff

Five out of the eight school staff working with male students loaded on factor 1: In control. None of the school staff working with female students loaded on factor 1. The latter evenly spread out loading on factor 2 (struggling), 3 (strugglers relying on parents), and 4 (support dependent). None of the school staff working with male students loaded on factor 4: Support dependent.

Most of the teachers (four out of six) loaded on factor 3 and 4 (strugglers relying on parents and support dependent). All the participants loading on factor 4 were teachers while the teacher assistants loaded on factor 1 and 2 (in control and struggling). The rest were spread out on factors 1, 2, and 3.

Discussion

This study explored what type of support the school staff needs in order to handle the challenging behaviour and academic development of students with SMS. Four distinct viewpoints were identified in what type of support the school staff needs to handle the challenging behaviour of these students in school.

Cooperation with Parents and Support from the School Leadership

One of the most important findings in this study was how the school staff perceived the support and cooperation from parents and the support from the school leadership and

Table 5. Statements and factor scores, including consensus and distinguishing statements.

Statement #		Factor 1	Factor 2	Factor 3	Factor 4
1*	*This student does not need preparation before an activity to make it work.*	−4	−5	−3	−4
2	I often use individual support conversations before and after challenging behaviours.	1**	4	4	3
3	Regular pedagogical/special education tools work well with this student.	3	0	−2*	2
4**	*The school staff can give guidance and help parents regarding behaviours.*	0	1	1	−1
5**	*It is easy to make choices regarding the academic work.*	0	−1	0	−1
6**	*We are lacking a structure that could prevent challenging behaviours.*	−3	−3	−2	−3
7*	*The parents are more preoccupied with the social rather than the academic.*	0	−1	2*	−1
8	I lack training regarding this disorder.	−3	−3	2**	−2
9	It is the parents that have given us information regarding this disorder.	1	−2	2	−2
10	It is difficult to follow the recommendations we have been given regarding the behaviours.	−1	1	0	−5**
11**	*I know how to work academically with this student*	1	2	0	2
12**	*We may avoid many problems by being ahead of possible tricky situations.*	4	5	5	4
13*	*I can work academically with this student the same way I do with all other students.*	−2	−3	−1	−4
14	It needs clear boundaries to be able to get any academically work done.	2	5	1	3
15	It is the challenging behaviours that makes it difficult to have focus on the academic	−3*	2	3	1
16**	*I have good tools to prohibit the challenging behaviours.*	1	−1	0	0
17	The parents have too high expectations regarding the academic work and that makes the cooperation with them difficult.	−2	1	−4	−1
18	I get a good follow-up after difficult situations with this student.	2	−2*	1	4*
19	It is not important to have knowledge regarding this disorder in order make adaptation to this student.	−1**	−5	−4	−4
20	I think it is hard to work with this student because if the behaviours.	−4	4*	0*	−3
21	I know what I should do if the student self-injures.	2	0	−1	3
22	The parents are difficult to cooperate with because the student behaves different at home and at the school.	−4	−1	−5	−2
23	I get good support from the parents and like to talk with them.	3	3	5**	1
24	I think it is challenging to cooperate with the parents of this student.	−5	−4	−5	−1
25	I am afraid when the student gets angry and is screaming, kicking, or hitting.	−5**	1	−4*	0
26	It is hard when the parents get upset regarding feedback about the student's act.	−1	4*	−2	0
27*	*It is hard to get a function cooperation around homework.*	0	2	−1	0
28	I receive good support from the school leadership, so I can focus on the academic work.	1	−4*	1	3
29	It is not important to me that my colleagues and leadership at the school gives me praise and value my work.	0	−4*	0	1
30	I have been given guidance in how to handle this student's challenges and feel safe.	5	0*	−3**	5
31	Cooperation with the parents are important regarding the adaptation in the school.	3	3	4	0*
32**	*I think it is hard to work with parents in despair and full of worry.*	−1	0	−2	0
33	I am looking forward to every day because of this student's charm, humour, and love	5**	2	3	1
34	It is the parents that have taught us how to handle the behaviours.	2	0	2	−5**
35*	*Visual tools do not work at all in the learning situations.*	−2	−1	−1	−2
36*	*Knowledge about this disorder is important regarding the academic adaptation.*	4	3	3	5
37	It is easy to put academic demands on this student.	0	−1	−3	0
38	It is hard to follow the academic demands from the reports and IEP.	−2	−2	1	2

(*Continued*)

Table 5. (Continued).

Statement #		Factor 1	Factor 2	Factor 3	Factor 4
39*	*There is a lot of knowledge regarding this disorder and academic functioning.*	−1	−2	−1	−3
40	The most important knowledge on how to work with this student have I gotten through my own practise in the school.	4	1	4	2

The first number in front of the statements is the statement number, the other column numbers are the ranking numbers; that is, how the cards are sorted into the grid. Factor scores marked with * are distinguishing statements with significance at $p < 0.05$ and factor scores flagged with a ** are distinguishing statements significant at $p < 0.01$. Statements in italics are consensus statements, and those marked with * at the statement number are non-significant at $p < 0.01$, and those marked with * at the statement number are non-significant at $p < 0.05$.

		Support from school leadership and colleagues	
		Positive	Negative
Parent support and cooperation	Positive	Factor 1, in control	Factor 3, strugglers relying on the parents
	Negative	Factor 4, support dependent	Factor 2, struggling

Figure 3. Factors divided on parent support and leadership support.

colleagues. How the participants in the four different factors perceived those two dimensions are illustrated in Figure 3.

It is evident that to maintain control and feel safe while working with students with SMS, the staff essentially requires the support of the school leadership and colleagues. Those loading on viewpoint 2 (struggling) seemed to be in a particularly difficult position as they lacked the support of the school leadership and colleagues and found it challenging to work with parents. Support and cooperation of parents was also an important factor, but that alone, without support from the leadership and colleagues, can make it hard to handle the challenging behaviour of the students in school. In a qualitative study of teachers teaching students with ADHD, similar results were observed and one of the major factors identified was the lack of support from the school leadership (Harazni & Alkaissi, 2016).

Gender Differences

Another interesting finding in this study was that the school staff teaching male and female students seemed to handle the challenging behaviour differently. Most of the staff working with male students loaded on viewpoint 1: in control. Based on this, it comes across that they are working well with the parents and also receive support from the school leadership and their colleagues. These findings may indicate that it is more challenging to work with females

with SMS than with males. Other studies have found some gender differences in SMS, with more autism spectrum symptomatology, hypersensitivity, and frustration with communication in females (Edelman et al., 2007; Laje et al., 2010; Nag et al., 2018). It has been observed that specifically in the social domain, females have more problems than males (Nag et al., 2018). It could be that the problems in the social domain were more challenging for the school staff than other behavioural challenges. Nag et al. (2018) also found lower levels of ID in females and lower score on adapted behaviour measured by Vineland Adaptive Behaviour Scale, but neither were significant. In general, it seemed like some of the important skills needed for school, such as social competence, adaptive behaviour, and cognitive level, were lower in females than in males. Consequently, it may seem that the school staff working with males handles the challenging behaviours better than those working with female students with SMS.

Lack of Focus on Academic Work

The third important finding in this study was the focus on academic work observed in students diagnosed with SMS. It is evident that neither of the statements related to academic work are placed on either ends of the grid. They were almost all concentrated from −3 to +3 in all four viewpoints, with a few exceptions. It can be stated that the school staff had an extremely strong opinion or attitude towards the challenging behaviour, cooperation with parents, or support from school leadership and colleagues. However, this was not seen with reference to academic work. In the statement, 'I know how to work academically with this student' (statement 11, Table 5) the scores on the different viewpoints were: 1, 2, 0, and 2, respectively. This is consistent with Udwin et al.'s findings (Udwin et al., 2001) where a lack of progress in educational achievement from childhood to adulthood were documented. They also found low abilities in other areas such as independence in daily living skills and occupational achievement. This discrepancy between different abilities and the cognitive level were attributed to the behavioural challenges (Udwin et al., 2001). Udwin et al. (2001) posed a question, stating if this lack of abilities could be a function of limited educational input or a ceiling in the abilities of individuals with SMS. This study indicates that there is a limited academic or educational focus in these students. It seems like the challenging behaviour is the main areas of focus regarding this disorder in schools. Recent research (Nag & Naerland, 2020) indicated a relation between daily living skills and challenging behaviour. Therefore, an effort to shift the focus from simply handling the challenging behaviour towards a focus on learning and educational outcome could possibly lead to a decrease in the challenging behaviour. In terms of general education, one of the suggestions to minimise or prevent challenging behaviour in school is to provide explicit and engaging academic instructions for these students (Alter, Walker, & Landers, 2013). It would be interesting to observe if this change would have an impact on the challenging behaviours associated with SMS, especially in schools.

As with all methods, the Q methodology has its limitations. First of all, results from Q studies cannot be generalised (John & Montgomery, 2015). The fact that the participants can only respond to pre-determined statements may also be perceived as a limitation (Cross, 2005). Further, the methodology of executing the Q sort may also be a limitation. The Q sort was sent in the mail to the participants and not performed face-to-face. In face-to-face settings misunderstandings can be resolved and body language can be interpreted. Furthermore, the small number of participants is also a limitation of this

study. This is a known challenge in research regarding rare disorders (Griggs et al., 2009). This limitation has to be taken into consideration while drawing conclusions. However, even though the results of this study cannot be generalised, they may guide future focus and research regarding challenging behaviour in schools, especially concerning students with SMS. The statements for this Q study were selected systemically by utilising the Fishers balanced block design and abductive reasoning (Brown, 1986; Fisher, 1960; Haig, 2008). Studies have also shown that Q sorts sent in the mail or performed using a computer have no differences in reliability or validity as compared to face-to-face Q sorts (Reber, Kaufman, & Cropp, 2000a; Van Tubergen & Olins, 1979).

This study may have implications in terms of both research and working directly with students with SMS. This is one of the several studies that indicate a gender difference in SMS (Edelman et al., 2007; Laje et al., 2010; Nag et al., 2019, 2018), however, these gender differences need to be researched further. The other two implications are more directed towards the school staff. It is important to note the difference in how school staff perceives the support from the school leadership and colleagues. It is also important to make a shift towards a focus on academic work for students with SMS. Specifically, research regarding how or if this shift towards academic work may influence the challenging behaviour of these students is needed.

To conclude, it can be stated that for school staff to be in control and feel safe when working with students with SMS, support from the school's leadership and colleagues, in addition to cooperation from parents, is imperative. School staff working with females with SMS struggle more than those working with males with SMS. This study also found that here is a higher focus on challenging behaviour of these students than on their academic performance and a shift in the focus is recommended.

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