

**School Refusal Behaviour: Are Children and Adolescents with Autism Spectrum Disorder
at a Higher Risk?**

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School refusal behaviour in students with autism spectrum disorder (ASD) is poorly studied despite being considered a serious problem. This study assessed the frequency, duration, and expression of school refusal behaviour in students with ASD, aged 9–16 years, without intellectual disability. Further, the associations between school refusal behaviour and sociodemographic factors were explored. Teachers and parents assessed this behaviour over 20 days in a cross-sectional study of 216 students, including 78 students with ASD and 138 typically developing (TD) students. School refusal behaviour was significantly higher in students with ASD as compared to TD students. Significant associations were found between school refusal behaviour and illness of other family members. The study concludes that school refusal behaviour is pervasive in students with ASD.

Keywords: Autism spectrum disorder, school refusal, frequency, sociodemographic factors

Introduction

School refusal behaviour is defined as child-motivated refusal to attend school and/or difficulties remaining in class for an entire day, that manifests in students aged 5–17 years (Kearney, 2008; Kearney & Silverman, 1999). This definition refers to an overarching term that covers behaviour associated with (1) students who want to go to school but stay home out of fear or anxiety, often described as school phobia or school refusal, and (2) students who skip school because of defiant behaviour or lack of interest in school, also referred to as truancy (Kearney, 2008; Kearney & Albano, 2004). The duration of school refusal needs to be considered when assessing the severity of the behaviour. Kearney and Silverman (1996)

proposed differentiation between varying durations, where 'self-corrective' indicates that the behaviour occurs occasionally in a period of less than 2 weeks, 'acute' indicates that the period of such behaviour lasts from 2–52 weeks, and 'chronic' indicates this behaviour occurs in a period lasting for 53 weeks or more. However, the severity of the problem may be independent of the duration, and its mode of expression needs to be considered as well. School refusal behaviour can have several expressions, including verbal or physical refusal (such as pleading, clinging, crying, or noncompliance), verbal and physical aggression, distress, tardiness, and partial or complete absenteeism. The condition may be understood to occur along a continuum, with different expressions and episodes which might change on a daily basis (Kearney, 2006) (Figure 1).

(Fig 1)

Kearney and others defend the use of this broad and more inclusive concept to meet the causal heterogeneity of the condition (Ingles, Gonzalvez-Macia, Garcia-Fernandez, Vicent, & Martinez-Monteagudo, 2015; Kearney & Silverman, 1996). This definition of school refusal behaviour has been more influential in recent years; however, some researchers prefer to differentiate between school refusal and truancy (Heyne, King, Tonge, & Cooper, 2001).

The prevalence of school refusal behaviour is indicated to be 5–28% in the general child and adolescent population (Havik, Bru, & Ertesvag, 2015; Kearney, 2008; Kearney & Bensaheb, 2006). Most studies have reported a prevalence rate of school refusal about 5 % (Egger, Costello, & Angold, 2003; Havik et al., 2015; Ingles et al., 2015; King & Bernstein, 2001). School refusal behaviour is more difficult to quantify because most studies and school statistics mainly report full time absenteeism and do not include refusal behaviour (Kearney, 2008). School refusal behaviour occurs in all ages; however, its onset is often reported in early adolescence.

Further, it is found to be equally common in girls and boys (Heyne et al., 2001; Ingles et al., 2015; Kearney, 2008).

A number of socio demographic factors are reported to be associated with school refusal behaviour in the general child and adolescent population (Heyne et al., 2001; Kearney, 2008). Physical or psychiatric disease in other family members, parental unemployment, low educational level of mothers, and disorganized and unsafe home environments with poor adult support and attendance are among the factors reported (Bahali, Tahiroglu, Avci, & Seydaoglu, 2011; Fernando & Perera, 2012; Ingul, Klockner, Silverman, & Nordahl, 2012; Kearney, 2008).

School refusal behaviour represents a stressful situation for the child, the family, and the teachers, and it is a serious public welfare problem. Several researchers point out the importance of early identification of this behaviour to prevent both short and long-term consequences. In the short term, failure to attend school may influence both academic and social achievement and attitudes towards school. The long-term consequences may negatively influence the students' academic, psychological, and social development, and it may ultimately be a risk factor for dropping out of school. The consequences in adulthood may include failure to enter the labour market, low social status, and marital and psychiatric problems, and it may lead to an increased need for social security benefits (Fremont, 2003; Havik et al., 2015; Kearney, 2008; Reid, 2005; Thambirajah, Grandison, & De-Hayes, 2008). Several studies have reported high rates of emotional and behavioural problems as well as somatic complaints in students with school refusal behaviour (Egger et al., 2003; Ingul et al., 2012; Kearney & Albano, 2004; McShane, Walter, & Rey, 2001). Further, language disorders and learning disabilities have been found to be associated with it (Havik et al., 2015; McShane et al., 2001; Naylor, Staskowski, Kenney, & King, 1994). Few studies explore such behaviour in students with ASD. The only study conducted on this topic reported school refusal behaviour in 27.3 % of students

with ASD with and without intellectual disability, mainly attending special classes or schools (Kurita, 1991).

ASD is a lifelong set of pervasive neurodevelopmental disorders with onset in childhood. Children with ASD are a heterogeneous group; sharing the core symptoms of persistent deficits in social communication; social interaction; and restrictive and repetitive patterns of behaviour, activities, or interests (American Psychiatric Association, 2013; Lai, Lombardo, & Baron-Cohen, 2014). The etiological factors of ASD are mostly unknown, but it might best be understood as a complex interaction between environmental factors and genetics (Lai et al., 2014). Estimates of the prevalence of ASD vary; however, most research indicates a prevalence rate of about 1 %. Further, boys are considered to be 2–3 times more likely to be affected than girls are (Lai et al., 2014). ASD affects children of all levels of cognitive functioning, but approximately 50 % have normal intellectual ability (Lai et al., 2014). Inclusion of students with ASD in mainstream schools, and especially those with intellectual abilities within the normal range, is increasing and may be beneficial for these children as they have greater access to peer role models, to relationships with peers, and to the general curriculum (Dillon, Underwood, & Freemantle, 2014; Osborne & Reed, 2011). However, there are indications based on clinical experiences, reports and contact with educational and mental health services, schools, and family support groups, that school refusal behaviour is a problem in students with ASD (Autism- och Aspergerförbundet, 2016; Socialstyrelsen, 2016). Nevertheless, no pertinent data are available regarding the prevalence, expression, and duration of school refusal behaviour in students with ASD without intellectual disability in mainstream schools. Further, no systematic studies of associations between sociodemographic factors and school refusal behaviour have been performed in this population. The lack of

knowledge in this field might impede necessary preventive steps and treatment by professionals in both educational and mental health services.

Aim of the Study

The present study assessed the frequency of school refusal behaviour in students with ASD aged 9–16 years without intellectual disability (IQ > 70) compared to typically developing (TD) students. Further, the aim was to explore the duration and expression of school refusal behaviour and possible sociodemographic factors associated with it in children with ASD.

Methods

Participants

A total of 216 students aged 9–16 years (88 with ASD and 138 TD) were recruited for this cross-sectional study. The participants were students in mainstream classes from 72 primary and secondary schools of different sizes and with geographical spread to ensure participation from both rural and urban areas. The age of 9 years was decided as the lowest age for recruitment because, in Norway, majority of the children diagnosed with ASD without intellectual disability are approximately of that age at the time of diagnosis (Surén et al., 2012). Of the 88 students with ASD who were recruited for the study, 78 were included (response rate: 88.6 %). Two withdrew from the study, five were excluded because they did not meet the inclusion criteria of an IQ score above 70, and three did not fill out the questionnaires. Students with an IQ score below 70 were excluded from the study because they often tend to attend more specialised school settings. Twenty-seven (34.6 %) of the 78 students with ASD had an additional psychiatric diagnosis, mainly attention deficit hyperactivity disorder (n = 13), tic disorder (n = 5), and obsessive compulsive disorder (n = 3). Specialists in child and adolescent

psychiatric and paediatric outpatient clinics diagnosed both the ASD and additional diagnoses using standard diagnostic criteria (ICD-10, 1993) and based on a comprehensive diagnostic process involving interviews, clinical observations, and cognitive ability tests.

TD students attended the same school and class, and were of the same gender as the students with ASD included in the study. TD students with any known somatic or psychiatric disorder were excluded. There were no significant differences between the students with ASD and the TD students regarding gender, age, or school level (Table 1).

Table 1.

Procedure

The study was introduced through written material to primary and secondary schools (fourth to tenth grades), and to child and adolescent psychiatric and paediatric outpatient clinics in the south-east region of Norway. Additionally, the study was advertised on the Norwegian Autism Society's website. Teachers and clinicians were asked to distribute written information and a consent form to parents through students with ASD. The students with ASD were eligible to participate after their parents provided written consent. The teachers informed the parents in the classes about the study before recruiting the comparison group of TD students. However, due to anonymous participation, written consent from the TD students' parents was not required.

The written instruction to the teachers was to include two anonymous TD students of the same gender as a student with ASD, without any known somatic or psychiatric disorders, by randomly drawing them from the students' list in the same class.

The clinicians were asked to confirm the ASD and additional diagnoses, and the level of intelligence, and to give information about the elements of the comprehensive diagnostic

process in a questionnaire. The instructions to the parents and teachers were to assess the children on 20 consecutive schooldays, within a period with the most regular timetable decided by the authors. Twenty days was deemed as both manageable for the parents and the teachers, and sufficient to answer the aim of the present study. The assessment period was between October and April, not preceding or following holidays. Teachers collected data on the same days for the student with ASD and the matched TD students. The period of 20 days may have been slightly different between the parents and teachers.

The teachers' assessments were used to compare the rates and duration of school refusal behaviour between the students with ASD and the TD students. The parents' assessments were used to measure rates and duration of school refusal behaviour, and to explore the expression of this behaviour in the students with ASD.

To explore the association between school refusal behaviour and sociodemographic factors in students with ASD, information was collected via the Norwegian educational information system, and from a socioeconomic questionnaire answered by parents.

Measures

To collect information about school refusal behaviour, a questionnaire based on Kearney's (2006) description of school refusal was developed for this study. The questionnaire consists of the following categories (shown in Figure 1): 'School attendance under duress and pleas for nonattendance', 'Misbehaviours in the morning to avoid school', 'Tardiness in the morning followed by attendance', 'Absences or skipping of classes', and 'Complete absence from school during a certain period of the school year'. The teachers and the parents of students with ASD noted the date and marked an 'x' in one of the categories in the questionnaire for each of the 20 days: 0) attendance, 1) pleas for not attending school, 2)

misbehaviour in the morning to avoid school, 3) tardiness followed by attendance, 4) pleas to not attend classes during the day, 5) did not attend classes, or 6) did not attend school. If they marked an 'x' in one of the categories, except for option 0, they were asked to write the child's motivation in the comment field in the questionnaire. Each 'x' was scored as one and was summarised into two categories: school refusal behaviour 'yes' or 'no'. The 'yes' category consisted of verbal/physical refusal and partial/complete unauthorised absenteeism. If a parent or a teacher had marked more than one 'x' within the same day, only one was counted. If one of those x's were noted in the categories 3, 5, or 6, without written excuse for the absenteeism, it was summarised as partial/complete unauthorised absenteeism. The attendance category served as a control variable to ensure that the questionnaire had been answered and was not summarised.

School refusal behaviour was defined as 1–20 days of refusal to attend school/classes expressed verbally or physically, or as partial or complete unauthorized absenteeism. The definition of unauthorized absenteeism was based on the categories and comments in the questionnaire. If a teacher/parent marked an 'x' in a category for absenteeism (days or classes) but did not provide a written excuse for the absenteeism, this was defined as unauthorized absenteeism and counted as school refusal behaviour. Further, if teachers/parents had recorded comments for excusable absenteeism, such as for gastric flu, leave of absence, or oversleeping, this was defined and counted as authorized absenteeism. Verbal and physical refusal were associated with Category 1, 2, and 4, and partial or complete absenteeism with 3, 5, or 6 in the questionnaire. The teachers and the parents of students with ASD were given the same questionnaire; however, Category 1 and 2 included information unavailable to the teacher. The teachers fully completed the questionnaire for 68 (87.2 %) students with ASD and

for 127 (92 %) TD students of the total sample. Parents of students with ASD fully completed the questionnaire for 62 (79.5 %) students.

Information regarding social demographic variables was assessed by using a socioeconomic questionnaire (Taylor, 1986). The questionnaire consists of 27 questions regarding mother's and father's education, work experience, their relationship, siblings, living, health conditions, and the family's financial status. The questions were answered by circling the alternative that suited the best. Mothers' educational level, parents' marital status, health conditions of other family members, and place and ownership of residence were chosen as the factors of interest. These factors are generally used and regarded as important socioeconomic variables associated with mental and psychosocial dysfunction in children and adolescents (Dennis et al., 2014; Hackman, Farah, & Meaney, 2010). Parents of students with ASD fully completed the questionnaire regarding the socioeconomic background for 68 (87.2 %) students. The Norwegian educational information system (The Norwegian Directorate, 2013) was used to collect data regarding the participating schools.

Statistical analysis

Continuous variables are presented as the mean \pm standard deviation (SD), and categorical variables are presented as the number of observations (percentages). Statistical comparisons between groups were assessed using chi-square tests or independent samples t-test, as appropriate. Statistical significance was defined as $p < .05$. Logistic regression analysis was used to analyse the associations between school refusal behaviour in students with ASD and the sociodemographic variables. Stepwise logistic multiple regression analyses, using both a forward and backward approach, were performed. The criterion for including a variable in the model for both forward and backward stepwise regression was set to $p < .20$. All analyses were

performed using SPSS version 21.0. The study protocol was approved on 11/04/2011, by the Norwegian National Committee for Research Ethics, and was carried out in accordance with the Declaration of Helsinki.

Results

Frequency of school refusal behaviour assessed by teachers

School refusal behaviour expressed as verbal or physical refusal (4) and partial or complete absenteeism (3, 5, or 6) assessed at school was present in 42.6 % of the students with ASD, compared to 7.1 % of the TD students during the 20-day period. The difference in rates between the students with ASD and the TD students was present also when analysing data from primary and secondary school students separately (Table 2).

The duration of school refusal behaviour was significantly longer in students with ASD as compared to that in the TD students: 58.6 % students with ASD showed the behaviour on more than four days, while none of the TD students displayed more than three days of school refusal behaviour (Table 2).

Table 2.

Frequency and expressions of school refusal behaviour in students with ASD assessed by parents.

School refusal behaviour, expressed as verbal or physical refusal (1, 2, or 4) and partial or complete absenteeism (3, 5, or 6) was present in 53.2 % of the students with ASD in primary and secondary schools. The difference in rates of school refusal behaviour between primary and secondary schools students was not significant (Table 3).

One third (30.3 %) of the students with ASD and school refusal behaviour in the primary and secondary school displayed the behaviour on 1–3 days, 42.4 % did so on 4–10 days, and

27.3 % did so on 11–20 days. The duration of school refusal behaviour was not significantly different between students in primary and secondary school (Table 3).

School refusal behaviour was expressed as verbal and physical refusal in 84.6 % of the students in primary school and in 35 % of the students in secondary school. Further, in 15.4 % of the students in primary school and 65 % of the students in secondary school, school refusal behaviour was expressed as partial/complete absenteeism. The parents noted avoiding specific subjects, conflicts with peers or teachers, and insufficient information concerning the subjects or activities in school as possible reasons for the school refusal behaviour. The difference in expression of school refusal behaviour between students with ASD in primary and secondary schools was significant (Table 3).

Table 3.

Associations with sociodemographic factors in students with ASD assessed by parents.

Illness of other family members was the only sociodemographic factor that showed a significant association with school refusal behaviour in students with ASD ($p = .004$). Both forward and backward variable selection resulted in the same model (Table 4).

Table 4.

Discussion

Our study revealed an increased risk for school refusal behaviour in students with ASD without intellectual disability, aged 9–16 years (42.6 %), as compared to matched TD students (7.1 %), based on teacher assessments. The difference in rates between the two groups was also present when analysing data from primary and secondary school students separately, showing that the difference in school refusal behaviour between students with ASD and TD students did not evolve in later school years. Thus, our results are in line with those of Mandy et

al. (2015), who found that the levels of psychopathology, adaptive functioning, and peer victimisation in students with ASD did not increase during the transition to secondary school, but they persisted through elementary school. However, the transition from primary to secondary school is considered to be challenging for students with ASD (Dillon et al., 2014; Mandy, Murin, Baykaner, Staunton, Cobb, et al., 2015).

Further, we found that students with ASD showed school refusal behaviour for a longer duration than did TD students. Nearly 60 % of students with ASD displayed the behaviour on 4 or more days, while none of the TD students displayed the same for more than 3 days during the 20-day period. This underlines the serious situation for students with ASD, with higher rates and more extended duration of school refusal behaviour as compared to TD students.

Defining school refusal behaviour from the first occurrence of refusal or absenteeism may have contributed to the high rates in our study as those compared to other studies. However, the rate in our comparison group of TD students corresponds with that of previous reports of school refusal behaviour in the general child and adolescent population (Egger et al., 2003; Havik et al., 2015; Ingles et al., 2015; Kearney, 2008; King & Bernstein, 2001).

The teachers' report of school refusal behaviour lacks information about the students' verbal and physical refusal displayed at home before attending school. The parents' assessment, on the other hand, covered both home and school settings, and thus are more in line with the broad definition of school refusal behaviour (Kearney & Silverman, 1999). Therefore, the parents' report was utilised to further explore its frequency, duration, and expression in students with ASD. The parents reported a rate of school refusal behaviour in 53.2 % of the students with ASD. Our findings exceed the overall rate reported in the only previous study assessing school refusal in students with ASD (27.3 %) (Kurita, 1991). However, the sample in the study by Kurita mainly included students with ASD and intellectual disability,

who attended both special and mainstream classes and schools. In a subsample of the students with ASD who had mild or no intellectual disability, Kurita's study (1991) revealed a frequency of 40.0 %, which is more in line with our findings. We may speculate that students with ASD without intellectual disability are especially vulnerable to stressful emotional events in coping with the school situation.

Parents reported that approximately 40 % of students with ASD displayed school refusal behaviour on 4–10 days and nearly 30 % on 11 or more days in the 20-day period. This may be considered as a severe duration of school refusal behaviour. In the general child and adolescent population this is reported to have considerable negative consequences, both academic and social, leading to a risk for dropping out of school (Havik et al., 2015; Kearney, 2008; Reid, 2005; Thambirajah et al., 2008). However, further studies are needed to explore if the long-term consequences of severe school refusal behaviour are the same for students with ASD.

Thirty percent of the students with ASD displayed school refusal behaviour on 1–3 days, which may correspond to self-corrective school refusal behaviour (Kearney & Silverman, 1996). Although the latter is not considered to be problematic, it is reported to precipitate more severe school refusal behaviour in the general child and adolescent population (Fremont, 2003; Havik et al., 2015; Kearney, 2006). It may be argued that students with ASD and self-corrective school refusal behaviour are especially at risk for developing more severe school refusal behaviour because their rigid pattern of behaviour may increase the risk of acquiring the habit of staying home from school. This speculation on whether the rigidity might be a risk factor for school refusal behaviour is in line with reports from Kurita (1991).

Our study revealed no significant difference in the frequency of school refusal behaviour between students with ASD in primary and secondary schools. However, we found a significant

difference in the expression of this behaviour between primary and secondary school students. Students in primary and secondary schools displayed it as verbal or physical refusal in 85 % and 35 % of the instances, respectively. Verbal or physical refusal may be considered a mild expression of school refusal behaviour in the general child and adolescent population. However, it should be taken seriously as it causes distress in itself, and may be an early sign of later school refusal behaviour expressed as absenteeism (Fremont, 2003). Students with ASD may have difficulties in expressing their emotions regarding situations linked to the school setting (Able, Sreckovic, Schultz, Garwood, & Sherman, 2015; Twachtman-Cullen, Baron, Groden, Groden, & Lipsitt, 2006). Thus, it might be particularly important to pay attention to and to interpret the refusal behaviour in students with ASD. These children may have problems verbalising their motives for displaying school refusal behaviour.

Approximately 15 % of the primary school students with ASD and 65 % of the secondary school students with ASD expressed school refusal behaviour as partial or complete absenteeism. This is in line with the findings of Kurita's study (1991), which found that the severity of school refusal behaviour increased in older students with ASD. Kearney (2006) reported similar results in the general child and adolescent population. In clinical practice, parents have reported that it is harder to encourage the child to attend school with an increase in age. This could indicate that the expression of school refusal behaviour evolves from refusal to absenteeism with age, or alternatively, that onset in secondary school is more likely to be expressed as absenteeism. However, further studies are needed to confirm whether this is the case for students with ASD.

Our study revealed a significant association between school refusal behaviour in students with ASD and the sociodemographic factor of illness of other family members. Kurita's study (1991) found no significant associations between school refusal behaviour in students

with ASD and sociodemographic factors. However, in the general child and adolescent population, illness in the family has been identified as one of the precipitating and associated factors for school refusal behaviour (Bahali et al., 2011; Fernando & Perera, 2012; Ingul et al., 2012; Kearney, 2008). Parenting children with ASD, and especially those without intellectual disability, is associated with high levels of anxiety and depression. Managing the children's general behaviour and psychiatric comorbidity, and not having adequate help are reported to be possible explanations for the increased level of stress, use of sick leave, and decreased work participation in parents of children with ASD as compared to other parents (McEvelly, Wicks, & Dalman, 2015; Mori, Ujiie, Smith, & Howlin, 2009). Further studies are needed to address whether school refusal behaviour in students with ASD triggers illness of other family members or whether, alternatively, illness in the family furthered this behaviour in students with ASD.

Strengths and limitations

The strength of this study lies in the fact that the broad definition of school refusal behaviour used in this study was appropriate for identifying its different expressions in students with ASD. Additionally, the inclusion of a TD student comparison group is a strength considering the diversity in previous studies on school refusal and the lack of studies on of school refusal behaviour. Further, students participating in the study were recruited from a number of schools of different sizes, from both rural and urban areas. Moreover, clinicians in child and adolescent psychiatric and paediatric outpatient clinics confirmed all of the diagnoses of the students with ASD. However, there are some limitations to this study that need to be recognized. We included absence in our definition of school refusal behaviour, which lacks justification by the teachers or the parents. This decision may have resulted in the higher rates of school refusal behaviour this study found. Assessing school refusal behaviour for 20 school days limits this study to

assessing self-corrective and acute school refusal behaviour, and not chronic school refusal behaviour. The methods used in the selection of the students with ASD may have led to a referral bias. Parents recognizing school refusal behaviour in their children may have been more motivated to participate, thereby contributing to the high rate of school refusal behaviour revealed in this study. Further, due to the low number of girls in the study, the impact of gender on school refusal behaviour was not analysed. The assessment period of 20 days may have differed slightly between parents and teachers with regard to students with ASD. This, together with teachers' missing information concerning school refusal behaviour at home, interfered with the possibility of comparing parents' and teachers' assessments of students with ASD. Further, due to limited information about demographic characteristics of the TD students, they might not have matched completely with the students with ASD.

Conclusions and practical implications

This study showed that having ASD is a major risk for displaying school refusal behaviour in students aged 9–16 years. Further, this predisposition pertained to the severity and the duration of school refusal behaviour. There was no difference in the frequency of this behaviour between students with ASD in primary and secondary school. However, exploring the different expressions of school refusal behaviour showed that majority of the students in primary school displayed it as verbal/physical refusal, while partial/complete absenteeism was a more prevalent expression in secondary school students with ASD. Our study underlined the importance of a broad understanding of school refusal behaviour to identify its early expressions in students with ASD. In line with other studies in the general child and adolescent population,

illness of other family members was found to be associated with school refusal behaviour in students with ASD.

These results are important for school authorities, professionals in educational and mental health services, and teachers and parents, in their efforts to include students with ASD in mainstream schools. Presently, school refusal behaviour in students with ASD is poorly understood. Both long-term follow-up studies and studies to explore individual characteristics and contextual variables are needed. Until then, this challenge must be met at the clinical level with thorough multi-method assessments of school refusal behaviour involving the parents, the student, the teacher, and other people who are significantly involved in the student's education and welfare.

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