Emotional and behavioural problems in adolescents with intellectual disability with and without chronic diseases


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Abstract

Background Adolescent with intellectual disability (ID) (ID-adolescents) and adolescents with chronic diseases are both more likely to have emotional and behavioural problems. The aim of this study was to assess the association between chronic diseases in ID-adolescents and emotional and behavioural problems in a large school-based sample.

Methods We obtained data on 1044 ID-adolescents, aged 12–18 years, attending secondary schools in the Netherlands. Parents of the adolescents completed the Dutch version of the Strengths and Difficulties Questionnaire and questions about chronic diseases in their child and about the background of the child.

Results Prevalence rates of emotional and behavioural problems were generally high in ID-adolescents with chronic diseases (45%), compared with ID-adolescents without chronic diseases (17%). The likelihood of emotional and behavioural problems was high in ID-adolescents with two [odds ratios (OR) 4.47; 95% CI: 2.97–6.74] or more than two chronic diseases (OR 8.01; 95% CI: 5.18–12.39) and for ID-adolescents with mental chronic diseases (OR 4.56; 95% CI: 3.21–6.47). Also ID-adolescents with somatic chronic diseases had a high likelihood of emotional and behavioural problems (OR 1.99; 95% CI: 1.33–2.99), in particular in the combination of somatic and mental chronic diseases (OR 5.16; 95% CI: 3.46–7.71).

Conclusions The current study showed that chronic diseases in ID-adolescents, in particular mental chronic diseases, largely increase the likelihood of emotional and behavioural problems. This should be taken in the provision and planning of care for ID-adolescents.

Keywords behavioural measurement methods, behavioural phenotypes, intellectual disability, mental health
Introduction

Adolescents with somatic or mental chronic diseases in the general population have a higher risk of emotional and behavioral problems compared with their healthy peers (Carter et al. 2000; Meijer et al. 2000; Glazebrook et al. 2003; Trzepacz et al. 2004; Caplan et al. 2005; Lecavalier 2006; Pearson et al. 2006; Berg et al. 2007; Hysing et al. 2007; Menon et al. 2007; Ding et al. 2008). In addition, adolescents with ID (ID-adolescents) also have a higher risk of emotional and behavioral problems compared with their peers without ID (Linna et al. 1999; Dekker et al. 2002; Tonge & Einfeld 2003; Emerson & Hatton 2007; Kaptein et al. 2008). Only a few studies examined the occurrence of emotional and behavioral problems in adolescents who had both problems, i.e. ID and one or more chronic diseases (Cormack et al. 2000; Lewis et al. 2000; Pearson et al. 2000; Buelow et al. 2003; Dekker & Koot 2003; Bradley et al. 2004; Brereton et al. 2006; Hill & Furniss 2006; Parkes et al. 2008; Turk & et al. 2008). These studies are focused on either: (1) the presence or absence of a somatic chronic disease or physical complaints without taking into account the number and nature of the chronic diseases (Cormack et al. 2000; Dekker & Koot 2003); or (2) one specific chronic diseases such as epilepsy, autism, cerebral palsy or attention-deficit hyperactivity disorder (ADHD) without taking into account the presence of other chronic diseases (Lewis et al. 2000; Pearson et al. 2000; Buelow et al. 2003; Bradley et al. 2004; Brereton et al. 2006; Hill & Furniss 2006; Parkes et al. 2008; Turk & et al. 2008).

It is important to determine whether there is an association between the number and nature of chronic diseases and emotional and behavioural problems in ID-adolescents. An association, if found, would inform early intervention and treatment strategies by allowing identification of individuals who are at greater risk of emotional and behavioural problems. Preventing mental health problems in ID-adolescents and adequate treatment of those with mental health problems are important because mental health problems have a profound effect on participation in educational programmes, occupational opportunities and the potential to live in the community, i.e. they are a major cause of failure of participation in the society (Reijneveld et al. 2003; Einfeld et al. 2006; Emerson & Hatton 2007; Turk et al. 2007). Finally, it is essential for the planning of interventions and services aimed at prevention or treatment.

The aim of this study is to assess: (1) the prevalence of emotional and behavioural problems in ID-adolescents with and without chronic disease; and (2) the impact of chronic diseases in ID-adolescents on the increase of the likelihood of emotional and behavioural problems.

Methods

Participants and procedure

We collected data on adolescents with a borderline, mild, moderate or severe ID aged 12–18 years in two provinces in the north of the Netherlands, Groningen and Drenthe. Nearly all adolescents of the target population attended secondary schools (schools for practical training) or special secondary schools (regional expertise centres). ID-adolescents not attending secondary schools, most of them with profound ID, were not included.

In the current school-based cross-sectional research project, 88% of the secondary schools or special secondary schools in both provinces participated. Non-participating schools did not differ from participating schools regarding urbanisation of the catchment area and number of students. All parents of the 2156 adolescents aged 12–18 years were sent a questionnaire and a reminder when they did not respond. A total of 1044 parents returned the questionnaire (48.4%). Adolescents in the response and non-response groups did not differ regarding age (t-test = 1.751, ns), but the response group had a higher proportion of girls ($\chi^2 = 5.9; P < 0.05$) and a higher proportion of adolescents with borderline or mild ID ($\chi^2 = 9.8; P < 0.05$). However, the effect sizes for both variables were negligible; Cohen’s $W$ were 0.06 and 0.07, respectively (Cohen 1988).

The study protocol was approved by the Medical Ethics Committee of the University Medical Center Groningen, the Netherlands.

Measures

ID

The target population had been officially classified as having ID by an independent committee estab-
lished by the Dutch Ministry of Education, Culture and Science (Dutch Eurydice Unit 2007). The classification of ID is based on a set of objective criteria, mainly the Dutch version of the Wechsler Intelligence Scale for Children-3rd Edition (Wechsler 1991; Kort et al. 2002), and the Snijders–Oomen Non-verbal Intelligence Test-Revised (Snijders et al. 2003).

**Chronic diseases**

Chronic diseases in ID-adolescents were measured by the National Permanent Survey on Living Conditions Questionnaire (POLS): module health and labour, part chronic diseases in children (Statistics Netherlands 2004). POLS part chronic diseases in children covers the most prevalent chronic diseases such as: ear, eye, skin diseases, diseases of the nervous, musculoskeletal, blood and circulatory, respiratory, digestive, and endocrine, nutritional and metabolic systems; and ADHD. Questions were added about the presence of pervasive developmental disorders. Parents were asked to fill in the presence or absence of specific chronic diseases like: diabetes, asthma, epilepsy and pervasive developmental disorder-not otherwise specified in the last 12 months in their children. Parents also had the possibility to mention the presence of chronic diseases that were not listed in the questionnaire.

POLS is developed by Statistics Netherlands and periodically used in a representative sample \(n = 10,000\) of the Dutch population (Otten & Winkels 1998).

**Emotional and behavioural functioning**

Emotional and behavioural functioning was assessed by the validated Dutch version of the Strengths and Difficulties Questionnaire (SDQ) (Muris et al. 2003; van Widenfelt et al. 2003; Crone et al. 2008). The SDQ consists of 25 symptom items describing positive and negative attributes of children and adolescents. The 25 items are divided between five scales: emotional problem, conduct problem, inattention–hyperactivity, peer problem and prosocial behaviour. Each item has to be scored on a 3-point scale with 0 = 'not true', 1 = 'somewhat true' and 2 = 'certainly true'. Sub-scale scores can be computed by summing scores on relevant items (after recoding reversed items; range 0–10). Higher scores on the prosocial behaviour sub-scale reflect strengths, whereas higher scores on the other four sub-scales reflect difficulties. A total difficulties score can also be calculated by summing the scores on the emotional symptoms, conduct problems, hyperactivity–inattention and peer problems sub-scales (range 0–40) (Goodman 1997). Several studies have shown the good reliability and validity of the SDQ in a non-ID population (Vostanis 2006; Achenbach et al. 2008). Recently, the SDQ is also used in studies with children and adolescents with ID to measure their emotional and behavioural functioning (Emerson et al. 2005; Hastings et al. 2005; Simonoff et al. 2007; Kaptein et al. 2008).

**Background characteristics**

The questionnaire comprised the following questions on background characteristics: age, gender and school type of the adolescent.

**Analysis**

The SDQ scores were dichotomised at the English 90th percentile cut-off of the sub-scales and total difficulties scale and the percentages of ID-adolescents with elevated scores was calculated (Meltzer et al. 2000). Subsequently, adolescents were categorised in a group with and without chronic diseases. Next, we delimited the chronic diseases group regarding the number of chronic diseases: one, two and more than two (with a maximum of seven), and the nature of the chronic diseases: somatic (e.g. epilepsy, diabetes, asthma, etc.), mental (autism, pervasive developmental disorder not otherwise specified, dyslexia and ADHD) or a combination of somatic and mental chronic diseases. Multivariate logistic regression analyses were performed and odds ratios (OR) were calculated, adjusted for level of ID (as measured by type of school), to compare the groups pair-wise and to identify groups of ID-adolescents with an increased likelihood for an elevated score on the SDQ scales.

**Results**

Table 1 shows the background characteristics of the adolescents. The gender ratio, 58.2% boys and 41.8% girls, was similar to the ratio of boys and
girls with ID in the Netherlands (Schrojenstein Lantman-de Valk et al. 2002).

With vs. without chronic disease

Sixty-one per cent (n = 1044) of the ID-adolescents had at least one chronic disease. ID-adolescents with chronic diseases were more likely to have an elevated score on the SDQ problem behaviour scales and total difficulties scale than ID-adolescents without chronic diseases (Table 2).

Number and nature of chronic diseases

The ID-adolescents with one or more chronic diseases were more likely to have an elevated score on the problem behaviour scales and total difficulties scale compared with ID-adolescents without chronic diseases, except for Total difficulties scale and Peer problems scale (Table 3). ID-adolescents with more than two chronic diseases were most likely to score above the cut-off on the problem behaviour scales and total difficulties scale. They also had a twofold higher likelihood to score above the cut-off on the prosocial behaviour scale, indicating problems in prosocial behaviour. With regard to the nature of chronic diseases, ID-adolescents with mental chronic diseases were as expected more likely to have an elevated score on the problem behaviour scales, prosocial behaviour scale and total difficulties scales compared with ID-adolescents without chronic diseases (Table 4). ID-adolescents with only somatic chronic diseases had a twofold higher likelihood to score above the cut-off on the emotional problem scale and total difficulties scale compared with ID-adolescents without chronic disease. ID-adolescents with a combination of somatic and mental chronic diseases had the highest likelihood to score above the cut-off on the problem behaviour scales and total difficulties scales compared with ID-adolescents without chronic diseases.

Discussion

Our results show that emotional and behavioural problems have a significantly higher prevalence in...
ID-adolescents with chronic diseases than in ID-adolescents without chronic diseases. The likelihood of emotional and behavioural problems increased by number of chronic diseases and was highest in ID-adolescents with two or more than two chronic diseases. Not surprisingly, ID-adolescents with mental chronic diseases had a high likelihood of emotional and behavioural problems. However, ID-adolescents with somatic chronic diseases also had a high likelihood of emotional and behavioural problems; in combination with mental chronic diseases they had the highest likelihood of emotional and behavioural problems.
Findings in relation to other studies

With respect to somatic chronic diseases, Dekker & Koot (2003) studied a similar group of children and adolescents in the Netherlands. They found that children and adolescents with ID and somatic chronic diseases had a 2.5-fold higher likelihood (OR 2.5) on Diagnostic and Statistical Manual of Mental Disorders-IV disorders compared with their peers without somatic chronic disease. This suggests that risks for parent-reported problems and for diagnosed disorders are increased among ID-adolescents with chronic diseases to a rather similar degree.

However, Cormack et al. (2000) found that children and adolescents with ID and severe physical disability had significantly lower mean scores on the Developmental Behaviour Checklist (DBC) primary carer version total score, the disruptive and anxiety sub-scales. The properties of the instrument are likely to explain these differences. The DBC has been specifically designed to tap the emotional and behavioural problems of ID children and may therefore be expected to measure more precisely the presence or absence of these problems among ID-adolescents than a more general instrument such as the SDQ. Lewis et al. (2000) used the DBC in a cohort study of children and adolescents with ID representative of the general Australian population of young people with ID. They found that children and adolescents with epilepsy did not differ from their non-epileptic peers in their level of behavioural or emotional disturbance. However, a potential source of error in their results was the accuracy of the parents to recall whether their children had epilepsy or not. Buelow et al. (2003) used the Child Behaviour Checklist (CBCL) in a sample of children and adolescents with epilepsy. They found that 68% of the children and adolescents with ID and epilepsy and 51% of the children and adolescents without ID and epilepsy scored above the cut-off on the CBCL total problem. Our results are in line with their results. Although items and scales of the SDQ and CBCL may have differential relevance among groups, comparable results are found in many populations (Achenbach et al. 2008). Turky et al. (2008) used the SDQ in a community-based population of children and adolescents with epilepsy. They found that children and adolescents with epilepsy and cognitive impairments had a higher likelihood to score above the cut-off on SDQ conduct problems (OR 14.78), inattention–hyperactivity (OR 9.44) and peer problems (OR 30.08) compared with children and adolescents with epilepsy and without special educational needs. Finally, Parkes et al. (2008) used the SDQ in a sample based on population-based registers of cerebral palsy in eight European regions. They found that ID (IQ < 70) was associated with a significantly increased likelihood (OR 3.2) to score above the SDQ total difficulties cut-off in children with cerebral palsy. In both studies (Parkes et al. 2008; Turky et al. 2008), the higher OR compared with the OR in our study could be explained by the fact that they included adolescents without ID as reference group, whereas in the current study ID-adolescents without chronic diseases were the reference group.

With respect to mental chronic diseases, Bradley et al. (2004) and Hill & Furniss (2006) found that a higher proportions of children, adolescents and young adults with ID and autism scored above the cut-off on sub-scales of the diagnostic assessment for the severely handicapped-II (DASH-II) compared with their peers with ID and without autism. The results we found in the current study were in line with their results. However, it is of importance to mention that the DASH-II is in contrary to the SDQ specifically developed for individuals with severe or profound ID or developmental disabilities. Brereton et al. (2006) used the DBC primary carer version in a sample drawn from the Australian Child and Adolescent Development Study, a longitudinal study of psychopathology in a representative sample of children and adolescents with ID in an Australian region. They found that children and adolescents with autism, 87% with ID, scored higher on the total behaviour problems mean score of the DBC primary carer version compared with children and adolescents with ID but without autism. Our results are in line with the results of Brereton et al. (2006), but it should be noted that the DBC is specifically developed for children and adolescents with ID, whereas SDQ is not. Group-specific instruments can in general be expected to tap more of the problems that such a group has than instruments that are more general. Finally, Pearson et al. (2000) used the Personality Inventory for Children-Revised (PIC-R) and found that chil-
dren and adolescents with ID and ADHD had a higher risk to score above the cut-off on externalising and internalising problem behaviour of the PIC-R than their peers with ID but without ADHD. Our results confirm this mostly but a full comparison is difficult because Pearson et al. (2000) reported about an undefined population of children and adolescents with ID. In addition, the scope of PIC-R is broader than the scope of SDQ, as the PIC-R also assesses cognitive development.

Compared with other studies that reported prevalence rates of emotional and behavioural problems between 35% and 61% in children and adolescents with ID (Linna et al. 1999; Dekker et al. 2002; Tonge & Einfeld 2003; Emerson & Hatton 2007; Kaptein et al. 2008), we found a large difference in prevalence rates of emotional and behavioural problems in ID-adolescents. In the current study, 17% of the ID-adolescents without chronic diseases and 30–64% of the ID-adolescents with chronic diseases had emotional and behavioural problems.

Strengths and limitations

This is the first study that examined the association between combinations of chronic diseases in ID-adolescents and emotional and behavioural problems in detail. A large school-based sample representative for about 95% of the ID-adolescents was used. A limitation of the study was the relatively low response rate (48%), but non-response analysis revealed that adolescents in the response and non-response groups did not differ on age, gender and educational level. Next to this, ID-adolescents not attending school were not included, which may have influenced the prevalence of emotional and behavioural problems. Finally, the SDQ may underestimate the emotional and behavioural problems in ID-adolescents.

First, because SDQ was not developed specifically for this group (Cooper et al. 2007). Second, non-verbal ID-adolescents may score as having fewer difficulties, because they cannot verbally lie or express headaches. Interpretation of this behaviour by the parent is more difficult compared with verbal ID-adolescents. However, because the population of non-verbal adolescents attending secondary schools in the Netherlands is very limited, it is unlikely that this will affect the results as we reported to an important degree.

Implications for clinicians

Our findings highlight the need for clinicians to be aware of the increased risk of emotional and behavioural problems in ID-adolescents who also have chronic diseases and that this risk potentially increases with the number of chronic diseases present. Early identification and treatment of emotional and behavioural problems in this population are likely to also improve their well-being and social participation (Reijneveld et al. 2003; Einfeld et al. 2006; Emerson & Hatton 2007; Turk et al. 2007). The SDQ may provide a simple means of identifying emotional and behavioural problems in ID-adolescents as it is widely used in preventive child health care in the Netherlands (Crone et al. 2008).

Implications for research

Additional research is needed on the causal mechanisms behind the association of emotional and behavioural problems, and chronic diseases among ID-adolescents. This association may be due either to common causes for both, or to the chronic diseases leading to emotional and behavioural problems. These two mechanisms may lead to different strategies for early treatment. To disentangle these mechanisms, longitudinal research design studies are needed (Wallander et al. 2003; Emerson & Hatton 2007). Moreover, our findings regarding the association of ID severity and chronic diseases with emotional and behavioural problems conflict with previous ones that used the DBC. Additional research is needed to explain these differences.

References


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Emotional and behavioural problems


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