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Prevalence of chronic diseases in adolescents with intellectual disability

B. Oeseburg [a,b,*], D.E.M.C. Jansen [a,c], G.J. Dijkstra [a], J.W. Groothoff [a], S.A. Reijneveld [a]

[a] Department of Health Sciences and Graduate School for Health Research (SHARE), University Medical Center Groningen, University of Groningen, The Netherlands
[b] Wenckebach Institute, School of Nursing and Health, University Medical Center Groningen, Groningen, The Netherlands
[c] Department of Sociology, Faculty of Behavioral and Social Sciences, University of Groningen, The Netherlands

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ABSTRACT

Valid community-based data on the prevalence of chronic diseases in adolescents (12–18 years) with intellectual disability (ID-adolescents) are scarce. The aim of this study was to assess the prevalence rates and the nature of chronic diseases in a population of ID-adolescents and to compare them with the rates among adolescents in the general population. Therefore, we obtained data on 1083 ID-adolescents attending secondary schools, day care centers or living in residential centers fully covering one region of the Netherlands. Parents of the adolescents completed a questionnaire about the occurrence of chronic diseases in their child during the previous 12 months and about background characteristics. The questionnaire was derived from the Dutch National Permanent Survey on Living Conditions questionnaire periodically administered in a representative population sample ($n \approx 10{,}000$). Prevalence rates of chronic diseases in ID-adolescents were compared with those in adolescents in the Dutch general population. Among ID-adolescents, high prevalence rates of a wide range of chronic diseases were found. The five most prevalent were: ADHD (21.1%), PDD-NOS (14.0%), dyslexia (13.9%), migraine or chronic headache (12.7%), and autistic disorder (10.9%). These prevalence rates were all higher ($p < 0.05$) than among adolescents in the general population. Of all ID-adolescents, 62.9% was reported to have at least one chronic disease. The burden of chronic diseases among ID-adolescents is very high, showing a high need for adequate care. These high prevalence rates should alert policymakers and clinicians regarding the widespread of chronic diseases among ID-adolescents.

1. Introduction

Valid community-based data on the prevalence rates of the full range of chronic diseases in adolescents (12–18 years) with intellectual disability (ID-adolescents) are scarce (Sawyer, Drew, Yeo, & Britto, 2007; Van Schrojenstein Lantman-de Valk & Walsh, 2008). A number of studies have reported on the prevalence of specific chronic diseases in young people with ID (Airaksinen et al., 2000; Bradley & Bolton, 2006; Bradley & Isaacs, 2006; Bryson, Bradley, Thompson, & Wainwright, 2008; Cans et al., 1999; Christianson et al., 2002; de Bildt, Sytema, Kraijer, & Minderaa, 2005; Dekker & Koot, 2003; Emerson & Hatton, 2007; Emerson, 2003; Fernell, 1998; Gothelf et al., 2008; Hou, Wang, & Chuang, 1998; Jelliffe-Pawlowski, Shaw, Nelson, & Harris, 2003; Koskentausta, Iivanainen, & Almqvist, 2002; Lewis et al., 2000; Magnusson & Saemundsen, 2001; Merrick & Morag, 2000; Molteno, Molteno, Finchilescu, & Dawes, 2001; Morgan, Baxter, & Kerr, 2003; Nielsen, Skov, & Jensen,

* Corresponding author at: University Medical Center Groningen (UMCG), Department of Health Sciences and Graduate School for Health Research (SHARE), P.O. Box 30.001, 9700 RB Groningen, The Netherlands. Tel.: +31 0 50 363 8914; fax: +31 0 50 363 6251.
E-mail address: b.oeseburg@med.umcg.nl (B. Oeseburg).

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2007a; Nielsen, Skov, & Jensen, 2007b; Nordin & Gillberg, 1996; Petterson, Bourke, Leonard, Jacoby, & Bower, 2007; Steffenburg, Gillberg, & Steffenburg, 1996; Stromme & Diseth, 2000; Stromme & Hagberg, 2000; Van Schrojenstein Lantman-de Valk, van den Akker, Maaskant, & Haveman, 1997; Voigt, Barbaresi, Colligan, Weaver, & Katusic, 2006; Yeargin-Allsopp, Murphy, Cordero, Decoufle, & Hollowell, 1997; Zhang & Ji, 2005). However, only few studies have reported such prevalence rates of a wide range of chronic diseases associated with ID (Fernell, 1998; Stromme & Diseth, 2000; Stromme & Hagberg, 2000; Van Schrojenstein Lantman-de Valk et al., 1997). Moreover, only some studies compared their results with the prevalence rates of chronic diseases in the general population (Emerson & Hatton, 2007; Emerson, 2003; Magnusson & Saemundsen, 2001; Petterson et al., 2007; Voigt et al., 2006), and none of these studies reported prevalence rates of chronic diseases among *ID-adolescents*.

Adolescence is a specific stage of life between child- and adulthood with specific health needs. It is a time of life marked by physical, emotional, behavioural and social changes, but also by relatively high risks for the onset of (chronic) health problems (Patton & Viner, 2007; Sawyer et al., 2007; Turk, Graham, & Verhulst, 2007). Literature about young people with ID suggests that adolescents have a greater risk on chronic diseases compared to adolescents without ID (Cooper, Melville, & Morrison, 2004; Emerson & Hatton, 2007; Emerson, 2003; Jansen, Krol, Groothoff, & Post, 2004; Kolaitis, 2008; Magnusson & Saemundsen, 2001; Petterson et al., 2007; Van Schrojenstein Lantman-de Valk & Walsh, 2008; Voigt et al., 2006), but inclusive data on this are lacking.

Age-specific community-based data are thus needed to support policymakers and professionals in the adequate provision and planning of care to ID-adolescents. Policymakers need these data for the planning and financing of adequate care arrangements (e.g. health, education, work) to enhance the well being and societal participation of ID-adolescents and their families. Professionals need these data to know who are at risk for chronic diseases and to prevent chronic diseases, to support the early detection and adequate treatment of chronic diseases and their consequences among ID-adolescents and their families (American Association on Mental Retardation, 2002; Goddard, Davidson, Daly, & Mackey, 2008; McDermott, Durkin, Schupf, & Stein, 2007; Newacheck, Rising, & Kim, 2006).

The aim of this study is: (1) to assess the prevalence and the nature of chronic diseases in a population of ID-adolescents; (2) to compare the prevalence rates of chronic diseases in ID-adolescents with that among adolescents in the general population.

2. Methods

2.1. Participants

2.1.1. Adolescents with ID

We collected data in 2006–2007 from adolescents with a borderline, mild, moderate, severe or profound ID aged 12–18 years living in two provinces in the north of the Netherlands, Groningen and Drenthe (total population of about 1.1 million people). Adolescents of the target population attended secondary schools, special secondary schools, day care centers or lived in residential centers. ID-adolescents attending secondary schools can be classified as mainly educable and have IQs between 60 and 84. ID-adolescents attending special secondary schools can be classified as mainly trainable and have IQs between 30 and 59. ID-adolescents not attending school, most of them with IQs < 30, attend day care centers or live in residential centers (Dekker, Koot, van der, & Verhulst, 2002). The target population had been officially classified as having ID by two independent committees. The Dutch Ministry of Education, Culture and Science established a committee for adolescents attending secondary or special secondary schools and the Dutch Ministry of Health, Welfare and Sport established a committee for adolescents attending day care centers or those living in residential centers. The classification of ID is based on the information from validated intelligence tests obtained by both committees (Care Assessment Centre, 2009; Dutch Eurydice Unit, 2007).

In the current community-based cross-sectional research project, 70% of the schools and centers in both the provinces participated, with a total of 2271 adolescents. Non-participating schools and centers did not differ from participating schools and centers with regard to urbanization of the catchment area and number of adolescents. All parents of the 2271 adolescents aged 12–18 years received a questionnaire and a reminder when they did not respond; 1083 parents returned the questionnaire (48%). Adolescents in the response and non-response group did not differ with regard to age (t-test = 1.86, $p > 0.05$), but in the response group girls ($\chi^2 = 4.35$; $p < 0.05$) and adolescents with borderline or mild ID ($\chi^2 = 8.96$; $p < 0.05$) were somewhat overrepresented. However, the effect sizes for both the variables were negligible; Cohen's w were 0.05 and 0.07, respectively (Cohen, 1988).

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

2.1.2. Adolescents in the general population

Statistics Netherlands conducts yearly the National Permanent Survey on Living Conditions (POLS) questionnaire in a representative sample ($n \approx 10{,}000$) of the Dutch population (Otten & Winkels, 1998). We used the data, adjusted for non-response, on adolescents aged 12–18 years in 2007 (Statistics Netherlands, 2009) (response: 64%). Prevalence data on chronic diseases in adolescents in the general population that were not available via Statistics Netherlands were derived from the National Institute for Public Health and the Environment (NIPHE). The NIPHE provides national and international