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Published in:
Journal of Intellectual Disability Research

DOI:
[10.1111/jir.12298](https://doi.org/10.1111/jir.12298)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2016

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

van Timmeren, E. A., van der Putten, A. A. J., Lantman-de Valk, H. M. J. V. S., van der Schans, C. P., & Waning, A. (2016). Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: a cross-sectional study of medical records and care plans. *Journal of Intellectual Disability Research*, 60(11), 1109-1118. <https://doi.org/10.1111/jir.12298>

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Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: a cross-sectional study of medical records and care plans

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Abstract

Background People with severe or profound intellectual and motor disabilities (SPIMD) experience numerous serious physical health problems and comorbidities. Knowledge regarding the prevalence of these problems is needed in order to detect and treat them at an early stage. Data concerning these problems in individuals with SPIMD are limited. Therefore, the aim of this study was to determine the prevalence of reported physical health problems in adults with SPIMD through a review of medical records and care plans.

Method We conducted a cross-sectional study employing data obtained from medical and support records. A sample of adults with SPIMD was recruited in eight residential care settings. Physical health problems that had occurred during the previous 12 months or were chronic were recorded.

Results The records of 99 participants were included. A wide range of physical health problems were found with a mean of 12 problems per person. Very high prevalence rates (>50%) were found for constipation, visual impairment, epilepsy, spasticity, deformations, incontinence and reflux.

Conclusions The results suggest that people with SPIMD simultaneously experience numerous, serious physical health problems. The reliance on reported problems may cause an underestimation of the prevalence of health problems with less visible signs and symptoms such as osteoporosis and thyroid dysfunction.

Keywords intellectual disabilities, physical health, profound intellectual and multiple disabilities, severe or profound intellectual and motor disabilities

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Introduction

People with severe or profound intellectual and motor disabilities (SPIMD) are characterised by

the combination of a severe or profound intellectual disability (ID) (i.e. estimated intelligence quotient <35 points) and profound motor disability (i.e. unable to move independently). Furthermore, they have sensory impairments and physical health problems (Nakken & Vlaskamp 2007). This group frequently experiences health problems such as dysphagia, epilepsy, spasticity, reflux disease, hearing impairment and visual impairment. Moreover, they have an increased risk for polypharmacy and secondary health problems (Van Schrojenstein Lantman-de Valk & Walsh 2008; Hermans & Evenhuis 2014). These problems negatively impact all aspects of the quality of life of people with SPIMD; the quality of life decreases if the number of physical health issues increases (Petry *et al.* 2009).

Furthermore, this group encounters various health risk factors associated with higher mortality rates such as a lower IQ, non-ambulation, poor motor skills, an inability to feed themselves, inadequate communication skills and self-help limitations (Hayden 1998; Sutherland *et al.* 2002). The estimated life expectancy of people with SPIMD is lower than the estimated life expectancy for people with a milder ID and the general population (Patja *et al.* 2000; Coppus 2013; Heslop *et al.* 2014). Moreover, this group is likely to have different patterns of health problems over time than those with mild or moderate ID (Hayden 1998; Sutherland *et al.* 2002).

It is important to detect and manage physical health problems as early as possible (Kerr *et al.* 2003; Robertson *et al.* 2014); therefore, knowledge regarding the prevalence of these issues is needed. The results of a recent systematic review indicate that data concerning physical health problems in individuals with SPIMD are limited. Previous studies focused on a single or a moderate number of particular health problems while none of the studies focused on the entire range of health issues in people with SPIMD. Therefore, the prevalence of these problems remains uncertain (Van Timmeren *et al.* Under Review), hence, the need to gain further knowledge regarding the entire range of physical health problems in this population.

The aim of this study was to determine the prevalence of reported physical health problems in

adults with SPIMD through a review of medical records and care plans.

Methods

We conducted a cross-sectional study utilising data obtained from medical records and care plans. Legal representatives provided informed consent for accessing residents' records. Service providers made the data of these residents accessible for the researchers. Approval from the medical ethics committee of the University Medical Centre Groningen was obtained prior to the study (METc2013/391).

Sample selection and recruitment

A purposive sample of adults with SPIMD was recruited in eight settings of five large residential care providers for people with ID located in different regions of the Netherlands.

In the eight settings, the mean number of residents was 474 (range 125–730).

Persons with SPIMD who were aged 18 years and older were selected according to the following combination of criteria: (1) severe or profound ID, estimated intelligence quotient was established at >35 according to the ICD-10 classification of level of cognitive impairment; (2) profound motor disability (fully wheelchair dependent); and (3) impairments in sensory function (visual and/or auditory). Adults that satisfied the criteria for inclusion were selected by specialised ID physicians and/or nurse specialists of the medical service of the residential facility.

To determine the sample size, we conducted a sample size analysis. The population of people with SPIMD is difficult to determine because of differences in the type of definition adopted (Pawlyn & Carnaby 2009). Furthermore, there are limitations within intellectual assessments, and it is extremely difficult, if not impossible, to reliably measure the IQ of people who have a severe or profound ID (Nakken & Vlaskamp 2007). Recently conducted research in the Netherlands indicated a population size of a maximum of 9639 adults with SPIMD with an estimated IQ ≤ 35 (Vugteveen *et al.* 2014).

A sample size analysis indicated that, given a population of 10 000 people, a confidence interval of

95% and a power of 90%, 97 participants would need to be included in order to find a prevalence rate of 50%. As we did not know beforehand what prevalence to expect, a sample size corresponding to the least favourable case ($P = 50\%$) was utilised (Sergeant 2015).

Description of participants

All participants were residential clients; 97% received medical care from specialised physicians/nurses in health care for people with ID, the remaining 3% received medical care from a general practitioner. Of the 99 participants, 49.5% were male (mean age 47 years, SD: 16), and 50.5% were female (mean age 45 years, SD: 17). For seven participants, the level of ID was not noted in the files, and the remaining 92 participants had a severe or profound ID (resp. $n = 24$, $n = 68$). All participants experienced profound motor disability. The aetiology of their SPIMD was prenatal ($n = 24$), perinatal ($n = 21$) and postnatal ($n = 15$). For 39 participants, the aetiology was unknown or not noted in the files. Notated syndrome related aetiology were Cri-du-chat-syndrome ($n = 1$),

Down syndrome ($n = 3$), Rett syndrome ($n = 2$), Aicardi syndrome ($n = 2$), tuberous sclerosis complex ($n = 1$), Micro syndrome ($n = 1$) and BPAN syndrome ($n = 1$).

Data collection tool

A data collection form was specifically designed for this study and was pilot tested by two reviewers (DvT and AW) with data from 10 participants in order to appraise the ease of use and efficiency of the data collection. We collected the data of these 10 participants again with the data collection form as described in Table 1.

The data collection form began with a number of identification markers such as gender and date of birth. We then collected information on the intellectual capabilities, aetiology of ID, sensory limitations (visual impairment and hearing impairment) and motor limitations (i.e. spasticity). Finally, we examined physical health problems. We used an open-ended question, and the ICD-10 (World Health Organization 1993) was utilised to classify the problems. The operationalisation of each characteristic is displayed in Table 1. Physical

Table 1 Operationalisation of each characteristic in the questionnaire

Aetiology of the intellectual disability	Prenatal: genetic causes (for example Fragile-X syndrome) and problems during pregnancy such as alcohol or drug use, malnutrition, certain infections or preeclampsia Perinatal: problems during childbirth; birth trauma, baby is deprived of oxygen during childbirth or born extremely premature. Intrauterine infections such as cytomegalovirus, toxoplasmosis, rubella, neonatal herpes and bacterial meningitis Postnatal: illness or injury; accidents (severe head injury, near-drowning, extreme malnutrition, exposure to toxic substances such as lead and severe neglect or abuse) and infections (like meningitis, whooping cough or the measles) (Murphy <i>et al.</i> 1998; Pawlyn & Carnaby 2009)
Level of intellectual disability	Severe ID: IQ of 20–34 Profound ID: IQ of under 20 (according ICD-10)
Visual impairment	Normal vision Low vision: visual acuity $<6/18$ (0.3) $\geq 3/60$ in the better eye with best correction Blind: visual acuity $<3/60$ (0.05) or corresponding visual field loss in the better eye with best possible correction (World Health Organization, 2013)
Hearing impairment	No hearing impairment Good hearing: slight impairment of up to 40 dB in best ear Poor hearing: severe impairment of 61–80 dB in best ear and moderate impairment of 41–60 dB in best ear Deaf: profound impairment including deafness >81 dB in best ear (World Health Organization, n.d.)
Motor disabilities	Bilateral: diplegia, tetraparesis and quadriplegia
spasticity	Unilateral: hemiparesis
Physical health problems	Medical diagnosis of the last year and chronic health problems

ID, intellectual disability.

health problems were recorded that had occurred during the previous 12 months or were chronic. Recurrent physical problems were counted only once.

Procedures

The data collection from medical records and care plans involved reviewing specific sources within the records. The most valuable sources of data varied depending on the care setting of the person with SPIMD. The different care providers all had unique medical and care plan documentation systems. Therefore, raw data such as the personal support plan and medical recordings concerning current medical diagnosis were first aggregated from the records in order to document the most precise and detailed data possible. Six nursing students were selected and trained to collect the raw data and were supervised by the first author. During data extraction, subject identity was encoded to ensure privacy. Two independent reviewers completed the data extraction form following a thorough analysis of the raw data (i.e. the collated information by the nursing students). Both data extraction forms were compared and merged into one form by the first author. Discrepancies were resolved by once again reviewing the raw data.

Data analyses

Data were analysed employing IBM SPSS Statistics 21.0. As this was an exploratory study, prevalence rates and 95% confidence intervals (CI) of health problems were calculated by using the descriptive statistics described in Table 2. The health problems were classified according to the 10th revision of the International Classification of Diseases and Related Health Problems (ICD-10). Confidence intervals (95% CI) were calculated for each health issue using the Confidence Interval Calculator for Proportions (McCallum Layton n.d.).

Results

Overall, 162 people were eligible for the study. Written informed consent was obtained from 113 participants (70%). Fourteen participants were excluded because of incomplete data and not

satisfying the inclusion criteria. Figure 1 outlines the process of inclusion.

Physical health problems

Participants with SPIMD had a mean of 12 reported physical health problems per person (range: 5–21; SD 3.6). Table 2 presents the prevalence rate per ICD-10 chapter. A large number of health problems were categorised in the ICD-category nervous system, eye, ear, respiratory system, digestive system, skin, musculoskeletal system and genitourinary system.

The most frequently reported physical health problem was constipation, which occurred in 94% of the individuals, and the second most frequent was visual impairment, reported in 87% of the sample. Other frequently recorded problems affecting at least 20% of the sample in decreasing frequency were epilepsy (79%), spasticity (76%), deformations (72%), incontinence (56%), gastro-oesophageal reflux (52%), impacted cerumen (49%), dysphagia (47%), deformity foot (38%), contracture (32%), eczema/dermatitis (29%), menstruation problems (29% of the women), pneumonia (27%), mycoses (25%), hearing impairment (22%), infection of eye (22%), otitis (21%) and decubitus/pressure area (20%).

Discussion

To our knowledge, the current study is the first that focuses on the entire reported range of physical health problems in people with SPIMD. The results emphasise that this population simultaneously experiences numerous serious physical health problems. Frequently reported were constipation, visual impairment, epilepsy, spasticity (>75%), deformations, incontinence, gastro-oesophageal reflux (50–75%) and impacted cerumen, dysphagia, deformity foot, contracture, eczema/dermatitis, menstruation problems, pneumonia and mycoses (25–50%).

Comparison to existing literature

The results suggest that the digestive system is vulnerable in individuals with SPIMD as indicated by three serious digestive health problems being highly prevalent, that is, constipation (94%) gastro-oesophageal reflux (52%) and dysphagia (47%). This

Table 2 Prevalence rate (%) per ICD-10 chapter $n = 99$

ICD-10 chapter	Physical health problem	Results % (95% CI)
Infectious and parasitic diseases	Herpes simplex labialis	5 (0.7–9.3)
	Gastroenteritis	4 (0.1–7.9)
	<i>Helicobacter pylori</i>	4 (0.1–7.9)
	<i>Klebsiella/Escherichia coli</i>	2 (–0.8–4.8)
Neoplasms	Benign neoplasms	5 (0.7–9.3)
	Carcinoma	1 (–1.0–3.0)
Blood, blood-forming organs	Anaemia	10 (4.1–16.0)
	Thrombocytopenia	1 (–1.0–3.0)
Endocrine, nutritional and metabolic	Thyroid dysfunction	8 (2.7–13.3)
	Hyponatremia ($n = 5$)	5 (0.7–9.3)
	Hypokaliemia ($n = 1$)	
	Hypercholesterolaemia	2 (–0.8–4.8)
	Vitamin deficiency (D, B11)	2 (–0.8–4.8)
	Diabetes mellitus	1 (–1.0–3.0)
Nervous system	Epilepsy	79 (71.0–87.0)
	Spasticity	76 (67.6–84.4)
	Parkinsonism	2 (–0.8–4.8)
	Hyperhidrosis	1 (–1.0–3.0)
	Myasthenia	1 (–1.0–3.0)
	Visual impairment	87 (80.4–93.6)
Eye and adnexa	• Severe/Moderate 47%	
	• Blind 40%	
	Infection of eye	22 (13.8–30.2)
	Cataract	19 (11.3–26.7)
	Glaucoma	1 (–1.0–3.0)
	Impacted cerumen	49 (39.2–58.9)
	Hearing impairment	22 (13.8–30.2)
	• Severe/Moderate 20%	
	• Deaf 2%	
	Otitis	21 (13.0–29.0)
Circulatory system	Cardiac disease	7 (2.0–12.0)
	Hypertension	5 (0.7–9.3)
	Hemorrhoid	1 (–1.0–3.0)
Respiratory system	Pneumonia	27 (18.3–35.8)
	Lower respiratory tract infection	15 (8.0–22.0)
	COPD/Asthma	15 (8.0–22.0)
	Upper respiratory tract infection	13 (6.4–19.6)
	Hay fever	9 (3.4–14.6)
	Thick phlegm	1 (–1.0–3.0)
	Constipation	94 (89.3–98.7)
Digestive system	Gastro-oesophageal reflux	52 (42.2–61.8)
	Dysphagia and feeding tube due to dysphagia	47 (37.2–56.8)
	Feeding tube other	12 (5.6–18.4)
	Diaphragmatic hernia	11 (4.8–17.2)
	Toothless	11 (4.8–17.2)
	Abdominal wall hernia	6 (1.3–10.7)
	Diarrhoea	5 (0.7–9.3)
	Gas in digestive tract	4 (0.1–7.9)
	Oral aphthae	2 (–0.8–4.8)
	Ileus	2 (–0.8–4.8)
	Irritable bowel syndrome	1 (–1.0–3.0)
	Hyper salivation	1 (–1.0–3.0)

Table 2. (Continued)

ICD-10 chapter	Physical health problem	Results % (95% CI)
Skin and subcutaneous tissue	Cirrhosis of liver	1 (−1.0–3.0)
	Calculus of gallbladder	1 (−1.0–3.0)
	Eczema/Dermatitis	29 (20.1–37.9)
	Mycoses	25 (16.5–33.5)
	Decubitus/Pressure area	20 (12.1–27.9)
	Skin problems	15 (8.0–22.0)
	Skin infection	10 (4.1–15.9)
	Diseases of the skin	8 (2.7–13.3)
	Verruca seborrhoica	5 (0.7–9.3)
	Erysipelas	3 (−0.4–6.4)
Musculoskeletal system + Congenital malformations, deformations	Herpes zoster	2 (−0.8–4.8)
	Deformations	72 (63.2–80.8)
	• Scoliosis 56%	
	• Hip 39%	
	Foot deformity	38 (28.4–47.6)
	Contracture	32 (22.8–41.2)
	Osteoporosis	13 (6.4–19.6)
	Arthrosis	9 (3.4–14.6)
	Incontinence	56 (46.2–65.8)
	Menstruation problems (women <i>n</i> = 51)	29 (16.6–41.5)
Genitourinary system	Urinary tract infection	17 (9.6–24.4)
	Retention of urine	14 (7.2–20.8)
	Disorder of kidney	4 (0.1–7.9)
	Ulcus preputium	1 (−1.0–3.0)
	Phimosis (men <i>n</i> = 49)	1 (−1.8–3.8)
	Oedema	14 (7.2–20.8)
	Hypothermia	11 (4.8–17.2)
	Cough	7 (2.0–12.0)
	Vomiting	4 (0.1–7.9)
	Epistaxis	1 (−1.0–3.0)
Symptoms and signs	Syncope	1 (−1.0–3.0)
	Headache	1 (−1.0–3.0)
	Wheezing	1 (−1.0–3.0)
	Superficial wound	14 (7.2–20.8)
	Fractured bone	3 (−0.4–6.4)
	Contusion of ankle	1 (−1.0–3.0)
Injury		

group has an elevated risk for constipation because of their non-ambulatory, use of anticonvulsive medicine, benzodiazepines, proton pump inhibitors and severe ID (Böhmer *et al.* 2001). Constipation is a significant issue and not always easily recognised in people with SPIMD. In literature, a lower prevalence of 44% (Petry *et al.* 2009) and 60% (Van der Heide *et al.* 2009) is ascertained for constipation. Furthermore, adults with ID are at high risk for death from respiratory problems (Heslop *et al.* 2014), and for people with SPIMD, chest infections are the leading cause of death (Cooper *et al.* 2004; Hogg *et al.* 2007).

The prevalence of dysphagia and gastro-oesophageal reflux increases the risk of chest infections such as aspiration pneumonia (Thillai 2010). This group is also at a greater risk of developing gastro-oesophageal reflux because of their non-ambulatory, scoliosis, use of anticonvulsive medicine and the severity of the ID (Haveman *et al.* 2010). In a recent systematic review, meta-analysis indicated a prevalence of 16%, which is lower compared with the current study (Van Timmeren *et al.*, in press). Gastro-oesophageal reflux is known to have non-specific symptoms and is frequently overlooked (Bohmer *et al.* 2000). It is

Figure 1 Flow chart – inclusion of the study participants.

possible that gastro-oesophageal reflux is more prevalent for the individuals in the current study because, in the Netherlands, reflux disease is a differential diagnosis in the event of unexplained symptoms of distress such as challenging behaviour in people with SPIMD (Braam *et al.* 2014). In addition, the prevalence of dysphagia (47%) was in accordance with previous studies (Van Timmeren *et al.*, in press).

For several health problems, a lower prevalence is reported in the current study compared with previous studies. For anaemia, a prevalence of 10% is found while, in another study, a rate of 41% is determined (Ohwada *et al.* 2006). The latter utilised existing health check-up data (blood profile tests) and therefore actively screened for anaemia. On the other hand, Ohwada *et al.* (2006) reported a very low prevalence of reflux disease (2.6%). There is a possible relationship between anaemia and gastro-oesophageal reflux; iron deficiency anaemia can be a reflux symptom (Böhmer *et al.* 1999). The prevalence of anaemia is lower in the current study most likely because of the adequate treatment of reflux. On the other hand, the low rate could also be due to underdiagnosis. Furthermore, parkinsonism is diagnosed in 2% of the participants whereas, in literature, a prevalence of 30% (Matson *et al.* 2008) and 45% (Fodstad *et al.* 2010) is ascertained for tardive dyskinesia in people with severe or profound ID who were using antipsychotic medications; parkinsonism and tardive dyskinesia are predominantly due to the use of antipsychotics (Kwok

& Cheung 2010). The more severe the ID, the greater the risk becomes for tardive dyskinesia when using psychotropic medication (Matson *et al.* 2010). The low prevalence of parkinsonism and the absence of tardive dyskinesia in the current study may be explained by conservative policies in prescribing psychotropic drugs or may possibly be a result of underdiagnosis. In addition, a prevalence of 5% was found for hypertension whereas, in previous studies, prevalence rates of 60% (De Winter *et al.* 2011) and 20% (Lin *et al.* 2012) were mentioned in people with severe or profound ID. In both studies, the mean age of the participants was 61 years. The differences in the prevalence rate could be due to older age because hypertension is significantly related to older age (Van de Louw *et al.* 2009). It might also be due to underdiagnosis as we had to accept the information of reported health problems from files without rediagnosis. Moreover, a relatively low prevalence rate of 13% for osteoporosis was found in accordance with a previous study (Lohiya *et al.* 2004). Because people with SPIMD are at a greater risk for osteoporosis because of several risk factors such as high levels of inactivity, severe level of ID, low levels of exposure to sunlight and high levels of long term use of anticonvulsants, a higher prevalence rate was expected (Haveman *et al.* 2010; Bastiaanse *et al.* 2014). The low prevalence rate is presumably an underestimation of the actual prevalence rate because clinical signs are less obvious, and checking bone health is often omitted in health checks (Srikanth *et al.* 2011; Bastiaanse *et al.* 2014).

Notable new findings, compared with literature (Van Timmeren *et al.* under Review), with a prevalence exceeding 20% are incontinence (56%), impacted cerumen (49%), deformity foot (38%), contracture (32%), menstruation problems (29% of the women), pneumonia (27%), infection of eye (22%), otitis (21%) and decubitus/pressure area (20%).

Strengths and limitations

The following methodological strengths and limitations must be considered in the interpretation of the results. First, we used medical records and care plans to obtain information about the estimated prevalence of all possible physical health problems. The advantage of this approach was that we were able

to provide an overview of a broad range of reported health problems. However, the reliance on reported problems may have caused an underestimation of the prevalence of physical health problems with less visible signs and symptoms in people with SPIMD. For example, the low rate of thyroid dysfunction in the current study could be a reflection of the true prevalence rate, or it could be false because of underdiagnosis. It was not possible to validate the health problems by performing formal assessments. By using two types of records, we were able to obtain results that are more valid. For example, constipation was sometimes not mentioned as a current problem in the medical files whereas, in the care plans, it was noted that a person had constipation and, according to the medication form, was using a laxative. Moreover, because of variability in the documentation among health care providers, the terminology of the documented health problems in the records were not always the same. Therefore, prior to the analysis, the health problems were grouped and categorised. It is plausible that a different grouping or classification would obtain different results. Secondly, several health problems were not (well) documented in the medical records and care plans, for example, weight and dental or oral diseases. Most participants in the current research visit the dentist on a regular basis; however, the dentist keeps the dental records, and they are not connected with the medical records and care plans. Consequently, there was only nominal or no documentation available on dental and oral health problems. Thirdly, participants were recruited in residential facilities because, in the Netherlands, most people with severe or profound ID live in residential facilities (93%); only 7% reside with their family (NVAVG 2012). Therefore, the results cannot be generalised to individuals with SPIMD living in small community settings.

These limitations notwithstanding, the results suggest high rates of reported health problems. By conducting a direct clinical assessment (such as health screening), previously unrecognised conditions could possibly be identified (Felce *et al.* 2008, Robertson *et al.* 2014). For screening, the measuring methods must be adjusted to the special needs of people with SPIMD and must take the interrelatedness of the intellectual, physical and sensory disabilities into account (Nakken & Vlakamp

2007); otherwise, it is difficult to obtain accurate measurements.

Implications for practice and research

People with SPIMD have complex health needs because of the concurrent numerous serious physical health issues, severe or profound cognitive and motor disabilities, and minimal communication skills. They are at risk for inadequate treatment of physical health issues, which can lead to exacerbation of these problems and can have considerable negative health consequences. Doctors and nurses should consider proactive clinical assessment tailored to the special needs of people with SPIMD and taking the interrelatedness of the intellectual, physical and sensory disabilities into account. Further research should focus on existing applicable measurement methods and the development and evaluation of specific instruments to assess the health problems in people with SPIMD.

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Accepted 13 April 2016