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Patterns of multimorbidity in people with severe or profound intellectual and motor disabilities

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ABSTRACT

Background: People with severe or profound intellectual and motor disabilities (SPIMD) experience multimorbidity and have complex health needs. Multimorbidity increases mortality, decreases functioning, and negatively influences quality of life. Information regarding patterns of multimorbidity in people with SPIMD may lead to proactive prevention, specifically detection and treatment of physical health problems at an early stage and prevention of secondary complications.
Aim: The aim of this study was to explore patterns of multimorbidity in individuals with SPIMD.
Methods and procedures: Data from medical records and care plans on reported physical health problems of 99 adults with SPIMD were analysed. To explore the co-occurrence of physical health problems, cross tabulations and a 5-set Venn Diagram were used.
Outcomes and results: The most common combination of two physical health problems comprise the most prevalent physical health problems, which included visual impairment, constipation, epilepsy, spasticity, and scoliosis. These five issues occurred as a multimorbidity combination in 37% of the participants. In 56% of the participants a multimorbidity combination of four health problems emerged, namely constipation, visual impairment, epilepsy, and spasticity.
Conclusions and implications: People experiencing SPIMD have interrelated health problems. As a consequence, a broad variety of potential interactions between physical health problems and their treatments may occur. Identifying multimorbidity patterns can provide guidance for accurate monitoring of persistent health problems and, early detection of secondary complications. However, the results require confirmation with larger samples in further studies.

What this paper adds

This paper explores patterns of multimorbidity in people with SPIMD. Former studies regarding multimorbidity focused on adults with intellectual disabilities (ID) in general. Individuals with SPIMD have a distinct physical health profile compared to those with

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less severe intellectual disabilities. Information regarding patterns of multimorbidity in people with SPIMD can lead to proactive prevention such as monitoring persistent diseases and early recognition of newly presenting problems. This is especially important for people with SPIMD who depend on their caregivers to identify health needs.

1. Introduction

People with severe or profound intellectual and motor disabilities (SPIMD) experience multimorbidity and have complex health needs (Nakken & Vlaskamp, 2007). In addition to the severe or profound cognitive and motor disabilities, and minimal communication skills, people with SPIMD encounter a wide range of physical health problems with a mean of 12 problems per individual (van Timmeren, van der Putten, van Schrojenstein Lantman-de Valk, van der Schans, & Waninge, 2016). Frequently reported physical health problems include constipation, visual impairment, epilepsy, spasticity, scoliosis, incontinence, gastroesophageal reflux disease, impacted cerumen, dysphagia, deformity in hips and feet, contractures, eczema/dermatitis, menstruation problems, pneumonia, and mycosis with prevalence rates above 25% (van Timmeren et al., 2016).

The simultaneous occurrence of various health problems in the same person is defined as multimorbidity (Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009; van den Akker, Buntinx, & Knottnerus, 1996). Multimorbidity increases mortality, decreases physical and mental functioning, and negatively influences quality of life (Diederichs, Berger, & Bartels, 2011). Studies on multimorbidity in adults with intellectual disabilities (ID) in general, have been limited to chronic diseases (Cooper et al., 2015; Hermans & Evenhuis, 2014; McCarron et al., 2013). The prevalence of multimorbidity is high for individuals of all ages and even increases with age (Cooper et al., 2015). The prevalence varies from 38.5% in adults aged 18 and older (Cooper et al., 2015), 71% in adults aged 40 and older (McCarron et al., 2013), and 80% in adults aged 50 and older (Hermans & Evenhuis, 2014). Furthermore, 47% of adults with ID aged 50 and older had at least four health conditions (Hermans & Evenhuis, 2014).

People with SPIMD have a distinct physical health profile compared to people with mild or moderate intellectual disabilities (Hayden, 1998; Sutherland et al., 2002). Comparison between the prevalence of physical health in people with ID in general and persons with SPIMD reveals large differences. For example a research regarding multimorbidity for adults with ID in general reported a prevalence of 14% for constipation, 3% for visual impairment and 19% for epilepsy (Cooper et al., 2015). For people with SPIMD a prevalence of 94% for constipation, 87% for visual impairment, and 79% for epilepsy was reported (van Timmeren et al., 2016).

For individuals experiencing SPIMD, multimorbidity usually presents at a young age due to clusters of health problems associated with the severe brain damage/dysfunction such as dysphagia, epilepsy, motor impairments, gastroesophageal reflux disease, hearing impairments, and visual impairments (Hermans & Evenhuis, 2014). Consequently, people with SPIMD are exposed to these health problems for longer and, therefore, are vulnerable to newly presenting health problems that could arise from one of the existing health problems or from their treatments (Muth et al., 2014). Combination of physical health problems may result in several additional adverse effects. For example, scoliosis may cause dysphagia (Papadopoulou, Exarchakos, Beris, & Ploumis, 2013), and dysphagia may be exacerbated from concurrent gastroesophageal reflux disease (Calis et al., 2008). Furthermore, the presence of scoliosis, dysphagia, and gastroesophageal reflux disease increases the risk of respiratory tract infection (Proesmans et al., 2015; Thillai, 2010) which is a possible leading cause of death for people with SPIMD (Heslop et al., 2014; Hogg et al., 2007).

The distinct epidemiological profile and greater morbidity burden, coupled with dependency on caregivers, for identification of health needs, can complicate the provision of health care for people with SPIMD. It is therefore imperative that caregivers are well informed, in order to proactively monitor physical health problems and to timely recognise newly presenting problems (Muth et al., 2014). Information regarding patterns of multimorbidity in people with SPIMD can lead to proactive prevention by detection and treatment of physical health problems at an early stage and, by preventing secondary complications (Hermans & Evenhuis, 2014). However, to date, research has not been focused on patterns of multimorbidity in specifically people with SPIMD. The aim of this study is to explore patterns of multimorbidity in people with SPIMD.

2. Method

2.1. Study design

The present study is based on data from a previous research on the prevalence of reported physical health problems in people with SPIMD (van Timmeren et al., 2016). In this exploratory retrospective study, data were collected from medical records and care plans in order to determine the prevalence of reported physical health problems. The present study focuses on physical health problems which tend to occur together in order to explore the patterns of multimorbidity.

2.2. Study participants

As described in van Timmeren et al. (2016) the study was conducted in a purposive sample of eight settings of five large residential facilities for people with ID located in different regions of the Netherlands. Specialised ID physicians and/or nurse specialists were asked to select medical records and care plans of adults with SPIMD according to the following combination of criteria: (1) severe or profound ID, estimated intelligence quotient was established at < 35 points 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). Legal representatives provided informed consent for accessing residents' records (van Timmeren et al., 2016). The medical ethics committee of the University Medical Centre Groningen gave their approval prior to the study (METc2013/391).