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The impact of visual impairment on the ability to perform activities of daily living for persons with severe/profound intellectual disability

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ABSTRACT

Background: The ability to perform activities of daily living (ADL) as a component of participation is one of the factors that contribute to quality of life. The ability to perform ADL for persons experiencing severe/profound intellectual disability (ID) may be reduced due to their cognitive and physical capacities. However, until recently, the impact of the significantly prevalent visual impairments on the performance of activities of daily living has not yet been revealed within this group.
Aim: The purpose of this prospective cross-sectional study was to investigate the impact of visual impairment on the performance of activities of daily living for persons with a severe/profound intellectual disability.
Method: The Barthel Index (BI) and Comfortable Walking Speed (CWS) were used to measure the ability of performing activities of daily living (ADL) in 240 persons with severe/profound ID and having Gross Motor Functioning Classification System (GMFCS) levels I, II or III; this included 120 persons with visual impairment. The impact of visual impairment on ADL was analyzed with linear regression.
Results: The results of the study demonstrated that visual impairment slightly affects the ability of performing activities of daily living (BI) for persons experiencing a severe/profound intellectual disability. GMFCS Levels II or III, profound ID level, and visual impairment each have the effect of lowering BI scores.

GMFCS Levels II or III, and profound ID level each have the effect of increasing CWS scores, which indicates a lower walking speed. A main effect of visual impairment is present on CWS, but our results do show a substantive interaction effect between GMFCS level III and visual impairment on Comfortable Walking Speed in persons with a severe/profound intellectual disability.
Conclusions: Visual impairment has a slight effect on ability to perform ADL in persons experiencing severe/profound ID.

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1. Introduction

The ability of performing activities of daily living (ADL) is a component of participation, according to the International Classification of Functioning from the World Health Organization (WHO, 2001). Mahoney and Barthel (1965) and De Haan et al. (1993) state that ADL is an operationalization of daily functioning, including individuals with intellectual disabilities (Hilgenkamp, Bastiaanse, et al., 2011). Daily activities influence not only the personal quality of life but also the need for support and/or care from others. Persons with intellectual disabilities experience greater degrees of dependence in addition to decreased levels of mobility (independence, walking with support, or using a wheelchair; Hilgenkamp, Van Wijck, & Evenhuis, 2011).

Persons with severe or profound intellectual disabilities (ID) frequently experience another important, though very specific, determinant of the ability to perform ADL: visual impairments. There is a high prevalence of visual impairments (WHO, 2001) in individuals with severe or profound intellectual disabilities and in persons with severe ID. Van Splunder, Stilma, Bernsen, and Evenhuis (2006) ascertained a prevalence of visual impairment of 23.4% in persons with profound ID and 67.7% and 92% in 76 persons with severe or profound ID (Van den Broek, Janssen, van Ramshorst, & Deen, 2006).

The importance of visual ability for any activity has been extensively demonstrated (Häkkinen, Holopainen, Kautiainen, Sillanpää, & Häkkinen, 2006; Hopkins, Gaeta, Thomas, & Hill, 1987; Houwen, Visscher, Lemmink, & Hartman, 2008; Seemungal, Glasauwer, Gresty, & Bronstein, 2007). Visual impairment may have impact on eye-hand coordination and neuromuscular function which are both essential for the ability to perform ADL. Furthermore, persons experiencing both visual impairment and an intellectual disability are particularly at risk for developing deficits in both locomotor skills and in the ability to perform ADL (Evenhuis, Sjoukes, Koot, & Kooijman, 2009)

Therefore, it is important to be aware if persons with ID and visual impairment require relatively more support in their daily functioning than persons with ID without visual impairment. This is necessary, on the one hand, because care providers must substantiate that additional support and funding for the care of these people will eventually be required. On the other hand, in order to provide the individuals experiencing these multiple disabilities an opportunity to participate optimally in society, the care must be adjusted accordingly as much as possible.

This leads to the following research questions:

What is the impact of visual impairment on the ability to perform ADL in persons with a severe/profound intellectual disability, measured by the BI and Comfortable Walking Speed?

2. Method

2.1. Design and participants

Persons experiencing severe or profound ID (ICD-10, WHO, 2010), Gross Motor Functioning Classification System (GMFCS) Levels I–III (Gorter, 2001; Palisano et al., 2000), with and without visual impairment (WHO, 2001) were included in the study. The GMFCS (Gorter, 2001; Palisano et al., 2000) is a five-level system used to classify the severity of motor disabilities in persons with intellectual and physical disabilities. Participants classified at "Level I" can generally walk without restrictions but tend to have limitations in more advanced motor skills. Participants with a "Level II" classification can walk with slight restrictions and do not spontaneously increase their speed during walking. Participants with a 'Level III' are able to walk with walking devices. Only participants experiencing GMFCS levels I–III could be included because they had to be able to perform the CWS.

Written consent was requested from the representatives of the participants. In this prospective cross-sectional study, data of participants were collected in two different samples. The majority of the participants, i.e., 201 were recruited from the 'Healthy ageing and intellectual disabilities' study (HA-ID) executed by a collaboration of three ID care organizations and two university departments in the Netherlands (HA-ID study Hilgenkamp, Bastiaanse, et al., 2011). In addition, 62 participants were recruited from a residential care facility for the profound or severe intellectually and visually disabled in the Netherlands.

The exclusion criteria consisted of psychoses, depression, or other severe psychological problems (such as behavioral stress and prolonged stress) somatic diseases defined as chronic diseases and/or diseases that do not resolve in a short period of time such as osteoarthritis, osteoporosis, pneumonia, and general illness or fever; taking antibiotics; worsening of asthma or epilepsy (recent insult or epileptic fits); fresh wound(s)/bruise(s); or other factors causing pain during movement; and, finally, stress as evidenced by the participant's behavior shortly prior to the date of measurement.

2.2. Measures and protocols

Age and gender were retrieved from the clients' records. Levels of GMFCS, intellectual disability and hearing impairment as well as the presence of epilepsy were retrieved from the client medical records. These levels were determined and categorized by a physician specialized in intellectual disabilities in collaboration with a health care psychologist. Data on visual impairment were determined by doctors and retrieved from the clients' medical records. The participants were evaluated to have no visual impairment, visual impairment or being blind. Data on dementia have been collected from the clients' medical records and psychological files. The etiology 'Intellectual disability caused by Down syndrome' has been