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Research in Developmental Disabilities



Prevalence of pain in institutionalized adults with intellectual disabilities: A cross-sectional approach



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ARTICLE INFO

Article history:

Received 4 December 2012

Received in revised form 10 April 2013

Accepted 16 April 2013

Available online 25 May 2013

Keywords:

Intellectual disabilities

Pain prevalence

Pain assessment

ABSTRACT

Information about pain prevalence in institutionalized individuals with intellectual disabilities is scarce, most likely because communication problems impede pain assessment. We aimed to inventory pain prevalence and actual pain management in intellectually disabled individuals living in a representative special care facility in the Netherlands.

Caregivers rated the residents' present pain and overall pain during the preceding week on an 11-point numerical rating scale (NRS-11). In addition, behavioral pain assessment was performed with validated pain scales; the Rotterdam Elderly Pain Observation Scale (REPOS) or Checklist Pain Behavior (CPG).

Ratings suggested that 47 of the 255 included residents (18%) suffered from pain either at present or during the preceding week, 14 of whom (30%) experienced pain on both occasions. Most of these 47 (85%) residents with pain had no analgesic prescription, not even in the case of severe pain (NRS 7 or higher).

Ratings for nearly one out of every five residents suggested they suffered pain. This proportion is lower than in other studies and could imply that caregivers probably underestimate residents' prevalence of pain. Pain treatment might be inadequate in light of the low percentage of analgesic prescriptions. To prevent unnecessary suffering in institutes for residents with an intellectual disability (ID) we recommend use of a pain protocol including a validated pain measurement instrument.

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1. Introduction

In the Netherlands it is common for individuals with severe intellectual disabilities (ID) to live in institutions since childhood. In 2010, the number of residents of institutions was approximately 20,550 (Centraal Bureau voor Statistiek, 2011). Residents of institutions have been systematically excluded from pain studies mainly because of the heterogeneity in etiology, their disease stage such as progressive neurodegenerative diseases, and immobility due to chronic illness (Oberlander & Symons, 2006; Sobsey, 2006).

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Lack of verbal communication skills, physical handicaps and concomitant morbidity are main determining factors that impede pain assessment in ID individuals (Blyth & Lee, 2011; Hadjistavropoulos et al., 2007; Scherder et al., 2009; van der Putten & Vlaskamp, 2011). A possible alternative is proxy report by relatives or caregivers, which, however, carries the risk of over reporting (relatives) or under reporting (professionals) of the pain intensity (Horgas & Dunn, 2001). A second alternative is the use of observational pain assessment instruments (Breau, McGrath, Camfield, & Finley, 2002; Burkitt, Breau, Salsman, Sarsfield-Turner, & Mullan, 2009; Duivenvoorden, Tibboel, Koot, van Dijk, & Peters, 2006; Hadjistavropoulos et al., 2007; Terstegen et al., 2004; van Herk, van Dijk, et al., 2009; McGuire & Kennedy, 2013; Voepel-Lewis, Merkel, Tait, Trzcinka, & Malviya, 2002).

Although these pain observations scales have been validated, implementation in daily practice is lagging behind (Oberlander & Symons, 2006), a problem also seen in other settings (Franck & Bruce, 2009).

As a consequence pain may be undertreated in individuals with an ID, not only in the Netherlands, but possibly world wide (de Knegt & Scherder, 2010; Malviya et al., 2001; Symons, Shinde, & Gilles, 2008). Possible undertreatment is alarming because individuals with ID often suffer from painful musculoskeletal disorders, such as arthritis of the cervical spine (de Knegt & Scherder, 2010). Also severe spasticity may be associated with painful contractures, joint dislocations and mobility and posture problems (de Knegt & Scherder, 2010; van der Putten & Vlaskamp, 2011). All of these health problems may be further complicated with painful conditions such as gastritis and pneumonia (Bottos & Chambers, 2006; de Knegt & Scherder, 2010; van der Putten & Vlaskamp, 2011). Pain treatment may be hampered by comorbidities because multi-medication increases the risk of adverse events and medication-medication interactions (Taddio & Oberlander, 2006). It is therefore understandable that physicians may be reluctant to prescribe analgesics.

In spite of all available knowledge about the presence of pain in comorbidities, information about the prevalence of pain in institutionalized individuals with an ID is still scarce (de Knegt & Scherder, 2010). An Irish survey among caregivers yielded an overall 13.4% prevalence of chronic pain (duration of three months or more) in adults with an ID; the prevalence for residents living in a group home was 15.4% (McGuire, Daly, & Smyth, 2010; Walsh, Morrison, & McGuire, 2011). Other studies, in the Netherlands and the USA, estimated the prevalence of (chronic) pain in cognitively impaired nursing home residents to range from 47% to 62% (Ferrell, Ferrell, & Rivera, 1995; Zwakhalen, Koopmans, Geels, Berger, & Hamers, 2009). Methods of data collection between studies differ however. Ferrell et al. (1995) used self-report while Zwakhalen et al. (2009) applied pain observation instruments.

A pain prevalence of 84% was reported for children with an ID (Breau, Camfield, McGrath, & Finley, 2003). Relatedly, pain prevalences of up to 84% have been reported by adults suffering from cerebral palsy, a condition often seen in individuals with an ID (Engel, Schwartz, Jensen, & Johnson, 2000; Jones, 2009; Odging, Roebroek, & Stam, 2006).

We report a study aimed at answering the following question: What is the prevalence of pain in individuals with a moderate to severe ID living in a representative special care facility in the Netherlands?

2. Method

2.1. Subjects and settings

The explorative cross-sectional study was performed in a special care facility for individuals with moderate to severe ID in the Netherlands. This facility is run by an organization employing a total of 3000 staff who provide care to approximately 1450 clients on 43 locations. In the study location 260 staff cared for 356 residents. These caretakers were educated on different levels of health and welfare vocational education (27% of staff completed the highest level of a secondary education; 40% intermediate level; 20% lowest level and 13% were students). Although this institution is not representative for the total population of individuals with an ID it is a representative facility for individuals with intellectual disabilities in the Netherlands (Ras, Woitiez, van Kempen, & Sadiraj, 2010).

Residents' ages ranged from 7 years to 91 years of age, and ID ranged from moderate to severe (maximum IQ of 70; American Psychiatric Association, 2000). None of the residents was able to self-report pain intensity. Approximately 20% of the residents were both intellectually and physically handicapped. All residents were represented by a legal representative. These legal representatives were sent a letter with detailed information about the project and were asked permission to access the resident's medical files and to perform pain assessments. The study was approved by the Medical Ethics Review Board of the Erasmus University Medical Center and the institution's local board of directors.

2.2. Material and procedure

2.2.1. Instruments

The Numerical Rating Scale-11 (NRS-11; Jensen, 2003; von Baeyer & Spagrud, 2007) is a validated pain instrument rating pain by number (0 = no pain and 10 = worst pain) either by self report or proxy report. In our study the caregivers gave a proxy rating based on their insight into the medical and personal circumstances of the residents which might relate to pain. Ratings from 4 to 10 are thought to suggest pain (Serlin, Mendoza, Nakamura, Edwards, & Cleeland, 1995).

The Checklist Pain Behavior (CPG; Duivenvoorden et al., 2006; Terstegen, Koot, de Boer, & Tibboel, 2003) has been validated for postoperative pain and daily pain in 3–12-year-old children with an ID. It consists of ten behaviors to be scored as present (1) or absent (0); thus the total score ranges from 0 to 10. These behaviors are: tense face; deepening naso-labial furrows;

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