



Pain report and musculoskeletal impairment in young people with severe forms of cerebral palsy: A population-based series



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ARTICLE INFO

Article history:

Received 24 February 2016

Received in revised form

27 September 2016

Accepted 13 October 2016

Available online 25 October 2016

Keywords:

Severe cerebral palsy

Pain

Musculoskeletal impairment

Health

ABSTRACT

Background: While pain is reportedly more prevalent in more functionally impaired children with cerebral palsy, information is scant in those with poor communication skills.

Methods: Young people (4–27 years) with severe forms of cerebral palsy were recruited from a population-based register. The Child Health Questionnaire (CHQ) provided information on general health and bodily pain; the Paediatric Pain Profile (PPP) was used for participants with limited communication; and the Spinal Alignment and Range of Motion Measure (SAROMM) described musculoskeletal impairment.

Results: 123 young people (GMFCS IV = 55 and V = 68) and their families/carers participated. Fourteen percent of CHQ responses (n = 123) reported severe/very severe pain in recent weeks, whilst 7% reported pain every/almost every day. CHQ pain report was significantly higher for young people in GMFCS level V and correlated significantly with both global health and musculoskeletal impairment. High levels of pain were recorded on the PPP for non-communicating children but only a weak correlation between PPP and CHQ scores was detected.

Conclusion: Managing pain in young people with severe musculoskeletal and cognitive impairment presents a huge challenge to carers and professionals. The PPP may represent a useful adjunct in those young people with severe communication difficulties.

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What this paper adds

This is the first paper that demonstrates the presence of severe pain and discomfort across a population series of children and young people with severe forms of cerebral palsy. In particular, it reports the presence of significant pain levels in non-communicating young people using a non-verbal pain assessment tool, the Pediatric Pain Profile (PPP). A significant relationship between parent/guardian reported pain levels and severity of musculoskeletal impairment as recorded by the SAROMM has also been demonstrated. The paper highlights the need for using clinically valid pain measures in more

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cognitively impaired young people as part of ongoing routine care. More importantly, it highlights the necessity for developing management strategies and treatment protocols that will reduce the significant musculoskeletal impairments that can develop in these young people throughout childhood. Other common sources of pain such as gastrointestinal and dental pain must also be considered.

1. Introduction

Pain is now recognised as a significant co-morbidity in population-based samples of young people and adults with cerebral palsy, and its relationship with reduced participation (Parkinson et al., 2013; Ramstad, Jahnsen, Skjeldal, & Diseth, 2012) and poorer quality of life (Colver et al., 2014; Dickinson et al., 2007) is well documented. Current prevalence figures for the pain experienced by children with cerebral palsy vary between 54% and 77% for parent/caregiver report and between 47% and 70% for self-report (Parkinson et al., 2013; Parkinson, Gibson, Dickinson, & Colver, 2010; Penner, Yan Xie, Binopal, Switzer, & Fehlings, 2013). While prevalence tends to be higher amongst girls (Parkinson et al., 2010), in older children (Penner et al., 2013; Ramstad, Jahnsen, Skjeldal, & Diseth, 2011) and amongst adults (Opheim, Jahnsen, Olsson, & Stanghelle, 2011), there has been less consensus on the relationship between prevalence of pain and severity of impairment; some studies reporting a significant correlation (Houlihan, O'Donnell, Conaway, & Stevenson, 2004; Ramstad et al., 2011) whilst others showing limited (Penner et al., 2013) or no relationship (Doralp & Bartlett 2010; Kennes et al., 2002; Tervo, Symons, Stout, & Novacheck, 2006). The correlation between motor impairment, and cognitive and communication impairments may result in under-reporting in children with more complex forms of the condition.

In a recent European population-based study (Parkinson et al., 2010, 2013), a significant correlation between parental report of pain and severity of impairment was demonstrated. However, no such relationship was demonstrated for young people able to self-report. In their discussion, the authors suggest that the lack of a statistical relationship seen in their data for those children able to self-report may be due to either the reduced inclusion of more severely impaired children, or a real difference between what a child reports and their parents' perception of the pain they are experiencing.

In terms of the sites and location of pain, the lower extremities and back tend to be the most frequently reported (Parkinson et al., 2013; Penner et al., 2013; Ramstad et al., 2011; Jahnsen, Villien, Aamodt, Stanghelle, & Holm, 2004). Penner et al. (2013), who collected additional reports from the child's physician, further identified pain resulting from hip dislocation/subluxation, dystonia and musculoskeletal deformity as being primary causes. Lesser causes included constipation, focal muscle spasm, muscle weakness/overuse/fatigue and spasticity. Earlier work by Hodgkinson et al. (2001) also reported a high prevalence of hip pain (47%) in adults (>15years) with non-ambulant spastic type quadriplegia.

In the studies highlighted above there is consistently poorer representation in self-report figures for young people who are more severely impaired, most likely due to poor cognition and an inability to communicate. Thus they are potentially at greater risk of pain neglect and management. An early study by Stallard, Williams, Lenton, and Velleman, (2001) highlighted this, showing that while everyday pain in children with severe cognitive impairment is common, it is rarely actively treated. Development of tools such as the Checklist Pain Behavior tool (Duivenvoorden, Tibboel, Koot, van Dijk, & Peters, 2006), the Paediatric Pain Profile (PPP) (Hunt et al., 2004) and the revised Face, Legs, Activity, Cry, Consolability observational tool (FLACC) (Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006) have attempted to remedy this, and use various aspects of altered behaviours and non-verbal cues as indicators of the presence of pain in cognitively impaired children. The PPP in particular has been shown to be a valid and reliable instrument (Hunt et al., 2004, 2007) with demonstrated responsiveness in children with quadriplegic type cerebral palsy (Lundy, Doherty, & Fairhurst, 2009). Yet despite the development of such tools no study to date has attempted to ascertain the prevalence of pain in a representative series of these young people.

Thus the primary aim of this study was to provide a description of the pain experienced in a population-based sample of young people with severe forms of cerebral palsy. This includes pain report in cognitively impaired non-communicating children. Secondly, to describe how these variables relate to gross motor ability, musculoskeletal impairment, age, gender, CP type and general health.

2. Material and methods

Approval for the study was granted from the Office for Research Ethics Committees in Northern Ireland. Written informed consent was obtained from the parents/carers of children, assent was obtained from children (when possible), consent was obtained from adults, and process consent was obtained for adults unable to independently provide consent.

2.1. Study design

Prospective, population-based survey.

2.2. Definitions

Cerebral palsy and clinical subtypes were defined according to the Surveillance of Cerebral Palsy in Europe Collaborative Group guidelines (SCPE, 2000). The Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997) was used to

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