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## Assessing, recognising and managing pain and discomfort in children and young people with Cerebral Palsy

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### Introduction

Cerebral Palsy (CP) refers to a range of conditions characterised by impairments in the child's ability to move or control their movement; these impairments are caused by damage or lesions to the brain that usually occur before, during, or shortly after birth.

Across Europe, approximately 2 in every 1,000 live births are affected by CP, and CP is the most common cause of physical disability in children. Clinicians have typically focused on recognising and treating the motor problems that characterise this condition.

However, recent studies have highlighted that pain is a key factor that limits these children's ability to participate in everyday activities and optimise their quality of life.

### The prevalence and role of pain

Children with CP may experience increased tone or stiffness in the muscles, which can cause pain. Indeed, estimates from representative samples of children and young people with CP suggest that approximately 70% of the population had experienced pain in the previous week.

In a study where we linked administrative data with the Northern Ireland Cerebral Palsy Register, 61% of persons with CP aged between 4 and 31 had received pain medication between 2010 and 2014: This was significantly higher compared to the 51% of the general Northern Ireland population that received pain medication in the same period. These findings provide convergent evidence that pain-related issues are more prevalent and significant among people with CP.

***Assessing, recognising and managing pain and discomfort in children and young people with CP is of paramount importance in order to ensure they have opportunities to reach their developmental potential.***

Experiencing pain is not solely a distressing experience, but evidence also shows that it represents a significant obstacle for the developmental opportunities of children and young people with CP.

In particular, pain experienced during childhood may limit opportunities to take part in a range of key activities, such as school activities (e.g. taking part in lessons, or after-school clubs), or recreational activities (e.g. sports, arts and crafts, cultural events). Reduced participation in age-appropriate activities can in turn curtail developmental opportunities. Furthermore, pain is significantly linked with poorer quality of life in childhood and adolescence.

### When and how to assess pain

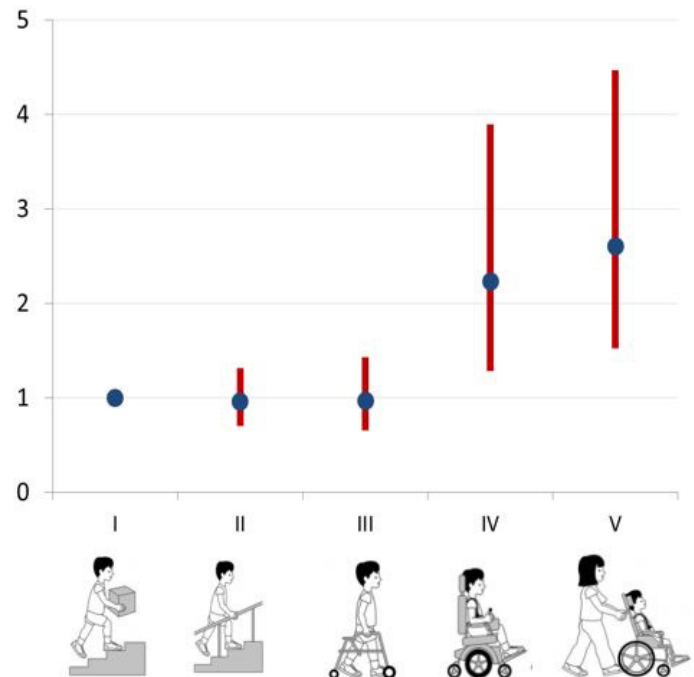
In recognition of the prevalence and role of pain among children and young people with CP, NICE guidelines recommend that pain and distress should be discussed at every clinical contact. Despite this, evidence shows that only over a third (36%) of paediatric outpatient organisations in the UK follow these recommendations and ask regularly about the presence of pain.

In community and disability paediatric organisations, this figure is marginally higher, with 41% of these organisations across the UK asking regularly about pain during consultations.

One of the obstacles in assessing pain among children and young people with CP lies in the fact that communication difficulties and cognitive problems may be present in this population. In particular, those with more severe forms of CP may be the most affected by pain, but are also those more likely to display significant communication and cognitive difficulties. Assessing pain in these children may be particularly challenging: pain may thus remain undetected and not treated among those that may be more severely affected by it.

***These results highlight that, unless addressed, problems and issues related to pain during key stages of development can hamper the wellbeing, development, and attainment of the children affected***

**Title: Dispensation of pain medication by severity of cerebral palsy**



**Legend: Adjusted OR (and 95% CI) of pain-specific medication (NSAIDs, opioid & non-opioid analgesics) for different levels of severity of cerebral palsy severity classified using the Gross Motor Function Classification System**

### Intervention

Once problems related with pain and discomfort are assessed, NICE guidelines recommend treating reversible causes of pain using specific and targeted intervention for the root problem.

However, in persons with CP the causes of pain may be complex and multifaceted, involving motor and muscle problems, other problems associated with the condition (e.g. gastro-intestinal problems), and psychological problems (e.g. anxiety and depression).

When pain and discomfort are linked to spasticity, NICE guidelines suggest the use of physical therapies to prevent pain. Oral drugs such as diazepam and oral baclofen are also recommended to manage pain. The use of pump-administered intrathecal baclofen is suggested whenever pain persists in spite of non-invasive treatments.

In our data-linkage study that looked at dispensed drugs between 2010 and 2014, people with CP were more likely to be in receipt of non-opioids, muscle relaxants, and axiolitics when they displayed more severe motor impairments. This evidences the complex needs of this population, and the variety of management options employed to treat pain and discomfort.

## Recommendations and Conclusion

The need to regularly assess pain and discomfort is paramount. To this end, the use of standardised tools to identify pain and assess its severity is crucial.

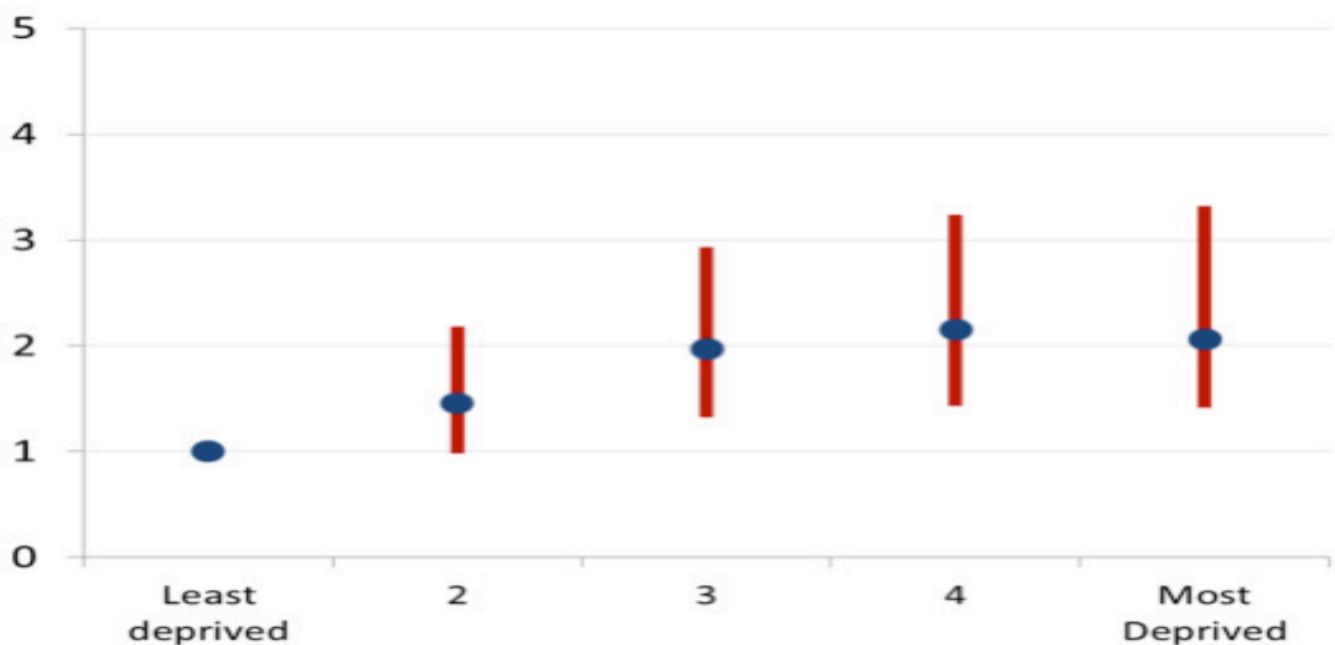
The choice of tools should be guided by the profile of communication and cognitive difficulties of the child. Different tools (e.g. the Paediatric Pain Profile, the Numeric Pain Rating Scale) have been developed and clinically validated among children with and without significant communication problems respectively.

The treatment of pain and discomfort also requires some understanding of the causes of pain: these can

be multi-faceted, and often are not just the result of spasticity and muscle tone problems. Multidisciplinary teams are therefore crucial in investigating these causes and in the subsequent management of pain. For example, NICE guidelines recommend monitoring the impact that psychological problems such as anxiety and depression have in moderating pain: these can be better assessed and tackled by psychology and mental health professionals.

In conclusion, pain experienced by children and young people with CP may limit their opportunities of developing and realising their potential: recognising and addressing pain early is critical to avoid long-term effects that can ultimately lead to failure to attain key skills, and impact on quality of life. Recognising and assessing pain in this population is a first necessary step, and professionals should strive to routinely implement the use of standardised and reliable measurement tools. Understanding the causes of pain and intervening on them requires concerted efforts by different professional figures liaising in multidisciplinary teams.

**Title: Dispensation of pain medications in people with cerebral palsy by deprivation quintile of residence**



**Legend: Adjusted OR (and 95% CI) of pain-specific medication (NSAIDs, opioid and non-opioid analgesics) by deprivation quintile (Northern Ireland Multiple Deprivation Measure 2010)**

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