

Can Parents Assess Dental Pain in Children with Cognitive Impairment?

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It is often said that the “gold standard” for pain assessment in both children and adults is verbal report. This means that the individual is best at describing his or her pain experience. This however does not take into account individuals who lack the ability to communicate their feelings including those with cognitive immaturity such as infants and very young children, people with cognitive impairment and adults with dementia. This is even complicated by the fact that children who experience the most pain are those who are least able to verbally describe it; those with greater physical and cognitive disability. This paper reviews past and current beliefs on the experience and expression of pain in children with cognitive impairment and how parents can be used as useful tools in diagnosing their pain.

Keywords: children, special health care needs, pain, cognitive impairment, parents.

J Clin Pediatr Dent 34(4): 313–316, 2010

INTRODUCTION

Since pain is inherently a subjective phenomenon, it is often said that the “gold standard” for pain assessment in both children and adults is verbal report.¹⁻³ That is to say that “pain is what people say it is”, or in other words, “the patient’s verbal report is the only way to determine the presence, intensity, and quality of pain.”⁴ This, however can be problematic for certain populations including infants, very young children, cognitively impaired individuals, and adults with advanced dementia. The difficulty in self- or verbal-reporting in these individuals has been the basis for the belief that these individuals were incapable of feeling or experiencing pain, or that they felt pain to a lesser degree than those who could self report, or that they felt pain but were indifferent to it i.e. pain did not cause them any suffering. It also lead to reduced pain assessment and management in these individuals.⁵ Until recently, newborns were considered to be insensitive to pain and were frequently not given analgesics or anesthetics during invasive procedures including surgery.⁶

One of the earliest references supporting the lack of pain

sensation in individuals with cognitive impairment (CI) comes from the work of Francis Galton (1907), the originator of the first intelligence test.⁷ In his observation of a group of individuals with profound intellectual disability Francis says:

“During a visit to Earlswood Asylum I saw two boys whose toe-nails had grown into the flesh and had been excised by the surgeon. This is a horrible torture to ordinary persons, but the idiot lads were said to have shown no distress during the operation; it was not necessary to hold them, and they looked rather interested at what was being done.”

The term *idiot* used by Galton, was described by his fellow eugenicist Davenport (1911) by saying “*at one extreme is the idiot, without language and incapable of attending to his bodily needs.*”⁸ Hence Francis’s observation was probably referring to individuals whom we describe today as having profound intellectual disability. Terminologies such as *idiots*, *morons*, and *imbeciles* have been used in the past to refer to children with developmental disability with each word referring to a specific level of function. These words became offensive and were subsequently substituted by severely, moderately, and mildly retarded. But these terminologies also became unacceptable over the years, and in the 1990s were changed to developmentally disabled.⁹ The latter is a generic label which includes conditions such as autism and cerebral palsy.

Developmental disability can refer to either mental or physical disability. Mental disability or what used to be called mental retardation is currently defined by the American Association on Mental Retardation (AAMR) as significantly subaverage intellectual functioning, existing

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concurrently with related limitations in two or more of the following adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work, manifesting before the age of 18 years.¹⁰ Mental disability may be referred to as Cognitive Impairment (CI), intellectual disability, or mental retardation.¹¹ A person's level of intellectual disability can be defined by their Intelligent Quotient (IQ), or by the amount of support they need. Mental retardation can result from a multitude of causes including prenatal, perinatal and postnatal, yet, in nearly 30-40% of cases no clear etiology is known. Some of the common conditions associated with mental retardation include genetic factors (Phenylketonuria and tuberous sclerosis), chromosomal abnormalities (Fragile-X and Down syndromes), maternal infections (rubella and syphilis), perinatal factors (brain injury and anoxia), and postnatal factors (malnutrition, meningitis, and encephalitis).¹⁰

According to the American psychiatric Association (APA) 2.5% of the population fulfill the definition of mental retardation, of which 85% fall into the range of mild mental retardation with an IQ of 50-70.¹² Children with mild mental retardation are considered educable and can learn new skills though at a slower rate than normal children. As adults, many of these individuals will blend into society and can start their own families. The remaining 15% fall into the range of moderate to profound forms and will require varying levels of assistance with their daily activities.^{9,13} Overall, mental retardation occurs more frequently in boys than girls with a ratio of 2:1 in mild mental retardation, and 1.5:1 in severe mental retardation.¹³

Children with CI form a heterogeneous group including those with cerebral palsy, Down syndrome, autism, Fragile-X syndrome and other conditions. These children often have higher rates of certain medical disabilities such as hearing, vision, orthopedic, motor, behavioral/ emotional, and seizure disorders compared to normally developing children.^{10,13} Generally, the greater the cognitive impairment, the greater the likelihood of associated chronic medical condition.¹⁴

Pain in developmentally disabled children

All children experience different kinds of acute and chronic pain in their daily lives. Children with developmental disability were until fairly recently thought to experience no pain, less pain than normal children or were believed to require the instilment of pain in order to learn and control their deviant behavior.¹⁵ In his article describing institutionalized individuals, Couston (1954) says that "*In these mentally defective patients there was a marked indifference to pain although some discomfort was felt in a few cases.*"¹⁶

It is currently believed that children with developmental disability generally experience more pain than normal children.^{17,18} Their experience however, may be underestimated or undervalued due to several issues. Since verbal-reporting of pain is still considered the "gold standard" for pain assessment, children with severe intellectual disabilities may

lack verbal communication skills and hence are unable to report their pain experience. Also, patients with cognitive impairment may have idiosyncratic behaviors such as moaning, grunting, and grimacing which may lead to overestimation of pain by those unfamiliar with the child.¹⁹ Therefore, the role of the parent or caregiver who knows the child is considered essential in assessing and reporting pain to the child's health care provider.

Children with developmental disabilities are believed to be more prone to painful events because of comorbid conditions associated with their disability or due to medical interventions necessary to monitor or treat the disability.²⁰ Also, in those who are mobile, there is greater risk for pain arising from accidental injuries.²¹ Breau et al (2003) found that the most common types of pain in children with intellectual disability included gastrointestinal discomfort (reported by 22%), pain related to infections (20%), musculoskeletal pain (19%), recurrent pains such as ear pain and diaper rash (13%), every day pain such as teething, menstruation and headaches (11%), and pain related to medical procedures including needle pricks, feeding tubes (13%).¹⁷ Unfortunately, it was found that children who experienced the most pain were those who were least able to verbally describe their pain; children with greater physical and cognitive disability.^{17,22}

Parents as proxies

Reliable description of pain may be difficult for children due to their cognitive immaturity and their inability to separate pain from fear and anxiety.²³ Children with CI frequently have the added challenge of not being able to express their pain or to verbalize it. Research shows that some children with CI can verbally express their pain.^{24,25} However, many cognitively impaired children may be non-verbal, have delayed speech development or difficulties with communications. This does not preclude the fact that these children can and do express their pain. Their expression however comes through a set of behavioral responses which are also common to normally developing children.²⁶ These behavioral responses may be detected by the parent, the caregiver, or the health care provider.

In their study of autistic children, Nader *et al* (2004) showed that these children displayed significant facial pain reaction in response to venepuncture procedure.²⁷ This not only refutes the common belief that autistic children have an altered mechanism of pain perception, but also shows that they respond to pain similar to normally developing children. Certain behavioral responses may even occur in infants at risk for neurological impairment. Stevens *et al* (2006) showed that there was a general consensus among pain experts that infants at higher risk for neurologic impairment generally showed more brow bulge, facial grimace, eye squeeze, and inconsolability.²⁸

The earliest reports of observable pain response in cognitively impaired children was reported by Reynell in 1965 in his observation of children with cerebral palsy.²⁹ In 1995 Giusiano *et al*, reported common pain behavioral responses

in a group of individuals with cognitive impairment aged 2–33 years living in a long-term care facility.³⁰ These behavioral responses to pain may include crying, mood changes, certain facial expressions, loss of appetite, aggressive behavior or change in socialization.³¹ In fact, some investigators showed that patients with CI exhibited more behavioral indicators of pain than normal individuals.³²

Multiple pain assessment tools have been designed and validated for the measurement of pain in cognitively impaired children including the Non-Communicating Children's Pain Checklist (NCCPC), the Paediatric Pain Profile (PPP), the Pain Indicator for Communicatively Impaired Children (PICIC), as well as others.^{33–35} These tools are designed to measure different sets of behavioral responses which are believed to be associated with pain in cognitively impaired children. Children demonstrate these behaviors or some of them to varying degrees.

These scales were developed to be used primarily by parents or caregivers who are familiar with the child's normal behavior in the absence of pain. The NCCPC however can be used by parents and researchers not familiar with the child but requires a long observation period by the researcher in order to detect some of the behavioral responses included in the scale. Some of the items parents are asked to rate include whether they have noticed the child moan, whimper, or cry, if the child has become less interactive with others, cranky or irritable, if there is a change in facial expression including frowning of eye brows, lack of smiling, clenching of teeth, if the child appears to be less active, floppy, eating less, or there is a change in sleeping pattern.

Parents and caregivers appear to have more difficulties assessing pain in developmentally delayed children than normally developing ones.^{36,37} Health care providers also face the same problem which may be due to lack of verbal ability owned by these children, or presence of idiosyncratic behavior such as moaning, grunting or grimacing which may lead to overestimation of pain.¹⁹

The literature is controversial regarding parental reporting of pain in children with CI. When parents of autistic children were asked to report pain in their children during a venepuncture procedure, results showed that there was more concordance between their reporting and the objectively coded response in the comparison group (non-impaired children) than in autistic children.²⁷ Whereas parents of children with mild to moderate CI report less pain in their children, parents of children with severe CI report more pain.^{17,36} Breau *et al* (2001) examined whether typical pain behavior as reported by caregivers of CI children can be used prospectively to predict future pain behavior. Their results showed seven significant behavioral indicators of pain including the child being cranky, seeking comfort, changing his/her eyes, being less active, gesturing to the part that hurt, having tears, and gasping.²⁶

Dental pain in children with CI

Children with CI may experience pain from a variety of sources, some of which are directly related to their illness

while others may be due to the medical procedures they undergo.^{17,18,20} Dental pain in children with CI is not an exception. Dental treatment has been reported to be the greatest unmet health need of the handicapped person.³⁸ Unless the child has some means of communication, it may be difficult for the parent as well as the healthcare provider to suspect pain or pinpoint its source in children with CI. Even when parents realize the existence of pain through verbal communication or change of behavior, they may not be able to localize it or trace it to a dental origin.

Studies show that children with disabilities have higher dental caries experience, unmet treatment needs, and prevalence of malocclusion, than those without disabilities.^{39–41} The dental treatment needs of children with disabilities may be more influenced by the functional ability of the child than the medical diagnosis.⁴² That is to say that children who are more independent performing their daily activities such as tooth brushing and toileting for example have less complicated dental treatment needs.³⁹ In their study of special needs children, Hennequin *et al* showed that there was a significant underestimation of dental treatment needs by parents and dentists suggesting that dental pain in this population was also underestimated.⁴³ Parents in this study reported difficulties localizing potential sites of pain unless obvious symptoms such as facial swelling or halitosis were present. This in turn has led to a delay of nearly 3.7 months in seeking dental consultation.

DISCUSSION

Current literature challenges previous beliefs about pain perception and experience in children with CI. These children are believed to experience pain similar (if not more than) to normally developing children despite their lack of ability to express their pain. Since dental pain may be an important source of distress to these children, we as dental care providers are encouraged to use all available tools to detect and understand the nature of pain in children with CI. This may require the utilization of verbal feedback from those who are able to do so, use parents and caregivers as proxies, as well as other available measures. Parents should be encouraged to look for behavioral cues indicating pain in children with CI and report them to their health care providers in order to look for possible underlying pathologies and provide immediate treatment and adequate pain management.

CONCLUSIONS

From this review we can conclude that:

- Children with developmental disabilities may experience more pain than normal children due to comorbid conditions associated with their disability or due to medical interventions necessary to monitor or treat the disability.
- Children with CI can express their pain either verbally or through certain behavioral responses which can be recognized by parents, caregivers or healthcare providers.

- Behavioral responses to painful stimuli may include crying, lack of appetite, gesturing to parts which hurt, facial grimacing or change in social behavior.
- The literature is controversial regarding parents' ability to report pain in children with CI. Whereas parents of children with mild to moderate CI report less pain in their children, those of children with severe CI report more pain.

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