PAIN ASSESSMENT TOOLS FOR THE CHILD WITH SEVERE LEARNING DISABILITY

Mary McKay and Sonya Clarke assess three validated tools to help nurses identify pain behaviours in this client group.

Abstract

This article aims to identify and critically review three pain assessment tools that have been recommended for use by the Royal College of Nursing (2009) in clinical practice for the child with severe learning disabilities. The tools are assessed and their application specifically to orthopaedic practice is discussed with a view to providing adequate pain relief for this group of children.

Keywords

Assessment tools, learning disability, orthopaedic surgery, pain

IN SEPTEMBER 2009 the Royal College of Nursing (RCN) published the Recognition and Assessment of Acute Pain in Children. These clinical practice guidelines were an update of the Pain Management in Children: Implementation Guide RCN (2001). In these guidelines, the RCN recognised pain and pain assessment in children and young people with cognitive impairment for the first time. In the literature, cognitive impairment is the preferred term, although nurses in the UK are more familiar with the term learning disability. This population of children and young people will be referred to as children with severe learning disabilities in this article. Orthopaedic surgery is classed as ‘severe’ when related to pain intensity (Goodarzi et al 1993), therefore pain assessment is fundamental in producing a positive pain experience after this type of surgery (Clarke 2003).

Literature review

The authors used the RCN’s (2009) guidelines reference list to review. The organisation had carried out a broad search on pain assessment, using all major databases. The search yielded significantly fewer studies for children with learning disabilities (n=256), than for children without learning disabilities (n=5,923). The authors carried out their own literature search for studies on pain and pain assessment in children with severe learning disabilities for the years 1998 to 2009.

Other literature relating to this topic was obtained through reading the studies already mentioned and scanning library journals until no new information could be found.

Nurses working with children are required to keep up to date with best practice in relation to pain management. The Nursing and Midwifery Council (NMC) (2008) code states that nurses must care to a high standard.

The National Service Framework for Children, Young People and Maternity Services (Department of Health, Department for Education and Skills 2004) states that healthcare professionals should be trained and competent to care for sick children. Evidence-based guidelines should be used to provide high-quality pain management using appropriate prevention, assessment and treatment.

Managing a child’s pain should involve the child. The Children (Northern Ireland) Order 1995 and Children Act 1989 recognise children’s welfare to be paramount and state that children with learning disabilities are vulnerable children. Also, children...
PAin Assessment tools for the child with severe learning disability
Literature review

with a learning disability, identified at an early age, should have access to good quality health care and treated as children first with the same rights to high quality health care as other children.

Children with severe learning disabilities have a higher risk of suffering pain as a result of different medical conditions and surgical procedures (Dowling 2004). Oberlander and O'Donnell (2001) recognised the unique pain experience among children with severe learning disabilities and stated that it is vital for nurses to understand pain to provide adequate and timely pain management. In a small study Stallard et al (2001) found it common for children with severe learning disabilities to experience pain every day. Pain can be associated with gastro-oesophageal reflux, contractures and epilepsy, and is rarely treated in this population. In the literature it is recognised that there are potential multiple sources of pain in this population; however, studies are limited on how these sources contribute to an individual’s pain, how to identify the source and effectively treat it (Vogtle 2009). Breau et al (2003) also found that children with severe learning disabilities experience frequent pain because of illness and those who experience the most pain are the children with the fewest abilities or with the most severe disabilities.

**Post-operative care**

Nursing a child post-operatively who cannot effectively communicate his or her pain is a source of frustration for the child and the nurse. Nurses may not be familiar with the child’s normal behaviour or the child’s behaviour when in pain, which makes pain assessment difficult. Further research is required to help parents and healthcare professionals diagnose pain when it occurs to improve the quality of life of children with severe learning disabilities (Breau et al 2003).

Pain and responses to pain are influenced by cognitive, developmental and cultural factors. Everyone’s pain experience differs. It is personal and unique to each individual and this factor impedes the measurement of pain (Abu-Saad 2000). Every child with a severe learning disability will experience pain differently. Accurate pain assessment is required so that appropriate pain relief can be provided (Stallard et al 2001). Nolan et al (2000) agreed that pain assessment in children with severe learning disabilities is difficult but also contended that it is expected that children will experience pain post-operatively. This should not be the case and every child should have a pain-free post-operative recovery following accurate assessment of pain with the appropriate analgesia administered following orthopaedic surgery.

Unrelieved pain following orthopaedic surgery is due to ineffective pain assessment (Clarke 2003). Less effective pain treatment can occur because of the difficulty assessing pain in children with severe learning disabilities. Another reason for this population receiving less analgesia is due to a belief that children with severe learning disabilities are indifferent or insensitive to pain (RCN 2009). Difficulties in recognising pain behaviours also mean that pain can easily be left unrecognised and untreated (Nolan et al 2000). Therefore it is imperative to use an appropriate pain assessment tool.

Effective pain management requires partnership with the child and his or her parents. As previously mentioned, children in this client group are at risk of poor pain management. In a small study, Carter et al (2002) explored how parents of children with severe learning disabilities assess and manage their child’s pain. Disturbingly, parents felt their children had learned to live with pain and accepted it as part of their lives, which places an emotional toll on them. Parents also expressed a common theme about how quickly they learned of their child’s pain behaviours through knowing their child.

Carter et al (2002) also found that parents felt that any pain assessment tool devised would have to be based on parental advice and assessment. Healthcare professionals would be unwise to disregard parents’ expertise in pain assessment of their children.

Self-report remains the ‘gold standard’ for pain assessment, however, this does not work in children who cannot communicate their pain (McGrath et al 1998, RCN 2009). Previously there has been a lack of valid and reliable pain tools for assessing pain in children with severe learning disabilities. The RCN’s (2009) three tools for use specifically with children with severe learning disabilities who cannot communicate their pain are: the Non-communicating Children’s Pain Checklist (NCCPC); the Face, Legs, Activity, Cry, Consolability (FLACC) tool and the Paediatric Pain Profile (PPP).

These tools are observer-rated behavioural pain assessment tools developed with the knowledge that children with severe learning disabilities do display predictable and observable behaviours (RCN 2009). Pain assessment tools need to be valid and reliable. Validity means that the tool should measure what it is supposed to measure, which in this case is pain, and a pain assessment tool is deemed reliable if it measures pain consistently (Polit and Hungler 1999).

All three tools have been validated for post-operative
use in a hospital setting, including post-operative orthopaedic surgery (RCN 2009).

Theoretical review
The NCCPC, which is an observational tool for assessing pain in children with severe learning disabilities, was initially devised using a 31-item checklist of behaviours found common to most children with severe learning disabilities (available at: www.aboutkidshealth.ca/En/Documents/AKh_Breau_everyday.pdf). In a study by McGrath et al (1998), semi-structured interviews were carried out with parents or caregivers retrospectively to describe their child’s behaviour during episodes of acute and chronic pain to create the checklist of behaviours.

These 31 behaviour items are divided into seven categories:

- Vocal.
- Social.
- Facial.
- Activity.
- Body and limbs.
- Physiological.
- Eating and sleeping.

This checklist requires validation before use. The 31 items were reduced to 30 with cringe, grimace being removed from the category of facial expression but the authors did not mention why. The NCCPC was found to discriminate between pain and calm consistently (Breau et al 2000) and could be used to predict future episodes of pain (Breau et al 2001). The authors of the tool recognised that pain at home could differ from post-operative pain and devised a checklist to assess pain specifically for children with severe learning disabilities post-operatively (Breau et al 2002). The NCCPC – Postoperative Version (NCCPC-PV) consists of a total of 27 behaviour items divided into six categories. The eating/sleeping category was removed due to fasting either pre- or post-operatively and analgesia may cause nausea and sleepiness (Breau et al 2002). Both the NCCPC and the NCCPC-PV have been found to show good psychometric properties; they are valid and reliable (RCN 2009). Application of the NCCPC-PV is reported to take ten minutes and be unproblematic when used at the bedside for a child who is unknown to the assessing nurse (Breau et al 2002). The NCCPC-PV gives a guide of scores indicative of mild, moderate and severe pain but no guidance about when or which type of analgesia should be administered.

The FLACC tool is a behavioural pain scale designed to be used at the bedside (available at: http://pain.about.com/od/testingdiagnosis/ig/pain-scales/Flacc-Scale.htm). Originally deemed valid and reliable for use in young children, its use has been extended to include children with severe learning disabilities (Voepel-Lewis et al 2002). This tool is comprised of five categories: face, legs, activity, cry and consolability, with three sub-categories for each with a score of zero to two. A score of zero indicates no pain and a maximum score of ten suggests severe pain. It has been reported that it is quick and easy to use, taking two to three minutes to complete, although it gives no guidance on when or which type of analgesia to administer. The FLACC tool was revised to include parents identifying unique pain behaviours for their child (Malviya et al 2006). The revised FLACC tool allows the tool to be individualised for each child, which may improve its reliability. Voepel-Lewis et al (2002) propose that to improve the precision of pain assessment in children with severe learning disabilities modification or adjustment of tools may be required.

Last, the PPP (available at www.ppprofile.org.uk) is a behaviour rating scale devised, developed and validated by Hunt et al (2004). PPP is a 20-item behaviour rating scale and is intended to be used as a parent-held record to be referred to in any setting. Using the PPP parents compile a detailed profile of the individual child’s pain-free behaviour and pain behaviour focusing on three current pain problems. A score for each of the 20 items ranges from 0 to 3. The minimum score is 0, showing no pain and the maximum score is 60, with a score of 14 and above indicating significant pain. This tool does not indicate a score where pain is serious and intervention is required.

The PPP is best used by someone who is familiar with the tool and the child, such as the child’s carer or parents. This tool should improve parents’ ability to identify pain behaviours and share their expertise with healthcare professionals. It would be of interest to find out their views on the compiling and upkeep of the profile.

Discussion
Ghai et al (2008) stated that effective pain management is more complex than simply choosing a pain assessment tool. Implementing a pain assessment tool requires education, healthcare professionals working as a team, documentation of outcomes and tool development. Pain tools require continuous work to ensure successful

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Implementation and quality care (Ghai et al 2008). However, recognition of pain and pain management are influenced by nurses’ attitudes and beliefs, and an understanding of pain is essential to be able to provide adequate analgesia (Oberlander and O’Donnell 2001).

In 1998 Hamers et al carried out a literature review that found nurses under-medicate children post-operatively, leaving their pain insufficiently relieved. Nurses’ knowledge, attitudes and beliefs were found to play an important role. Hamers et al (1998) also concluded that analgesia is often prescribed on a pro re nata (prn) basis, which means that nurses decide when analgesia is administered according to need and in doing so, sometimes leave administering analgesics for as long as possible.

Hamers et al (1998) made two suggestions: nurses’ assessment of pain should be standardised and there should be a standard prescription of analgesia for a fixed period of time and not on a prn basis. More than ten years later and some nurses still fail to deliver the best pain management to children post-operatively without fully knowing the reasons why (Simons and Moseley 2009).

Possible reasons found by Simons and Moseley (2009) are that nurses do not assess pain consistently or that administration of analgesia is not based on a systematic assessment. Also, nurses may not recognise their own lack of knowledge and may not feel the need to change their pain management practice. Simons and Moseley (2009) suggest that nurses undertake further education to enable them to identify pain and treat it appropriately, and to ensure that they provide children with evidence-based pain management.

Evidence highlights the great need to use a pain assessment tool specifically for children with severe learning difficulties. This population can easily get forgotten because of nurses’ lack of knowledge and understanding. Nurses need to remember they should be delivering best evidence-based practice (NMC 2008), also improving pain management (DH/DFES 2004), and children with severe learning disabilities have the same rights as all children.

Application of assessment tools

All three assessment tools are validated and fully involve parents. At present it is difficult to assess which pain tool would best suit current practice. The PPP is an excellent assessment of a child’s pain behaviours, showing different pain types and intensity, which could involve all healthcare professionals. Children with a learning disability should be identified at an early age with appropriate input from different healthcare professionals. Therefore, the child’s health visitor or community children’s nurse could introduce the PPP to parents. The PPP appears to be an invaluable guide to help parents systematically identify their child’s pain type and intensity. As Carter et al (2002) found, parents quickly learn their child’s pain behaviours. This tool could also enable parents to articulate their child’s pain to healthcare professionals so that their pain does not go untreated. If kept up to date, the PPP would be invaluable in any hospital admission to ensure nurses become familiar with a child’s pain behaviours and deliver effective pain management to minimise all pain experienced, as well as post-operative pain. The PPP appears to be the most comprehensive assessment tool and in an ideal world all children with severe learning disabilities should have one although, as previously mentioned, it would be of interest to find out parents’ views on compiling and keeping the profile up to date.

The NCCPC-PV is reported to take ten minutes to use at the child’s bedside and does not require the user to be familiar with the child (Breau et al 2002). The FLACC is also reported to be quick and easy to use, taking two to three minutes at the child’s bedside (Voepel-Lewis et al 2002).

Each of these pain tools appears acceptable, although it would require extensive staff training to ensure they are used quickly and effectively. Instead, the concept of the Individualised Numeric Rating Scale is appealing where parents grade their child’s pain behaviour on a scale of zero to ten (Solodiuk and Curley 2003), as a tool that incorporates parents’ assessment and description of pain. Nursing staff are familiar with the Numeric Rating Scale zero to ten for pain assessment, which could be used along with the NCCPC-PV or FLACC pain tools to give parents a guide for rating their child’s pain behaviour. This might result in an individualised pain tool that would be quick and easy to use, and would not require familiarity with the child or parental presence, which may give parents confidence to take a break and leave their child.

The first author of this article proposes that all three tools could be more effective if they were graded zero to ten similar to the INRS and Wong and Baker (1988) face rating scale as this numerical scale is commonly applied in children’s orthopaedic
units, thus causing less confusion and error about pain score/intensity. However, this would require assurance of validity and reliability. It would be beneficial to assess the beliefs and attitudes of the nursing staff on pain, assessment and assessment tools before implementing a pain tool.

Conclusion

Effective pain assessment of the child or young person with severe learning difficulties will continue to challenge the children’s nurse. No pain tool is considered ‘perfect’ but progress is evident through the work undertaken by the RCN (2009). This article suggests three validated tools are hypothetically available to the children’s nurse in orthopaedic practice where pain can be severe. Additional contributing factors that may affect successful pain assessment include the involvement of an effective pain management team, staff education, and the availability of the parent and nursing time to teach the preferred tool. Evaluation and the use of clinical audit can also play a central role.

References


Conflict of interest

None declared

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None declared