



Detecting pain in people with an intellectual disability

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Summary The assessment of pain in a person with an intellectual disability (ID) is often a difficult undertaking complicated by idiosyncratic reactions or vague descriptions. The person with an ID may also be unable to verbally communicate their discomfort. For the carer who knows the individual with an ID, knowing how they respond to painful stimuli assists the carer to detect new instances of pain. The emergency nurse is unlikely to have met the person with an ID and therefore detecting pain by observing behaviour or using self-report measures is unlikely to succeed. There have been some attempts to categorise behavioural responses to pain by people with an ID, however, they have not been developed into a useful assessment tool. Emergency nurses must therefore rely on the person who knows the person with an ID.

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Introduction

People who have an intellectual disability (ID) and who present to the emergency department (ED) with pain, need to be carefully assessed as they are more likely to have a pre-existing co morbidity which increases the likelihood of significant morbidity (Beange et al., 1995). However, determining the presence of pain in someone with an ID is difficult and often cannot be accomplished by the use

of self-reporting measures such as the visual analogue pain scale. It is therefore important that other means of pain assessment are investigated and the nature of pain in the person with an ID understood.

Assessing pain in the emergency department

Determining the presenting complaint of a person arriving in the ED and formulating a diagnosis are principal functions of emergency care which rely

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heavily on a history of the complaint, the person's report of their symptoms, interpretation of physical signs and interpreting behaviour (Vayda et al., 1973). Reporting painful symptoms and behavioural responses to pain are dependent on the patient's cognitive ability to describe the location and nature of the pain and to behave in a manner consistent with their description. This expectation is important to emergency nurses who use this information about a patient's pain to predict pathology and to provide adequate analgesia (Teanby, 2003).

Expected or normal pain reporting and behaviour

When a person has pain they are expected to behave in a manner that is consistent with the pain that they are suffering. Such expected behaviour might include grimacing, groaning or guarding. These are ways in which people communicate their pain to others around them (Labus et al., 2003). However, for many clinicians the gold standard of pain intensity assessment is the patient's self-report. This is based on the assumption that a self-report on a visual scale or by a verbal account of the pain intensity more accurately reflects the level of pain than direct observations of pain behaviours. A patient's description of their pain by using a visual analogue scale or by grading the intensity of their pain with a score between 0 and 10 is the usual method of determining pain in the clinical setting, rather than reporting on such behaviours as restricted gait, grimacing or groaning. For many nurses in the ED determining how much pain their patient has based on their behaviour would be perceived to lack objectivity and be prone to errors. Yet it is well known that when a person has significant amounts of pain their behaviour will reflect this. In order to provide a more accurate assessment of pain levels Labus et al. (2003) suggest that a combination of approaches amalgamating pain assessment through traditional pain scoring methods and observation of behaviour may be required. They base this assertion on a meta-analysis of the research that has attempted to correlate pain behaviour with self-reported levels of pain intensity. The idea that behaviours associated with pain can be formally categorised and assessed is a recent initiative in pain research. Labus et al. (2003) report that Keefe and Block in 1982 were amongst the first to systematically attempt this. Since that time there have been numerous attempts to reproduce this earlier work and expand on the concept that pain might be assessed from behaviour.

The meta analysis undertaken by Labus et al. (2003) was of 30 studies that attempted to correlate pain behaviour with self-reports of pain levels. It was concluded that interpreted descriptions of pain behaviour and self-reports of pain levels are more likely to be significantly related to each other when the individual has acute pain ($z\ 1/4\ 0:35$) and the data on self-reports of pain intensity is collected soon after the observation of pain behaviour (Labus et al., 2003). This finding has an important implication for ED nurses as this accounts for the majority of patients who report significant pain; it is acute and behaviour can be assessed at the time of self-reporting. For people with an ID this also has an important implication. Given that persons with an ID may not be able to use verbal communication and self-report their pain levels, this study suggests that these patients can have their pain assessed through direct observation and interpretation of their behaviour. The authors state that this is one of the compelling reasons to demonstrate reliable alternatives to self-reporting so that pain can be assessed and recognised in people with an ID as well as in infants. This assertion relies on two assumptions, ED staff are able to interpret behaviours associated with pain and that people with an ID will behave in a way similar to the subjects of this meta-analysis. However, there appears to be some evidence that people with pain who have an ID may not necessarily behave in a manner that is expected of someone with pain, even though the pain may be acute (Cheetham, 2001; Chivell, 2001; McGrath et al., 1998).

Idiosyncratic pain behaviour and pain in people with an intellectual disability who need emergency department care

There are reports that people with an ID have idiosyncratic reactions to injury and illness that complicates the process of establishing the presenting complaint and diagnosis. This is exemplified in a case study describing a man ('Ray') who normally exhibited marked obsessive compulsive behaviours, which included touching the doorway, flicking the light switch and then flushing the toilet in the same sequence repeatedly (Cheetham, 2001). However when injured and in pain with fractured ribs the obsessive compulsive behaviour was not evident so that he appeared to be cured of this disorder and yet he also gave no indication that he was in pain or discomfort. This prompted the man's carers to assess him more carefully and discover the injury to five of his ribs. In this case study it

was suggested that some people with ID appear to be without pain even with very significant injuries. In the past this observation has led to a misconception that people with an ID do not suffer pain, or have a reduced pain threshold.

A second example of idiosyncratic pain behaviour involves the case of Mr Saverio Gadaleta who was a 28-year-old man with cerebral palsy, spastic quadriplegia, and epilepsy. At the age of 26, he entered a residential care facility, where the staff described him as "incapable of verbal communication; a very happy and pleasant man who communicated with smiles and gestures" (Chivell, 2001, p. 1) One evening Mr Gadaleta gave staff the impression that he was suffering from abdominal pain and several hours later he was transferred to the local ED. At the triage desk he was given a triage category of three (indicating needs to see medical officer within 30 min). Three hours after arriving in the ED he suffered a cardiac arrest at which time he saw a medical officer for the first time. At autopsy it was determined that the cause of death was 'Peritonitis and septic shock complicating perforation of the terminal small bowel by a swallowed screw top lid of a Coca-Cola bottle' (Chivell, 2001). In this coroner's case the usual carers for this man described how during the period that peritonitis was developing he became "verbally aggressive, lying flat on the floor and refusing to stand". This abnormal behaviour was replaced later with quiet inactivity and when his abdomen was palpated he gave no impression of pain or guarding.

It could be argued that Saverio did exhibit predictable pain behaviours as this is what prompted his usual carers to notice that something was wrong with him and that the source of his discomfort was in his abdomen. However, he was incapable of self-reporting his pain and the level of his pain was not judged in the ED to reflect the seriousness of the subsequently fatal pathology. Perhaps this reflected an indifference to significant pain or that he was now so unwell that his behaviour was now consistent with reduced mentation as a result of reduced perfusion caused by sepsis.

Absence of pain in people with intellectual disability

In the instances of Ray and Saverio their usual behaviour was replaced by different 'abnormal' behaviour in the presence of pain. These responses were possibly misinterpreted and did not correlate with the usual response to significant pathology that would be expected to produce severe pain. In the case of Ray this may have been interpreted as an absence

of pain and when Saverio did not react to abdominal palpation he was possibly indifferent to pain.

The apparent absence of pain in a person with an ID may create two unhelpful responses from people assessing or caring for these people: a misconception that people with an ID have a decreased sensitivity to pain and a failure to notice behavioural changes consistent with having pain, as these may be subtle or different from an expected response. While it may be a common misunderstanding that people with an ID have a decreased sensitivity to pain there is some evidence that people with an ID have a significantly altered experience of pain (Biersdorff, 1994). There are also a very small number of individuals who are insensitive to pain who are broadly categorised under the label '*Congenital insensitivity to pain*'. In this category are currently five types of 'hereditary and sensory autonomic neuropathies' (HSAN) and in many of these types the gene responsible has been isolated (Nagasako et al., 2003). These disorders are usually associated with ID and all of them include nerve fibre pathology that can be observed under an electron microscope (Nagasako et al., 2003). This small group of people can be clearly identified and are unique in their circumstances. HSAN is rare and even in people with an ID the prevalence of this disorder is very unusual. While indications of the prevalence of this group of disorders are not available, a study in Saudi Arabia determined that only 2% of children with neuropathies had HSAN, this compared with Acute Guillain-Barre Syndrome with a prevalence of 45.1% (Koul et al., 2002). Given that the Guillain-Barre is a rare condition with an incidence of about 1.7 per 100,000 per year, (Alter, 1990) it can be assumed from Koul et al. (2002) that HSAN occurs at a rate 20 times less than this.

Pain indifference and pain insensitivity

The concept that individuals can be insensitive to pain has a pathological basis that comes from the understanding that these individuals are actually unable to sense pain due to impairment in pain signal transmission (Nagasako et al., 2003). People who are pain insensitive are distinct from individuals who have been characterised as indifferent to pain, in whom the perception of pain is present but it does not produce the expected affective response of aversion or withdrawal (Nagasako et al., 2003).

In a study of 123 individuals with developmental disabilities it was revealed that the pain threshold for slightly more than a quarter of participants was elevated and that if the person had a more

profound ID they were more likely to demonstrate signs of 'pain indifference' or 'pain insensitivity' (Biersdorff, 1994). Pain indifference was defined, as being able to distinguish sharp from blunt but these people did not find the sharp end painful (Biersdorff, 1994). Pain insensitivity, was described as being unable to determine sharp from blunt and also being unable to discriminate between temperatures (Biersdorff, 1994). Family members and carers who worked with the person assessed these symptoms; they completed survey forms asking them to describe the person's response to obviously painful experiences (Biersdorff, 1994). This small study, while highlighting that a large proportion of the small sample of 123 were less responsive to pain, also revealed that the majority of participants showed normal responses to pain.

While pain insensitivity and indifference may be more prevalent among people with ID than in the general population, the majority of people with ID are likely to show normal responses to pain. Biersdorff (1994) interviewed staff who cared for people with an ID to assess their responsiveness to pain. Her study revealed that 11% of people seemed to be overly sensitive to pain, 52% demonstrated a typical responsiveness, and 37% appeared to show some indifference. Out of this indifferent group, a significantly elevated pain threshold was apparent in 25% of them. This judgement about elevated pain thresholds occurred when informants reported that they had to be 'very observant' to detect when the person was in pain. The most important difficulty with this study was the reliance on subjective third person observations. However this is the central difficulty when assessing the amount of pain that someone with an ID has. Pain has always been difficult to assess even in the people who do not have an ID. In people without an ID, pain assessment relies on the person's cognitive ability to describe the nature, severity and location of the pain. Even in people with an ID and understandable speech the cognitive impairment of these individuals may make it difficult for them to localise and describe the pain. In a study of individuals with Down syndrome it was found that subjects expressed pain more slowly and with less precision (Hennequin et al., 2000). This study was conducted on 26 adults with Down syndrome who were compared to 75 controls; pain responses were elicited by getting participants to apply ice to their wrists and temples. This was an important study as it provided empirical evidence on the experience of pain in people with Down syndrome (Abu-Saad, 2000). However, it was a study in a more homogenous group of people who were able to use language to describe when a stimulus was painful and where it was painful.

It was not a study that could be applied to people with more profound ID who lack language skills.

Assessing pain in people with an intellectual disability

Prior to assessing pain in people with an ID there is a need to make a judgement about their cognitive abilities as people with more profound ID are less able to self-report pain intensity (Biersdorff, 1994). People with mild or moderate ID such as occurs with Down syndrome may be able to self-report pain. However, there is evidence to suggest that they are less accurate localising the pain, slower to acknowledge it and do not demonstrate recognisable pain behaviours (Hennequin et al., 2000). There is also some evidence from animal models that people with Down syndrome may have a decreased response to painful stimulation (Martinez-Cue et al., 1999). In these people caution needs to be taken when considering pain and its pathological cause as descriptions by individuals of their pain may be vague and as they have difficulty localising pain, it may also be misleading.

For individuals with more severe cognitive impairments in which speech is not possible, self-reporting of pain will not be a viable method of determining the severity and location of pain. In fact Davies and Evans (2001, p. 513) concluded that 'Pain assessment tools that rely on self-report are inadequate'. In assessing pain in these people it is important to realise that communication is often non-verbal and may occur through the use of more than one method (Davies and Evans, 2001). Unfortunately these methods of communication used to convey an individual's pain may be difficult to interpret, particularly to the nurse who does not know the person. It has therefore been proposed by Davies and Evans (2001) that assessment tools used for pre-verbal infants may be appropriate to assess pain in people with an ID who are non-verbal. This form of tool focuses on behavioural and physiological indicators of distress. While these tools that have been adapted for pre-verbal infants may be useful, they may not be valid when used with people who have an ID. McGrath et al. (1998) developed a list of behaviours in people with a cognitive impairment who were thought to have pain. From this descriptive list it may be possible to determine the presence of pain or with additional work construct a tool to assess pain in the person with a cognitive impairment who is also non-verbal.

Determining the presence of pain from the work of McGrath et al. (1998) would however be difficult given the internal contradictions, as someone who is

in pain can be: "jumping around" or "not moving", "sleeping more" or "sleeping less", "floppy" or "stiff" (McGrath et al., 1998). It is apparent that more work needs to be done to construct a pain assessment tool that can be used by someone not familiar with the person who has an ID. Currently pain investigation measures should not replace careful examination and sound clinical reasoning (McGrath et al., 1998). It would appear that the best available form of pain assessment is skilled clinical assessment combined with a familiarity and understanding of the person (Davies and Evans, 2001). This is difficult for ED nurses as they are unlikely to know the person with an ID who has presented to the ED and while frequently assessing people with pain, their skills are infrequently practised on people with severe cognitive impairments.

Conclusion

The assessment of pain is a vital role of ED nurses in order to provide comfort and determine the presence of illness. In assessing pain the nurse is expected to use a self-reporting measurement such as a visual analogue scale. It is also usual to observe and document behaviours that are consistent with the presence of pain, until now this has not been a formalised process. A recent meta-analysis (Labus et al., 2003) of research into pain behaviour has demonstrated a correlation between self-reporting of pain and pain behaviour. This correlation was most evident in acute pain that was assessed while the person was suffering pain or just after the pain occurred. The effectiveness of interpreting pain behaviour is dependent on an ability to recognise behaviour caused by pain. Unfortunately the person with an ID may be vague about the nature and location of their pain, or if non-verbal their behaviour may be idiosyncratic. Pain behaviours are unlikely to be consistent across the population of people with a severe cognitive impairment, which makes it difficult to construct a tool that can usefully determine the presence of pain. However, it is evident that people familiar with the person who has the ID and skilled in understanding their behaviour will be able to detect when they have pain. ED nurses need to use these people to competently care for their patients who have an ID and ideally they should accompany the person with an ID to the ED. Where this is not pos-

sible, detailed descriptions of how the person behaves when in pain should be provided. It is imperative that research be conducted, investigating what happens to people when they attend EDs in order to determine the most efficacious methods of pain assessment in people with an ID.

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