Identifying pain in people who have complex communication needs

People with learning disabilities have a shorter life expectancy than the general population and experience greater morbidity and preventable premature death (Heslop et al, 2013). Ill health in this group often goes undiagnosed and untreated (van Timmeren et al, 2017), with one contributing factor being diagnostic overshadowing, in which behaviour changes that could indicate a health problem are wrongly assigned to a person’s learning disability or autistic spectrum condition (Javaid et al, 2019).

Pain can be an important indicator of health problems – however, it is subjective and the experience and expression of pain is unique in every individual. Most pain assessment strategies rely on self-reporting, but identifying expressions of pain in people with limited and complex communication needs can be challenging. Some people with learning disabilities or autistic spectrum condition have minimal language skills and difficulty using non-verbal communication, such as gestures, eye contact or facial expressions. This can make it hard for them to say when they are in pain, or to explain the location, nature and severity of that pain.

McGuire et al (2010) suggested that pain, like ill health, may be “under recognised and under treated”, especially in those who have difficulty communicating. Although a learning disability or autistic spectrum condition can affect a person’s ability to understand and express their pain, it does not mean they experience no discomfort; rather, it is a case of carers and professionals not identifying cues and behaviours that indicate pain (Rothschild et al, 2019).

There is a misconception that people who have learning disabilities have a higher pain tolerance than their peers. This can be true for a small percentage of those with impaired neural pathways, but others may have increased sensitivity to pain. Research by Doody and Bailey (2017) suggests people with learning disabilities are more likely to experience frequent and severe pain than the general population. This can have serious consequences because these individuals are at higher risk of developing health conditions that...
cause pain (NHS Health Scotland, 2017). As life expectancy in people with learning disabilities increases, diseases of old age and the pain and discomfort associated with these conditions become increasingly prevalent in this group (Kinnear et al, 2018).

**Pain assessment**

In some cases there may be evidence of chronic pain but distress in people with learning disabilities can sometimes be misinterpreted as 'just the way the person is', or explained away as 'they always make that noise' or have 'attention seeking behaviour' (Rothschild et al, 2019). Nurses and other carers may become desensitised to the signs that someone is in pain or discomfort, either because they are inadequately trained or because they wrongly assume that information about the person from other carers is evidence based. It is important not to make these assumptions and to consider the possibility that pain might be present, particularly in people who are immobile and unable to articulate.

There is a range of established tools for assessing pain (Burckhardt and Jones, 2003). These include:

- Verbal reporting tools that describe pain, such as the McGill Pain Questionnaire, as highlighted by (Melzack, 1975);
- Numerical description tools that rate pain by numbers according to severity, such as the Descriptor Differential Scale (Doctor et al, 1995);
- Picture-based tools that rate pain according to facial expressions that reflect how the person feels, such as Wong-Baker Faces (Wong and Baker, 2001).

Some pain assessment tools also use physiological observations of known signs of pain, for example:

- Facial expressions;
- Body language;
- Physical reactions like guarding, bracing or excess sweating.

Pain assessment tools are not always accessible for people who have learning disabilities or autistic spectrum condition, as they usually rely on abstract concepts that are difficult to understand. Observational assessment may also be difficult if people have altered physiological and behavioural responses to pain (Foley and McCutcheon, 2004). Nurses may find it particularly hard to judge whether responses such as crying or laughing are usual for a person who has complex, multiple or profound disabilities.

Pain assessment tools that have been designed or adapted specifically for use with people who have learning disabilities are mostly used infrequently or inconsistently; added to this, there is little validated evidence of their effectiveness. A combined holistic and person-centred approach is often needed for pain assessment, as in much of the care for people who have learning disabilities.

Identifying likely pain may involve consideration of a broad health and social assessment including:

- Physical and emotional signs and symptoms of wellbeing;
- Behavioural observations;
- Opinions of others who know the person well (Doody and Bailey, 2017).

This can be challenging for busy nurses and other health professionals who need to ensure their assessment and diagnosis is made quickly.

**Pain picture**

As an aid to nurses, a proactive approach has been developed for gathering key information about the patient and how that person responds to pain or distress (Moulter, 2015). This gives a person-centred pain picture, which can be used as part of any health consultation to:

- Improve assessment and diagnosis of possible pain;
- Allow early intervention.

The pain picture is based on common physiological and behavioural signs of pain, along with the family or carer's knowledge of that person when they are feeling well and when they are not. The nurse holds a discussion with the family, carer and/or others who know the patient well and focuses questions on how the patient has responded in past situations when pain and distress were thought to be present. The information obtained can then be used to create a detailed picture of:

- How the patient appeared and behaved during previous episodes of pain or distress;
- How this was managed and treated.

The information is matched against the Abbey Pain Scale (Abbey et al, 2004) to give an impact score that is linked to either acute or chronic pain, or a combination of both.

A traffic-light colour scheme is used to highlight the perceived severity of pain. Explicit nursing observations are added to information provided by the family or carer, and the patient's own experiences are sought where possible. The nurse identifies commonly used interventions known to be effective for that person; these can be range from pain relief (including

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**Box 1. Case study**

Mohammed Abad* was 23 years old and had multiple and profound disabilities. He lived in the family home and his mother, Khadija Abad, was his full-time carer. He attended a range of supported daytime activities three days a week, but was unable to mobilise independently and used a moulded wheelchair. Mr Abad needed 24-hour care and support, and had limited communication capabilities. All of his nutrition and medication was administered through a percutaneous endoscopic gastronomy tube.

Mr Abad was very frail. Throughout his life he had experienced life-threatening infections requiring hospital care, and he had been admitted to hospital 15 times during the previous 12 months. His mother was concerned that he was experiencing pain, but was unsure how to identify this and when to seek help. She agreed to help develop a pain picture, and her unique knowledge of him allowed her to describe him in detail. This information was used to create Mr Abad's pain picture, which is illustrated in Fig 1.

Following the introduction of the pain picture, Mr Abad had several bouts of ill health. His mother and family used the pain picture as a checklist to enable early interventions to be undertaken based on an overview of the combined observations; this reduced Mr Abad's number of hospital visits.

Mr Abad's GP added a copy of the pain picture to his health records alongside his health action plan and hospital passport. He also provided the family with a prescription for paracetamol suppositories and antibiotics to enable speedy treatment at home. The unique and complex descriptions in the pain picture gave Mr Abad a ‘voice’, while the graphical picture provided a simple profile that could be used by the GP and other health staff to decide whether Mr Abad could be in pain or was becoming unwell.

*Patient and family names, along with other identifying details, have been changed.

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**Clinical Practice**

**Review**

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**Fig 1. Pain picture – known indicators of pain for Mohammed Abad**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Family observation – normal</th>
<th>Family observation – pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin colour</td>
<td>Flawless mid-brown with slight glow</td>
<td>Lacklustre and sometimes mottled. Eyes appear sunken with very dark shadows underneath</td>
</tr>
<tr>
<td>Sweating</td>
<td>Not particularly sweaty, even in warm conditions. Skin can be quite cool to touch</td>
<td>Excess perspiration, especially hands and neck</td>
</tr>
<tr>
<td>Absence of contentment/facial expression</td>
<td>Very contented, smiles and laughs a lot. Very sociable and likes people. Watches people and animals, and is generally happy</td>
<td>Very quiet and withdrawn. Looks sad and does not watch people. Limited attempts to relate to others and is unsociable</td>
</tr>
<tr>
<td>Aggression</td>
<td>Occasionally rocks and gently bangs his ear, but no injury caused</td>
<td>Ear banging increases if he is in pain or unwell, and can be quite frenzied and frequent, causing redness and bruising</td>
</tr>
<tr>
<td>Breathing</td>
<td>Normal breathing, but is sometimes a little wheezy and gurgly</td>
<td>Becomes breathless and distressed, making loud wheezing sounds</td>
</tr>
<tr>
<td>Facial expression</td>
<td>Very smiley, happy, good eye contact, engaging</td>
<td>Looks down and avoids eye contact. Appears sad and distant</td>
</tr>
<tr>
<td>Behaviour (for example, eating, sleeping, behaviour patterns)</td>
<td>Sleeps well, usually from around 10pm until 7am. Has postural care supports in bed to improve body posture and help with breathing. Does not usually sleep during the day</td>
<td>Wants to sleep all the time, but is restless. Closes eyes and drops off wherever he is. Wakeful and restless at night, and sometimes cries and moans</td>
</tr>
<tr>
<td>Body tension</td>
<td>Quite relaxed</td>
<td>Increased tension. Can stretch legs in a tense way, but all changes are quite subtle</td>
</tr>
<tr>
<td>Increased vocalisation</td>
<td>Can be quite noisy, shouting and laughing. Uses a range of sounds. Can be quite loud, protesting at movement of limbs when he is moved out of his chair or bed</td>
<td>Vocalisation increases, with crying and moaning. Responds to sudden pain by screaming</td>
</tr>
<tr>
<td>Crying</td>
<td>Not when well and comfortable</td>
<td>Cries out, but usually no tears. Crying can be sustained for several minutes at a time, resulting in increased wheezing</td>
</tr>
<tr>
<td>Other</td>
<td>Likes to be in his wheelchair and able to engage with others</td>
<td>Does not like getting in wheelchair when unwell or in pain</td>
</tr>
</tbody>
</table>

### PAIN PROFILE

**Green**

Little or no pain identified. No need for extra clinical intervention; maintain interventions that reduce likelihood of pain

**Interventions:**
- General massage; rubbing of limbs and feet; likes lively music, especially the Kaiser Chiefs and Snow Patrol; enjoys being out and about with family and friends; hydrotherapy and physiotherapy

**Yellow**

Evidence of some pain. Consider pain relief, including therapeutic approaches known to be helpful (for example, massage, change of position, simple analgesia)

**Interventions:**
- As for green, plus 1,000mg paracetamol (soluble, administered through PEG), which should also be given if grumpy or unwell

**Red**

Evidence of significant pain. Provide pain relief as appropriate for the person

**Interventions:**
- As for green and amber. If vomiting or temperature raised administer 2 x 500mg paracetamol suppository (follow prescription guidelines for frequency, check dose against any soluble paracetamol already administered to ensure prescribed levels are not exceeded). Seek medical advice

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*The patient’s name has been changed.
PEG = percutaneous endoscopic gastronomy.*
prescribed and over-the-counter medications and remedies) to alternative soothing approaches, such as:
- Changing lighting levels;
- Introducing music or some form of distraction;
- Helping people to change their bodily position;
- Massaging affected areas of the body.

The pain picture also includes advice on when to seek additional medical help.

The case study (Box 1) illustrates how the approach was used for a patient with multiple and profound disabilities, while Fig 1 illustrates the pain picture for that patient, along with the traffic-light system and chosen interventions.

The tool in use
Once completed, the person-centred pain picture shows the likely indicators of pain, compared with indicators for when the patient is well. It is a helpful reference tool for nurses, GPs and other health professionals and is designed to sit alongside the patient’s health action plan and health passport. The pain picture can be easily updated if things change, but should be reviewed at least annually at the free health check they are entitled to if they are on their GP’s learning disability register.

When the GP or hospital team sees the person, the pain picture can help to identify the likelihood of pain being present. Clinicians can then look further for causes of pain and provide timely, appropriate treatment and onward referral as needed. Families can also use the pain picture in a structured approach to help identify changes early, thereby facilitating an early response and intervention, while also potentially reducing the need for hospital admissions.

Following the successful implementation of this approach by learning disability nurses in London, development of the pain picture was piloted in Shropshire. This generated positive feedback from families, paid carers and health professionals, showing the tool was of benefit and easy to use. Feedback on the tool is given in Box 2.

Summary
Pain assessment in people who have complex communication needs can be challenging for nurses. However, the possibility of pain being present must be considered rather than ignored, as it can be a useful indicator of underlying illness. Failure to provide relief to a person who has learning disabilities or an autistic spectrum condition, and who is likely to be in pain, can:
- Seriously reduce quality of life;
- Result in behaviours that other people find challenging;
- Affect the person’s relationships with others.

Learning disability nurses have enhanced communication and other clinical skills, so are well placed to enable the development of pain pictures, which can help support diagnosing pain for people with complex communication needs. The case study illustrates the pain picture’s use for a person with profound and multiple disabilities, but it can also be used for any individuals who are unable to effectively communicate that they are in pain.

Busy nurses in primary, acute and tertiary health settings may need help from others who know the patient well to identify whether pain might exist in someone with learning disabilities. Using the pain picture for reference gives health professionals well-researched, observational information, which has been gathered proactively with involvement from the family and others close to the patient.

“Research suggests people with learning disabilities are more likely than the general population to experience frequent and severe pain”

Scrutiny has increased around the provision of effective healthcare for people with learning disabilities or autistic spectrum condition. Nurses can use the pain picture as a reasonable adjustment, which can highlight the need for further investigation into the possible existence of pain and illness. NT

References