Debate & Analysis

Assessing pain in dementia:

tools or tacit knowledge (or both)?

INTRODUCTION

In the UK approximately 770 000 people are affected by dementia, with the prevalence predicted to rise to 1.2 million by 2040 as the population ages.[1] It is clearly important that GPs are confident in their treatment of people living with dementia.

Estimates of the prevalence of pain vary, but probably about 50% of people with dementia experience pain regularly.[2] This is understandable given that older patients are likely to have a variety of painful chronic comorbidities and when communication is compromised it becomes difficult to identify pain in people with dementia. Seminal studies suggested that pain in people with severe dementia has been under-recognised and under-treated.[3] In 2007, the National Institute for Health and Clinical Excellence (NICE)–Social Care Institute for Excellence (SCIE) guidelines on dementia suggested:

'If a person with dementia has unexplained changes in behaviour and/or shows signs of distress, health and social care professionals should assess whether the person is in pain, using an observational pain assessment tool if helpful. However, the possibility of other causes should be considered.'[4]

In recent years, there has been a proliferation of observational pain tools. A systematic review found 28 such tools, which had been studied in a variety of settings, and confirmed that *'no one tool can be recommended given the existing evidence'*.[5] The NICE–SCIE guidelines seem exactly right and go on to commend holistic assessment. They acknowledge the concern *'that pain assessment tools might detect distress caused by other factors'*.[4]

Our concern is that, despite the guidelines, (a) some practitioners might not see how assessment tools can be helpful and, contrariwise, (b) pain assessment tools might encourage other possible causes of distress to be overlooked.[6]

In this article, we use three case vignettes to illustrate both how objective and observational pain tools can be useful in assessing people with dementia and how they can be misleading. In discussing this we shall go on to make a point about the continuing importance of clinical judgement. The cases are based on real patients, but are anonymised.

> *"... pain assessment tools might detect distress caused by other factors."*

CASE VIGNETTES

Mrs Smith

Mrs Smith is a 92-year-old woman with a history of Alzheimer's disease and osteoarthritis. Her medication includes donepezil 5 mg daily and paracetamol 1 g four times a day. She lives in a residential home and uses a Zimmer frame to mobilise.

She was also prescribed a 10 mcg/hour buprenorphine patch, which had been started by a previous GP for pain. She was trialled without this, but became agitated and it was restarted. With time there were further behavioural issues such as spitting at or hitting staff members at her residential home when they were helping with personal care. Her score on an objective pain scale was high. Buprenorphine was increased to 15 mcg/hour and she seemed to be more mobile with no further episodes of aggression. At the same time her pain score went down.

Mr Pasha

Mr Pasha, at the age of 82 years, is a man with a diagnosis of vascular dementia. He has spent 30 years working as a building labourer. Shortly after admission to a care home, over the course of a week he became increasingly aggressive. Urinalysis was negative. A full review revealed that his regular analgesia for chronic back pain, caused by a crush fracture, had been omitted from his prescription when he was admitted. He had a high score on an objective measure of pain. He refused to take his medication by mouth. On the advice of the local palliative care team, lidocaine 5% medicated plasters were used until oral medication could be reinstated once he was less agitated. Mr Pasha calmed down almost immediately and a week later was willing to accept oral medication once more. His pain score also settled.

Mr Kowalski

Mr Kowalski has dementia with Lewy bodies. In the care home, during some meals he would become very distressed, agitated, and verbally aggressive towards those who sat with him. It was questioned whether he was hallucinating. The care team also considered that he might be in pain because, when agitated, he scored high on the observational pain tool. However, a member of staff then noticed that another man at his table was stealing Mr Kowalski's chips, which seemed to precipitate the aggression. A change of table settled the problem and the scores on the pain tool diminished.

DISCUSSION

These vignettes make the point that observational pain tools can be used as an adjunct to diagnosis and as a means to record change.[7] They also show that distress might have a number of causes, one of which is pain. So pain needs to be considered, but a high score on an observational pain tool is not diagnostic of pain.[8] A structured, thorough, holistic medical assessment — and, in complex cases, specialist help — will be useful; but it is also worthwhile and important to seek the views of care staff or family who know the patient well. When multiple carers are involved in a patient's care, a range of interpretations of potential signs of distress may be available and beneficial to consider. An observational pain tool can be useful in showing a reduction in signs of distress and can help to create a consensus as to its cause while demonstrating the effectiveness of the intervention.

> *"... a correct clinical judgment is based on a holistic assessment that is greater than the sum of its parts."*

"... at root there is clinical judgement based on the GP's most essential resource: their access to those who know the patient well and the GP's knowledge of the patient as a whole"

Deciding that someone is in pain and monitoring change in response to treatment, with or without the help of a pain tool, still requires clinical judgement. It might be tempting to think that such judgement functions simply like a highly refined pain tool, amalgamating discrete observations to form a more or less valid conclusion.

Of course we know that human judgement can err. Studies have shown, for instance, that nursing professionals, albeit (crucially) *'without further contextual information'*, are no better at assessing pain from facial expression than lay people.[9] Nevertheless, there are good conceptual grounds on which to think that a correct clinical judgement is based on a holistic assessment that is greater than the sum of its parts. And the ability to make holistic judgements is seen as the mark of expertise.[10] Regarding the observations as part of a whole picture, where judgements also have to be made about the informing contextual background, is also key. That background involves, however, shared understandings that it may not be possible to codify, as would be required for an objective tool.

This takes us into the territory of tacit knowledge, which is a notion derived from the work of Michael Polanyi (1891–1976). Space does not allow this to be pursued here (but see Hughes[11] and Gascoigne and Thornton[12]). Still, it is instructive to quote Polanyi:

'When we accept a certain set of pre-suppositions and use them as our interpretative framework, we may be said to dwell in them as we do in our own body ... They are not asserted and cannot be asserted, for assertion can be made only within a framework with which we have identified ourselves for the time being; as they are themselves our ultimate framework, they are essentially inarticulable.'[13]

In other words, we understand — as our background framework — that a certain sort of grimace is a smile, that a certain mien indicates contentedness, that a certain sort of soft noise is a moan. We cannot say why; these things just are the case. And against this background we place our understanding of pathophysiology, of history, of the reaction to specific injuries and drugs, and so forth. In this context of understanding, the results of an observational pain tool can be useful. But they do not provide the complete answer. Instead, crucially, at root there is clinical judgement based on the GP's most essential resource: their access to those who know the patient well and the GP's knowledge of the patient as a whole.

CONCLUSION

People living with dementia should not be left in pain. Observational pain tools can be useful in advanced dementia, but they must be used judiciously and always with clinical judgement.

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