

People with severe communication problems: pain or distress?

Comment

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A 56 year old man with severe learning disability was investigated for weight loss and found to have multiple liver metastases from an unknown primary cancer. His carers had noted he would laugh intermittently in a frightened way, similar to previous occasions when he had been distressed or in pain. Medical advice was sought for his pain, but the doctor did not feel he was distressed because of his laughter. The carers did not feel confident enough in their assessment to challenge this view. He died with good support from his carers but only paracetamol and a hot water bottle for his pain.

'Body-language' is most carers view of communication other than speech. The importance of such non-verbal communication is well recognised as is the observation that few carers have the skills to use it well.(Kacpere, 1971) Communication is more difficult when a person has difficulty expressing their choices and struggles to understand information. In addition, distress may show itself as silence or a reduction in activity. This is not surprising when it is recognised that suffering often produces loneliness and alienation from others.(Younger, 1995) Reduced activity may be wrongly interpreted as someone being quiet and content, while an increase in activity due to distress may be misinterpreted as a challenging behaviour. Not surprisingly, professional carers find it difficult to estimate the client's ability to communicate.(Purcell *et al*, 1991; Porter *et al* 2001; Banat *et al*, 2002) Carers can view a change in behaviour pessimistically as something that is unlikely to

change.(Whitehouse *et al*, 2000) Forty per cent of people with severe learning disability have challenging behaviours, (Ashcroft *et al*, 2001) and up to 45% are on antipsychotics drugs.(Ahmed *et al*, 2002; Ingram, 1991) It is not just clients that have communication problems, carers have a problem understanding their communication.

What are the distressing symptoms?

The frequency and severity of physical and psychosocial problems in advanced disease is very similar in cancer, cardiac disease, respiratory disease, AIDS, dementia and other neurological disease.(Addington-Hall *et al*, 1998; Edmonds P *et al*, 2001; Anderson *et al*, 2001) In a small series of people with dementia 81% had breathlessness, and 59% had pain.(Lloyd-Williams, 1996) A larger series of 170 people with dementia showed that they had needs comparable to cancer patients.(McCarthy *et al*, 1997) In a series of 105 elderly people who could not respond verbally, 78% had pain.(Simons and Malabar, 1995)

What is the language of distress?

Despite their communication difficulties, these people are communicating and this has been termed 'alternative communication'.(Glennen, 1997) However, there is a surprising lack of published research and observations on alternative communication.(Hunt, 2001; Tuffrey-Wijne, 2003) This is the case in adults, children and in a range of causes of communication difficulties. What literature exists has focused on pain. But there is a fundamental problem with this approach. There is no evidence to support assumptions that signs or behaviours caused by a physical cause such as pain are different to the signs or behaviour caused by psychological distress such as

anxiety. This is supported by the similarity between the signs and behaviours for pain and general distress (Table), and reflects the well established concept that pain is a complex experience that includes distress.(Craig, 1994; IASP, 1979) Much of the work claiming that pain can be identified has been in adults and children undergoing painful procedures, or in patients able to self-report pain. (Grunau, 1987; Grunau, 1990; Prkachin, 1992; Prkachin, 1994; Scott, 1999; Feldt, 2000; Manfredi, 2003) These studies lack the evidence that such observations can be transferred to other distressing situations. Hunt observed that the context in which the sign or behaviour was occurring was crucial if pain is to be differentiated from emotions.(Hunt, 2001) Hunt also acknowledges that ‘distinguishing cues of pain from other sources of physical or emotional distress can be difficult’. This means that when using pain tools in people with severe communication difficulties it is not possible to guarantee that pain is being measured rather than other causes of distress. Surveys of communicating patients show that 3 out of 4 patients with advanced disease will have pain.(Twycross, 2001) Consequently if a distress is interpreted as pain, treatment will succeed in up to three-quarters, giving the impression of a successful assessment. However, this misses the remaining 1 in 4 patients who had causes of distress other than pain, as well as concurrent causes of distress in the other patients with pain.

Clinicians continue to believe that pain assessment is a realistic goal in the presence of severe communication difficulties.(Simons, 1999; Astor, 2001) There may be many reasons for this. Evidence that pain in communicating patients can be under-diagnosed or ignored(Whitehouse *et al*, 2000) encourages the choice of pain relief as a worthy goal. It is understandable that carers want to identify a single symptom which can then be treated. In reality, there are many different types of pain, often with very different treatments. Just identifying ‘pain’ is only one step in helping a person in pain. The incorrect use of analgesics then risks further confusing the picture. Finally, distress may be perceived as too vague and therapeutically dissatisfying.

The concept of ‘comfort’ has been described as a state of ‘physical or mental well-being’.(Flaherty and Fitzpatrick, 1978) The opposing concept of ‘discomfort’ rather than pain was explored by Hurley and others.(Hurley *et al*, 1992; Kovach *et al*, 1999) Morse and her

colleagues questioned whether relieving pain equated with comfort.(Morse *et al*, 1994) They suggested that comfort remains central to effective care and is achieved by easing and relieving distress. Fullerton and her colleagues have used comfort as the baseline for assessing the unconscious, terminal patient.(Fullerton A, 2002) The reality is that distress is what the individual says it is, and without that communication it cannot be easily identified.

Features used to identify pain	Features used to identify distress
Aggression, wincing, holding head, protecting limb, moaning (Feldt and Warne, 1998)	Noisy breathing, absence of contentment, facial expression, body tension, increased body movement (IASP, 1979)
Quiet withdrawal, rapid blinking, improved vocalisation, refusing food, agitation (Mazinski, 1991)	Fidgeting, repetitive vocalisation, aggression, withdrawal, facial expression, increased body tension, noisy breathing (Hunt, 2001)
Facial expression (Grunau, 1987; Prkachin, 1992; Scot <i>et al</i> , 1999)	Reduced locomotor activity (van't Land and Hendrickson, 1995)
Guarding, bracing, rubbing, grimacing, sighing (Keefe and Block, 1982; Weiner <i>et al</i> , 1996; Hadjistavropoulos <i>et al</i> , 2000)	Autonomic changes (increased BP, PR, sweating, skin colour changes) (Weiner <i>et al</i> , 1996)
Crying, rigidity, withdrawal, increased body movement (Craig <i>et al</i> , 1984)	Facial appearance, vocalisation, skin changes, eye appearances, posture, habits/mannerisms, speech (Regnard <i>et al</i> , 2003)
Quality of non-verbal vocalisations (Baker and Kenner, 1993)	Facial expression, moaning, twitching, rigidity, tachypnoea, tachycardia, restlessness (Fullerton, 2002)
Autonomic changes (increased BP, PR, sweating, skin colour changes) (Stevens <i>et al</i> , 1995)	

Table: categories of features that have been used to identify pain or distress.

* from Northgate DisDAT pilot

How do you identify the cause of distress?

In considering symptoms in infants, Selekmán and Malloy observed that adult carers subconsciously identified ‘cues’.(Selekmán and Malloy, 1995) This corresponds to our experience that the recognition of distress seems to be an implicit act rather than one that is explicit. Cues have been viewed as ‘pieces of information which can be connected together to form patterns’,(Thiel *et al*, 1986) This pattern recognition has been a crucial step missing from much of the work to date on distress in people with severe communication difficulties. In palliative care this pattern recognition has been used since 1992 in producing clinical decision flow diagrams and protocols for communicating

patients with advanced disease, mainly cancer. (Regnard and Tempest, 1992; Regnard and Hockley, 1995; Regnard and Hockley, 2003) More recently, work has started to adapt these for people with severe communication difficulties (Regnard *et al*, 2002)

Although they may disagree about the meaning of cues, carers are able to pick up cues, (Porter *et al* 2001; Holmes, 1989), but the claim that care providers 'sense' patients' feelings is a less likely explanation. (Sundin, 2000) A major problem is that carers do not routinely document and monitor these cues (Porter *et al* 2001). The consequence is that carers are often uncertain about their interpretation of these cues. Identifying distress requires knowledge of the patient, the context in which it is occurring, knowledge of the population and knowledge of the science. These four knowledge groups correspond with those identified by Liaschenko and Fisher, and by Hunt. (Liaschenko *et al*, 1999; Hunt, 2001)

Three steps are needed to identify distress:

- 1) Documentation of the signs and behaviours in both content and distressed situations and the context in which they occur. This enables carers to clarify and record observations they already make.
- 2) A screening decision checklist This enables an initial decision to be made on the general cause of the distress.
- 3) Specific decision checklists for specific causes of distress that have been suggested by the screening checklist such as fear or pain These are used to narrow down general categories of distress to one, or a few, possible causes which then suggest a specific treatment.
- 4) Testing of the treatment and reassessment of the distress.

Conclusion

Research on distress in people with a profound learning disability has been sparse. Carers have lacked the means of articulating their intuitive sense that the individual has an unmet need. The difficulty in identifying distress is magnified when people move between care environments or come into contact with new carers. The use of pain or distress scoring tools in these patients is questionable when there is no evidence that

any single cause of distress produces distinct signs or behaviours. The concept of identifying distress, rather than pain, is an essential component of achieving comfort in people with severe communication difficulties. The key is to document the carers' existing skills in identifying distress, taking note of the context and then applying clinical decisions to identify the cause. Distress may be hidden, but it is never silent.

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