

People with severe communication problems: pain or distress?

Comment

Regnard C, Consultant in palliative Care Medicine (St. Oswald's Hospice and Northgate Hospital),
Mathews, D. Senior Nurse, Gibson L, Senior Physiotherapist (NHS Beacon Learning Disability Palliative Care Team,
Northgate Hospital, Northgate and Prudhoe NHS Trust)
Clarke C, Professor of Nursing Practice Development Research (University of Northumbria)

Key words

Communication methods, communication barriers, distress, learning disorders, pain, psychological stress, quality of life

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.

Acknowledgements

The Northgate DisDAT development team consists of Joan Gilmore (Carer representative), Christine Armstrong (Clinical Co-ordinator), Lynne Gibson (Senior Physiotherapist), Dorothy Matthews (Senior Nurse), Claud Regnard (Consultant in Palliative Care Medicine), Charlotte Clarke (Professor of Nursing Development Research Practice), Bill Watson (Senior Lecturer), Heather McVittie (Clinical Governance), and Pam Richold (Quality Officer).

The team is grateful to the NHS Beacon scheme for their financial support, and to the Northgate and Prudhoe NHS Trust for funding the evaluation research. Finally we would like to thank the staff of the Medical Centre at Northgate Hospital for contributing to the initial pilot of the Northgate DisDAT tool.

References

- Addington-Hall J, Fakhoury W, McCarthy M. Specialist palliative care in nonmalignant disease. *Palliative Medicine*, 1998; **12**: 417 – 427
- Ahmed Z, Fraser W, Kerr M, Kiernan C, (2001) Emerosn E, Robertson J *et al*. The effects of reducing antipsychotic education in people with learning disability. *British Journal of Psychiatry* **176**: 42-6.
- Anderson H, Ward C, Eardley A, Gomm SA, Connolly M, Coppinger T, Corgie D, Williams JL, Makin WP. (2001) The concerns of patients under palliative care and a heart failure clinic are not being met. *Palliative Medicine*. **15**(4):279-86.
- Ashcroft R, Fraser B, Kerr M, Ahmed Z. (2001) Are antipsychotic drugs the right treatment for challenging behaviour in learning disability? The lace of a randomised trial. *Journal of Medical Ethics*, **27**: 338-43.
- Astor R. (2001) Detecting pain in people with profound learning disabilities. *Nursing Times*, **97**: 38-39.

- Baird SM, Mayfield P, Baker P. (1997) Mother's interpretations of the behaviour of their infants with visual and other impairments during interactions. *Journal of Visual Impairment and Blindness*, **91**: 467-83.
- Baker A, Kenner AN. (1993) Communication of pain: vocalization as an indicator of the stage of labour. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, **33**: 384-5.
- Banat D, Summers S, Pring T. (2002) An investigation into carer's perceptions of the verbal comprehension ability of adults with severe learning disabilities. *Br J Dev Disabilities*, **30**: 78-81.
- Craig KD, McMahan RJ, Morison JD, Zaskow C. (1984) Developmental changes in infant pain expression during immunization injections. *Social Science in Medicine*, **19**: 1331-7.
- Craig KD. (1994) Emotional aspects of pain. In, , Wall PD, Melzack R, eds, *Textbook of Pain on CD-ROM*, 3rd ed. Edinburgh: Churchill Livingstone.
- Edmonds P, Karlsen S, Khan S, Addington-Hall J. (2001) A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. *Palliative Medicine*. **15**(4):287-95.
- Feldt KS, Warne MA. (1998) Examining pain in aggressive cognitively impaired older adults. *Journal of Gerontological Nursing*, **November**.
- Feldt KS. (2000) The checklist of nonverbal pain indicators (CNPI). *Pain Management Nursing*, **1**: 13-21.
- Fisher- Morris M, Gellatly A. (1997) The experience and expression of pain in Alzheimer patients. *Age and Ageing*, **26**: 497-500.
- Flaherty GG, Fitzpatrick JJ. (1978) Relaxation techniques to increase comfort level of postoperative patients: a preliminary study. *Nursing Research*, **27**: 352-5.
- Fullerton A. Examining the comfort of the unconscious patient.(2002) *European Journal of Palliative Care*, **9**: 232-3.
- Glennen SL (1997) Introduction to augmentative and alternative communication. In, Glennen ST, DeCoste DC, eds. *Handbook of Augmentative and Alternative Communication*. San Diego, Singular Publishing Group:. pp3-19.
- Grunau RVE, Craig KD. (1987) Pain expression in neonates: facial action and cry. *Pain*, **28**: 395-410.
- Grunau RVE, Johnston CC, Craig KD. (1990) Neonatal facial and cry responses to invasive and non-invasive procedures. *Pain*, **42**: 295-305.
- Hadjistavropoulos T, LaChapelle DL, MacLeod FK, Snider B, Craig KD. (2000) Measuring movement-exacerbated pain in cognitively impaired frail elders. *The Clinical Journal of Pain*, **16**: 54-63.
- Holmes S, Eburn E. (1989) Patients' and nurses' perceptions of symptom distress in cancer. *Journal of Advanced Nursing*, **14**: 840-846.
- Hunt A. (2001) Towards an understanding of pain in the child with severe neurological impairment. Development of a behaviour rating scale for assessing pain. PhD thesis. Manchester: University of Manchester,.
- Hurley AC, Volicer BJ, Hanrahan PA, Houde S, Volicer L. (1992) Assessment of discomfort in advanced Alzheimer patients. *Research in Nursing and Health*, **15**: 369-77.
- Ingram R. (1991) Learning difficulties and communication. *Nursing Standard* , **5**: 36-9.
- International Association for the Study of Pain (IASP) (1979) Pain terms: a list of definitions and notes on usage recommended by the IASP Subcommittee on Taxonomy, **6**: 249-52.
- Keefe FJ, Block AR. (1982) Development of an observational method for assessing pain behaviour in chronic low back pain patients. *Behaviour and Therapeutics*, **13**: 363-75.
- Kovach CR, Weissman DE, Griffe J, Matson S, Muchka S. (1999) Assessment and treatment of discomfort for people with late-stage dementia. *Journal of Pain and Symptom Management*, **18**: 412-9.
- Liaschenko J. & Fisher A. (1999) Theorizing the Knowledge that nurses use in the conduct of their work. *Scholarly Inquiry for Nursing Practice: An International Journal*; **13**: 29-41.
- Lloyd-Williams M. (1996) An audit of palliative care in dementia. *European Journal of Cancer Care*, **5**: 53-5.
- McCarthy M, Addington-Hall J, Altmann D. (1997) The experience of dying with dementia: a retrospective study. *International Journal of Geriatric Psychiatry*. **12**(3):404-9.
- Manfredi PL, Breurer B, Meier D, Libow L. (2003) Pain assessment in elderly patients with severe dementia. *Journal of Pain and Symptom Management*, **25**: 48-52.
- Mazinski LR. (1991) The tragedy of dementia: clinically assessing pain in the confused, non-verbal elderly. *Journal of Gerontological Nursing*, **17**: 25-8.
- Morse JM, Bottorff JL, Hutchinson S. (1994) The phenomenology of comfort. *Journal of Advanced Nursing*, **20**: 189-95.
- Nagasako EM, Oaklander AL, Dworkin RH. Congenital insensitivity to pain: an update. *Pain*, **101**: 213-219.
- Porter J, Ouvry C, Morgan M, Downs C. (2001) Interpreting the communication of people with profound and multiple learning difficulties. *British Journal of Learning Disabilities*, **29**: 12-16.

- Prkachin KM. (1992) The consistency of facial expressions of pain: a comparison across modalities. *Pain*, **35**: 71-78.
- Prkachin KM, Berzins S, Mercer SR. (1994) Encoding and decoding of pain expressions: a judgement study. *Pain*. **58**(2): 253-9.
- Purcell M, Morris I, McConkey R (1999) Staff perceptions of the communicative competence of adult persons with intellectual disabilities. *Br J Dev Disabilities* **45**: 16-25.
- Regnard C, Tempest S. (1992) *A Guide to Symptom Relief in Advanced Cancer. 3rd edition*. Manchester: Haigh and Hochland.
- Regnard CFB, Hockley J (1995) eds. *Flow Diagrams in Advanced Cancer and other Diseases*. London: Edward Arnold.
- Regnard C, Thompson JWT, Kindlen M, Matthews D, Gibson L, Jensen C. (2002) Diagnosing the cause of pain. In, *Regnard C, ed. CLiP (Current Learning in Palliative Care) 15 minute worksheets*. Abingdon: Radcliffe Medical Press.
- Regnard CFB, Hockley J. (2003) *A Clinical Decision Guide to Symptom Relief in Palliative Care*. Abingdon: Radcliffe Medical Press.
- Regnard C, Gibson L, Matthews D, Clarke C, Reynolds J, Watson B. (2003) Developing and validating a clinical tool to assess distress in people with profound communication problems. Poster presented at the 3rd European Congress in Palliative Care, April 2003.
- Scott CS, Riggs KW, Ling EW, Fitzgerald RN, Hill ML, Grunau RVE, Solimano A, Craig KD. (1999) Morphine pharmacokinetics and pain assessment in premature new-borns. *Journal of Paediatrics*, **135**: 423-9.
- Selekman J, Malloy E. (1995) Difficulties in symptom recognition in infants. *Journal of Paediatric Nursing*, **10**: 89-92.
- Simons W, Malabar R. (1995) Assessing pain in elderly patients who cannot respond verbally. *Journal of Advanced Nursing*, **22**:663-9.
- Stevens BJ, Johnston C, Grunau RVE. (1995) Issues of assessment of pain and discomfort in neonates. *Journal of Obstetric, Gynaecologic and Neonatal Nursing*, **24**: 849-55.
- Sundin K, Jansson L, Norberg A. (2000) Communicating with people with stroke and aphasia: understanding through sensation without words. *Journal of Clinical Nursing*, **9**: 481-488.
- Thiel J, Baltwin J, Hyde R, Sloan B, Strandquist G. (1986) An investigation of decision theory: what are the effects of teaching cue recognition? *Journal of Nursing Education*, **25**: 319-24.
- Tuffrey-Wijne I. (2003) The palliative care needs of people with intellectual disabilities: a literature review. *Palliative Medicine*, **17**: 55-62.
- van't Land CJ, Hendrickson CFM. (1995) Change in locomotor activity pattern in mice: a model for recognition of distress? *Laboratory Animals*, **28**: 286-93.
- Weiner D, Peiper C, McConnell E, Martinez S, Keefe FJ. (1996) Pain measurement in elders with chronic low back pain: traditional and alternative approaches. *Pain*, **67**: 461-7.
- Whitehouse R, Chamberlain P, Tunna K. (2000) Dementia in people with learning disability: a preliminary study into care staff knowledge and attributions. *Br J Learn Disabilities* **28**: 148-153.
- Younger J. (1995) The alienation of the sufferer. *Advances in Nursing Science*, **17**: 53-72.

