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Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT)

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Abstract

Background Meaningful communication with people with profound communication difficulties depends on the ability of carers to recognize and translate many different verbal cues. Carers appear to be intuitively skilled at identifying distress cues, but have little confidence in their observations. To help in this process, a number of pain tools have been developed, but this sits uncomfortably with the lack of evidence that pain has any specific signs or behaviours. A palliative care team working with people with intellectual disabilities developed the Disability Distress Assessment Tool (DisDAT) to document a wide range of signs and behaviours of distress and when an individual is content.

Method The tool was piloted with 16 carers and 8 patients. It was then assessed using quantitative and qualitative methods, employing 56 carers in routine clinical situations with 25 patients, most with severe communication difficulties. Carers of 10 patients participated in semi-structured interviews exploring the signs and behaviours demonstrated by patients when distressed and when content. These same 10 patients were observed for distress cues during different activities.

Results It became clear that distress did not have a common meaning among carers, but there was a clear understanding that distress did not just cover physical pain. The range of distress cues was wide, with no evidence that any cues were specific to particular causes. Although some distress cues were common between patients, each patient had a distinct pattern of distress cues. In addition, different carers identified a different range of distress cues, while the length of the relationship did not influence the number of cues identified. Most distress cues were a change from the norm, but some patients demonstrated distress as an absence of content cues. Carers found the DisDAT simple to use and useful, and several felt that DisDAT would have helped advocate for the patients in previous conflicts with clinical teams.

Conclusions There was no evidence that pain has any specific signs or behaviours. The preliminary and assessment phases showed that distress was a useful clinical construct in providing care. The DisDAT reflected patients' distress communication identified by a range of carers, and provided carers with evidence for their intuitive observations of distress.

Keywords dementia, distress, intellectual disability, pain assessment, palliative care

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Introduction

Distress may be hidden, but it is never silent.

Words can facilitate the engagement in social activities, form bonds of love, trust and security, communicate needs, and may convey embarrassment, forgiveness, distress and pain. However, people with an intellectual disability (ID) can have widely differing capacities for receiving, understanding, remembering and expressing their experiences through language. Meaningful communication with this group of people depends upon the ability of carers to recognize and translate a language of signs and behaviours. This has been called 'alternative communication' (Glennen 1997) and can be considered as a 'language of observable communication', or LOC, an abbreviation derived from an old-stage direction 'Loq.' from the Latin *loquitur*, meaning 'He/she speaks' (Regnard *et al.* 2003a).

Background

John Murdy (Murdy & O'Leary 1999), the manager of an ID medical centre in the UK, realized that the palliative care needs of his patients were not being fully met. His foresight and encouragement led to the establishment of a palliative care team for people with IDs. In addition to clinical outreach work, this partnership between palliative care and ID teams has explored new frameworks for issues such as resuscitation decisions (Regnard & Randall 2005), but identifying distress was a challenge from the start (Regnard *et al.* 2003b). There is a growing understanding that distress can be identified in people with little or no verbal communication by observing changes in their behaviour, posture and expression (Donovan 1997), but there is a surprising lack of published research on identifying distress (Hunt 2001; Tuffrey-Wijne 2003). A common experience of the team was that carers had the skills to identify distress but did so intuitively and lacked confidence in their observations. This corresponds to the observations that carers pick up distress cues subconsciously (Selekman & Malloy 1995). Most research in this area has tried to identify pain (Manfredi *et al.* 2003), but crucially, no published evidence supports the existence of specific behaviours and signs of pain (Regnard *et al.* 2003b). This suggested to the team that it was necessary to identify distress first, and then identify the cause of that distress. The team felt that there was a need to create a tool that would simplify the complexity of communication by documenting the intuitive observations of staff. An observation checklist was therefore devised, which took into account the signs and behaviours in both content and distressed states. This led to the development of the Disability Distress Assessment Tool (DisDAT).

Methods

The DisDAT was developed during a 7-year period in two phases. Each phase recruited patients with a severe ID who were resident or receiving care from the Northgate and Prudhoe NHS Trust, the largest trust for people with ID in England. Their carers were also recruited.

Preliminary phase

Up to six carers were recruited for each patient: the patient's named nurse, a keyworker, another health professional who saw the patient regularly (i.e. every few days), a health professional who saw the patient infrequently (e.g. once weekly or less often), a health professional who had never met the patient, and a relative. Each carer was asked to complete the DisDAT form based on his or her usual observations of the patients. The carer who did not know the patients was asked to look for distress cues documented in the clinical records. All the carers were given 1 month to complete the DisDAT forms and were asked not to discuss the completion of these forms with each other. Each patient's level of communication difficulty was assessed by the team using the Kidderminster curriculum communication scale for children and adults with a profound multiple intellectual difficulty (Jones 1999), adapted for this study by adding an extra level (level 0).

Assessment phase

Investigating DisDAT in practice

In order to investigate the use of this tool in practice, two DisDATs were completed independently by the named nurse and keyworker for 25 patients. From the sample of 25, 10 patients were chosen for detailed case studies. For each case-study patient, a total of four DisDATs were completed by the named nurse, a keyworker, an additional healthcare professional and a family member. Descriptive statistics were conducted on the data collated from these independent assessments, in order to explore different aspects of the use of the DisDAT in practice, including whether different carers identified the same signs and behaviours of distress in an individual, and how easy carers felt the tool was to use.

Investigating the construct of distress

For each patient included in a case study, semi-structured interviews were conducted with the named nurse, keyworker, additional healthcare professional and family member in each of the case studies. The aim was to unpack the construct of distress and identify its meaning for each of the carers (Robson 2002). The interviews explored each carer's understanding of distress, his or her beliefs about its causes and indicators, and the way that his or her particular patient expressed distress and contentment using non-verbal communication. The way in which familiarity of a patient influenced a carer's ability to pick up distress was a key theme within the interviews. Other issues were the examination of implicit knowledge and the identification of the process in which implicit knowledge becomes explicit knowledge.

Investigating a 'shared language' of distress

A series of non-participant observations (Robson 2002) were conducted for each case-study patient. The patients were observed for 10 min across each of four contexts (at rest, in social activity, in therapeutic activity and during mealtimes), using methods developed for the observation of non-verbal communication in children with severe IDs (Reynolds 2005). The observation schedule developed for the study contained eight mutually exclusive and exhaustive categories of signs and behaviours inherent in non-verbal communication (Bakeman & Gottman 1997), which are also featured in the DisDAT. The observer noted signs and behaviours that fell within these categories, and highlighted those the carer believed signified distress. When any sign or behaviour was noted, it was coded as either a distress or content cue. The frequencies and durations of these cues were noted, enabling comparisons both within and between patients. Patterns in distress cues observed for each patient were mapped across each context, enabling comparisons within and between patients.

Consent

Standard procedures of obtaining informed consent were followed, including gaining informed consent from professional and family carers to participate in semi-structured interviews. For patients, informed assent was gained from family carers to observe their relative, as professional and family carers agreed that the patients did not have the capacity to provide informed consent.

Results

Samples

In the preliminary phase, 16 carers and 8 patients were recruited. In the assessment phase, 56 carers and 25 patients were recruited, of whom 10 patients participated as case studies. The median age of patients in the assessment phase was 55 years, and 64% were male. All the patients had a severe ID, some with Down's and Alzheimer-type dementia. Most had profound communication difficulties:

- 1 (3%) was assessed at level 4 (able to communicate detail, qualify, specify and/or indicate opinions);
- 3 (9%) were assessed at level 3 (at best, able to ask for and anticipate their like or dislike of something);
- 9 (27%) were assessed at level 2 (at best, able to show that they want more, or have had enough of something);
- 17 (52%) were assessed at level 1 (at best, able to show that they like or do not like something); and
- 3 (9%) were assessed as level 0 (unable to show likes or dislikes).

Preliminary phase results

The DisDAT specifically identifies 77 changes in signs and behaviours with the option to add more (see Appendix). There was a median of 24 changes in signs or behaviours per patient during episodes when distress was present (range 10–30). A total of 61 changes was noted in all eight patients, which is 79% of the changes identified on the DisDAT. The collation of results from all the carers for each patient produced more distress cues than from a single carer, while reviewing the patient notes uncovered the fewest cues (Fig. 1). All the patients demonstrated at least one change in facial appearance, quality of vocalization (e.g. higher pitch) and autonomic skin changes (e.g. flushed skin). Changes in posture, habits, mannerisms or the appearance of the eyes were common. Facial appearance and the appearance of the eyes were the categories producing most agreement among the carers. Distress was usually associated with new signs and behaviours, but some patients were active and vocal when content, becoming silent and quiet when distressed.

Once the carers had used the DisDAT more than once, nearly all found it easy to use, and two-thirds found it useful and simple to use (see Table 1). Most found that they could complete the form at one sitting. Although some discussion between carers was inevitable, this was about the patient rather than about completing the DisDAT. Carers who saw the patients daily picked up the most changes, but carers with much less contact still managed to pick about two-thirds of changes (see Fig. 1). A trend was identified in the preliminary phase data, whereby different carers identified a common set of cues, with each carer identifying additional cues.

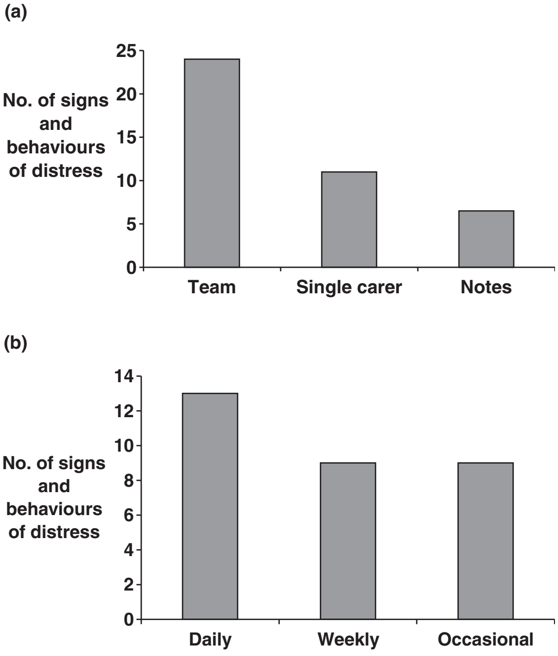

Figure 1 (a) Number of changes in signs and behaviours during distress observed by multiple carers, single carers or extracted from the patient notes (preliminary phase). (b) Number of changes in signs and behaviours during distress depending on the frequency of contact with the carer (preliminary phase).

Assessment phase results

What is distress?

The interview and DisDAT assessment data indicated that distress as a construct did not have a common meaning. Carers found it difficult to define what they meant by distress, and there were several different descriptions of what distress 'looked like'. Physical discomfort defined distress for 24% of carers. However, 76% of carers described a spectrum of distress, which included physical and emotional causes. For example:

> Well I think there are different types of distress. There is physical distress, psychological distress … you know and I think it means that something is not good, or you are not feeling very well, you know. (Nurse)

What are the distress cues?

Carers identified various vocal and non-vocal signs and behaviours as cues of distress. The structured observation confirmed many of these cues (see Table 2). The largest numbers of cues were in the area of the face and eyes, for both content and distressed states. However, compared with the content state, there was a sharp increase in the number of skin cues recognized during distress. A change from the norm was cited as a key indicator of distress. These changes could be new or a qualitative change in con-

Table 1 Carers' views of DisDAT on first and subsequent use (preliminary phase)

Understanding	Hard	Not sure	Easy
First use	44%	25%	31%
Subsequent use	0%	17%	83%
Simplicity	Difficult	Not sure	Simple
First use	67%	0%	33%
Subsequent use	17%	17%	67%
Usefulness	Not useful	Not sure	Useful
First use	6%	50%	44%
Subsequent use	0%	33%	67%

Table 2 Content and distress cues: rank order of most common signs and behaviours presented by patients when content and when distressed (assessment phase)

Content cues (signs and behaviours observed in patients when content)	Percentage presenting with these cues (%)	Distress cues (signs and behaviours observed in patients when distressed)	Percentage presenting with these cues (%)
Smile	80	Lifting hands to head	50
Vocalizes without prompting	70	Screams, wails	40
Relaxed body/face	50	Being withdrawn	40
Laughs	40	Becoming quiet	30
Respond vocally to social interaction	40	Groans	30
Bright eyes	40	Face bright red	30
Eye contact	40	Body rigid	30
Eyes moving around	30	Tearful/looks sad	20
Gesture towards social partner (spontaneous and response)	30	Being restless	20
Affectionate	30	Clenching/grinding teeth	20
Quiet	30	Grimace/face distorted	20
Sits straight/upright	20	Body slumped	20
Blows raspberries	20	Different tone in vocalization	20
Grimaces	10	Face rigid	10
Grinds teeth	10	Curling into themselves	10
Head upright	10	Not smiling	10
Involved in interactions/environment	10	Growling noises	10
Likes close proximity	10	Eyes widen	10
Content sighs	10	Increase in eye movement	10
Co-operative with interventions	10	Shallow breathing	10
Taps feet to music	10	Shortness of breath	10

tent cues. Therefore, the absence of content signs or behaviours could be an indicator of distress.

Are distress cues specific to the individual?

All carers expressed the view that each person had unique ways of showing that he or she was distressed, but many cues were shared. Data collated from the structured observation of patients confirmed a set of distress cues specific to each individual, with shared elements across individuals. For example, each individual had his or her own specific vocalization, which was unique to him or her. However, many individuals altered the pitch, tone or duration of their vocalization when distressed, and it was this change that was a common indicator of distress across many individuals.

Are distress cues specific to the cause of distress?

Some carers were able to recognize situation-specific distress cues. However, the majority of carers noted that the communication was non-specific, and described a process of looking through an 'A–Z' of possible causes in order to interpret the causes of the distress communication. The observational data showed that each patient varied his or her levels of distress within each situation and across each situation, demonstrating the patient's lack of situation-specific cues. The patients were observed to produce 'signature' cues which indicated their distress, but which did not suggest the cause of this distress.

Early distress cues

Some carers highlighted the accumulative impact of distress. For many patients, distress was described as building in stages, to a final state of maximum distress. At each stage leading to the final distress state, the individual was reported to display 'indicator' cues. Those familiar with the individual recognized these as early indicators of distress and could ameliorate the cause of distress at an early stage, thus preventing the final distress state. For example, one patient was reported to make good eye contact when content, and produce over-exaggerated eye contact with staring eyes when distressed, but an early sign of distress for him was the loss of eye contact.

Does knowing the patient make a difference?

Carers indicated that knowledge of, and familiarity with, the individual was necessary in order to detect early distress cues, whereas someone who was unfamiliar with the individual may well only recognize distress at the final stage. One mother explained the accumulative impact of distress in her daughter:

> She gets distressed on her own … once she's gone through the process of 'I am now alone, I am fine. Now I'm feeling uncomfortable, where is … [whoever is looking after her at the time]. Where have they gone?' Then I think you get panic before you get distress … You go through a lot of stages before you get distressed. I've never seen anybody become instantly distressed. (Relative)

In contrast, the length of relationship was not found to influence the number of signs identified using the DisDAT. Infrequent contact could be an advantage by allowing gradually developing changes to be more easily noticed.

Are there differences across the carer groups?

The data showed notable differences in the number of communication cues elicited by different categories among the 56 carers (see Fig. 2). Each carer recognized different numbers and types of cues, with the named nurse and additional healthcare professional reporting the highest number in DisDAT assessments, and the named nurse and keyworker noting the highest number of cues in the interviews. Although the number and type of cues identified varied across carer groups, there was a core of cues that was recognized by all carers. This identification of a common set of cues supports the existence of a signature set of cues in each individual that is recognized by all carers.

Is DisDAT a good idea?

Carers recognized the necessity and importance in formally documenting an individual's signature cues, and agreed that the DisDAT was particularly useful in achieving this aim. The majority of respondents (72.7%) found the tool either useful or very useful, with 27% unsure. Both professional and family carers recounted episodes where they have acted in an advocacy role for their relative or patient, particularly in general hospital settings, and where the DisDAT would have aided their explanation of the person's idiosyncratic behaviours. A high proportion of carers (63.6%) reported that the DisDAT was either simple or very simple to use, while just under a third of the sample said that they were not sure (Table 3). A small proportion of the sample said that they found the DisDAT very difficult to use.

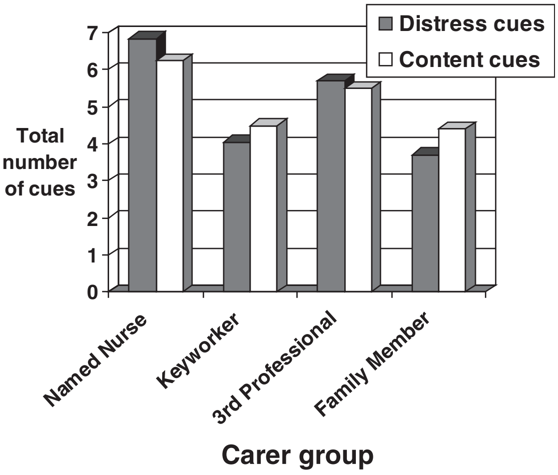

Figure 2 Representation of the difference in cue recognition (face, tongue, jaw, eyes and skin) between carer groups (assessment phase).

Discussion

The frequency and severity of physical and psychosocial problems in neurological disease is the same as in cancer (Simons & Malabar 1995; Lloyd-Williams 1996; McCarthy *et al.* 1997; Addington-Hall *et al.* 1998; Anderson *et al.* 2001; Edmonds *et al.* 2001), and yet strong analgesics are prescribed less often in elderly people with cognitive impairment (Semla *et al.* 1993; Bernabei *et al.* 1998), even when a clear cause of pain such as a hip fracture is present (Morrison & Siu 2000). However, in the absence of an obvious cause of pain such as a hip fracture, it is unclear in many of these surveys whether the distress identified was due to pain (Scherder *et al.* 2005).

Table 3 Carers' views of the simplicity of DisDAT (assessment phase)

	Not answered		Not sure		Simple		Very simple		Total	
Carer category	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
Named nurse	0	0.0	7	29.2	16	66.7	1	4.2	24	100
Keyworker	2	11.8	5	29.4	10	58.8	0	0.0	17	100
3rd professional	1	12.5	3	37.5	3	37.5	1	12.5	9	100
Family member	0	0.0	2	33.3	4	66.7	0	0.0	9	100
Total	3	5.5	17	30.9	33	60.0	2	3.6	56	100

Is it pain?

The lack of published evidence that pain has reliably specific signs or behaviours sits uncomfortably with the increasing number of pain tools developed for people with communication difficulties such as dementia (Hurley *et al.* 1992; Kovach *et al.* 1999, 2002; Wary & Doloplus 1999; Lefebvre-Chapiro & the DOLOPLUS Group 2001; Breau *et al.* 2002; Scherder *et al.* 2003; Villanueva *et al.* 2003; Warden *et al.* 2003; Abbey *et al.* 2004; Fuchs-Lacelle & Hadjistavropoulos 2004; Snow *et al.* 2004).

There are four major concerns with such tools:

1 There was no evidence in this study or in the published literature that any one cause of distress reliably produced specific signs or behaviours in this group of patients. This suggests that, rather than attempting to identify a specific cause of distress such as pain, identifying global distress is the only possible starting point. In patients with severe communication difficulties, it is probable that existing pain tools are, in reality, distress tools.

2 It is common to include autonomic changes in pain tools (e.g. sweating, pallor, pulse and blood pressure). However, in Alzheimer's disease, of which there is a high incidence in Down's syndrome, there is evidence that autonomic responses to pain are reduced (Rainero *et al.* 2000; Benedetti *et al.* 2004). Also in dementia, pain can be expressed in less obvious or atypical ways (Herr & Decker 2004), and it has been observed that there is greater language impairment in Alzheimer's than in the vascular dementias (Lindeboom & Weinstein 2004).

3 Many pain tools have been validated for pain in advanced dementia. However, a pain tool will correctly identify pain in many patients, not because the tool is specific for pain, but because pain is so common in advanced diseases.

4 Using pain tools in people with severe communication difficulties encourages the indiscriminate use of analgesics. On learning that a patient has pain, no palliative care or pain clinician would start an analgesic without first ascertaining the likely cause or causes of the distress (Regnard & Hockley 2004). If analgesics are given for a cause of distress other than pain, there is a real possibility that the resulting sedation will create the false impression that pain was the cause of the distress.

Identifying distress

Professionals already find it difficult to estimate the communication ability of a person with an ID (Porter *et al.* 2001; Banat *et al.* 2002), and view behaviour changes pessimistically as a part of disease progression that is unlikely to change (Whitehouse *et al.* 2000). When professionals try communicating with comatose or aphasic patients, they have difficulty in understanding the process, but they realize its importance (Baker & Melby 1996; Elliott & Wright 1999; Sundin *et al.* 2000; Sundin & Jansson 2003). Although some patients have profound communication difficulties, it seems that professional carers have just as many problems understanding their patient's communication.

Little work has been conducted on distress, perhaps because it is believed to be too vague to be useful. Comfort has been described as a state of 'physical or mental well-being' (Flaherty & Fitzpatrick 1978), and the concept of comfort has been used to assess the unconscious terminal patient

(Fullarton 2002). The opposing concept of discomfort has been explored in dementia (Kovach *et al.* 1999). Morse *et al.* (1994) suggested that comfort is at the core of effective care and is achieved by relieving distress. There is little difference in the literature between the signs and behaviours of pain and those of distress (see Table 4), but this should not be surprising as pain is a complex experience that includes distress (IASP 1979). In addition to distress cues, it is essential to document changes in cognitive behaviours and activities and the context in which they are occurring (Scherder *et al.* 2005).

In this study, patients demonstrated a surprisingly high number of distress cues that carers could easily identify and document, usually by contrasting them with content cues. In some patients, the main change was an absence of content signs and behaviours through silence or reduction in activity. These changes are important because a reduction in activity may be misinterpreted as contentment, while an increase in activity due to distress may be misinterpreted as a challenging behaviour. Up to 45% of people with ID in hospital and up to 20% in the community are on antipsychotic drugs for challenging behaviours (Ingram 1991; Ahmed *et al.* 2000).

The different cues noted by each carer in this study may be explained by the different relationship that each carer had with the same individual. This suggests that different carers pick up different elements of the patient's distress communication and inter-observer variation in observations has been observed in experimental studies (Hogg *et al.* 2001). Alternatively, each carer may have perceived the individual uniquely, and different cues may have a different meaning to each carer. Another explanation may be that the DisDAT uses an objective and rather clinical language, and the carers who reported the highest number of cues may be those who are more familiar with the adjective used or with clinical assessment tools in general. A fourth explanation may be that certain carers needed fewer cues to recognize that their relative or patient is distressed, and therefore reported fewer cues within the DisDAT assessment.

This study found that each patient has his or her own language of distress. Some distress cues were common across patients and were recognizable as distress cues by all carers. Individual carers were found to observe additional cues. These findings suggest that tools covering only the common cues will miss distress cues from an individual patient. It is also suggested that tools based on scoring systems are inappropriate because a standard level of distress or content cues cannot be ascertained. This supports the

Table 4 Signs and behaviours that have been described in the literature to identify pain or distress

Signs and behaviours indicating pain	Signs and behaviours indicating distress
Aggression, wincing, holding head, protecting limb, moaning (Feldt & Warne 1998)	Fidgeting, repetitive vocalization, aggression, withdrawal, facial expression, increased body tension, noisy breathing (Hunt 2001)
Quiet withdrawal, rapid blinking, improved vocalization, refusing food, agitation (Mazinski 1991)	Reduced locomotor activity (van't Land & Hendrickson 1995)
Facial expression (Grunau & Craig 1987; Prkachin 1992; Scott *et al.* 1999)	Autonomic changes (increased blood pressure or pulse rate, sweating, skin colour changes) (Weiner *et al.* 1996)
Guarding, bracing, rubbing, grimacing, sighing (Keefe & Block 1982; Weiner *et al.* 1996; Hadjistavropoulos *et al.* 2000)	Body posture (Coulson 2004)
Crying, rigidity, withdrawal, increased body movement (Craig *et al.* 1984)	Tone of voice (Rothman & Nowicki 2004)
Quality of non-verbal vocalizations (Baker & Kenner 1993)	Changes in facial appearance, vocalization, skin colour, sweating, eye appearances, body posture, habits/mannerisms, speech (this study)
Autonomic changes (increased BP, PR, sweating, skin colour changes) (Stevens *et al.* 1995)	
Noisy breathing, absence of contentment, facial expression, body tension, increased body movement (IASP 1979)	

decisions to (1) make the DisDAT a tool that documents any observable distress or content cues; and (2) avoid using a score to decide whether distress is present. The DisDAT has the option of monitoring sheets, which provide a score, but only as a means of monitoring change.

Observation and interview data emphasized the existence of early indicators of distress, an important finding for two reasons. First, it suggests the possibility of being able to manage early distress before it becomes severe. Second, it suggests that the nonverbal vocabulary of distress is much larger than previously thought, as it includes early distress cues in addition to severe distress cues.

What comes after identifying distress?

The context in which distress occurs is important in identifying its cause. This highlights the need for clinical decisions, and a clinical decision checklist now forms part of the DisDAT (see Appendix). 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 patients with advanced diseases who are able to communicate using verbal language (Regnard & Tempest 1992; Regnard & Hockley 1995; Regnard & Hockley 2004).

Conclusion

The DisDAT was developed from the principle that the specific symptom of pain cannot be identified in people with severe communication difficulties; therefore, it makes no assumptions about the cause of the distress. The DisDAT documents a wide range of signs and behaviours in both content and distressed states. Documenting these cues increases carers' confidence and enables them to identify possible causes. Monitoring sheets allow repeated observations to be made to monitor a therapeutic intervention. The DisDAT empowers carers to have more confidence in their observations of distress, and provides a means of identifying the cause and then monitoring the effects of treatment. It may have applications in any patients with severe communication difficulties.

Carr (1997) advocates that, 'Those who have problems expressing their own discomfort need to be recognised, they must also have skilled understanding and trust'. It is our duty and every patient's right for this understanding and trust to be provided. This study has suggested that it may be possible to change the identification of distress from an implicit skill to an explicit observation.

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References

Abbey J., Piller N., De Bellis A., Esterman A., Parker D., Giles L. & Lowcay B. (2004) The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. *International Journal of Palliative Nursing* **10,** 6–13.

Addington-Hall J., Fakhoury W., McCarthy M. (1998) Specialist palliative care in nonmalignant disease. *Palliative Medicine* **12,** 417–27.

Ahmed Z., Fraser W., Kerr M., Kiernan C., Emerosn E., Robertson J., Felce D., Allen D., Baxter H. & Thomas J. (2000) 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 S. A., Connolly M., Coppinger T., Corgie D., Williams J. L. & Makin W. P. (2001) The concerns of patients under palliative care and a heart failure clinic are not being met. *Palliative Medicine* **15,** 279–86.

Bakeman R. & Gottman J. M. (1997) *Observing Interaction: An Introduction to Sequential Analysis (2nd edition).* Cambridge University Press, Cambridge.

Baker A. & Kenner A. N. (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.

Baker C. & Melby V. (1996) An investigation into the attitudes and practices of intensive care nurses towards verbal communication with unconscious patients. *Journal of Clinical Nursing* **5,** 185–92.

Banat D., Summers S. & Pring T. (2002) An investigation into carer's perceptions of the verbal comprehension ability of adults with severe intellectual disabilities. *British Journal of Developmental Disabilities* **30,** 78–81.

Benedetti F., Arduino C., Vighetti S., Asteggiano G., Tarenzi L. & Rainero I. (2004) Pain reactivity in Alzheimer's patients with different degrees of cognitive impairment and brain electrical activity deterioration. *Pain* **111,** 22–9.

Bernabei R., Gambassi G., Lapane K., Landi F., Gatsoni C., Dunlop R., Lipsitz L., Steel K. & Mor V. (1998) Management of pain in elderly patients with cancer. *Journal of the American Medical Association* **279,** 1877–82.

Breau L. M., McGrath P. J., Camfield C. S. & Finlay G. A. (2002) Psychometric properties of the non-communicating children's pain checklist- revised. *Pain* **99,** 349–57.

Carr E. (1997) Assessing pain: 'A Vital part of nursing care'. *Nursing Times* **93,** 46–8.

Coulson M. (2004) Attributing emotion to static body postures: recognition accuracy, confusions and viewpoint dependence. *Journal of Nonverbal Behaviour* **28,** 117–39.

Craig K. D., McMahon R. J., Morison J. D. & Zaskow C. (1984) Developmental changes in infant pain expression during immunization injections. *Social Science in Medicine* **19,** 1331–7.

Donovan J. (1997) Pain signals. *Nursing Times* **93,** 60–3.

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,** 287–95.

Elliott R. & Wright L. (1999) Verbal communication: what do critical care nurses say to their unconscious or sedated patients? *Journal of Advanced Nursing* **29,** 1412–20.

Feldt K. S. & Warne M. A. (1998) Examining pain in aggressive cognitively impaired older adults. *Journal of Gerontological Nursing* **24,** 14–22.

Flaherty G. G. & Fitzpatrick J. J. (1978) Relaxation techniques to increase comfort level of postoperative patients: a preliminary study. *Nursing Research* **27,** 352–5.

Fuchs-Lacelle S. & Hadjistavropoulos T. (2004) Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). *Pain Management Nursing* **5,** 37–49.

Fullarton A. (2002) Examining the comfort of the unconscious patient. *European Journal of Palliative Care* **9,** 232–3.

Glennen S. L. (1997) Introduction to augmentative and alternative communication. In: *Handbook of Augmentative and Alternative Communication* (eds S. T. Glennen & D. C. DeCoste), pp. 3–19. Singular Publishing Group, San Diego, CA.

Grunau R. V. E. & Craig K. D. (1987) Pain expression in neonates: facial action and cry. *Pain* **28,** 395–410.

Hadjistavropoulos T., LaChapelle D. L., MacLeod F. K., Snider B. & Craig K. D. (2000) Measuring movement-exacerbated pain in cognitively impaired frail elders. *Clinical Journal of Pain* **16,** 54–63.

Herr K. & Decker S. (2004) Assessment of pain in older adults with severe cognitive impairment. *Annals of Long Term Care* **12,** 46–52.

Hogg J., Reeves D., Roberts J. & Mudford O. C. (2001) Consistency, context and confidence in judgements of affective communication in adults with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research* **45,** 18–29.

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. University of Manchester, Manchester.

Hurley A. C., Volicer B. J., Hanrahan P. A., 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. *Pain* **6,** 249–52.

Jones L. (1999) *The Kidderminster Curriculum for Children and Adults with Profound Multiple Learning Difficulties: Assessment Checklist*. University of Birmingham School of Psychology, Birmingham.

Keefe F. J. & Block A. R. (1982) Development of an observational method for assessing pain behaviour in chronic low back pain patients. *Behaviour and Therapeutics* **13,** 363–75.

Kovach C. R., Weissman D. E., Griffie J., Matson S. & Muchka S. (1999) Assessment and treatment of discomfort for people with late-stage dementia. *Journal of Pain and Symptom Management* **18,** 412–19.

Kovach C. R., Noonan P. E., Griffie J., Muchka S. & Weissman D. E. (2002) The assessment of discomfort in dementia protocol. *Pain Management Nursing* **3,** 16–27.

van't Land C. J. & Hendrickson C. F. M. (1995) Change in locomotor activity pattern in mice: a model for recognition of distress? *Laboratory Animals* **28,** 286–93.

Lefebvre-Chapiro S. & the DOLOPLUS Group (2001) The DOLOPLUS-2 scale – evaluating pain in the elderly. *European Journal of Palliative Care* **8,** 191–4.

Lindeboom R. & Weinstein H. (2004) Neuropsychology of cognitive ageing, minimal cognitive impairment, Alzheimer's disease, and vascular cognitive impairment. *European Journal of Pharmacology* **490,** 83–6.

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,** 404–9.

Manfredi P. L., 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 L. R. (1991) The tragedy of dementia: clinically assessing pain in the confused, non-verbal elderly. *Journal of Gerontological Nursing* **17,** 25–8.

Morrison R. S. & Siu A. L. (2000) A comparison of pain and its treatment in advanced dementia and cognitively intact patients with a hip fracture. *Journal of Pain and Symptom Management* **19,** 240–8.

Morse J. M., Bottorff J. L. & Hutchinson S. (1994) The phenomenology of comfort. *Journal of Advanced Nursing* **20,** 189–95.

Murdy J. & O'Leary L. (1999) Understanding the issues of palliative care for someone with a learning disability. In: *Living with Loss* (ed. N. Blackman), p. 39. Pavillion Publishing, Brighton.

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 K. (1992) The consistency of facial expressions of pain: a comparison across modalities. *Pain* **35,** 71–8.

Rainero I., Vighetti S., Bergamasco B., Pinessi L. & Benedetti F. (2000) Autonomic responses and pain perception in Alzheimer's disease. *European Journal of Pain* **4,** 267–74.

Regnard C. & Hockley J. (eds) (1995) *Flow Diagrams in Advanced Cancer and Other Diseases*. Edward Arnold, London.

Regnard C. & Hockley J. (2004) *A Guide to Symptom Relief in Palliative Care*, 5th edn. Radcliffe Medical, Oxford.

Regnard C. & Randall F. (2005) A framework for making advance decisions on resuscitation. *Clinical Medicine* **5,** 354–60.

Regnard C. & Tempest S. (1992) *A Guide to Symptom Relief in Advanced Cancer*, 3rd edn. Haigh and Hochland, Manchester.

Regnard C., Mathews D., Gibson L. & Jenson C. (2003a) Identifying distress. In: *Helping the Patient with Advanced Disease: A Workbook* (ed. C. Regnard), pp. 185–8. Radcliffe Medical, Oxford (Also available at http://www.helpthehospices.org.uk, click on 'e-learning').

Regnard C., Matthews D., Gibson L., Clarke C. & Watson B. (2003b) Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing* **9,** 173–6.

Reynolds J. (2005) *Early development in communication, cognition and play in children with autism and severe intellectual disabilities: identifying strengths and difficulties*. PhD Thesis. Northumbria University.

Robson C. (2002) *Real World Research (2nd Edition)*. Blackwell, Oxford.

Rothman A. D. & Nowicki S. Jr (2004) A measure of the ability to identify emotion in children's tone of voice. *Journal of Nonverbal Behaviour* **28,** 67–92.

Scherder E. J., Slaets J., Deijen J. B., Gorter Y., Ooms M. E., Ribbe M., Vuijk P. J., Feldt K., van de Valk M., Bouma A. & Sergeant J. A. (2003) Pain assessment in patients with possible vascular dementia. *Psychiatry* **66,** 133–45.

Scherder E. J., Oosterman J., Swaab D., Herr K., Ooms M., Ribbe M., Sergeant J., Pickering G. & Benedetti F. (2005) Recent developments in pain in dementia. *British Medical Journal* **330,** 461–4.

Scott C. S., Riggs K. W., Ling E. W., Fitzgerald R. N., Hill M. L., Grunau R. V. E., Solimano A. & Craig K. D. (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.

Semla T. P., Cohen D., Paveza G., Eisdorfer C., Gorelick P., Luchins D., Hirschman R., Freels S., Levy P., Ashford J. W. (1993) Drug use patterns of persons with Alzheimer's disease and related disorders living in the community. *Journal of the American Geriatric Society* **41,** 408–13.

Simons W. & Malabar R. (1995) Assessing pain in elderly patients who cannot respond verbally. *Journal of Advanced Nursing* **22,** 663–9.

Snow A. L., Weber J. B., O'Malley K. J., Cody M., Beck C., Bruera E., Ashton C. & Kunik M. E. (2004) NOPPAIN: a nursing assistant-administered pain assessment instrument for use in dementia. *Dementia and Geriatric Cognitive Disorders* **17,** 240–6.

Stevens B. J., Johnston C. & Grunau R. V. E. (1995) Issues of assessment of pain and discomfort in neonates. *Journal of Obstetric, Gynaecologic and Neonatal Nursing* **24,** 849–55.

Sundin K. & Jansson L. (2003) 'Understanding and being understood' as a creative caring phenomenon – in care of patients with stroke and aphasia. *Journal of Clinical Nursing* **12,** 107–16.

Sundin K., Jansson L. & Norberg A. (2000) Communicating with people with stroke and aphasia: understanding through sensation without words. *Journal of Clinical Nursing* **9,** 481–8.

Tuffrey-Wijne I. (2003) The palliative care needs of people with intellectual disabilities: a literature review. *Palliative Medicine* **17,** 55–62.

Villanueva M. R., Smith T. L., Erickson J. S., Lee A. C. & Singer C. M. (2003) Pain Assessment for the Dementing Elderly (PADE): reliability and validity of a new measure. *Journal of the American Medical Directors Association* **4,** 1–8.

Warden V., Hurley A. C. & Volicer L. (2003) Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *Journal of the American Medical Directors Association* **4,** 9–15.

Wary B. & Doloplus C. (1999) Doloplus-2, a scale for pain measurement. *Soins Gerontologie* **19,** 25–7.

Weiner D., Peiper C., McConnell E., Martinez S. & Keefe F. J. (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. *British Journal of Learning Disabilities* **28,** 148–53.

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Disability Distress Assessment Tool

Client's name:
DoB: **Gender:**
Unit/ward: **NHS No:**
Your name: **Date completed:**
Names of others who helped complete this form:

INFORMATION AND INSTRUCTIONS ARE ON THE BACK PAGE

Facial appearance when CONTENT
Face
Tongue/jaw
Eyes

Facial appearance when DISTRESSED
Face
Tongue/jaw
Eyes

Vocal signs when CONTENT
Sounds
Speech

Vocal signs when DISTRESSED
Sounds
Speech

Habits and mannerisms when CONTENT
Habits
Mannerisms
Comfortable distance

Habits and mannerisms when DISTRESSED
Habits
Mannerisms
Comfortable distance

Posture & observations when CONTENT
Posture
Observations

Posture & observations when DISTRESSED
Posture
Observations

Context of distress and communication/action which helps ease distress
(You can record either a specific episode, using dates, or just describe what usually causes this person to be distressed)

Date	Context of distress	Actions that can alleviate distress

Appendix *Continued*

DisDAT- Disability Distress Assessment Tool

Please take some time to think about and observe your client's appearance and behaviours when they are both content and distressed, and describe these cues in the spaces given. We have listed words in each section to help you to describe your client or patient. You can circle the word or words that best describe the signs and behaviours when your client or patient is content and when they are distressed. Document the cues in each category and, if possible, give a fuller description in the spaces given. Your descriptions will provide you with a clearer picture of your client's 'language' of distress.

COMMUNICATION LEVEL *

This person is unable to show likes or dislikes ☐ Level 0
This person is able to show that they like or don't like something ☐ Level 1
This person is able to show that they want more, or have had enough of something ☐ Level 2
This person is able to show anticipation for their like or dislike of something ☐ Level 3
This person is able to communicate detail, qualify, specify and/or indicate opinions ☐ Level 4

* This is adapted from the Kidderminster Curriculum for Children and Adults with Profound Multiple Intellectual Difficulty (Jones, 1994, National Portage Association).

FACIAL SIGNS Appearance

Information / instructions	Appearance when content	Appearance when distressed
Ring the words that best describe the facial appearance	Passive Laugh Smile Frown Grimace Startled Frightened Other:	Passive Laugh Smile Frown Grimace Startled Frightened Other:

Jaw movement

Information / instructions	Movement when content	Movement when distressed
Ring the words that best describe the jaw movement	Relaxed Drooping Grinding Biting Rigid Other:	Relaxed Drooping Grinding Biting Rigid Other:

Appearance of eyes

Information / instructions	Appearance when content	Appearance when distressed
Ring the words that best describe the appearance	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils Other:	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils Other:

SKIN APPEARANCE

Information / instructions	Appearance when content	Appearance when distressed
Ring the words that best describe the appearance	Normal Pale Flushed Sweaty Clammy Other:	Normal Pale Flushed Sweaty Clammy Other:

Appendix *Continued*

VOCAL SOUNDS (NB. The sounds that a person makes are not always linked to their feelings)

Information / instructions	Sounds when content	Sounds when distressed
Ring the words that best describe the sounds *Write down* commonly used sounds (write it as it sounds; 'tizz', 'eeiow', 'tetetetete'): ……………………………… ………………………………	**Volume**: high medium low **Pitch**: high medium low **Duration:** short intermittent long **Description of sound / vocalisation**: Cry out Wail Scream Laugh Groan / moan Shout Gurgle Other:	**Volume**: high medium low **Pitch**: high medium low **Duration:** short intermittent long **Description of sound / vocalisation**: Cry out Wail Scream Laugh Groan / moan Shout Gurgle Other:

SPEECH

Information / instructions	Words when content	Words when distressed
Write down commonly used words and phrases. If no words are spoken, write NONE		
Ring the words which best describe the speech	Clear Stutters Slurred Unclear Muttering Fast Slow Loud Soft Whisper Other:	Clear Stutters Slurred Unclear Muttering Fast Slow Loud Soft Whisper Other:

HABITS & MANNERISMS

Information / instructions	Habits and mannerisms when content	Habits and mannerisms when distressed
Write down the habits or mannerisms		
Write down any special comforters, possessions or toys this person prefers.		
Please Ring the statements which best describe how comfortable this person is with other people being physically close by	Close with strangers Close only if known No one allowed close Withdraws if touched	Close with strangers Close only if known No one allowed close Withdraws if touched

BODY POSTURE

Information / instructions	Posture when content	Posture when distressed
Ring the words that best describe how this person sits and stands.	Normal Rigid Floppy Jerky Slumped Restless Tense Still Able to adjust position Leans to side Poor head control Way of walking: Normal / Abnormal Other:	Normal Rigid Floppy Jerky Slumped Restless Tense Still Able to adjust position Leans to side Poor head control Way of walking: Normal / Abnormal Other:

BODY OBSERVATIONS

Information / instructions	Observations when content	Observations when distressed
Describe the pulse, breathing, sleep, appetite and usual eating pattern, eg. eats very quickly, takes a long time with main course, eats puddings quickly, "picky".	Pulse: Breathing: Sleep: Appetite: Eating pattern:	Pulse: Breathing: Sleep: Appetite Eating pattern:

Appendix *Continued*

Information and Instructions

DisDAT is

Intended to help identify distress cues in people who because of cognitive impairment or physical illness have severely limited communication.
Designed to describe a person's usual content cues, thus enabling distress cues to be identified more clearly.
NOT a scoring tool. It documents what many staff have done instinctively for many years thus providing a record against which subtle changes can be compared. This information can be transferred with the client or patient to any environment.
Only the first step. Once distress has been identified the usual clinical decisions have to be made by professionals.
Meant to help you and your client or patient. It gives you more confidence in the observation skills you already have which in turn will help you improve the care of your client or patient.

When to use DisDAT

When the team believes the client is NOT distressed
The use of DisDAT is optional, but it can be used as
- a baseline assessment document
- a transfer document for other teams
When the team believes the client IS distressed
If DisDAT has already been completed it can be used to compare the present signs and behaviours with previous observations documented on DisDAT. It then serves as a baseline to monitor change.
If DisDAT has not been completed:
a) When the client is well known DisDAT can be used to document previous content signs and behaviours and compare these with the current observations
b) When the client or the distress is new to the team, DisDAT can be used document the present signs and behaviours to act a baseline to monitor change.

How to use DisDAT

Observe the client when content and when distressed – document this on the inside pages. *Anyone* who cares for the patient can do this.
Observe the context in which distress is occurring.
Use the clinical decision distress checklist on this page to assess the possible cause.
Treat or manage the likeliest cause of the distress.
The monitoring sheet is a separate sheet, which may help if you want to see how the distress changes over time.
The goal is a reduction the number or severity of distress signs and behaviours.

Remember

- Most information comes from the whole team in partnership with the family.
- The assessment form need not be completed all at once and may take a period of time.
- Reassessment is essential as the needs of the client or patient may change due to improvement or deterioration.
- Distress can be emotional, physical or psychological. What is a minor issue for one person can be major to another.
- If signs are recognised early then suitable interventions can be put in place to avoid a crisis.

Clinical decision distress checklist

Use this to help decide the cause of the distress

Is the new sign or behaviour?

- **Repeated rapidly**?
Consider pleuritic pain (in time with breathing)
Consider colic (comes and goes every few minutes)
Consider: repetitive movement due to boredom or fear.

- **Associated with breathing?**
Consider: infection, COPD, pleural effusion, tumour

- **Worsened or precipitated by movement?**
Consider: movement-related pains

- **Related to eating?**
Consider: food refusal through illness, fear or depression
Consider: food refusal because of swallowing problems
Consider: upper GI problems (oral hygiene, peptic ulcer, dyspepsia) or abdominal problems.

- **Related to a specific situation?**
Consider: frightening or painful situations.

- **Associated with vomiting?**
Consider: causes of nausea and vomiting.

- **Associated with elimination (urine or faecal)?**
Consider: urinary problems (infection, retention)
Consider: GI problems (diarrhoea, constipation)

- **Present in a normally comfortable position or situation?**
Consider: pains at rest, infection, nausea, anxiety, depression, anger.

**Distress may be hidden,
but it is never silent**