

## CURRENT TOPIC

## Paediatric patients' distress and coping: an observational measure

Ursula Pretzlik, Kathy Sylva

In the 1980s, the amount of behavioural distress in ill children was seen by researchers as an indirect measure of children's coping; low distress was taken to indicate successful coping had occurred.<sup>1A</sup> By the 1990s, coping strategies were assessed by self report.<sup>2</sup> However, observing a young patient's distress behaviour is still a useful measure of their coping, and has been shown to be a good indicator of the way they feel about a particular medical treatment.<sup>3</sup> Observational measures of distress have the added advantage that they can be used with very young children.

In general, infants confronted with the sudden onset of a painful stimulus respond with a scream, followed by tears, grimaces, and body movements. At around 6 months of age, they show apprehension of a painful event—for example, an injection or a blood test—and the discomfort that this involves initiates distress behaviour. The capacity to anticipate an unpleasant event is a mark of a child's development of learning and memory. During a toddler's 2nd year, the period of screaming and crying generally decreases, and they visually begin to search out the mother and/or nurse before an injection.

The first part of our paper describes an assessment procedure for distress behaviour, and the second part explains how the same instrument can be extended and used to assess the child's coping behaviour.

### Measuring observed behaviour

Structured behaviour observations are objective and easy for clinicians and researchers to carry out. A distress behaviour instrument

measures how children behave in the situations that cause them to be distressed—the term distress in this case is used to describe discomfort reactions to pain or anxiety during invasive medical treatments. The systematic observation of distress and coping of children in hospital allows individual responses to the medical treatment to be assessed and monitored. Because this method is so precise, it can lead to the development of improved practice and, ultimately, to theoretical understanding of distress and coping.<sup>4</sup>

Three instruments that measure children's distress behaviour during medical treatments are frequently cited in the literature (table 1).<sup>1-7</sup> We think that the observation scale for behavioural distress (OSBD) is the most useful for appraising distress in individual patients and paediatric groups. The OSBD has been shown to be valid and reliable, and was designed in the paediatric setting.<sup>3,8</sup> It is also the instrument most often used in current paediatric research.<sup>3,9-11</sup> Once inter-rater reliability is established, the OSBD is quick and convenient to use, and is useful in practice and research. It is appropriate for use with infants and toddlers as well as school age children (6 months to 14 years).

### Administration of the observation scale for behavioural distress

Research into distress in paediatric patients often involves the observation of procedures. The OSBD is a time sample checklist. It is made up of eight behaviour categories indicating the child's anxiety and/or pain (table 2). These behaviours are coded for their presence

Table 1 Observation measures to be used in the medical setting

Author and instrument	Method	Variables
Katz <i>et al</i> (1980). <sup>1</sup> The procedure behaviour rating scale (PBRs-R)	8 months to 17 years; the observer registers the presence/absence of behaviours at four specific moments in time; the degree of discomfort is determined by the total number of behaviours registered	25 (reduced to 13) distress behaviour categories indicating distress (for example, tears, screams, resisting, refusal position)
LeBaron and Zeltzer (1984). <sup>3</sup> The procedure behaviour checklist (PBCL) is based on the PBRs-R)	6-18 year olds; the observer rates their intensity on a 1-5 scale (1, very mild; 5, extremely intense); good reliability and validity	13 (reduced to 8) distress behaviour categories (for example, pain verbalised, screams, anxiety verbalised)
Jay and Elliott (1984; 1986). <sup>6,7</sup> Observation scale for behavioural distress (OSBD)*	6 months to 20 years; number and intensity of distress behaviour before/during/after the procedure; multiple behaviours during 15 second intervals; presence/absence; structured recording sheet; good reliability and validity	11 (reduced to 8) distress behaviours (table 2)

Department of Child Development and Learning, Institute of Education, 20 Bedford Way, London WC1H 0AL, UK  
U Pretzlik  
K Sylvia

Correspondence to:  
Dr Pretzlik

\*Available from first author.

Table 2 The OSBD: eight behaviour categories<sup>7</sup>

Category	Definition	Examples	Non-examples
Information seeking	Any question regarding medical procedure	"When will it stop?" "Is the needle in?" "Is the blood coming?"	"Will I get a present?"
Cry	Crying sound and/or onset of tears	Sobbing; booh; crying sounds; tears while they flow	Sniffing; heavy breathing
Scream	Loud vocal expression at high pitch	Sharp; shrill; harsh; high tones; shriek	Loud yelling but at low pitch
Restraint	Child must be physically held down by member of staff or parent		
Verbal resistance	Any verbal expression of delay, termination, resistance; must be intelligible	"I want to go" "Stop" "No more" "Don't hurt me" "I don't like this!" "No, no!"	
Emotional support	Verbal or non-verbal; seeking hugs, hand holding; physical or verbal comfort by child	"Hold me" "Help me" reaching out to be held	"Mummy get me out of here" is VR not ES
Verbal pain	Any word, phrase or statements referring to pain or discomfort	"That hurts" "It stings" "Owww!" "Oh!"	"Will it hurt?" is IS not VR
Flail	Random, gross movements of arms and legs or whole body; flail in response to restraint	Pounding fists; kicking legs repeatedly and randomly; flapping of arms on self	Must be random

ES, emotional support; IS, information seeking; OSBD, observation scale for behavioural distress; VR, verbal response.

or absence during 15 second intervals. A predetermined number of intervals make up a phase—for example, anticipation of the procedure—and the phases make up a complete observation. The intervals are defined by the sharp sound of an automatic bleeper in the observer's ear. The multiple behaviours displayed by the child are ticked on a record sheet during these regularly timed intervals. Each category has a relative value in a 1–4 range, where 4 represents the highest degree of distress. As examples, "cry" is weighted at 1.5, "verbal pain" 2.5, and "scream" at 4.0. The OSBD yields a total score that includes intensity of distress.<sup>8</sup>

Once distress levels have been reliably measured on a baseline, therapeutic methods such as distraction, imagery, and relaxation exercises, in combination with pain relief drugs, can be introduced to establish whether the intervention had been successful. Systematic observations in conjunction with physiological measures—for example, heart rate and/or breathing rate or cortisol concentrations—might be helpful to assess the effect of treatment interventions on groups of young patients. The results will enable medical teams to make informed decisions about treatment regimens.

Although the OSBD is used with children of all ages to compare results across a wide age range, it has some weaknesses—for example, "flailing" (gross movements of arms and legs or whole body) is a distress behaviour used by very young children only, whereas "information seeking" is used only by children able to talk. Therefore, the meaning of some OSBD behaviour categories will vary according to the age of the child.

### Measuring coping through observation

Although coping is measured indirectly through structured behavioural observations of distress, such as the OSBD, avoidant and active coping is sometimes measured through self

report questionnaires and interviews.<sup>12</sup> There are two appropriate instruments available to observe children's coping behaviour during medical treatments.

One instrument, the behaviour approach avoidance subscale, was devised by Hubert *et al* to measure the behaviour of paediatric cancer patients undergoing a bone marrow aspiration.<sup>11</sup> Observers rated children's behaviour on a 1–5 Likert-type scale; high approach behaviour was defined as looks, touches, and questions to initiate involvement; high avoidance as turning away, trying to escape, or trying to change the situation. It was found that children whose coping was characterised by more approach behaviours rather than avoidant behaviours displayed less distress than those who used avoidant coping behaviours. The behaviour approach avoidance subscale can be used independently, and also in conjunction with the OSBD.

The other instrument, the active/avoidant coping behaviour measure, is administered by adding two behaviour categories to the eight distress behaviours of the OSBD (U Pretzlik and K Sylva, the VIIth European Conference on Developmental Psychology, Krakow, Poland, 1995). Behaviour is defined as active coping if the child takes an interest in a medical procedure—for example, a blood test; that is to say, if the child looks at the needle going into the skin and watches the blood coming out. Children who show "no interest" in the blood test (take no active part, and simply ignore the procedure or deliberately look the other way) show avoidant coping behaviour. These two coping behaviours are coded for presence or absence during 15 second intervals. The total of active/avoidant coping intervals give each child an active or avoidant score. This subscale has the advantage of being quick and easy to apply and enables clinicians and researchers to identify a child's preferred coping style. High inter-rater reliability for the subscale has been demonstrated.<sup>3</sup>

Once a coping style has been identified, psychological and practical support for avoiders can be tailored in the direction of distraction, whereas additional information can be provided for active copers. Children who used avoidant coping behaviour—for example, while having their blood taken—showed increased distress behaviour and reported being more distressed during that period than those children who took an active interest (Pretzlik and Sylva, the VIIth European Conference on Developmental Psychology). These results endorse the findings by other workers,<sup>11 13</sup> as well as Peterson's summary review of eight studies,<sup>12</sup> all of which found that active copers on the whole fare better than avoidant copers.

### Implications and conclusion

Empirical studies involving the widespread use of the OSBD and its extension, which includes the two coping behaviour categories, active/avoidant, will add to the knowledge of individual and contextual factors associated with distress and coping. This knowledge can facilitate improvement in existing interventions and provide input for new interventions to enhance children's coping. It might also broaden their application beyond medical procedures to other aspects of adjustment to serious and long term illness.

To find out more about infants' and toddlers' resilience and vulnerability, structured observation carried out in the clinical setting is recommended. It is only with the development of verbal skills that children are provided with the fundamental means of conveying directly the nature of pain, its location, intensity, and duration, which are all elements that contribute to

the distress of paediatric patients. These elements are essential for clinicians to be aware of, through their own observations or through research findings.

- 1 Katz ER, Kellerman J, Siegel SE. Behavioural distress in children with cancer undergoing medical procedures: developmental considerations. *J Consult Clin Psychol* 1980;48:356–65.
- 1A Hynson JC. Going to the doctor: a developmental study of stress and coping. *J Child Psychol Psychiatry* 1983;24:247–59.
- 2 Pretzlik U, Sylva K. Paediatric patients' distress and coping: a self-report measure. *Arch Dis Child* 1999;81:525–7.
- 3 Pretzlik U. *Children coping with a serious illness: a study exploring distress and coping in children with leukaemia or aplastic anaemia*. Amsterdam: SCO-Kohnstamm Instituut University of Amsterdam, 1997.
- 4 Sylva K. Behaviour measurement review: number 3. Observational measures for assessing distress during medical treatment. *Association for Child Psychology and Psychiatry Newsletter* 1992;14:24–7.
- 5 LeBaron S, Zeltzer L. Assessment of acute pain and anxiety in children and adolescents by self-reports, observer reports and a behaviour checklist. *J Consult Clin Psychol* 1984;52:729–38.
- 6 Jay S, Elliott C. Behavioural observation scales for measuring children's distress: the effects of increased methodological rigour. *J Consult Clin Psychol* 1984;52:1106–7.
- 7 Jay S, Elliott C. *Observation scale of behaviour distress—revised*. Los Angeles: Children's Hospital of Los Angeles, 1986.
- 8 Elliott CH, Jay SM, Woody P. An observation scale for measuring children's distress during medical procedures. *J Pediatr Psychol* 1987;12:543–51.
- 9 LaGreca AM, Siegel LJ, Wallander JL, Walker CE, eds. *Stress and coping in child health*. New York: The Guilford Press, 1992.
- 10 Bradford R. Short communication: The importance of psychosocial factors in understanding child distress during routine x-ray procedures. *J Child Psychol Psychiatry* 1990;31:973–82.
- 11 Hubert N, Jay S, Saltoun M, Hayes M. Approach/avoidance and distress in children undergoing preparation for painful medical procedures. *J Clin Child Psychol* 1988;17:194–202.
- 12 Peterson L. Coping by children undergoing stressful medical procedures: some conceptual, methodological and therapeutic issues. *J Consult Clin Psychol* 1989;57:380–7.
- 13 Gil K, Williams D, Thompson R, Kinney T. Sickle cell disease in children and adolescents: the relation of child and parent pain coping strategies to adjustment. *J Pediatr Psychol* 1991;16:643–63.