



The development of the DEGR^R: A scale to assess pain in young children with cancer

Annie Gauvain-Piquard^a, Chantal Rodary^b, Ali Rezvani^b and Saïd Serbouti^c

^aPsychiatry and Psycho-Oncology Unit; ^bDepartment of Biostatistics and Epidemiology, Institut Gustave Roussy, 94805 Villejuif, France; ^cQIS Consulting, 28 rue Thiers, 59800 Lille, France

The Gustave Roussy Child Pain Scale (Douleur Enfant Gustave Roussy, DEGR^R Scale) is a scale for grading prolonged pain in children aged 2–6 years with cancer. The scale comprised six behaviours specific to pain items, five psychomotor inertia items, and four anxiety items, with a total score ranging from 0 to 60. This work was designed to confirm the scale structure and to study its construct validity and convergent validity.

Our work was composed of two parts. In the first part of the study, 152 children with progressive cancer were scored by two nurses using the DEGR^R scale, in a cross-sectional design. And in the second part, 53 of these 152 children were video-recorded. The tapes were assessed both by a panel of four pain specialists using a 0 to 7 Likert scale and by a nurse using DEGR^R scale.

As for the 152 children, the mean of the total scores derived from the DEGR^R is 20.2 (SD = 6.2). Both the degree of agreement between the nurses (the weighted κ coefficient) and the internal consistency of the scale (Cronbach α coefficient = 0.90) were high, providing evidence of good reliability. Multivariate factor analyses showed a first factor of intensity of pain (51% of the total variance) and a second factor (14% of the total variance) which distinguishes the psychomotor inertia items from the items concerning voluntary expression of pain. Also, the results showed that psychomotor inertia items contribute to both factors and that it is an important sign of prolonged pain. Construct validity was strengthened by the absence of correlation between DEGR^R scores and variables not related to pain, including fever, neutropenia and anaemia (indicative of poor medical condition) and the absence of parents' visits (indicative of psychological distress).

Concerning the 53 video-recorded children, the nurses' DEGR^R ratings were strongly correlated with the specialists panel scores indicating a fairly good case for convergent validity.

KEYWORDS: pain, pain scale, young child, cancer, assessment, validation.

INTRODUCTION

The measurement of pain intensity in children remains a major concern to health care professionals. During these last two decades, several studies have been set up to prove that young children are able to feel pain (Nover, 1973;

Williamson & Williamson, 1983; Anand *et al.*, 1987; Giannakouloupoulos & Sepulveda, 1994). However, clinical practice and research studies have both suffered from the failure to use valid and appropriate instruments to measure pain, resulting in unnecessary suffering for children or incorrect conclusions by researchers. Without measurement, one cannot determine whether treatment is necessary, whether the prescribed treatment is effective, or whether it should be stopped.

Up to now, three types of method were available (McGrath, 1989; McGrath & Unruh, 1994; Finley & McGrath, 1998):

Paper received 3 July 1998 and accepted in revised form 9 March 1999.

Correspondence to: Annie Gauvain-Piquard, Psychiatry and Psycho-Oncology Unit, Institut Gustave Roussy, 39 rue Camille Desmoulins, 94805 Villejuif, France.
Email: gauvain@igr.fr

- (1) Physiological indices such as heart rate, transcutaneous oxygen saturation or sweating (Sweet & McGrath, 1998): although they are useful in the evaluation of acute pain in neonates and infants (Porter, 1993), they seem of less value in older children (O'Hara *et al.*, 1987). Concerning longer pain, the changes that occur in physiological variables are virtually unknown (Sweet & McGrath, 1998).
- (2) Self report methods: when they can be obtained, these self-report measures should be regarded as the 'gold standard'. However, preschool children have relatively limited cognitive ability to understand what is being asked of them in pain measurement (Champion *et al.*, 1998). Furthermore, several authors have pointed out that children may deny their pain (Eland, 1981; Mather & Mackie, 1983; Beyer & Aradine, 1987; Lander *et al.*, 1992). Alternatively, some children may be motivated to feign or exaggerate pain. Consequently, direct report methods are insufficient on their own to provide reliable and valid assessment in preschool-aged children, especially if very ill (Champion *et al.*, 1998).
- (3) Behavioural methods: behaviour is a useful measure and indicator of pain in children. It is the main way to assess pain in children unable to provide a self assessment, particularly in neonatal units, intensive care and in the recovery room. Scales of pain behaviour use not broadband judgments but judgments focusing upon highly focal aspect of behaviour as a means of becoming specific of pain. They have been developed on different levels or different types of behaviour, including: (i) very detailed descriptions of minute behaviours, such as facial action; (ii) molar descriptions of behaviour, such as grimacing or movement of limbs; (iii) complex behaviours such as 'play less than usual' (McGrath, 1998). It seems that reaction to pain can be divided into different phases (Wall, 1979; McGrath, 1998). The most obvious is the immediate distress caused by noxious stimuli. This reaction may last for a few minutes and is characterised by a wide range of behaviours, including flailing and crying (McGrath, 1998). It was firstly considered in

order to assess acute pain in painful procedures (Katz *et al.*, 1980; Jay *et al.*, 1983; Fradet *et al.*, 1990; Craig, 1992), pain in neonates (Craig *et al.*, 1984; Grunau & Craig, 1987; Pigeon *et al.*, 1989; Grunau *et al.*, 1990) and immediate postoperative pain (McGrath *et al.*, 1985; Attia *et al.*, 1987; Norden *et al.*, 1991; Tyler *et al.*, 1993). However, doubt was raised as to the ability of these methods to distinguish between pain and other sources of distress, i.e. anxiety or fear (Shacham & Daut, 1981; Lebaron & Zeltzer, 1984; Fuller, 1991). Furthermore, it appears that many behaviours habituate when pain persists. A second phase of pain reaction can be described when pain is lasting, consisting mainly of a shutdown of activity. Only one scale (Chambers *et al.*, 1996) comprises such behaviour.

Over the last 15 years, we have developed an observational rating scale for prolonged pain in children with cancer aged 2–6 years: the 'Douleur Enfant Gustave Roussy' scale (DEGR^R) (Gauvain-Piquard *et al.*, 1987). This scale is simple to use. Training a nurse for the use of this instrument takes about 2–3 h, and for a child who has spent half a day in the Paediatrics Unit, a trained-nurse is perfectly able to complete *his* DEGR^R scale. Filling in this scale takes only 5–10 min. The scorings are based on the usual activity of children of this age, such as might be observed during play.

In a previous study (Gauvain-Piquard *et al.*, 1987), this scale had 17 items which were tested and had good characteristics in reliability and sensitivity. Three dimensions were highlighted: behaviour specific to pain (6 items), and two less specific dimensions, psychomotor inertia (5 items, named previously depression-like items) and anxiety (4 items). These 15 items build the present version of the scale. Each item includes a definition of a complex behaviour and the description of its increasing severity in five stages, 0 to 4 (see for example Table 1). Theoretical values of DEGR^R ratings range from 0 to 60, 0–24, 0–20, 0–16, respectively, for the total score and the subscores of the three dimensions (behaviour specific to pain, psychomotor inertia and anxiety). Table 2 gives the definition of the items within each dimension. All behaviours except one (item 3)

TABLE 1. DEGR^R scale: example of the rating for one of the 15 items.

ITEM 10 : Pain avoidance when moving
 The child spontaneously avoids all movement or tries not to move part of his body. To be scored during sequences of movements (e.g. walking) possibly induced. Motor slowing should not be noted here.

RATING:

0 : The child moves without any difficulty. His movements are supple and easy.
 1 : The child moves with some difficulty, and sometimes a little unnaturally.
 2 : The child is careful when making certain movements.
 3 : The child clearly avoids certain movements, and moves, in general with great care.
 4 : The child must be helped to avoid unduly painful movements.

were to be rated on the basis of the observation of the child at any time except during painful procedures.

FIRST PART OF THE STUDY

This first part was designed to confirm the scale structure and to study its construct validity.

PATIENTS AND METHODS

Patients

During a 3-year period, 152 children aged 2–6 were included, regardless of their native language, pain level or antalgic treatment. All patients presented with progressive cancer and were hospitalised in the Paediatrics Unit of the largest cancer hospital in France (Gustave Roussy Institute).

Methods

(The 152 children were rated independently by two nurses during their daily shifts (morning and afternoon nurse). The only overlap period when both nurses were working together was between 11.00 am and 3.00 pm; consequently, DEGR^R rating was usually performed at the beginning of the afternoon, after the overlap period. The 16 nurses who participated had no specific pain assessment training but were trained to complete the scale during a session of 1 h. The rating was done during the normal clinical work of each nurse. For each child, a number of general characteristics

(sex, age, place of residence, stage of verbal development), psychosocial characteristics (frequency of the parents' visits, duration of the illness), medical characteristics (diagnosis, phase of the disease), and current clinical conditions (presence or absence of fever, neutropenia, anaemia) were also recorded.

Statistical analysis

Reliability was assessed by the following approaches: (1) the degree of agreement between the two nurses (morning and afternoon) was measured for each item by the weighted κ coefficient, which expresses the level of agreement that is observed beyond the level that would be expected from chance alone (Fleiss *et al.*, 1979); (2) the internal consistency was measured by Cronbach's α coefficient (Nunnally & Bernstein, 1995); (3) the correlation coefficient was used to assess the test-retest reliability.

Several stages of validity were estimated: (1) the internal structure of the scale was studied using principal component analysis (PCA). In a PCA, linear combinations of observed variables are formed. The first principal component is the combination that accounts for the largest amount of variance in the sample. The second principal component accounts for the next largest amount of variance and is uncorrelated with the first (Cooley & Lohnes, 1971); (2) the relationships between the psycho-social and medical characteristics of the patients and the DEGR^R ratings were assessed by Pearson's correlation coefficients. Absence of significant correlation would provide additional support for validity.

TABLE 2. DEGR^R scale : description of the 15 items, with respect to the 3 dimensions. The items numbering refers to their order in the scale.

BEHAVIOURS SPECIFIC TO PAIN : 6 ITEMS

ITEM 2 : Unnatural postures

The child avoids certain painful positions or adopts a particular position in order to relieve a painful area. This item should be studied when the child is sitting or lying down with no physical activity. It should not be confused with the antalgic position during movement.

ITEM 4 : Protection of painful areas

The child seems continuously to avoid all contact with painful areas.

ITEM 6: Expressing pain

This item concerns the way in which the child says he is in pain, either spontaneously or when asked, during the period of observation.

ITEM 8 : Indicating painful areas

The child locates his pain, either spontaneously or when asked.

ITEM 10 : Pain avoidance when moving

The child spontaneously avoids all movement or tries not to move part of his body. To be scored during sequences of movements (e.g. walking) possibly induced. Motor slowing should not be noted here.

ITEM 14 : Reactions to examination of the painful area

When a painful area is examined, the child resists, pulls away or reacts emotionally. Only the child's reactions to the examination should be noted and not any previous reactions.

PSYCHOMOTOR INERTIA : 5 ITEMS

ITEM 3 : Resignation

The child is resigned to everything that happens to him. He does not try to protest or resist. Should be scored during an unpleasant situation, such as venipuncture.

ITEM 5 : Withdrawal

The child sometimes 'withdraws into his shell'

ITEM 7 : Lack of expression

Concerns the ability of the child to register and express feelings by his tone of voice, eyes and facial expression. Should be scored when the child is active, e.g. during games, meals and chatter.

ITEM 11 : Lack of interest in surroundings

Concerns the child's available energy for interaction with his environment.

ITEM 13 : Slowness and paucity of movement

The child's movements are slow, restricted and rather stiff, even some distance away from painful areas. The trunk and large joints are particularly motionless. Should be scored in relation to a normal child's movements.

ANXIETY BEHAVIOURS : 4 ITEMS

ITEM 1 : Tenseness

Concerns the degree of nervous tension in the child's body.

ITEM 9 : Hostility

Measures the child's hostility towards those around him.

ITEM 12 : Wariness at being moved

When the child is moved for a meal, bath, etc. he is wary, says or shows how he wants to be moved, resists or holds onto the adult's hand.

ITEM 15 : Crying easily

Concerns the extent to which the child cries in order to express himself.

RESULTS

Population

The psychosocial and medical characteristics of the 152 children are given in Table 3. The median age was 3.9 years. Our population consisted of patients with cancers commonly seen in young children, at various phases of the disease. Half of them had metastases at the time of assessment. The overall proportion of children receiving analgesic

treatment at the time of assessment was 31%. Most of the children receiving analgesics had neuroblastoma, rhabdomyosarcoma or Wilm's tumours.

DEGR^R scores

There were no missing values. The scale was easy to fill in except for item 5 (withdrawal), which concerned the child's behaviour when the nurse was not necessarily present.

TABLE 3. General, psychosocial and medical characteristics of the two samples

Characteristics	Total sample (152 children) <i>n</i> (%)	Video sample (53 children) <i>n</i> (%)
Gender		
males	88 (58)	31 (58)
Age (years)		
2	43 (28)	10 (19)
3	34 (22)	13 (25)
4	43 (28)	13 (25)
5	32 (22)	17 (32)
Place of residence		
France (vs other)	95 (62)	26 (49)
Verbal development		
Sentences	130 (86)	46 (87)
parents' visits		
Daily	114 (75)	34 (64)
Weekly	8 (5)	3 (6)
None	23 (15)	13 (25)
Unknown	7 (5)	3 (5)
Duration of illness		
< 1 month	25 (16)	5 (9)
1-12 months	96 (63)	37 (70)
+ 12 months	25 (16)	9 (17)
Unknown	6 (5)	2 (4)
Diagnosis		
Lymphoma	40 (26)	17 (32)
Neuroblastoma	44 (29)	12 (23)
Rhabdomyosarcoma	21 (14)	8 (15)
Wilms'tumour	12 (8)	2 (4)
Others	35 (23)	14 (26)
Phase of disease		
Initial	102 (67)	35 (66)
Relapse	31 (20)	10 (19)
Others	19 (13)	8 (15)
Fever		
> 38.5°C	10 (7)	2 (4)
Neutropenia		
< 1500/mm ³	43 (28)	11 (21)
Anaemia		
< 9 g/100 ml	40 (26)	14 (26)
Pain treatment		
Yes	62 (41)	19 (36)

Means (and SD) of each item, the total DEGR^R score, and the DEGR^R dimensions are given in Table 4. The total DEGR^R score was distributed as shown in Table 5. Pearson's correlation coefficients between DEGR^R rating (total scores) and gender or age were not significant ($p>0.05$).

Furthermore, Pearson's correlation coefficients between DEGR^R rating (total scores) and psychosocial characteristics (frequency of the parents' visits, duration of the illness) or medical characteristics (diagnostic, phase of the disease,

fever, neutropenia and anaemia), described in Table 3, were all not significant ($p>0.05$).

Internurse agreement

The agreement between the two nurses was satisfactory: the weighted κ coefficients were significant for each of the 15 items (all with $p<0.001$), they varied between 0.28 (item 'Resignation') to 0.45 (item 'Indicating painful areas') (Table 4). The percentage of perfect agreement between the nurses varied between 39% (item 'Lack of expression') and 54% (item 'Indicating painful areas'), depending on the item. The percentage of marked disagreements, defined by a difference of three points or more between the ratings of the two nurses (ratings between 0 and 4), was less than 10% for each item.

Internal consistency

Cronbach α coefficient was 0.90, illustrating good internal consistency of the scale. (Behaviour specific to pain subscore: 0.93; psychomotor inertia: 0.84; anxiety: 0.74.)

Factorial structure

With PCA, the first factor explained 50% of the total variance, and the items (2, 4, 10 and 12) contributing the most to this factor were protective behaviours items. The second factor accounted for 15% of the total variance, and also contrasted the group of items measuring the expressions of pain (items 15, 14, 6 and 8) with the group reflecting psychomotor inertia (items 3, 5, 11 and 7) (Table 6).

All the behaviour specific to pain items contributed to the first factor. The items reflecting psychomotor inertia (3, 5, 7 and 11) contributed mainly to the second factor and were opposed to items 6, 8 and 15 (expression of pain). Except for item 12, anxiety items (items 1, 9, 15) did not contribute to the first two factors. Furthermore, item 3 was shown to be unstable in the different multivariate factor analyses.

TABLE 4. First part of the study : means, standard deviations and weighted κ of each item, the total DEGR^R score and the 3 DEGR dimensions ($n=146$). All weighted κ were significant with $p<0.001$.

	Mean			Standard deviation			Weighted κ
	Nurse 1	Nurse 2	Nurses 1+2	Nurse 1	Nurse 2	Nurses 1+2	
Items (0 to 4)							
1 :Tenseness	1.57	1.53	1.55	1.13	1.13	0.97	0.34
2 :Unnatural posture	1.23	1.26	1.24	1.23	1.35	1.14	0.44
3 :Resignation	0.70	0.83	0.76	0.91	0.99	0.78	0.28
4 :Protection of painful area	1.01	1.14	1.07	1.11	1.27	1.06	0.39
5 :Withdrawal	1.58	1.47	1.52	1.22	1.20	1.03	0.37
6 :Expressing pain	1.18	1.10	1.14	1.23	1.20	1.03	0.34
7 :Lack of expression	1.79	1.76	1.77	1.17	1.13	1.0	0.37
8 :Indicating painful areas	1.13	1.06	1.09	1.38	1.32	1.19	0.45
9 :Hostility	1.23	1.22	1.22	1.10	1.09	0.95	0.37
10 :Pain avoidance when moving	1.46	1.59	1.52	1.29	1.28	1.14	0.43
11 :Lack of interest	1.73	1.69	1.71	1.16	1.15	0.99	0.34
12 :Wariness at being moved	1.18	1.24	1.21	1.02	1.10	0.93	0.36
13 :Slowness of movement	1.77	1.96	1.86	1.12	1.12	0.98	0.44
14 :Reaction to examination	1.44	1.39	1.41	1.07	1.05	0.90	0.34
15 :Crying easily	1.05	1.08	1.06	1.07	1.24	0.99	0.37
Total DEGR ^R score (0 to 60)	20.1	20.3	20.2	11.2	11.6	11.4	0.71
DEGR ^R dimensions							
Pain behaviours (0 to 24)	7.46	7.54	7.5	5.8	6.24	3.4	0.68
Psychomotor inertia (0 to 20)	7.58	7.71	7.6	4.37	4.28	2.6	0.63
Anxiety behaviour (0 to 16)	5.04	5.06	5.05	3.25	3.48	2.0	0.65

SECOND PART OF THE STUDY

This second part was designed to study the convergent validity and the performance of the DEGR^R scale (Sackett *et al.*, 1997).

PATIENTS AND METHODS

A correlation was studied between pain specialists' scores and nurses' DEGR^R rating as it was done for CHEOPS (McGrath *et al.*, 1985). Out of the 152 children, 53 were video recorded. Parents' informed consent was required for recording the video. Each video recording lasted 30 min and included sequences of the medical examination, and sequences during washing, dressing, and game sessions.

The resulting video recordings were viewed and scored independently by a panel of four pain expert with a 0 to 7 Likert scale. This panel

consisted of one nurse, one physiotherapist, one psychologist and one paediatrician, all professionally experienced and considered as pain specialists. Prior to this, the only instruction given to the panel was a training by viewing a sample of various other video recording to score pain with a Likert scale. The video recordings were also assessed by the nurses using DEGR^R scale.

The degree of agreement between the four specialists was studied (κ coefficient using a modified version for categorical data and multiple observers) (Landis & Koch, 1977).

RESULTS

Inter specialist agreement

The degree of agreement between the pain specialists scores, measured by the κ coefficient, was 0.40. The percentage of marked disagreements,

TABLE 5. First part of the study: total DEGR^R score distribution ($n=146$; nurse 1 scores). The median is 20.

Total DEGR ^R score Distribution	0-3	3-6	6-11	11-20	20-28	28-40	40-49	50-60
	5%	5%	15%	25%	25%	20%	5%	0%

TABLE 6. First part of the study: principal component analysis ($n=152$): contributions and correlations of each item to the two axes, in order of contributions. The first factor explained 50% of the total variance, and the second factor 15%.

Item	Contributions (%)		Correlations (%)	
	First axis	Second axis	First axis	Second axis
2: Unnatural postures	0.31	-0.02	0.82	-0.03
4: Protection of painful areas	0.31	-0.12	0.82	-0.17
10: Pain avoidance when moving	0.30	-0.01	0.81	-0.02
12: Wariness at being moved	0.29	-0.24	0.76	-0.34
13: Slowness of movement	0.28	0.23	0.74	0.33
14: Reactions to examination	0.26	-0.26	0.69	-0.37
7: Lack of expression	0.25	0.36	0.66	-0.51
1: Tenseness	0.24	0.07	0.63	0.10
6: Expressing pain	0.24	-0.27	0.65	-0.38
11: Lack of interest	0.24	0.35	0.65	0.50
5: Withdrawal	0.23	0.37	0.61	0.53
8: Indicating painful areas	0.23	-0.26	0.61	-0.38
9: Hostility	0.22	0.06	0.57	-0.58
15: Crying easily	0.12	-0.23	0.32	-0.33
3: Resignation	0.09	0.43	0.23	0.62

defined by a difference of three points or more on a 0 to 7 Likert scale between two specialists' ratings, was 6% (3 cases).

Agreement between nurses' DEGR^R ratings and panel scores

The correlations between the individual nurses' DEGR^R total ratings and the individual pain specialists' scores, ranged from 0.74 to 0.87, were all significant ($p < 0.001$) (Table 7). These results indicated that the nurses' DEGR^R rating were highly correlated to the specialists scores.

Mean differences were assessed between standardised nurses' DEGR^R and standardised specialists' scores. This did not show any significant difference between the two assessments ($p < 0.01$).

Performance status of the scale as a diagnostic test

Table 8 shows the performance of DEGR^R scale according to the specialists' scores, assumed to be

true diagnoses. In order to emphasise sensitivity and positive predictive value, the cut off score was fixed at 12. If one assumes that a total DEGR^R score greater than 12 may indicate pain, the sensitivity of the scale is 87%, its specificity is 64%, its positive predictive value is 77%, its negative predictive value is 78%, for a prevalence of 58% of children in pain in the sample. The DEGR^R scale failed to detect pain in 7.5% (4 out of 53) of all cases, and several children without pain were classified wrongly as being in pain (15%, 8 out of 53).

DISCUSSION

We have presented here an important step in the validation of the DEGR^R scale, an observational rating scale for prolonged pain, in 152 child cancer patients aged 2-6 years.

With regard to the patient sample, some comments about selection of patients can be made. Only children with progressive cancer were included, because the DEGR^R scale was

TABLE 7. Second part of the study: correlation (Coefficient r , Pearson) between the nurse ratings (DEGR^R total score) and the pain specialist assessments (Likert scale). $n=53$ children. All correlations are significant at $p<0.001$.

Pain specialists' Likert score (0 to 7)	Nurses DEGR ^R total score (0 to 60)	
	Nurses 1	Nurses 2
Nurse	0.78	0.87
Physiotherapist	0.83	0.83
Psychologist	0.79	0.74
Pediatrician	0.74	0.80

intended for children likely to be in pain. Inclusion of all the children with cancer would lead to inclusion of a population of children (about 50%) without pain (Miser *et al.*, 1987), and therefore discriminant power could be reduced. The large size of the sample required a 3-year recruitment study. During this period, the only change was that analgesic prescribing became more frequent. We verified that the DEGR^R scale had the same structure (PCA) on the first 51 children included and the last 50 included.

This analysis confirmed that the DEGR^R demonstrated good reliability and validity. Both inter-rater agreement and Cronbach α coefficients (reliability) were good. The high percentage of the total variance explained by the multivariate analyses provide some evidence of content validity. The fact that the DEGR^R total score is independent of poor medical condition or psychological distress strengthened the construct validity. The high degree of agreement between the nurses' rating and the specialists' evaluations pointed to good convergent validity.

Among these 15 items, three dimensions are distinguished by multivariate analysis: protective behaviours, expression of pain and psychomotor inertia. Two of these are similar to the findings of a previous study (Gauvain-Piquard *et al.*, 1987), the third dimension (expression of pain) is a new one.

Four items contributed to the first dimension (unnatural posture, protection of painful areas, pain avoidance when moving and wariness at being moved). These items differ from molar physical movements previously used in acute pain behavioural scales, as described in the McGrath's review (McGrath, 1998). The difference is due to the fact that children older than 2 years have good neurological motor maturity and that, in our context, children had no limitation of mobility, except pain. Hence, more explicit qualitative behavioural changes can be observed in these children, such as guarded movement (Jaworski *et al.*, 1991) and abnormal patterns of movement, as observed by Truckenbrodt (1993) in children with juvenile rheumatoid arthritis.

The second dimension comprises pain expression items (crying easily, reactions to examination of painful area, expressing pain and indicating painful area). It contributed only to the second factor, and thus was opposed to items of psychomotor inertia. Interpretation can be the following: when a child in pain displays psychomotor inertia, he is unable to complain; or, when a child in pain is able to complain and explain his pain, he usually presents only mild psychomotor changes. In our clinical practice, the first case occurs in prolonged intense or diffuse pain, the second in recent mild localised

TABLE 8. Second part of the study: performance of the DEGR^R scale ($n=53$). Children in pain are defined here as having at least a specialist's score greater than 2. Sensitivity = $a/(a+c) = 87\%$; specificity = $d/(b+d) = 64\%$; positive predictive value = $a/(a+b) = 77\%$; negative predictive value = $d/(c+d) = 78\%$; prevalence of pain = $(a+c)/(a+b+c+d) = 58\%$.

Total DEGR ^R score	Specialists' scores		
	Children in pain	Children without pain	Total
> 12	a=27	b=8	35
≤ 12	c=4	d=14	18
Total	31	22	53

pain. This assumption is similar to that of McGrath (1998), who speculates that many behaviours habituate when pain persists. More psychometric work is needed in exploring this phenomenon.

The third dimension comprises psychomotor inertia items (resignation, withdrawal, lack of interest in surroundings, lack of expression and slowness and paucity of movement). This dimension was referred to as depression-like in our previous study. It contributed to the two first factors, and thus was opposed to items of expression of pain. This confirms that psychomotor inertia is an important sign of pain, but is not always present when a child is in pain. Likewise, psychomotor inertia is not usually a feature on which pain assessment is based, although it has been partially described in earlier articles (Burton & Derbyshire, 1958; McCaffery, 1977; Wall, 1979; Stoddart, 1982; Fosburg & Crone, 1983; Kavanagh, 1983; Mather & Mackie, 1983; Taylor, 1983), and then more recently has been considered as a pain response (Mills, 1989; Zeltzer & Zeltzer, 1989; Eland, 1990; McCready *et al.*, 1991). A child exhibiting psychomotor inertia appears sad and immobile from the end of the bed. His gestures are slow and movements are rarely initiated, even well away from painful area. He reduces communication with the outside world and seems 'to have no fight left in him'. When moved, the child remains passively in the new position, 'too well-behaved'. He does not display any overt distress behaviour. (Toddlers are normally extremely active individuals, rarely resting for any reason.) In our experience, psychomotor inertia responds remarkably well to major analgesic treatment. This fact strongly suggests that pain is the main cause.

This symptomatology is very close to that seen in several clinical conditions: (1) chronic pain behaviour in adult (Wall, 1979), or recuperative phase of pain in which Bolles and Fanselow (1980) suggested that pain inhibits other kinds of motivation; (2) retardation associated with depression in adult (Hardy *et al.*, 1984) or in infant (Spitz, 1951). Confusion between the two conditions is easy (Steif & Heiligenstein, 1989), for instance Poznanski *et al.* (1979) elaborated their scale (Children Depression Rating Scale),

one of the most famous, in 30 children with severe organic pathologies, such as metastatic neuroblastoma, and possibly in severe pain; (3) sickness behaviour, such as fatigue and malaise (Hart, 1988); (4) changes in behavioural state induced by disturbing, repetitive stimuli in neonates (Brazelton, 1977) and premature infants (Newman, 1981)—the baby 'shuts down' by going into a deep sleep, flaccid but with extremities tightened and little 'jerky startles'. This behavioural pattern is also seen in response to a noxious stimulus (Franck, 1993); (5) passive coping behaviour (Broome *et al.*, 1990); (6) learned helplessness, as observed by Kavanagh (1983) and Kavanagh *et al.*, (1991). It has been interpreted as a stress-induced analgesia (Maier, 1983) described as 'passivity and withdrawal (rather than fight or flight) with apparent analgesia in response to uncontrollable painful events'. Our data lead us to question this interpretation.

It is difficult to understand the theory behind this. Are these six observations expressions of the same behavioural pattern? Feelings of isolation and depression are certainly part of pain experience, but this extreme lack of movement is reminiscent of the immobilisation reaction in animals faced with pain or danger (Wall, 1979; Bolles & Fanselow, 1980; Porro & Carli, 1988). Furthermore, the experience of pain probably induces a combination of distorted body image and diminished perception of non-painful sensations which may contribute to this phenomenon.

Two major factors could interfere with prolonged pain assessment in young cancer patients: the effect of emotional distress and poor medical condition of the patient (construct validity). The fact that the DEGR^R rating are independent of possible causes of psychosocial distress (absence of parents' visits, duration of illness, bad prognosis related to diagnosis and phase of the disease) or poor medical condition (fever, neutropenia and anaemia) is an indication that the DEGR^R scale concentrates on measuring pain rather than another emotional distress. In fact, the present DEGR^R scale does not contain any distress behaviour items included in other scales (Katz *et al.*, 1980; Jay *et al.*, 1983). However, the variables chosen here may be over-simplified. For instance, the mood

of the children was not directly investigated, but only indirect items such as the frequency of the parents' visits or the prognosis were recorded.

Convergent validity requires comparison of the DEGR^R scale with an external reference. Since no other behavioural scale was available for prolonged pain in young children, our solution was to compare the DEGR^R ratings with the scores of a pain specialist committee. The results showed a high correlation between the ratings obtained by non pain-educated nurses using the DEGR^R scale and the pain specialists with clinical experience, and also did not show any significant difference between them.

Concerning the performance of the scale, the two important indices emphasised here are sensitivity and positive predictive value, rather than specificity and negative predictive value. In a practical setting, the DEGR^R scale score serves as an alarm signal, and then a physical examination confirms the pain status of the child. In this respect, the level of false negative scoring (7.5%) appeared quite satisfactory.

CONCLUSION

In summary, the DEGR^R scale displays high reliability and validity for assessing persistent pain in young children, and we believe that it could be useful both in the clinical setting and in research.

Further studies are needed to confirm the accuracy of the generalisability of the DEGR^R scale. With regard to children's age, in our clinical practice the DEGR^R is a good assessment of pain in children under 6 years, but not for the older ones, because of their increasing ability to control their pain responses.

However, further research is needed to confirm the validity of the DEGR^R scale, such as using the scale in contrasted populations, testing it before and after analgesic treatment, and using it concurrently with self-reports and parents' ratings.

'The tendency to underestimate suffering in other may be a robust phenomenon with potentially serious consequences for the sufferer', concluded Prkachin *et al.* (1994) in a study in adults with shoulder pain. This tendency could well

explain the severe undertreatment of pain in young children. Observers may not be sensitive to specific components of pain responses. The DEGR^R scale highlights several little-known persistent pain-related behaviours in young children, and may help care teams to recognise them, and thus avoid overlooking severe pain in young children.

ACKNOWLEDGEMENTS

This work was supported by IGR Grant N° 84D3, and by INSERM CNAMTS 85/3/33/2/E. We wish to thank all the staff of the paediatric unit who participated in this study. We particularly wish to thank the members of the specialist committee: Chantal Kalifa, paediatrician, Nathalie Lecuyer, psychologist, Micheline Cosse, physiotherapist, France Lesbros, nurse, and Rainer Harnisch (+) psychiatrist. We also wish to thank Pierre François for videorecordings. Thanks are also due to Pr Fermanian, J.P. Benzecri, A. Verdier, R. Hain, G.W. Hanks, C. Hills and C Wood for their kind assistance.

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