

Pain assessment in intellectually disabled people: non-verbal indicators

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Background. Although important progress has been made during the past decade, research on pain in people with intellectual disabilities is still scarce. Pain assessment in people with intellectual disabilities is a frequent and difficult problem, especially for nurses working with people with intellectual disabilities on a daily basis. Gathering more information about pain in people with intellectual disabilities is of major importance and relevance for nursing, and adds to the developing body of knowledge.

Objective. To investigate the nature and relative importance of non-verbal indicators used by nurses to assess pain in people with a severe or profound intellectual disability.

Methods. A questionnaire consisting of 158 indicators of pain was used. A total of 135 nurses from nine institutions specializing in the care of people with intellectual disability were asked to rate each indicator on a scale of 1–10 to show which non-verbal expressions they considered important in diagnosing pain.

Results. A total of 109 nurses responded. All 158 indicators were mentioned as being important to indicate pain. All except four had a range of 9. Seven (moaning during manipulation, crying during manipulation, painful facial expression during manipulation, swelling, screaming during manipulation, not using (affected) body part, and moving the body in a specific way of behaving) were reported as 'very important' by more than 50% of nurses. The lowest score (median 5.5; minimum 1, maximum 10) was given to the indicator 'waving arm movements'. The pain of people with severe intellectual disability appeared to be assessed differently from that of people with profound intellectual disability. Indicators belonging to the

'physiological' category scored relatively higher in the group of nurses specializing in profound disability. In contrast, indicators belonging to the 'social-emotional' category were scored relatively higher by nurses specializing in severe disability.

Conclusion. Nurses used a wide range of indicators to assess pain in people with intellectual disability. Functional abilities and level of disability seem to influence the indicators used.

Keywords: intellectual disability, pain assessment, indicators, nurse

Introduction

Pain is always a subjective and complex response, and different people may react in different ways to the same stimulus, or the same person may react differently in different situations or at different moments (Pigeon *et al.* 1989). Assessing pain can be extremely difficult if the person has a severe or profound intellectual disability and lacks the ability to communicate verbally. Gathering more information about pain in people with intellectual disabilities is of major importance and relevance for nursing, and adds to the developing body of knowledge. Discovering what nurses, health care workers, and parents consider important is the first step in understanding pain in people with an intellectually disability. Having a clear insight into pain is necessary for the development of a valid and reliable assessment scale for use with people with an intellectual disability.

Assessment of pain allows nurses to detect and relieve it in clients. Without objective assessment, pain could be misinterpreted or underestimated, which might lead to inadequate management and undermine quality of life (Malviya *et al.* 2001). The preliminary findings of a recent study suggest that everyday pain in people with severe intellectual disability is common, yet is rarely actively treated (Stallard *et al.* 2001). Concurrent health problems, directly or indirectly linked to the disability, often lead to painful situations. An example is gastroscopy, a medical procedure performed in suspected gastro-oesophageal reflux, which is a common condition in people with severe or profound intellectual disability (Tracy & Wallace 2001). People with this level of intellectual disability are more likely to have other disabling conditions, or to have multiple complex medical problems coupled with communication difficulties. Recent studies showed that people with intellectual disability appeared to have 2.5 times more health problems than people without intellectual disability (Van Schrojenstein Lantman-De Valk *et al.* 2000).

Few studies on pain among people with intellectual disability have been published. There are several reasons why pain assessment in this group of people has lagged behind. To begin with, many have neurological problems that

may alter the neurological system and affect their ability to comprehend and communicate pain (Oberlander *et al.* 1999). In view of an inability to communicate pain verbally and a relative lack of intellectual ability, the gold standard of pain measurement, i.e. self-report, cannot be used. Furthermore, people with severe and profound intellectual disability often have multiple handicaps and form an extremely heterogeneous group in terms of functional and behavioural repertoires. Behaviour that is typically associated with pain may well appear at times when they are not in pain, or behavioural limitations may mask expressions of pain (McGrath *et al.* 1998). Although, recently, more information about expressive behaviour related to pain in people with intellectual disabilities has been gathered (Fanurik *et al.* 1999, Oberlander & O'Donnell 2001, Stallard *et al.* 2001, Carter *et al.* 2002, Donovan 2002, Hadden & von Baeyer 2002, Stallard *et al.* 2002a), research on this topic is still scarce. Only a few tools for assessing pain in this specific population have been developed, most of which have been psychometrically tested in a paediatric population (Breau *et al.* 2001, 2002a, 2002b, Collignon & Giusiano 2001, van Dongen *et al.* 2002, Hunt *et al.* 2002, Stallard *et al.* 2002b).

Giusiano *et al.* (1995) developed a scale consisting of 22 items that physicians felt were indicative of pain. Results provide evidence of a common set of pain behaviours in people with cerebral palsy and severe intellectual disabilities. Different items were found to be important in determining pain, depending on the person's level of development. Collignon *et al.* (1997), members of the same research group as Giusiano, later developed a 10-item observational scale to evaluate pain and facilitate therapeutic decisions in children with severe handicap and adults with cerebral palsy. This study built on their earlier work. Recently, Collignon and Giusiano (2001) concluded that this tool seems to be sensitive and reliable enough to assess pain in this population.

McGrath *et al.* (1998) created a checklist of 31 behaviours that caregivers could use to assess pain in people with intellectual disability who lack verbal communication. Breau *et al.* (2002a) report that a revised version of the Non-Communicating Children's Pain Checklist (Breau *et al.*) is

internally consistent, sensitive and specific to pain, and produces results that are significantly related to pain intensity ratings provided by caregivers and consistent over time. In addition, Stallard *et al.* (2002a) conducted a study that explores the expression of chronic pain in non-communicating children with a significant intellectual disability. As a result of this study, six core items were identified and the Pain Indicator for Communicatively Impaired Children (PICIC) was produced. In a further study, Stallard *et al.* (2002b) demonstrated a significant relationship between five of the six core items and the presence and severity of pain.

In an ongoing programme of research in the Netherlands, van Dongen *et al.* (1999) have conducted several studies to gain insight into non-verbal pain expressions in children and adolescents with severe intellectual and communicative disabilities. This ongoing programme should, ultimately, lead to the development of an instrument to assess pain in children with profound intellectual and verbal disability. In addition to a review of the literature, these researchers used qualitative methods as a first step in creating an item bank that consists of 209 expressions of pain. In view of this overwhelming number, the study presented in this paper was designed to evaluate the importance of a number of these non-verbal expressions, by investigating which indicators nurses consider important in diagnosing pain in people with severe and profound intellectual disability. In particular, the study aimed to investigate: (1) the nature, frequency and relative importance of the indicators that nurses use to determine pain in people with severe or profound intellectual disability; and (2) the differences between two groups of nurses (those working only with people with severe intellectual disability vs. those working only with people with profound intellectual disability) in terms of the indicators considered important.

The study

Objective

The objective of the study was to investigate the nature and relative importance of non-verbal indicators used by nurses to assess pain in people with a severe or profound intellectual disability.

Defining the research population: 'severe or profound intellectual disability'

According to the American Association on Mental Retardation (AAMR):

Mental retardation is a disability characterized by significant limitations in both intellectual functioning and conceptual, social, and practical adaptive skills. This disability originates before age 18. (AAMR 2002, p. 19)

Furthermore, the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV) distinguishes four levels of 'mental retardation', based on intelligence quotient (IQ) scores, namely: mild (IQ 50–70), moderate (IQ 35–49), severe (IQ 20–34) and profound (IQ below 20) (American Psychiatric Association 1994). Although the term 'mental retardation' is still valuable in terms of diagnostic use, it had been replaced by several other terms. 'Cognitive impairment', 'neurological impairment', 'developmental disability' and 'intellectual disability' are often used in the literature, usually to describe the same condition. The term 'intellectual disability' is preferred for several reasons. The World Health Organization (2002) and the International Association for the Scientific Study of Intellectual Disabilities (IASSID), which is a sister organization of the AAMR, also use the term 'intellectual disability'. Furthermore, the term is used in a number of journal names all with clear links to 'mental retardation'.

Participants

As self-reports cannot be obtained, acquiring information on behaviour related to pain requires informants who are expert at observing and interpreting pain. Because of their expertise, nurses and other health care workers were expected to be able to provide pain-relevant information about the people they cared for on a regular basis. They were expected to know which behaviours were indicative of pain and to be sensitive to clients' ability to communicate without expressive language. Therefore, in our study, nurses specializing in nursing people with intellectual disabilities (children and/or adults) were asked to complete a questionnaire. While this article focuses on nurses, parents are another important source of information about pain. In an ongoing study (van Dongen *et al.* 2002b), information from parents is being gathered on indicators that they use to determine pain in children with severe or profound intellectual disability who are living at home.

Methods

A cross-sectional design was used to answer the research questions. Nurses were selected from nine residential homes throughout the Netherlands, specializing in the daily care of people with severe and/or profound intellectual disability.

More than 1 year of experience in this specific field of nursing was required. In each institution, a contact person was designated who was responsible for distributing and collecting questionnaires. A covering letter, detailing aims and procedures, was sent with the questionnaire and nurses were asked to respond within 2 weeks. Of the 135 nurses that were invited, 109 eventually participated, 96 women and 13 men.

Questionnaire

The questionnaire was developed especially for this study. A total of 158 possible indicators of pain was included, based on the results of an ongoing project (van Dongen *et al.* 1999) and existing pain measurement scales for people with intellectual disability (Giusiano *et al.* 1995, McGrath *et al.* 1998).

The first part of the questionnaire sought demographic information, including gender, educational level and years of experience working with people with intellectual disability. The second part listed the 158 indicators. A 10-point scale was used for responses, with one indicating that an item was ‘not important at all’ as an indicator of pain and 10 indicating that it was ‘very important’ (see Table 1). The 158 indicators were divided into seven categories: facial (*n* = 26 items), vocal (*n* = 24), motor (*n* = 32), physiological (*n* = 22), social-emotional (*n* = 28), injured body part (*n* = 11) and activities of daily life (*n* = 15). The categories were based on a facet design, in order to improve face and content validity, and related to the ways in which pain can be expressed non-verbally. A facet design is a scheme covering all the relevant dimensions of a construct that is going to be measured (Shye 1978). Categories, as well as indicators, were based on comparison of common categories of existing scales for the measurement of pain in non-verbal populations and scales developed for the assessment of communication in people with profound intellectual disabilities (McGrath *et al.* 1985, Velthausz 1987, Mills 1989, Van der Maat 1992, Wielenga 1994, McGrath *et al.* 1998). Nurses were asked whether or not the questionnaire was comprehensive and could suggest additional indicators.

Content validity was further tested by consulting 11 experts in the field of intellectual disabilities. Data on reliability will be presented in the results section.

Ethical considerations

Permission to conduct the study was obtained from the managing directors of the institutions, who gave permission to consult nurses. Each institution was asked to provide the names of 15 nurses who might be willing to participate in the study. Nurses were approached through each institution’s contact person and participated on a voluntary basis.

Data analysis

All data were analysed using SPSS 10.0. Descriptive statistics were generated for the characteristics of the participants. The indicators that nurses used to identify pain were examined using frequency tables. Both medians and trimmed means were computed and are reported in the paper. The 5% trimmed means were computed by ranking the values within each group from the smallest to largest, trimming 5% from the top and 5% from the bottom of each group, and then computing the usual means for the remaining observations. This procedure ensures that unusual values in the tails of the distribution do not affect the value of the mean. However, emphasis is placed on the median, as data are not normally distributed and, strictly speaking, trimmed means should be regarded as parametric statistics. Current literature, however, shows a growing interest in trimmed means taking into account outliers while still information on distribution can be provided (Wilcox 2001). Ranking is based on valid percentage scores. Non-parametric Mann–Whitney *U*-tests were used to investigate whether there was a significant difference between the ways in which nurses in the two study groups assessed pain. Because of the risk of type-I errors, alpha was set at 0.001 in order to correct for multiple testing.

Internal consistency analyses were carried out for all seven categories. Table 2 shows high Cronbach’s alpha values for

Table 1 Pain indicator section from the questionnaire (for the ‘vocal’ category)

How important are the following indicators for identifying pain in severely or profoundly intellectually disabled individuals?										Very
	Completely unimportant									important
(1) Verbal expressions	1	2	3	4	5	6	7	8	9	10
(2) Moaning/groaning	1	2	3	4	5	6	7	8	9	10
(3) Moaning during manipulation	1	2	3	4	5	6	7	8	9	10
(4) Moaning more than usually	1	2	3	4	5	6	7	8	9	10
(5) Crying	1	2	3	4	5	6	7	8	9	10

Table 2 Comparison of mean scores from three different groups of nurses over the seven categories of indicators as well as internal consistency

Category	Description of the category	Number of indicators	Cronbach's alpha	Mean overall group ($n = 109$)	Mean severe group ($n = 14$)	Mean profound group ($n = 42$)
1	Facial	26	0.97	7.3	6.9	7.2
2	Vocal	24	0.96	7.5	7.2	7.4
3	Motor	32	0.97	7.0	6.5	6.9
4	Physiological	22	0.97	7.9	7.0	7.9
5	Social emotional	28	0.96	6.8	6.8	6.6
6	Injured body part	15	0.96	7.6	7.3	7.3
7	Activities of daily life	11	0.95	7.4	7.8	7.3

all categories, ranging from 0.95 to 0.97. Furthermore, it can be reported that all item-total correlations were over 0.4.

Results

Participants

Questionnaires were returned by 89.6% of nurses ($n = 121$). Twelve questionnaires were excluded: five were incomplete, four were not related to pain in people with severe or profound intellectual disability, and three because nurses had less experience than was required.

Nurses ranged in age from 21 to 50 years (mean = 32.2; $SD = 6.6$ years). With regard to nurses' education, the vast majority (94.5%, $n = 103$) had completed in-service education provided by the institution (diploma level), but only two had completed Middle Level Professional Education in Nursing and four a Higher Professional Education in Nursing. The mean number of years of experience in nursing was 8.8 ($SD = 6.7$ years) and the mean number of years of experience with the client group was also 8.8 ($SD = 6.0$ years). Many nurses (43%, $n = 47$) worked full-time and only three were employed for less than 15 hours a week. Thirty-eight per cent were working primarily with people with profound intellectual disabilities, 13% with people with severe intellectual disabilities, and 49% were involved with both.

Pain indicators used by nurses

The first research question related to the nature, frequency and relative importance of the indicators that nurses used to determine pain in people with severe or profound intellectual disabilities.

To assess which of the seven categories nurses considered most important in determining pain, means were computed using the summed scores of the indicators in each category. Table 2 shows that the 'physiological' category achieved the highest overall mean score (7.9), while the 'social-emotional' category (mean = 6.8) was less frequently classed as being

important. The 109 participants scored a wide variety of indicators as important for assessing pain in people with severe or profound intellectual disability. All 158 indicators were selected at least once as being important, and 94.5% of respondents thought that combinations of indicators were important in assessing pain. The list of 158 indicators seemed to be content valid, as only two relevant additional items were mentioned as being possibly indicative of pain.

All indicators had a range of 9 (minimum 1, maximum 10), except for 'mood changes' (3–10), 'reacting differently to nursing staff' (5–10), 'facial expressions' (4–10) and 'pale-ness' (3–10). Furthermore, it can be reported that the lowest score, was given to the indicator 'making waving arm movements' (median 5.5; minimum 1, maximum 10; trimmed mean 5.39; $SD = 2.48$). Based on calculated medians, the highest item scores, for the overall sample were given to the indicators 'moaning during manipulation (of the affected body part)', 'crying during manipulation', 'painful facial expression during manipulation', 'swelling', 'screaming during manipulation', 'not using (affected) body part', and 'moving the body in a specific way of behaving'. These seven indicators were reported as 'very important' (10 on a 10-point scale) by more than 50% of nurses and are presented in Table 3. Ranking is based on valid percentage of nurses scoring a 10.

Severely vs. profoundly disabled clients

The second research question referred to the difference between nurses caring only for people with severe intellectual disability ($n = 14$) and those caring only for people with profound intellectual disability ($n = 42$). A comparison was made in terms of the indicators that they considered important in determining pain in their clients. The remaining nurses ($n = 53$) were taking care of both groups.

In the group of nurses working with people with severe disabilities the indicator 'unusual way of crying' received the highest score (median 10; minimum 1, maximum 10; trimmed mean 8.6; $SD = 3.02$). In this group, only this single

Table 3 The highest scoring indicators based on the medians which scores 10 in the overall group ($n = 109$)

Indicator	Minimum/ maximum	Valid percentage (median = 10)	Trimmed mean; SD
Moaning during manipulation	1/10	60.2	9.29; 1.76
Crying during manipulation	1/10	58.7	9.30; 2.11
Painful facial expression during manipulation	1/10	56.1	9.43; 1.80
Swelling	1/10	54.1	9.22; 1.98
Screaming during manipulation	1/10	52.8	8.95; 2.36
Not using (affected) body part	1/10	51.9	9.24; 1.99
Moving the body in a specific way of behaving	1/10	50.9	8.82; 2.38

indicator received such a high score. All other computed medians were lower than 10. Several indicators, all referring to eating and drinking, also scored high in this group, 'refusing to drink' (median 9; minimum 5, maximum 10; trimmed mean 9.06; SD 1.66), 'refusing to eat' (median 9; minimum 4, maximum 10; trimmed mean 9.01; SD 1.56), and 'eating little' (median 9; minimum 7, maximum 10; trimmed mean 8.82; SD 1.05). These indicators were of less importance in determining pain for nurses working with clients with profound intellectual disability.

The scores of nurses caring for those with profound disabilities ($n = 42$) were more similar to those of the total group ($n = 109$). Within this group, the following indicators were considered most important (median for all indicators = 10): 'screaming during manipulation' (minimum 1, maximum 10; trimmed mean 8.70; SD 2.79); 'painful facial

expression during manipulation' (minimum 1, maximum 10; trimmed mean 9.49; SD 1.48); 'moaning during manipulation' (minimum 2, maximum 10; trimmed mean 9.40; SD 1.65); 'crying during manipulation' (minimum 1, maximum 10; trimmed mean 9.31; SD 2.44); 'swelling' (minimum 1, maximum 10; trimmed mean 9.24; SD 1.84); 'not using affected body part' (minimum 2, maximum 10; trimmed mean 9.19; SD 1.72), and 'moaning more than usually' (minimum 1, maximum 10; trimmed mean 8.96; SD 2.13). Six of the seven indicators mentioned by nurses working with people with profound disabilities as being most important also occurred in the highest scoring indicators for respondents as a whole (Table 3).

Although the group of nurses working with people with severe disabilities was not very large ($n = 14$), there seemed to be some differences between the way they assessed pain

Table 4 Indicators with largest relative differences in medians between nurses working with severely intellectually disabled individuals ($n = 14$) and those working with profoundly disabled individuals ($n = 42$)

Indicator	Category	Median profound ($n = 42$)	Minimum/ maximum	Median severe ($n = 14$)	Minimum/ maximum	P-value
Moaning during manipulation	Vocal	10.0	2/10	8.0	1/10	0.000*
Crying during manipulation	Vocal	10.0	1/10	9.0	1/10	0.014
Turning red in the face	Physiological	8.0	1/10	6.0	1/10	0.034
Seeking comfort	Social-emotional	6.0	1/10	8.0	1/10	0.036
Vomiting	Physiological	9.0	1/10	7.0	1/10	0.040
Being grouchy	Social-emotional	6.0	1/10	7.0	5/10	0.042
Gasping for breath	Physiological	9.0	1/10	8.0	1/10	0.048
Change in respiration	Physiological	9.0	1/10	8.0	1/10	0.051
Decreasing heart rate	Physiological	8.0	1/10	7.0	1/10	0.051
Moaning	Vocal	9.0	3/10	8.0	1/10	0.059
Eating little	Activities of daily life	8.0	1/10	9.0	7/10	0.062
Increasing heart rate	Physiological	8.0	1/10	6.5	1/10	0.067
Breath holding	Physiological	8.0	1/10	7.0	1/10	0.079
Being angry	Social-emotional	6.5	1/10	7.5	1/10	0.086
Increased grimacing	Facial	9.0	1/10	8.0	5/10	0.088
Irritable, cranky	Social-emotional	6.0	1/10	7.0	5/10	0.091
Stretching the body	Motor	8.0	1/10	6.0	1/10	0.100
Refusing to eat	Activities of daily life	8.5	1/10	9.0	5/10	0.103

A non-parametric test (Mann-Whitney *U*-test) was used to test for differences between groups.

*Significant difference, P -value < 0.001.

and the way it was assessed by nurses working with people with profound disabilities ($n = 42$). Using an α of 0.001, a Mann-Whitney U -test indicated that, strictly speaking, only the indicator 'moaning during manipulation' showed a clear significant difference. Table 4, however, presents the 18 indicators with the largest relative differences in medians. Since a plot of the P -values did not show a clear cut-off point, this absolute line was drawn because the 19th indicator was the first indicator not to show an absolute difference in median between the groups of nurses.

Table 4 presents relative differences in the median scores for indicators, which show a trend that is relevant to comparing the two groups of nurses. It shows that indicators belonging to the 'physiological' and 'vocal' category scored relatively higher in the group of nurses specializing in profound disability. In contrast, indicators belonging to the 'social emotional' and 'activities of daily life' categories were scored relatively higher by nurses specializing in severe disability people.

Discussion

We used a cross-sectional design and questionnaires focusing on the non-verbal indicators that nurses consider important in assessing pain in people with severe or profound intellectual disability. Some limitations need to be addressed before conclusions can be drawn.

First, the results must be interpreted with caution, given the limited number of respondents ($n = 109$), and the large number of indicators ($n = 158$) included in the questionnaire. Respondents were selected from nine institutions, a factor which limits generalizability. Second, there is the problem that the people cared for by respondents were very heterogeneous in terms of age, abilities and disabilities, behaviour and health status, and this poses the question of whether it is feasible to answer questions in relation to such a broad spectrum of people. This may explain the large number of indicators that were regarded as important. Furthermore, the nurses in this study provided information based on their estimation of the severity of disability. Although it is not uncommon to use the judgments of respondents to assess the severity of disability (Fanurik *et al.* 1999), it might have been better to verify the correctness of this judgement by using a more objective assessment method. Third it can also be questioned whether nurses are able to provide pain-relevant information in a situation that does not allow self-assessment. So far, however, there is no hard evidence that nurses working on a daily basis with people with severe or profound intellectual disability are insensitive to changes in pain behaviour.

The aim of the study was to examine the nature and relative importance of the indicators that nurses use to determine pain in people with severe or profound intellectual disability. The analysis showed that all indicators were rated as important by at least one respondent. This suggests that nurses used a multitude of indicators in assessing pain in this client population. Several explanations for these results can be proposed. First, nurses working with people with severe or profound intellectual disability in a residential setting may use all possible pain-relevant information and, therefore, choose a broad range of pain indicators. Our findings suggest that many behaviours and signs that occur during painful events are used to identify pain.

Another explanation for our findings might be that the numerous pain indicators included in the questionnaire showed some overlap and sometimes only differed from another slightly. The indicators may have been too specific, reducing their power of discrimination as is underlined by the high internal consistency ratings. Furthermore, nurses were asked what indicators seemed to be important in determining pain. This question might be one of the reasons why almost all indicators had a range of 9. More relevant information might have been gathered by means of a more specific question, such as 'Imagine a painful situation. What indicators occur when a client is exposed to this situation?' A third explanation might relate to individual pain responses. It is conceivable that specific indicators would have to be selected for specific people. The wide range found for almost every indicator might underline the importance of individual pain responses. Pain is a complex response, in that the same person may react differently in different situations and at different times, and in that different people may react differently to the same stimulus. This complexity, and the heterogeneity of clients, may well explain why such a large number of possible cues was selected by nurses. This might suggest that nurses do not want to discriminate between possible pain indicators in these people, as is also suggested by the wide range found for almost all indicators.

However, seven indicators were considered as being very important by more than half of the 109 participants, namely: 'moaning during manipulation'; 'crying during manipulation'; 'painful facial expression during manipulation'; 'swelling'; 'screaming during manipulation'; 'not using affected body part' and 'moving the body in a specific way of behaving'.

For the most part, these indicators were derived from 22 items described in a study by Giusiano *et al.* (1995) and refer to medical examination. Thus, in diagnosing pain, nurses seem to rely mostly on behaviours relating to the situation in

What is already known about this topic

- Pain in people with intellectual disabilities remains an under-researched area.
- Earlier studies have provided information about complexities in this specific area and a few studies have focused on pain assessment.
- Pain assessment in this population has been shown to be complex but is of major importance for nurses and clients.

What this paper adds

- This paper provides information about the nature and relative importance of non-verbal indicators used by nurses to assess pain in severely or profoundly intellectually disabled people.
- Gathering information about what nurses consider important is a significant step in understanding about pain in people with intellectual disabilities, and could improve their assessment and management.

which they occur. In this context 'moaning during manipulation' is regarded as more important (median 10; minimum 1, maximum 10; trimmed mean 9.29; SD 1.76) than 'moaning more than usually' (median 9.5; minimum 1, maximum 10; trimmed mean 8.93; SD 1.87), which on its own is regarded as more important than just 'moaning' (median 9.0; minimum 1, maximum 10; trimmed mean 8.64; SD 1.90). In addition to items relating to a context of medical examination, symptoms of nociception are also regarded as being important in labeling behaviour as pain behaviour. These findings are underlined by the result that, in respondents as a whole, the 'physiological' category had the highest mean score (mean = 7.9) of all the categories, although many of the items belonging to this category are, in fact, symptoms rather than pain indicators.

Three of the seven indicators rated as most important by respondents as a whole are in the 'vocal' category. These findings are in line with those of other researchers who have stressed the importance of vocal information when diagnosing pain in people with profound intellectual disabilities. Donovan (2002), for example, found that nurses caring for a mostly preverbal population of people with intellectual disability reported that crying was often the only indication of pain. This finding is supported by Carter *et al.* (2002) who also report that, according to parents, vocalizations such as crying and moaning are often key means of pain expression in children with profound

special needs. In their study, facial expression was another important indication that a child was in pain. Other authors have stressed the importance of both facial and vocal expressions of pain in people with severe intellectual disabilities (Breau *et al.* 2002a, 2002b, van Dongen *et al.* 2002, Stallard *et al.* 2002a, 2002b). In our study several items relating to facial expression of pain were also rated as being important, although the 'facial expression' category was not among the most highly rated. The high number of detailed indicators within this category might explain this finding.

Another aim of our study was to examine differences in pain indicators used by nurses for people with severe vs. profound intellectual disability. Although the group of nurses specializing in severe disability was small ($n = 14$), the results suggest that there are differences in this respect, as nurses in the two groups referred to different indicators as being important. Medians calculated were generally higher in the 'profound disability' group. Significantly different scores were found for the indicator 'moaning during manipulation'. Although not statistically significant, the indicator 'crying during manipulation' showed a relatively higher score in the group of nurses working with people with profound disability. Both these indicators belong to the 'vocal' category. This finding might indicate that nurses working with people with profound disabilities search for pain-relevant information more actively. This client group often have very limited verbal communication, leading to greater difficulties in identifying and assessing pain. Several of the physiological indicators, such as 'gasping for breath', 'vomiting' and 'turning red in the face', were also given relatively higher scores by those specializing in profound disability. By contrast, relatively higher scores on the indicators 'seeking comfort' and 'being grouchy' show the importance of social-emotional indicators to nurses caring for people with severe disability. Furthermore, verbal expression was important for nurses diagnosing pain in clients with severe intellectual disability. The differences between nurses specializing in severe disability vs. those specializing in profound disability seem to relate to the functional abilities of clients as well as their levels of intellectual disability. Although not resulting in significantly different scores, three indicators relating to eating and drinking aspects of the 'activities of daily life' category seemed to be rated differently by nurses working with clients with severe disabilities, as shown by higher median scores.

Conclusions

Studies contributing further to the understanding of pain in people with severe and profound intellectual disability would expand the knowledge base of nursing science. Research in this

area of pain has important implications for nursing practice and patient care. Nurses play a unique role in pain assessment and management. They are at the bedside for long periods of time and have major responsibilities during the whole process. Without objective assessment, pain could be misinterpreted or underestimated, which might lead to inadequate pain management and undermine quality of life. Therefore, nurses need a set of valid and reliable 'pain indicators' to identify pain. The more specific and accurate the pain assessment, the more adequate nursing interventions could become, which would obviously be in patients' and nurses' best interests. It is hoped that the findings of our study will stimulate further research in this highly specific area, which could contribute to more effective assessment and management of pain by nurses.

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