Better than health professionals at assessing pain in their child and feel that health professionals ignore their expertise (Carter, McArthur, & Cunliffe, in submission; Ljungman, Gordh, Sorensen, & Kreuger, 1999). Some studies find caregivers underestimate or undermedicate pain (Chambers, Reid, McGrath, & Finley, 1996; Finley, McGrath, Forward, McNeill, & Fitzgerald, 1996). Chambers, Reid, Craig, McGrath, and Finley (1999) argue there is a lack of agreement between studies exploring caregivers’ ability to assess pain, with methodological problems making the findings unclear. Most studies are based on caregivers’ perception of pain in children without learning disabilities and therefore may not reflect caregivers’ assessment of pain in their noncommunicating child.

Two groups of researchers have devised scales for assessing pain in noncommunicating children,
specifically those with cerebral palsy. Giusiano, Jimeno, Collignon, and Chau (1995) developed a scale consisting of 22 items that medical staff considered to indicate pain. McGrath et al. (1998) notes that these items are mainly elicited in response to medical examination and so may have only limited value in assessing pain in other situations.

McGrath et al. (1998) devised a checklist (Non-communicating Children’s Pain Checklist) to be completed by caregivers of noncommunicating children. Caregivers were asked to recall pain episodes and to describe the pain behaviors they observed. In total, 31 behaviors covering seven different domains were identified, although most items were used by less than half the respondents. McGrath et al. note that it may not be possible to identify a single set of items that can be used reliably with this population, as the expression of pain is very individualized. However, the authors argue that the widespread use among respondents of all seven categories suggests commonality across individuals, even though the specific nature of the child’s response may vary.

The commonality of cues was explored in a subsequent study where the checklist was completed by 33 caregivers (Breau, Camfield, McGrath, Rossmus, & Finley, 2001). A core set of seven items was found to be significantly predictive of pain. The items were seeking comfort, gesturing to part that hurts, tears, crankiness, change in eyes, less activity, and gasping, with the first three being the strongest predictors of pain. Although this study focused on noncommunicating children, over half of those assessed were suffering from cerebral palsy.

The purpose of this study is to extend the work undertaken by McGrath et al. to children with conditions other than cerebral palsy. The study aims to develop an observational measure based on caregiver reports to assess chronic pain in children with significant cognitive impairment who are unable to communicate verbally. We investigated the issue of whether a core set of cues is used to express pain.

**Method**

**Participants**

Participants were the main caregivers of children in receipt of clinical services from Lifet ime, a National Health Service community-based nursing and psychology service for children with nonmalignant life-limiting conditions based in Bath, United Kingdom (UK). Children meeting the project criteria of no expressive language (or alternative communication system such as sign language) and age 2 years or older were identified from the clinical database.

We contacted a total of 34 eligible caregivers, of whom four declined to participate (one was moving away from the area; one was too busy; one did not want to take part in research; and one declined to give a reason). Only one eligible participant was male; to avoid any possible gender effects, information from this participant was not entered into the analysis. This study therefore reports information from 29 female caregivers, ages 24–60 years, with a median age of 37 years. Of these, 25 were the child’s birth mother, 2 were adoptive mothers and 2 were foster parents.

All 29 children studied had a chronic or life-limiting condition. The largest group (n = 10) were those with a primary diagnosis of static central nervous system disorders such as cerebral palsy, spina bifida, and postencephalitis. Nine were diagnosed with either chromosomal disorders (e.g., partial trisomy of chromosome 13, deletion of chromosome 1) or other syndromes affecting the central nervous system (e.g., Goldenhar syndrome, Opitz C). A further five had progressive central nervous system disorders such as Retts syndrome and MPS. The remaining five children had no specific diagnosis and at the time of the study were still undergoing further investigations. The children consisted of 13 girls and 16 boys, ranging in age from 2 to 21 years, with a mean age of 7.8 years (SD = 5.28 years).

**Measures**

Caregivers undertook a semi-structured interview lasting approximately 1 hour. The interview focused on general and chronic pain rather than specific (i.e., bumps and bruises occurring during play) and acute episodes. They were asked how often they thought their child experienced pain, the duration of these episodes, and the suspected nature of the pain (constant vs. intermittent). The interviewer asked the caregivers to list the cues they used to identify pain in the child. They were prompted to elaborate on their answers to provide a full and clear picture. Specific cues thought to indicate severe/mild and chronic/transient pain were assessed, and caregivers were asked to identify those cues they considered to definitely reflect pain. After spontaneously generating pain cues, the caregiver was shown a list of the pain cues identified by McGrath et al. (1998) and asked whether this con-
tained any cues that had been overlooked. Finally, the interviewer completed a summary chart with the caregiver to check that the information had been recorded correctly.

**Procedure**

Approval was obtained from the local ethics committees for all phases of the project. Participating families received an information sheet and completed an informed consent form.

The main caregivers of the children received a letter explaining the aims and method of the project and were followed up by telephone a few days later. Interviews were undertaken in the caregiver’s home by a trained clinical psychologist with experience working with parents of severely cognitively impaired children. While undertaking this project, the psychologist also worked part-time as a member of the Lifetime clinical team.

**Results**

**Caregiver Perceptions of Child Pain**

A total of 12 (41%) caregivers assessed their child as experiencing pain almost every day, with a further five (17%) reporting their child to experience pain at least once a week. The duration of typical pain episodes was judged by nine (31%) to be less than 3 hours, while 11 (38%) assessed their child as experiencing pain for longer than 24 hours. Of the 26 caregivers who felt their child experienced regular pain, half (54%) recalled that their child was in pain within the first year of life.

All caregivers rated themselves on a four-point Likert scale as “accurate” or “very accurate” at detecting pain in their child. The majority, 25 (86%), believed they were correct nearly all of the time, with a further three believing they were right on 75% of occasions. One respondent believed she was correct only 50% of the time.

**Behavioral Pain Cues Identified by Parents/Caregivers**

In total, the respondents spontaneously identified 251 cues they felt indicated pain in their child. Mean number of cues identified was 8.65, with a range of 4–13. There was exact overlap between some of these cues, so, for example, 19 caregivers reported that the child “cried.” Identical cues were combined, resulting in 203 separate pain cues identified.

**Categorization of Pain Cues**

A two-stage Delphi process (Dalkey, 1972; Jones & Hunter, 1995) was undertaken in order to sort the 203 pain cues into common groupings. The pain cues were distributed to 10 Delphi participants, comprising three clinical psychologists, one consultant community pediatrician, one community children’s nurse, two university researchers, two parents of noncommunicating children (who were not involved in the study), and one university psychology student. The raters were given the full list of pain cues and asked to sort them in a way that made sense to the rater and to give each category a name.

After the first round the 10 raters generated a total of 77 categories (mean = 7 categories, range = 5–11). Although some categories were used by only one rater, there was considerable overlap in the way many of the cues were grouped.

For the second stage, the 77 categories were circulated to the original raters, who were asked to consider their responses in the light of the categories identified by the other raters. Each was provided with a list of their original categories along with the categories devised by the others. In total, 16 categories were identified in the second round. Of these, 11 categories were endorsed by two or more raters, with 5 being endorsed by only one. These five categories were discarded. The data were checked to ensure that the cues included in these categories were not identified by parents as “definite signs of pain,” occurring “only when the child was in pain” or indicated “severe pain.” None of the five categories contained any cues that met these criteria. The remaining 11 categories identified by the Delphi process were defined as follows: vocal, facial, physical, withdrawal, seeks comfort, physiological, agitation, tense, inconsolable, pain sites, anger/irritability.

The 203 pain cues were assigned by one of the authors (LW) to the category in which they were most frequently placed during the Delphi process. The complete set of categories and cues was circulated to the original Delphi participants, who were asked to identify any cues they considered to be incorrectly allocated and to suggest a more appropriate category; 179 (88%) were judged to be correctly placed. They made a total of 28 suggestions about 24 separate cues. These cues were dis-
Identified Pain Cues

During the interview, caregivers were asked to identify the cues they felt indicated either severe pain or were considered as a definite sign of pain. They identified 95 cues as indicating definite pain and 68 as indicating severe pain. The 11 categories that emerged from the Delphi process were examined to determine where these cues fell (Table II).

The three most frequently endorsed categories for definite or severe pain were vocal, facial, and inconsolable. Within these categories, there was considerable overlap in the cues caregivers reported, with the following four being the most commonly identified: screams/yells; cries with or without tears; unable to be comforted; face screwed up/looks distressed. The next most frequently endorsed cues were flinches from contact (physical category) and appears tense and stiff (tense category). Cues in the remaining six categories derived from the Delphi process were less frequently endorsed as indicating either severe or definite pain. Important pain cues were therefore identified in almost half of the categories and did not cluster within a single domain.

An analysis was undertaken to determine how many caregivers endorsed one or more of the most frequently reported six core cues. A total of 26/29 (90%) caregivers identified one or more of these cues as signs of definite pain with 20/29 (69%) identifying two or more. In terms of severity, 22/29 (76%) identified one or more as indicating severe pain, with 14/29 (48%) identifying two or more.

Discussion

This study extends the work of McGrath et al. exploring the expression of pain in noncommunicating children, to those with a wider range of severe cognitive impairments. In considering these findings, the limitations of this study need to be acknowledged. In particular, the study cohort was comparatively small; although none of the children had any verbal communication, the range of pri-
mary diagnoses often resulted in only one child with a particular condition. These results should therefore be viewed as preliminary, since further research with larger, more homogeneous samples is required to substantiate these findings.

All of the parents we interviewed rated themselves as accurate or very accurate assessors of pain. Independent verification by comparing caregiver and child ratings is not of course possible with this client group, so the degree of caregiver accuracy remains unclear. However, the confidence expressed by caregivers was noticeable, with 86% reporting that they nearly always could detect pain in their child. This was further reflected during interview in their ability to identify possible pain cues. On average, each caregiver identified seven different pain cues, suggesting that they were aware of, and sensitive to, possible indicators of pain.

Our results suggest that a core set of six cues is used most frequently and that these were used by 90% of caregivers as indicators of pain. Of these, two cues, crying (with or without tears) and screaming/yelling, were used by 23 (79%) of caregivers. These results are consistent with the findings of McGrath et al. (1998) and Breau, McGrath, Camfield, Rosmus, and Finley (2000). The cues of crying and moaning were found to be used by 80% of the parents of children with cerebral palsy (McGrath et al., 1988) and over 70% of the parents of cognitively impaired children (Breau et al., 2000) to indicate pain. In a subsequent study, Breau et al. (2001) identified a core set of seven pain cues that caregivers used to identify pain in their child. These findings therefore lead us to suggest that, although the specific expression of pain may be very individual, there does appear to be a set of shared core cues.

The six core cues used by caregivers were not focused around one domain of behavior. The cues were spread across five of the eleven categories identified by professionals during the Delphi process. Caregiver perception was therefore based on vocal (screaming/yelling), visual (crying, distressed face, tense body), and physical (difficult to comfort; flinches if touched) cues. However, these cues are often identified during acute pain episodes, and it is unclear whether they also reflect chronic and enduring pain. For example, during chronic pain the cues may become more subtle and may result in decreased activity and the person may become more withdrawn or subdued (Chambers et al., 1996; McGrath et al., 1998). Whether caregivers are sensitive to and can identify these more subtle cues as indicating possible pain in their children is unclear.

There is some similarity in the domains of the core pain cues identified by Breau et al. (2001) and those in this study. Although the specific terminology and exact nature of the cues differ, both studies found that crying, comforting, and facial changes were important cues used by caregivers to detect childhood pain. In other respects, there were important differences. In our study, screaming and yelling were frequently identified as pain cues, whereas Breau et al. (2001) did not find a significant relationship between vocal behavior and pain. This finding is surprising since vocalization is one of the core ways in which the sensation of pain is signalled to another. This discrepancy may be due to methodological differences in that Breau et al. (2001) used a checklist, whereas our study used an interview format. Alternatively, differences in the vocal ability of the client groups assessed or greater or lesser caregiver sensitivity to subtle changes in vocal behavior may be pertinent. Further work is required to establish whether vocal behavior is an important domain of the core cues used by noncommunicating children to express pain.

Finally, it is important to acknowledge that, while we have identified a shared set of cues, these are not exclusively related to pain. Children will, for example, cry and scream for many reasons other than being in pain. The core cues we have identified may be indicators of general childhood distress rather than specific indicators of pain. Further psychometric evaluation is required to determine whether these cues can reliably distinguish between pain and nonpain episodes. A further challenge is to ensure that any scale based on these cues has clinical utility and can easily and readily be used on an everyday basis to assess and monitor long-term pain in noncommunicating children. Once a psychometrically robust and clinically useful scale has been developed, its use with other groups of noncommunicating children, such as those with pervasive developmental disorders, could be explored.

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