Measurement of Pain in Infants and Children

G. Allen Finley and
Patrick J. McGrath, Editors

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Measurement of Pain in Infants and Children

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This book is based on the first biennial International Forum on Pediatric Pain, held October 4–6, 1996, in White Point Beach, Nova Scotia, Canada. The meeting was sponsored by McNeil Consumer Products, Canada, and we thank them for the vision and enthusiastic support that made the meeting and the book possible.

The commitment of the IASP Press to develop high-quality, low-cost books has been an inspiration to us. The outstanding volumes that have preceded this one have been a constant spur for us to do better. We thank our spouses, Linda and Anita, and our children, Mika, Linnet, Nigel, and Meghan, for their patience and support. Finally, we must acknowledge the tremendous debt that we owe our patients. They provide a constant challenge to our ideas and encourage us to think of new ways of dealing with pain. Their suffering has prompted us to continue in the search for a scientific approach to pain.

G. ALLEN FINLEY, MD, FRCPC
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Introduction: The Roles of Measurement in Pain Management and Research

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I often say that when you can measure what you are speaking about, and express it in numbers, you know something about it, but when you cannot measure it, when you cannot express it in numbers, your knowledge is of a meagre and unsatisfactory kind; it may be the beginning of knowledge, but you have scarcely, in your thoughts, advanced to the state of science whatever the matter may be.

—Lord Kelvin, quoted in Thomas 1983

Measurement is the foundation of scientific investigation, but it is also impossible to manage a clinical problem without having a measure on which to base treatment. Without measurement, one cannot determine whether treatment is necessary, whether the prescribed treatment is effective, or when to stop it. One cannot determine whether the risks of a treatment outweigh the harm caused by the condition, and so one cannot logically choose between different types of treatment. Measurement enables us to examine the nature, origins, and correlates of pain in children. At times only the crudest of measures, such as "pain present" or "pain absent," are needed for clinical interventions, but to truly understand the phenomenon and to evaluate the efficacy of interventions we require sophisticated measures of intensity and affective response. 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.

For many years, health professionals expressed the belief that young children did not feel pain in the same way as adults (or, at least, did not

remember it), so it was not important to deal with it. Even if pain did exist, pharmacological treatment was felt to be too dangerous for small infants, so there was no incentive to study or manage it. A dramatic change in attitude over the past 10 to 15 years has resulted in the general acceptance that all children, even premature babies, have the capacity to feel pain and therefore deserve humane treatment. In addition, there is a growing realization that pain has significant, potentially permanent, and sometimes life-threatening effects on neurophysiology and immune response, and so should be prevented as part of the attempt to control disease, as well as to reduce suffering.

Pain presents particular problems in measurement. It is defined by the International Association for the Study of Pain (IASP) as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey and Bogduk 1994, p. 210). The IASP definition goes on to note that pain is always subjective. We assume, therefore, that self-report is intrinsically the most valid method for measuring pain. Unfortunately, there is a widespread belief that children do not accurately report their pain, or that they may exaggerate it. Health professionals are often reluctant to accept a child's own ratings of pain, especially when they do not correspond to their own expectation of how intense the pain "should be" or to their interpretation of the child's behavior. There is no evidence that children are less truthful or accurate in expressing their pain than are adults. A number of valid tools for self-report of pain in children have been devised and a detailed discussion of the challenges of self-report measures is presented in Chapter 8.

In a recent editorial in the journal *Pain*, two of our contributors present an urgent call for a new definition of pain (Anand and Craig 1996). They express the concern that a definition based on self-report cannot apply to any organisms that are incapable of self-report, including newborn or preverbal infants and those with neurological or developmental conditions that impair cognition or communication. If we regard behavioral manifestations in newborns as an early form of self-report, we may be able to develop a definition and tools that allow us to make definitive statements regarding pain in the very young or the otherwise uncommunicative child.

Many scientists and clinicians have an innate desire to base their understanding of a condition on something they can see or touch and not on the patient's report of a subjective sensation. Fortunately, there is research underway on neuro-imaging techniques (Chapter 3) and on peripheral neurological tests (Chapter 4) that may not only enhance our understanding of the process but may also, eventually, provide us with clinical tools for pain measurement. Physiological reactions have been widely used as pain mea-

sures by clinical staff, but there are varying results when these techniques are evaluated critically (Chapter 5).

Behavioral manifestations of pain are discussed in Chapters 6 and 7. As will be seen, most of the indicators studied to date tend to attenuate after a short period, making them appropriate only for measurement of brief or acute pain. Unfortunately, because they may appear to be more "scientific," many clinicians assume that they are more valid than self-report. Work is being done on a number of fronts to develop behavioral tools that can apply to more prolonged pain and pain in different groups of patients. However, pain is a complex and multifaceted construct, so it may be that the best approach to measurement is a composite of different techniques. Some of these approaches are described in Chapter 9.

Evaluating the reliability and validity of measurement tools is an arduous task, but of critical importance, as described in Chapter 2. It is equally important that clinicians and researchers understand the assumptions made and the techniques used to validate the tools they use. Fortunately, the difficulties of pain measurement in children have had the effect of forcing investigators to provide evidence for reliability and validity far beyond that provided by researchers in adult pain.

For measurement techniques to be useful, they must be applied, and even those tools that have scientific support are not in common use. Providing information does not guarantee a change in behavior. The task of implementing a new approach in clinical care is complex, and the contributors to Chapter 10 present some approaches to this problem.

The first biennial International Forum on Pediatric Pain was held at White Point Beach Resort, Nova Scotia, Canada, on October 4–6, 1996. Speakers and participants came from Australia, Canada, Europe, and the United States to discuss the issues of measurement of children's pain from many different perspectives. This volume is the result of the formal presentations at the meeting, plus one additional chapter, but much other discussion and exchange of ideas took place without being easily recorded. We hope that this book will provide a starting point for health professionals and researchers to develop and use reliable, robust, and practical techniques for measuring pain in children, which will result in improved care and, eventually, in the universal acceptance that pain prevention and treatment are of the highest priority in the care of children.

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Psychometric Issues in the Measurement of Pain

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MEASUREMENT AND ASSESSMENT

The purpose of measurement is to assign a value to a concept. Therefore, the purpose of the measurement of pain is to assign a value to it for a particular child at a particular time. The purpose of assessment is to provide as complete a picture as possible of pain, which will also include some quantification of the pain. Asking a child to describe what it is like when he or she is having pain can result in a rich portrait of the child's experience and may include such information as the meaning of the pain, the contextual influence on the pain experience, and even coping strategies that the child may use. It may or may not include giving the pain a value.

There are different levels of measuring pain, each giving different information. The first level is nominal or, in the case of pain, dichotomous; that is, there is pain or there is not pain. Such information is simple and easy to obtain. It can be useful in screening or triage situations, such as the emergency department, when no further information will be elicited about the pain if the response is that there is no pain. The second level is ordinal, in which levels of levels of pain are ranked. It can answer the question, "Is there more or less pain, or is it the same?", but it cannot address the question of how much more or less. Finally, there is the interval or ratio level. The difference between interval and ratio measurement is that there is a true 0-point with a ratio scale. Since most pain scales have a true 0, that is, the absence of pain is a possibility, the distinction between interval and ratio measures is inapplicable and they can be combined in the case of pain. The difference between ordinal and interval levels of measurement is that interval

measures of pain can answer the question "How much more or less pain?" The attribute of interval measurement that distinguishes it from ordinal measurement is that the distance between any two points on the scale, that is, the interval between points, is equal. There is often confusion between ordinal and interval scales, especially with some of the faces pain scales, where changes in the faces are clearly ordinal but the distance between them has not been established as equal. This will be further addressed in the section on format of the measure. An important point to note is that these levels of measurement are themselves hierarchical, that is, the dichotomous level is subsumed under ordinal, which is subsumed under interval/ratio. More specifically, if the question "How much more pain does the child have?" can be answered, then the questions "Is it more than yesterday?" and "Does he or does he not have pain?" can all be answered, whereas if only a dichotomous level is used, then only the question, "Does he or does he not have pain?" can be answered.

There are implications of the level of measurement selected. First of all, as mentioned above, the questions that can be answered are not the same. Secondly, as a result of the different kinds of questions that can be asked with each level of measurement, the kinds of comparisons that can be made are different. Thirdly, the type of statistics that can be used is determined by the level of measurement, which thus influences the type of studies that can be conducted using a given measure.

THE CONSTRUCT OF PAIN

Like other human experiences, pain is not a simple concept. Melzack et al. (1983) describe three components of pain: the quantitative, the qualitative, and the affective. Furthermore, other concepts such as anxiety, culture, health, and development are related to pain. Of utmost importance in the measurement of pain is the definition of pain selected. This definition needs to match the operational definition, which is essentially how the concept is going to be measured. If the definition is "pain exists whenever a person says it exists" (McCaffery et al. 1989), then an operational definition must be a form of self-report and would exclude infants. If, however, the definition of pain is "an unpleasant experience of varying degrees," then an operational definition needs to tap the "varying degrees" component of the unpleasant experience.

THE ELEMENTS OR ITEMS

How the elements of a pain measure are selected is rarely reported, particularly with pain measurements for children. This is less relevant if a self-report measure of pain intensity in a visual analog scale (VAS) is the measure being examined, since there is only one element in the VAS. Items for other types of measures—such as word checklists, facial scales, and observation scores—need to be generated in different ways. Occasionally these items appear to be generated solely by the developer of the measure, reflecting his or her understanding of the components of the construct. This is less acceptable than when the items are generated by representatives of the target population who can best reflect the experience of that population.

LITERATURE

The first source of items is the research and clinical literature. Are there descriptions of children's response to pain that can generate items? What are the components of these descriptions? How many articles refer to each of these components? Is there a magnitude associated with the descriptions? For example, descriptions of infant response to pain have typically included an increase in heart rate of at least 10 beats per minute, whereas only a few studies have included an increase in palmar sweat. It would therefore be reasonable to include increase in heart rate as an item, but further investigation might be needed before inclusion of palmar sweat.

CLINICAL EXPERTS

Clinicians who work closely with certain populations are able to identify items that they have observed to be related to pain. These experts might respond individually or in the format of a focus group during which they would agree which items are always present during a pain response, those that are often present, those that are sometimes present, and those that are never present (Taylor et al. 1996).

CLINICAL POPULATIONS

Patients themselves can act as key informants about their pain. Qualitative words in the McGill Pain Questionnaire, for example, were initially generated by patients (Melzack 1975). Information from patients can be obtained formally, with prestructured interviews, or informally, during clini-

cal care. Children can generate or select items that will ultimately go into a measure. For example, children can select pictures or facial features that represent aspects of pain. (Bieri et al. 1990)

Items can also be generated based on the observation of children. This is particularly true for items that will form an observational scale. Children can be observed in situations in which it would be reasonable to assume that they were experiencing pain, as following surgery before an analgesic infusion is begun, or on presentation to the emergency department for a complaint of pain and before analgesics are given.

When evaluating a measure of pain, it is of interest to ascertain the source of the items. Researchers are becoming more sophisticated, and it is increasingly common for members of the patient population to generate items, either through direct or indirect report (choosing from among a group of items), or through observations of the patients. In cases where the source of the items is not reported, it is likely that they were not empirically generated and so will be less likely to withstand psychometric testing.

HOMOGENEITY OF THE ITEMS

Although pain is complex, most measures of pain in children address only the intensity component of pain, with a few exceptions (e.g., Varni et al. 1987; interview and diary in McGrath 1990), and those exceptions do not have reports of internal consistency. Many measures of pain in children have only a single question or item that yields the score, thus the issue of homogeneity of the items is of less concern. If there are more than one item on the measure, these items should be measuring the same construct; in other words, the items on the measure should be homogenous. To this end, the items should be moderately correlated with each other, but not highly correlated, or else there is redundancy. Furthermore, each item should correlate with the total score. Estimations of the relations between and among the items is referred to as internal consistency.

FORMAT

Finding a format that children or staff can understand and use easily has posed challenges for clinicians and researchers alike. Besides the usual issues in measurement development, there is the additional issue of wide ranges of developmental levels and comprehension. Self-report measures can be used only with children who are old enough or cognitively competent enough to understand language and to quantify. Self-report measures are the major focus of this section, although there will be some brief discussion

about observational scales used by staff. In reviewing the issues concerning format, the reader is referred to Streiner and Norman (1995).

The level of measurement desired—nominal, ordinal, or interval/ratio—will in part determine the format of the measure. If pain were to be dichotomized into "yes" or "no," or even into the ordinal levels of mild, moderate, or severe, then information is lost. A child may answer "yes" to having pain four sequential times, but the pain could be fluctuating tremendously within the category of "yes." One estimate of loss of information is 67% (Streiner et al. 1995). Furthermore, words like "mild," "moderate," or "severe" may have very different meanings to different children. Again, information is lost in using ordinal scales.

Continuous measurements can be in the form of direct estimation, comparative methods, or econometric methods. With comparative methods, subjects choose from comparative words or phrases. In adult pain measures, this is seen as, e.g., choosing between "dull" and "sharp" to describe the quality of the pain. Econometric methods involve choosing a value or risk to optimize a choice. This has not been used in pain scales because it is inappropriate, but an example might be, "There is a new pain killer that will work perfectly for your pain relief, but it causes deep sleep. How many days in a week could you tolerate a pain level of 8/10 before asking for this pain killer?" Direct estimation means that the child or observer gives a direct response, as opposed to a comparative or hypothetical response, that quantifies their pain. Most pain measures are in the form of direct estimation.

CONTINUOUS MEASURES

Visual analog scales (Huskisson 1974; Scott et al. 1978)

In its simplest form, the visual analog scale (VAS) is a 10-cm line with the anchor words "no pain" and "the worst pain possible" at the ends. The child then puts a mark on the line that represents the amount of pain he or she has. Proponents of this simple form believe that it is more universally useful and less subject to bias than when modifications, such as added adjectives, are used. Others feel that not enough information is provided for it to be sensitive, and thus they believe that the addition of adjectives with markers along the line makes the VAS more easily understood. Interestingly, there are high degrees of correlation between various forms of the VAS (Downie et al. 1978), which suggests that the simplicity is more a matter of preference than importance.

Because of children's cognitive development and the relative abstractness of the VAS format, modifications specifically for children have been made to the VAS. The simplest change is to rotate the axis 90 degrees so

that the child reads it in the vertical plane. This is based on the assumption that children's vertical quantification abilities precede horizontal quantification abilities. Adjectives can be added, and this has typically been done with adolescents. A final modification can be the addition of color which varies in intensity, typically from white to deep red (McGrath et al. 1996).

Other forms

Another type of continuous measure is a series of faces representing "no pain" to "the most pain" (Bieri et al. 1990). Poker chips (Hester 1979) are another, more concrete, form of continuous measure. Each of four red poker chips is "a piece of hurt," with one piece being a little hurt and four being the most hurt anyone could have. A white chip representing "no pain" is sometimes added. Sequentially sized blocks (Poulain et al. 1995) are another example of a less abstract continuous measure.

OBSERVATIONAL MEASURES

Many measures of pain in children are not dependent on self-report but rather on assessment by a caretaker. The same issues apply to these as to self-report measures. A particular behavior selected as an item on the scale could be coded as dichotomous (present or absent), ordinal (more or less), or interval (how many times the behavior occurred over a given period of time). In instances where interval data are counts of incidence of specified behaviors, an assumption is made that the more often that behavior is observed, the more pain the child is experiencing.

SCALING OF MEASUREMENTS

How many points should there be on a scale, or how many categories of response? For example, how many faces should there be on a scale? Reliability tends to drop when there are fewer categories. However, the change in reliability between seven and ten points is not substantial. Streiner and Norman (1995) suggest that the minimum number of points or steps be between five and seven. There is also evidence that people have difficulties discriminating beyond seven categories (Miller 1956). Since there is sometimes a reluctance to use extreme ends of a scale, there is some benefit to using nine points. In summary, it would therefore seem that seven plus or minus two is a good number of levels. Whether there should be an even or odd number of points depends on whether the scale is unipolar or bipolar, that is, whether it goes in one direction (no pain to most pain) or whether it is a Likert-type scale that goes from "strongly agree" to "strongly disagree."