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Not knowing—the problem of pain in children with severe neurological impairment

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Abstract

This study uses a grounded theory approach to explore the diagnostic and clinical decision-making processes used by parents and healthcare professionals in relation to pain in children with severe to profound neurological impairment. Three forms of knowledge are required for optimal pain assessment and management (1) knowing the child, (2) familiarity with children with the same or similar conditions and (3) knowing the science. Pain relief can be compromised by systems of care that fragment rather than integrate care. A model which integrates knowledge of child, population and science is proposed together with an intersubjective attitude to assessing pain.

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1. Introduction

The issue of pain assessment in children with neurological impairments has been the focus of scientific investigation only in the last 5–6 years (Breau et al., 2000; Collignon and Giusiano, 2001; Fanurik et al., 1999b; McGrath et al., 1998; Oberlander et al., 1999). Previously, such children were typically excluded from pain studies despite the fact that they are at increased risk of experiencing acute, chronic and procedural pain (McGrath, 1998). This raises the possibility that pain might be inadequately treated because it is not adequately recognised. Communication difficulties already make children with neurological impairments vulnerable, without the additional burden of enduring unnecessary pain.

2. Background

Pain assessment in children can be difficult. Verbal report has often been characterised as the “gold standard” in pain assessment for both children and adults (McIntosh, 1997). Examples of pain assessment measures include visual analogue scales, numerical scales, “pain thermometers” or “faces scales”, all of which require the person to describe and evaluate their pain (Champion et al., 1998). However, there are individuals, including those with neurological impairments, who through lack of speech or cognitive ability do not have the means to describe their pain (Shapiro, 1999). Whilst children in general are reported to receive less effective pain management than adults (Schechter, 1989), handicapped children may be at particular risk of having their pain underestimated and undertreated (McGrath, 1998). With the exception of a few specialist groups the literature has until recently either failed to recognise pain as an issue for children with neurological impairments or been uncertain or ambivalent about its presence. In addition, whilst guidelines exist, for

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instance, for the management of acute pain in children (Agency for Health Care Policy and Research, 1992) and pain associated with childhood cancer (World Health Organization, 1998), no such guidelines exist for the management of pain in children with neurological disease.

It has been proposed that the behavioural alterations caused by pain in non-verbal populations should be recognised as forms of self-report and that attention to these behavioural responses would help to optimise pain management (Anand and Craig, 1996). This, however, can be problematic in children with neurological impairments, because “typical” pain behaviours such as moaning or facial changes may not actually reflect pain, whilst other idiosyncratic behaviours may be pain related (Breau et al 2000; McGrath, 1998). There is increasing evidence that parents are best qualified to assess behavioural changes that suggest that their child is unwell (Callery, 1997; McGrath et al, 1998). Recent research highlights the concerns of parents that health care providers do not accurately assess the pain of their cognitively impaired children and fail therefore to treat their children’s pain appropriately (Fanurik et al., 1999a). This presents professionals with a dilemma. How can we make decisions about effective pain management if we lack the skills or ability to recognise pain in the first place?

3. Aims

The aim of this qualitative study was to gain an understanding of the context in which pain occurs and of issues that could affect pain assessment and management in this group. This paper explores the processes used in (1) identifying pain in children with severe neurological impairment and (2) in seeking and providing pain treatment. The analysis described here was part of a larger study which aimed to develop a behaviour rating scale to aid the assessment of pain in this group (Hunt, 2001).

4. Methodology

Parents and professionals make interpretations of the behaviour of children and ascribe meaning to it. The task for the researcher of unraveling this process is one ideally suited to the perspectives and methods of symbolic interactionism and grounded theory. In grounded theory the researcher is encouraged to use preexisting experience and knowledge, alongside on-going reading of the literature and discussion with colleagues, to increase theoretical sensitivity to the data (Glaser, 1978; Strauss and Corbin, 1990). The basic principle of the grounded theory method is to discover

the salient problem in a given scene from the point of view of the actors and how they process it (Glaser, 1992). Similarly, symbolic interactionism directs the investigator to take, to the best of his or her ability, the standpoint of those studied (Blumer, 1969).

A number of studies have used this methodology to explore the nature and understanding of pain in various populations (Chew and May, 1997; Chew-Graham and May, 1999; Fagerhaugh and Strauss, 1977; Woodgate and Kristjanson, 1996). Chew-Graham and May (1999), for example, used grounded theory to investigate the difficulties experienced by general practitioners (GPs) in responding to and managing chronic back pain in their patients. Results highlighted differences in explanatory models of pain between patients and doctors. They also found a link in doctors’ perceptions between chronic back pain and psychological distress, which legitimised long-standing illness behaviour.

5. Methods

Guided conversations (Rubin and Rubin, 1995) with parents of children with severe neurological impairments and with healthcare professionals were used to investigate the context in which pain was assessed and managed.

5.1. Selection of the patient and staff participants

A purposive sampling strategy was used to recruit participants to the study. The population that is the focus of this research is children with a severe to profound neurological impairment who are unable to communicate by speech or by any augmentative communication aid (British Association for Community Child Health and Department of Health, 1994). This population includes children with complex and multiple handicaps such as those with severe cerebral palsy as well as those with degenerative and progressive neurological disease such as Sanfilippo Syndrome (a mucopolysaccharidosis), the leucodystrophies and the ceroid lipofuscinoses (Batten’s Disease).

Four centres recruited patients, parents and staff to this study:

- the neuro-disability centre of a large tertiary referral children’s hospital,
- a charitable trust offering respite, long-term care and schooling to children with complex health needs,
- two hospices for children. The children’s hospices offer respite and terminal care to children with a wide range of life-threatening conditions. A high proportion have serious and life-threatening neurological impairment.

Ethical review committees responsible for each centre gave approval for the study.

5.2. Recruitment

Each centre was asked to recruit parents of five children who had no verbal means of communication and either had currently, or in the past, a pain problem that had been acknowledged by both the parents and the centres. This was to ensure that the parents were good informants on the presentation of pain in their child. The centres were also asked to inform their staff of the study and to ask for volunteers with at least 18 months experience of caring for children with severe neurological impairment. Information sheets were provided and acceptance forms from parents and staff were returned directly to the first author.

5.3. Participants

Parents of 21 children were interviewed. One family had two children with the same progressive condition so 20 parental interviews were conducted. In 15 interviews the mother was interviewed alone, in the remainder the parents were interviewed as a couple. The 21 children described by their parents were aged from 2–18 years (median 11 years). Thirteen (62%) had static encephalopathies which included cerebral palsy (9), spastic quadriplegia following infection or trauma (2) and cerebral malformations (2). Eight (38%) children had a progressive encephalopathy. These were: adrenoleucodystrophy (1), Hallervorden Spatz (1), Sanfilippo (1) Rett (1), a variant of late infantile batten's disease (1) and undiagnosed degenerative conditions (3).

Twenty-six healthcare professionals were interviewed, 23 of whom were female. They had from 1–30 years (median 10 years) experience of working with this population of children. They were: registered sick children's nurses (6); registered general nurse (1); carers without formal nursing qualifications (4); physiotherapists (4); speech therapists (2); occupational therapists (2); teacher (1); teaching assistant (1); children's hospice general practitioners (2); paediatric neurologist (1); paediatrician (1); school doctor (1).

5.4. Conduct of interviews

Parents and staff were interviewed in the place of their choice, usually the home in the case of parents and their work place in the case of the staff. All interviews were conducted by the first author. The interviews were conducted as guided conversations whereby "the interviewer introduces the topic then guides the discussion by asking specific questions" (Rubin and Rubin, 1995). The interviews focused on

- the child's history of pain,
- behaviours observed in relation to pain,
- processes used by the participants to determine that the behaviours they identified were pain related,
- processes of providing and seeking treatment for the pain.

The particular questions asked of the participants, and later of the data itself, were guided by the evolving thematic categories and theories in keeping with the premises of theoretical sampling (Glaser, 1978). The aim was to respond to cues from the participants with an emphasis on (1) hearing the data (Rubin and Rubin, 1995), (2) believing the participants (McCracken, 1988), and (3) learning from them. All but one of the parents agreed to the interview being tape-recorded. Interviews tended to be in the region of $\frac{3}{4}$ to $1\frac{1}{2}$ h long. Those with parents averaged 10,000 words, those with staff 6,000 words.

5.5. Analysis of interview transcripts

Interview tapes were transcribed in full. Multiple themes emerged from the data and the qualitative data analysis program, QSR-Nudist (Richards and Richards, 1998) was used to help manage the work of coding the texts and organizing categories. All codes were derived inductively from the interview texts.

During coding sessions, text coded under each category and subcategory was constantly reviewed to determine whether coded segments were coding similar concepts. Where two codes were found to be coding virtually the same concept these were merged under a single heading. As the analysis proceeded, categories were regrouped according to the developing theory.

5.6. Establishing trustworthiness of the findings

The first author conducted the fieldwork and analysis for the study. The role of the co-investigators was to advise, monitor the data collection and analysis and generally to support and supervise the first author in the conduct of the study. Prior to the research, the first author had worked as a nurse for some 20 years, first in an acute paediatric neurology setting, then in the long-term care of profoundly disabled children and later in children's hospice/palliative care. In these roles, she had had considerable experience working alongside children with severe neurological impairments and with their families. This experience had led her to believe that pain could be a significant problem for children with severe neurological impairment and one that considerably interferes with the potential quality of life of children and of their families. As a researcher she did not, therefore, enter the study without pre-existing opinions and impressions. It was important therefore to check

that the interpretation of the interviews was one that was supported by the data and not biased by previous experience.

One of the processes used in establishing truth-value (ensuring that the findings are supported by the data) is looking for rival hypotheses. The three co-investigators manually coded portions of text from two interviews, looking for similarities and differences in their interpretations. The process of combined checking of transcript coding can help to increase sensitivity to the variation in behaviour and its meaning (Strauss, 1987) as well as increase sensitivity to the theoretical issues (Glaser, 1978).

After completion of the coding, each of the co-investigators was provided with 6 randomly selected parent and 6 randomly selected staff interview transcripts. They were asked to answer a number of questions posed to them from their reading of the transcripts. They were then asked to summarise each group of transcripts, to look for similarities and differences between parent and staff reports and to be aware of any important or alternative themes present in the data that were being missed. Each reviewer identified and described very similar pains, pain cues and processes and no obvious discrepancies were found. Acknowledging that this was an interpretive process, no attempt was made to demonstrate reliability of coding in any psychometric sense.

Applicability of the findings was addressed by the process of member checking (Lincoln and Guba, 1985). Interview transcripts were returned to interviewees (unless the interviewee had said they preferred not to see it) so that they could check the content of the transcript. Reports of the findings have been shared with some of the informants as well as others who are familiar with the issues of pain and/or with the population. Throughout, the generated hypotheses have been verified against new data (Strauss, 1987) and presentations of the findings at meetings have been used to assess the extent to which the delegates recognise the findings.

In reporting the results, professional interviewees are referred to as “staff” (with the prefix “S” to indicate their quotes). The prefix “P” refers to quotes by parents. The term “professional” is used in the text to refer to healthcare professionals in general. Where names of children or healthcare professionals are used in the interviews these have been changed to provide anonymity.

6. Findings

In order to set the context in which pain existed, participants were asked for descriptions of the types of pain the child had suffered and of the cues that led them

to believe that the child had pain. These are described only briefly here as they will be the subjects of future papers.

6.1. Sources of pain

The sources of pain described fell mainly into four categories

- Pains associated with alterations in gut motility such as gastro-oesophageal reflux, wind and constipation.
- Pains related to musculo-skeletal problems, particularly muscle spasm, dislocated hip, joint and back pain and pain generally associated with the child's immobility.
- Co-incidental pains that can also occur in otherwise well children, for instance, ear and tooth ache.
- Pain related to poorly fitting aids and equipment.

6.2. Pain cues

Pain cues fell largely in to the following groups:

- Changes in facial expression.
- Changes in movement and posture.
- Vocal cues such as crying, moaning, groaning or whimpering.
- Changes in the child's usual patterns, such as how well the child slept or tolerated feeds.
- Physiological changes affecting the child's appearance such as change in colour or sweating.
- Changes in mood including withdrawal and depression.

6.3. Identifying pain

This section describes the processes parents and staff use in interpreting the behavioural cues as indicative of pain.

6.3.1. Comparing with normal—knowing the child

The parent very often determined that the child was in pain through comparison with how they were normally. This process of assessing pain was related to the parent's intimate knowledge of the child. One mother describes how her daughter is when in pain:

She'll wake during the night constantly, not just maybe once to be moved, but constantly in the night and just generally be more irritable, more stiff. School have even noticed it as well that generally her whole demeanour seems to change (P2 209–216. Mother of 9 year old with undiagnosed neurodegenerative disorder).

As demonstrated in the quote above, this process of “comparing with normal” might also be accessible to

professionals who had prolonged experience and knowledge of the child. Here a nurse says:

It is very difficult, and it is also to a certain extent with the children up here, knowing what they look like normally and then being able to see a difference in them which might not be noticeable to other people. It is very hard to explain what that difference is but you just know by looking at them that they're not what they normally would be like. (S26 298–304. RSCN 2–3 years experience).

However, not all professionals would have that degree of familiarity with a particular child and parents described an advantage that their knowledge of their own child could give them over a doctor or other professional who might see the child only occasionally. They felt that such a professional would lack the context in which to place their child.

For parents, as well as for professionals, “knowing the child” is not instantaneously acquired. Some parents described that there had been times when they did not realise the child was in pain because they themselves did not yet know their child. A mother says:

Well, he was just screaming like this really, going in to spasm and sort of bringing milk up. I had him at home all the time with me and I don't think I'd fully appreciated what he was actually going through. It was just such a shock having Ben like he was, and not having a normal child, you don't know what a normal child..., perhaps a normal child makes... (this noise). Do you know what I mean? (P5 168–175. Mother of 5 year old with cerebral palsy).

Here the difficulty is setting the child, his behaviour and appearance within the larger context of what a normal child or a pain free disabled child would be like. This mother had no way of knowing until she was assured by others that this was not how it should be.

Since the early 1990s “knowing the patient” has become a major theme in nursing literature (Jenny and Logan, 1992; Tanner et al., 1993; Radwin, 1996; Liaschenko and Fisher, 1999). For staff in this study “knowing the child” appears similar to the concept described by Tanner et al. (1993) as “knowing the patient”. Here the authors describe the meaning of this “knowing” as being one of understanding the patient's situation and the patient's responses, an understanding that is directly apprehended but often remains largely ineffable and difficult to articulate. They suggest that “knowing the patient” pertains to both an in depth knowledge of the patient's pattern of responses and knowing the patient as a person. Liaschenko and Fisher (1999), however, differentiate between knowledge of the *patient* and knowledge of the *person* and add a third category, knowledge of the *case*. The authors describe

case knowledge as biomedical knowledge, this being knowledge that the nurse has of physiology, surgery, protocols, indicators and range of patient outcomes, anticipated complications, and usual therapeutic interventions.

“Knowing the *patient*” as described by Liaschenko and Fisher (1999) occurs when the generalised knowledge of physiology, pathology, diagnosis, and therapeutics becomes particularised in the body of the sick individual and hence transforms *case* knowledge to *patient* knowledge. In contrast, to know an individual as a *person* is to know him or her as a subject who acts with his or her own desires and intentions. This entails knowing something of his personal biography and life history. According to Liaschenko and Fisher, such an understanding necessarily implies knowing about how the person is situated in and engages with the world.

What is meant by “knowing the child” in the context of this study? Whilst parents did attribute some professionals, particularly at school, with knowing their child well, and staff (particularly the nurses) in the study claimed it was important, it is uncertain whether “knowing the child” means the same for the health-care professional as it means for a parent. For the professional caregiver it may in many cases be more one of “knowing the patient” than “knowing the person”. However, knowing the child's parents can bring the professional nearer to knowing the child as a person.

Nurses in Tanner's study often learnt to know the patient through the patient's family. They used the family's ability to recognise minute changes in the patient and what would comfort and discomfort the patient (Tanner et al., 1993). Although it is often difficult in a short period of time to establish a relationship, one of “knowing the person”, with the child with a profound neurological impairment, hearing the parents' stories and narratives helps to build up a shared understanding with parents of the child's history and biography. In addition, staff in this study were for the most part working in centres where they could build relationships with the children and parents and where children could become well known to them and this would be true also of teachers and other caregivers working in schools. Here too they have the opportunity to learn to attune to the child, a process Newson (1977) and Stern (1998) described as the development of an intersubjective relationship of parents with their infants.

“Knowing the patient” has in the past been a feature of family medicine and general practice, and one that is often used as the reason why the family/general practitioner is highly valued. In this study, however, several parents reported that their doctors did not know their child. This was often given as the reason why the parents found it difficult to communicate to the doctor about the child's pain.

P3: And one time there were eight in the class and the teacher was saying that there was time for one more person to have a massage and she said that she'd never seen Beth manage to put her hand up so fast in her life and she got her right hand up and her left hand touching her chest going "My turn". ...So, I think, I think they do know her quite well.

Interviewer: Yes. Would they be able to tell...what was hurting?

P3: Yes, yes. I mean I think sometimes you can get an idea by how she's sitting or lying or whatever it is...but sometimes it isn't.

AH: What about your GP and...?

P3: Oh they wouldn't have the foggiest, wouldn't have the foggiest. No, they don't know her at all. Yeh, and they're not interested in knowing her either.

AH: Why do you say that?

P3: Well, basically because she (the GP) is just like the rest of us. I mean they're so busy, GPs have a terrible time now, particularly in a town. (Mother of 11 year old with cerebral palsy. Lines 807–825).

6.3.2. *Recognising patterns—knowing the population*

Tanner et al (1993) links "knowing the patient" with another theme of the current study, that of "knowing the population", whereby knowing individual patients sets up learning about patient populations. Instances and contrasts are collected over time. Whilst nurses in particular spoke of "knowing the child" as being necessary for identifying pain cues, other staff, in particular doctors and therapists at tertiary level, used their knowledge and experience of the population. They described how they recognised patterns in appearance or behaviour they had seen in other children. Different behaviours can be exhibited with different pains (Harré, 1991) and professionals with significant domain knowledge can become skilled at identifying these patterns. Staff, particularly those from the tertiary referral centre, described how they inferred a particular pain from the appearance and pattern of behaviour that a child displayed, for instance, "posturing", as in Sandifer Syndrome (Gellis and Feingold, 1971; O'Donnell and Howard, 1971), was associated with gastro-oesophageal reflux. The components of "posturing" were "stretching" or "elongation" of the body together with a twisting movement of the head or body to one side. This same behaviour was described in similar terms by other respondents but not necessarily recognised as being associated with a particular source of pain. A neurologist describes how she links particular behaviours and appearance with a particular source of pain.

...then in addition to the history I suppose I would use observation and look at the child and see how they are posturing and that then would make me think, for example, this looks like the type of child who might have reflux, if you're sitting looking at some malnourished child that's sort of got a lot of choreo-athetoid type of movements that in our experience does go with a high risk of reflux. (S14 160–167 Pediatric neurologist, 10 years experience).

6.3.3. *A process of elimination—hypothesis testing*

Where parents or staff were aware of changes in the child they then had to set about determining if the differences were associated with pain, and if so what the source of that pain was. This they did mainly by a process of elimination. A parent here says

So then it's a matter of what's wrong. Is it the shoes that are wrong? Is it the brace? Is it because he's tired? Is it because he's hungry? Thirsty? And then gradually you end up thinking, well has he got a headache? Is he in pain? And you end up sort of going through a list of eliminations and eventually you start coming up with hopefully the right conclusion. (P6 577–583, mother of 17 year with spastic quadriplegia following neonatal meningitis).

This "process of elimination" was used by both parents and staff in one form or another, with a hypothesis being set and then tested. In several cases respondents spoke of "having a checklist". This checklist would vary depending upon the knowledge base from which the person was acting. The parent could use methods available to them at home to check out possible hypotheses, whilst professionals might have access to other skills or more invasive or technological methods. For instance, as part of the diagnostic process, doctors were called in by parents or nurses to "listen to the child's chest" or "look in his ears". In the hospital settings, X-rays might be taken to check whether the child's hip was dislocated or pH (oesophageal acidity) monitoring might be undertaken to assess the likelihood of pain from gastro-oesophageal reflux.

6.3.4. *Inferring pain*

Occasionally both parents and staff might infer either from their own experience, from that of others, or from their imagination of being in that situation themselves, that the child has pain. This might be done in the absence of any obvious pain cues.

AH: So what makes you think he's had pain from his back?

P6 (father): Well, I just think because ... I had back pain myself and it was only a small thing and I thought, well if your back's that much out of

alignment sort of down the bottom end here and you're sitting on it all the time and you're sitting on it actually at an angle it would seem to me that it must be quite painful, but uh, maybe that isn't so, I don't know.

AH: Did he give you sort of cues that he was in pain?

P6f: Perhaps I thought it just looked painful (P6 244–255 father of 17 year old with spastic quadriplegia following neonatal meningitis).

The Batten's children,...well I don't know how to describe this, I mean I assume that they will have pain because they have such a lot of tremor and such a lot of unnatural movement and the body can't move like that for such a long time without causing some muscle fatigue and they must have aching muscles. So for me, with them I often would assume they are in pain more than (they) give me a sign that they are in pain. (S2 145–153 physiotherapist 15 years experience).

Hence it is the situation or context rather than the child's behaviour which suggests pain in these cases. However, even in the case of behavioural change, context is important in the interpretation of behaviour.

6.3.5. *Intuition*

Whilst a few parents and staff (nurses in particular) talked about “just knowing” and “intuition” as a means of identifying pain, they tended at the same time to describe behaviours through which they knew.

I think observation comes into it so much that when you've been here for a bit you can (tell), you know whether they're in pain. It's very difficult to explain to somebody else how you know it. It's just sort of a feeling that you've got. And by looking at them more than anything you just know that there is a pain, and then it's a case of just finding out...where it is and what it is and not forgetting the most obvious things that it could be. [...]. It's intuition, it's something that comes from within you. Empathy maybe with the children. [...] I can't really express it. I don't know, you just know. (S15 622–694 RSCN 5 years experience).

Offredy (1998) describes intuitive decision-making as “pattern matching at an unconscious level”.

6.3.6. *Paying attention to parents and child*

One of the factors, which appeared necessary to identifying pain cues, was paying attention to parents and to the child. Some staff, particularly those from the tertiary referral centre, rather than simply being reactive

to the child's pain cues would proactively look for them. This ability seemed to come from the confidence of the practitioner that they were in a position to advise or effect treatment. However, whether it was with the particular purpose of seeking out pain cues, or just in the everyday care of the child, paying attention to the child appeared to be something necessary to the identification of pain in the child. Seeking out pain cues was signposted in the interviews by the respondents use of words such as “looking” and “listening”. Using the sense of “feeling” was equally important.

A staff participant says... When we started to do this approach you could actually feel the slightest movement, the uncomfortable movements, the things that you wouldn't actually pick up by looking, you know. It's actually feeling. But, you couldn't pick that child up and five seconds later expect to feel it. But if you spent time with them, you know, and you knew that child very well, maybe if you didn't know the child very well, you could pick up and I'm sure that's where mums pick some of the signs up, how they feel when they hold them, you know, I'm sure that's one of the cues they would pick up. (S20 412–422, physiotherapist, 20 years experience).

The child's change in tone when in pain appears to be a significant cue, therefore the ability to sense the child's state through kinaesthetic sensations is important. This could be unavailable to practitioners who in a clinic situation, might observe the child but not handle them, a fact pointed out by one of the parents. Rather as the owner and frequent driver of a car might notice a change in how the car handles, parents or carers familiar with the child might pick up very subtle alterations in the child's posture and tone. However, although the owner might notice the alteration in handling, unless they were mechanically trained they might not be able to put the correct interpretation on it. Here, in the case of the child, the practitioner with knowledge of the science may be necessary to interpret the cues the parent or professional perceives. Notably, parents reported difficulties in accessing individuals with these skills and knowledge.

6.4. *Management of pain*

On determining that the child's cues indicated pain, both parents and nurses would do what they could to relieve it, but might eventually call on the doctors for help in diagnosing or treating the pain.

Accessing treatment could be difficult. Sometimes the GP or paediatrician might refer the problem back to the parent with a remark such as “you know best” or “you're doing a really good job”. This could leave the

parent feeling isolated and carrying too much responsibility.

P16: ...well we always did take on the responsibility but I suppose we feel..., I do strongly feel now that we know her a lot better than anybody else and I didn't always feel that before, but I still bowed to their expertise.

AH: You still do?

P16: No, I did do. I don't at all now which is unfortunate because I think it does put the responsibility back on us the whole time.

AH: What would be your ideal?

P16: Em...well, I think it ought to be a joint responsibility. I don't think it should be totally on us. (Mother of 11 year old with Lissencephaly. Lines 1253–1264).

Whilst some parents might appreciate the amount of freedom and control that they had been given, this was noted usually to be within a secure relationship with the doctor.

Parents also described a tendency for the professionals to find ways to discount the child's pain with the consequence that the process of referral to a specialist centre could be delayed. Several parents described the professionals as having a stereotypical view of what a child with pain should look and sound like which meant that their child's pain was not recognised. Professionals might try to reassure parents that their child was not in pain, or the presence of pain would be discounted because it was something that happened "in children like this". Alternatively, because the child was not distressed at the time they were seen, the parent's report might not be taken seriously.

I'm sure I saw a doctor down at school. We have them that come out at school but, some days she wouldn't be as bad and then they'd say, "Oh, she seems all right today" kind of thing, [...] I'd say it was about a year on and off that we thought, it must be hurting her, her legs. (P4 413–418. Mother of 12 year old with cerebral palsy).

The consequence of these difficulties in accessing treatment and the tendency of professionals to discount the parent's report of pain was to leave parents feeling frustrated, angry and powerless.

P12: ...we went up to see Mr B (the orthopaedic surgeon) about the hip, [...] and he said to me "how do you know she's in pain?" Now how many classic signs of pain were there to start with? And fair enough he said "how do you know its the hip?" so I can understand that one a little more, but anybody could see that she was in huge distress...It was like

the time that we were in with the Nissan's (surgical treatment for gastro-oesophageal reflux), I mean it seems that we had gone full circle in a way, she was in huge distress and there was nothing we could do. ...(becoming tearful)... And I kept being told the only thing you can use is Calpol (paracetamol) and Calpol was just, I mean, you might as well tickle her big toe. (Mother of 2 year old with cerebral palsy. Lines 578–589).

For parents there was no distinct line drawn between their child's pain and other issues, such as feeding, day to day managing, and the child's ultimate prognosis. This was true for professionals too, where addressing the child's pain was often within the context of other issues affecting the child's and the family's life. Staff talked about the dissonance between the sort of time and attention that could be required to be given to the child's pain problem and that which might be available to them in their everyday practice. A hospice doctor, himself a GP, explains how difficult this can be:

In terms of volume of work and the time you have to set aside to deal with one individual, it's a lot of time to put in. Standard GP consultation time is, you know, 7½ min, [...] as a GP, if you're going to be putting that much time into a child it's quite a slice out of what's a busy day with a lot of folk to see. [...] I don't think that's the biggest offput (though). I think most GPs would be prepared to put the time in and I think the bigger offput isn't that, it's just that they just feel so uneasy about dealing with the problems. (S23 620–672 GP and hospice doctor with 10 years experience).

Individual GPs can be reluctant to engage in this type of work. This may be due to a lack time, lack of emotional energy or feelings of inadequacy. Furthermore, each professional may have his or her own agenda, resulting in a failure to see the child's and family's position as a whole.

6.4.1. *Clinical and ethical decision making*

There are difficult decisions to be made around treatment in this group of children. Many of the pains described in association with neurological disability (such as pain from gastro-oesophageal reflux or dislocated hip) can be difficult to treat. Parents and professionals face dilemmas about major surgery in what can be a very vulnerable child, with no guarantees that pain relief will follow. Listening to the parents is necessary to understand their stance and the meaning of this experience for them (Altschuler, 1997).

Em, it's very difficult sometimes, [...] because you are asked to make all these dreadful decisions and play God if you like, and it's very, very hard. Very hard,

but I think primarily one doesn't want to see Sophie suffer. So, whatever has to be done to alleviate her suffering, you know, whichever way it is, has to be done. And certainly having this; well again, it was my request with the tracheostomy, it wasn't at a doctor's recommendation [...], the attitude very much, from that ENT department, was let nature take its course, but it didn't and it wasn't over a period of weeks or months, it was years, and it didn't. (P13 530–545. Mother of 15 year old with spastic quadriplegia following accident as toddler).

Some parents described how the professionals could distance themselves. However, others described professionals who were able to stay engaged with them and their child. Indeed, whilst the state of the art might not always meet the needs of the children, the capacity of the professional to stay alongside appeared to mitigate the isolation and distress felt by some parents in this situation.

...but the type of doctor that we're involved with now is not one where she's totally detached for six months at a time, she's the type of doctor that wants to know holistically, the whole of Sam, and what's going on with Sam in every way and wants to be updated, so if there's a problem with him I could ring up the hospital and ask her to be bleeped and talk to her about it, and that's the sort of continuity I need (P17 878–884, Mother of 8 year old with cerebral palsy).

Other professionals also took this role

Interviewer. How easy has it been to talk to doctors about Ryan and his problems, say his pain problems...?

P7: Not easy at all. I've never spoken to anybody about his pain. The only one that I really talk to is Amy (the community paediatric nurse) that comes out and she's more of a good friend, I think now. So, if I need anything or I'm upset about Ryan, she'll come out to me and we'll just have a good talk and we'll sort him out somehow. (Mother of 18 year old with Batten's disease. Lines 494–507).

7. Discussion

The analysis suggests that three forms of knowledge (Fig. 1) are important for assessing and managing pain in this population of children. These are (1) knowing the child and thereby having the capacity to recognise changes in their behaviour in different contexts, (2) familiarity with the population and thereby the capacity to recognise similarities and differences between children, and (3) knowing the "science", which might be

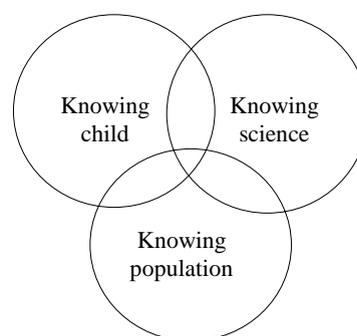


Fig. 1. Stocks of knowledge required for comprehensive pain assessment and management.

thought of as the *knowing that* and *knowing how* described by Ryle, 1949 or *case knowledge* described by Liaschenko and Fisher (1999). It is apparent from this study that each form of knowledge required for the assessment and relief of pain is held differentially by different parties to the child's care and only in a minority of cases will all these forms of knowledge be held by a single person. Consequently, only in a proportion of cases, is each form of knowledge readily available to the child and family. The social problem revealed by the study is that access to the "experts" in a particular field will often require referral by non-experts. Gaining access to the expert in the management of the child's pain (the science) will remain a problem if pain goes unrecognised by the practitioner at the local level. Lack of knowledge of the child and the population increases this possibility.

These findings are situated here within the theoretical context of the social distribution of knowledge (Berger and Luckman, 1966; Schutz and Luckman, 1973). The sociology of knowledge suggests that different perceptions of the child's pain will almost inevitably result when assessments are being made from different data sets. Anspach (1987), for instance, describes a situation in which different members of an organisation, because of their different roles and stocks of knowledge are liable to make different prognostic judgements and consequently different treatment decisions. Along with variation in judgements with variation in roles, there is also a tendency to prioritise certain forms of knowledge over and above others (Anspach, 1987; Popay and Williams, 1996; Parke, 1998). For instance, a judgement based on an "objective" test (for example, the result of a pH test or X-ray) although not an indication of pain in itself, may be given higher value than the "subjective" assessment of the child's behaviour by a parent.

Whilst pain is often described as a subjective experience (IASP, 1979; Merskey and Bogduk, 1994), it need not be a private experience (Sullivan, 1999). As

well as subjective components, pain has more objective criteria that can be observed (Wittgenstein, 1953) and measured (McGrath, 1987). It is also an intersubjective phenomenon; we have a shared understanding of what pain is (Sullivan, 1995), a capacity that allows us to have empathy and sympathy for those in pain. For parents in this study it was important that professionals could recognise and understand the effect of the child's pain both on their lives and that of the child. That understanding alone could help to ease the parent's distress. In addition, that understanding motivates the professional to seek measures by which they can ease the child's distress. The primary task in pain assessment is to gain an intersubjective understanding of the other's pain experience and the meaning that experience has for them. Seeing pain assessment in this light makes us more likely to listen to the reports of parents and attend to the child behavioural cues and less likely to readily or carelessly discount the child's pain.

This Grounded Theory study took place in order to understand the context of pain in this group of children prior to the development of a behaviour rating scale to assess pain. The emphasis has hitherto been on tools as more objective means of measuring the child's pain. They may equally be conceived of as aids to communication of pain, first between child and adult, then between parent and professional, thus empowering,

child, parent and professional. Implementation of pain assessment strategies alone may, however, not be sufficient to address all the difficulties in this area. As is apparent from the data presented here, the way care is organised can act as a barrier to both pain assessment and management. Increasing specialisation can lead to fragmentation of the child's care (Liptak and Revell, 1989) and organisational innovations, aimed at integrating rather than fragmenting the child's care, are required. One means suggested for reducing fragmentation is the presence of a "key-worker" (Turner and Sloper, 1992; Sloper, 1999). A key-worker with knowledge and experience in the speciality (that is, familiar with the population), can work at local level alongside the families (where they gain knowledge of the individual child and family). From this position they will be well placed to refer on to other practitioners as and when necessary. Nurses can have a key function here but were to a great extent absent from the stories of parents, perhaps because of the lack of paediatric nurses in community settings (While and Dyson, 2000). Even if present, professionals (and parents) may have multiple and varying agendas and priorities. Pain needs to be put on the agenda so that we are not only attentive to the child but prepared to proactively look, listen and feel for pain cues. In addition, provision of specialist advice closer to and more readily accessible to families (perhaps

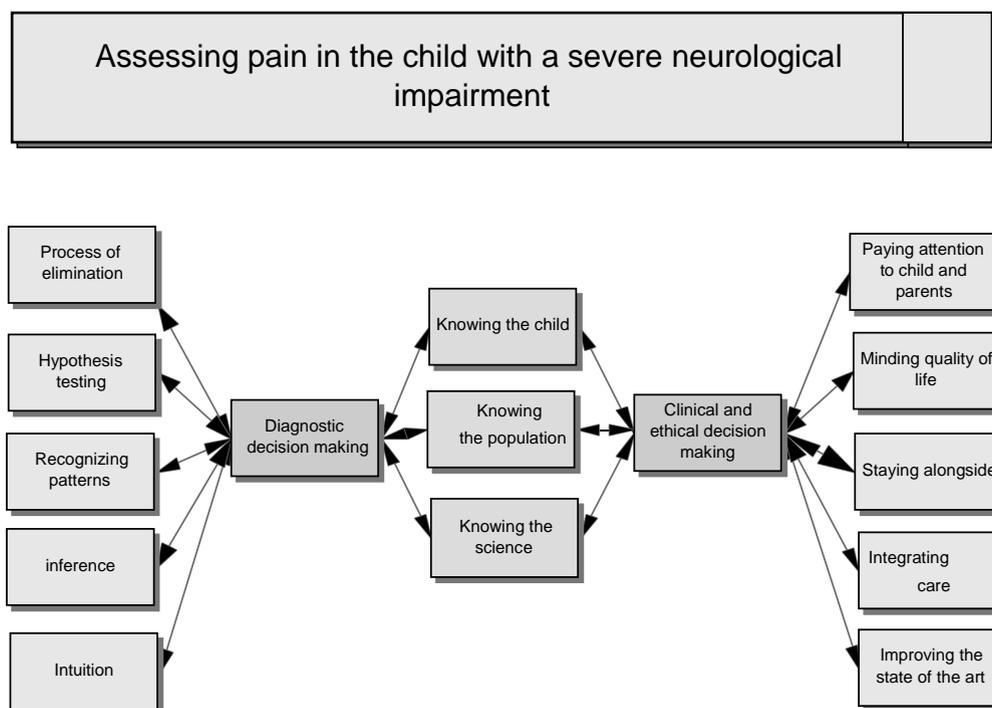


Fig. 2. Pain assessment in the child with severe to profound neurological impairment. A model of diagnostic, clinical and ethical decision making in which various processes, skills and attributes are used, drawing upon the individual's knowledge of child, population and science.

within schools) might enable more timely attention to the child's pain problems.

Fig. 2 represents a model of pain assessment and management for children with severe to profound neurological impairment, a model in which knowledge of child, population and science underpins diagnostic and clinical/ethical decision making. In addition to the knowledge bases themselves, a number of skills, processes and attributes are used in assessing and managing pain in this population. This model is one that might optimise pain assessment and management in this group of children and one that might be kept in mind when assessing and/or designing services for children with severe to profound neurological impairment.

7.1. Limitations of the study

Professionals interviewed in this study were from centres where recognition and treatment of pain was high on the agenda. Both parents and professionals described situations where this was not always the case. The study may have been illuminated by interviews with professionals who were more sceptical about the children's capacity to experience pain. It would also have been valuable to talk to general practitioners who did not have specific roles in relation to the care of children with neurological impairments but encountered individual children in their practice.

Because pain is principally a subjective experience, "self-report" is often described as the gold-standard in pain assessment (Craig, 1997). Children who are the subjects of this study are not able to self-report but do signal their pain in other ways. There remains however a degree of uncertainty about the child's experience, an uncertainty that can make it difficult both for clinicians and for researchers. The research is therefore limited by the inherently uncertain and ambiguous nature of the territory and the knowledge that one can never completely capture the child's experience.

8. Conclusion

Findings from this grounded theory study suggest

- (1) that pain assessment would be optimised by knowing the child well, being familiar with the population and knowing the science,
- (2) that the way services are organised can act as a barrier to prompt pain assessment and management, and
- (3) that pain assessment needs to be seen, not as an objective process, but as an intersubjective process in which the professional engages with the child and family and endeavours to reach an under-

standing of the meaning that the pain experience has for them.

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