

## Lessons learned from a study implementing the Paediatric Pain Profile in the community

A. Hunt<sup>1</sup>, S. H. Robertson<sup>1</sup>, J. Rycroft-Malone<sup>2</sup>, K. Seers<sup>3</sup>, N. Crichton<sup>4</sup>, A. Thompson<sup>5</sup>, A. Newlove<sup>6</sup>.

<sup>1</sup>*School of Nursing and Caring Sciences, University of Central Lancashire, Preston;* <sup>2</sup>*School of Health Care Sciences, Bangor University, Bangor;* <sup>3</sup>*RCN Research Institute, School of Health and Social Studies, University of Warwick;* <sup>4</sup>*Faculty of Health and Social Care, South Bank University, London;* <sup>5</sup>*Children's Services, Warwickshire PCT;* <sup>6</sup>*Coventry PCT, Coventry.*

The Paediatric Pain Profile (PPP) is a pain assessment tool for non-verbal children with severe and complex disability. The tool incorporates a validated 20-item behaviour rating scale with scores ranging from 0 to 60. Scores of 14 and over have been associated with moderate or worse pain. The tool emphasises the need for partnership between parent and professional in assessing and managing children's pain (1-3).

**Aims.** The aims of the study were to implement the tool in the community as a parent-held document and evaluate its acceptability and feasibility for parents and professional care providers.

**Methods. Implementation:** The implementation was guided by the PARIHS model, where evidence, facilitation and context are key concepts in transferring evidence to practice (4). Following training in use of the tool, community children's nurses sent information on the study together with a questionnaire on parents' experience of their child's pain to parents of appropriate children on their caseload. 71 parents completed the pre-implementation survey. 39 parents expressed interest in evaluating the tool. A study facilitator took informed consent from the parents and collected demographic data and names of professionals working with the child. These individuals were informed about the study and the PPP.

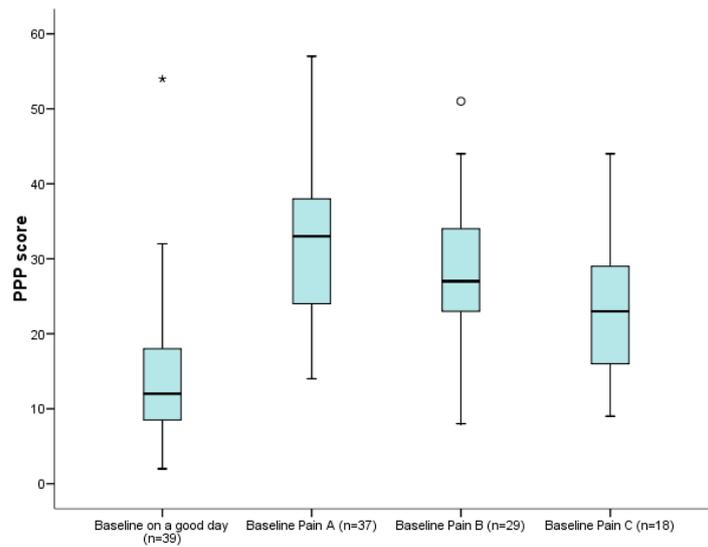
**Set-up / establishing baseline scores:** Community nurses helped parents set up the tool, record a pain history and determine baseline pain scores. They agreed with parents a way of using the PPP appropriate to the child's needs.

**Ongoing use:** Parents were supported to return copies of completed pages four monthly.

**Post-implementation evaluation:** A second questionnaire to evaluate both the child's pain and parents' experience of the tool was sent after 12 months. Focus groups and telephone interviews were held, providing opportunities for parents and professionals to report their views. These were recorded, transcribed and analysed thematically.

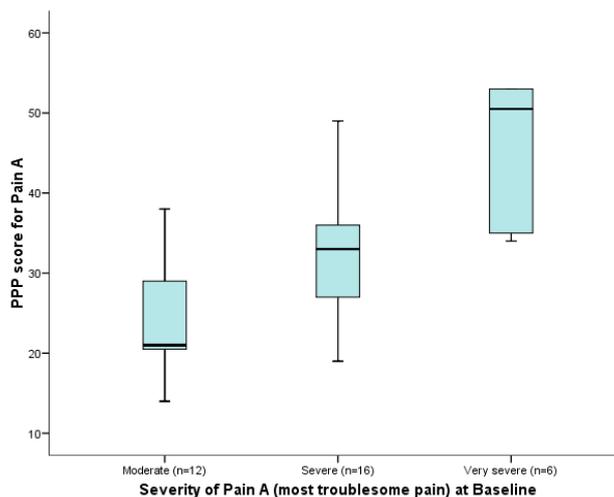
**Results.** Children of participating families were 26 boys, 13 girls with mean age 8.3 years (SD 5.6). Median developmental age was 8 months (range 1 to 19 months). 30 (77%) were in Gross Motor Classification System Levels IV and V. 35 (90%) were of white British ethnic origin, two were Asian, 1 mixed White British / Asian and one Black Caribbean. (A further 7 Pakistani and Bangladeshi families where parents were not able to use the English version of the PPP evaluated an Urdu translation. Data from these families are reported separately). Diagnostic categories were Cerebral palsy (23.1%), Neurodegenerative disease (23.1%), Congenital or chromosomal disorder (23.1%), Autism (10.3%), Severe learning disability (7.7%), Developmental delay (7.7%), No known diagnosis (5.1%).

**Set-up / Baseline scores:** 37 (95%) children had current pain problems. Pain scores for children's current pain problems were significantly higher than scores at their best (32.9 (SD 11.4) vs 14.4 (SD 9.8) (paired t-test  $p < 0.001$ ) (Figure 1).



**Fig 1. Baseline PPP scores - at best and current pain problems**

In the case of each pain there is a linear relationship between PPP scores and the verbal pain rating scores provided by parents (Analysis of variance for linear trend,  $p < 0.001$ ;  $p = 0.013$ , and  $p = 0.008$  for pains A to C respectively) (Figure 2).



**Fig 2. PPP scores for children's most troublesome pain by parents' verbal pain rating**

**Ongoing use:** Fifteen families returned pages from their ongoing use of the tool. There was a median of 8 assessments per child with the number varying from 2 to 276 over the period of one year. The overall range of scores was from 5 to 55 with the mean PPP score for each child being from 11.4 to 37.6. Eleven (73.3%) children had instances when pain was rated as severe or very severe.

**Post-implementation evaluation:** Post-implementation questionnaires were returned by 19 families (50%) with 5 (26%) wishing to keep the tool after the study. There were no significant differences in levels of pain from before implementation.

### **Themes from qualitative analysis**

A thematic analysis of interviews identified three areas of particular importance, these being around the workload involved in setting up and maintaining the tool, difficulties in communicating across boundaries between settings, and feelings of increasing empowerment and understanding of the child and his or her pain problems with use of the tool.

#### ***Work-load, paper-work and complexity***

“I’d definitely recommend it to other parents but not really in its present form because I’m really keen to get back on it but only if there’s a single form to fill in.” (Parent).

“... generally you can’t be too prescriptive...for some people it would be useful in the form it is but I think other people just have to realise that they might be able to adapt it, and from our point of view having adapted it quite successfully we would continue to use it in that way (Professional).

“..I think it’s just another piece of stuff they (the professionals) have got to do, you know what I mean? I’m not sure, I think you need to come across the right people to take it in under their wing at first and distribute it and advertise it as a good thing” (Parent).

“Um, and although we were willing to sit down with the parents and do the initial assessments if you like ...it’s actually, it was getting parents to commit time to that because they’re parents who are struggling to cope with the day to day things that they’ve got to do” (Professional).

“...providing you’ve got the time. And it was done systematically and logically as well. The things seemed to flow, sort of as you were using it and I think if any of that was removed to make it less time consuming I think it would actually dilute the quality of it” (Professional).

#### ***Communicating across boundaries***

“What’s happened sadly is that we’ve found one or two of the families brought it in in the beginning and bearing in mind there’d only be a handful anyway that were using it and then we’ve not seen it since” (Professional).

“But yeah because there’s so many different carers involved I think having a tool like that, I mean it should actually work but for some reason, I don’t know why, they just didn’t fill in the forms and there must have been occasions when they would have thought he was in pain” (Parent).

#### ***Reassurance, empowerment and self-efficacy***

“...sometimes you just don’t know whether you’re coming or going .... whereas this gives you a tool, you can go away, you can tick your boxes, you can think right, I’ve got a better idea now of what’s going on and you know, when there’s chaos in the house that’s really quite useful [laughter]”. (Parent).

“Yeah. It’s been quite, it’s been quite good as well because at least I can look back on the pain. And I can, you know, tell the consultants and everything” (Parent).

“..... reassuring in some ways because you could see over the period of time an improvement in how he was responding to the pain relief” (Professional).

“Yeah, I would (recommend it) because of the experiences that we’ve had that parents have felt very empowered by it”. (Professional).

**Conclusions.** The PPP remains psychometrically robust in this setting but further work is needed on its packaging and presentation if it is to be transportable across different settings used by the child. Ongoing educational strategies are also required to sustain its use across home, health, education and social care boundaries. The tool has potential to increase self-efficacy for parents and professionals but research and interventions need to minimize additional workload for families and professionals. *See Phase 6 for information on developments to ‘package’ since Phase 5 study.*

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