

Independent Learning Project

Final Report

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1 Abstract

Objective The purpose is to confirm the need to implement an education program for parents with children experiencing chronic pain by 1) examining the characteristics of our clinic sample of children with regard to consistency with chronic paediatric pain in published studies., 2) investigate if parental behaviour is associated with and potentially predictive of the child's pain symptoms and function. In addition, a qualitative study was conducted of parents' understanding of their child's condition to ensure that the education content is comprehensive, relevant and useful.

Methods Forty eligible children and their parents completed a set of questionnaires, which covers various domains of the child's pain outcomes and parental behaviour and characteristics. Twenty-one parents were given an additional questionnaire for the qualitative study.

Results Our sample's characteristics were similar to other studies. Parental behaviour and characteristics were found to be positively correlated mainly with, and implying potential unfavourable influence on, the child's functional capacity and social functioning. Although many parents had some understanding of their child's condition, a few parents had very little knowledge about it. Most of the issues raised by the parents were also covered in the parent education content.

Conclusion Given that our sample showed that parental cognitions and behaviour is associated with some of the child's pain outcomes and given the efficacy of parental education in the literature, the implementation of the parental education program at our clinic is justifiable. The education materials were found to be relevant to the parents expressed needs.

2 Introduction

Chronic pain is a relatively common condition among children with an incidence of approximately 1 in 4 (Perguin *et al.*, 2000). It affects many domains of the child's life and its impacts include: impaired social functioning (Simons *et al.*, 2010), functional disability (Gauntlett-Gilbert & Eccleston, 2007), decreased school attendance (Logan *et al.*, 2008) and sleep disturbances (Long, Krishnamurthy & Palermo, 2008).

Some studies have found that parental behaviour impacts on the child's chronic pain condition. In a study on recurrent abdominal pain, children whose parents responded to their pain behaviour with more attention had greater symptomatic complaints than those whose parents responded with distraction (Walker *et al.* 2006). Also, parental solicitous behaviour has been seen to increase the pain intensity and functional disability of children with chronic pain (Claar, Simons & Logan, 2008; Simons, Claar & Logan, 2008; Peterson & Palermo, 2004). Parental minimisation was found to increase pain intensity and encouragement and monitoring from the parents was associated with worse functional disability (Claar, Simons & Logan, 2008; Simons, Claar & Logan, 2008). Besides that, the presence of parental depression and/or anxiety was predictive of the level of distress experienced by the child (Vuorimaa *et al.*, 2009).

Given the complex interactions between the parent and child, there has been interest in targeting parents for an educational intervention to benefit children experiencing chronic pain. As the child's chronic pain can result in parental emotional distress (Eccleston *et al.*, 2004; Kashikar-Zuck, *et al.*, 2008), a parent education intervention could also possibly benefit the parents as well. Various studies have investigated the efficacy of such educational intervention, mostly in the form of a family-focused cognitive behavioural therapy. Parental education has shown to be beneficial in some other chronic conditions like behavioural problems, and has limited success in Autism spectrum disorder and Attention Deficit Hyperactivity Disorder (ADHD) (Law *et al.*, 2009).

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There are several studies on parental education in chronic pain but only a few showed that it improved pain intensity in the children (Allen & Shriver, 1998; Robins *et al.*, 2005; Palermo *et al.*, 2009). Robins *et al.* (2005) and Allen & Shriver (1998) also showed that parent education was related to improved school attendance. However, there seems to be no significant effects of parental education on the child's functional disability (Gerber *et al.*, 2010; Sanders *et al.*, 1994; Robins *et al.*, 2005). The lack of significant findings could be due to the small sample size of the studies. Interestingly, the study by Allen & Shriver (1998) found that parental education is beneficial to the parents themselves. Although the satisfaction and acceptability of the treatment have been previously measured (Allen & Shriver, 1998; Sanders *et al.*, 1994), there are no studies so far that evaluated the usefulness and relevance of the education content.

Currently in our Paediatric Chronic Pain clinic, informal parent education is offered by various allied health members of the team. However, given the promising evidence that parental education may benefit children with chronic pain and their parents, our ultimate goal is to implement a structured education program for parents with children experiencing chronic pain in our Paediatric Chronic Pain clinic and evaluate the effectiveness of this intervention. To maximise the effectiveness of the education program, we decided to have individual sessions with each parent to meet their specific concerns and needs. Such an approach is also supported by Dunst, Trivette & Hamby (2007). The educational material was created collaboratively by members of the Paediatric Chronic Pain team, with a medical student compiling and organising the information.

At this stage, we are in the process of finalising the education content (Refer to Appendix 1 for the outline) and recruiting participants for our study. Before implementation of the parental education program, we have conducted a cross-sectional study to evaluate the characteristics of our patient sample. This is to determine if this sample's characteristics are consistent with what is reported in other similar studies. Also, we have tested whether in our sample, parental cognition and behaviour are associated with and potentially predictive of the child's pain condition. This would allow us to justify the implementation the Parent Education program. At the same time, in order to ensure that the education material is

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relevant and useful to the parents, we conducted a qualitative study to identify any issues that we may have missed in developing the pilot parent education materials.

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3 Methods

3.1 Participants

Our target participants were patients of ages 7 – 18 seen at the multidisciplinary Chronic Pain Clinic in Sydney Children’s Hospital from January 2009 to November 2010. A set of questionnaires, including a consent form to participate in this study, were mailed to the parents of the patients prior to the first clinic appointment. In preparation for the study on the effect of parental education, an additional qualitative questionnaire was included and only new patients who were admitted from May 2010 completed this questionnaire. Upon return of the completed questionnaires, patients were then offered their first appointment. Only patients who experienced pain for at least two months prior to the first consultation with the Paediatric Chronic Pain team were included in the study.

Of the 41 patients who agreed to participate in the study, only one had less than 2 months’ duration of pain.

The total sample for the quantitative study has 40 patients and their ages ranged from 7 to 17 years, with a mean age of 13.43 years (SD = 2.47). The mean duration of pain was 33.98 months (SD = 35.02). Most of the chronic pain patients were females (72.5%) and 82.5% of the parents who responded about their children were mothers. The types of pain diagnoses are summarised in table 1. With regards to family history, 45.0% of participants had at least one parent with a pain condition and 47.5% had a family history of psychiatric illness.

Table 1: Summary of pain diagnoses in quantitative study

Pain diagnosis	%
Chronic regional pain (thoracic and abdominal)	25.0
Chronic pain including CRPS of the limbs	35.0
Back pain	7.5
Headache	5.0
Chronic widespread pain	27.5

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The total sample for the qualitative study has 21 patients and their ages ranged from 7 to 17 years, with a mean age of 14.1 years (SD = 2.34). The mean duration of pain was 31 months (SD = 35.4). In the sample, 76.2% of the patients were females and 90.5% of the parents who responded about their children were mothers. A summary of the types of pain diagnoses is found in table 2. Also, 52.4% of participants had at least one parent with a pain condition and 47.6% had a family history of psychiatric illness.

Table 2: Summary of pain diagnoses in qualitative study

Pain diagnosis	%
Chronic regional pain (thoracic and abdominal)	14.3
Regional pain including CRPS of the limbs	38.1
Back pain	9.5
Chronic widespread pain	38.1

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3.2 Measures

3.2.1 Quantitative measures

For the full list of items in each measure, refer to Appendix 2.

3.2.1.1 Pain intensity and frequency

Both parents and children completed identical questionnaires on the pain intensity and frequency. Pain intensity was assessed via the Faces Pain Scale – Revised (FPS-R). The FPS-R has six faces, ranging from no pain to very much pain and respondents had to rate the worst pain that the child experienced in the last week. Each face corresponds to the scale from 0 to 10, with *no pain* being 0 and *very much pain* being 10. This scale has been validated by Hicks *et al.* (2001) for use in children from ages 4 onwards. Pain frequency was measured in two ways. Firstly, a Likert-type rating scale was used to measure the amount of awake time that the child is bothered by the pain in a day. The responses ranged from 0 = *no time* to 10 = *every moment*. A second question then asked for the number of days in a week that the child is pain-free.

3.2.1.2 Functional Disability

Both parents and children completed parallel versions of the Functional Disability Inventory (FDI) to assess the child's limitations in daily activities due to the pain. The FDI describes 15 daily activities spreading over different domains like home, school, recreation and social interactions. Respondents had to rate the difficulty they had doing those activities on a 5 point scale from 0 = *No trouble* to 4 = *Impossible* (range = 0-60). The FDI has been validated by Claar & Walker (2006) and Walker & Greene (1991) and was also shown to have a good test-retest reliability and strong internal consistency reliability.

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3.2.1.3 Family, partner-relationship and financial stress

All three types of stresses were measured using the Likert-type rating scale and were assessed separately. Responses ranged from 0 = *None at all* to 10 = *A lot*. Both parents and children completed parallel versions for family stress while only the parents completed the evaluation for the stress between them and their partners, and the financial stress.

3.2.1.4 School absence

Parents filled in the number of days that their child had missed school as a result of the pain in the last term. As some parents stated their answers in percentages, the figure was translated into the number of days, with the assumption of an average of 68 days in a term.

3.2.1.5 Sleep behaviour and patterns

Five areas of sleep were evaluated: the level of sleep disturbances, difficulty falling asleep, waking during the night because of the pain, tiredness in the day and whether the child sleeps in his/her own bed. The first four areas were measured using the Likert-type rating scale, ranging from 0 = *Not at all* to 10 = *A lot*. Respondents were required to answer *yes* or *no* to whether the child sleeps in his/her own bed for the whole night. Both parents and children completed parallel questionnaires for this section.

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3.2.1.6 Social and school functioning

This questionnaire was adapted from the Pediatric Quality of Life Inventory Version 4.0 (PedsQL 4.0) (Varni, Seid & Kurtin, 2001), which measures the health-related quality of life. Out of the four subscales, only the social and school subscales were used, which had five items each. The social subscale measures how well the child is getting along with others. The school subscale measures how school attendance is affected by health-related problems and the difficulties in general school functioning. Children were asked to self-report how much of a problem each item has been in the past one month. A 5-point rating was used, from 0 = *Never a problem* to 4 = *Almost always a problem* (Range = 0-20). This questionnaire has shown good reliability and validity (Varni, Seid & Kurtin, 2001).

3.2.1.7 Depression

The Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure depressive symptoms in the child. There are 20 items in the scale and the children rated how often they experienced those feelings in the past week on a 4-point scale, from 0 = *Not at all* to 3 = *A lot* (Range = 0-60). Test-retest reliability and validity were adequate (Faulstich *et al.*, 1986).

3.2.1.8 Social consequence of pain

The Social Consequence of Pain (SCP) scale (Walker, Claar & Garber, 2002) measures the social consequences delivered by parents, teachers and peers. It has 32 items that can be classified into four categories of social consequences: Positive attention (11 items), activity restriction (11 items), negative attention (6 items) and privileges (4 items). Children rated how often these social consequences occur on a 5 point scale, from 0 = *Never* to 4 = *Always*. The score for each subscale is computed as the average item rating for each type of social consequence.

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3.2.1.9 Pain catastrophising

The Pain Catastrophising Scale (PCS) is used to measure both the parents' and children's level of catastrophising. Parents and children completed parallel questionnaires about themselves. There are three subscales in the PCS, namely rumination, magnification and helplessness. There are 13 items in all and respondents rated the strength of each of the thoughts or feelings on a 5 point scale, from 0 = *Not at all* to 4 = *Extremely*. The score for each subscale is computed as the sum for all the items in each factor. Adequate validity was shown for both the parent and child version (Goubert *et al.*, 2006; Crombez *et al.*, 2003).

3.2.1.10 Adult responses to children's symptoms

The Adult Responses to Children's Symptoms (ARCS) scale (van Slyke & Walker, 2006) measures the parent's reaction to their child's pain. There are 29 items in total and the items fall into 3 categories of responses: Protect, minimise, and encourage and monitor. Protective behaviour is defined by limiting the child's activities, relieving the child from responsibilities and giving special privileges. Responses that dismiss or criticise the child's pain behaviour fell into the category of minimise. Encourage and monitor behaviour included responses that distracts the child from pain, encouraging activity and reassuring the child. Parents used a 5 point scale to indicate how often they responded to their child in the way that is stated in the item: 0 = *Never* to 4 = *Always*. The score for each subscale is calculated by taking the average item rating for each type of response.

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3.3 Statistical analysis

All quantitative data were analysed using the program Predictive Analytics SoftWare (PASW) version 18. In describing demographic and descriptive characteristics of our sample, means and standard deviations were used for continuous variables while proportion was used for categorical variables. To look for associations between the child's and parent's report of the same measure, Pearson's test was used to investigate 2 continuous variables (e.g. Pain intensity, FDI, etc.) and chi-squared test was applied to investigate 2 categorical variables (e.g. If child sleeps in own bed). Pearson's test was also used to find association between parental characteristic and behaviour (PCS-P, ARCS, family stress, relationship stress and financial stress) with child's pain outcomes (e.g. Pain intensity and frequency, FDI, etc.). T-test was used to investigate differences in characteristic and behaviour of parents whose children who sleep in their own bed and parents whose children who do not. For scales with more than 20% of missing data within one questionnaire, the score for that scale would be considered missing. If less than 20% of data were missing, then the average from all the ratings for the same item was used to replace the missing value.

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3.4 Qualitative questionnaire

The qualitative questionnaire was developed by the researchers and the clinical psychologists in the Paediatric Chronic Pain team to investigate issues that are important in evaluating the progress of the child's and his/her family's with the child's chronic pain. It also served another purpose of identifying issues that may be critical to address in the parental education. This questionnaire was completed by the parent only. The questionnaire consisted of open-ended items that covered a range of topics: Understanding of child's pain condition, child's social and educational development, child's stress levels and emotional adjustment, overall family functioning, parent stress and emotional adjustment, and expectations of intervention. For the full list of questions, refer to Appendix 3.

As the goals of the Paediatric Chronic Pain Clinic are to improve both the medical and functional aspects of pain, we have used this to construct the framework to analyse the qualitative data. The broad responses were first grouped into the common issues. These issues were then further classified into the 3 main categories: medical, functional and both (mix of medical and functional). Issues from the categories that were not addressed in the parental education content were then highlighted and placed in the grey boxes (Refer to table 3). Two of the researchers worked together to categorise all the issues.

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Table 3: Example of how responses are categorised

Question	Broad responses	Categories	Framework				
1. What do you understand about your child’s pain?	<ul style="list-style-type: none"> • Psychological • Stress • Emotional • Medical causes • Unknown • Unclear • Impacts of pain on life • Understanding what to do • Not understanding what to do 	<ul style="list-style-type: none"> • Medical causes • Psychological causes • Impacts of pain • Management • Unclear 	Medical	<ul style="list-style-type: none"> • Medical causes 			
				Functional	<ul style="list-style-type: none"> ▪ Psychological causes ▪ Impacts of pain 		
			Both		<ul style="list-style-type: none"> • Management 		
			3. What makes your child’s pain better?		<ul style="list-style-type: none"> • Positive moods • Sleep • Distractions • Comfort and reassurance • Meds • Heat packs • Massage • Nothing/I don’t know • Rest • Walking • Ointment rub • Stretching • Visualisation • Deep breathing • Posture • TENS machine • Understanding • Supportive • Empathy 	<ul style="list-style-type: none"> • Medications • Alternative medicine • Adjunct therapy • Exercise • Positive moods • Sleep/rest • Distraction • Psychological methods • Massage • Posture • Comfort and reassurance • Nothing/I don’t know 	Medical
				Functional			
	<ul style="list-style-type: none"> • Adjunct therapy • Exercise • Positive moods • Sleep/rest • Distraction • Psychological methods • Massage • Posture 						
	<ul style="list-style-type: none"> • Comfort and reassurance • Nothing/I don’t know 						
Both							

Note: Issues in the grey boxes were not covered in the parental education content.

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4 Results

4.1 Quantitative results

4.1.1 Descriptive data

Tables 4, 5 and 6 show the baseline measurements of the parent's assessment of child, the parent's self-assessment and the child's self-assessment.

Table 4: Baseline measurement from parent's assessment of child

Parent's assessment of child	Range	Mean	SD
Pain intensity (Worst pain in the last week)	0: No pain 10: Very much pain	7.63	2.48
Amount of time bothered by pain	0: No time 10: Every moment	6.72	2.97
Number of pain-free days in the week	0: 0 days 7: All days in a week	1.08	2.15
Total FDI score	0: No functional disability 60: Extreme functional disability	21.61	13.77
Number of days missed in a school term	0: 0 days 68: All days in a term	17.33	18.43
Level of sleep disturbances	0: Not at all 10: A lot	4.36	3.63
Level of difficulty falling asleep	0: Not at all 10: A lot	4.93	3.76
Level of being awoken by pain	0: Not at all 10: A lot	3.69	3.73
Level of tiredness	0: Not at all 10: A lot	6.35	3.39

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Table 5: Baseline measurement from parent's self-assessment

Parent's self-assessment	Range	Mean	SD
PCS total score	0: No pain catastrophising 52: Extreme pain catastrophising	26.88	12.26
PCS - Rumination	0: No rumination 16: Extreme rumination	11.23	4.17
PCS - Magnification	0: No magnification 10: Extreme magnification	4.49	3.13
PCS - Helplessness	0: No helplessness 10: Extreme helplessness	11.19	5.90
ARCS - Protect	0: None 4: Extreme	1.71	0.62
ARCS - Minimisation	0: None 4: Extreme	0.86	0.57
ARCS - Encourage and monitor	0: None 4: Extreme	2.78	0.63
Level of family stress	0: None at all 10: A lot	4.85	2.35
Level of partner-relationship stress	0: None at all 10: A lot	3.01	2.46
Level of financial burden	0: None at all 10: A lot	4.08	3.21

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Table 6: Baseline measurements from child's self-assessment

Child's self-assessment	Range	Mean	SD
Pain intensity (Worst pain in the last week)	0: No pain 10: Very much pain	7.54	2.32
Amount of time bothered by pain in a day	0: No time 10: Every moment	7.10	3.00
Number of pain-free days in a week	0: 0 days 7: All days in a week	0.94	1.81
FDI	0: No functional disability 60: Extreme functional disability	23.11	13.04
Social functioning (Getting along with others)	0: No difficulty with function 20: Extreme difficulty with function	4.92	3.70
School functioning	0: No difficulty with function 20: Extreme difficulty with function	9.51	4.77
Level of family stress	0: None at all 10: A lot	3.96	3.05
SCP - Positive attention	0: None 4: Extreme	1.60	0.72
SCP - Negative attention	0: None 4: Extreme	0.93	0.61
SCP - Activity Restriction	0: None 4: Extreme	2.05	0.86
SCP - Privileges	0: None 4: Extreme	0.75	0.65
Depression	0: No depression 80: Extreme depression	25.48	10.46
PCS total score	0: No pain catastrophising 52: Extreme pain catastrophising	28.36	9.83
PCS - Rumination	0: No rumination 16: Extreme rumination	10.58	3.32
PCS - Magnification	0: No magnification 10: Extreme magnification	4.81	2.89
PCS - Helplessness	0: No helplessness 10: Extreme helplessness	12.97	4.95
Level of sleep disturbances	0: Not at all 10: A lot	4.64	3.75
Level of difficulty falling asleep	0: Not at all 10: A lot	4.27	3.76
Level of being woken up by pain	0: Not at all 10: A lot	4.47	3.79
Level of tiredness	0: Not at all 10: A lot	6.63	3.41

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4.1.2 Association between parent's and child's reports of child's variables

Correlations were found between the parent's and child's reports for pain intensity and frequency, FDI, family stress, sleep disturbances, difficulty falling asleep, frequency of being woken by pain and tiredness. Results are shown in table 7.

Table 7: Correlation between parent's and child reports of child's variables

Measure	Pearson correlation
Pain intensity	0.67***
Amount of pain bothered by pain	0.57***
Number of pain-free days in a week	0.54***
FDI	0.79***
Family stress	0.51**
Sleep disturbances	0.84***
Difficulty falling asleep	0.81***
Being woken by pain	0.76***
Tiredness	0.63***

*p≤0.05; **p<0.01; ***p<0.001

An association was also found between the two reports for whether the child sleeps in his/her own bed, $\chi^2(1, N=40)=9.85, p=0.002$.

The associations between the parent's and child's reports support the validity of these measures in our sample.

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4.1.3 Association between parental characteristics/behaviour with child's pain outcome

4.1.3.1 Association between parental behaviour and the child's pain intensity and frequency

Table 8 summarises the results for this section. The parent's report of their child's pain intensity was found to correlate significantly with the parent's total PCS, PCS–Rumination, PCS–Helplessness, ARCS–Encourage and monitor, family stress and partner-relationship stress. However, the child's self-report of pain intensity was found to correlate only with family stress.

The parent's report of the amount of time their child was bothered by pain was associated with family stress and partner-relationship stress.

Table 8 Correlation of child's pain intensity and frequency with parental behaviour and characteristics

Parental variables	Child's variables		
	Pain intensity		Amount of time bothered by pain
	Parent's report	Child's report	Parent's report
Total PCS	0.36*	0.16	0.18
PCS - Rumination	0.39*	0.20	0.23
PCS - Helplessness	0.36*	0.20	0.15
ARCS - Encourage and monitor	0.37*	0.22	0.27
Family stress	0.50**	0.31*	0.33*
Partner-relationship stress	0.32*	0.11	0.37*

* $p \leq 0.05$; ** $p < 0.01$

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4.1.3.2 Association between parent behaviour and child's FDI

Table 9 summarises the following results. The child's FDI reported by both the child and parent were positively correlated with many of the parental behaviour and characteristics (Refer to table 9). The parent's report of their child's FDI was positively correlated with the parent's PCS total, PCS–Rumination, PCS–Magnification, PCS–Helplessness, ARCS–Protect, family stress, partner-relationship stress and financial stress. The child's report of their own FDI was positively correlated with parent's PCS total, PCS–Rumination, PCS–Magnification, PCS–Helplessness, ARCS–Encourage and monitor and family stress. Hence, these parental measures correlate with worse function of the children.

Table 9 Correlation of child's FDI with parental behaviour and characteristics

Parental variables	Child's FDI	
	Parent's report	Child's report
Total PCS	0.49**	0.53***
PCS - Rumination	0.45**	0.52**
PCS - Magnification	0.46**	0.38*
PCS - Helplessness	0.45**	0.53***
ARCS - Protect	0.45**	0.24
ARCS - Encourage and monitor	0.25	0.36*
Family stress	0.46**	0.43**
Partner-relationship stress	0.42**	0.31
Financial stress	0.32*	0.31

* $p \leq 0.05$; ** $p < 0.01$; *** $p < 0.001$

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4.1.3.3 Association between parental behaviour and child's social function

The results are summarised in Table 10. How poorly the child gets along with his/her peers was positively correlated with parent's PCS total, PCS–Rumination, PCS–Magnification, PCS–Helplessness, ARCS–Minimisation, ARCS–Encourage and monitor, family stress and financial stress. The child's poor functioning in school was positively correlated with parent's ARCS–Protect, ARCS–Encourage and monitor and family stress. The child's poor functioning at home was positively correlated with parent's report of family stress and partner-relationship stress.

Table 10 Correlation of child's social function with parental behaviour and characteristics

Parental variables	Child's variables		
	Difficulty getting along with others	Poor school function	Poor home function
PCS total	0.46**	0.31	0.08
PCS - Rumination	0.42**	0.30	0.05
PCS - Magnification	0.39*	0.22	0.03
PCS - Helplessness	0.46**	0.30	0.12
ARCS - Protect	0.20	0.33*	0.19
ARCS - Minimisation	0.52**	0.06	0.05
ARCS - Encourage and monitor	0.34*	0.41*	0.14
Family stress	0.39*	0.39*	0.51**
Partner-relationship stress	0.27	0.28	0.34*
Financial stress	0.40*	0.19	0.20

* $p < 0.05$; ** $p < 0.01$

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4.1.3.4 Association between parental behaviour and the child's SCP

The various subscales in SCP had positive correlations with some of the parental behaviours and characteristics (Refer to table 11). Positive attention was correlated positively with parent's PCS-Rumination, ARCS–Protect and ARCS–Encourage and monitor. Negative attention was correlated positively with parent's PCS–Helplessness and ARCS–Minimisation. Activity restriction was correlated positively with parent's ARCS–Encourage and monitor, family stress and partner-relationship stress. Privileges was correlated positively only with ARCS–Protect and financial stress.

Table 11 Correlation of child's SCP with parental behaviour and characteristics

Parental variables	Child's variables			
	Positive attention	Negative attention	Activity restriction	Privileges
PCS - Rumination	0.34*	0.29	0.26	0.17
PCS - Helplessness	0.31	0.32*	0.31	0.24
ARCS - Protect	0.49**	0.27	0.30	0.49**
ARCS - Minimisation	0.12	0.35*	0.07	0.14
ARCS - Encourage and monitor	0.54**	0.04	0.37*	0.29
Family stress	0.22	0.17	0.51**	0.19
Partner-relationship stress	0.32	0.15	0.34*	0.27
Financial stress	0.29	0.08	0.22	0.44**

*p<0.05; **p<0.01

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4.1.3.5 Association between parental behaviour and the child's depression and their level of catastrophising.

A summary of the results is shown in Table 12.

The child's level of depression was correlated positively with parent's ARCS–Encourage and monitor and family stress.

In general, the child's level of catastrophising was correlated with parent's PCS total, PCS – Rumination, PCS–Magnification, PCS–Helplessness, ARCS–Protect and ARCS–Encourage and monitor. The level of rumination in the child was positively correlated with parent's PCS total, PCS–Rumination, PCS–Helplessness, ARCS–Protect and ARCS–Encourage and monitor. The level of magnification in the child was positively correlated with parent's ARCS–Minimisation and ARCS–Encourage and monitor. Finally, the level of helplessness in the child was correlated positively with parent's PCS total, PCS–Rumination, PCS–Magnification, PCS–Helplessness, ARCS–Protect and ARCS–Encourage and monitor.

Table 12 Correlation of child's depression and pain catastrophising levels with parental behaviour and characteristics

Parental variables	Child's variables				
	Depression	PCS total	PCS - Rumination	PCS - Magnification	PCS - Helplessness
PCS total	0.21	0.47**	0.40*	0.31	0.48**
PCS - Rumination	0.24	0.48**	0.45**	0.30	0.48**
PCS - Magnification	0.12	0.38*	0.30	0.29	0.38**
PCS - Helplessness	0.20	0.44**	0.36*	0.29	0.46**
ARCS - Protect	0.30	0.37*	0.45**	0.16	0.34*
ARCS - Minimisation	0.13	0.22	0.09	0.34*	0.17
ARCS - Encourage and monitor	0.52**	0.54**	0.52**	0.33*	0.51**
Family stress	0.38*	0.15	0.20	0.05	0.14

* $p \leq 0.05$; ** $p < 0.01$

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4.1.3.6 Association between parental behaviour and the child's sleep behaviour

Table 13 summarises the results of the correlations. The parent's report of the frequency that their child is being woken by pain was correlated positively with parent's ARCS–Protect and partner-relationship stress. The parent's report of their child's tiredness was also correlated positively with parent's PCS total, PCS–Rumination, PCS–Magnification, PCS–Helplessness, family stress, partner-relationship stress and financial stress.

Table 13 Correlation of child's sleep behaviour with parental behaviour and characteristics

Parental variables	Parent's report of child's variables	
	Being awoken by pain	Tiredness
PCS total	0.20	0.42**
PCS – Rumination	0.18	0.32*
PCS – Magnification	0.22	0.41**
PCS – Helplessness	0.18	0.43**
ARCS – Protect	0.34*	0.21
Family stress	0.08	0.45**
Partner-relationship stress	0.35*	0.40*
Financial stress	0.20	0.42**

* $p \leq 0.05$; ** $p < 0.01$

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Significant differences in the means of parental variables were found when we compared children who sleep in their own bed and children who do not (Refer to table 14). In the parent's report on their child's sleep, significant differences were found for the means of parent's PCS total, PCS–Magnification and PCS–Helplessness, with children sleeping in their own beds having parents with lower catastrophising levels. In the child's self-report on sleep, children who slept in their own beds had parents who “encourage and monitor” less.

Table 14 Parental variables means for whether child sleeps in own bed

Parental variables		Does child sleep in own bed?		t	df
		Yes	No		
Parent's report on child's sleep	PCS total	24.96 (11.71)	36.14 (11.29)	-2.306*	38
	PCS – Magnification	3.89 (2.82)	7.29 (3.15)	-2.835**	38
	PCS – Helplessness	10.31 (5.53)	15.57 (6.08)	-2.249*	38
Child's self-report on sleep	ARCS - Encourage and monitor	2.69 (0.60)	3.39 (0.54)	-2.214*	38

* $p \leq 0.05$; ** $p < 0.01$. Standard Deviations appear in parentheses below means.

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4.2 Qualitative Results

Full results can be found in Appendix 3. Overall, responses could be categorised into the 3 categories and only a small number of issues were identified that were not covered in the Parent Education material.

4.2.1 Understanding of child's pain condition

Though most parents showed some understanding of their child's condition, a few of them had very little understanding about it. Some parents understood that aside from the medical cause, psychological causes also played a part in their child's pain. Most of them had some idea of how they should manage their child's pain.

Also, most parents were able to identify factors that made their child's pain better or worse. Most of these factors, for example: medications and distraction in making pain better, were covered in the education content. A few parents mentioned certain types of alternative medicine that were useful in alleviate their child's pain, which were not covered in the education content. Other issues not covered include factors that made their child's pain worse, such as certain food, isolation, certain posture, not opening bowels and cold. A few parents mentioned issues around consoling their child or making their child comfortable as a tool of managing their child's pain or that is useful in making the pain better. Such issues were also not included in the education content.

4.2.2 Child's social and educational development

Parents mentioned various emotional changes that the child has undergone including becoming socially withdrawn, sad, and anxious, etc. These emotional changes in the child were not in the parental education content.

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4.2.3 Child's stress levels and emotional adjustments

Again, responses to the child's feelings towards his/her pain which include being anxious, depressed, loss of control, etc. are not covered in the education modules.

When asked about what the child is scared/sad/angry about the pain, two main responses were found, which were the poor understanding of their condition and how to manage it, and thoughts of the pain not going away or getting better. Parents also stated some issues that were not covered in the education content, which include the pain being too intense to handle, unknown future, others not understanding and not fitting in with peers. There were also other more specific and individual issues not covered like fear of thunderstorms, heater, hospital, mum not being around, and the world and anyone who was involved in the accident.

Things that the child looks forward to that are not included in the education materials are going home and meeting family members.

4.2.4 Overall family functioning

The responses from this section were all found to be covered in the education content. Some of the impacts on the family were disruptions in normal routine and the various emotional changes in the family members.

4.2.5 Parent stress and emotional adjustment

There were many different responses to this section ranging from the cause of the pain and the management of it, to their other concerns of their family and career. These issues were addressed into the various modules of the education material.

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4.2.6 Expectations of intervention

There were areas which the parents expected of the clinic which were not included in the parental education. The issues include help in losing weight, listening to the child's needs and wants, giving the child more confidence and skills to cope with pain, and removing pain. Besides that, it was interesting to note that one parent felt that the pain clinic does not help and the child is left to suffer. This issue was not addressed directly in the education content as well.

5 Discussion

This study has two main aims. Firstly, it aims to examine the characteristics of our clinical sample and investigate any associations between parental behaviour and cognition, and the child's pain outcome. Secondly, it aims to investigate parents' understanding of their child's pain condition and identify any gaps in the provisionally created education materials.

Some of the measurements could not be compared to the other studies as they were either used to investigate a different condition or a different measure evaluating the same variable (e.g. Pain intensity) was used. However, we were able to compare the baseline measurements of FDI and ARCS in our clinical sample and found them to be similar to other studies (Claar, Simons, Logan, 2008; Robins *et al.*, 2005). Interestingly, the parent's PCS total score in our sample was similar to Goubert *et al.*'s (2006) study but the child's PCS total score (mean=28.36, SD=9.83) was much higher than in Crombez *et al.*'s (2003) study (mean=21.88, SD=11.44). The reason for this difference in score might be worth investigating to better understand and manage the child's pain.

Despite our small sample size, our study was able to show that parental behaviour and characteristics was associated with some of the child's pain outcomes like pain intensity, school functioning, depression, tiredness and SCP. In particular, the child's functional disability, social functioning and pain catastrophising had many correlations to the various types of parental behaviour and characteristics.

Children with higher functional disability were associated with parents who had higher levels of catastrophising and parents who exhibited greater protective behaviour (according to parent's report) or encouraging and monitoring behaviour (according to child's report). These findings are consistent with the literature (Goubert *et al.*, 2006; Claar, Simons & Logan, 2008). At the same time, our results also showed that the child's functional disability was associated with the parent's perceived amount of family stress, partner-relationship stress and financial stress. However, there have been no studies so far that investigated on these relationships.

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Furthermore, there are no studies that have examined the relationship of the child's social function and pain catastrophising with their parent's catastrophising levels and behaviour. These relationships may be worth investigating as the child's catastrophising is predictive of their pain severity and disability (Crombez *et al.*, 2003). Also, the child's social function is one of the important areas that the Chronic Pain Team manages in the clinic.

From the results, we observed that only the parent's report, and not the child's, of the child's pain intensity and tiredness correlated with many variables of parental behaviour. This may be due to the higher levels of catastrophising in the parents compared to the children, which led to slightly higher reports of their child's pain intensity and tiredness.

Unexpectedly, encouraging and monitoring behaviour by the parents had positive correlations with some of the child's pain outcomes like increased functional disability, difficulties with social and school function, etc. This may be because the Encourage and Monitor subscale contained a combination of adaptive and non-adaptive (e.g. *Ask questions about how she feels*) items. Hence, the Encourage and Monitor subscale may not be an accurate measure of this particular type of parental behaviour, resulting in mixed results in our study.

In the qualitative study, our results showed that many parents had some knowledge about their child's condition and how they should manage it. However, there were a few parents who understood very little about it. This highlights the potential need for parental education to help parents better understand their child's chronic pain.

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Most of the issues that were identified were covered in the education content. However, there were a few issues that were not addressed in the current version of the education material. Although these issues are all important to address, we feel that they should not be included in the education materials due to the following reasons:

1. Not recommended by the Chronic Pain Clinic; and/or
2. Issues that are more appropriate for discussion and management in the Chronic Pain clinic; and/or
3. Not directly addressed in the education content but parents should gradually understand as they go through the education sessions.

Firstly, parental behaviour like making the child comfortable and providing reassurance and consolation are not encouraged by the Chronic Pain team and hence are not usually discussed with the parents unless the issue is brought up by the family.

Also, we felt that certain issues that require intervention targeted at the child (e.g. Child's emotions and feelings of isolation) and issues that are specific to the individual patient (e.g. Alternative medicine, certain food and posture that makes pain better/worse) are more appropriate for discussion and management in the clinic.

Lastly, we felt that a few of the issues are addressed through the education sessions in a more subtle manner. An example would be the issue about the unknown future. With a good understanding of the nature of chronic pain and how it should be managed, we hope that parents would have more realistic expectations about their child's condition.

5.1 Limitations

Our sample size was small, but nevertheless there were a number of significant findings of interest. The small sample size did not allow for us to conduct a satisfactory multiple regression analysis to investigate potential causal relationships between variables. Furthermore, as this is a cross-sectional study, we were not able to assess any causal relationships and thus unable to determine if parental behaviour and characteristics are

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influential and predictive of the child's pain outcomes. Nevertheless, reasonable causal hypotheses can be derived.

5.2 Future directions

As the effect of parental behaviour and characteristics on many of the child's pain outcome like depression, pain catastrophising, social and school functioning, SCP and sleep behaviour have not been investigated previously, this study may be valuable in gaining further insight on the impacts of parental behaviour. Hence, further research including prospective cohort evaluation would be appropriate to evaluate these child's pain outcomes with a larger sample size to provide sufficient power to the study.

Also, there is a need to test the hypothesis that the current version of our parental education content is sufficiently comprehensive and relevant. Hence, the parental education program should be trialled and undergo further evaluation by both the participants and the educators to refine the content.

6 Conclusion

We feel that the implementation of a Parent Education program in our Paediatric Chronic Pain Clinic is justifiable as our study has shown that parental behaviour and cognition was associated with some of the child's pain outcomes, in particular functional disability, difficulty with social functioning and pain catastrophising. This is further supported by the literature that parental education has some benefits to the child's pain outcomes. Also, the provisionally created education content is sufficiently comprehensive, relevant and useful.

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References

Allen, K.D. & Shriver, M.D. (1998). Role of parent-mediated pain behavior management strategies in biofeedback treatment of childhood migraines. *Behavior Therapy*. 29, 477-490.

Claar, R.L., Simons, L.E. & Logan, D.E. (2008). Parental response to children's pain : The moderating impact of children's emotional distress on symptoms and disability. *Pain*. 138, 172-179.

Claar, R.L. & Walker, L.S. (2006). Functional assessment of pediatric pain patients: Psychometric properties of the Functional Disability Inventory. *Pain*. 121(1-2), 77-84.

Crombez, G., Bijttebier, P., Eccleston, C., Mascagni, T., Mertens, G., Goubert, L., *et al.* (2003). The child version of the pain catastrophizing scale (PCS-C) : a preliminary validation. *Pain*. 104, 639-646.

Dunst, C.J., Trivette, C.M. & Hamby, D.W. (2007). Meta-analysis of family-centered helping practices and research. *Mental Retardation and Developmental Disabilities Research Reviews*. 13, 370-378.

Eccleston, C., Crombez, G., Scotford, A., Clinch, J. & Connell, H. (2004). Adolescent chronic pain: patterns and predictors of emotional distress in adolescents with chronic pain and their parents. *Pain*. 108, 221-229.

Faulstich, M.E., Carey, M.P., Ruggiero, L., Enyart, P. & Gresham, F. (1986). Assessment of depression in childhood and adolescence : an evaluation of the Center for Epidemiological Studies Depression Scale for Children (CES-DC). *American Journal of Psychiatry*. 143, 1024-1027.

Gauntlett-Gilbert, J. & Eccleston, C. (2007). Disability in adolescents with chronic pain: Patterns and predictors across different domains of functioning. *Pain*. 131(1-2), 132-141.

Gerber, W., Petermann, F., Gerber-von Muller, G., Dollwet, M., Darabaneanu, S., Niederberger, U., *et al.* (2010). MIPAS-Family – evaluation of a new multi-modal behavioral

Final report

training program for pediatric headaches : clinical effects and the impact on quality of life. *Journal of Headache Pain*. 11(3), 215-225.

Goubert, L., Eccleston, C., Vervoort, T., Jordan, A. & Crombez, G. (2006). Parental catastrophizing about their child's pain. The parent version of the Pain Catastrophizing Scale (PCS-P): A preliminary validation. *Pain*. 123, 254-263.

Hicks, C.L., von Baeyer, C.L., Spafford, P.A., van Korlaar, I. & Goodenough, B. (2001). The faces pain scale – revised: toward a common metric in pediatric pain measurement. *Pain*. 93(2), 173-183.

Law, J., Plunkett, C., Taylor, J. & Gunning, M. (2008). Developing policy in the provision of parenting programmes: integrating a review of reviews with the perspectives of both parents and professionals. *Child: care, health and development*. 35(3), 302-312.

Logan, D.E., Simons, L.E., Stein, M.J. & Chastain, L. (2008). School impairment in adolescents with chronic pain. *The Journal of Pain*. 9(5), 407-416.

Long, A.C., Krishnamurthy, V. & Palermo, T.M. (2008). Sleep disturbances in school-age children with chronic pain. *Journal of Pediatric Psychology*. 33(3), 258-268.

Kashikar-Zuck, S., Lynch, A.M., Slater, S., Graham, T.B., Swain, N.F. & Noll, R.B. (2008). Family factors, emotional functioning, and functional impairment in juvenile fibromyalgia syndrome. *Arthritis & Rheumatism*. 59(10), 1392-1398.

Palermo, T.M., Wilson, A.C., Peters, M., Lewandowski, A. & Somhegyi, H. (2009). Randomized controlled trial of an internet-delivered family cognitive-behavioral therapy intervention for children and adolescents with chronic pain. *Pain*. 146, 205-213.

Perguin, C.W., Hazebroek-Kampschreur, A.A.J.M., Hunfeld, J.A.M., Bohnen, A.M., van Suijlekom-Smit, L.W.A., *et al.* (2000). Pain in children and adolescents: a common experience. *Pain*. 87(1), 51-58.

Peterson, C.C. & Palermo, T.M. (2004). Parental reinforcement of recurrent pain: The moderating impact of child depression and anxiety on functional disability. *Journal of Pediatric Psychology*. 29(5), 331-341.

Final report

Robins, P.M., Smith, S.M., Glutting, J.J. & Bishop, C.T. (2005). A randomized controlled trial of a cognitive-behavioral family intervention for pediatric recurrent abdominal pain. *Journal of Pediatric Psychology*. 30(5), 397-408.

Sanders, M.R., Shepherd, R.W., Cleghorn, G. & Woolford, H. (1994). The treatment of recurrent abdominal pain in children: A controlled comparison of cognitive-behavioral family intervention and standard pediatric care. *Journal of Consulting and Clinical Psychology*. 62(2), 306-314.

Simons, L.E., Claar, R.L. & Logan, D.L. (2008). Chronic pain in adolescence: Parental responses, adolescent coping, and their impact on adolescent's pain behaviors. *Journal of Pediatric Psychology*. 33(8), 894-904.

Simons, L.E., Logan, D.E., Chastain, L. & Stein, M. (2010). The relation of social functioning to school impairment among adolescents with chronic pain. *Clinical Journal of Pain*. 26(1), 16-22.

Varni, J.W., Seid, M. & Kurtin, P.S. (2001). PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core scales in Healthy and Patient Populations. *Medical Care*. 39(8), 800-812.

Vuorimaa, H., Tamm, K., Honkanen, V., Komulainen, E., Konttinen & Santavirta, N. (2009). Parents and children as agents of disease management in JIA. *Child: care, health and development*. 35(4), 578-585.

Walker, L.S., Claar, R.L. & Garber, J. (2002). Social consequences of children's pain: When do they encourage symptom maintenance? *Journal of Pediatric Psychology*. 27(8), 689-698.

Walker, L.S. & Greene, J.W. (1991). The functional disability inventory: measuring a neglected dimension of child health status. *Journal of Pediatric Psychology*. 16, 39-58.

Walker, L.S., Williams, S.E., Smith, C.A., Garber, J., Van Slyke, D.A. & Lipani, T.A. (2006). Parent attention versus distraction: Impact on symptom complaints by children with and without chronic functional abdominal pain. *Pain*. 122, 43-52.

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Appendix 1 – Outline of Parent Education content

Module 1 – About the pain team

- Philosophy of the Chronic Pain Clinic
- Members of the Pain team and their roles

Module 2 – Nature of chronic pain

- The normal pain experience
 - Pain detection and signalling
 - Descending dampening pathways
 - Pain Matrix
 - Examples of acute pain
- Neurobiology and physiology of chronic pain
 - Definition of Chronic Pain
 - 3 major factors
 - The injured, inflamed or disordered structures
 - **Emphasise that the pain is real.**
 - The disordered function occurring in the nerves and the central nervous system
 - Psychological influence
 - In the parent-child relationship
 - Importance of psychological response
 - Catastrophising

Module 3 – Medications

- Analgesics
- Antidepressants
- Anti-convulsants
- Provide medications brochure.

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Module 4 – Parental role and behaviour

- The story about Johnny.
- Look at how the following parental roles and behaviour can fit into their family life and jot down in workbook.
 - Parents as role models for their child's pain behaviour
 - Protection **vs** minimisation **vs** encourage and monitor
 - Boundary setting
 - Reinforcing timetables given and own routines at home
 - Balance of activities including physical activity, leisure time, schoolwork and family time.
 - Use of distraction.
 - Creating a positive environment – asking about child's achievements and accomplishments around activities. However, allow space for failure and being unhappy.
 - Spending quality time with child
 - Designated time to go out and share or participate in activities together
 - Allowing time for talking outside “dinner time”
 - Child knowing that he/she will have their parent's attention at some time.
 - However, be mindful that the child's pain should not take up all of your time and attention.
 - Being confident of their own ability as a parent to maintain family structure and behavioural boundaries.

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Module 5 – Therapeutic approach (Acceptance and commitment therapy)

- There may not be a “quick fix” or cure and the diagnosis may be that of a complex or chronic ongoing pain. Due to the nature of this diagnosis, a combined therapeutic rehabilitation program is the most effective way to improve function and participation in activities of daily living.
- Going through investigations conducted and reassure that it is safe to function even with pain.
- Acceptance of challenges that life presents us. E.g. Chronic pain.
 - Willingness/openness to learn new skills to assist in improving function even with pain.
 - Acting according to values and goal
 - Improving skills to be in the present moment
- Methods include mindfulness. “Mindfulness is about making what you are doing the most important thing in the world.”
 - Mindfulness exercise
- Breathing exercise (1 min):
 - Close your eyes or focus on some object in the room. Sit comfortably and breathe in through your nose and feel the coolness of the air. When you breathe out, notice how the air feels warmer and touches the top of your lips.
 - When you are concentrating on your breathing, for a very small amount of time you are giving your brain a break.
- Believe that the pain is real! However, be mindful of other acute injuries that causes pain and requires medical attention. Contact the nurse if unsure.

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Module 6 – Parents’ emotional status

Explore the following issues briefly. Parents may take any notes in their workbook.

- Guilt – Parents may feel guilty that they are unable to fix their child’s pain.
- It is important to understand that it is not their fault and that we will provide them with information to enable them to help their child manage their pain.
- Role of parent – caring for your child
- Parents may also feel anxious/angry and/or upset because of the fear of/that...
 - Misdiagnosis or a missed diagnosis
 - Having no cure.
 - Doctors/parents/pain team have missed something.
 - Pain is never going to get better.
 - Prolonged illness – long journey
 - Loss of control
 - Abstract nature of chronic pain and “social stigma”
 - Not being a good enough parent, feelings of inadequacy
 - Child is not going to have a good education. – Need to get back to school
 - Re-injury – Participation in daily activities and exercise will not harm your child and will in fact aid their recovery.

Module 7 – Bedtime routine

- Reinforce the need for regular bedtime and wake-up time.
- Sleeping in one day can cause a lot of sleep disturbances.
- Going to bed late or playing videogames late isn’t good preparation for a good night’s sleep.
- Need for relaxing and quiet activities.
- Encourage your child to sleep in his/her own bed.

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Module 8 – Daily activities

School

- Important for education
- Continuing relationship with friends
- There needs to be a good balance of extra-curricular activities without impinging on school time.

Physical activities

Parents to explore how they can fit physical activities into their daily lives.

General information:

- Physical exercise is important to maintain and regain function
- Evidence shows that being fitter and stronger assist in daily function, and elevate moods and feelings of well-being.
- Your child might experience a different kind of pain (muscle aches and pains) but it does not worsen their condition.
- He/She need to continue with physical activity even when they feel that his/her pain is stopping them from exercising as it is important to maintain a training effect on muscles
- A healthy moderation of physical activity is recommended. (Minimum 30mins daily but not more than 2 hours).
- The exercise plan is tailored for your child's current pain level. However, some level of activity must be negotiated. That's why it's important to have variety, enjoyment and routine. Low impact activities can be introduced (e.g. Aqua-aerobics and swimming).
- Learning new physical skills (like juggling) can train your brain and modify existing pain pathways to reduce sensitivity to stimuli.

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Parent's role:

- Encourage your child to participate in school sports and any commitments they have to extra-curricular activities
- Participate in the physical activities with them. Activities don't have to be a huge event. They could be as simple as a few sit-ups or push-ups.
- Do not be discouraged when your child says that he/she doesn't like a particular sport. There are other physical activities (e.g. Dancing) that he/she might be interested in.
- Be reassured that physical activity doesn't worsen the underlying condition. Research has shown that physical activity will not harm children with chronic pain. Consideration of your child's physical function is taken and some activities (e.g. contact sports) may not be recommended for a period of time.
- Try to follow your physio's recommended daily exercise program
 - It is important to gradually increase the amount of physical activity to the recommended healthy level (min 30 mins daily). Sudden bursts of high levels of activities may result in feeling exhausted or cause injury.
- Nonetheless, any physical activity may result in acute injuries. But these should be treated with the usual recommendation of RICE (Rest, Ice, Compression, Elevation). Be mindful that some acute injuries may need medical attention (e.g. Fractures).
- Do not allow children to replace physical activities with computer games and TV
 - Recommend that total TV and computer time not more than 2 hours/day
 - Wii sports and Wii fit type games are allowed (included in TV and computer time) but are still not complete substitutes for proper physical activities

Physical activity should be thought of as a routine that's natural and necessary like homework and should not always be rewarded. Use encouragement, praise and reassurance instead and lead by example whenever possible.

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Problems that parents may face:

- Lack of time or not making time to exercise
 - Try to do activities together, as a family or social group. E.g. Start with a walk at the beach/park, tennis morning on Sat.
 - Opportunity for incidental exercise – walking to bus or to school on a daily basis, taking the stairs instead of the elevator.
 - Encourage child to participate in school-based activities. Especially since they are supervised, structured and with their peers. It's the participation that matters, not the need to be the best at the sport.
- Common misconception that physical activity always makes things worse and rest makes things better

So unless there's a physiological reason to immobilise a limb such as treatment for a fractured bone, then physical activity and weight-bearing needs to be consistently maintained for healthy bone and muscle structure. Healing is also helped by the increased blood flow and decreased swelling.

Other adjunct therapy (Will be covered in greater detail by Marianne if needed):

- Ankle supports, strapping of joints
- Electrotherapy – TENS machine
 - These can be hired or purchases if they are found to assist in physical activities being completed.

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Leisure (restful) activities

- Equally important, as they are means of distraction especially when parents are not around.
- There is recent strong evidence in favour of what we all know anyway, that spending time in natural environment improves mood and well-being. We all know anyway but don't take sufficient time to do.

Social activities

- Bringing an influential friend into the story and letting her know what is happening with the child.

Module 9 – Emotional and behavioural problems in the child

Two reasons:

- Parents not being able to discipline their child.
- Child using the excuse of “being sick” to escape from stressful situations.

What to do:

- Recognise non-functional behaviour.
- Name the behaviour and ask for alternatives (what else could you do now?).
- Re-direct them to a functional behaviour/ replace the non-functional behaviour with a functional one.
- Try to understand where the behaviour came from.

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Module 10 – Parents’ well-being

- Planning time for themselves.
- Looking after themselves.
- Keeping child in his/her bed.
- Going out together as a couple. (If couple)
- Going out with friends or other social supports.

Module 11 – Siblings’ well-being

- Acknowledge their feelings of isolation, guilt and anger, and normalising them.
- Ensure that the siblings have someone to talk to about their feelings.
- Parents to explain to the siblings about the child’s condition and any special concerns in the house (e.g. avoiding chores).
 - With house chores, there should be a fair division of labour and the child with chronic pain should not totally escape from the chores.
- Parents to discuss with the siblings about the feelings that they may be experiencing.

Module 12 – Other issues in the family/parents

- Differences between parents in their beliefs about their child’s pain
 - Parents need to discuss and be consistent in the messages that they give to their child.
 - Chaotic family life – other caring responsibilities, financial problems
 - Isolated family
 - Single parents – need to structure activities when parents are not around.

Module 13 – Information resources

Appendix 2 – Clinical questionnaires



Parent Information Sheet: Pain Clinic Baseline Questionnaires

Thank you for taking the time to complete these Pain Clinic questionnaires. Given that you know your child best, your responses provide very important information to us. Some of the questions are specifically about your child, others are about your family. They all give us important information to help understand your child's pain and functioning better so that we can identify how he/she can best be helped. Please do not discuss your responses with your child. They may have a different perspective on some questions. You and your child will also be asked to complete some questionnaires in a few months' time so that we can see whether there have been any changes in your child's pain and functioning. Please do not leave any questions out. If there is something that you don't understand you can ask someone from the Pain Team to help you when you come in for your child's first appointment.

All questionnaire responses will be treated confidentially and will not be disclosed outside of your child's treating team, except with your permission or if required by law.

PLEASE NOTE: In addition to using the questionnaires for clinical purposes to help in the management of your child's pain, we would like to request your permission to use the questionnaire responses provided by you and your child for research purposes. Specifically, from time to time we will compile all the responses that we have received from all our patients/parents so that we can look at overall patterns and trends and to address certain research questions. This is very important for furthering our knowledge about children's pain.

If results are published or presented, it will be done in a way in which you and your child cannot be identified. Questionnaires will be stored in securely in locked filing cabinets and will be kept for up to 3 years after your child is discharged from the Pain Clinic and then shredded. Questionnaire responses will also be entered into an electronic database which will be password protected and used only by the Pain Team. When questionnaire responses are entered into the database we will use a code number for you and your child so that data will not be stored together with your name.

Your decision whether or not to allow us to use the questionnaire responses from you and your child for research purposes will not prejudice you or your child's future relations with the Sydney Children's Hospital. If you decide to allow us to use your responses, you and your child are free to withdraw at any time. If you have any questions, please feel free to contact Dr Tiina Jaaniste (02) 9382 1585 (or anyone else in the Pain Team) who will be happy to answer them.

Any complaints may be directed to the Research Ethics Secretariat South Eastern Sydney and Illawarra Area Health Services-Northern Network. Prince of Wales Hospital, RANDWICK NSW 2031 AUSTRALIA (ph: (02) 9382 3583, fax: 9382 2813, email: ethicsnhn@sesiahs.health.nsw.gov.au)

Final report



CONSENT FORM

Use of Pain Clinic Questionnaires for Research Purposes

You are making a decision whether or not to allow us to use the responses from you and your child to the Pain Clinic questionnaires for research purposes. Your signature indicates that, having read the information statement, you have decided that we may use your responses and your child's responses for research purposes in furthering our knowledge of children's pain management.

Child's name:

.....

Signature of parent/guardian

.....

Signature of Witness

.....

.....

(Please PRINT name)

(Please PRINT name)

.....

Date

Signature of Investigator

.....

(please PRINT name)

[Cut here]

REVOCATION OF CONSENT

Use of Pain Clinic Questionnaires for Research Purposes

I hereby wish **WITHDRAW** my consent to participate in the research proposal described above. I understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with the Sydney Children's Hospital.

.....

.....

Signature

Date

.....

Please PRINT Parent/Guardian Name

.....

Child's Name

Pain Clinic Questionnaires – Parent Baseline

Child's Name:

Child's Date of birth: Child's gender: Male Female

Parent/Guardian's name (who is completing this questionnaire):

.....

Relationship to child (e.g. mother, father, guardian):.....

A. Pain History and Description

1. How did your child's pain start?

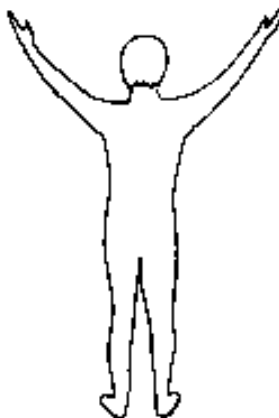
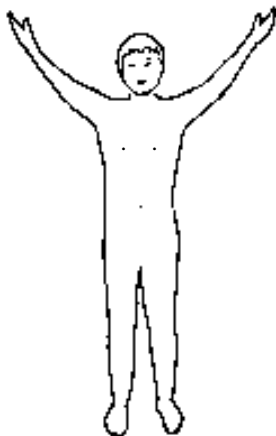
.....

.....

2. When did your child's pain start?

3. Did it start: gradually suddenly (please tick)

4. Colour in these pictures to show where your child gets pain or feelings that bother him/her. If he/she has more than one pain, please draw a circle around the pain or feeling that bothers him/her the most.



[© PA McGrath, 1990]

Final report

5. Here are 6 faces that show how much something can hurt. The face on the left shows no pain. The faces show more and more pain up to the face on the right which shows very much pain.

Circle the face that represents the *worst* pain he/she had during the ***last week***:

No Pain

Very much pain

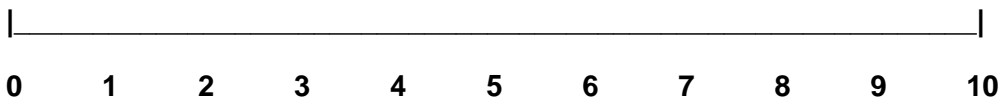


What was he/she doing at the time:.....

6. How much of his/her awake time is your child bothered by pain?

No time

Every moment



7. Lately, how many days a week is he/she pain-free or not bothered by the pain?

.....days a week

Final report

B. Family

1. What is Father's current job:.....

2. What is Mother's current job:.....

In responding to the following questions about family members, please consider *immediate* family members as well as *extended* family (e.g., aunts, uncles, grandparents etc).

3. Do other family members have **pain problems**? Yes No

If yes, please provide the following details:

Relation of person to child patient (e.g. father)	Description of pain/diagnosis (e.g., back pain following car accident)
_____	_____
_____	_____
_____	_____

4. Do any family members have any problems with **alcohol or the use of drugs**?

Yes No

If yes:

Relation of person to child patient	Type of problem
_____	_____
_____	_____
_____	_____

5. Do any family members have any **mental health** problems (e.g., depression, anxiety disorder)?

If yes:

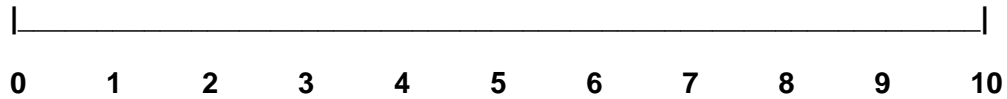
Relation of person to child patient	Type of problem
_____	_____
_____	_____
_____	_____

Final report

Please circle the number that corresponds with your responses.

6. How much stress is there currently within your family?

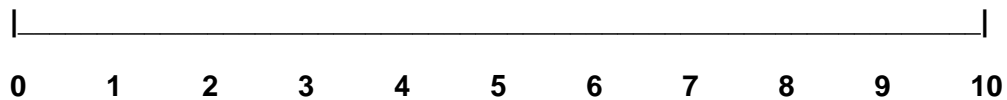
No stress Extreme stress



7. How much stress is there currently in your marriage / relationship?

Not applicable, I am not in a relationship.

No stress Extreme stress



Any comments?

.....

.....

Final report

C. Functioning (FDI)

When people are sick or not feeling well, it is sometimes difficult for them to do their regular activities. **In the last few days** would your child have had any physical trouble or difficulties doing these activities: Please circle the number to indicate your response to each question.

	No trouble	A little trouble	Some trouble	A lot of trouble	Impossible
1. Walking to the bathroom	0	1	2	3	4
2. Walking up stairs	0	1	2	3	4
3. Doing something with a friend	0	1	2	3	4
4. Doing chores at home	0	1	2	3	4
5. Eating regular meals	0	1	2	3	4
6. Being up all day without a nap or rest	0	1	2	3	4
7. Riding the school bus or travelling in the car	0	1	2	3	4
8. Being at school all day	0	1	2	3	4
9. Doing the activities in gym class (or playing sports)	0	1	2	3	4
10. Reading or doing homework	0	1	2	3	4
11. Watching TV	0	1	2	3	4
12. <i>Walking</i> the length of a football field	0	1	2	3	4
13. <i>Running</i> the length of a football field	0	1	2	3	4
14. Going shopping	0	1	2	3	4
15. Getting to sleep at night and staying asleep	0	1	2	3	4

Final report

D. Impact of Pain

1. During the last school term, how many days off school did your child have because of:

(i) pain-related reasons:days

(ii) other reasons:days *Please specify:.....*

.....

2. In the last month, how many days off **paid** work have you and/or your partner needed to take because of your child's pain problems?

..... days

3. In the last month, how many days have you or your partner been unable to take part in your usual **unpaid** activities (e.g., domestic duties, volunteer work, recreational activities) because of your child's pain problems?

..... days

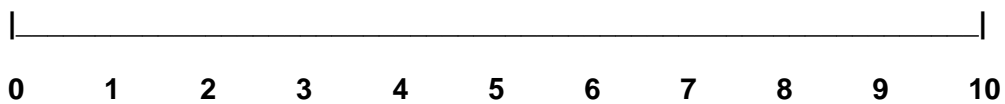
4. Please estimate how much you have paid for treatments that your child has had during the past 6 months for his/her pain problem. (Please include cost of attending appointments as well as cost of medications – prescription and other.)

\$.....

5. How much of a **financial burden** has your child's pain/health problems placed on you:

No burden

Huge burden



Final report

E. PCS-P**Thoughts and feelings when your child is in pain**

We are interested in the thoughts and feelings **you** have when your child is in pain. Below are 13 sentences of different thoughts and feelings. Please put a circle around the word or phrase under each sentence that best reflects how strongly you have each thought when your child is in pain.

1. When my child is in pain, I worry all the time about whether the pain will end.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

2. When my child is in pain, I feel I can't go on like this much longer.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

3. When my child is in pain, it's terrible and I think it's never going to get better.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

4. When my child is in pain, it's awful and I feel that it overwhelms me

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

5. When my child is in pain, I can't stand it anymore

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

6. When my child is in pain, I become afraid that the pain will get worse

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

7. When my child is in pain, I keep thinking of other painful events

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

8. When my child is in pain, I want the pain to go away

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

9. When my child is in pain, I can't keep it out of my mind

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

10. When my child is in pain, I keep thinking about how much he/she is suffering

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

11. When my child is in pain, I keep thinking about how much I want the pain to stop

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

12. When my child is in pain, there is nothing I can do to stop the pain.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

13. When my child is in pain, I wonder whether something serious may happen

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

Final report

F. Sleep

1. Does pain disturb your child's sleep?

Not at all A lot

|-----|

0 1 2 3 4 5 6 7 8 9 10

2. Does your child find it hard to get to sleep in the evening?

Not at all A lot

|-----|

0 1 2 3 4 5 6 7 8 9 10

3. Does your child wake during the night because of the pain?

Not at all A lot

|-----|

0 1 2 3 4 5 6 7 8 9 10

4. Does tiredness bother your child during the day?

Not at all A lot

|-----|

0 1 2 3 4 5 6 7 8 9 10

5. Does your child sleep in his/her own bed the whole night? Yes No

If "No" please comment.....

Final report

G. Adult Responses to Children's Symptoms (ARCS)

What happens when your child is sick?

The next questions are about what you do when your child has a pain. For each question, choose one of the answers:

Never	means that you never do this.
Once in a while	means that you only do this once in a while.
Sometimes	means that you do this some of the time.
Often	means that you usually do this.
Always	means that you always do this.

**When your child has a pain,
how often do you . . .**

	Never	Once in a while	Sometimes	Often	Always
1. Ask your child what you can do to help?	0	1	2	3	4
2. Express irritation of frustration with your child?	0	1	2	3	4
3. Do your child's chores or pick up your child's things instead of making him/her do it?	0	1	2	3	4
4. Talk to your child about something else to take your child's mind off it?	0	1	2	3	4
5. Give your child some medicine?	0	1	2	3	4
6. Reassure your child that he/she is going to be OK?	0	1	2	3	4
7. Get your child something to eat or drink?	0	1	2	3	4
8. Bring your child special treats or little gifts?	0	1	2	3	4
9. Try not to pay attention to your child	0	1	2	3	4
10. Ask your child questions about how he/she feels?	0	1	2	3	4
11. Let your child stay home from school?	0	1	2	3	4
12. Encourage your child to do something he or she enjoys (like watch TV or play a game)?	0	1	2	3	4
13. Tell your child that he/she doesn't have to finish all of his/her homework?	0	1	2	3	4
14. Tell your child there's nothing you can do about it?	0	1	2	3	4
15. Give your child special privileges?	0	1	2	3	4

Final report

When your child has pain,**how often do you...**

		Never	Once in a while	Sometimes	Often	Always
16.	Stay home from work or come home early (or stay home instead of going out or running errands)?	0	1	2	3	4
17.	Tell others in the family not to bother your child or to be especially nice to your child?	0	1	2	3	4
18.	Tell your child not to make such a fuss about it?	0	1	2	3	4
19.	Pay more attention to your child than usual?	0	1	2	3	4
20.	Let your child sleep in a special place (like in your room or on the couch)?	0	1	2	3	4
21.	Tell your child that he/she needs to learn to be stronger?	0	1	2	3	4
22.	Let your child sleep later than usual in the morning?	0	1	2	3	4
23.	Keep your child inside the house?	0	1	2	3	4
24.	Try to involve your child in some activity?	0	1	2	3	4
25.	Spend more time than usual with your child?	0	1	2	3	4
26.	Try to make your child as comfortable as possible?	0	1	2	3	4
27.	Tell your child you still expect him/her to do his/her chores or pick up his/her things	0	1	2	3	4
28.	Check on your child to see how he/she is doing?	0	1	2	3	4
29.	Call the doctor or take your child to the doctor?	0	1	2	3	4

Thank you very much for taking the time to complete these questionnaires.

If you have any other comments that you would like to share with us please write these below or over the page.



Child / Adolescent Baseline Pain Clinic Questionnaire

Thank you for taking the time to fill in these questionnaires. We are interested in your views so please be as honest as possible. Your responses will help us to better understand your pain condition so that we can better help you.

Please do not leave any questions out. If there is something that you don't understand you can ask your parents or ask someone from the Pain Team to help you when you come in for your first appointment. You and your parents will also be asked to fill out some questionnaires in a few months' time so that we can measure any change in your pain and functioning.

PLEASE NOTE: In addition to using your answers to the following questions to help understand and manage your pain condition, we would like to ask if you agree for us to use your answers for research purposes. This means we look at your answers and the answers of other children to help us answer important research questions so that we can learn more about children's pain and can better help children with pain problems. If we publish any findings based on the questionnaire results we will only be reporting overall patterns and not identifying your individual responses.

"I **(your name)**

Agree Do not agree

for my answers to the following questions to be used to for research purposes so that the Pain Team can learn more about children's and adolescents' pain experiences. I understand that my decision whether or not to allow my answers and comments to be used for research will not affect how I get treated by the Pain Team or at Sydney Children's Hospital."

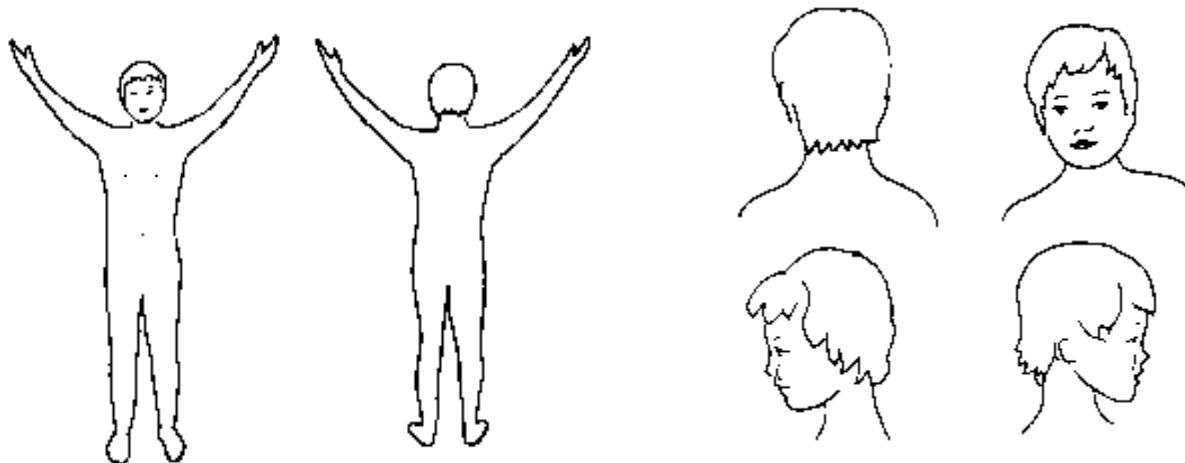
Your age **Your gender:** boy / girl (*please circle*)

The date you completed this questionnaire

Final report

A. Pain description

1. Colour in these pictures to show where you get pain or feelings in your own body that bother you. If you have more than one pain, please draw a circle around the pain or feeling in your body that bothers you the most.



[© PA McGrath, 1990]

2. Here are 6 faces that show how much something can hurt. The face on the left shows no pain. The faces show more and more pain up to the face on the right which shows very much pain.

Circle the face that represents the *worst* pain you had during the **last week**:

No Pain

Very much pain

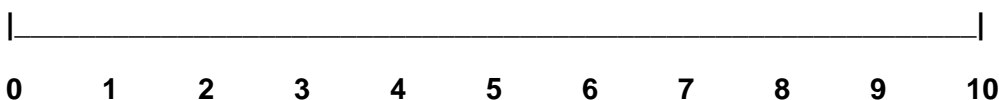


What were you doing:.....

3. How much of your awake time are you bothered by pain?

No time

Every moment



4. Lately, how many days a week are you pain-free or not bothered by the pain?

.....days a week

Final report

B. FDI

When people are sick or not feeling well, it is sometimes difficult for them to do their regular activities. **In the last few days** would you have had any physical trouble or difficulties doing these activities: Please circle the number to indicate your response to each question.

	No trouble	A little trouble	Some trouble	A lot of trouble	Impossible
1. Walking to the bathroom	0	1	2	3	4
2. Walking up stairs	0	1	2	3	4
3. Doing something with a friend	0	1	2	3	4
4. Doing chores at home	0	1	2	3	4
5. Eating regular meals	0	1	2	3	4
6. Being up all day without a nap or rest	0	1	2	3	4
7. Riding the school bus or travelling in the car	0	1	2	3	4
8. Being at school all day	0	1	2	3	4
9. Doing the activities in gym class (or playing sports)	0	1	2	3	4
10. Reading or doing homework	0	1	2	3	4
11. Watching TV	0	1	2	3	4
12. <i>Walking</i> the length of a football field	0	1	2	3	4
13. <i>Running</i> the length of a football field	0	1	2	3	4
14. Going shopping	0	1	2	3	4
15. Getting to sleep at night and staying asleep	0	1	2	3	4

Final report

C. Social

In the past ONE month, how much of a problem has this been for you...

How I get along with others (problems with...)	Never	Almost never	Sometimes	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up with other kids	0	1	2	3	4

About school (problems with...)	Never	Almost never	Sometimes	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

[From: Varni PedsQL 4.0]

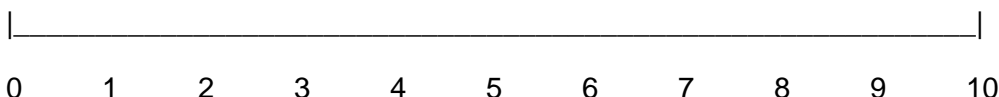
Any comments:

.....

How much stress is there in your family at the moment?

None at all

A lot



Any comments:

.....

..

Final report

SCP Questionnaire

When you have a bad pain,
how often...

		Never	Once in a while	Some- times	Often	Always
1.	Do you stay home from school?	0	1	2	3	4
2.	Does your Mum or Dad spend more time than usual with you?	0	1	2	3	4
3.	Do you sleep later than usual in the morning?	0	1	2	3	4
4.	Do you get behind in your schoolwork?	0	1	2	3	4
5.	Does your Mum or Dad tell you not to make such a fuss about your pain?	0	1	2	3	4
6.	Do you spend less time with other kids?	0	1	2	3	4
7.	Do you get special food or drinks?	0	1	2	3	4
8.	Do you sleep or rest somewhere special, like in your parents' room or on the couch?	0	1	2	3	4
9.	Does your Mum or Dad get made or frustrated with you?	0	1	2	3	4
10.	Do you miss a test at school?	0	1	2	3	4
11.	Does your Mum or Dad tell you that you'll be OK?	0	1	2	3	4
12.	Do you get special privileges like staying up late or watching more TV?	0	1	2	3	4
13.	Do you spend more time inside?	0	1	2	3	4
14.	Is you Mum or Dad extra nice to you?	0	1	2	3	4
15.	Do kids hassle you?	0	1	2	3	4
16.	Does your Mum or Dad tell you there nothing they can do about your pain?	0	1	2	3	4
17.	Do you miss gym class (P.E.) at school?	0	1	2	3	4
18.	Do you have to stay at home and not go anywhere?	0	1	2	3	4
19.	Does your Mum or dad let you get away with more things?	0	1	2	3	4
20.	Does your Mum or Dad stay at home with you more?	0	1	2	3	4

Final report

**When you have a bad pain,
how often...**

		Never	Once in a while	Some- times	Often	Always
21.	Do you do fewer chores (like not putting things away)?	0	1	2	3	4
22.	Does your Mum or Dad ignore you when you talk about your pain?	0	1	2	3	4
23.	Do you do less homework and other schoolwork?	0	1	2	3	4
24.	Do you spend more time in bed or on the couch?	0	1	2	3	4
25.	Does your Mum or Dad check on you a lot to see how you're feeling?	0	1	2	3	4
26.	Is the teacher extra nice to you?	0	1	2	3	4
27.	Does your Mum or Dad give you a lot of extra attention	0	1	2	3	4
28.	Do you spend less time doing sports or exercise?	0	1	2	3	4
29.	Does your Mum or Dad tell others in the family not to bother you?	0	1	2	3	4
30.	Do you spend more time doing things you like?	0	1	2	3	4
31.	Does your Mum or Dad expect you to do things anyway?	0	1	2	3	4
32.	Are kids extra nice to you?	0	1	2	3	4

Walker, L.S., Claar, R.L. & Garber, J. (2002)

Final report

D. Mood (CES-D)

Below is a list of the ways you might have felt or acted. Please show *how much* you have felt this way **during the past week**. (Circle a number for each question.)

	Not at all	A little	Some	A lot
1. I was bothered by things that usually don't bother me	0	1	2	3
2. I did not feel like eating, I wasn't hungry	0	1	2	3
3. I wasn't able to feel happy, even when my family or friends tried to help me feel better	0	1	2	3
4. I felt that I was just as good as other kids	0	1	2	3
5. I felt like I couldn't pay attention to what I was doing	0	1	2	3
6. I felt down and unhappy	0	1	2	3
7. I felt like I was too tired to do things	0	1	2	3
8. I felt like something good was going to happen	0	1	2	3
9. I felt like things I did before didn't work out right	0	1	2	3
10. I felt scared	0	1	2	3

DURING THE PAST WEEK**Not at all****A little****Some****A lot**

11. I didn't sleep as well as I usually sleep	0	1	2	3
12. I was happy	0	1	2	3
13. I was more quiet than usual	0	1	2	3
14. I felt lonely, like I didn't have any friends	0	1	2	3
15. I felt like kids I know were not friendly or that they didn't want to be with me.	0	1	2	3
16. I had a good time.	0	1	2	3
17. I felt like crying.	0	1	2	3
18. I felt sad.	0	1	2	3
19. I felt people didn't like me.	0	1	2	3
20. It was hard to get started doing things.	0	1	2	3

Final report

E. PCS-C**Thoughts and feelings during pain**

We are interested in what you think and how strong the feelings are when you are in pain. Below are 13 sentences of different thoughts and feelings you can have when you are in pain. Try to show us as clearly as possible what you think and feel by putting a circle around the word under each sentence that best reflects how strongly you have each thought..

1. When I am in pain, I worry all the time about whether the pain will end.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

2. When I am in pain, I feel I can't go on like this much longer.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

3. When I am in pain, it's terrible and I think it's never going to get better.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

4. When I am in pain, it's awful and I feel that it takes over me

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

5. When I am in pain, I can't stand it anymore

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

6. When I am in pain, I become afraid that the pain will get worse

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

7. When I am in pain, I keep thinking of other painful events

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

8. When I am in pain, I want the pain to go away

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

9. When I am in pain, I can't keep it out of my mind

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

10. When I am in pain, I keep thinking about how much it hurts

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

11. When I am in pain, I keep thinking about how much I want the pain to stop

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

12. When I am in pain, there is nothing I can do to stop the pain.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

13. When I am in pain, I wonder whether something serious may happen

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

Final report

F. Sleep

1. Does pain disturb your sleep?

Not at all A lot

|-----|

0 1 2 3 4 5 6 7 8 9 10

2. Do you find it hard to get to sleep in the evening?

Not at all A lot

|-----|

0 1 2 3 4 5 6 7 8 9 10

3. Do you wake during the night because of the pain?

Not at all A lot

|-----|

0 1 2 3 4 5 6 7 8 9 10

4. Does tiredness bother you during the day?

Not at all A lot

|-----|

0 1 2 3 4 5 6 7 8 9 10

5. Do you sleep in your own bed the whole night? Yes No

If "No" please comment.....

Thank you very much for taking the time to complete these questionnaires.

If there is anything else that you would like to tell us please do so over the page.

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Appendix 3 – Results of qualitative analysis

Note: Issues that are not covered in the education content are in the grey boxes.

Question	Broad responses	Categories	Framework	
1. What do you understand about your child’s pain?	<ul style="list-style-type: none"> • Psychological • Stress • Emotional • Medical causes • Unknown • Unclear • Impacts of pain on life • Understanding what to do • Not understanding what to do 	<ul style="list-style-type: none"> • Medical causes • Psychological causes • Impacts of pain • Management • Unclear 	Medical	<ul style="list-style-type: none"> • Medical causes
			Functional	<ul style="list-style-type: none"> ▪ Psychological causes ▪ Impacts of pain
			Both	<ul style="list-style-type: none"> • Management
3. What makes your child’s pain better?	<ul style="list-style-type: none"> • Positive moods • Sleep • Distractions • Comfort and reassurance • Meds • Heat packs • Massage • Nothing/I don’t know • Rest • Walking • Ointment rub • Stretching • Visualisation • Deep breathing • Posture • TENS machine • Understanding • Supportive • Empathy 	<ul style="list-style-type: none"> • Medications • Alternative medicine • Adjunct therapy • Exercise • Positive moods • Sleep/rest • Distraction • Psychological methods • Massage • Posture • Comfort and reassurance • Nothing/I don’t know 	Medical	<ul style="list-style-type: none"> • Medications
			Functional	<ul style="list-style-type: none"> • Adjunct therapy • Exercise • Positive moods • Sleep/rest • Distraction • Psychological methods • Massage • Posture
				<ul style="list-style-type: none"> • Comfort and reassurance • Nothing/I don’t know
			Both	

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Question	Broad responses	Categories	Framework	
4. What makes your child's pain worse?	<ul style="list-style-type: none"> Stress Lagging behind Inactivity Certain food Isolation Hitting Use of affected part Movement Tiredness Not opening bowels daily Cold Exercise Nothing Stretching Touch Posture Depression 	<ul style="list-style-type: none"> Certain food Stress Depression Inactivity Isolation Exercise/use of affected limb Lethargy Posture Contact with affected part Not opening bowels Cold Nothing 	Medical	<ul style="list-style-type: none"> Contact with affected part (hypersensitivity)
				<ul style="list-style-type: none"> Certain food
			Functional	<ul style="list-style-type: none"> Stress Depression Inactivity Exercise/Use of limb Lethargy
				<ul style="list-style-type: none"> Isolation Posture
			Both	<ul style="list-style-type: none"> Nothing
				<ul style="list-style-type: none"> Not opening bowels Cold (CRPS)
7. What do you understand of how to manage your child's pain?	<ul style="list-style-type: none"> TENS machine Organised, routine Removing stressors Keep expectations low Making her comfortable Support prescribed management Talking about pain Appropriate rest Encourage activity Sleeping in own room Nothing Distraction Hugs/Consolation Let child self-manage 	<ul style="list-style-type: none"> Carrying out prescribed management Establishing routine Adjunct therapy Making child comfortable Talking to the child about pain Appropriate rest Encourage activity Getting child to sleep in his/her own room Using distraction Consolation Letting child self-manage Keeping expectations low 	Medical	
			Functional	<ul style="list-style-type: none"> Adjunct therapy Establishing routine Appropriate rest Encourage activity Getting child to sleep in his/her own room Using distraction Letting child self-manage Keeping expectations low
				<ul style="list-style-type: none"> Consolation Making the child comfortable Talking to the child about pain
			Both	<ul style="list-style-type: none"> Carrying out prescribed management

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Question	Broad responses	Categories	Framework	
8. What emotional changes is your child experiencing?	<ul style="list-style-type: none"> • Extreme mood swings • Lethargy • Disinterest • Socially withdrawn • Depression • Impatience • Anger • Frustration • Anxiety • Obsession about certain things • Demoralising • Emotionally exhausting • Affected when child can't do things as before • Becoming aware of financial stress at home • Clingy, loss of confidence • Worry • Irritability • No change 	<ul style="list-style-type: none"> • Socially withdrawn • Sad • Anxiety • Heated emotions (Anger, Frustration) • Obsession about certain things • Lethargy • Loss of confidence • Extreme mood swings • Becoming aware of financial stress at home • Affected when child can't do things as before. • No change 	Medical	
			Functional	<ul style="list-style-type: none"> • Socially withdrawn • Sad • Anxiety • Heated emotions (Anger, Frustration) • Obsession about certain things • Lethargy • Loss of confidence • Extreme mood swings • Becoming aware of financial stress at home • Affected when child can't do things as before. • No change
			Both	
9. What are your child's feelings towards his/her pain?	<ul style="list-style-type: none"> • Worried • Uncertain about how to manage it • Thinks parents don't understand • Depressed • Anxious • Angry at disruptions • Inconsolable • A bit sad but coping • Wish she didn't have it • Complains only to mum and don't tell others • Acceptance • Overwhelmed • Hates it • Tired • Stressed • Fearful that it may get worse • "Why me?" • Don't know 	<ul style="list-style-type: none"> • Anxious • Feels not in control • Thinks parents don't understand • Depressed • Angry • Acceptance • Hates it • Tired • Stressed • Fearful • Parent doesn't know 	Medical	
			Functional	<ul style="list-style-type: none"> • Anxious • Feels not in control • Thinks parents don't understand • Depressed • Angry • Acceptance
			Both	

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Question	Broad responses	Categories	Framework	
10. What is your child scared about the pain?	<ul style="list-style-type: none"> Scared of the cause Pain will not go away Pain cannot be cured Pain too intense to handle Unable to do what he/she wants in the future Mum not around Thunderstorms Heater Hospital Condition more serious than thought Not knowing what to do to relieve the pain Not knowing what will happen in the future Unable to do usual activities and missing out Being less able to cope Parent not sure 	<ul style="list-style-type: none"> Cause (Unknown or more serious than told) Pain will not go away/never get better Pain too intense to handle Not knowing how to relieve the pain/coping Forced to miss out Thunderstorms, heater, hospital, mum not around Unknown future Parent not sure 	Medical	<ul style="list-style-type: none"> Cause (Unknown or more serious than told)
			Functional	<ul style="list-style-type: none"> Not knowing how to relieve the pain/coping
				<ul style="list-style-type: none"> Pain too intense to handle Unknown future
			Both	<ul style="list-style-type: none"> Pain will not go away/never get better Parent not sure
				<ul style="list-style-type: none"> Thunderstorms, heater, hospital, mum not around
11. What is your child sad about the pain?	<ul style="list-style-type: none"> Not able to do things that she/he likes Not fitting in with peers Friends who don't understand IBD Losing hair Having the pain Unable to get rid of the pain Not sad Not able to spend time with friends Not able to do things that he/she was able to do before Expects that he is going to be a cripple in the future Having to do things despite the pain Not able to exercise 	<ul style="list-style-type: none"> Inability to do things Having the pain and the pain not going away Not fitting in with peers Friends who don't understand Other accompanying symptoms (losing hair) Having to do things despite the pain Might be worse in the future Not sad 	Medical	
				<ul style="list-style-type: none"> Other accompanying symptoms (losing hair)
			Functional	<ul style="list-style-type: none"> Inability to do things Having to do things despite the pain
				<ul style="list-style-type: none"> Not fitting in with peers Friends who don't understand
			Both	<ul style="list-style-type: none"> Having the pain and the pain not going away Not sad
				<ul style="list-style-type: none"> Might be worse in the future

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Question	Broad responses	Categories	Framework	
12. What is your child angry about the pain?	<ul style="list-style-type: none"> Parents not understanding Not knowing the cause Not being able to participate in usual activities Pain not going away Not understanding the pain condition Affecting studies Teachers not understanding Medication doesn't cure the pain Not knowing how to manage the pain Feeling left out The pain condition happening to "her" Angry at the world and anyone who had anything to do with the accident 	<ul style="list-style-type: none"> Poor understanding of their own condition and how to manage Others not understanding their condition Pain not going away/getting better Not being able to participate in usual activities Studies affected Being afflicted by chronic pain Feeling left out The world and anyone who was involved in the accident 	Medical	<ul style="list-style-type: none"> Poor understanding of their own condition and how to manage
			Functional	<ul style="list-style-type: none"> Not being able to participate in usual activities Studies affected Being afflicted by chronic pain
			Both	<ul style="list-style-type: none"> Feeling left out The world and anyone who was involved in the accident
				<ul style="list-style-type: none"> Pain not going away/getting better
				<ul style="list-style-type: none"> Others not understanding their condition
13. What is your child looking forward to?	<ul style="list-style-type: none"> Finding a cure Finding a cause Learning piano Leaving school Family gatherings Being a normal person Being pain free School holidays Dancing, horse riding, drama, singing, netball Not needing a rest during the day Seeing friends Fun things No medication Enjoy meals Not having to wear knee caps Getting driver's license Year 10 formal Going home Independence away from family Visiting grandparents Dad getting home from work Playing xbox Bowling, swimming, gym 	<ul style="list-style-type: none"> Finding a cause Being pain-free Meeting family members Being independent Physical activities Social life Not feeling tired Being normal? No meds/adjunct therapy Going home 	Medical	<ul style="list-style-type: none"> Finding a cause
			Functional	<ul style="list-style-type: none"> Being independent Physical activities Social life
			Both	<ul style="list-style-type: none"> Meeting family members Going home
				<ul style="list-style-type: none"> No meds/adjunct therapy Being pain-free Not being tired Being normal

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Question	Broad responses	Categories	Framework	
15. What is the effect of your child's pain on your family's life?	<ul style="list-style-type: none"> • Stress in relationships • Family outings have to be cancelled/cut short • Younger sibling has become anxious • Family worries • Having to wake up at night • Ferrying child to school and home • Child venting on sibling • Have to chase child to take meds • Older sister missing out • Family feels sad • Other family members taking over household chores • Working less • Very little effect • Unable to do chores and daily activities • Having to help child with daily activities including homework • Financial stress • Family life stops when child is in hospital • Parent not having her own priorities • Time and effort to make trips to the hospital • Frustration • Disruptive to normal routine 	<ul style="list-style-type: none"> • Changes in emotions • Additional activities/chores /work • Disruptions to normal routine/ Giving up on some activities • Parent not having her own priorities • Stresses 	Medical	
				Functional
			Both	

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Question	Broad responses	Categories	Framework	
17. What do the other children do when the child is in pain?	<ul style="list-style-type: none"> • Listens to the child • Bunker down • Worries • Continue life as normal • Ignore it • Older sibling helps out • Stay away from child • Sometimes baby the child • Play their own games • Spend time with the child • Help with suggestions (lending a book) • Tip-toe around the child • Try to cheer the child up • Sometimes become withdrawn 	<ul style="list-style-type: none"> • Supportive • Ignore • Tip-toe around the child • Become withdrawn 	Medical	
Functional	<ul style="list-style-type: none"> • Supportive • Ignore • Tip-toe around the child • Become withdrawn 			
	Both			
18. How do the other children feel about the child's pain?		<ul style="list-style-type: none"> • Helpless • Frustrated that they can't help more • Something major is wrong • Feeling bad • Frightened • Confused • Sad • Distressed • Keep feelings to themselves • Understands • Supportive • Advocates for him • Doesn't notice • Don't care • Hoping things will go back to normal • Sympathy • Angry if (because) child doesn't take care of himself • Angry at the world that her brother is suffering • Frustration • Resentful • Pain is made up • Seeks attention • Missing out on family 	<ul style="list-style-type: none"> • Helpless • Negative emotions • Keep feelings to themselves • Understanding and supportive • More passive reactions • Sympathy • Anger and frustration • Resentful 	Medical
Functional	<ul style="list-style-type: none"> • Helpless • Negative emotions • Keep feelings to themselves • Understanding and supportive • More passive reactions • Sympathy • Anger and frustration • Resentful 			
	Both			

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Question	Broad responses	Categories	Framework	
19. How do you feel about your child's pain?	<ul style="list-style-type: none"> • Want to know the cause • Want to know if the pain is real • Want to know how to manage child's pain • Wants child to be without pain • Concerned about meds • Not sure when to be supportive/loving and when to be hard and tell child to get on with life • Upset that the child finds it hard to cope • Distressed • Helpless • Lack support and have to search for own answers • Sympathy • Confused • Angry • Frustration • Worried • Want to fix it • Making progress • Begrudging acceptance • Scared of what is going to happen in the future • Concerned about other kids' stress level • Worried about job • More relaxed and confident that child is on right track and responding well to treatment 	<ul style="list-style-type: none"> • Want to know the cause/if pain is real • Want child to be without pain • Concerned about meds • Want to know how to manage child's pain • Not sure when to be supportive/loving and when to be hard and tell child to get on with life. • Various emotions like distress, sympathy, confused, angry, worried • Lack support and have to search for own answers • Concerned about other children's stress level • Worried about job • More relaxed and confident that child is on right track and responding well to treatment 	Medical	<ul style="list-style-type: none"> • Want to know the cause/if pain is real • Concerned about medications
				Functional
			Both	

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Question	Broad responses	Categories	Framework	
22. What do you understand that will happen in the pain clinic?	<ul style="list-style-type: none"> • Parent and child to develop better management strategies • Education • Assessment • Medication • Think that pain clinic doesn't help and child is left to suffer • Removing pain • Multidisciplinary approach • Parental involvement • Listening to child's needs and wants • Assessing child's life as a whole • Being asked about past treatments • No idea • Reduce medications • Educating parents about how to help the child • Give child more confidence and skills to cope with pain • Possible referral • Help in losing weight 	<ul style="list-style-type: none"> • Prescribe/adjust medications • Assessment • Education, including management • Think that pain clinic doesn't help and child is left to suffer • Remove pain • Multidisciplinary approach with parental involvement • Listening to the child's needs and wants • Give child more confidence and skills to cope with pain • Possible referral • Help in losing weight • No idea 	Medical	<ul style="list-style-type: none"> • Prescribe/adjust Medication
				<ul style="list-style-type: none"> • Possible referral
			Functional	
				<ul style="list-style-type: none"> • Help in losing weight • Listening to the child's needs and wants • Give child more confidence and skills to cope with pain
			Both	<ul style="list-style-type: none"> • Assessment • Education, including management • Multidisciplinary approach with parental involvement
				<ul style="list-style-type: none"> • Think that pain clinic doesn't help and child is left to suffer • Remove pain • No idea