

**Relationship Between Biopsychosocial Factors and
School Functioning in Children and Adolescents with Chronic
Pain: Are these Mediated by Parental Mental Health?**

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Table of Contents

List of Figures.....	5
List of Tables.....	6
Introduction.....	8
1.1 Overview.....	10
1.2 Etiology, Prevalence and Classification.....	11
1.3 Chronic Pain Management in Australia.....	12
1.4 Biopsychosocial Factors.....	14
1.4.1. Functional Disability.....	14
1.4.2. Emotional Wellbeing.....	15
1.4.3. Sleep Problems.....	16
1.4.4. Parental Mental Health.....	17
1.5.Treatment.....	18
1.6 The Current Study.....	18
Method.....	20
2.1 Participants.....	20
2.1.1.Children and Adolescents’ Characteristics.....	21
2.1.2. Caregivers Characteristics.....	23

2.2 Procedure.....23

 2.2.1. MDT Service Pathway.....24

 2.2.2. CAP Service Pathway.....25

 2.2.3. Discharge.....26

2.3 Measures.....26

 2.3.1. CARRA Body Chart (CARRA).....26

 2.3.2. Faces of Pain Scale – Revised.....27

 2.3.3. Modified Brief Pain Inventory (BPI – M).....28

 2.3.4 Functional Disability Inventory (FDI).....28

 2.3.5. Pediatric Quality of Life Inventory Version 4.0 Generic Core Scales (PedsQL)...29

 2.3.6. Bath Adolescent Pain – Parent Impact Questionnaire (BAP – PIQ).....30

2.4 Analysis Plan.....31

Results.....34

 3.1 Power Analysis.....34

 3.2 Descriptive Statistics.....34

 3.3 Correlations.....36

 3.4 Parental Depression as a Mediator for the association between Functional
 Disability and School Performance.....38

3.5 Parental Depression as a Mediator for the association between Sleep Problems and School Performance.....	38
3.6 Parental Depression as a Mediator for the association between Emotional Wellbeing and School Performance.....	39
3.7 Parental Self-Blame and Helplessness as a Mediator for the association between Sleep Problems and School Performance.....	39
3.8 Parental Self-Blame and Helplessness as a Mediator for the association Emotional Wellbeing and School Performance.....	40
3.9 Effects of Multidisciplinary Team Therapeutic Intervention.....	41
Discussion.....	42
References.....	50
Appendices.....	63
A. Omnibus Assessment Questionnaires.....	63
B. Parent/Carer Impact Questionnaire.....	97

List of Figures

Figure 1. *Agreement between PedsQL Emotional self-report and parent-proxy report.....32*

Figure 2. *Agreement between PedsQL School self-report and parent-proxy report.....33*

List of Tables

Table 1. *Number (%) of Children and Adolescents who did not meet Eligibility or Inclusion Criteria by Category*.....20

Table 2. *Percentage (n) of Children and Adolescents with Co-occurring Health Condition or Pre-existing Disability by Category*22

Table 3. *Summary of Primary Pain Sites of Children and Adolescents (% , n)*22

Table 4. *Descriptive Statistics for Functional Disability, Sleep Problems, Emotional Wellbeing, School Performance, and Parental Mental Health Variables*36

Table 5. *Pearson Correlation Coefficient Matrix for Functional Disability, Sleep Problems, Emotional Wellbeing, School Performance, and Parental Mental Health Variables*37

Table 6. *Baseline and End of Treatment Means, Standard Deviations, t value, p value, and Cohen’s d*42

Abstract

Background: Research has identified that paediatric chronic pain reduces their quality of life. Childhood and adolescent developmental changes and parental influence throughout childhood differentiate the experience of paediatric chronic pain to adulthood chronic pain. The purpose of this study was to: (1) extend our knowledge of the effect of paediatric chronic pain on functional disability, sleep problems, emotional wellbeing and school performance; (2) assess the effect of parental mental ill-health on children and adolescents with chronic pain ; and (3) assess the effectiveness of a multidisciplinary team therapeutic intervention. Methods: South Australian Women's and Children's Paediatric Chronic Pain Unit patients between March 2018 and December 2019 were invited to participate. Eighty-two participated in the study. Results: Increased functional disability and sleep problems, and reduced emotional wellbeing reduced participants school performance. Parental depression mediated the associations between functional disability; sleep problems; emotional wellbeing; and school performance, whereas parental self-blame and feelings of helplessness mediated the association between sleep problems; emotional wellbeing; and school performance. Multidisciplinary team therapeutic intervention was effective in reducing functional disability and increasing emotional wellbeing. Discussion: The findings are discussed in terms of factors that will increase children and adolescent's with chronic pain's quality of life.

Keywords: paediatric chronic pain, school performance, parental mental ill-health, multidisciplinary team intervention

Running head: CHRONIC PAIN, SCHOOL FUNCTION AND PARENT MENTAL HEALTH

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, and to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digit thesis repository, the Library Search and through web search engines, unless permission has been granted by the school to restrict access for a period of time.

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A solid black rectangular box redacting the signature of the author.

March, 2020

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Relationship between biopsychosocial factors and school functioning in children and adolescents with chronic pain: Are these mediated by parental mental health?

1.1 Overview

Even though each child and adolescent is unique and has different needs at various stages of their development (Berk, 2012), all have a right to be healthy, a right to relax, play and engage in leisure activities, and a right to attend school (United Nations Human Rights Office of the High Commissioner, 1989). Chronic pain impairs the ability of children and adolescents to engage in these developmentally typical and beneficial activities, impacting significantly on their quality of life (Forgeron & Stinson, 2001; Greenley, Kunz, Schurman, & Swanson, 2013). Chronic pain can be debilitating and if left untreated can lead to high rates of co-occurring mental illness (Australian Government Department of Health, 2019; Soltani, Kopala-Sibley, & Noel, 2019), increased functional disability (Eccleston, Wastell, Crombez, & Jordan, 2008; Rolfe, 2019), impaired emotional wellbeing (Eccleston, Crombez, Scotford, Clinch, & Connell, 2004), impaired social functioning (Eccleston et al., 2008; Forgeron et al., 2010), diminished sleep quality (Australian Government Department of Health, 2019; Whibley et al., 2019), and poor school attendance and performance (Australian Government Department of Health, 2019; Groenewald, Giles, & Palermo, 2019; Rolfe, 2019). Additionally, chronic pain during childhood and adolescence increases the risk of pain, and increased physical and psychiatric symptoms (Fearon & Hotopf, 2001; Westendorp et al., 2016), impaired social functioning (Ostlie, Aasland, Johansson, Flato, & Moller, 2009; Westendorp et al., 2016), and reduced vocational attainment (Murray, Groenewald, de la Vega, & Palermo, 2020) during adulthood compared to those who did not experience chronic pain in childhood.

1.2 Etiology, Prevalence and Classification

Pain is defined as ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or is described in terms of such damage’ (International Association for the Study of Pain, 2018a, para.1). It is a normal phenomenon prompting your body to engage protective strategies to avoid tissue damage (Butler & Moseley, 2016; Treede et al., 2019).

Pain is usually a symptom warning of a medical condition or injury, and if successful treatment of the underlying condition or injury occurs then pain usually dissipates.

However, pain may persist despite successful management of the condition that initially caused it, or because the underlying medical condition cannot be treated successfully. If pain persists or recurs for more than 3 months and is associated with significant emotional distress and/or functional disability it is defined as chronic pain (International Association for the Study of Pain, 2018a; Treede et al., 2019). Chronic pain is connected to changes in neural pathways resulting in hypersensitivity to pain (Butler & Moseley, 2016; Fitzgerald, 2011).

A systematic review of pediatric chronic pain concluded that chronic pain is highly prevalent in children and adolescents with median prevalence rates ranging from 11% to 38%, girls generally experienced more pain than boys, and prevalence rates increasing with age (King et al., 2011). Similarly, a recent study, with a sample size of 214,000 adolescents, reported 44% experienced chronic weekly pain during the preceding 6 months, with headache pain more prevalent in girls than boys (Gobina et al., 2019)

Bandell-Hoekstra et al. (2001) compared headache prevalence, a leading cause of chronic pain, with data from a comparable sample of around 12 years previously (Passchier & Orle, 1985). They found between 1983 and 1995 the prevalence of weekly headaches increased from 15% to 21% in children aged 10 to 17 years, and prevalence of headaches ‘a few times a week’

increased from 17% to 30% in children aged 9 to 12 years. In addition, the number of Years Lived with Disability (YLDs) due to chronic low back pain, the current leading global cause of YLDs, has increased by 47.5% from 1990 to 2017 (James et al., 2018). Together, this evidence suggests the prevalence of chronic pain is increasing, it is a major cause of human suffering and disability globally, and that these trends extend to children and adolescents.

This increased understanding of chronic pain and its effect globally prompted a systematic and pragmatic classification of chronic pain being developed for inclusion in the International Classification of Diseases 11th edition (ICD-11), coming into effect from 2022 (World Health Assembly, 2019). In ICD-11, chronic pain includes seven sub-categorisations: chronic primary syndrome, a disease in its own entirely such as fibromyalgia; chronic cancer-related pain; chronic postsurgical or posttraumatic pain; chronic neuropathic pain; chronic secondary headache or orofacial pain; chronic visceral pain; and chronic secondary musculoskeletal pain (Treede et al., 2019; World Health Assembly, 2019) .

1.3 Chronic Pain Management in Australia

In 2009, Australia's first National Pain Strategy was developed. The strategy's aim is to improve assessment and treatment of all forms of pain, including chronic pain. The National Pain Strategy was presented at the 2010 Australian Pain Management Summit and was endorsed by the 150 stakeholders in attendance (PainAustralia, 2011). The National Pain Strategy informed development of A Model of Care for Chronic Pain Management in South Australia (SA Model of Care for Chronic Pain), one of the models of care developed to drive implementation of the South Australian government's 2015 - 2019 Transforming Health vision (Government of South Australia, 2016; SA Academic Health Science and Translation Centre, 2018). At the time services for people experiencing chronic pain in South Australia (SA) was

limited. For example, there were no dedicated paediatric chronic pain assessment and management services (Government of South Australia, 2016). However, in response to SA Model of Care for Chronic Pain and Transforming Health initiatives South Australia's first paediatric chronic pain unit opened at Women's and Children's Hospital (WCH) in March 2017.

In 2019, the government developed Australia's first National Strategic Action Plan for Pain Management (Action Plan); a key initiative towards a national and holistic policy framework to support consumers, health practitioners and wider community to minimise the impact of pain and improve quality of life for people with pain and their support networks. It adopts and extends the 2010 National Pain Strategy (Australian Government Department of Health, 2019) and is based on current research indicating pain should be viewed through a biopsychosocial lens; i.e. pain is a result of an interaction between physical, psychological and sociocultural factors (Wade & Halligan, 2017). The Action Plan promotes face-to-face discussion between the individual with chronic pain, their support network and multidisciplinary team members on the relevant importance of biopsychosocial factors impacting the individual with chronic pain (Australian Government Department of Health, 2019). The identified biopsychosocial risk factors then inform the therapeutic treatment plan for the individual with chronic pain (Australian Government Department of Health, 2019).

The next section discusses the biopsychosocial factors addressed in this study of children and adolescents with chronic pain, namely functional disability, sleep problems, emotional wellbeing, and parental mental health, and their relationship with each other and with school performance.

1.4 Biopsychosocial Factors

1.4.1. Functional Disability. Children and adolescents with chronic pain experience increased functional disability, including loss of engagement with age-appropriate physical activities, and impairment in everyday activities, such as walking and playing sports, compared to those without chronic pain (Hunfield et al., 2001; Sinclair, Meredith, Strong, & Feeney, 2016). In a sample of 560 schoolchildren, 37% who experienced chronic pain, Huguet and Miro (2008) reported functional disability of youth with chronic pain increases as severity of chronic pain increases; boys and girls experienced similar levels of functional disability; and age was not significantly related to level of functional disability.

Recent research undertaken by Clementi, Chang, Gambhir, Lebel and Logan (2020), in a sample of 109 schoolchildren with persistent headache, reported sleep problems co-occurring with chronic pain increased functional disability. Claar, Walker and Smith (1999) reported, adolescents with chronic pain who perceive they are not successful academically experience greater school avoidance than adolescents who perceive they are successful academically. This finding supports a learning theory model of illness behaviour (Insitute of Medicine, 1987; Wooley, Blackwell, & Winget, 1978), which is based on operant learning and posits that if an experience has previously been rewarding, such as succeeding academically, the individual will endeavour to achieve that experience again. Whereas if an experience has not been rewarding, such as failing academically, the individual will exhibit avoidance behaviours, such as experiencing pain that is too debilitating to attend school, to avoid a previously endured negative experience.

Sinclair et al.'s (2016) systematic review reported as emotional wellbeing decreases in youth with chronic pain their functional disability increases, and increased mental ill-health of parents

of children and adolescents with chronic pain is associated with increased functional disability in the child or adolescent. Parents mostly decide whether their child or adolescent attends school, and it is unknown if parents with mental ill-health have the mental capacity to facilitate and maintain school attendance by their child or adolescent with functional disability, especially those children and adolescents who have had prior negative school experiences.

1.4.2. Emotional Wellbeing. Children and adolescents with chronic pain experience impaired emotional wellbeing, including feeling scared and worried about what will happen to them (Fisher, Heathcote, Eccleston, Simons, & Palermo, 2018; Tran, Mano, Khan, & Hainsworth, 2016). In a sample of 80 adolescents with chronic pain, Eccleston et al. (2004) reported about three quarters experienced depressive symptoms above normal range, and generally anxiety scores were double a non-clinical population and similar to those with social anxiety disorder. Internalizing negative thoughts about their pain was associated with higher levels of depression and anxiety, whereas seeking support to cope with their pain was associated with lower levels of depression and anxiety.

Parents continue to play a key role in providing support to their children during the adolescent years (Moretti & Peled, 2002; Peterson, 2014), however this may not be the case for depressed parents. Families with a depressed parent have been reported to experience less cohesion and expressiveness and more conflict than families with non-depressed parents (Billings & Moos, 1983). These factors negatively impact on the parent-adolescent bond, reducing the likelihood of adolescents with chronic pain seeking parental support if they experience mental ill-health. Depressed or anxious adolescents are not motivated to attend school, and the limited capacity of depressed parents to increase their adolescents' motivation, as

well as the weakened parent-adolescent bond may further reduce the likelihood of school attendance and engagement.

A recent review by Soltani et al., (2019) reported adolescents with co-occurring sleep problems and chronic pain reported higher levels of depression compared to adolescents with only chronic pain. Also, Yoon, Sturgeon, Feinstein and Bhandari (2019), in a sample of 285 children with chronic pain, reported poorer school performance was associated with higher levels of depressive symptoms, but found this relationship may be mediated by fatigue. In addition, Tsao, Meldrum, Kim and Zelter (2007) found higher levels of anxiety were associated with lower school performance in children with chronic pain.

1.4.3. Sleep Problems. Children and adolescents with chronic pain experience diminished sleep quality, including disturbed sleep patterns, difficulty falling or staying asleep, and daytime tiredness (Australian Government Department of Health, 2019; Badawy, Law, & Palermo, 2019). In a sample of 100 children with chronic pain, Long, Krishnamurthy and Palmers (2008) reported 53% were above the clinical cutoff for sleep disturbances and all children reported clinical levels of daytime sleepiness. Further research, in a sample of 109 youths with persistent headache, found greater sleep problems were associated with poorer school performance, and this association continued for at least 6 months after treatment (Clementi et al., 2020).

Badawy, Law and Palermo's (2019) review reported poorer sleep habits and higher depressive symptoms were associated with elevated insomnia symptoms in children and adolescents with chronic pain compared to those without chronic pain, and more severe sleep disturbances were seen in older children and girls. No studies were found directly investigating parent mental health and sleep quality in children or adolescents with chronic pain. However, Newton et al.'s (2019) literature review reported parents of children with chronic pain are likely

to experience parental distress, catastrophise about their child's symptoms and encourage illness behaviours, such as not enforcing routines that ensure good sleep habits. How a child functions at school is determined by the quality of their sleep. If distressed parents are unable to assist their child to develop good sleeping habits then this will in turn negatively affect the child's schooling.

1.4.4. Parental Mental Health. Caring for a child or adolescent with chronic pain can be distressing, and parents of children and adolescents with chronic pain regularly report feeling hopeless and helpless, and experience greater levels of anxiety and depression compared to parents of healthy children and adolescents (January et al., 2019; Newton, Schosheim, Patel, Chitkara, & van Tilburg, 2019). However, not all parents of children and adolescents with chronic pain experience mental ill-health.

Recent research undertaken by January et al. (2019), in a sample of 318 caregivers of youth with chronic pain, identified 3 distinct caregiver coping profiles: adjusted/low copers who used acceptance coping strategies; constructive copers who focused on confronting and solving problems, and sought out friends and family for support; and avoidant copers who used distraction, denial and self-blame to cope. Findings showed avoidant coping caregivers and their children or adolescents experienced increased anxiety symptoms compared to the two other coping style groups caregivers and their children or adolescents. However, overall the constructive coping caregiver experienced more mental ill-health than the other two caregiver coping groups. In addition, the adjusted/low coping group thought their children or adolescents enjoyed school more than the caregivers in the other two groups. Understanding the coping style of a parent with impaired mental health will assist in developing strategies to support the parent to impact positively on their child or adolescent with chronic pain.

1.5 Treatment

As paediatric chronic pain is detrimental to the functioning and development of children and adolescents (Forgeron & Stinson, 2001), and impacts negatively on the individual's quality of life in adulthood (Fearon & Hotopf, 2001), effective therapeutic intervention is critical. A multidisciplinary approach which incorporates a biopsychosocial perspective to assess and treat chronic pain in children and adolescents has been reported to be effective in increasing the individuals quality of life (de Blecourt, Schiphorst Preuper, Van Der Schans, Groothoff, & Reneman, 2008; Dysvik, Kvaloy, Stokkeland, & Natvig, 2010). In accordance with such an approach, medication usage, and both physical and psychological treatments should be incorporated into the individuals therapeutic intervention plan (Gallagher, 2005; Reid, Lander, Scott, & Dick, 2010). Indeed, such an approach has been shown to be associated with greater and more sustained improvements compared to more traditional and non-traditional treatment approaches such as pharmacological and surgical interventions, intramuscular injections, acupuncture, and conductive education (Myrhaug, Odgaard-Jensen, & Jahnsen, 2019; Ostojic, Paget, & Morrow, 2019). As such, this study will additionally investigate patient improvement following a multidisciplinary approach to paediatric chronic pain management.

1.6 The Current Study

Birth to adolescent is not only a period of major developmental changes (Berk, 2012), but also a period when parents are influential in their children and adolescents with chronic pain's development (Palermo, Valrie, & Karlson, 2014). For example, assisting school aged children with chronic pain to succeed academically and socially. These two factors, major developmental changes occurring and parental influence, differentiate the experience of paediatric chronic pain

to adult chronic pain, and therefore research on adult chronic pain cannot be translated to paediatric chronic pain.

Further research is needed to extend our understanding of the impact of parental mental ill-health on children and adolescents with chronic pain, and increase our knowledge of effective therapeutic interventions. This study addresses this gap in the literature which is essential to reduce the prevalence of paediatric chronic pain, improve the quality of life of children and adolescents with chronic pain and their parents, and prevent much adult disease.

This study aims to investigate the relationship between biopsychosocial factors, in children and adolescents with pediatric chronic pain, and their schooling, and whether these relationships are mediated by parental mental health. Specifically, it was hypothesised that higher levels of both functional disability and sleep problems would be associated with lower school performance, and lower levels of emotional wellbeing would be associated with lower levels of school performance. Furthermore, these relationships are hypothesised to be mediated by greater mental health symptoms.

The secondary aim of this study is to assess the effectiveness of a multidisciplinary team approach to improve the quality of life of children and adolescents with chronic pain. Specifically, it was hypothesised that levels of both functional disability and sleep problems would be lower after treatment by a multidisciplinary team than before treatment, and levels of both emotional wellbeing and school performance would be higher after treatment by a multidisciplinary team than before treatment.

Method

2.1 Participants

Participants were children and adolescents who attended the Adelaide Women's and Children's Hospital (WCH) Paediatric Chronic Pain Unit between 1st March 2018 and 30th November 2019. Eligibility criteria required children and adolescents to be aged between 5 and 18 years and themselves, or their parent, to have completed at least part of one Paediatric Persistent Pain Outcomes Collaboration (PaedePPOC) assessment prior to 1st January 2020. Inclusion criteria required children and adolescents to meet World Health Organisation (WHO) chronic pain diagnostic criteria i.e. experiencing pain that had persisted or recurred for longer than 3 months (World Health Organization, 2019). Of the 104 children and adolescents, 19 children or adolescents (18.27%) were not eligible or did not meet the inclusion criteria, leaving a total of 85 children and adolescents. Eligibility and inclusion details are presented in Table 1.

Table 1

Number (%) of Children and Adolescents who did not meet Eligibility or Inclusion Criteria by Category

Eligibility or inclusion criteria category	<i>n</i>	(%)
Age parameters (5 to 18 years)	2	(1.92%)
Questionnaire completed by 31 st December 2019	15	(14.43%)
Chronic pain diagnosis	2	(1.92%)
Total	19	(18.27%)

2.1.1. Children and adolescents' characteristics. Ages ranged from 7.18 to 18 years ($M = 14.44$ years, $SD = 2.55$ years) and 73% ($n = 60$) attended secondary school. Seventy-six percent ($n = 62$) were girls, 95% ($n = 78$) born in Australia, and about 1% ($n = 1$) Aboriginal or Torres Strait Islander origin. Socio-economic status, measured using deciles of the Australian Bureau of Statistics' Index of Relative Socio-economic Advantage/Disadvantage 2016 national census data (Australian Bureau of Statistics, 2018), was $M = 4.88/10$, $SD = 2.78$. Based on these values the sample for this study was considered to be representative of the general population of children and adolescents in South Australia. Approximately 60% ($n = 48$) had one or more co-occurring health condition and 35% ($n = 29$) had one or more pre-existing disability. Co-occurring health conditions and pre-existing disabilities are presented in Table 2.

Ninety-five percent of children and adolescents reported their pain severity. Of these 32% experienced severe pain, 38% moderate pain and 30% mild pain. Approximately 85% of children and adolescents reported cause of pain, pain duration, pain frequency and body areas where pain was experienced. In this cohort, injury and illness, both approximately 20%, were the most common causes of pain, 72% experienced pain for more than 12 months, and 81% always experienced pain. The most common primary pain sites were abdomen (19.2%) and back (17.8%), and 59% experienced pain in more than one site. Primary pain site details are presented in Table 3.

Table 2

Percentage (n) of Children and Adolescents with Co-occurring Health Condition or Pre-existing Disability by Category

	% (n)
Health condition	
Mental health diagnosis	25.6% (21)
Chronic disease	18.3% (15)
Cancer	1.2% (1)
More than one	13.4% (11)
Disability	
Physical	11.0% (9)
Sight impairment	7.3% (6)
Intellectual	4.9% (4)
Hearing impairment	2.4% (2)
More than one	9.8% (8)

Table 3

Summary of Primary Pain Site of Children and Adolescents (% , n)

	% (n)
Abdomen	19.2% (14)
Back	17.8% (14)
Knee	12.3% (9)
All other areas	< 10% each site (36)

2.1.2. Caregiver characteristics. Approximately 85% of caregivers reported their gender and relationship to participant. Ninety-two percent were women and 97% were the child or adolescent's parent/step-parent.

2.2. Procedure

The study was approved by Women's and Children's Health Network Human Research Ethics Committee and University of Adelaide Human Research Ethics Committee. The data was retrospective and families of children and adolescents were emailed or posted study details and given the option of opting-out. Three children and adolescents (3.53%) opted-out, leaving 82 participants.

WCH Paediatric Chronic Pain Unit has two service pathways: multidisciplinary team (MDT) pathway for children and adolescents aged 0 to 18 years; and Comfort Ability Pain Management (CAP) pathway for children and adolescents aged 10 to 18 years. The primary goal of both service pathways is to promote autonomous health management by being proactive.

Patients were referred to WCH Paediatric Chronic Pain Unit (CPU) by either their general practitioner, paediatrician, or a hospital medical specialist. When a referral was received and triaged by the service coordinator, a baseline PaedePPOC questionnaire was forwarded to the patient (Australian Health Services Research Institute and University of Wollongong, n.d.-a). PaedePPOC questionnaires were managed using REDCap (Research Electronic Data Capture), a secure web-based application designed to support data capture for research studies (Harris et al., 2009).

When the patients completed baseline PaedePPOC questionnaire was received the CPU's service coordinator reviewed the information to determine if they were suitable for MDT or CAP service pathway, or both service pathways. For instance, medical complexity, or evidence of an

intellectual, learning or physical disability, or complex psychiatric presentations might result in a patient being referred for MDT review appointment prior to considering them for CAP service pathway. There is flexibility for patients to move between service pathways depending on their needs. For example, a patient may start MDT service pathway, then switch to CAP service pathway and then back to MDT service pathway.

MDT service pathway patients completed further assessments at treatment start if more than 3-6 months from baseline assessment date, at treatment end, and 3-6 months after treatment end. CAP service pathway patients completed further assessments 1 month pre- and 1 month post CAP workshop. Patient's carers completed assessments at the same MDT or CAP time points, and also 12 months after treatment start.

2.2.1. MDT Service Pathway. The MDT service pathway involved an initial MDT review appointment with the patient and carer which assessed, through clinical interview, patient's history; severity of pain; impact of pain on patient's functioning, mood, schooling, sleep, and social interactions; patient's medication usage; family structure; and coping and pain management skills. It also involved pain education delivered to the family which started the process of therapeutic intervention. This initial meeting concluded with development of a therapeutic plan, derived with the patient and carer, prior to organisation of outpatient appointments, either with one, or all members of the CPU team, or a combination of appointments with one, or all members of the CPU team and community providers already engaged. All MDT members, service coordinator, physician, psychologist, and physiotherapist, attended the initial review meeting and contributed to the assessment process. MDT subsequent review meetings were conducted based on the needs of each patient.

2.2.2. CAP Service Pathway. The CAP service pathway involved a pre CAP appointment one-month prior to the workshop, the CAP workshop and a post CAP appointment one-month afterwards that sometimes included MDT assessment and review though did not occur if the patient had adequate community support systems and symptoms started to resolve as a result of the pre CAP intervention and CAP. The pre and post CAPs were usually completed by a psychologist or MDT review. If completed by a psychologist, the pre CAP would focus on assessing how pain impacted lifestyle, current coping methods and some pain education delivered by way of a quiz. If MDT, then the assessment method was as above. Post CAP appointments with a psychologist reviewed new steps taken to manage pain better post CAP and assessment of successes and barriers. Further consideration of additional supports was also assessed so that services could then be implemented as required.

The CAP workshop provided both adolescents and carers education about the biopsychosocial model of pain and taught them evidence-based cognitive behavioural pain management skills to better manage adolescents' pain. It involved a 6.5 hour workshop for adolescents and carers, divided into their respective groups. The groups ran simultaneously, but separately. The adolescent group was facilitated by a psychologist, physiotherapist and masters psychology student, and carer group was facilitated by two psychologists.

The adolescent and carer group programs both included: neuroscience education; psychoeducation; practical activities, such as pain reduction visualisation for the adolescents and reflective listening for the carers; and a peer mentor session, which included, for the adolescents, the peer mentor reflecting on their personal experience of managing pain and, for the carers, the peer mentor reflecting on their journey of supporting and caring for their adolescent in pain. In addition, the adolescents developed individualised pain management plans, and took home a

comfort kit which included, among other things, the knitted blanket they used during the day for relaxation, and a mindful colouring pad. The carers were provided with information on evidence-based relaxation interventions, and techniques to encourage their adolescent to participate in these practices at home; and they developed a behavioural plan to increase their adolescent's daily functioning (Coakley, Wihak, Kossowsky, Iversen, & Donado, 2018).

2.2.3. Discharge. Patients were discharged from the CPU when either their functioning had improved significantly and they were managing their pain independently, or they had established effective links with community providers.

2.3 Measures

Participants completed omnibus assessment questionnaires which consisted of age-valid measures separated across the following ranges: 5-7 years; 8-12 years; and 13-18 years (see Appendix A, for sample). Participants' parents completed omnibus assessment questionnaires and Parent/Carer Impact Questionnaire (BAP-PIQ) (see Appendix B, for sample).

Six standardised measures were used for analyses: CARRA body chart; Faces of Pain Scale-Revised; Brief Pain Inventory – Modified (BPI-M); Functional Disability Inventory (FDI); Paediatric Quality of Life – emotional functioning (PedsQL Emotional) and school Functioning dimensions (PedsQL School); and Bath Adolescent Pain Parent Impact Questionnaire (BAP-PIQ). Five of these measures were included in the omnibus questionnaires, CARRA, BPI-M, FDI, PedsQL Emotional, and PedsQL School. BAP-PIQ was forwarded to patient's carers separately. These measures are described in detail below.

2.3.1. CARRA body chart (CARRA). CARRA records pain location. It consists of a two-sided (front and back) body map with 21 delineated areas (head; face/jaw/temple; throat/neck; chest; abdomen; groin/public area; back (upper, mid and low); and left and right

shoulder, upper arm, elbow, forearm, wrist, hand, hip, thigh, knee, calf, ankle, foot)

(Childhood Arthritis and Rheumatology Research Alliance, 2011; von Baeyer, 2011).

Any mark in a delineated area is scored as 1. Laterality is ignored for example, a mark on the left forearm, the right forearm, or both forearms all score the same. Scores range from 0 to 21 with higher numbers indicating greater number of pain areas (Australian Health Services Research Institute and University of Wollongong, n.d.-b).

An equivalent version of the CARRA reported sound psychometric properties. It reported high test-retest reliability ($r(82) = .69; p < .001$), and significant, medium to strong, positive correlation with a measure of pain intensity ($r(132) = .50; p < .001$) and a measure of pain duration ($r(132) = .33, p < .001$) demonstrating sound convergent validity (Foxen-Craft et al., 2019).

2.3.2. Faces of Pain Scale – Revised. The Faces of Pain Scale – Revised assesses pain intensity (International Association for the Study of Pain, 2018b). The child circles one of six faces, scored as either 0, 2, 4, 6, 8, or 10 (0 = *no pain* and 10 = *very much pain*), which shows their pain intensity at its usual, worst and least in the last week, as well as their current pain intensity. An average pain severity rating is calculated by summing the scores of the four questions, then dividing by number of questions answered. Average pain severity scores can range from 1 to 10 with 1 to 4 representing mild pain, 5 to 6 representing moderate pain and 7 to 10 representing severe pain (Australian Health Services Research Institute and University of Wollongong, n.d.-b).

The Faces of Pain Scale – Revised has sound psychometric properties. It reported strong inter-rater correlations ranging from 0.84- 0.99, and significant, strong, positive correlation with Visual Analogue Scale ($r(43) = .92, p < .001$) and Coloured Analogue Scale ($r(43) = .84, p <$

.001) demonstrating strong convergent validity (Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001).

2.3.3. Modified Brief Pain Inventory (BPI-M). BPI-M assesses pain intensity (The University of Texas MD Anderson Center, 1991). Youth rate their pain at its usual, worst, and least in the last week, and their current pain on an eleven-point Likert scale ranging from 0 (*no pain*) to 10 (*pain as bad as you can imagine*). An average pain severity rating is calculated by summing the scores of the four questions, then dividing by number of questions answered. Scores can range from 1 to 10 with 1 to 4 representing mild pain, 5 to 6 representing moderate pain and 7 to 10 representing severe pain (Australian Health Services Research Institute and University of Wollongong, n.d.-b).

Chiarotto et al.'s (2019) recent systematic review found BPI psychometric properties to be suboptimal. Quality of evidence for test-retest reliability, content validity and construct validity were rated between very low and moderate. Therefore, BPI should be used with caution until further studies assess its psychometric properties.

2.3.4. Functional Disability Inventory (FDI). FDI assesses the difficulty youth had performing 15 activities during the last two weeks, such as, walking to the bathroom, getting to sleep at night and staying asleep (Mapi Research Trust, 2020). Youth select one of five responses ranging from 0 (*no trouble*) to 4 (*impossible*.) Total FDI score is calculated by summing the scores to give a score out of 60 with < 13 representing no/minimal disability, 13 to 29 representing moderate disability, ≥ 30 representing severe disability (Australian Health Services Research Institute and University of Wollongong, n.d.-b). Total FDI score and FDI Question 15 (FDI Q15), a single sleep question, were utilised for health-related quality of life related analyses.

FDI has sound psychometric properties. It reported strong internal consistency (Cronbach's α ranging from .85 to 0.90), and significant, strong, positive correlation with Pennebaker Inventory of Limbic Languidness ($r(45) = .71, p < .001$) and Children's Depression Inventory ($r(45) = .62, p < .001$) demonstrating sound convergent validity (Walker & Greene, 1991).

2.3.5. Pediatric Quality of Life Inventory Version 4.0 Generic Core Scales (PedsQL).

PedsQL self-report and parent/carer proxy-report assesses children and adolescents health-related quality of life in four dimensions: physical; emotional; social; and school (Australian Health Services Research Institute and University of Wollongong, n.d.-a; Varni, 2019). Child and adolescent self-report PedsQL Emotional and PedsQL School were used in this study.

Children 5-7 years select one of three faces ranging from 0 (*never*) to 4 (*almost always*) and youth 8-18 years select one of five responses ranging from 0 (*never*) to 4 (*almost always*) to five emotional functioning statements, such as 'Do you feel sad', and five school functioning statements, such as 'I have problems paying attention in class'. Each score is transformed to a 0 to 100 scale where 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0. These transformed scores are summed and divided by number of, either emotional or school, functioning statements answered to determine a mean emotional and school functioning score. Higher scores indicate better functioning. (Australian Health Services Research Institute and University of Wollongong, n.d.-b).

PedsQL emotional and school dimensions have sound psychometric properties. PedsQL Emotional reported strong internal reliability (Cronbach's α ranging from .70 to .78) and PedsQL School reported acceptable to strong internal reliability (Cronbach's α ranging from .59 to .75) (Varni, Seid, & Kurtin, 2001). Varni, Burwinkle and Seid (2005) found, in published data on

over 25,000 youth, PedsQL distinguished between healthy children and children with acute and chronic health conditions demonstrating sound convergent validity.

2.3.6. Bath Adolescent Pain - Parent Impact Questionnaire (BAP-PIQ). BAP-PIQ assess caregivers' of youth with chronic pain functioning and behavioural changes (Bath Centre for Pain Research, n.d.). BAP-PIQ includes eight sub-scales measuring depression, anxiety, child-related catastrophising, self-blame and helplessness, partner relationship, leisure functioning, parental behaviour and parental strain. Four sub-scales: depression, anxiety, child-related catastrophising, and self-blame and helplessness were used in this study.

Caregivers select one of five responses ranging from 0 (*never*) to 4 (*always*) to 27 questions, such as 'In the past 2 weeks living with my child in pain I avoided activities I usually enjoy'. Total sub-scale score is calculated by summing the individual sub-scale scores to give a score out of 36 for depression, 24 for anxiety, 20 for child-related catastrophising and 28 for self-blame and helplessness, with higher scores indicating more impaired functioning (Australian Health Services Research Institute and University of Wollongong, n.d.-b).

BAP-PIQ has sound psychometric properties. The sub-scales of depression, anxiety, child-related catastrophising, and self-blame and helplessness have reported high test-retest reliability (r ranging from .77 to .81; $p < .001$) and strong internal consistency (Cronbach's α ranging from .84 to .86). Depression, anxiety, child-related catastrophising, and self-blame and helplessness subscales all demonstrated significant, strong, positive, correlation with comparable measures (Depression: Beck Depression Inventory ($r(192) = .76, p = < .001$); Anxiety: Medical Outcome Short Form (36) Health Survey version 2 - Mental health subscale ($r(192) = .73, p = < .001$); Child-related catastrophising: Pediatric Inventory for Parents – Emotional functioning difficulty subscale $r(192) = .67, p = < .001$; and Self-blame and helplessness: Paediatric Inventory for

Parents – Emotional Functioning sub-scale ($r(192) = .68, p = < .001$) demonstrating sound convergent validity (Jordan, Eccleston, McCracken, Connell, & Clinch, 2008).

2.4 Analysis Plan

Bland-Altman plot analysis was used to analyse the agreement between PedsQL self-report and parent proxy-report data for emotional and school functioning dimensions. Results are presented in Figure 1 and Figure 2. As Bland-Altman analyses reported minimal variance between self-report and parent-proxy report data for both PedsQL Emotional and PedsQL School self-report data were used for this study.

Data analyses were conducted using Statistical Package for Social Sciences (SPSS) Version 25.0 (IBM Corp., 2017). First, Shapiro-Wilk (S-W) test was used to assess normality for each measure. S-W test values were significant for all values except FDI Q15 and PedsQL School. Visual inspection of FDI Q15 and PedsQL School data through Q-Q plots and histograms showed kurtosis values appeared to cluster around zero, which is indicative of a normal distribution, however there was some slight skewness for both. Data visually satisfied the requirements of a normal distribution, and were therefore considered suitable for parametric analyses.

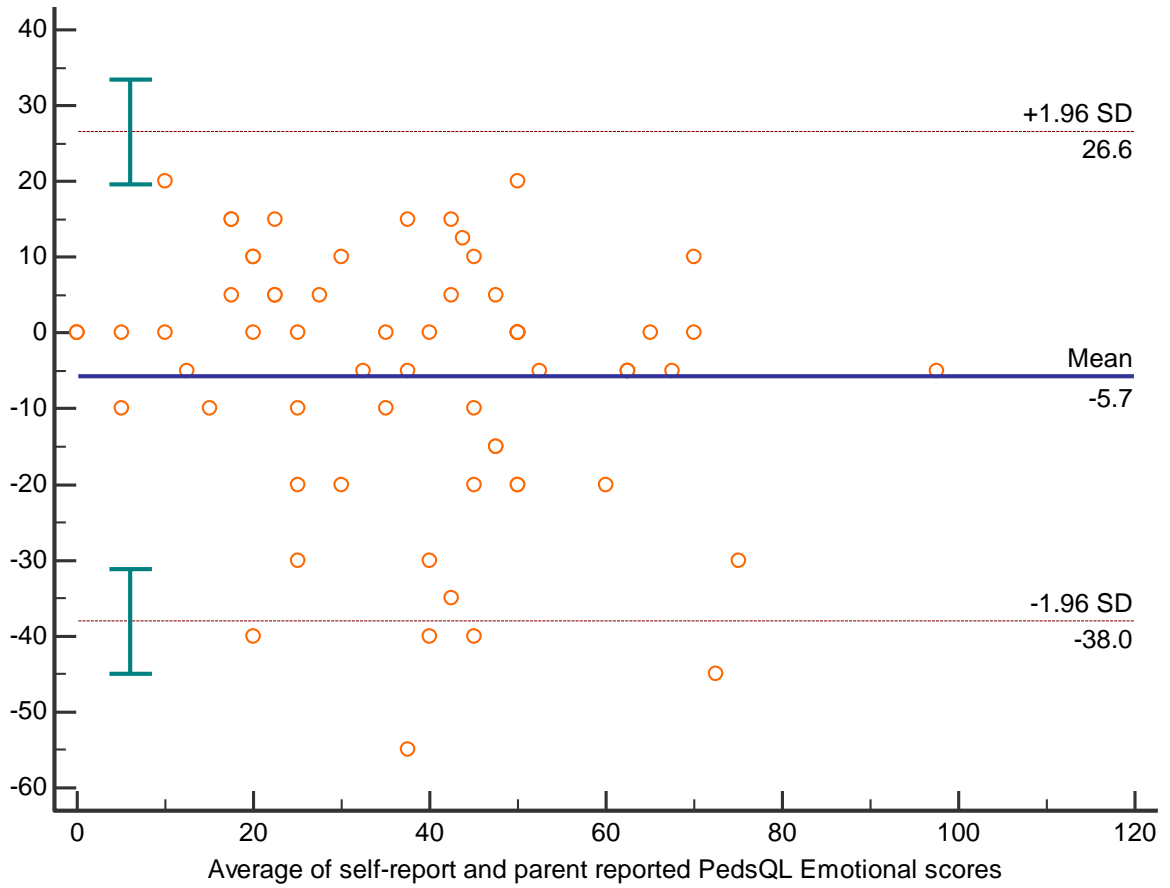


Figure 1. Agreement between PedsQL Emotional self-report and parent-proxy report

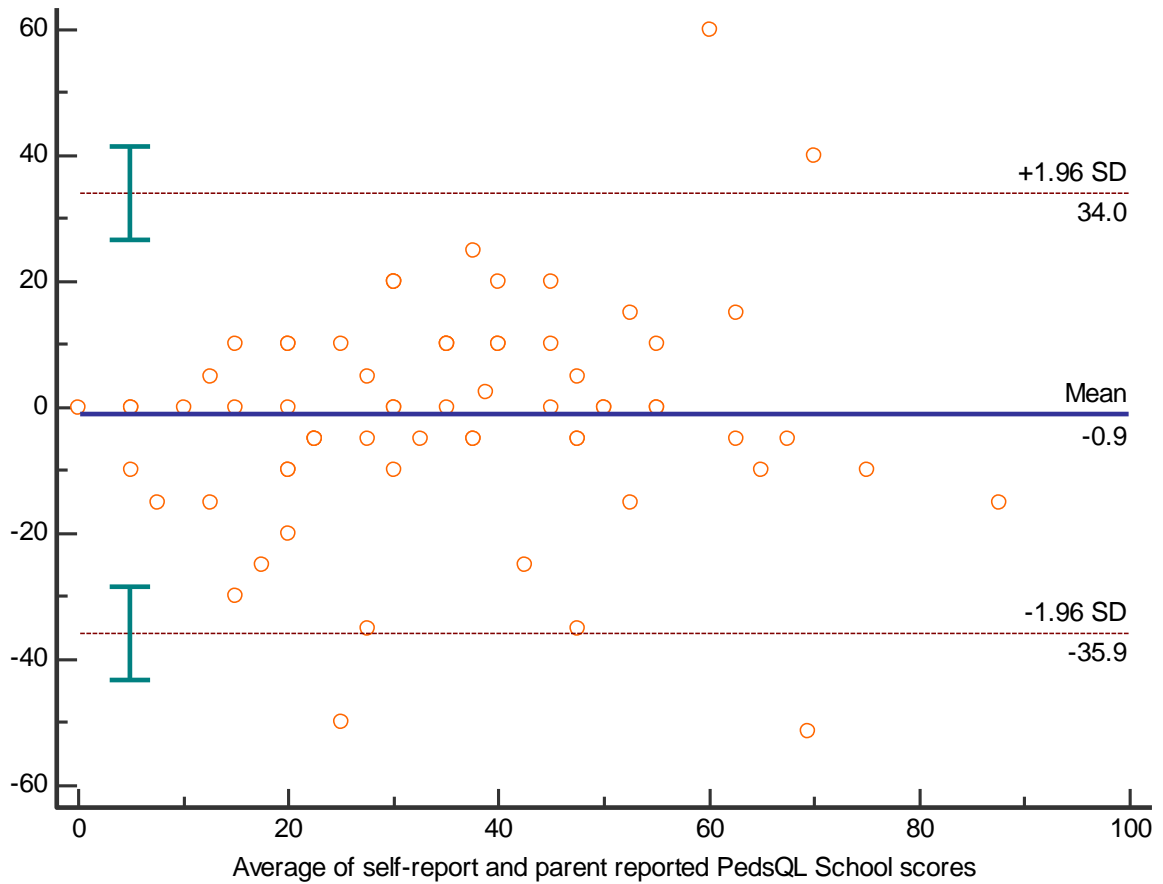


Figure 2. Agreement between PedsQL School self-report and parent-proxy report

Associations between measures of functional disability, sleep difficulties, emotional wellbeing, school performance, and parental mental health were analysed with Pearson’s correlation. A series of simple and hierarchical regressions were used to examine parental mental health dimensions, depression, anxiety, child-related catastrophising, and self-blame and helplessness, as possible mediators for the relationship between: (a) functional disability and school performance; (b) sleep difficulties and school performance; and (c) emotional wellbeing and school performance.

Paired-samples t-tests were used to compare functional disability, sleep difficulties, emotional wellbeing and school performance before and after treatment by either an MDT or CAP service pathway, or both combined. Alpha was set at 0.05, and means and standard deviations are displayed unless otherwise stated.

Results

3.1 Power Analysis

Given the predefined clinical sample available for this study, a post-hoc power analysis was conducted using G*Power 3.1 (Faul, Erdfelder, Buchner, & Lang, 2009). As number of participants varied substantially between child-related variables, parent-related variables, and the therapeutic intervention three post-hoc analyses were completed. In relation to both child-related and parent-related variables, the input parameters for a correlational point biserial model were set to two tailed, alpha level of .05, and effect size of .414. The number of participants for child-related variables was set to 78, and the number of participants for parent-related variables was set to 46. The results indicated a power of .98 for child-related variables, and a power of .85 for parent-related variables indicating the current study had a sufficient number of participants to detect significant effects. In relation to the therapeutic intervention, the input parameters for a difference between dependent means (matched pairs) were set to: two tailed, alpha level of .05, effect size of .84, and 19 participants. The results indicated a power of .93 indicating the current study also had a sufficient number of participants to detect significant effects.

3.2 Descriptive Statistics

Descriptive statistics for functional disability, sleep problems, emotional wellbeing, school performance, and parental mental health variables are presented in Table 4.

From this table it can be seen, on average participants experienced severe physical difficulty performing everyday activities, often had problems at school, and sometimes had difficulty sleeping, felt sad, angry and afraid. In addition, on average participants' carers were sometimes depressed, were sometimes anxious, sometimes catastrophised about their child's health, and sometimes blamed themselves for their child's health problems and felt they were powerless to help their child.

Turning now to consider the primary aim of this study, which is the association between functional disability, sleep problems, emotional wellbeing, and school performance. In addition, consideration is given to whether greater mental health symptoms mediate the association between: (a) functional disability and school performance; (b) sleep problems and school performance; or (c) emotional wellbeing and school performance.

Table 4

Descriptive Statistics for Functional Disability, Sleep Problems, Emotional Wellbeing, School Performance, and Parental Mental Health Variables

	N	M (SD)	Min.	Max.
Functional disability	77	30.98 (10.30)	4	52
Sleep problems	77	2.62 (1.01)	0	4
Emotional wellbeing	78	41.96 (23.78)	0	100
School performance	78	31.15 (20.66)	0	95
Parental depression	46	16.33 (6.31)	4	29
Parental anxiety	46	10.65 (5.45)	1	24
Parental child-Related catastrophising	46	12.09 (4.19)	0	20
Parental self-blame and helplessness	46	13.98 (6.20)	0	28

Note: N = number of participants; M = mean; *SD* = standard deviation; Min. = Minimum result obtained; Max. = maximum result obtained

3.3 Correlations

Results of correlational analyses between functional disability, sleep problems, emotional wellbeing, school performance and parental mental variable are presented in Table 5. As predicted, greater functional disability and greater sleep problems were both associated with poorer school performance, and greater emotional wellbeing was associated with greater school performance.

Table 5:

Pearson Correlation Coefficient Matrix for Functional Disability, Sleep Problems, Emotional Wellbeing, School Performance, and Parental Mental Health Variables

	1	2	3	4	5	6	7	8
1. Functional disability	—							
2. Sleep Problems	.46**	—						
3. Emotional wellbeing	-.53**	-.40**	—					
4. School performance	-.60**	-.41**	.54**	—				
5. Parental depression	.32*	.33*	-.36*	-.42**	—			
6. Parental anxiety	.19	.18	-.35*	-.25	.79**	—		
7. Parental child-related catastrophising	.15	.26	-.22	-.19	.58**	.60**	—	
8. Parental self-blame and helplessness	.23	.32*	-.42**	-.35*	.71**	.75**	.67**	—

* $p \leq .05$ (two-tailed), ** $p \leq .01$ (two-tailed)

Contrary to expectations, parental depression and parental self-blame and helplessness were the only two parental mental health variables that were significantly associated with school performance. In addition, parental depression was significantly associated with all predictor variables, functional disability, sleep problems and emotional wellbeing, whereas parental self-blame and helplessness was only significantly associated with two, sleep problems and emotional wellbeing.

3.4 Parental Depression as a Mediator for the association between Functional Disability and School Performance

As can be seen from Table 5, greater parental depression was significantly associated with greater functional disability, and significantly associated with reduced school performance. Therefore, the pre-requisites for parental depression mediating the association between functional disability and school performance were met.

A simple regression revealed functional disability explained 35.9% of the variance in school performance, $R^2 = .359$, $F(1,75) = 41.95$, $p < .001$. When the effect of parental depression was controlled for in Step 2 of a hierarchical regression, functional disability was a weaker predictor of school performance, explaining only 21.8% of the variance, $R^2_{\text{Change}} = .218$, $F_{\text{Change}}(1,40) = 14.15$, $p \leq .001$. Therefore as variance explained diminished from 35.9% to 21.8%, parental depression partially mediated the association between functional disability and school performance, supporting the mediation hypothesis in relation to parental depression.

3.5 Parental Depression as a Mediator for the association between Sleep Problems and School Performance

As can be seen from Table 5, greater parental depression was significantly associated with greater sleep problems, and significantly associated with reduced school performance. Therefore, the pre-requisites for parental depression mediating the association between sleep problems and school performance were met.

A simple regression revealed difficulty sleeping explained 16.8% of the variance in school performance, $R^2 = .168$, $F(1,75) = 15.17$, $p < .001$. When the effect of parental depression was controlled for in Step 2 of a hierarchical regression, difficulty sleeping was a weaker predictor of school performance, explaining only 9.6% of the variance, $R^2_{\text{Change}} = .096$, $F_{\text{Change}}(1,40) =$

5.20,

$p = .03$. Therefore as variance explained diminished from 16.8% to 9.6%, parental depression partially mediated the association between sleep problems and school performance, supporting the mediation hypothesis.

3.6 Parental Depression as a Mediator for the association between Emotional Wellbeing and School Performance

As can be seen from Table 5, greater parental depression was significantly associated with both reduced emotional wellbeing and school functioning. Therefore, the pre-requisites for parental depression mediating the association between emotional wellbeing and school performance were met.

A simple regression revealed emotional wellbeing explained 28.7% of the variance in school performance, $R^2 = .287$, $F(1,76) = 30.62$, $p < .001$. When the effect of parental depression was controlled for in Step 2 of a hierarchical regression, emotional wellbeing was a weaker predictor of school performance, explaining only 20.6% of the variance, $R^2_{\text{Change}} = .206$, $F_{\text{Change}}(1,41) = 13.63$, $p < .001$. Therefore as variance explained diminished from 28.7% to 20.6%, parental depression partially mediated the association between emotional wellbeing and school performance, supporting the mediation hypothesis.

3.7 Parental Self-Blame and Helplessness as a Mediator for the association between Sleep Problems and School Performance

As can be seen from Table 5, greater parental self-blame and helplessness was significantly associated with greater sleep problems, and significantly associated with reduced school performance. Therefore, the pre-requisites for parental self-blame and helplessness mediating the association between sleep problems and school performance were met.

A simple regression revealed difficulty sleeping explained 16.8% of the variance in school performance, $R^2 = .168$, $F(1,75) = 15.17$, $p < .001$. When the effect of parental self-blame and helplessness was controlled for in Step 2 of a hierarchical regression, difficulty sleeping was a weaker predictor of school performance, explaining only 11.3% of the variance, $R^2_{\text{Change}} = .113$, $F_{\text{Change}}(1,40) = 5.85$, $p = .02$. Therefore as variance explained diminished from 16.8% to 11.3%, parental self-blame and helplessness partially mediated the association between sleep problems and school performance, supporting the mediation hypothesis.

3.8 Parental Self-Blame and Helplessness as a Mediator for the association between Emotional Wellbeing and School Performance

As can be seen from Table 5, greater parental self-blame and helplessness was significantly associated with both reduced emotional wellbeing and school performance. Therefore, the pre-requisites for parental self-blame and helplessness mediating the association between emotional wellbeing and school performance were met.

A simple regression revealed emotional wellbeing explained 28.7% of the variance in school performance, $R^2 = .287$, $F(1,76) = 30.62$, $p < .001$. When the effect of parental self-blame and helplessness was controlled for in Step 2 of a hierarchical regression, emotional wellbeing was a weaker predictor of school performance, explaining only 22.1% of the variance, $R^2_{\text{Change}} = .221$, $F_{\text{Change}}(1,41) = 13.72$, $p \leq .001$. Therefore as variance explained diminished from 28.7% to 22.1%, parental self-blame and helplessness partially mediated the association between emotional wellbeing and school performance, supporting the mediation hypothesis.

Overall, these results indicate that for children and adolescents experiencing chronic pain, parental depressive symptoms explain a significant but partial part of the association between child and adolescent's functional disability, sleep problems, and emotional wellbeing on their

school performance. Similarly, greater parental self-blame and helplessness symptoms explain a significant but partial part of the association between child and adolescent sleep problems and emotional wellbeing on their school performance.

Turning now to consider the secondary aim of this study, which is to assess the effectiveness of an MDT therapeutic intervention to improve the quality of life of children and adolescents, in particular their functional ability, sleeping, emotional wellbeing, and school performance.

3.9 Effects of Multidisciplinary Team Therapeutic Intervention

Baseline and end of treatment data for 19 participants was analysed. Eight patients participated in the MDT service pathway, 9 participated in the CAP service pathway, and 2 participated in both the MDT and CAP service pathways. However, due to the small numbers in each group all participants data were analysed together.

Paired-samples t-test analyses were conducted to examine differences between child and adolescents at baseline and end of treatment for the variables of functional disability, sleep problems, emotional wellbeing and school performance. Cohen's *d* was also calculated as an estimate of effect size. Results of these analyses are presented in Table 6.

As can be seen from Table 6, the difference between before and after MDT therapeutic intervention for functional disability, emotional wellbeing and school performance was significant. However, no significant difference was found before and after MDT therapeutic intervention for sleep problems, which is contrary to expectations. Overall, these results indicate that MDT therapeutic intervention reduces a child or adolescents functional disability, and increases their emotional wellbeing and school performance, but does not significantly affect the quality of their sleep.

Table 6

Baseline and End of Treatment Means, Standard Deviations, t value, p value, and Cohen's d

	Baseline	Treatment	<i>t</i> (19)	<i>p</i>	Cohen's <i>d</i>
	Mean (SD)	End Mean (SD)			
Functional disability	29.42 (8.62)	20.78 (11.04)	3.62	.002	0.87
Sleep problems	2.47 (1.07)	2.16 (1.50)	1.24	.230	0.24
Emotional wellbeing	44.47 (20.68)	63.49 (22.85)	-3.94	.001	0.87
School performance	44.47 (18.10)	58.95 (19.12)	-2.95	.009	0.78

Discussion

The purpose of this study was to explore the relationship between functional disability, sleep problems, emotional wellbeing and school performance in children and adolescents with chronic pain. In addition, this study explored whether the mental health of parents of child and adolescent chronic pain sufferers mediated this relationship. The final question explored whether treatment by an MDT improved the quality of life for children and adolescents with chronic pain, particularly by reducing their functional disability, their sleep problems, or by increasing their emotional functioning or school performance.

With respect to the first research question, it was found when functional disability or sleep problems increased, or emotional wellbeing reduced in children and adolescents with chronic pain their school performance would decrease. This finding supported the first research question. In addition, it was found parents who were experiencing depression, or feelings of self-blame or helplessness mediated these relationships, whereas higher parental symptoms of anxiety or child-related catastrophising did not. Therefore, the second research question was partially supported. Treatment by an MDT reduced the functional disability and increased emotional wellbeing and school performance in children and adolescents with chronic pain but had no effect on sleep problems. Therefore, the final research question was mostly supported.

The association between functional disability and school performance in this patient group is further supported by Hunfield et al.'s (2001) research, which found the diminished functional disability of children and adolescents with chronic pain reduced their ability to perform daily activities, such as attending school. In addition, Sinclair et al. (2016) noted increased mental ill-health of parents of children and adolescents with chronic pain is associated with increased functional disability in their children and adolescents, which aligns with the biopsychosocial model of heal and illness (Lakhan, 2006). This study only supports this for parents with depressive symptoms, not parents experiencing anxiety, child-related catastrophising, or feelings of self-blame and helplessness. A possible explanation for this variance may relate to children and adolescent's mental health. Sinclair et al. (2016) found parents of children or adolescents with chronic pain and high levels of depressive symptoms were high catastrophisers which impacted on their children or adolescents' level of functional disability. In the current study we did not assess child or adolescent depressive symptoms, however differences between previous study cohorts may explain the discrepancy in level of parent catastrophising (low vs high).

Assessing level of parental catastrophising and level of depressive symptoms in children and adolescents with chronic pain in future studies will enable a better understanding of these potential relationships.

In addition, this study found parental depression accounted for around 14% of the effect a child or adolescent's level of functional disability had on their school performance. This finding partially supported the second research question. It extends our understanding of the mediating effect parental depression has on the relationship between functional disability of children and adolescents with chronic pain and their school performance. An implication of this is that parents should undertake psychological interventions, such as cognitive behaviour therapy (CBT) and interpersonal psychotherapy to reduce their depressive symptoms (Linde et al., 2015), which may also lead to improved school performance in children or adolescents with chronic pain. Linde et al. (2015) found that CBT that was less resource intensive, such as conducted via phone or internet might have effects similar to more intense treatments. Parents of children and adolescents have a reduced amount of time, due to the number of medical appointments they attend with their child, so they would be more likely to engage in less intense CBT intervention than more intense treatment.

Additionally, this study found as sleep problems increased in children and adolescents with chronic pain, they performed poorer at school. This finding supported the first research question and confirms Clementi et al's. (2020) research which found greater sleep problems were associated with poorer school performance. As more than half of children and adolescents with chronic pain experience clinically significant sleep disturbances, and possibly all experience daytime sleepiness (Long et al., 2008) effective treatment to improve their sleeping is needed. A recent systematic review and meta-analysis found cognitive and behavioural interventions were

effective in improving sleep in school-age children and adolescents (Aslund, Arnberg, Kanstrup, & Lekander, 2018). However, they recommended large and rigorous trials are needed to further explore their effectiveness. The benefit of better sleep quality may be an improvement in school performance, which will increase future vocational opportunities in children and adolescents with chronic pain.

Parents of children and adolescent's with chronic pain experience depression (Billings & Moos, 1983) and catastrophise about their child or adolescent's chronic pain (Newton et al., 2019), which aligns with the biopsychosocial model of heal and illness (Lakhan, 2006). This study confirmed findings by Newton et al. (2019) that increased parental depression resulted in increased sleep problems for their children or adolescents with chronic pain. Contrary to expectations, no significant difference in sleep problems was found for parents who catastrophised about their child or adolescent's chronic pain. A possible explanation for this difference is this study only included one sleep question, and how the children and adolescents interpreted the question may have affected findings. A more in-depth sleep questionnaire in future research would improve the accuracy of findings relating to sleep, as well as capture a broader range of potential sleep problems experienced. In addition, this study found higher feelings of self-blame and helplessness of parents of children and adolescents with chronic pain is associated with increased sleep problems in their children and adolescents.

This study found parental depression accounted for around 7% of the effect a child or adolescent's level of sleep problems had on their school performance, and feelings of self-blame and helplessness accounted for around 6% of the effect their level of sleep problems had on their school performance. This finding partially supported the second research question. In addition, it extends our understanding of the mediating effect parental depression and feelings of self-blame

and helplessness has on the relationship between sleep problems of children and adolescents with chronic pain and their school performance.

Parents with mental ill-health encourage illness behaviours, which aligns with operant conditioning theory (Burton, Westen, & Kowalski, 2015), in their children or adolescents with chronic pain, such as not developing good sleep routines (Newton et al., 2019). As good sleep routines reduce daytime tiredness, which improves school performance, further research on supporting parents with mental ill-health to encourage their children or adolescents to develop positive coping strategies, rather than promoting illness behaviours, may be beneficial to improve child school performance. As mentioned previously, psychological interventions, such as CBT and interpersonal psychotherapy may reduce parents' depressive symptoms, as well as reduce parents' feelings of self-blame and helplessness and support parents to assist their children or adolescents to develop good sleep habits. Ultimately this may lead to improving their child or adolescents school performance.

Additionally, this study found as children and adolescents with chronic pain's emotional wellbeing increased, they performed better at school. This finding supported the first research question, and confirms research which found children and adolescents with chronic pain who experience depression or anxiety performed worse at school than children and adolescents with chronic pain who were not depressed or anxious (Tsao et al., 2007; Yoon, Sturgeon, Feinstein, & Bhandari, 2019).

Depression is prevalent among both children and adolescents with chronic pain (Eccleston et al., 2004) and their parents (Billings & Moos, 1983). Having a depressed parent impacts negatively on the adolescent-parent bond which decreases the likelihood that depressed children and adolescents will ask their parents for support to cope with their depression (Billings & Moos,

1983). This study found parental depression accounted for around 8% of the effect a child or adolescent's level of emotional wellbeing had on their school performance, and feelings of self-blame and helplessness accounted for around 7% of the effect their level of emotional wellbeing had on their school performance. This finding partially supported the second research question. In addition, it extends our understanding of the mediating effect parental depression and feelings of self-blame and helplessness has on the relationship between emotional wellbeing of children and adolescents with chronic pain and their school performance.

The final research question was whether treatment by an MDT, based on based on the biopsychosocial model of health and illness (Lakhan, 2006), reduced functional disability or sleep problems, or increased emotional functioning or school performance in children and adolescents with chronic pain. This study found that treatment by an MDT improved child and adolescent quality of life by reducing their functional disability and improving both their emotional wellbeing and school performance. This finding mostly supported the final research question, and further supported de Blecourt et al.'s (2008) research which found as functional ability improved in children and adolescents with chronic pain so did their school attendance. There was no significant difference in sleep problems before and after MDT treatment in the current study, however only one question in this study assessed sleep problems. Further research incorporating a more in-depth analysis of sleep quality of children and adolescents with chronic pain is warranted, especially in light of findings suggesting that sleep may affect school performance (Clementi et al., 2020).

This study has a number of limitations that should be mentioned. First, the participants were patients of a city paediatric chronic pain unit and may not be representative of all children and adolescents with chronic pain in the community. Second, these results are based on self-report

data, which although reliable and validated measures were used, still have a subjective component. This subjective component may be exacerbated given the study population include those who have sought assistance for their chronic pain symptoms. Thirdly, sleep problem data only consisted of one question and therefore does not encompass the entire spectrum of problems affecting sufferers of pain and sleep more broadly. Fourthly, these results are based on cross-sectional data and it is not possible to determine the direction of the relationship. An experimental study will help to identify if the before and after treatment findings are indicative solely of the MDT intervention, or if passage of time also impacted the outcomes reported. Despite these limitations this study advances the field of paediatric chronic pain, especially among an Australian population.

The purpose of this study was threefold: (1) explore the relationship between functional disability, sleep problems, emotional wellbeing and school performance in children and adolescents with chronic pain; (2) assess whether mental health of parents of children or adolescents with chronic pain mediates this relationship; and (3) assess if treatment by an MDT improved the quality of life for children and adolescents with chronic pain. The study found that increased functional disability, increased sleep problems, and reduced emotional wellbeing meant poorer school performance. In addition, it found parent's level of depressive symptoms and amount of self-blame and helplessness they experienced did mediate significantly the relationships between functional disability, sleep problems, and emotional wellbeing, and school performance. Treatment by an MDT was found to be effective in reducing functional disability and increasing emotional wellbeing and school performance. These findings support Hunfield et al.'s (2001) research which found children and adolescents with chronic pain's functional disability reduced their ability to attend school. Further, the findings support Clementi et al.'s

(2020) research which found greater sleep problems in children and adolescents with chronic pain were associated with poorer school performance. Finally, the results are also consistent with Tsao et al.'s (2007) research which found children and adolescents who experienced depression performed worse at school than children and adolescents with chronic pain who were not depressed. Although participants were patients of a city paediatric chronic pain unit, and findings may not be representative of all children and adolescents with chronic pain, the results add to the current understanding of paediatric pain by finding that parental depression and feelings of self-blame and helplessness mediate the relationship between functional disability, sleep problems and emotional wellbeing, and school attendance. These findings indicate that psychological interventions, such as CBT and interpersonal psychotherapy which reduce parents' depressive symptoms and feelings of self-blame and helplessness may improve their children and adolescents with chronic pain school performance. Sleep also significantly impacts children and adolescents with chronic pain school performance, and a more in-depth sleep questionnaire in future research would increase our understanding of this relationship. An increased understanding has the potential to not only improve children and adolescent's current quality of life, but also their future quality of life, as increased school performance improves vocational opportunities and financial independence.

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Appendix A: Omnibus Assessment Questionnaires

YOUNG CHILD REFERRAL QUESTIONNAIRE

Child's name

Today's date

___ / ___ / ___

Section 1 – Your pain

In the following instructions, say "hurt" or "pain", whichever seems right for a particular child

"These faces show how much something can hurt. This face [point to left-most face] shows no pain. The faces show more and more pain [point to each from left to right] up to this one [point to right-most face] – it shows very much pain".

Circle the face that shows your *worst* pain in the **last week**



Circle the face that shows your *least* pain in the **last week**



Circle the face that shows your *usual* pain in the **last week**



Circle the face that shows how much you hurt **right now**



0

2

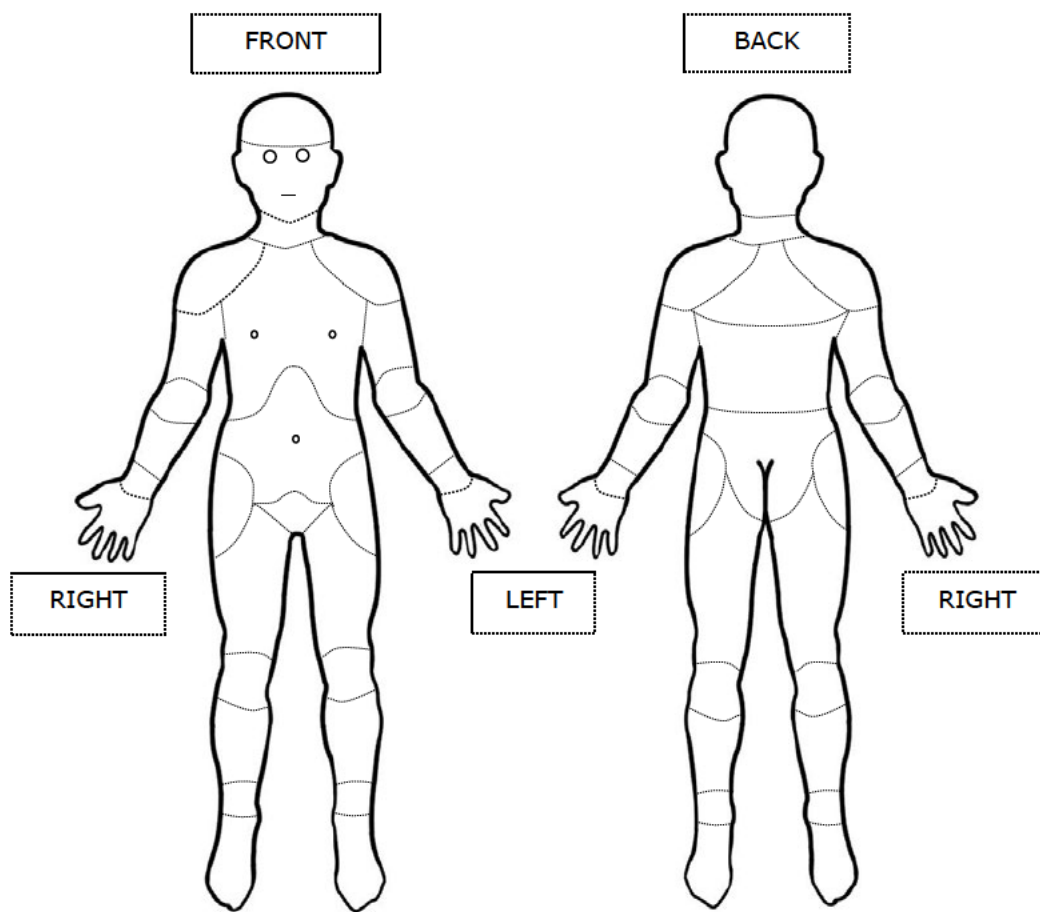
4

6

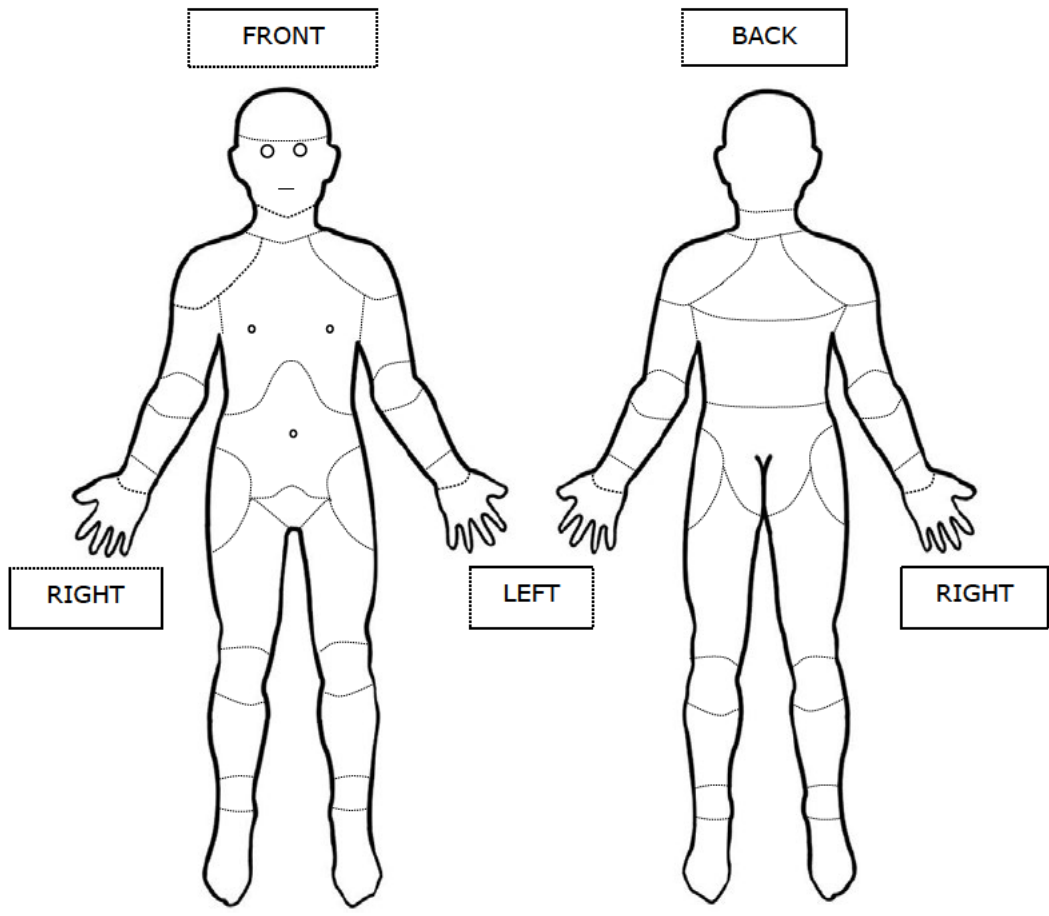
8

10

On the diagram below, shade in ALL the areas where you feel pain



On the diagram below, put an X on the ONE area that hurts most



PedsQL™

Paediatric Quality of Life Inventory

Version 4.0 – English (Australia)

YOUNG CHILD REPORT (ages 5-7)

Instructions for interviewer:

I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these things might be for you.




Show the child the template and point to the responses as you read.

If it is never a problem for you, point to the smiling face

If it is sometimes a problem for you, point to the middle face

If it is almost always a problem for you, point to the frowning face

I will read each question. Point to the pictures to show me how much of a problem it is for you. Let's try a practice one first.

	Never	Sometimes	Almost Always
Is it hard for you to click your fingers ?			

Ask the child to demonstrate clicking his or her fingers to determine whether or not the question was answered correctly. Repeat the question if the child demonstrates a response that is different from his or her action.

Not to be reproduced without permission **Think about how you have been for the last few weeks. Please listen carefully to each sentence and tell me how much of a problem this is for you.**

After reading the item, gesture to the template. If the child hesitates or does not seem to understand how to answer, read the response options while pointing at the faces.

PHYSICAL FUNCTIONING (problems with...)	Never	Some-times	Almost Always
1. Is it hard for you to walk?	0	2	4
2. Is it hard for you to run?	0	2	4
3. Is it hard for you to play sport or do exercise?	0	2	4
4. Is it hard for you to pick up big things?	0	2	4
5. Is it hard for you to have a bath or shower?	0	2	4
6. Is it hard for you to help around the house (like pick up your toys)?	0	2	4
7. Do you get aches and pains? (<i>Where?</i>)	0	2	4
8. Do you ever feel too tired to play?	0	2	4

Remember, tell me how much of a problem this has been for you for the last few weeks.

EMOTIONAL FUNCTIONING (problems with...)	Never	Some-times	Almost Always
1. Do you feel scared?	0	2	4
2. Do you feel sad?	0	2	4
3. Do you feel angry?	0	2	4
4. Do you have trouble sleeping?	0	2	4
5. Do you worry about what will happen to you?	0	2	4

SOCIAL FUNCTIONING (problems with...)	Never	Some-times	Almost Always
1. Is it hard for you to get along with other kids?	0	2	4
2. Do other kids say they do not want to play with you?	0	2	4
3. Do other kids tease you?	0	2	4
4. Can other kids your age do things that you cannot do?	0	2	4
5. Is it hard for you to keep up when you play with other kids?	0	2	4

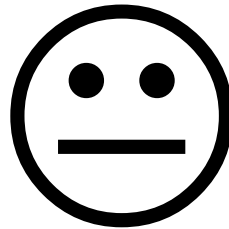
SCHOOL/PRESCHOOL FUNCTIONING (problems with...)	Never	Some-times	Almost Always
1. Is it hard for you to pay attention at school/preschool?	0	2	4
2. Do you forget things?	0	2	4
3. Is it hard to keep up with work at school/preschool	0	2	4
4. Are you away from school/preschool because you feel sick?	0	2	4
5. Are you away from school/preschool because you have to go to the doctor or hospital?	0	2	4

How much of a problem is this for you?

Never



Sometimes



Almost Always



We acknowledge use of the following assessment tools:

- Pain Chart: Childhood Arthritis and Rheumatology Research Alliance, www.carragroup.org von Baeyer CL et al, Pain Management, 2011;1(1):61-68
- Faces Pain Scale – Revised, ©2001, International Association for the Study of Pain www.iasp-pain.org/FPSR
- PedsQL, Copyright© 1998 JW Varni, Ph.D



CHILD REFERRAL QUESTIONNAIRE

Your name

Today's date

__ __ / __ __ / __ __ __ __

Section 1 – Your pain

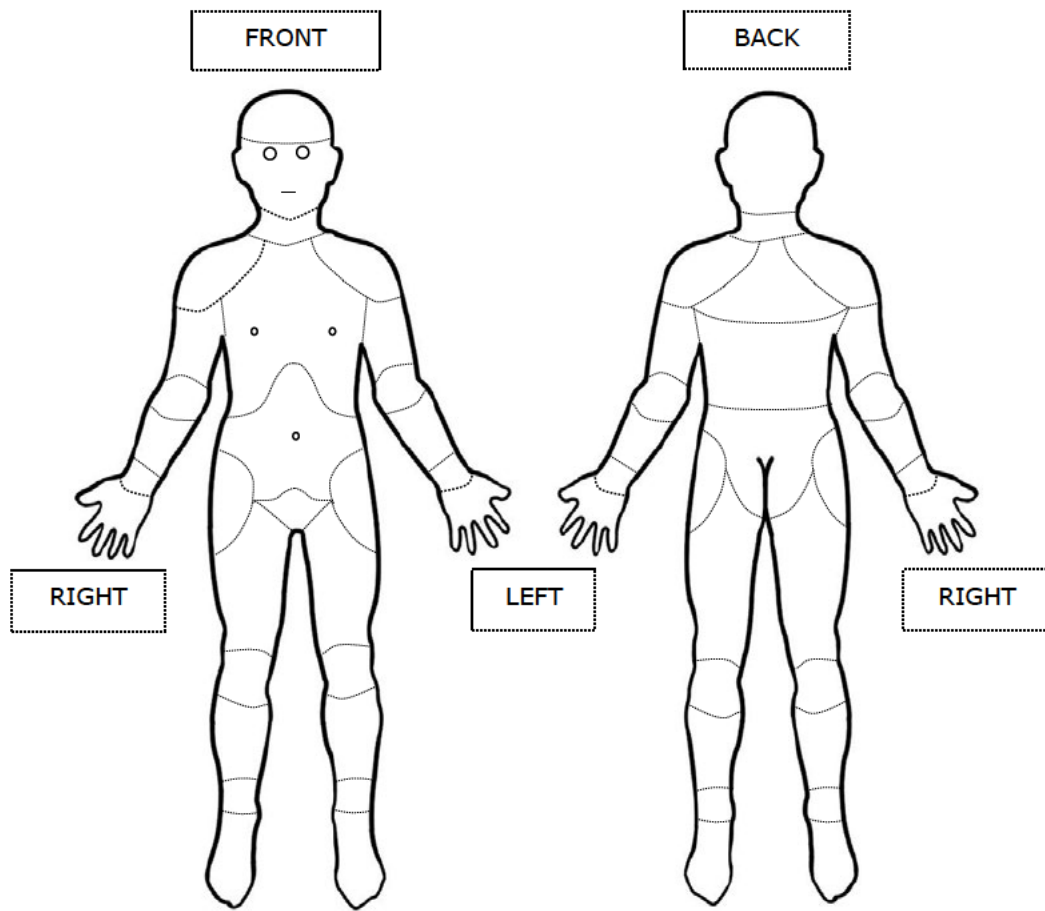
Which statement best describes your pain? (tick **one** box only)

- I always have pain
- I always have pain but the amount changes
- I often have pain
- I sometimes have pain but not all day
- I sometimes have pain but not every day

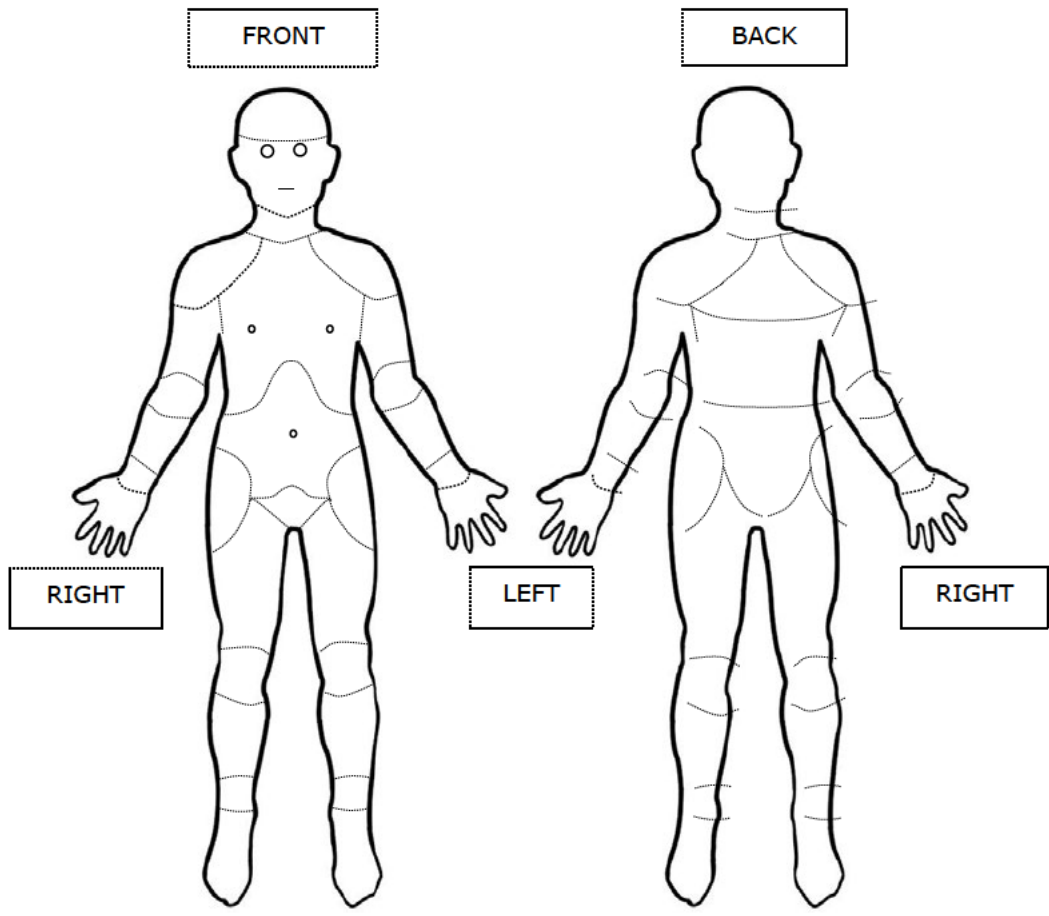
Please rate your pain by circling the **ONE** number that best describes the following:

1. Your worst pain in the last week?	0	1	2	3	4	5	6	7	8	9	10
	No pain										Worst pain ever
2. Your least (smallest) pain in the last week?	0	1	2	3	4	5	6	7	8	9	10
	No pain										Worst pain ever
3. Your usual pain in the last week?	0	1	2	3	4	5	6	7	8	9	10
	No pain										Worst pain ever
4. How much pain do you have right now ?	0	1	2	3	4	5	6	7	8	9	10
	No pain										Worst pain ever

On the diagram below, shade in ALL the areas where you feel pain



On the diagram below, put an X on the ONE area that hurts most



Section 2 – FDI

When people are sick or not feeling well it is sometimes difficult for them to do their regular activities.

In the **past two weeks**, would you have had **any physical trouble or difficulty doing these activities?**

	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 (for example, playing a game)	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
<i>Remember, you are being asked about difficulty due to physical health</i>					
8. Being at school all day	0	1	2	3	4
9. Doing 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. Walking the length of a football field	0	1	2	3	4
13. Running 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

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Paediatric Quality of Life Inventory

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CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you in the **LAST MONTH** by circling:

- 0** If it is **never** a problem
- 1** If it is **almost never** a problem
- 2** If it is **sometimes** a problem
- 3** If it is **often** a problem
- 4** If it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the **LAST MONTH**, how much of a **problem** has this been for you ...

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is difficult for me to walk a few houses from home (about 100 metres)	0	1	2	3	4
2. It is difficult for me to run	0	1	2	3	4
3. It is difficult for me to play sport or do exercise	0	1	2	3	4
4. It is difficult for me to lift something heavy	0	1	2	3	4
5. It is difficult for me to have a bath or shower by myself	0	1	2	3	4
6. It is difficult for me to help around the house	0	1	2	3	4
7. I get aches and pains	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Some- times	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 when I play with other kids	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost Never	Some- times	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 school work	0	1	2	3	4
4. I am away from school because I feel sick	0	1	2	3	4
5. I am away from school to go to the doctor or hospital	0	1	2	3	4

Acknowledgements

We acknowledge use of the following assessment tools:

- Pain Chart: Childhood Arthritis and Rheumatology Research Alliance, www.carragroup.org von Baeyer CL et al, Pain Management, 2011;1(1):61-68
- Modified Brief Pain Inventory questions, reproduced with acknowledgement of the Pain Research Group, the University of Texas MD Anderson Cancer Centre
- Functional Disability Inventory (FDI), Walker and Greene Journal of Pediatric Psychology, 1991;16(1):39-58
- PedsQL, Copyright© 1998 JW Varni, Ph.D



ADOLESCENT REFERRAL QUESTIONNAIRE

Your name

Today's date

__ __ / __ __ / __ __ __ __

Section 1 – Your pain

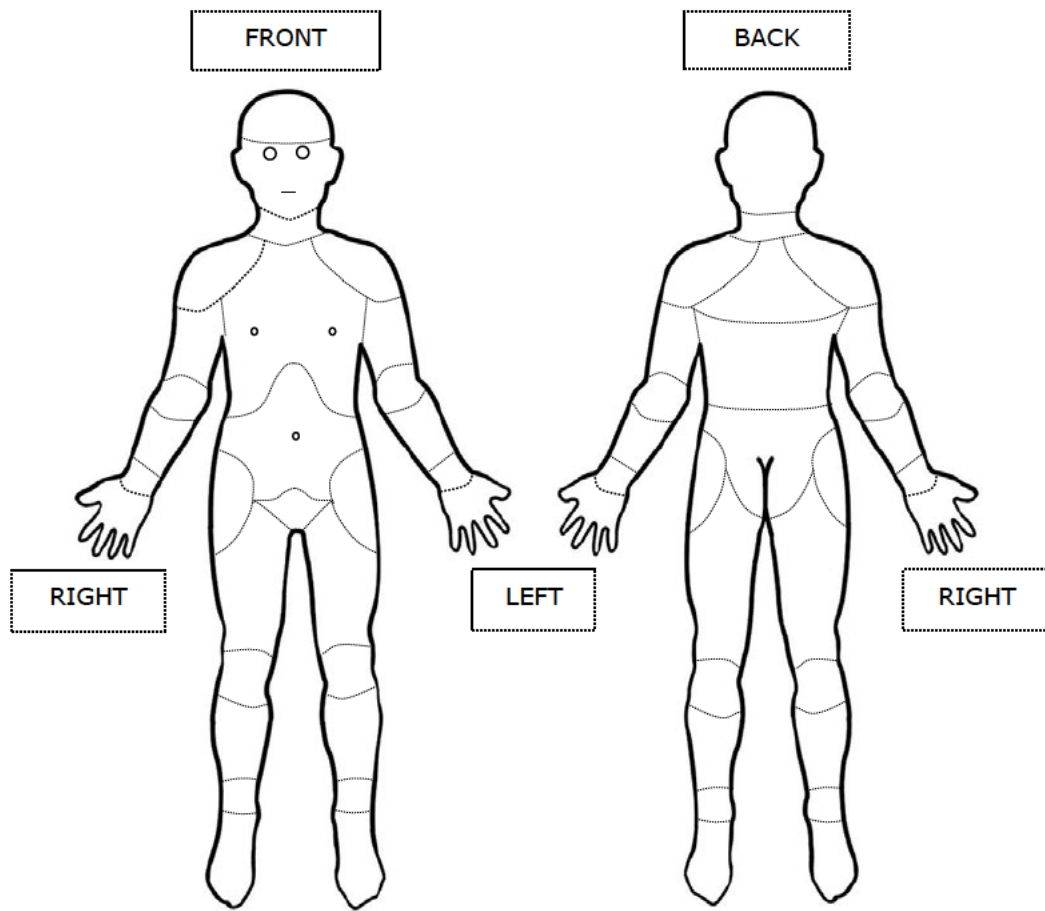
Which statement best describes your pain? (*tick one box only*)

- Always present (always the same intensity)
- Always present (intensity varies)
- Often present (pain free periods last less than 6 hours)
- Occasionally present (pain occurs once to several times per day, lasting up to an hour)
- Rarely present (pain occurs every few days or weeks)

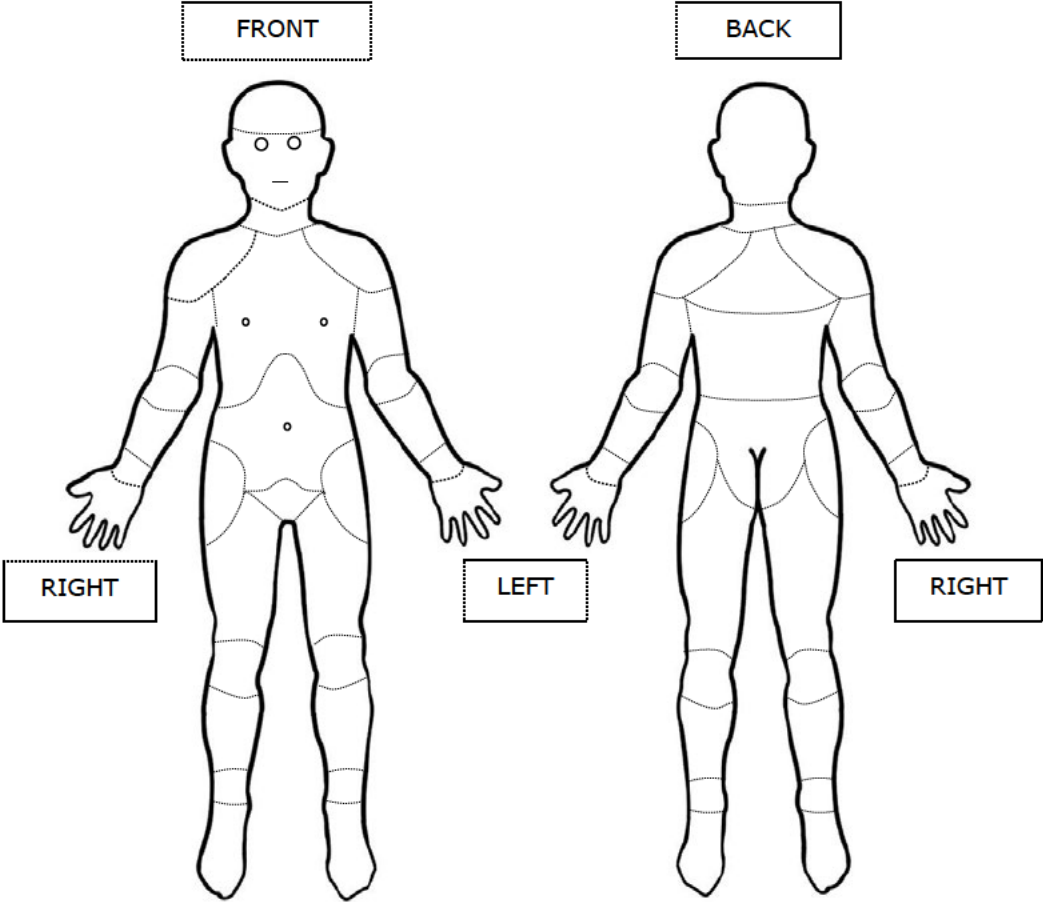
Please rate your pain by circling the ONE number that best describes the following:

1. Your worst pain in the last week?	0 No pain	1	2	3	4	5	6	7	8	9	10 Pain as bad as you can imagine
2. Your least pain in the last week?	0 No pain	1	2	3	4	5	6	7	8	9	10 Pain as bad as you can imagine
3. Your usual pain in the last week?	0 No pain	1	2	3	4	5	6	7	8	9	10 Pain as bad as you can imagine
4. How much pain do you have right now?	0 No pain	1	2	3	4	5	6	7	8	9	10 Pain as bad as you can imagine

On the diagram below, shade in ALL the areas where you feel pain



On the diagram below, put an X on the ONE area that hurts most



Section 2 – BAPQ5

There are many possible ways that pain can affect the lives of young people. Below are some statements that may or may not apply to you. Please read each statement and put a cross in the box (x) under the word that describes how often you have experienced each of these things in the **LAST TWO WEEKS**. Please make sure that you answer all questions.

Please tell us about any specific worries or concerns you have about your pain.

	Never	Hardly ever	Some-times	Often	Always
1. I worry about my pain problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I avoid activities that cause pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. When I think about my pain, it makes me upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Pain scares me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I worry that I will do something to make my pain worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. When I have pain, I think something harmful is happening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I am afraid to move due to pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please continue to the next page

Section 3 – FDI

When people are sick or not feeling well it is sometimes difficult for them to do their regular activities.

In the **past two weeks**, would you have had **any physical trouble or difficulty doing these activities?**

	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 (for example, playing a game)	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
<i>Remember, you are being asked about difficulty due to physical health</i>					
8. Being at school all day	0	1	2	3	4
9. Doing 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. Walking the length of a football field	0	1	2	3	4
13. Running 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

Section 4 – Your Work

Are you currently employed (working for pay)?

- Yes - If yes, are you:
- Working full-time
 - Working part-time/casually

Please answer the questions below



- No - If no, are you:
(tick **one** only, then go straight to the next page)
- Unable to work due to a condition other than pain
 - Unable to work due to pain
 - Not working by choice
 - Seeking employment (I consider myself able to work but cannot find a job)
 - Too young to work

During the past seven days, how many hours did you miss from work because of problems associated with your pain?

(Include hours you missed on sick days, times you went in late, left early, etc. because of your pain. *Do not include time you missed to attend this pain clinic*). hours

During the past seven days, how many hours did you actually work? (If '0' skip the next question and go to the next page)

..... hours

During the past seven days, how much did your pain affect your productivity while you were working?

Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual.

If pain affected your work only a little, choose a low number.
Choose a high number if pain affected your work a great deal.

Consider only how much pain affected productivity while you were working

Pain had no effect on my work

0 1 2 3 4 5 6 7 8 9 10

Pain completely prevented me from working

CIRCLE A NUMBER

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TEENAGER REPORT (ages 13-18)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you in the **LAST MONTH** by circling:

- 0** If it is **never** a problem
- 1** If it is **almost never** a problem
- 2** If it is **sometimes** a problem
- 3** If it is **often** a problem
- 4** If it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the **LAST MONTH**, how much of a **problem** has this been for you ...

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is difficult for me to walk more than 100 metres	0	1	2	3	4
2. It is difficult for me to run	0	1	2	3	4
3. It is difficult for me to play sport or do exercise	0	1	2	3	4
4. It is difficult for me to lift something heavy	0	1	2	3	4
5. It is difficult for me to have a bath or shower by myself	0	1	2	3	4
6. It is difficult for me to help around the house	0	1	2	3	4
7. I get aches and pains	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I have trouble getting along with other teenagers	0	1	2	3	4
2. Other teenagers do not want to be my friend	0	1	2	3	4
3. Other teenagers tease me	0	1	2	3	4
4. I cannot do things that other people my age can do	0	1	2	3	4
5. It is hard to keep up with other teenagers	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost Never	Some- times	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 school work	0	1	2	3	4
4. I am away from school because I feel sick	0	1	2	3	4
5. I am away from school to go to the doctor or hospital	0	1	2	3	4

Acknowledgements

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- Bath Adolescent Pain Questionnaire, Bath Centre for Pain Research
- Functional Disability Inventory (FDI), Walker and Greene Journal of Pediatric Psychology, 1991;16(1):39-58
- Work productivity questions from the Work Productivity and Activity Impairment Questionnaire, Reilly MC, Zbrozek AS & Dukes EM (1993)
- PedsQL, Copyright© 1998 JW Varni, Ph.D

PARENT/CARER REFERRAL QUESTIONNAIRE

Section 1 – Parent/Carer details

Title <input type="checkbox"/> Mr <input type="checkbox"/> Mrs <input type="checkbox"/> Ms <input type="checkbox"/> Miss	Family name (surname)	Given name(s)
Gender <input type="checkbox"/> Male <input type="checkbox"/> Female	Postcode	Today's date (dd/mm/yyyy) _ _ / _ _ / _ _ _ _
Email address		
Relationship to child: <input type="checkbox"/> Parent/Step-parent <input type="checkbox"/> Relative (e.g. grandparent, kinship carer) <input type="checkbox"/> Foster carer <input type="checkbox"/> Other		
Do you require help with written or spoken communication? <input type="checkbox"/> Yes <input type="checkbox"/> No		

Section 2 – Information about your child

Family name (surname)	Given name(s)	Gender <input type="checkbox"/> Male <input type="checkbox"/> Female
Date of birth (dd/mm/yyyy) _ _ / _ _ / _ _ _ _	Height (in cm)	Weight (in kg)
Country of birth <input type="checkbox"/> Australia <input type="checkbox"/> New Zealand <input type="checkbox"/> Other (please specify)		
Is your child of Aboriginal or Torres Strait Islander origin? (more than one may be ticked) <input type="checkbox"/> No <input type="checkbox"/> Yes, Aboriginal <input type="checkbox"/> Yes, Torres Strait Islander		
What is your child's current level of school? <input type="checkbox"/> Preschool <input type="checkbox"/> Primary school <input type="checkbox"/> Secondary school <input type="checkbox"/> Other		
How did your child's main pain begin? (please select one box only) <input type="checkbox"/> Injury <input type="checkbox"/> After surgery <input type="checkbox"/> Illness <input type="checkbox"/> No known cause <input type="checkbox"/> Other		
How long has your child's main pain been present? (Tick one box only) <input type="checkbox"/> Less than 3 months <input type="checkbox"/> 3 to 12 months <input type="checkbox"/> More than 12 months		
Is there a current or potential legal case relating to your child's pain problem? (e.g. Compensation/public liability claim) <input type="checkbox"/> Yes <input type="checkbox"/> No		
Has your child previously attended a specialist pain service at a children's hospital? <input type="checkbox"/> Yes <input type="checkbox"/> No		

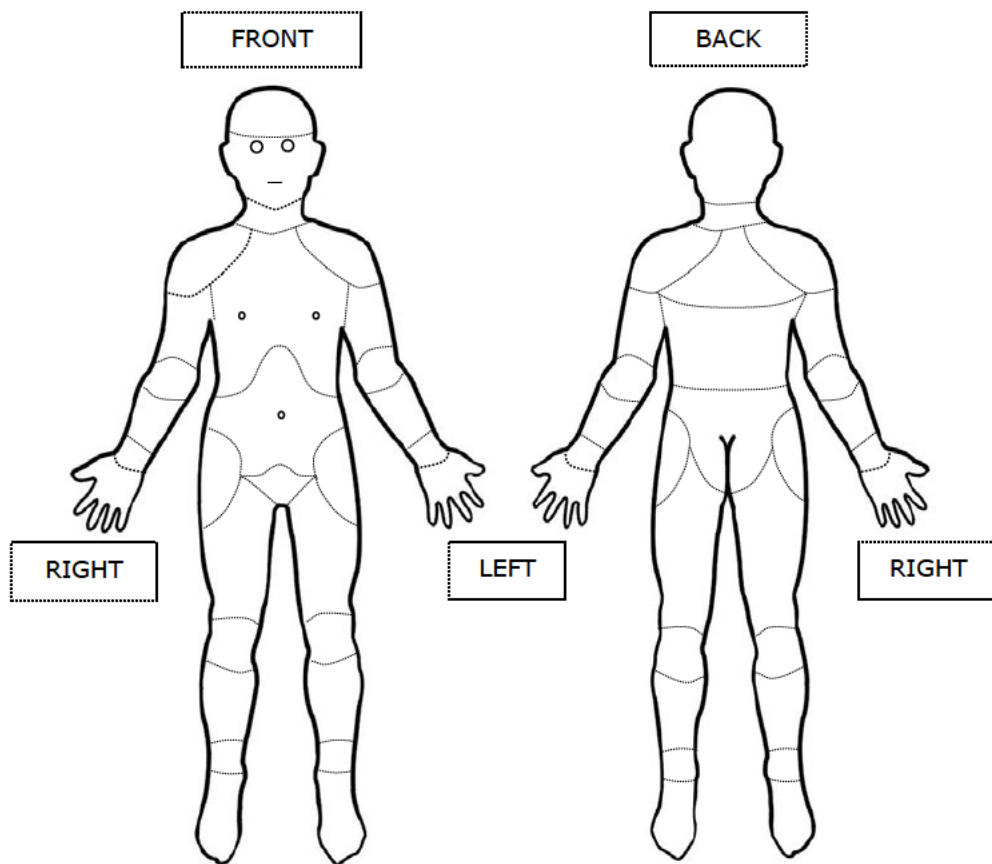
Section 3 – Your child’s pain

Which statement best describes your child’s pain? (*tick one box only*)

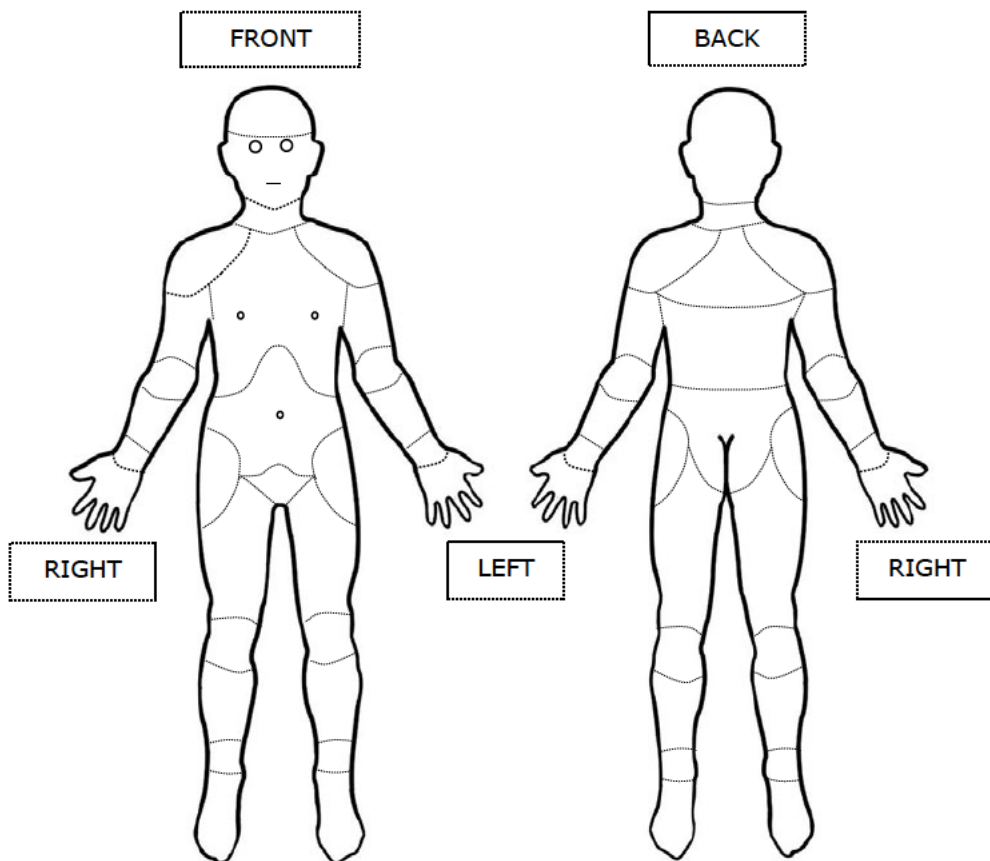
- Always present (always the same intensity)
- Always present (intensity varies)
- Often present (pain free periods last less than 6 hours)
- Occasionally present (pain occurs once to several times per day, lasting up to an hour)
- Rarely present (pain occurs every few days or weeks)

How many school days has your child missed in the previous two weeks because of pain? (*include whole and part days missed because of pain and/or pain-related appointments/treatment*) days

On the diagram below, shade in ALL the areas where your child feels pain



On the diagram below, put an X on the ONE area that hurts most for your child



Please rate your child's pain by circling the ONE number that best describes the following:

1. Your child's pain at its worst in the last week?	0	1	2	3	4	5	6	7	8	9	10	
	No pain										Pain as bad as you can imagine	
2. Your child's pain at its least in the last week?	0	1	2	3	4	5	6	7	8	9	10	
	No pain										Pain as bad as you can imagine	
3. Your child's pain on average ?	0	1	2	3	4	5	6	7	8	9	10	
	No pain										Pain as bad as you can imagine	
4. How much pain your child has right now ?	0	1	2	3	4	5	6	7	8	9	10	
	No pain										Pain as bad as you can imagine	

Section 4 – Health care (other than your child's visits to the pain clinic)

1. How many times in the **past 3 months** has your child seen a general practitioner in regard to pain? times
2. How many times in the **past 3 months** has your child seen a medical specialist (e.g. paediatrician, surgeon) in regard to pain? times
3. How many times in the **past 3 months** has your child seen health professionals other than doctors (e.g. physiotherapist, psychologist) in regard to pain? times
4. How many times in the **past 3 months** has your child seen other therapists (e.g. naturopath, chiropractor) in regard to pain? times
5. How many times in the **past 3 months** has your child visited a hospital emergency department in regard to pain? *(Include all visits, regardless of whether or not your child was admitted to the hospital from the emergency department)* times
6. How many times in the **past 3 months** has your child been admitted to hospital as an inpatient because of pain? times
7. How many diagnostic tests (e.g. X-rays, scans) has your child had in the **last 3 months** relating to their pain? tests

Section 5 – Medication use

How often has your child used any of the following medicines for pain in the last month ?	Daily	Often	Some-times	Rarely	Never
Paracetamol-only medicines e.g. Panadol®, Panamax®, Panadol® Osteo, Paracetamol suspension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anti-inflammatory medicines purchased without a prescription e.g. Ibuprofen, Nurofen®, Naprogesic®, Naprosyn®, Voltaren®	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anti-inflammatory medicines needing a prescription e.g. Celebrex®, Celecoxib capsules	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary or alternative medicines e.g. herbal or homeopathic medicines, non-prescribed vitamins, fish oil	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opioid medicines containing Codeine e.g. Panadeine®, Pain Stop®, Nurofen Plus®, Mersyndol®, Panadeine Forte®, Codalgin Forte®	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opioid medicines other than Codeine e.g. Morphine, Oxycodone, Endone®	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medication for nerve pain e.g. Amitriptyline, Endep®, Nortriptyline, Gabapentin, Pregabalin, Neurontin®, Lyrica®	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please continue to the next page

We acknowledge the use of the following questions and assessment tools

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- Work productivity questions from the Work Productivity and Activity Impairment Questionnaire, Reilly MC, Zbrozek AS & Dukes EM (1993)
- PedsQL, Copyright© 1998 JW Varni, Ph.D

Section 6 – Parent/Carer Work

Are you currently employed (working for pay)?

Yes - If yes, are you:

Working full-time

Working part-time

Please answer the questions below



No - If no, are you:

*(tick **one** only, then go straight to the next page)*

Unable to work due to reasons associated with your child's pain

Not working by choice (student, retired, homemaker)

Seeking employment (I consider myself able to work but cannot find a job)

During the past seven days, how many hours did you miss from work because of problems associated with your child's pain?

(Include hours you missed on sick days, times you went in late, left early, etc. because of your child's pain. Do not include time you missed to attend this pain clinic.)

..... hours

During the past seven days, how many hours did you actually work? *(If '0' skip the next question and go to the next page)*

..... hours

During the past seven days, how much did your child's pain affect your productivity while you were working?

Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual.

If your child's pain affected your work only a little, choose a low number.

Choose a high number if your child's pain affected your work a great deal.

Consider only how much your child's pain affected your productivity while you were working

My child's pain had no effect on my work

0 1 2 3 4 5 6 7 8 9
10

My child's pain completely prevented me from working

CIRCLE A NUMBER



PedsQL™

Paediatric Quality of Life Inventory

Version 4.0 – English (Australia)

PARENT REPORT for YOUNG CHILDREN (ages 5-7)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**.

Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0** If it is **never** a problem
- 1** If it is **almost never** a problem
- 2** If it is **sometimes** a problem
- 3** If it is **often** a problem
- 4** If it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with ...

PHYSICAL FUNCTIONING (problems with ...)	Never	Almost Never	Sometimes	Often	Almost Always
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores, like picking up his or her toys	0	1	2	3	4
7. Having aches or pains	0	1	2	3	4
8. Having a low energy level	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with ...)	Never	Almost Never	Sometimes	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Having trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

SOCIAL FUNCTIONING (problems with ...)	Never	Almost Never	Sometimes	Often	Almost Always
1. Getting along with other children	0	1	2	3	4
2. Other children not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not being able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

SCHOOL FUNCTIONING (<i>problems with ...</i>)	Never	Almost Never	Some- times	Often	Almost Always
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with schoolwork	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

Appendix B: Parent/Carer Impact Questionnaire



Government of South Australia
SA Health

PARENT/CARER IMPACT QUESTIONNAIRE

Parent/Carer details

Title <input type="checkbox"/> Mr <input type="checkbox"/> Mrs <input type="checkbox"/> Ms <input type="checkbox"/> Miss	Family name (<i>surname</i>)	Given name(s)
Gender <input type="checkbox"/> Male <input type="checkbox"/> Female	Postcode	Today's date (<i>d/m/y</i>) _ _ / _ _ / _ _ _ _
Email address		

This questionnaire asks about different ways in which caring for a young person with pain affects your life. There are no right or wrong answers, but please try to be as accurate as possible. Please read each question carefully. Do not spend too much time on any one question as your first answer is usually the most accurate. It is extremely important that you answer all the questions, even if some of them may not seem relevant to you.

BAP-Parent Impact Questionnaire

There are many ways in which caring for a young person with pain can affect people's lives. Below are some statements that may or may not apply to you. Please read each statement and put a cross in the box (x) under the word that describes how often you have experienced each of these things in the **LAST TWO WEEKS**. Please make sure that you answer all questions.

Section One

Please tell us about feelings and experiences you have encountered.

In the last two weeks living with my child in pain I have:	Never	Hardly ever	Sometimes	Often	Always
1. felt sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. had difficulty falling asleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. been satisfied with my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. had little appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. felt hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. had difficulty making decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. made an effort with my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. felt worthless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. avoided activities I usually enjoy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section Two

Please tell us about worries or concerns you may have experienced.

In the last two weeks living with my child in pain I have:	Never	Hardly ever	Sometimes	Often	Always
1. not been able to get my mind off my worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. felt shaky	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. found that my mind wandered easily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. felt tense	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. felt anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. been bothered by feelings of panic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section Three

Please tell us about any feelings or thoughts you have experienced.

In the last two weeks living with my child in pain I have:	Never	Hardly ever	Sometimes	Often	Always
1. thought my child's pain would get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. thought that my child will have difficulty being independent in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. been concerned that my child will always experience pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. thought that my child's pain my lead to something more serious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. been unable to think of anything other than my child's pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section Four

Please tell us about worries or concerns you have experienced.

In the last two weeks living with my child in pain I have:	Never	Hardly ever	Some-times	Often	Always
1. thought that I had failed my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. blamed myself for my child's situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. felt powerless to help my child's pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. not been able to accept that there is no cure for my child's pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. felt guilty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. believed that my child's pain is out of control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. found it difficult to tolerate my child's suffering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section Five

In this section, please tell us about your relationship with your partner/spouse. By partner we mean someone that you feel close to and who has regular contact with both you and your child, such as your husband, wife, boyfriend or girlfriend.

If you do not have a partner, please put a cross (x) in the box below and go straight to **Section Six**.

I have no partner/spouse

In the last two weeks living with my child in pain I have:	Never	Hardly ever	Some-times	Often	Always
1. done fun activities with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. thought that my partner understood my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. felt that my partner supported me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. felt that our physical relationship was strained	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. made time to spend with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. discussed things with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. felt distant from my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section Six

Please tell us about your social life and leisure time.

In the last two weeks living with my child in pain I have:	Never	Hardly ever	Some-times	Often	Always
1. spent time with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. had little time for socialising	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. felt supported by friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. cut back on my usual leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. spent time talking to people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. had an interest in pursuing hobbies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. found it difficult to do leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. spent time doing activities that I enjoy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section Seven

Please tell us about feelings or thoughts you may have experienced, or other things you may have done when your child was in pain.

In the last two weeks living with my child in pain I have:	Never	Hardly ever	Some-times	Often	Always
1. helped my child to avoid pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. made things as easy as possible for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. thought that my child should avoid activities that might cause more pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. believed that my child needed my help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. participated in an activity with my child regardless of his/her pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. suggested that my child got on with an activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. been concerned with my child's level of pain when planning activities for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. suggested that my child rests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. done whatever I could to reduce my child's pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. believed that my child should do activities regardless of pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. thought that it was okay for my child to have some pain when they were doing something important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section Eight					
Please tell us about your relationship with your child who experiences pain.					
In the last two weeks living with my child in pain I have:	Never	Hardly ever	Some-times	Often	Always
1. felt that my child was dependent on me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. enjoyed being the parent of my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. found it difficult to be patient with my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. felt close to my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. shown my child affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. felt that my relationship with my child was strained	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. found my relationship with my child difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. felt loving towards my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. felt irritated by my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>