The assessment and management of chronic pain in children and adolescents: an overview of selected literature

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Executive Summary

Background
The ACC has expressed an interest in developing a multidisciplinary pain management service for children under the age of 18 years, to be administered on either an inpatient, semi-residential or outpatient basis. The aim of this report is to provide an international overview of published information on multidisciplinary management programmes and services for children and adolescents living with chronic pain. Selected, recent peer reviewed and non-peer reviewed literature is examined and summaries of key publications provided.

Methods
Eight key questions were identified by the ACC to guide the overview. These questions focused on (a) the identification of programmes and services, their sponsors, content, referral procedures/criteria and evidence of effectiveness, (b) screening tools for early identification of cases and (c) assessment tools for paediatric chronic pain. A systematic search of the scientific and “grey” literature was carried out prior to the preparation of this overview using the key questions to focus the search. 1126 potentially relevant publications were identified; 63 scientific articles, reports and websites were selected for review. A further 46 publications of various types were added as a result of hand searching and cross-referencing.

General characteristics of the literature
Most publications focused on pain management/therapeutic intervention (n=124), pain in adolescents (n=76) and pain assessment/measurement (n=25). Fewer focused on the validation of assessment measures (n=12), specific services or programmes (n=10), pharmacological interventions (n=9), effectiveness (n=8), or gender issues (n=6); only 3 publications focused on early referral.

Paediatric chronic pain programmes and services
Eleven individual programmes/services from Australia, Canada, Europe, UK, USA and Jordan provided sufficient information to be included in the overview. Programmes were generally guided by an explicit theoretical model with similar goals which included a desire to (a) improve patients' understanding of their situation, (b) improve their level of physical functioning, (c) modify perceived level of pain and suffering, (d) provide coping strategies for dealing with disability and distress, (e) promote self-management and (f) reduce or modify their future use of healthcare service.

Patient referral and service providers
Referral patterns were generally similar and usually comprised a referral letter from a physician or nurse practitioner outlining a brief medical history, current issues and how the service/programme may help. In one or two cases it appeared that patients could refer themselves for evaluation directly by calling one of the clinic nurses. The services reported in the literature were provided by children’s hospitals/children’s health care organisations, a National Health Service, charitable trust or university pain centre.

Programme and services content
Collectively, the literature suggested that (a) an interdisciplinary approach was an imperative for the management of chronic pain, (b) the ideal multidisciplinary pain clinic should provide
at a minimum, medical specialists, extensive diagnostic, therapeutic and rehabilitative services and (c) that it should also include the services of (most of) anaesthesiologists, nurses, physiotherapists, occupational therapists, psychologists, social workers, psychiatrists, physiatrists and administrative staff. Well developed programmes also included research and education components in addition to clinical services. A multidisciplinary team evaluation (with at minimum a medical doctor/primary clinician, a psychologist and a physiotherapist/physical therapist) of the patient was undertaken upon referral. Large or specialist programmes/services often included a number of other services/interviews with, for example, a social work/family therapist, occupational therapist or child life specialist. The assessment structure, treatment planning and follow-up varied considerably across the centres depending on (a) the theoretical model underpinning the service and (b) the nature of the patient population. Services providing palliative care and end of life services to cancer and terminally ill patients tended to offer a wider range of pharmacological interventions.

Service evaluation
Although there were a large number of publications evaluating specific interventions there were comparatively few evaluations of whole services or programmes.

Chronic pain screening tools
No published studies were identified that reported the development or use of screening tools that would allow clients to be identified early and before the pain became chronic. A brief overview of studies that explored the prerequisites for the development of chronic pain or its prevention was presented, since these are likely to form the basis for the development of early screening tools. A number of parental and patient characteristics were identified as risk factors for chronic pain which included the child’s psychological characteristics, the parent’s psychological characteristics, and characteristics of pain management such as an excessive use of health care services.

Paediatric chronic pain assessment tools
Research into the assessment of paediatric has generated a large amount of literature describing and assessing a variety of instruments. However, few have undergone a rigorous assessment (i.e. are valid and reliable) or are appropriate for different cultures and languages. Inconsistent use in different studies makes comparisons difficult. Four systematic reviews of published pediatric pain measures carried out between 2005 and 2009. Each identified 6-12 measures for detailed assessment/review in the context of chronic pain assessment, and between them identified 13 tools of potential value. Following the publication of these reviews a consensus statement recommended 10 tools for the assessment of pain outcomes in this population. These tools assessed pain intensity, physical functioning, emotional functioning and role functioning; no tool was recommended for the assessment of sleep pattern, however, a sleep questionnaire was considered to be potentially “helpful”.

Summary
This overview provides a guide to the more recent literature pertaining to programmes, services and assessment tools for the management of chronic pain in children and adolescents. The literature described has not been critically appraised and individual treatment modalities and management of particular types of chronic pain are not included. To

1 In the hospital situation this may be a paediatrician, pain specialist or anaesthetist
address these shortcomings a systematic review of the literature using more narrowly focused research questions would be required.
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<tr>
<td>ACC</td>
<td>Accident Compensation Corporation</td>
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<td>HSAC</td>
<td>Health Services Assessment Collaboration</td>
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<td>IMMPACT</td>
<td>Pediatric Initiative on Methods, Measurement and Pain Assessment</td>
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<td>NHS</td>
<td>National Health Service</td>
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<td>VAS</td>
<td>Visual Analogue Scale</td>
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Introduction

Background
The New Zealand Accident Compensation Corporation (ACC) requested an overview of published information on international multidisciplinary pain management services for children and adolescents. Specifically, they noted that they were interested in developing a multidisciplinary pain management service for children under the age of 18 years to be administered on either an inpatient, semi-residential or outpatient basis. The aim of the service would be to rehabilitate children and adolescents with chronic/persistent pain of cancer and/or non-cancer origin. ACC considered chronic/persistent pain to be pain that lasted for more than 12 weeks. Although ACC indicated an interest in literature reporting on pain that has resulted from trauma (and more likely to be covered by ACC) and non-cancer pain, it was acknowledged that literature of interest may exist for the management of other conditions. The ACC indicated that they were interested in outcomes which may inform the development of a service/contract model for these clients. Outcomes from pain management of interest were pain reduction treatments (other than drugs); functional improvement; impairment, schooling and social and or work preparation/participation.

Characteristics of the report
This report provides an overview of selected peer reviewed and “grey” (i.e. non-peer reviewed) literature. Summaries of key publications are provided, but no formal quality appraisal of the literature has been undertaken. Since ACC’s purpose in commissioning the report was to inform the development of a multidisciplinary pediatric pain service, the report has focused on recent and current literature (2005-2008).

Eligibility criteria
Consistent with the broad aims of the report, eligibility criteria were broad. To be considered publications were required to have a pediatric pain focus and report (in English) on pain management centres and their services or pediatric pain assessment tools in a clinical context.

Chronic pain definitions
Chronic pain is usually defined as pain that lasts longer than 3 months (Dangel, 2005). However, studies vary in the definition of chronic pain (Apkarian et al., 2009). The standard definition of chronic pain endorsed by the International Association for the Study of Pain defines chronic pain as “pain that persists past the healing phase following an injury”(Merskey & Bogduk, 1994). Determining the end of the healing phase is difficult and varies for different conditions e.g. for chronic back pain the usual time is 6 months, whereas in post-herpetic neuralgia it is 3 months. Given this variation, the approach taken in this overview has been to consider all relevant literature pertaining to “chronic” regardless of definition.

2 http://www.iasp-pain.org
**Key questions**

The key questions posed by the ACC to guide this overview were:

**For pain services:**

1. Describe programmes and services reported in the literature.
2. What are the criteria for referral to these programmes?
3. How are clients referred?
4. Who provides the services?
5. What is the content of these programmes?
6. Does research support good outcomes following these programmes?

**For pain assessment tools:**

1. Are there specific screening tools available/published for these groups that would allow these clients to be identified early (i.e. < 12 weeks) before the problem becomes chronic and more difficult to treat?
2. What tools have been shown to be useful for children?
Methods

Literature search and scoping
A systematic search of the literature was carried out prior to the preparation of this overview\(^3\). The publications identified by the search were the primary source of information for this overview. The searches were limited to articles published from 1998 and there were no language restrictions. Preliminary-search investigations conducted in EMBASE.com revealed a substantial number of records on this topic:

- 870 published papers were retrieved from the EMBASE and MEDLINE databases related to **pain management services** for children and adolescents.
- 240 published papers were retrieved from the EMBASE and MEDLINE databases related to **pain assessment tools** used in children and adolescents.
- 292 published papers were retrieved from The Cochrane Library, of which 95 related to pain measurement.

A search of the “grey” literature from relevant websites identified additional documents, pain assessment tools and pain service organisations as well as some scholarly articles. Twenty key **pain services** documents were identified in the search of web-based resources and 11 relating to pain assessment. Twelve pain organisation websites were also identified (the web-addresses appear as footnotes when cited in the text). Overall, 1126 publications were identified as potentially relevant to this overview.

Selection of publications
The titles and abstracts of all articles were scanned and 297 potentially relevant papers shortlisted for closer examination; more than half (n=154) of these were published in the last four years. Because of the large number of potentially relevant publications and the need for a reasonably current perspective, it was decided to limit the initial assessment to information published between 2005 and 2008. The full texts of all relevant papers published during the period were obtained and analysed for information relating to the eight research questions (see page 2). Earlier papers were then scanned for any relevant publications/studies.

After the exclusion of one non-English publication, 63 papers were retrieved in full-text to provide information for this overview. A further 46 publications were added to this library during the course of the study as a result of hand searching and cross-referencing. All publications and electronic resources/websites identified in the “grey” literature search were examined for relevant information.

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The assessment and management of chronic pain in children and adolescents: an overview of selected literature
The Literature

The search identified 1126 publications which were potentially relevant to this overview. 297 were shortlisted as potentially relevant to this overview. A number of ‘themes’ were apparent from an examination of these publications including:

- pain management/therapeutic intervention (n=124)
- pain in adolescents (n=76)
- pain assessment/measurement (n=25)

A large proportion of publications focused on a particular type of pain/injury including:

- cancer pain (n=18)
- headache/migraine (n=15)
- chronic pain syndrome/fibromyalgia (n=13)
- sickle cell disease (n=10)
- abdominal pain (n=11)
- juvenile arthritis (n=9)
- burn injury (n=5)
- sport pain/injury (n=3)

Twelve publications focused on the validation of assessment measures, 10 on specific services or multidisciplinary programmes, 9 on pharmacological interventions, 8 on effectiveness, 6 on gender issues; only 3 publications focused on early referral.
The assessment and management of chronic pain in children and adolescents: an overview of selected literature
Describe programmes and services reported in the literature

Seven relevant peer reviewed publications that described existing programmes and services were identified for the period 2005-2008 (De Blecourt, Preuper, Van Der Schans, Groothoff, & Reneman, 2008; Finley et al., 2008; Friedrichsdorf, Remke, Symalla, Gibbon, & Chrastek, 2007; Kozlowska et al., 2008; Munro, 2003; Peng et al., 2007; Vetter, 2008) and 20 documents and 12 pain services websites were identified in the grey literature search. These sources varied in the amount of information given about the service/programme, their relevance to chronic pediatric pain and the quality and purpose of the reporting. For example, a high proportion of publications focused on individual aspects of the treatment provided rather than the service or programme as a whole. Only publications/websites focusing on and providing a useful amount of information on specific pediatric chronic pain programmes or services are reported below. Services are listed according to country/geographic region.

Australia

Chronic Pain Management Clinic Royal Children’s Hospital, Melbourne

This tertiary pediatric referral centre was established in 1998 (Chalkiadis, 2001). It comprises a multidisciplinary chronic pain management team which meets weekly to assess new children and adolescents with chronic pain and to review current patients. An outpatient approach is preferred, with an emphasis on return to school and normal function. There is an initial structured interview with the child and parents to obtain information about pain, functioning and sleep patterns. Patients are assessed by one of three pediatric anaesthetists and one or more allied health professional (physiotherapist, occupational therapist or clinical psychologist). Cognitive behavioural approaches are often employed in conjunction with analgesic techniques including acupuncture, occupational therapy and physiotherapy. Follow-up duration and frequency are as clinically indicated.


In 2004, a unique programme brought together eight high volume cancer hospitals to take part in the first pain management improvement programme in Australia. The pilot programme involved multidisciplinary teams working together to improve the day-to-day assessment and management of pain, beginning with a focus on cancer services. The programme had three main objectives:

- to improve the day-to-day identification and management of pain in hospitals.
- to integrate effective routine pain management into the core business of hospitals.
- to capture and disseminate the lessons learned about improving routine pain management from the eight hospital pilot project.

Each hospital formed pain management improvement teams. These included various combinations of medical and nursing staff from pain, palliative care and oncology departments, along with pharmacists, quality unit staff and overarching executive support. Three, two-day workshops for the teams during 2004 focused on existing evidence for improving routine pain management practices, generic improvement methods and sharing of experiences among the hospitals.

Canada

The Pain Management Centre Columbia University⁵ (director William Schechter)
This centre has a pediatric pain management programme for acute and chronic pain with a specialised team of physicians and nurses who work in consultation with child life specialists⁶, psychologists, psychiatrists and physical and occupational therapists to provide a comprehensive and multidisciplinary approach to pain management. A wide range of techniques are used to treat inpatients including, opioids infusions, patient controlled analgesia, epidural analgesics, regional nerve blocks, acupuncture, hypnosis, meditation, guided imagery and cognitive and behavioural therapies. An outpatient Pediatric Pain Centre provides consultation and treatment services for chronic pain syndromes afflicting children with chronic cancer related pain, recurrent abdominal pain, complex regional pain syndromes and neuropathies. It also provides a service for pain associated with sickle cell disease, arthritis and the autoimmune disorders, cystic fibrosis, sports related pain, HIV/aids related pain, head and oro-facial pain and palliative care.

Europe (excluding the UK)

An in-patient multidisciplinary pain management programme for children and adolescents with disabling chronic musculoskeletal pain at the University of Groningen Centre for Rehabilitation.

De Blecourt et al. (2008) described a programme carried out during a 3 month in-patient stay in the rehabilitation centre. The programme was described as “a cognitively-behaviourally orientated activity programme based on operant therapy; positive behaviour is stimulated and reinforced and negative behaviour is ignored”. The aim of the programme was to improve the child’s daily functioning on the level of activities and participation of the International Classification of Functioning Disability and Health⁷.

United Kingdom

The Bath Centre for Pain Services, U.K.⁸ (director Christopher Eccleston)

The Bath Centre is one of the most famous and most quoted pain services in the international literature. This national referral centre for pain services was opened in 1994. A number of different programmes and services are described in the literature including:

- **The adolescent programme.** Launched in 1999. This three week, residential adolescent programme was the first of its kind in Europe. The programme aims to help children aged 11-18 years with complex pain conditions to become less disabled and manage important aspects of their lives more successfully. The focus is on increasing function and returning to age-appropriate activity such as school and social activities. The course is group based with six adolescents per programme. Each adolescent is accompanied by an adult, most often a parent, who also takes part in the sessions. Adolescents and adults stay in flats close to the hospital or in local hotel accommodation.

- **The young adult programme.** Launched in 2006, this programme was the first in the UK designed to meet the specific needs of the 18-30 year age group. This three-week residential programme is specifically tailored for those who are finding it difficult to

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⁵ http://cpmcnet.columbia.edu/dept/anesthesiology/pain/pediatric.html
⁶ http://www.childlife.org/
⁷ http://www.who.int/classifications/icf/training/icfchecklist.pdf
⁸ http://www.bathcentreforpainservices.nhs.uk/
make or sustain the transition to independent living because of chronic pain. The programme focuses on issues such as work, education, leaving home and relationships. Young adults stay in nearby flats and a parent, partner or significant other is encouraged to attend for the first week.

- **The intensive individualised pre-programme rehabilitation programme.** This programme is designed to help treat highly disabled patients who may be bed bound. Staff work intensively with the patient to begin reducing their medication, improving their psychological readiness and increasing their fitness, so that they become ready to manage one of the other Bath Centre residential programmes.

- **The outreach assessment service.** Available in exceptional cases, this programme is for those patients who are unable to attend an assessment in Bath. There is also a consultancy which works in an outreach capacity service to help other teams treat complex pain patients.

An interdisciplinary team of health care professionals service the various programmes. The team comprises a number of professional groups which include 3 part-time doctors, 5 clinical psychologists, and a number of physiotherapists, occupational therapists, nurses and an administration team.

**A “care pathway” for children in pain in poorly resourced areas of South West England**

In response to access to service issues for children in pain in poorly resourced areas of South West England, Connell, Clinch and Brook (2008) discussed the development of a cost-effective service delivering appropriate level of care to children when they need it. A “care pathway” was reported that directed children to an appropriate service and provided routes to medical management, physiotherapy, transcutaneous electrical nerve stimulation (TENS), psychological intervention and a residential pain management programme. The model is designed to ensure that children access the most appropriate level of service quickly to prevent escalation of pain and disability.

**USA**

**Pediatric Advanced Care Team, Children’s Hospital Boston** (director Joanne Wolfe)

The Pediatric Advanced Care Team at the Boston Children’s Hospital provide a chronic pain management clinic with both inpatient and outpatients services. Treatments and services are intended to optimise the quality of life, promote healing and comfort for children with life-threatening illness and optimise pain and symptom management. The team advocate family and health care provider communication, and coordinate inpatient, outpatient and home care. The team includes two doctors, a nurse, a social worker and a coordinator. Team members consult with patients, families and the primary care team to bring together the information and guidance needed to make the right treatment choices for the child. Two services were described:

- **The Outpatient Chronic Pain Management Clinic.** The clinic offers multidisciplinary treatment for children and adolescents with a variety of pain problems, including headaches, reflex sympathetic dystrophy, fibromyalgia, low back pain, and patellofemoral syndrome. In addition to receiving care by anaesthesiologists, all patients seen in this clinic are evaluated by a psychologist who specialises in pain management through behavioural medicine, and by a physical

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9 http://www.childrenshospital.org/clinicalservices/Site1854/mainpageS1854P0.html
therapist. Closely associated with the clinic are specialists in orthopaedic surgery, rheumatology, neurology, neurosurgery and psychopharmacology, who are consulted on an individual basis.

- **The Mayo Family Pediatric Pain Rehabilitation Centre (PPRC).** The PPRC offers an intensive in-patient rehabilitation programme for children and adolescents with chronic musculoskeletal and neuropathic pain who have not responded to traditional outpatient treatment. The PPRC is the most comprehensive stand-alone day hospital programme of its kind in the United States. Programme participants are typically between 7 and 18 years old.

**University of California at Los Angeles School of Medicine Pediatric Pain Programme**

The work of the pediatric pain team is guided by a theoretical model which is biological/physical in nature and influenced by the thoughts, emotions, behaviours, skills, and cognitive processing of the patient. The Pediatric Pain Programme is an interdisciplinary programme that treats acute, chronic and debilitating pain in children and includes research, clinical service, and education. It is based within a mind-body framework (biopsychosocial model) that takes into account the complex interaction between physiology, emotions, cognitions, and the environment in all aspects of clinical evaluation and treatment as well as in research. Often, the children treated by the Pediatric Pain Programme are considered medically complicated or difficult to treat, mainly because paediatricians or subspecialists have been unsuccessful in their treatment effort. Patients treated in the programme initially present a variety of symptoms, including headaches, recurrent abdominal pain, chest pain, back pain, fibromyalgia, limb pain and regional sympathetic dystrophy. The programme is led by a medical doctor and a medical psychologist and integrates a variety of other healing disciplines into the team including acupuncture, biofeedback, hypnotherapy, yoga, art therapy, massage therapy, movement therapy and physical therapy.

**An interdisciplinary outpatient pain clinic at the Children's Hospitals and Clinics of Minnesota USA**

Friedrichsdorf et al. (2007) described the development of an interdisciplinary hospital based outpatient pain clinic which was part of a combined pain and palliative care programme. The clinic was established in 2006 to provide a comprehensive evaluation and treatment follow-up for children and their families. The service aims were to control acute, chronic and recurrent pain in all in- and outpatients at the hospitals with follow-up at home. The model provided a continuum of care from acute, chronic or recurrent pain to palliative and hospice care. The most common conditions treated were complex regional pain syndrome type 1, musculoskeletal pain, sickle cell disease, avascular necrosis, chronic tension-type headache, migraine and progressive neurodegenerative/metabolic conditions. The interdisciplinary pain team comprised a clinic nurse co-coordinator, social worker family therapist, physical therapist, pediatric psychologist and pediatric/pain specialist.

10 http://www2.healthcare.ucla.edu/pedspain/clinical.htm
11 http://www.childrensmn.org/web/hospice/128726.pdf
12 http://www.childrensmn.org/web/hospice/182462.pdf
Pain and Palliative Care service, Children's Clinics and Hospitals of Minnesota\(^{13}\) (director Timothy Culbert)

The programme includes both inpatient and outpatient services. The team includes physicians, nurses, pharmacists, psychologists, child life specialists, integrative medicine staff and social workers. Four chronic pain services were reported:

1. **Inpatient Pain and Palliative Care Team**: an inpatient rounding team providing care to children with acute pain, chronic pain and palliative care needs.
2. **Pain and Palliative Care Clinic**: an intradisciplinary pain clinic managing chronic and recurrent pain in close collaboration with pediatric specialties.
3. **Home-based Karuna Palliative Care**: programme staff work with a child’s physicians to provide pain and symptom management to children with potentially life limiting conditions and their families.
4. **Home-based Hospice Care**: provides the only licensed hospice in the state of Minnesota that focuses solely on children.

**Other**

Pediatric pain management programme King Hussein Cancer Centre, Amman, Jordan

Finely et al. (2008) described the development and implementation of a pediatric pain management programme at the King Hussein Cancer Centre in Amman, Jordan, following a survey at the hospital which revealed unacceptable pain prevalence amongst the pediatric patients. The programme was developed around four major themes which included misconceptions about opioids and addiction and misgivings about the use of self reported pain assessment by children. The publication describes the steps (protocols) required to bring an inadequate pediatric pain service up to standard. In doing so fundamental aspects of pediatric pain management such as assessment with validated age-appropriate tools, involvement of family in pain management strategies, a pain consultation service and the development of appropriate analgesic protocols are discussed.

A comparative assessment of centres with different models of multidisciplinary pediatric pain units in Canada, USA, Sweden and the United Kingdom.

This report describes the activities and programmes of six Pediatric Pain Units\(^{14}\) visited in 2003 during a Churchill Fellowship with a view to improving local Victorian pediatric pain services (Munro, 2003). The programmes and services of the individual pediatric units were not described separately. Instead the report summarised the main features of chronic pain management programmes or services across the six units. Pain teams were multidisciplinary with between 1-3 physicians (often anaesthetists), a doctor in training and nursing staff. Several clinics had advanced practice nurses or nurses who co-ordinated the clinic and acted as a contact and advocate for patients. Chronic pain teams also included physiotherapy and psychology staff. In Los Angeles the team meeting comprised 14 staff, including therapists representing professions such as acupuncture, yoga, massage, craniosacral therapy, art therapy and psychology. The clinic organisation was reported to be very variable in terms of the treatment clinicians and treatment modalities.

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\(^{13}\) [http://www.childrensmn.org/Communities/hospice.asp](http://www.childrensmn.org/Communities/hospice.asp)

\(^{14}\) Vancouver, Canada: Pediatric Rheumatology clinic at BC Children’s Hospital, San Francisco, USA: Lucille Packard Children’s Hospital, Los Angeles, USA: chronic pain Pediatric Pain Program at Mattel Children’s Hospital, Milwaukee, USA: Children’s Hospital of Wisconsin, Pediatric Pain and Palliative Care Team, Stockholm, Sweden: the Astrid Lindgren Children’s Hospital Sedation Service, Bath, United Kingdom: Pain Management Unit, Royal National Hospital for Rheumatic Diseases.
Summary

Services and programmes identified were generally guided by an explicit theoretical model such as the biopsychosocial model or the cognitively-behaviourally orientated model. The goals of pain management programmes and services were similar and included a desire to:

- improve patients' understanding of their situation
- improve their level of physical functioning
- modify perceived level of pain and suffering
- provide coping strategies for dealing with disability and distress
- promote self-management
- reduce or modify their future use of healthcare service.

Collectively, the literature suggests that an interdisciplinary approach is an imperative for the management of chronic pain at all levels of the health care system (Nova Scotia Chronic Pain Working Group, 2006). The literature also suggests that the ideal multidisciplinary pain clinic should provide medical specialists, extensive diagnostic, therapeutic and rehabilitative services and should include most of the following:

- anaesthesiologists
- nurses
- physiotherapists
- occupational therapists
- psychologists
- social workers
- psychiatrists
- physiatrists
- administrative staff

Well developed programmes included research and education components in addition to clinical services. Barriers to implementation were reported and included limited access to services and concerns about the use of opioids in children. The most commonly cited centre was the Bath Centre for Pain Services in the UK which is a national pain referral centre.

- The websites of six additional organisations were identified as offering pain services, however these sites provided little information about the services offered and are not reported further (see Appendix).
What is the content of these services?

Introduction

The information obtained relating to the content of the programme or services was limited to that provided in the identified publications and websites. Not all programmes or services reported in the previous section provided detail of the content in these information sources. Those that did are reported below with the programmes or services listed by country.

Australia

The Chronic Pain Clinic at the Children's Hospital at Westmead, Australia

This is a hospital-based, pediatric pain service for children 0-18 years. A three-hour multidisciplinary assessment with the child and his or her family takes place in the morning. The purpose of the assessment is to clarify whether the child’s symptoms can be understood by a disease process alone, or whether psychological and relationship factors are judged to have an important role in onset, severity, exacerbation, or maintenance of the child’s pain and associated impairment. The assessment involves:

- a review of the child’s pain history
- formulation of the case by the pain team while the family takes a break
- communication of the formulation and treatment recommendations to the child and family.

Recommendations may include a suggestion for further medical investigations if previous ones have not been adequate to exclude a medical explanation for the pain or for the severity of pain experienced. If further medical tests are not indicated, a physiotherapy assessment for a home programme takes place in the afternoon of the same day. At the conclusion of the daylong pain clinic assessment, families are either:

- referred back to the referring agent with a clearly articulated management plan (with or without subsequent follow-up by the Chronic Pain Clinic)
- offered outpatient treatment by the Chronic Pain Clinic
- offered further assessment sessions.

The goal of further assessment with the mental health clinician is to engage the child and family in the process of first identifying and then addressing the psychosocial factors that contribute to the child’s subjective experience of pain. This more comprehensive family assessment generally takes place with a clinical psychologist over one to four sessions, depending on the complexity of the case. Attendance of the family is a requirement of the first session, with later interviews involving various family relationships. The psychological assessment with the mental health clinician explores the contributing and perpetuating factors on multiple system levels. At the conclusion of the further assessment families are either:

- returned to the referring agent with a clearly articulated management plan, usually together with recommendations or a referral to local psychological services
- offered family outpatient treatment with the Chronic Pain Clinic psychologist
- in a small proportion of cases, the child is offered a rehabilitation admission followed by outpatient treatment with the psychiatry team.

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15 It is possible that more information is available; individual institutions were not contacted for additional information.
Rehabilitation admissions are intensive, consume significant clinician time, and are offered only to children whose symptoms result in significant physical impairment, for example, children who are bed bound or wheelchair dependent, or who have missed many months of school.

**Europe (excluding the UK)**

**University of Groningen multidisciplinary pediatric pain management programme**

The three month pain management programme was divided into main three phases:

1. In week one (starting phase) treatment goals were set, baselines set and treatment start level set. Goals were set by each child individually (supported by the team) and included, for example, to improve the level of physical functioning and to reduce the use of pain medication.

2. During weeks 2-8 (treatment phase) patients underwent treatment which included positive reinforcements, extinction of pain behaviour, time contingency, verbal instruction, modelling and imitation, prompting and shaping. Feedback on the progression of the rehabilitation process was given in the weekly physiatrist/patient meeting.

3. During weeks 8-12 (generalisation phase) the patient learns to incorporate the learned principles and activities in daily (home) situations and to become more and more independent of the professionals (weeks 10-12, discharge phase).

Three months after ending treatment the child is seen by the members of the team. Main aim of the follow-up is to prevent relapse. The goals and content of the physiotherapy, occupational and psychological, family social therapy programmes are outlined in the publication. The overall progression of the child and monitoring of the rehabilitation process is undertaken by a physiatrist; he/she also attends to the reduction in pain medication.

From: De Blecourt, et al. (2008)

**UK**

**The Bath Centre for Pain Services, Royal National Hospital for Rheumatic Diseases**

The residential short course for adolescents with complex pain conditions: this aims to help adolescents (11+) with complex pain conditions to become less disabled and manage important aspects of their lives more confidently. All treatments are delivered by specialists and are based on the latest research. The programme focuses on increasing function and return to age-appropriate activity such as school attendance. Programme participants learn the skills and strategies of pain management which include:

- graded exercise - including a gym
- goal setting, planning and activity management
- mood management
- life skills - including healthy eating and communication
- medication and chronic pain
- education - return to school

Residential interdisciplinary programme of cognitive behavioural and physical therapy for adolescents with long standing chronic pain (Eccleston, Malleson, Clinch, Connell, & Sourbut, 2003): this programme was developed as a tertiary service at a national referral
centre for chronic pain patients. Patients were assessed using a battery of 10 measures pre-treatment, post treatment and at the 3 month follow-up. The programme themes were (a) the promotion of positive change despite pain, (b) independence from medical and social care, and (c) return to normal everyday activity.

Treatment contact time was 110 hours which comprised, 60 hours physical and occupational activity, 35 hours of cognitive therapy and 15 hours of education. Treatment sessions were 50 minutes each. The programme was run over an 18 month period with seven programmes of six dyads and 3 programmes of five dyads. The day was structured as a school day (9.00 am-3.45 pm) with many of the sessions requiring written or skill practice “homework”.

Course components included (a) education, with topics such as the physiology and anatomy of pain and exercise, possible causes of chronic pain and the side effects of medication (b) activity, including paced core daily exercises and activities with baseline calculations and increasing daily activity targets and (c) cognitive therapy, where cognitive-behavioural coping skills were developed for each patient with daily practice and monitored homework included. Family orientated cognitive therapy was also provided which focused on fear related thinking and behaviour that involved the whole family and somatic or illness relevant thinking. Parent attended group sessions (without the patient), that focused on adaptation to living with a disabled child, managing health related anxiety and problem solving skills.

Other countries

A comparative assessment of centres with different models of multidisciplinary pediatric pain units in Canada, USA, Sweden and the United Kingdom.

Assessment structure: the assessment structure varied widely between the models and centres and included:

- An intake assessment with the primary clinician (paediatrician, pain specialist or anaesthetist), clinic nurse, pain fellow, psychologist, and possibly the physiotherapist present.
- An initial assessment by the doctor alone with referral of the patient for further multidisciplinary assessment as indicated.
- An initial assessment by the paediatrician and psychologist who then discussed the patient privately and presented their findings to the family and patient who could then elect what treatment they would undertake.
- An assessment of the patient by the doctor and the physiotherapist while the family was interviewed by the psychologist or psychiatrist with the patient interviewed immediately afterwards.

Formulation, feedback and treatment planning: this also varied widely between models and centres and included:

- A separate team meeting to formulate a diagnosis and plan which was then presented to the patient and family.
- Written information given to the patient (a typed personalised plan from computer templates with contact details) at the time of feedback.
- Formulation carried out openly in front of the patient and family in a way that was sometimes confronting but seen by the team to be honest and therapeutically useful.
Follow-up: this varied depending on where the patient lived and local resources.

- The Bath unit followed-up patients for a half day at 3 and 9 months. However the aim of this inpatient programme was to help the patient to gain acceptance and take control of their pain and it was reported that closer follow up could undermine this; the unit and the patient’s allocated mentor were available for contact in this period.

Referral base: the referral base varied considerably with the largest referral base often from within the institution.

- Locally based pediatricians and general practitioners as well as interstate or national referrals made up a large proportion of referrals in some centres.

Waiting lists: varied from several weeks to many months.

- Several centres were able to see new patients within several weeks to a month and felt this was an important and appropriate message to send to these children and adolescents in chronic pain.
- Milwaukee was able to see up to 8 new patients a week and their clinic’s organisational set-up was very streamlined.

Good Initiatives:

- Some units provided written material for patients and families about what to expect at the clinic assessment and the treatment phase; or in the case of where there were long delays simple generic advice about pain and strategies to minimise its impact upon the patient in the waiting period was sent out.
- Two centres encouraged patients to bring whomever they chose to the initial assessment rather than just their parents.

Inpatient Rehabilitation Services: access to inpatient rehabilitation services was felt to be an area where significant improvements could be made.

- In the USA (with managed care) it was reported to be exceptionally difficult to access these services for children and adolescents with chronic pain.
- Many patients with chronic pain have secondary physical deconditioning which requires a considerable amount of physical and psychological therapy to improve their condition as well as conscious sedation to manage bone marrow aspiration and lumbar punctures.

Data collection: Most clinics had patient questionnaires (pain and quality of life data collection) completed prior or at the visit. Clinics with a chronic pain nurse or research assistant performed best in this area, and data entry occurred more rapidly.
Summary

Each of the programmes or services reviewed provided a multidisciplinary team evaluation of the patient upon referral. The number and composition of the team varied between the programmes or services but generally included at minimum a medical doctor/primary clinician\(^\text{16}\), a psychologist and a physiotherapist/physical therapist.

Additionally, well developed larger or specialist programmes or services often included one or more of: social work/family therapist, occupational therapist, nurse administrator, pediatric pain specialist, psychiatrist, anaesthesiologist, physiatrist and child life specialist.

The assessment structure, treatment planning and follow-up varied considerably across the centres; a useful international comparison of the programme content of six centres by Munro (Munro, 2003) details some of the variations.

The services and interventions provided depended on (a) the theoretical model underpinning the service and (b) the nature of the patient population. For example services providing palliative care and end of life services to cancer and terminally ill patients tended to offer a wider range of pharmacological interventions.

Generally, a multimodal treatment approach was adopted and an impressive range of interventions were available and included at least the first three of the following:

- Medical management
- Physical therapy
- Psychological therapy
- Family system work
- Biofeedback
- Relaxation training
- Self hypnosis
- Acupuncture/acupressure
- Aromatherapy/therapeutic massage
- Occupational therapy
- Counselling
- Art therapy
- Music therapy
- Academic therapy
- Healing touch and Reiki
- Herbals and botanical
- Reflexology
- Mind body skills group
- Self regulation skill training

The key elements of the programmes or services described are summarised in Table 1.

\(^\text{16}\) In the hospital situation this may be a pediatrician, pain specialist or anesthetist
### Table 1: Key content elements of the pain management programmes and services described

<table>
<thead>
<tr>
<th>Intervention components reported by the different services or programmes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assessment</strong></td>
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<tr>
<td>- Patients assessed using a battery of 10 measures</td>
</tr>
<tr>
<td>- A review of the child’s pain history</td>
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<tr>
<td>- Formulation of the case by the pain team</td>
</tr>
<tr>
<td>- Communication of the formulation and treatment recommendations</td>
</tr>
<tr>
<td>- Comprehensive family assessment with clinical psychologist</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
</tr>
<tr>
<td>- Graded exercise - including a gym</td>
</tr>
<tr>
<td>- Goal setting, planning and activity management</td>
</tr>
<tr>
<td>- Mood management</td>
</tr>
<tr>
<td>- Life skills - including healthy eating and communication</td>
</tr>
<tr>
<td>- Medication and chronic pain</td>
</tr>
<tr>
<td>- Education - return to school</td>
</tr>
<tr>
<td>- Physical and occupational activity</td>
</tr>
<tr>
<td>- Cognitive therapy</td>
</tr>
<tr>
<td>- Education</td>
</tr>
<tr>
<td>- Written or skill practice</td>
</tr>
<tr>
<td>- Cognitive-behavioural coping skills</td>
</tr>
<tr>
<td>- Parents attended group sessions</td>
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<tr>
<td>- Goal setting</td>
</tr>
<tr>
<td>- Positive reinforcements</td>
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<tr>
<td>- Extinction of pain behaviour</td>
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<tr>
<td>- Verbal instruction</td>
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<tr>
<td>- Modelling and imitation</td>
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<tr>
<td>- Prompting and shaping</td>
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<tr>
<td>- Feedback on the progression of the rehabilitation process</td>
</tr>
<tr>
<td>- Written information</td>
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<tr>
<td><strong>Follow-up</strong></td>
</tr>
<tr>
<td>- Follow-up assessments</td>
</tr>
<tr>
<td>- Patient questionnaires</td>
</tr>
<tr>
<td>- Pain and quality of life data collection</td>
</tr>
</tbody>
</table>
How are clients referred and who provides the services?

The referral patterns of patients to the services and programmes described in the previous section were generally similar:

- A referral letter from a physician or nurse practitioner outlining a brief medical history, current issues and how the service/programme may help. In some cases there is a referral form that is faxed to the practitioner on request that provides all the required information and authorisations.
- The Bath Centre for Pain Services in the UK also provides a self referral system for patients that have already been seen at a pain clinic.
- In one or two cases it appeared that patients could refer themselves for evaluation directly by calling one of the clinic nurses e.g. Mayo Family Pediatric Pain Rehabilitation Centre.17

Most hospital based clinics with websites list their contact details and invite clients to call to discuss the programmes and services offered to see if it meets the needs of the child and the family.

The services reported in the literature were provided by:

- Children’s hospitals/children’s health care organisations, e.g. Children’s Hospitals and Clinics of Minnesota.18
- National Health Service, e.g. The Royal National Hospital for Rheumatic Diseases NHS Foundation Trust19 and the Westmead Hospital Chronic Pain Clinic.
- Charitable trusts, e.g. The King Hussein Cancer Foundation which is an independent, non-governmental, not-for-profit institution founded in 1997 by a Royal Decree to combat cancer in Jordan and the Middle East region.20
- University pain centres, e.g. The Pain Management Centre University of Columbia.21

17 http://www.childrenshospital.org/clinicalservices/Site2585/mainpageS2585P8.html
18 http://www.childrensmn.org/Communities/AboutUs.asp
Does research support good outcomes following these programmes?

Although there is good evidence for the efficacy of integrated team approaches to treating complex chronic pain syndromes in adults (Becker, Sjogren, Olsen, & Eriksen, 2001; Haldorsen et al., 2002; Jensen, Turner, & Romano, 2001; Patrick et al., 2004; Thomsen, Sorensen, Sjogren, & Eriksen, 2001), sound evidence for pediatric pain services is reported to be lacking (Peng, et al., 2007).

There have been a number of systematic reviews and evaluations of specific treatment interventions for chronic pediatric pain (Eccleston, Morley, Williams, Yorke, & Mastroiannopoulou, 2002; Eccleston, Yorke, Morley, Williams, & Mastroiannopoulou, 2009; Lee et al., 2002; McCracken et al., 2005; Sully, Eccleston, Connell, & Clinch, 2002); however, few studies have been performed to investigate the results of multidisciplinary programmes or services for the treatment in children and adolescents. Thus, not all programmes or services described in the earlier section were evaluated (Munro, 2003); for those that were, evaluations are reported below.

**The Chronic Pain Clinic at the Children’s Hospital at Westmead, Australia**

Kozloeska et al. (2008) evaluated a hospital-based pediatric pain clinic in Westmead, Australia.

Effectiveness was illustrated using detailed case histories and a quantitative evaluation of pain score and function data for 28 children with disabling somatoform pain disorder. Children participated in a family systems intervention for 12 months. Outcomes were documented using changes in subjective pain (VAS) (Scott, Ansell, & Huskisson, 1977), self-reported pain frequency, school attendance and participation of activities of daily living.

At discharge, 12 of the 28 children (43%) were pain free (pain score = 0), 11 children (39%) rated their pain as having improved (mean pain score = 3.8) and 5 children (18%) reported no change in their pain score. Of the 16 children who continued to have pain (57%) only 6 rated their pain as constant, whereas 2 described it as intermittent daily and 8 (half the group) as occurring once a week or less. Functional recovery was independent of reported pain levels for the majority of children. Of the 23 children who had had school-time loss, 20 had returned to school full time, with the others attending part time. In terms of activities of daily living (including sporting and other extracurricular activities) the majority of children (n =20 [of 28] or 71%) had returned to their premorbid levels, with 8 children still manifesting some impairment. Specifically, 7 children had not fully returned to sporting or music activities, and 1 continued to use a slope board when writing at school.

**Chronic Pain Management Clinic, Royal Children’s Hospital, Melbourne**

Chalkiadis (2001) evaluated the outcomes of 207 patients referred to the clinic over a two year period. Patients (aged 1-18 years) were referred; most (57%) were by orthopaedic surgeons. Good outcomes i.e. marked reduction in pain intensity and improvement in function and resumption of normal sleep pattern, were reported in 65% (134 cases). Moderate outcomes i.e. partial reduction in pain intensity and/or some improvement in function or

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resumption of normal sleep pattern 15% (32 cases) and poor i.e. no improvement in pain insensitive or functional activity in 8% (16 cases) and unknown i.e. no follow-up in 12% (25 cases). In total, 147 patients who had an impaired ability to participate in sport because of pain 88% (122 cases) regained the ability after treatment. Sleep disturbance was successfully managed in 88% of those who reported sleep disturbance. Three therapy related complications were reported; two were epidural related and one related to a lumbar sympathetic nerve block. The authors concluded that functional improvement could be achieved using a multidisciplinary approach to pain management in children.

**British Columbia Children’s Hospital, Vancouver**

Bennett et al. (2000) provided descriptive data evaluating outcome and treatment satisfaction for patients and family undergoing an interdisciplinary treatment programme at British Columbia Children’s Hospital Vancouver. Twenty four patients with complex pain syndromes were treated according to the programme for three years and were evaluated using a semi structured phone interview. Perceived pain intensity was significantly lower than recalled pre-treatment levels according to both child and parental ratings. Pain frequency was also significantly reduced. There were no significant differences between the child’s and parental ratings. The degree of improvement in pain was rated as “somewhat better” in 83% of children and by 95% of parents. Other areas evaluated were attainment of treatment goals and participation in activities of daily living; improvements were reported in both areas. The overall level of treatment satisfaction was reasonably good with most patients reporting that they were “quite satisfied”.

**University of Groningen Multidisciplinary Pediatric Pain Management Programme: Centre for Rehabilitation, Groningen, Netherlands**

Recently De Blecourt et al. (2008) described the outcome of a multidisciplinary pain management for children and adolescents with musculoskeletal pain carried out at the centre for rehabilitation, Groningen, Netherlands. The study involved 70 children who attended the programme and 57 (81%) attended the follow-up meeting three months post treatment. Improvements were achieved in motor performance (94%, 64 cases). All children were reported to have returned to a regular school programme and “most” were reported to have started to participate in sport. There was a significant improvement in both parental and patient global assessment scores (Ruperto et al., 1999). However differences between VAS scores at discharge and follow-up were not significant. The authors concluded that “a multidisciplinary pain management for children and adolescents with chronic musculoskeletal pain may be effective”

**Pain management Unit, University of Bath, UK**

The residential interdisciplinary programme of cognitive behavioural therapy incorporating physical therapy was assessed for effectiveness (Eccleston, et al., 2003). Fifty seven adolescents underwent a 3 week residential multidisciplinary programme of group cognitive behavioural therapy. Significant post treatment improvements were reported for self reported disability, physical function and sit to stand. At the three month follow-up they maintained their physical improvements and reduced anxiety, disability and somatic awareness. Adults reported significant improvement in their children disability, adult anxiety, depression and stress. At the three month follow-up significant improvements were maintained. The authors concluded that interdisciplinary cognitive behavioural pain management (with family
involvement) is a promising approach to the management for pain, pain related distress, and disability.

**Summary**

Although there were a large number of publications evaluating specific interventions there were comparatively few evaluations of whole services or programmes and the quality of the evaluations was generally low. Limitations included weak study design, lack of control groups, and lack of blinded assessment, small numbers, short follow-up, retrospective reporting and lack of validated and objective outcome measures.
Are there specific screening tools that allow early identification of chronic pain?

There is a clear indication from research that early identification and treatment of pain is desirable in both adults and children.

1. Peripheral and central sensitisation are the major underlying causes of hypersensitivity to pain that arise following tissue injury. If inflammation from an injury is treated appropriately and the disease process is controlled, hypersensitivity usually resolves. If inflammation or pain persists, long-lasting neuronal changes occur which result in the distortion of stimulus-response characteristics of these neurons. This in turn leads to increased activity of neurons in the central pain pathway producing persistent (or chronic) pain.

2. Recent research has demonstrated that chronic pain in children has the potential to permanently alter a child’s development and future role functioning. (Konijnenberg et al., 2005) In the light of this knowledge it is acknowledged that children with unexplained chronic pain should be identified and acknowledged in an early phase.

3. Better management of pain in its acute phase can contribute greatly to improved overall pain control and reduce healthcare utilisation. Poorly controlled acute pain can progress to chronic pain. For example, in a population survey of 474 respondents with reported chronic pain, acute injuries were the leading cause accounting for 38% of the chronic pain reports.

Thus, well controlled pain can be a factor in helping to reduce progression to chronic pain, which in turn may reduce costs and provide benefit for patients with acute pain. Conversely, the under-treatment of acute or recurrent pain is believed to be an important factor in the prevention of or reduction of the development of chronic pain (Howard, 2003).

Whilst the literature abounds with statements of the effect of unrecognised and untreated pain (Currie, 2006; Jones, Silman, Power, & Macfarlane, 2007; Miranda & Sood, 2006) underpinning the need for early treatment of chronic pain and effective treatment of acute pain, research leading to the identification of patients most likely to benefit from such an approach is sparse. Since such research is a prerequisite for the development of early screening tools (Atluri, Sudarshan, Atluri, & Sudarshan, 2004) it perhaps not surprising that few studies reporting early screening tools were identified (Melloh et al., 2008; Wissmann et al., 2007).

Given the dearth of information relating to early screening for chronic pain an overview of studies that explored the prerequisites for the development of chronic pain or its prevention is presented, since such risk or predicative factors are likely to form the basis for the development of early screening tools.

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23 Tools designed to distinguish children who would benefit from early treatment from those whose conditions were unlikely to lead to chronic conditions
Risk and predictive factors for the development of chronic pain in children

Miro et al. (2007) noted that while programmes that prevent chronic pain (i.e., secondary prevention) have been suggested and tested in adults with some promising results for chronic back pain, similar programmes for children had not been reported. In a study employing a Delphi poll to establish a consensus on the factors that predict chronic pediatric pain and pain-related disability, the authors reported a number of parental and patient characteristics including:

- the child’s psychological characteristics e.g. a tendency to somatise, a depressed personality and an anxious personality
- the parent’s psychological characteristics e.g. parental emotional instability
- characteristics of the pain experience e.g. constant pain, family history of chronic pain
- characteristics of pain management e.g. an excessive use of health care services, inappropriate consumption of medicines to relieve pain, doctors search for the pain problem without finding anything wrong and a low compliance with health care professional’s recommendations
- psychological factors related to the child’s pain experience e.g. catastrophic thinking of the child and parents about the child’s pain, child’s negative expectations about the course of their pain problems
- a stressful environment
- anxious parents who are unable to deal with their child’s pain.

The results supported the hypothesis that social psychological factors are central to the development of chronic pain and disability in children. The authors concluded that:

“If findings from this study were supported, then they could provide valuable information that could be used to develop a screening instrument for children at risk of suffering psychological characteristics e.g. chronic pain and disability, and to design and implement treatment programmes tailored to affect (or prevent) chronic pain, disability or both.”

For early detection of pediatric headache and migraine Winner (2008) has argued that better diagnostic tools and biomarkers are required to allow early effective intervention to prevent progression, lifelong consequences and co-morbidities.

For pediatric chronic pain associated with sport, a number of publications (Mirca, 2008; Paulska, 2005; Willems, 2007) focused on injury prevention and the likelihood of repeat injury and its consequences.

Curtis et al. (2007) examined the diagnosis and management of back pain in adolescents and, in particular, in adolescent athletes. These injuries are of particular concern because they tend to recur, are difficult to overcome and can lead to the development of overuse injuries. The report suggested that physicians maintain a high index of clinical suspicion when evaluating pediatric patients, and in particular athletes, presenting with back pain. A thorough evaluation, including history, physical examination and imaging was advised to improve the likelihood of early detection/prevention of such conditions as spondylolysis and facet syndrome.
Screening tools for the early identification of children at risk of developing chronic pain

No published studies were identified that reported the development or use of screening tools that would allow clients to be identified early and before the pain became chronic. One study (Len et al., 2006) reported the development of a screening tool for early referral to a specialist of children and adolescents with signs and symptoms suggestive of chronic arthropathies. The instrument targeted parents or guardians of apparently healthy children and adolescents aged 1-16 years. The final tool comprised 12 questions and took 3-5 minutes to complete. However, because the population of interest already had chronic pain, this study was not considered further.
What assessment tools have been shown to be useful for children?

Background
Different measures are used to assess the different dimensions of pain. Some tools measure pain intensity others assess functional impairment and behavioural maladaption. For pediatric pain assessment, tools also have to be developmentally appropriate to accommodate the different pediatric populations e.g. non-verbal or preverbal children, cognitively impaired children etc. The assessment of pain not only varies with the child’s age but with the type of pain, the situation in which pain occurs, the child’s prior pain experience, behavioural and emotional factors, and the caregiver’s response and attitudes.

Modern pain treatment centres adopt a multidisciplinary approach to pain, and accredited centres employ a battery of tools to assess pain and pain associated disability. Unfortunately there is no standard battery of tests, and internationally pain centres use tools that they believe have the characteristics they desire and suit their theoretical management model, service goals and patient population. Despite this general lack of conformity there are a number of principles that guide the development and selection of tools by established pain centres. It is widely agreed that screening or assessment tools for pediatric pain should be:

- established as valid and reliable
- developmentally appropriate
- easily and quickly understood
- liked by patients, families and clinicians
- inexpensive
- appropriate for different languages and culture

Core outcome domains in the assessment of pediatric pain
The Pediatric Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials has recommended eight core outcome domains which should be considered when designing clinical trials for recurrent/chronic pain (McGrath & Walco, 2008):

- pain
- physical functioning
- emotional functioning
- role functioning
- symptoms and adverse events
- global judgment of satisfaction
- sleep
- economic factors

Assessment tools have been developed for most of these domains either for adults (and subsequently adapted for children) or specific pediatric populations.
Systematic reviews of measures for the assessment of pediatric pain

The literature search identified five systematic reviews of instruments used to measure pediatric pain ( Eccleston & Clinch, 2007; Jordan & Eccleston, 2006; Jordan, Eccleston, & Crombez, 2005; Stinson, Kavanagh, Yamada, Gill, & Stevens, 2006; von Baeyer & Spagrud, 2007); all were published between 2005 and 2008. Two of these reviews (Jordan & Eccleston, 2006; Jordan, et al., 2005) were only reported in a conference abstract and are not reported further. In addition a systematic review of parental functioning in the context of pediatric pain (Jordan, Eccleston, & Crombez, 2008) was identified but not considered to be eligible. In October 2008 the Journal of Pediatric Psychology published a special issue devoted to evidence-based Assessment in Pediatric Psychology which included an evidence-based review of pediatric pain measures and a commentary on the review (Cohen et al., 2008; Tsao & Zeltzer, 2008).

The findings of the four relevant fully reported reviews are summarised in Table 2, with measures recommended or designed to assess chronic pediatric pain in these publications given in Table 3.
Table 2: Summary of findings of four relevant systematic reviews of assessment tools for pediatric pain

<table>
<thead>
<tr>
<th>Review</th>
<th>Number/ characteristics of assessment tools</th>
<th>Results</th>
<th>Authors’ conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eccleston C, Jordan A, Crombez G.</td>
<td>43 instruments were identified and subjected to detailed content analysis. 7 instruments in the physical domain, 22 instruments in the psychological domain, 5 instruments in the social domain, and 9 instruments in the multiple domains category. Of the nine multiple domain instruments eight contained sub domains of physical, psychological, and social items.</td>
<td>The majority of instruments were found to be in the psychological domain (n=22), with a self-report format (n=36). Thirty instruments were specifically developed for adolescent populations whilst only 12 instruments had undergone psychometric evaluation with adolescent chronic pain patients. The median use of any instrument in published studies was 2.</td>
<td>There is a diversity of instrumentation available to assess the impact of chronic pain on adolescent health. Most instruments have been used infrequently and there are important areas of health status that are not well covered or are missing. More information is needed on the content validity, temporal stability, and sensitivity to change in existing instruments.</td>
</tr>
<tr>
<td>von Baeyer, C.L. and L.J. Spagrud. Systematic review of observational (behavioral) measures of pain for children and adolescents aged 3 to 18 years. Pain, 2007. 127(1-2): p.140-150</td>
<td>20 observational pain scales were identified including behaviour checklists, behaviour rating scales, and global rating scales. Scales varied in their reliance on time sampling and inclusion of physiological items, facial and postural items, as well as their inclusion of multiple dimensions of assessment (e.g., pain and distress).</td>
<td>7 instruments were recommended; Four scales were for assessing pain associated with medical procedures/operations. One for use in critical care, two for assessing pain-related distress or fear. No observational measures were recommended for assessing chronic or recurrent pain.</td>
<td>This review was commissioned by the Pediatric Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (<a href="http://www.immpact.org">www.immpact.org</a>). No single observational measure is broadly recommended for pain assessment across all contexts. Directions for further research and scale development are offered.</td>
</tr>
<tr>
<td>Stinson, J.N., et al., Systematic review of the psychometric properties, interpretability and feasibility of self-report pain intensity measures for use in clinical trials in children and adolescents. Pain, 2006. 125(1-2): p.143-157.</td>
<td>34 single-item self-report measures were identified. A total of 6 single-item pain intensity measures met the inclusion criteria for the review. Reasons for excluding the remaining 28 measures are summarized.</td>
<td>Only 6 measures have well-established evidence of reliability and validity. These 6 measures have varying degrees of responsivity and modest evidence of interpretability, none of these scales was found to be reliable and valid across age groups or pain types, with the majority of scales lacking reliability and validity in pre-school children.</td>
<td>This systematic review provides evidence of the psychometric properties and feasibility of commonly used self-report pain intensity measures in children and adolescents. Findings highlight the critical developmental issues that affect pediatric pain measurement. Recommendations were made based on the best available psychometric evidence to date. No single pain intensity measure is appropriate across ages or types of pain.</td>
</tr>
</tbody>
</table>

Table 2: Summary of findings of four relevant systematic reviews of assessment tools for pediatric pain (continued)

<table>
<thead>
<tr>
<th>Review</th>
<th>Number/characteristics of assessment tools</th>
<th>Results</th>
<th>Authors’ conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohen, L.L., et al., Evidence-based Assessment of Pediatric Pain. J. Pediatr. Psychol. 2008. 33(9): p. 939-955.</td>
<td>17 measures including five pain intensity self-reports, four questionnaire and diary, and eight observational instruments were reviewed.</td>
<td>11 measures met criteria for “Well-established,” 6 “Approaching well-established”.</td>
<td>There are a number of well-established assessment tools that can be used to evaluate pain in children of varying ages and with different types of pain in a variety of situations. However, the best measure will depend on the purpose of its use, the questions being asked, and the context in which it will be implemented.</td>
</tr>
</tbody>
</table>

Collectively, these reviews reported on and/or recommended 35 different measures that might be considered for use in the assessment of pediatric pain. It is not possible to fully describe all of these measures in this overview and only instruments that appeared to be ‘recommended’ as potentially useful for chronic pain are listed in Table 3.
Table 3: Pain assessment tools reported/recommended in four relevant fully reported reviews of measures for the assessment of pediatric pain

<table>
<thead>
<tr>
<th>Pain Assessment tool</th>
<th>Brief description</th>
<th>Reviewed by/class of measure</th>
<th>Comments/usage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The revised Faces Pain Scale (Hicks et al., 2001)</td>
<td>Six faces are used, rather than seven, and scoring ranges from 0 to 5.</td>
<td>Stinson et al 2006 Self-report pain intensity measures</td>
<td>The Faces Pain Scale- Revised appears to be the most psychometrically sound measure in school-aged children. It has been validated for use in both acute and chronic pain.</td>
</tr>
<tr>
<td>The Wong–Baker FACES Pain Scale (Wong and Baker, 1988)</td>
<td>Consists of six hand-drawn faces that range from smiling to crying. The faces represent ‘no hurt’ to ‘hurts worst’ and the scale is scored from 0 to 5.</td>
<td>Stinson et al 2006 Self-report pain intensity measures</td>
<td>Designed originally for acute procedural and post op pain. Psychometrically sound and widely used in clinical practice.</td>
</tr>
<tr>
<td>The Oucher Beyer and Aradine (1986)</td>
<td>A combination of two separate scales: the photographic faces scale of six photographs of culturally sensitive faces that are scored from 0 to 5and a 0–100 mm vertical numerical rating scale.</td>
<td>Stinson et al 2006 Self-report pain intensity measures</td>
<td>Its use in young children (3-4 years) requires further testing. Cultural limitations with the original version. Facial expressions are of acute rather than chronic pain.</td>
</tr>
<tr>
<td>Visual analogue scales (VAS) Scott et al. (1977)</td>
<td>Consist of a pre-measured vertical or horizontal line, where the ends of the line represent the extreme limits of pain intensity.</td>
<td>Stinson et al 2006 Self-report pain intensity measures</td>
<td>The VAS appears to be the best measure for clinical trials. Adolescents indicate preference for visual analogue and numerical rating scales compared to faces scales.</td>
</tr>
<tr>
<td>Varni-Thompson Pediatric Pain Questionnaire (PPQ; Varni &amp; Thompson, 1985)</td>
<td>Assesses chronic pain intensity, location, sensory, evaluative, and affective qualities of pain via self-report and parent / physician proxy-report.</td>
<td>Cohen et al. 2008 Observational measures</td>
<td>Used with a variety of populations (e.g., JRA, SCD, fibromyalgia).</td>
</tr>
<tr>
<td>Pain Response Inventory, Walker et al.,1997;</td>
<td>Active, passive and accommodative coping.</td>
<td>Eccleston 2006 Psychological domain</td>
<td>Developed explicitly with adolescent chronic pain populations</td>
</tr>
<tr>
<td>Children’s Somatization Inventory, Walker &amp; Garber, 1992</td>
<td>Physical complaints.</td>
<td>Eccleston 2006 Physical domain</td>
<td>Developed explicitly with adolescent chronic pain populations</td>
</tr>
<tr>
<td>Functional Disability Inventory, Walker &amp; Greene, 1991</td>
<td>Interference with daily activities.</td>
<td>Eccleston 2006 Physical domain</td>
<td>Developed explicitly with adolescent chronic pain populations ** MOST USED**</td>
</tr>
</tbody>
</table>
Table 3: Pain assessment tools reported/recommended in four relevant fully reported reviews of measures for the assessment of pediatric pain (continued)

<table>
<thead>
<tr>
<th>Pain Assessment tool</th>
<th>Brief description</th>
<th>Reviewed by/class of measure</th>
<th>Comments/usage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life Questionnaire for Adolescents with Chronic Pain, Merlijn et al., 2002</td>
<td>Interference with daily activities, distress, social functioning, health and life satisfaction.</td>
<td>Eccleston 2006 Multiple domains</td>
<td>Developed explicitly with adolescent chronic pain populations.</td>
</tr>
<tr>
<td>Quality of Life Headache in Youth, Langeveld et al., 1996</td>
<td>Interference with daily activities, distress, social functioning, health and life satisfaction.</td>
<td>Eccleston 2006 Multiple domains</td>
<td>Developed explicitly with adolescent chronic pain populations.</td>
</tr>
<tr>
<td>Children’s Headache Assessment Scale, Budd &amp; Kedesdy, 1989</td>
<td>Antecedents and consequences of headache.</td>
<td>Eccleston 2006 Multiple domains</td>
<td>Developed explicitly with adolescent chronic pain populations.</td>
</tr>
<tr>
<td>Children’s depression Inventory Kovacs, M. (1981).</td>
<td>Interview, developed with children and adolescents with depressive disorders.</td>
<td>Eccleston 2006 Psychological domain</td>
<td>A commonly used measure for chronic pain in adolescents designed for a variety of situations, including schools, child guidance clinics, pediatric practices, and child psychiatric settings.</td>
</tr>
</tbody>
</table>
Thus, despite a number of systematic reviews designed to provide information to assist in the choice of appropriate measures, difficulties remain relating to the choice of pediatric pain measures to be used in a given circumstance. In September 2008 the Pediatric Initiative on Methods, Measurement and Pain Assessment (IMMPACT\textsuperscript{25}) published a consensus statement outlining recommendations for core output domains and measures for pediatric acute and chronic/recurrent pain\textsuperscript{26} in clinical trials (McGrath & Walco, 2008). In this statement IMMPACT made the following recommendations relating to tools for the assessment of chronic/recurrent pediatric pain:

**Pain intensity**
- 3-4 years: Poker chip tool– Hester (1979)
- 4-12 years: Faces pain scale revised– Hicks et al. (2001)
- 8 years and above: Visual analog scale– Scott, et al. (1977)

**Physical functioning**
- 3-7 years: PEDsQL– Varni et al. (1999); Varni et al. (1985)
- 8 years and above: Functional Disability Inventory– Walker and Greene (1991)

**Emotional functioning**
- Less than 7 years: PedsQL– Varni et al. (2007)
- 7-17 years: Children’s Depression Inventory– Kovacs (1981)
- Revised Child Anxiety and Depression Scale– Chorpita et al. (2005); Chorpita et al. (2000)

**Role functioning**
- 6-18 years: PedMIDAS– Hershey et al. (2001; 2004)
- All years: PedsQL– Varni, et al. (1999)

**Sleep**
- School age children: No measure was recommended but it was suggested that the Sleep Habits Questionnaire (Owens, Spirito, & McGuinn, 2000) may be useful.

The consensus statement acknowledged the finite lifespan of the recommendations and noted that new composite measures of chronic pain in adolescents (e.g. the Bath Adolescent Pain Questionnaire (Gauntlett-Gilbert & Eccleston, 2007)) and a new measure of pain-related functional impairment in school-age children and adolescents (T.M. Palermo, Lewandowski, Long, & Burant, 2008; T. M. Palermo, Witherspoon, Valenzuela, & Drotar, 2004) were promising but required further research before they could be recommended.

**Summary**
Research into the assessment of pain in children and adolescents has generated a large amount of literature describing and assessing measures relating to different aspects/domains of pain and different types of pain for various pediatric populations. Not all of these tools have undergone a rigorous assessment (i.e. are valid and reliable) or are appropriate for different cultures and languages. Moreover, they tend to be used inconsistently in studies making comparisons difficult. Over the last four years, four systematic reviews of pediatric pain measures have been carried out, each identifying a large number of published measures.

\textsuperscript{25} www.immpact.org
\textsuperscript{26} Pain in neonates and cognitively impaired children were not included in this consensus as they will be the focus of future IMMPACT meetings.
These reviews each identified 6-12 measures for detailed assessment/review in the context of chronic pain assessment and between them identified 13 tools of potential value in this pediatric pain population. Following the publication of these reviews a consensus statement on the assessment of pediatric populations with chronic pain in clinical trials recommended 10 tools for the assessment of pain outcomes in this population. These tools assessed pain intensity, physical functioning, emotional functioning and role functioning; no tool was recommended for the assessment of sleep pattern, however, a sleep questionnaire was considered to be potentially “helpful”.

This overview provides a guide only to the more recent literature pertaining to programmes, services and assessment tools for the management of chronic pain in children and adolescents. The literature described has not been critically appraised and individual treatment modalities and management of particular types of chronic pain are not included. To address these shortcomings a systematic review of the literature using more narrowly focused research questions would be required.
The assessment and management of chronic pain in children and adolescents: an overview of selected literature

References


The assessment and management of chronic pain in children and adolescents

an overview of selected literature


Munro, J. (2004). *The Jack Brockhoff Foundation Churchill Fellowship to evaluate and compare several centres with different models of multidisciplinary paediatric pain units with a view to improving local Victorian paediatric pain services - USA, Canada, U.K., Sweden*. Victoria, AU: The Winston Churchill Memorial Trust.


Appendix: Additional Resources

Below are a number of additional pain services websites and recent textbooks which may be of interest.

- Pediatric Pain Service, Johns Hopkins Children’s Centre

- Pediatric Supportive Care Team, St John Hospital, Detroit, Michigan

- David Centre for Children's Pain and Palliative Care, a division of The Joseph M. Sanzari Children’s Hospital at Hackensack University Medical Centre

- Pediatric Pain Management Service, Morgan Stanley Children's Hospital, New York
  http://www.childrensnyp.org/mschony/pediatric-anesthesia-expertise.html

- Pediatric Pain Management Service. Glasgow Palliative Care
  http://www.palliativecareglasgow.info/Professional%20Resources/kpainpub.asp

  http://www.smj.ejnal.com/e-journal/showdetail/?show_detail=T&art_id=82

Guidelines for Multidisciplinary Programme Development. CRC Press, 2007. This is a textbook on the multidisciplinary approach to chronic pain management. It provides guidelines for the development of a successful multidisciplinary chronic pain management programme within the context of current medical and insurance reimbursement climates. The only source to offer these strategies, backed by the American Academy of Pain Management.

Clinical Pain Management: Chronic Pain (Second Edition). Peter Wilson, Troels Jensen, Paul Watson and Jennifer A Haythornthwaite. Chapter 44. Chronic pain in children. Hodder Arnold. 2008 In Part Three of this textbook specific and non-specific pain syndromes and their management are described, including pain in neurological disease, in HIV and AIDS patients, and after surgery or spinal cord injury, regional pain in the head, face, neck, back, joints, chest, abdomen and pelvis, and issues related to pain in children, the elderly and in association with substance misuse.