

Managing complex and persisting pain in children and adolescents

JOHN COLLINS MB BS, PhD, FRACP; **NATASHA HAYNES** MN (NP)
MEG POUNDER BAppSc(Physiotherapy); **RENEE SANDELLS** MPsyCh(Clin)

Persisting pain in children and adolescents is prevalent. GPs should consider early referral of young patients with complex or persisting pain to a multidisciplinary paediatric pain clinic that adopts a biopsychosocial approach to assessment and management. This may prevent the possible consequences of long-term pain, including psychological sequelae, school and social disruption and disability.

Pain is experienced as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'.¹ Pain is a subjective experience modified not only by biological factors, but also by previous painful experiences, the meaning and social context of the pain, fear, anxiety, depression and a range of other issues.

Chronic pain is defined as continuous or recurrent pain that persists past the normal time of healing, most commonly greater than three months' duration.¹ If chronic pain simply refers to any pain with this predetermined duration, then all persistent pain of childhood, such as that related to chronic disease (e.g. cancer, arthritis, sickle cell disease), neuropathic pain (e.g. complex regional pain syndrome, phantom limb pain) and recurrent pain syndromes (e.g. migraine, recurrent abdominal pain), could be classified as causes of chronic pain in children. An emerging term, 'complex pain', is increasingly used as an alternative term to describe pain in children which is persisting beyond the expected time of healing or pain which is recurrent and has become complicated to manage and includes medically unexplained pain. This is a new term that is clearer and reduces the stigma of the word 'chronic', which for many implies never-ending

MedicineToday 2019; 20(4): 47-50

Dr Collins is Head of Department, Ms Haynes is Nurse Practitioner, Ms Pounder is Physiotherapist and Ms Sandells is Clinical Psychologist in the Department of Pain Medicine at The Children's Hospital at Westmead, Sydney, NSW.
 SERIES EDITOR: Dr Chris Elliot BMed(Hons), FRACP, General and Developmental Paediatrician, St George Hospital, Sydney; and Conjoint Lecturer, School of Women's and Children's Health, UNSW Sydney, NSW.



pain, especially when persisting pain in children can be treated.

To prevent the possible consequences of long-term pain in children, which may include psychological sequelae, school and social disruption and disability, early referral to a paediatric pain clinic should be considered (Box 1).

Epidemiology of complex pain in children and adolescents

A systematic review has shown that the prevalence rates of chronic pain conditions in children vary substantially.² Lower socioeconomic status was associated with higher pain prevalence, especially for headache. However, most studies included in the review did not meet high methodological quality criteria. A prospective, descriptive study of the characteristics of 207 children presenting to the chronic pain clinic at Royal Children's Hospital, Melbourne, over two years reported concomitant medical conditions were present in more than 50% of patients, the most common conditions being cerebral palsy and malignancy.³ The incidences of school absenteeism, sleep disruption and inability to play sport were high (95%, 71%, 90%, respectively). Implied in these data is a significant burden of suffering for the children and families caring for them.

Complex pain in children may be under-recognised by clinicians. Barriers to recognition may include a child's dependency on caregivers to be advocates and a reduced economic impetus towards a comprehensive approach for children with chronic pain as children do not impose a burden on the insurance and compensation system.⁴ In addition, children may be met with a dismissive attitude from caregivers, especially if no obvious cause of pain is found (Box 1).

How does a paediatric pain clinic operate?

In recent years a multidisciplinary approach to chronic pain in children, through specialised clinics, has evolved in Australian and overseas centres (Box 2).⁵ There are now seven paediatric multidisciplinary pain clinics in Australia. All clinics have teams consisting of at least medical, physiotherapy and psychology support. For details of paediatric pain clinics in Australia, including contact details for referrals, see www.painaustralia.org.au/getting-help/pain-services-programs/pain-services. Indications

1. PRACTICE POINTS ON COMPLEX OR PERSISTING PAIN IN CHILDREN

- A key aspect of good healthcare for children and young people is the prevention and management of pain.
- Complex pain in children occurs when pain persists beyond the expected time of healing or pain that is recurrent and has become complicated to manage.
- The experience of complex or persisting pain in children and adolescents has a major impact not only on the individual's physical, emotional, social and developmental wellbeing, but it also may have an impact on the broader world, which may include family, school and social networks.
- A clinical history and examination, and investigations if necessary, should all be devoted to making a diagnosis of the underlying cause of pain.
- A referral to a paediatric multidisciplinary paediatric pain clinic should be considered for all children and adolescents with complex pain.
- A paediatric pain clinic adopts a holistic approach to care using a biopsychosocial model for assessment and management.
- An outcome of an initial paediatric pain clinic review is the development of a pain management plan that addresses the pharmacological, physical and psychological management, as well as other domains of care.
- Paediatric pain clinics are improving access by embracing technology through telehealth and treatment options through internet programs.
- Outcome measurement will guide the development of models of care in the future.

for a referral to a paediatric pain clinic are listed in Box 3.

After a triage process ensuring an appropriate diagnostic process has been completed, the initial assessment in the pain clinic begins with a review of the electronic Persistent Pain Outcomes Collaborative (ePPOC) assessment data. A thorough medical history, including psychological and social factors, and a physical examination follow. After formulation of the key pain management issues, a discussion by the multidisciplinary team results in the

2. A MODEL OF CARE FOR COMPLEX PAEDIATRIC PAIN MANAGEMENT⁵

Attributes of services providing a comprehensive approach to complex pain management are included below.

- Recognition of the biopsychosocial factors in the experience and response to pain and provision of interventions and therapies to address these issues
- Early assessment and intervention
- Health promotion and prevention
- Development of greater self-management of chronic pain
- Collaboratively working with the community and primary care sector
- Multidisciplinary and interfaced with the paediatric sector and the acute care setting
- Provision of specialised pain services for inpatients and outpatients
- Orientation towards determining outcomes
- Informed by the best available evidence, including expert opinion

development of a pain management plan. This plan must consider the nuances of each case and offer a support structure to support adherence. The pain management plan includes pharmacological and non-pharmacological approaches (Box 4) and individual and family therapy as required.⁶ In the discussion of the plan with the child and family, pain education occurs and arrangements are made to ensure the plan is implemented through referral to, or liaison with, local practitioners as indicated and follow up (telephone, clinic and/or telehealth). Liaison with the school and the implementation of a school pain management plan is often needed.

What is the success of psychological therapies for complex pain in children and adolescents?

Psychological therapies are broad ranging and target pain-related cognitions and/or behaviours. They range in delivery modes, including face-to-face, internet, phone and, more recently, apps and web-sites. The effectiveness of psychological therapies across a range of delivery modes

3. INDICATIONS FOR A REFERRAL TO A PAEDIATRIC PAIN CLINIC

Consider referral to a paediatric pain clinic if a child has persisting pain OR if the natural history of the painful condition predicts this is likely to be the case OR if episodic severe pain occurs which interferes with daily life AND when:

- all reasonable investigations have been completed
- reasonable and accessible management in the primary care sector has been tried with insufficient success
- pain has significant impact on some aspects of life: sleep, self-care, mobility, work or school attendance, recreation, relationships and/or emotions
- pain exacerbations have resulted in an emergency department presentation or hospital admission
- complex psychosocial influences on pain behaviour require specialised assessment and care
- current or past history of addiction or prescribed medication use seem to be complicating current management
- difficult-to-control neuropathic pain is present
- difficult-to-control cancer pain is present

for children and adolescents with pain conditions has been evaluated recently by Cochrane and systematic reviews.⁷⁻⁹ These studies concluded that psychological therapies were effective in reducing pain intensity and disability for children with headache and nonheadache pain conditions.⁷⁻⁹

Referrals and categorisation of new presentations to a paediatric complex pain clinic

Referrals to paediatric pain clinics are generally accepted from GPs and medical specialists based in the community and within paediatric hospitals across Australia. From July 2017 to June 2018, the Children's Hospital at Westmead (CHW) complex pain clinic saw 152 new patients. In keeping with previously published data, 64.1% of new patient referrals were female. Most presentations were for children over 13 years of age, which is also reflected in previously

4. NONPHARMACOLOGICAL METHODS OF PAIN CONTROL FOR CHILDREN

Nonpharmacological methods of pain control include techniques categorised as follows.

- Physical (e.g. exercise and physical activity, heat, cold, transcutaneous electrical nerve stimulation [TENS], acupuncture, massage)
- Behavioural (e.g. relaxation, biofeedback, modelling, reinforcement, desensitisation)
- Cognitive (e.g. distraction, imagery, thought stopping, hypnosis, mindfulness, music therapy), according to whether the intervention is focused on modifying an individual's sensory perception, behaviours or thoughts and coping abilities.⁶

The choice of which nonpharmacological method to use is based on the child's age, behavioural factors, coping ability, fear and anxiety, and the type of pain experienced.⁶ Cognitive behavioural techniques are commonly used to decrease distress and enhance a child's ability to cope.

published Australian data.³ Most patients required at least one follow-up review in the clinic and adherence with treatment was generally good, resulting in most having a clinically significant improvement in quality of life and an improvement in functional disability.

Most patients presented to the CHW complex pain clinic with musculoskeletal pain (39%), including limb and joint pains (without hypermobility), back pain and avascular necrosis. Presentations of abdominal pain, complex regional pain syndrome, hypermobility with joint pain and post-operative pain were all similar in number (ranging from 8 to 13%). Persisting post-operative pain was defined as pain occurring beyond the time of tissue healing following a surgical intervention. Generalised body pain with somatising features and headaches was less commonly seen. Several additional presentations to the CHW complex pain clinic could not be categorised, including vaginal pain, ear pain, pain secondary to Fabry's disease, itch and peripheral neuropathic pain.

New innovations in access to specialist services

Telehealth

In 2015, a six-month pilot study evaluating the use of telehealth as a modality for chronic pain management was conducted by the Agency of Clinical Innovation at two NSW chronic pain clinics: the CHW complex pain clinic and Orange Hospital.¹⁰ Healthdirect Australia provided the platform to the two pilot sites. The platform is internet browser based and has no licensing fees, necessity to download software or expensive cameras or screens, enabling direct access into clinician's rooms and the patient's home.¹⁰ During the six-month pilot phase at the CHW complex pain clinic, there was a total of 14 sessions and 3346 km were saved in patient travel. During the trial, 100% of patients and clinicians stated they found it convenient, effective and educational and would recommend its use.¹⁰ Patients reported the large benefit was prevention of a flare up of pain which would likely have been the outcome of travel to such appointments. There was an increase in subsequent referrals from professionals who participated in telehealth sessions.¹⁰ This successful pilot study provided evidence for the use of telehealth in the management of children with complex pain. Most paediatric pain services have this capability in Australia.

Paediatric day pain program

In response to the need to create a new treatment option for high-school students who were making minimal improvements in the community and did not require inpatient admission and based on growing international evidence, the CHW complex pain clinic conducted its first multidisciplinary moderate-intensity group pain day program in 2013, titled 'T.A.M.E Your Pain' (Teaching Adolescents to Manage Pain through Exercise and Empowerment).¹¹ The program runs for five days, split over two weeks, during school holidays.

The program integrates land- and pool-based physiotherapy, supervised practice of nonpharmacological pain management

5. MEASURES OF OUTCOME FOR A PAEDIATRIC PAIN CLINIC

The following parameters are measures of positive outcomes for the child with persisting pain following the interventions of a pain clinic:

- increased school or work attendance
- improved quality of life
- reduced functional disability
- reduced emotional disability
- decreased health service use
- decreased pain severity and frequency
- decreased analgesic use

strategies, including deep breathing, mindfulness, relaxation and hypnosis, with education on goal setting, pacing, sleep management and flare-up prevention and management. Validated outcome measures used to evaluate the program demonstrated sustained improvements at 12 months' follow up. These outcomes potentially support a cost-effective day program as an alternative to a costly hospital admission rehabilitation program.

Paediatric pain clinic outcomes

With the aim of improving pain services and patient outcomes through benchmarking of care and research, a chronic pain treatment outcomes registry, the ePPOC, was established in 2013 (<http://ahsri.uow.edu.au/eppoc/index.html>).¹² In paediatric pain clinics, child self-report measures (for those aged 5 years and above) and parent/carer measures are collected. The paediatric measures selected are banded into age groups ensuring levels of development and language are appropriate. Measures of positive outcomes for a child with persisting pain after attending a complex pain clinic are listed in Box 5. The case study in Box 6 gives an example of a specific pain management plan.

A German study has confirmed inpatient and outpatient treatments elicit substantial changes in pain intensity, disability and school attendance in children with chronic pain.¹³ Of 105 patients who missed five or more days of school

6. CASE STUDY

Brienne is a 13-year-old patient who is referred to a paediatric pain clinic by her GP with a three-month history of persisting pain in her foot following a minor twisting injury. Her GP made a diagnosis of complex regional pain syndrome (CRPS) based on the clinical findings of colour and temperature changes, swelling and allodynia. Brienne has not been to school for the past three months because of pain, despite her mother administering simple analgesics daily and support from a local physiotherapist who had recommended a daily exercise program with which Brienne has not been adherent. Brienne needs crutches to ambulate.

Brienne completes screening questionnaires before attending the clinic. The results indicate high-level anxiety and sleep disturbance.

Brienne attends the paediatric pain clinic with her mother and is seen by a multidisciplinary team consisting of medical, nursing, psychology and physiotherapy clinicians. The team concur with the diagnosis of CRPS but elicit further history, which uncovers significant school bullying and reduced exercise performance because of anticipatory anxiety before exercise. She has difficulty initiating sleep because of pain but remains asleep without disturbance once sleep commences.

Brienne's pain management plan is outlined below.

- **Medicine:** simple analgesics before exercise are recommended, if effective.
- **Movement:** a graded comprehensive exercise plan are created by the team physiotherapist, including strategies for functional desensitisation incorporating distraction and relaxation. A paediatric physiotherapist in her local area is contacted for ongoing physiotherapy. A plan for her anticipatory anxiety is discussed (see below) as well as a plan for the gradual removal of crutches. The local physiotherapist recommends hydrotherapy. The local physiotherapist was supported by telephone advice from the pain clinic physiotherapist.
- **Mind:** strategies for anticipatory anxiety before exercise are given by the team psychologist, as well as instructions on breathing techniques for management of her anxiety. Brienne is referred for psychologist review in her local area. The team's psychologist contacts the local psychologist with the clinical details and advises about additional strategies for pain management. The team psychologist remains available for further contact. Brienne has ongoing psychological support and is assisted with further strategies for anxiety and nonpharmacological pain management.
- **School:** a plan for a graded return to school is made. The plan includes pain management strategies while Brienne is at school. Direct contact is made with her school teacher to address the bullying issue.
- **GP review:** contact is made with Brienne's GP regarding the pain management plan and a date is made for a subsequent teleconference with the GP, Brienne and her mother. The family receive ongoing telephone support throughout the course of treatment by the pain clinic nurse practitioner who answers ongoing questions and supports adherence to the pain management plan.

The outcome is highly successful. Within two months, Brienne is pain free, not using crutches and is attending school full-time.

because of pain, 93 attended school regularly after treatment.³ Additionally, sleep disturbance improved in 88% of patients and 88% resumed sporting activity after multidisciplinary intervention.³ Outcome was classified as good in 134 patients (65%), moderate in 32 (15%) and poor in 16 (8%).³ Following further collection and analysis of ePPOC data, it is hoped further objective data will be obtained to determine the effectiveness of pain clinic outcomes and allow opportunities for improvement.

Conclusion

Persisting pain in children and young people is prevalent and distressing. It is important to recognise this as an entity and adopt a biopsychosocial approach to assessment and management. The indications for considering referral to a paediatric pain clinic are discussed in this article. Paediatric pain clinics are becoming more accessible to those who need them through use of telehealth, and the measurement of outcomes will guide the development of models of care in the future.

References

1. Classification of chronic pain. Descriptions of chronic pain syndromes and definitions of pain terms. Prepared by the International Association for the Study of Pain, Subcommittee on Taxonomy. *Pain Suppl* 1986; 3: S1-S226.
2. King S, Chambers CT, Hugue A, et al. The epidemiology of chronic pain in children and adolescents revisited: a systematic review. *Pain* 2011; 152: 2279-2738.
3. Chalkiadis GA. Management of chronic pain in children. *Med J Aust* 2001; 175: 476-479.
4. McGrath PJ, Unruh AM, Branson SM. Chronic nonmalignant pain with disability. In: *Advances in Pain Research and therapy*, eds Tyler DC, Krane EJ; 1998; Raven press; New York
5. Conway J, Higgins I. Literature review: models of care for pain management, 2011. Available online at: www.health.nsw.gov.au/PainManagement/Documents/appendix-3-literature-review.pdf (accessed April 2019).
6. McGrath PA. Intervention and management. In: Bush JP, Harkins SW, eds. *Children in pain*. New York: Springer-Verlag; 1991. p. 83-115.
7. Eccleston C, Palermo TM, Williams ACDC, et al. Psychological therapies for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database Syst Rev* 2014; (5): CD003968.
8. Fisher E, Palermo TM, Williams ACDC, Lau J, Eccleston C. Systematic review and meta-analysis of psychological therapies for children with chronic pain. *J Pediatr Psychol* 2014; 39: 763-782.
9. Fisher E, Law E, Palermo T, Eccleston C. Psychological therapies (remotely delivered) for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database Syst Rev* 2015; (3): CD011118.
10. NSW Agency for Clinical Innovation (ACI). Chronic pain telehealth pilot project. Evaluation report 2016. ACI Pain Management Network. Agency for Clinical Innovation 2016. Available online at: www.aci.health.nsw.gov.au/__data/assets/pdf_file/0005/297842/Chronic_Pain_Telehealth_Pilot_Project_Evaluation_report_2016_v2.pdf (accessed April 2019).
11. Logan D, Carpino, EA, Chiang G, et al. A day-hospital approach to treatment of pediatric complex regional pain syndrome: Initial functional outcomes. *Clin J Pain* 2012; 28: 766-775.
12. Tardif H, Arnold A, Hayes C, Eager K. Establishment of the Australasian Electronic Persistent Pain Outcomes Collaboration. *Pain Med* 2016; 18: 1007-1018.
13. Hechler T, Wager J, Zernikow B. Chronic pain treatment in children and adolescents: less is good, more is sometimes better. *BMC Pediatrics* 2014; 14: 262.

COMPETING INTERESTS: None.