



# Management of chronic pain in children

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## KEYWORDS

Chronic pain;  
Children

**Summary** Children can experience many types of chronic pain caused by disease and injury such as cancer, arthritis, sickle-cell anaemia, haemophilia, neuralgia, accidental trauma, HIV infection, and burns. They can also develop chronic pain caused by anxiety, depression, and emotional distress associated with a prolonged illness. Most children who have chronic or recurrent types of pain cope quite well. However, there is a small group of children whose lives become significantly disrupted because of chronic pain. Inability to cope with pain may lead to disability. General treatment goals include increasing independent functioning; remediating specific symptoms, deficits, or problems revealed in a comprehensive biopsychosocial assessment; enhancing effective communication; and facilitating more active problem solving skills. Depending on the results of the assessment, treatment might include a combination of cognitive strategies, behavioural techniques, family interventions, physical interventions, and pharmacological interventions.

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## Practice points

- Many children experience recurrent 'benign' pains, there are few serious chronic pain syndromes
- There is a small group of children whose lives become significantly disrupted because of chronic pain
- Most children who have chronic or recurrent types of pain cope quite well
- Inability to cope with pain leads to disability (e.g. school absenteeism)

- Three factors are necessary for the development of severe 'psychosomatic' illness in children: (1) the child must be physiologically vulnerable; (2) the family must possess the following characteristics: enmeshment, overprotectiveness, rigidity, and lack of conflict resolution; (3) the child must play an important role in the family's pattern of conflict avoidance, and this role must be important in the reinforcement of the child's symptoms
- The failure to find an organic cause of the pain does not mean that the pain is psychogenic but simply that the cause is unknown

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- Pharmacological approaches to chronic pain management, except cancer pain, have limited effectiveness
- Multidisciplinary approach is fundamental in chronic pain management

## Introduction

Chronic pain has been recognized as that pain which persists past the normal time of healing.<sup>1</sup> In practice this may be less than 1 month, or more often, more than 6 months. With non-malignant pain, 3 months is the most convenient point of division between acute and chronic pain, but for cancer pain, 3 months is too long to wait before regarding a pain as chronic. The definition related to the time of normal healing is not sufficient. Many syndromes are treated as examples of chronic pain although normal healing has not occurred.<sup>2</sup>

Children can experience many types of chronic pain caused by disease and injury such as cancer, arthritis, sickle-cell anaemia, haemophilia, neuralgia, accidental trauma, HIV infection, and burns. They can also develop chronic pain caused by anxiety, depression, and emotional distress associated with a prolonged illness.<sup>3</sup>

It is useful to distinguish between the common recurrent 'benign' pains of childhood and the less common forms of chronic persistent pain. A large proportion of otherwise healthy children experience recurrent episodes of non-specific headache, chest pain, abdominal pain, or limb pains. The art of general paediatric practice lies in distinguishing these unpleasant but essentially benign problems from those symptoms that suggest more serious illness.<sup>4</sup>

Crue<sup>5</sup> distinguishes four types of long-term pain from varying sources and with different coping effectiveness:

1. Recurrent acute pain—refers to pain from underlying recurrent or continued nociceptive input (e.g. migraine or arthritis).
2. Ongoing acute pain—refers to pain from malignant disease.
3. Chronic benign pain—refers to ongoing pain with no known nociceptive input but with adequate coping.
4. Chronic benign intractable pain syndrome (i.e. chronic non-malignant pain with disability, according to McGrath et al.)<sup>6</sup>—pain can be of unknown origin; it is long lasting and interferes, in a major way, with the child's life; there is no

pathological organic process that can account for the disability, or the child's pain far exceeds the known cause.

Most children who have chronic or recurrent types of pain cope quite well. However, there is a small group of children whose lives become significantly disrupted because of chronic pain. McGrath et al.<sup>6</sup> estimated that chronic non-malignant pain with disability occurs in less than 10% of children who have a pain disorder, i.e. about 1% of the paediatric population.

According to McGrath et al.<sup>6</sup> seven explanatory models can be applied to the syndrome of chronic non-malignant pain with disability: family functioning, modelling, depression, coping with stress, reinforcement, somatization disorder, and central nervous system pain mechanisms.

## Family functioning

Family overinvolvement and enmeshment of parents in the lives of their children, which tend to be expressed in excessive caregiving and control over the adolescent's behaviour, may cause chronic benign intractable pain syndrome. This pattern is often evident in the initial clinical interview when questions addressed to the child are repeatedly answered by the parent. Minuchin et al.<sup>7</sup> suggested that three factors are necessary for the development of severe 'psychosomatic' illness in children. First, the child must be physiologically vulnerable. Second, the family must possess the following characteristics: enmeshment, overprotectiveness, rigidity, and lack of conflict resolution. Finally, the child must play an important role in the family's pattern of conflict avoidance, and this role must be important in the reinforcement of the child's symptoms. Several factors in combination can produce parental overinvolvement: presence of long-term pain; at least one parent who is overinvolved (i.e. very sympathetic and domineering); the other parent must be collaborating in the overinvolvement or be absent physically or emotionally; finally, the child or adolescent must be unassertive in dealing with the pain and his or her parents.

## Modelling

Modelling may influence the development of chronic non-malignant pain with disability in several ways. Children may learn from their parent's specific pain syndromes, avoidance behaviour, the tendency to attend to pain sensations,

poor coping skills, and the value of pain as source of reinforcement.

### Depression

Depression may be seen as the result of having a longstanding pain disorder or as the initial condition generating pain as a symptom.

### Stressful life events

Stressful life events may precipitate recurrent pain. Children who are not coping well with pain may not only experience more stressful situations, but are likely to precipitate more stressful events in their lives.

### Reinforcement of pain behaviour

This may be an important factor in maladaptive coping with pain.

### Somatization disorder

This refers to a psychiatric disorder in which the patient reports a large number of physical symptoms that have interfered with everyday life and for which no organic cause can be found. Children who have numerous widespread or changing pain symptoms without specific physical findings, who are missing school, and whose parents have similar types of problems, are at risk of developing serious problems, including somatization disorder.

### Central nervous system pain mechanisms

Although a complete understanding of the neurophysiology of pain has not yet emerged, it may be that chronic non-malignant pain with disability is, in part, due to changes in functioning neurophysiology.

### Management of chronic non-malignant pain

Clinical guidelines for the management of chronic non-malignant pain with disability according to McGrath et al. are:<sup>6</sup>

1. Begin psychosocial assessment as soon as non-coping occurs. Children who are not attending school regularly or who are curtailing their social activities because of pain are not coping. Assessment consists mostly of interviewing, record keeping (e.g. pain diary), and observation of the interaction among family members.
2. Unless the cause of the pain is clearly evident, avoid the organic/psychogenic dichotomy. Most chronic non-malignant pain of childhood cannot be diagnosed as either organic or psychogenic and is of unknown origin. The failure to find an organic cause of the pain does not mean that the pain is psychogenic but simply that the cause is unknown. A finding of psychological causation cannot rule out organic factors or vice versa.
3. Use the least intrusive methods possible. Simple treatments such as reassurance and brief training in coping strategies should precede extensive psychological therapy, and outpatient therapy should be thoroughly tried before inpatient treatment is attempted.
4. Emphasize coping rather than curing. Children should be encouraged to engage in as many activities as they can that do not result in physical harm or debilitating levels of pain. Analgesics may be helpful, however, they do not provide a solution to the problem.
5. Focus on family strengths. The strengths of each family will vary. In one family, enmeshment can be reframed into closeness. In another family, strong identification with a parent can be used to model coping behaviour, or rebellion can be constructively channelled.
6. Investigate the school situation. A child who is not coping with chronic non-malignant pain may have a number of school-related stresses that could be triggering avoidance behaviour and non-coping pain behaviour. On the other hand, a child may be succeeding in school but have an overwhelming fear of failure. Telephone calls to the child's teacher may reveal serious stresses. Private discussions with the child may uncover hidden problems.
7. Teach coping skills. For example: total and partial muscle relaxation, self-hypnosis, deep breathing, cognitive and behavioural distraction, thought stopping, positive self-talk, problem solving, and assertiveness.
8. Listen to the patient. Never doubt patients' statements that they are in pain.
9. Do not blame the patient or family. Blaming the patient may be a response to our own frustration and inability to help. Some chronic pain patients may be skilled in triggering such responses.
10. Educate about pain. Knowledge can make the family and child feel they in a stronger position to discuss their situation with health professionals, it can correct misconceptions about

pain, and help to form an alliance with the doctor.

11. Understand without pitying. There is no place in chronic pain for self-pity. Tender loving care and extra attention for pain is appropriate when the pain is acute but is destructive for the patient who is not coping with chronic pain. Positive and firm expectations set by the health professional can provide a model for parents and hope for the child. Unrealistic goals will only encourage failure and future avoidance of attempts to cope effectively may lead families to drop out of therapy because of discouragement.

Bursch et al.<sup>8</sup> introduced a concept of pain-associated disability syndrome, which describes a subset of patients with chronic pain with common and severe difficulties in functioning, regardless of the location or cause of their pain. It is a model of disability that can help the clinician shift focus to a rehabilitation model of care while avoiding dichotomization of the pain as physical or psychological. Rather, it is assumed that all pain is physically mediated with biologic, psychologic, and social factors maintaining it. Disability in the above definition refers to school absenteeism and/or severe restriction of functioning in other activities. To meet the criteria for pain-associated disability syndrome, the severe disability has to have been present for at least 2 months. General treatment goals include: increasing independent functioning; remediating specific symptoms, deficits, or problems revealed in a comprehensive biopsychosocial assessment; enhancing effective communication; and facilitating more active problem solving skills. Depending on the results of the assessment, treatment might include a combination of cognitive strategies, behavioural techniques, family interventions, physical interventions, and pharmacological interventions.

Unfortunately, in situations when psychological treatment could be helpful, it is seldom available. Many psychologists do not understand the complexities of significant pain, and few clinicians have a psychological orientation.<sup>9</sup>

Pharmacological approaches to chronic pain management in both adults and children have limited effectiveness. Treatment of chronic pain in children is based on extrapolation from experience with adults, limited controlled trials, surveys, and physicians' preferences. Therefore, clinicians often have to prescribe medications despite the lack of efficacy data or approval for paediatric use.<sup>10</sup>

Recurrent abdominal pain is experienced by approximately 5% of children and refers primarily

to a condition in which children who are otherwise medically well suffer episodes of pain interspersed with pain-free periods. A subgroup of these children has recognizable causes, such as constipation, lactose intolerance, uretero-pelvic junction obstruction, inflammatory bowel disease, endometriosis, or gastro-oesophageal reflux. Another subgroup has been hypothesized to have visceral hyperalgesia or visceral neuropathic pain. A major component of the therapeutic approach involves the education of patients and parents regarding the fact that these pains do not imply serious or progressive illness, and that continued participation in school and normal activities will not cause harm. Cognitive-behavioural treatment approaches are emphasized. Pharmacological treatments such as fibre supplementation, anti-cholinergics, sedatives, and tricyclic antidepressants have been tried, but there are comparatively few controlled trials.<sup>11</sup>

Recurrent headaches are experienced by 5–10% of school-aged children. The most common types are migraine and tension headaches. As with abdominal pains, most children cope well with them and they do not produce disability. The subgroup of children referred to pain clinics are commonly those with very severe pain episodes or those who have assumed a pattern of disability and school absenteeism. Many of the drugs commonly used for prophylaxis or interruption of migraine episodes have recently undergone clinical trials in children, including magnesium, ibuprofen, acetaminophen, sumatriptan, flunarizine, trazodone, and propranolol. Cognitive-behavioural treatments, return to school, and lifestyle interventions are emphasized. For example, education on how to improve sleep hygiene may result in reduction in the frequency of migraine episodes.<sup>11</sup>

Sickle cell anaemia may be associated with both recurrent acute severe pain and chronic persistent pain. The dominant pain is that associated with unpredictable and relentless vaso-occlusive episodes. Pain management should integrate pharmacologic, cognitive-behavioural and psychologic, and physical approaches within a supportive framework.<sup>12,13</sup>

Musculoskeletal pains are experienced by 15% of all school-age children. This group comprises chronic arthritis, juvenile primary fibromyalgia syndrome, back pain, knee pain, growing pains, and overuse injuries.

Neuropathic pain is due to abnormal excitability in the peripheral or central nervous system that may persist after an injury heals or inflammation subsides.<sup>2</sup> The pain is often described as burning or stabbing and may be associated with cutaneous

hypersensitivity (allodynia). Neuropathic pain conditions in childhood are not rare, and are often unrecognized by physicians.<sup>11</sup>

Phantom pain is defined as pain referred to a surgically removed limb or portion thereof.<sup>2</sup> Krane and Heller<sup>14</sup> found a 92% prevalence of phantom pain in paediatric amputees. Pre-emptive analgesia has not consistently prevented postoperative phantom limb pain.<sup>15</sup> Large-scale surveys of amputees show the ineffectiveness of treatments for phantom limb pain that fail to address its underlying mechanisms. Mechanism-based treatments were relatively effective in a few small studies. Pharmacological and behavioural treatments resulting in vasodilatation of the residual limb helped the burning component of phantom limb pain but not other features. Treatments to decrease muscle tension in the residual limb reduced cramping, but not other features.<sup>16,17</sup>

Complex Regional Pain Syndrome Type I (CRPS I), also known as reflex sympathetic dystrophy, is a syndrome that usually develops after an initiating noxious event, is not limited to the distribution of a single peripheral nerve, and is apparently disproportionate to the inciting event. It is associated at some point with evidence of oedema, changes in skin blood flow, abnormal sudomotor activity in the region of the pain, allodynia or hyperalgesia. The site is usually the distal aspect of an affected extremity or with a distal to proximal gradient.<sup>2</sup> As Berde and Kuttner<sup>11</sup> pointed out, treatments for CRPS I have followed the aphorism 'if your only tool is a hammer, the whole world looks like a nail'. Historically, anaesthetists performed sympathetic blocks; rheumatologists recommended steroids; physical therapists prescribed physiotherapy; neurologists prescribed anticonvulsants, beta blockers or alpha blockers; surgeons performed operative sympathectomy, and psychologists have recommended cognitive-behavioural treatment or psychotherapy, etc. Comparatively few treatments have received controlled trials. More comprehensive reviews have been published elsewhere.<sup>18</sup>

Chronic cancer pain may be cancer-related or therapy-related. Cancer-related pain is caused by the natural history of the tumour and may present as bone pain, soft tissue or organ pain, and neuropathic pain. Examples of therapy-related chronic pain include phantom pain, neuropathy secondary to vincristine or irradiation of a nerve plexus, prolonged post-lumbar puncture headache, pain due to mucositis or dermatitis, and others.<sup>19</sup> Although the principles of cancer pain management in children have been well-established,<sup>20</sup> cancer pain is still inadequately treated in children. Wolfe et al.<sup>21</sup> recently showed that 89% of children who

died from cancer in Boston between 1990 and 1997 suffered from pain during their last month of life. According to the parents, treatment of pain was successful only in 27% of cases.

Pain is the most frequent symptom in children with life-limiting conditions who require palliative care. The author's experience is based on 254 children with malignant and non-malignant life-limiting conditions, the patients of the Warsaw Hospice for Children, who were treated at home during the terminal phase of disease between 1994 and 2004. The cancer group ( $n=133$ ) consisted of 66 children with solid tumours, 39 children with brain tumours, and 28 children with leukaemia. The average time of home care in the malignant group was 50 days. Pain was experienced by 96% of children with cancer during this period. Paracetamol (1st step of the WHO analgesic ladder) was used in 49%, tramadol (2nd step of the WHO analgesic ladder) was used in 68%, and strong opioids (3rd step of the WHO analgesic ladder) were used in 63% of the cancer patients. Pain rated as moderate to severe (i.e. required treatment with strong opioid) was experienced by 76% of children with solid tumours, 46% of children with brain tumours, and 61% of children with leukaemia. In the group with non-malignant life-limiting conditions ( $n=121$ ), the prevalence of pain was 71%, however, only 6% of children experienced pain rated as moderate to severe and required strong opioids. The average time of home care in the non-malignant group was 447 days.

We evaluated the effectiveness of our palliative home care programme. Parents' primary expectation was that the programme would relieve their children's suffering. Hospice services appeared effective in this regard, as most parents felt that their children died at home peacefully and free from suffering. Additionally, parents felt their children's symptoms were well managed. Parents also noted a range of understandable psychological stresses such as helplessness, fear, and emotional exhaustion. The results suggest that the hospice program was limited in its effectiveness in reducing parental psychological distress. Naturally, not all components of human suffering can be eliminated and it is likely that some aspects of suffering are so personal and individual that hospice services cannot affect any significant change. Even so, levels of satisfaction with hospice services indicate that, despite their suffering, parents appreciated and benefited from the hospice care.<sup>22</sup>

The author's opinion, despite the results obtained by Wolfe et al.<sup>21</sup>, is that cancer pain in children can be successfully controlled in the terminal phase in the majority of cases. In the



**Figure 1** Effective symptom management and consecutive new aspects ('faces') of suffering—a 'multi-curtain effect'.

upper mentioned group, only one patient out of 133 required terminal sedation because of refractory pain and inadequate pain control. He was a 3-year-old boy dying of rhabdomyosarcoma of the nose and pharynx. The factors which are crucial for effective pain control are: home setting, fast access to a pain specialist 24h a day, nurses experienced in palliative care, reliable and continuous pain assessment, availability of advanced pain management techniques (e.g. PCA, epidurals, TENS) at home, and methadone as a drug of choice in refractory cancer pain.

However, freedom from pain is not necessarily synonymous with freedom from suffering at the end of life. Suffering is not directly related to the severity of unrelieved physical symptoms. It is experienced and can occur in relation to any aspect of the patient's life—physical, psychological, social, or spiritual. A sense of loss of meaning and purpose, helplessness, hopelessness, endlessness, and lack of control are major causes of suffering.<sup>23</sup> Sometimes, especially in adolescents, effective pain management leads to the discovery of new (hidden) aspects of suffering (see Fig. 1).

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