

## MISE AU POINT/IN DEPTH REVIEW CHRONIC PAIN IN YOUNG PEOPLE: THE SITUATION IN LEBANON

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**ABSTRACT** • Chronic pain in young people has become a public health problem worldwide with an enormous societal impact. However, chronic pain in children is still an understudied and undertreated problem, particularly in low income countries. A better understanding of the problem is critical to help improve the care this population receives. The objective of this review was to summarize the state of knowledge about children and adolescents with chronic pain in Lebanon by looking into the studies published in the previous 10 years. The data shows that young people living in Lebanon suffer from different chronic pain problems, and that the management of pain is far from being satisfactory. The re-view identified significant gaps in the study and treatment

of this problem. Research, with a specific sociocultural approach, is critical in order to help take informed decision on what to do and how to best use the limited resources. Improved education is also crucial to improve the treatment that professionals are currently providing, and to increase the awareness that chronic pain in young people is a public health problem which deserves close attention.

Keywords: children; chronic pain; Lebanon; pediatrics

Finianos J, Abu-Saad Huijer H, Miró J. Situation des enfants et adolescents souffrant de douleur chronique au Liban. *J Med Liban* 2021; 69 (1): 30-38.

**RÉSUMÉ** • La douleur chronique chez les jeunes est devenue un problème de santé publique dans le monde entier avec un énorme impact sur les sociétés. Cependant, la douleur chronique chez les enfants reste un problème sous-étudié et sous-traité, en particulier dans les pays à faible revenu. Une meilleure compréhension du problème est essentielle pour améliorer les soins que cette population reçoit. L'objectif de cette mise au point est de résumer la situation des enfants et adolescents souffrant de douleur chronique au Liban en examinant les études publiées au cours des 10 dernières années. Les résultats montrent que les jeunes vivant au Liban souffrent de différents problèmes de douleur chronique et que le contrôle de la douleur dans cette population est loin d'être satisfaisant, identifiant des lacunes importantes dans l'étude et le traitement de ce problème. La recherche, avec une approche socioculturelle spécifique, est essentielle pour aboutir à prendre des décisions éclairées, et comment utiliser au mieux nos ressources limitées. Une meilleure éducation est également cruciale pour améliorer les traitements actuellement dispensés et pour faire prendre conscience que la douleur chronique chez les jeunes est un problème de santé publique qui mérite une attention particulière.

Mots-clés: enfants; douleur chronique; Liban; pédiatrie

### INTRODUCTION

Chronic pain has been conceptualized as an unpleasant sensory and emotional experience that has persisted beyond the normal healing time, currently considered three months [1]. From a biopsychosocial perspective, chronic pain is a complex experience that arises from a dynamic interaction among physical (e.g. pain extent [2,3], cognitive (e.g. pain beliefs [4,5], emotional (e.g. depression [6], cultural (e.g. religion [7]), and contextual factors (e.g. parental responses to their children's pain behaviors [8]). The International Association for the Study of Pain

(IASP) distinguishes between primary and secondary chronic pain [9]. Primary chronic pain is understood as a disease in itself (e.g. abdominal pain, idiopathic back pain), whereas secondary chronic pain is the dominant problem of an underlying medical condition (e.g. cancer, juvenile arthritis [10]).

#### Chronic pain in young people is a public health problem

Chronic pain in young people has been described as a public health problem [11]. Existing estimates show that between 20% and 37% of young people have chronic pain [12], and about 5% suffer from high levels of pain-related disability [13]. Despite the use of different definitions and research methods which can influence results [14], female and older children have consistently reported significantly higher prevalence rates [13,15-17].

Chronic pain can severely impact an individual's physical and psychological function and as such negatively impact wellbeing and quality of life [18-21]. Young people

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with chronic pain usually report that pain severely interferes in their daily life such as absence from school, memory and attention problems, reduced contact with peers, decreased activity levels and emotional problems like depression and anxiety [21-25]. When left untreated, pain in children delays healing and recovery and makes future pain experiences worse [26]. Finally, the effects of chronic pain in these individuals may prolong well beyond adolescence. For example, having a chronic pain problem as an adolescent has been found to be a significant risk factor for chronic pain as an adult [26-28].

The negative impact of chronic pain extends to family members and society [16,20,29-30]. For example, parents with a child suffering from chronic pain show a lack of affective expressiveness and rigidity [31], and avoidance of activities such as staying away from other people [22] and even feelings of guilt for not being able to help their children [32]. Similarly, siblings of children with chronic pain have been found at a higher risk to develop emotional and behavioral symptoms than their peers [33-34].

Although common and with a highly detrimental impact, chronic pain in children is still an understudied and undertreated problem [35-38]. This is particularly true in low income countries [38-39]. For instance, it has been suggested that the prevalence of chronic pain in children and adolescents could be higher than currently thought [21] as most studies have been conducted in western high-income countries, and lower socioeconomic status has been significantly and positively associated with pain [6, 38,40-41]. Thus, low income countries may potentially suffer from higher chronic pain prevalence and incidence rates [21,38,42]. Future studies will have to elucidate this hypothesis.

Almost 10 years ago, Abu-Saad studied the situation of chronic pain in children living in Lebanon (2010). The author reported that despite the well-known impact of chronic pain on the children's lives no study had ever been conducted in Lebanon to tackle this issue, and cogently recommended the study of chronic pain prevalence and its correlates in Lebanon to be able to prevent and manage chronic pain in Lebanese youth. The objective of this review was to summarize the state of knowledge about children and adolescents with chronic pain in Lebanon, ten years after Abu-Saad's seminal review and suggestions [42], to help improve our understanding of the specific characteristics and needs of this young population suffering from chronic pain.

## METHODS

To determine the current situation of pediatric chronic pain in Lebanon and its treatment, and in order to maximize the number of papers retrieved, a two-stage search

strategy was used, similar to that implemented in analogous works [43]. First, we electronically searched the PsycINFO, MEDLINE, Scopus for studies published in the last ten years, that is, after the publication by Abu-Saad in 2010. Second, as it is common practice, the reference lists of relevant retrieved papers were specifically checked to identify other works that had not been found in the computerized search [40,44]. We focused on empirical articles, but we also searched for reviews which could help to provide the most comprehensive and updated information. In this search, we used the following terms: Pain AND (child\* OR adolescent OR infant OR pediatric OR paediatric OR young OR youth) AND Lebanon. Studies with participants up to 18 years of age were included in this review. Only articles written in English were included.

## RESULTS

Our initial search retrieved 71 citations. After removing duplicate publications and with the inclusion of six additional works – identified through searching the reference lists – 22 articles were selected based on their title and abstract. Of those, 14 articles were excluded, and eight were read in full for this review. See Figure 1 for a flow diagram of the article selection process.

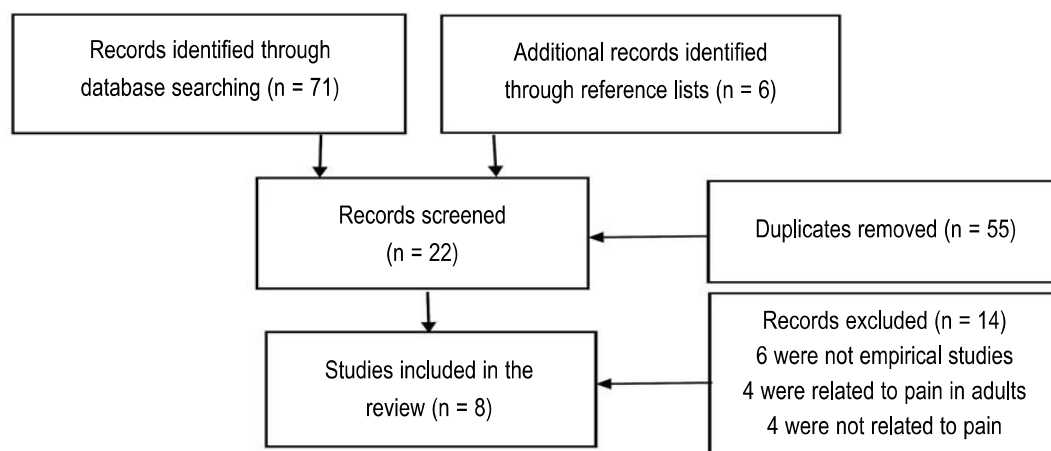
In this work, a narrative review approach has been used to synthesize the most important data. Relevant information of the studies is listed in Table I.

Half of the studies (N=4; 50%) were devoted to adolescents, particularly addressing assessment-related issues. Only two articles (25%) were on pain management, both on cancer pain problems. The sample size in these studies ranged from 12 to 180 participants with almost equal numbers of males and females. In three (37%) studies, the focus of interest was the parents of the children suffering from pain, and participants were mostly mothers.

Most studies dealt with secondary chronic pain (N = 7; 87%): six of them focused on cancer-related pain (75%), one was on sickle cell disease pain (12%) and another on pain in neurological injuries (12%). One study addressed primary chronic pain (i.e. neck pain). Studies were mostly cross-sectional (N = 7; 87%), only one included a follow-up.

### Cancer-related pain

Five studies were published on cancer-related pain. Two of them were devoted to children and adolescents. One focused on symptoms' prevalence, quality of life and palliative care in a sample of 85 children and adolescents who were being treated from cancer, mainly leukemia, at an academic teaching hospital in Lebanon [45]. The data



**Figure 1.** Flow chart of the selection process

showed that pain was one of the most commonly reported symptoms (53% of participants). The findings also showed that participants attending school regularly reported less pain and that despite the distressing symptoms, including pain, children reported good quality of palliative care [45].

In the second study, 62 children with cancer (mostly leukemia; 20) were interviewed. The purpose of the study was to describe pain characteristics and functional ability of children under treatment. The results showed that all children suffered from pain, which was mostly of moderate intensity (see Table I). Most of them not only suffered from pain due to their illness but also from treatment-related procedures. Half of the children reported that pain episodes lasted for at least two hours, and 8% reported having pain all the time. The forehead was the most common location of pain (38%). In addition to pain, most children (71%) suffered from moderate functional disability due to their pain (like not being able to run and play [20]).

The other three studies were related to parents of children with cancer and pain. One involved 125 parents whose children were suffering from leukemia that were requested to complete a questionnaire about the use of complementary and alternative medicine (CAM) therapies [46]. The objective of the study was to examine the types, frequency and reasons of CAM use. The results showed that CAM therapies (e.g., dietary supplements, prayer and spiritual healing, and unconventional cultural practices such as bone ashes ingestions) were used for different purposes, including pain management, especially in families that had previously dealt with painful cancer experiences. The authors made specific recommendations about the need to increase awareness on the effects and risks of CAM therapies, and suggested that only empirically-supported CAM therapies should be used [46].

The second study included 29 parents who lost their children to cancer [47]. The aim of the study was to evaluate the quality of palliative care provided in the last month of their children's lives. The parents were individually interviewed and requested to inform about the symptoms, their burden and management, communication, decision-making and quality of palliative care delivered. Among other severe problems, the authors found that most children ( $N = 23$ ; 79%) suffered from pain during the last month of their lives [47]. Among these, 82% ( $N = 19$ ) sought treatment to manage pain, however, less than half (42%) fully benefited from the treatment. Parents suggested some areas for improving palliative care, specifically mentioning: communication with health care providers and between the team, organization of care and teamwork, competence of the staff involved and psychological and social support for patients and their families [47].

The last study included 85 parents of children with cancer, mostly Leukemia [48]. The purpose of this study was to evaluate the quality of life and of palliative care, symptoms prevalence and management in children suffering from cancer from the parent's perspective.

The parents' input showed that 47% of children reported pain in addition to other frequent symptoms such as irritability, decreased energy and appetite. Of those, 67% sought treatment but only 66% succeeded. The study also showed that girls significantly reported more pain and that overall, parents were highly satisfied with the quality of care provided.

#### **Sickle cell disease pain (SCD)**

One of the studies reviewed included 12 adolescents with SCD [49]. The objective of this work was to study participants' daily responses and experiences with SCD, including pain. Participants reported pain as the most

**TABLE I** SUMMARY OF REPORTED FINDINGS

Authors	Sample Size	Sample Age	Study Design	Type of Pain Location / Diagnosis	Findings
Studies with children suffering from pain as participants					
Fares Ayoub Fares Khazim Khazim & Gebeily (2013)	122	< 18 years old Mean age = 14	Prospective study	Cluster munitions injuries	<ul style="list-style-type: none"> <li>- 88% diagnosed with PTSD.</li> <li>- 74% (N = 83) of children with non-lethal injuries were amputated.</li> <li>- 100% of children with amputations reported pain.</li> <li>- Types of pain reported were RLP (N = 59; 71%) and PLP (N = 31; 37%).</li> </ul>
Abu-Saad Sagherian & Tamim (2013)	85	7-18 years old Mean age = 12.5	Cross-sectional study	Cancer (Leukemia 37 Lymphoma 17 Head & Neck 12 Bones 11 Others 8)	<ul style="list-style-type: none"> <li>- 28% of children and 25% of adolescents reported pain as one of the most common symptoms.</li> <li>- 90% of children and 68% of adolescents seek treatment for pain.</li> <li>- Children attending schools reported better pain scores.</li> </ul>
Atoui Kurdahi Drenttel Khoury Shahine & Abboud (2015)	12	12-17 years old	Cross-sectional study	SCD	<ul style="list-style-type: none"> <li>- Pain was reported as the most common and limiting symptom affecting their functioning.</li> <li>- Acute pain was treated by medications.</li> <li>- Chronic pain was either downplayed in terms of severity to avoid guilt, denied or accepted as part of daily life and/or God's will.</li> <li>- School, physical and psychological problems were reported.</li> <li>- Families were identified as a source of support, but also a source of guilt.</li> </ul>
Fares Fares & Fares (2017)	180	8-17 years old	Cross-sectional study	Neck	<ul style="list-style-type: none"> <li>- School grades were declining in 64% (N = 114) of patients.</li> <li>- 82% (N = 147) of patients had behavioral changes (irritability) and poorer communication as reported by the parents.</li> <li>- Some became stressed (N = 112; 62%), anxious (N = 107; 59%) and/or showed depressive symptoms (N = 17; 9%).</li> </ul>
Madi & Clinton (2018)	62	8-17 years old	Cross-sectional correlational study	Cancer (Leukemia & Lymphoma 31 CNS tumor 16 Bone tumor 5 Other 10)	<ul style="list-style-type: none"> <li>- All children suffered from pain, mostly from a moderate and severe intensity: 16% (N = 10) mild, 71% (N = 44) moderate, and 13% (N = 8) severe.</li> <li>- Median duration of pain was 2h per episode.</li> <li>- The forehead was the most common location of pain (38%).</li> </ul>
Studies involving parents of children with pain					
Naja Alameddine Abboud Bustami & Al Halaby (2011)	125	Mean age = 38	Cross-sectional study	Leukemia	<ul style="list-style-type: none"> <li>- 15% of the parents reported using CAM at least once.</li> <li>- Types of CAM reported were dietary supplements, prayer and spiritual healing and unconventional cultural practices.</li> <li>- 42% reported using CAM to strengthen immunity, 21% to improve chance of cure and 11% to decrease pain.</li> </ul>
Saad Huijer Nouredine Muwakkit Saab & Abboud (2011)	29	Mean age = 43	Cross-sectional study	Cancer (different types of Leukemia and Sarcoma)	<ul style="list-style-type: none"> <li>- 79% of parents reported pain as one of the most prevalent and distressful symptoms for their children.</li> <li>- 82% informed that their children received treatment, but only 42% fully benefited from treatment.</li> <li>- Reported areas of improvement of PC were communication, empathy and competence of staff, accessibility to HCP, organization of care and teamwork, involvement of parents in decision making, and psychological and social support.</li> </ul>
Abu-Saad Sagherian & Tamim (2013)	85	**	Cross-sectional study	Cancer (Leukemia 38 Lymphoma 18 Head & Neck 12 Bones 10 Lung 2 Gastric 2 Spinal cord 2 Kidney 1)	<ul style="list-style-type: none"> <li>- 47% of parents reported that pain, aside other symptoms, is frequent among their children.</li> <li>- 66% of parents reported the success of pain treatment.</li> <li>- Girls significantly reported more pain.</li> <li>- Parents were highly satisfied with the quality of care despite inadequate management of some physical and psychological symptoms.</li> </ul>

Abbreviations : **PTSD** : Post-traumatic stress disorder **RLP** : Residual limb pain **PLP** : Phantom limb pain **SCD** : Sickle cell disease **CNS** : Central nervous system **CAM** : Complementary alternative medicine **PC** : Palliative care **HCP** : Health care provider

\*\* Not available

common and limiting problem that affected their function. When acute, pain was controlled with medications. However, authors believed that patients with chronic pain were either denying their pain and/or underreporting it, to reduce their sense of guilt deriving from the burden they impose on their caregivers, or accepting it as divine intervention and a part of their daily lives [49]. Adolescents also mentioned school issues (e.g., difficulty to focus, attendance), and physical and psychological limitations (e.g. inability to engage in physical activities, frustration for not being able to perform) due to their pain. In addition, they identified their families both as source of support (e.g. *“When hospitalized, my mother helps me to eat and go to the bathroom.”*) and guilt (e.g. *“When hospitalized, my mother sometimes sleeps on the floor all night which makes me feel guilty.”*).

### Neck pain

A study conducted with 180 children with chronic neck pain with spasms showed, as reported by their parents, that most of the children's (64%) school grades were declining. Eighty-two percent of the parents reported seeing behavioral changes (i.e., irritability) and poor communication in their children. Psychological effects such as stress (62%) and anxiety (59%) were commonly reported by participants, some of them (9%) also reported depressive symptoms [50].

### Munitions injuries pain

In a study with 122 young people from South Lebanon, symptoms of neurological injuries and pain related to cluster munitions were prospectively evaluated [51]. Ten children (8%) died during the time of the study. Among those that survived, all were diagnosed with post traumatic stress disorder (PTSD), and 74% of them were amputated. All children with amputations reported having pain. Common types of pain were residual limb pain (71%) and phantom limb pain (37%).

## DISCUSSION

Our work reviewed the studies that have been published about pediatric pain in Lebanon since the seminal work of Abu-Saad (2010). The review only identified eight studies that were of interest granted its scope and boundary conditions. Studies were mostly descriptive and cross-sectional with small samples.

The data from reviewed publications demonstrate that young people living in Lebanon suffer from different pain problems. Most importantly, reviewed studies suggest that there still are significant gaps in key areas in the study and treatment of pain as related to children. Most studies addressed secondary chronic pain, particularly

cancer related. Interestingly, primary chronic pain like headaches, or abdominal pain, causing an enormous societal negative impact worldwide [12], has not critically attracted the interest of researchers.

Despite studies reporting on interventions to improve the management of pain in young people [20,49,51], the control of pain in this population in Lebanon seems to be far from being satisfactory, as suggested by Noun *et al.* [52]. For example, data from two of the studies involving parents of children undergoing treatment for their cancer-related pain showed that parents perceived that their children pain was not properly managed. In one, 42% of parents reported that their children, while undergoing palliative care, did not fully benefit from pain treatment [47]. In the other, parents reported to be using complementary and alternative medicine (CAM) therapies, hoping to reduce pain of their children, relying on cultural beliefs (e.g. congestion of bone ashes) more than on empirical-based evidences [46]. Interestingly, in the third study, parents were however satisfied with the quality of care delivered [48].

The need to improve the management of pain in young people has been described in several works by Lebanese researchers [e.g. 18,20,39,47]. Thus, additional experimental treatment studies are necessary to improve the care provided. Some authors have suggested including family support and religion in pain management programs [e.g. 42,53]. Regardless of the content, treatment programs should be specially tailored for children, affordable, based on the culture and easily accessible. One way to progress, would be promoting the use of mobile health-related applications among health care practitioners and patients in Lebanon. A recent study has shown that there is a widespread use of mobile phones in the country, with almost four million and a half cell phones currently in use [54], which could increase the access to assessment and treatment for those in need. There are many mobile applications created for pain [43]. Although the field is undergoing some adjustments [55], there are mobile applications that have already undergone usability and effectiveness studies, accredited with quality seals, both for the assessment (e.g. [43]) and treatment (e.g. [56]) of young people with pain problems, that could be used at a very low or no cost to improve pain management of young people living in Lebanon.

In this review, we were not able to identify any epidemiological study. This type of studies is key to clarify what is most needed to improve the care provided to children with pain living in Lebanon. Epidemiological cross-sectional studies are important to identify what resources and treatments would result in the best benefit-cost ratio, whereas longitudinal studies are needed to identify what are the most important factors that might

negatively (and positively) influence the adjustment to and coping with pain among young people in Lebanon. Epidemiology studies are therefore needed to help policy makers and health care managers make informed decisions on whether and how to invest the resources available to manage chronic pain in children in Lebanon.

Similarly, no studies on the assessment of children with pain were retrieved in our search. Sound psychometric questionnaires are critical to pain management. Therefore, works might also be needed to develop novel and better measures or to study the psychometric properties of those that are already being used in the assessment of this population. Translation is not enough to ensure a proper function of a questionnaire; measures need to undergo thorough validation procedures [57-58]. For example, psychosocial variables like pain-related attitudes have been suggested to influence pain intensity reports and function among children suffering from chronic pain (e.g. [59]). In Lebanon, beliefs about pain are somewhat related to God's will, shame or stigma [53] and gender [20] issues. Illness and pain are commonly understood as God's will – thus, a problem that no one should interfere with –, felt as shameful – which could explain why many Lebanese keep it as a secret – and assumed that boys – if they are brave and strong – should endure pain with stoicism, whereas girls – somehow weaker –, can express their pain and emotional distress.

Recent studies with very diverse samples from different countries have shown that pain intensity questionnaires not only provide information about pain intensity, and that such “additional” information depends on the self-report questionnaire that is being used (e.g. [60-62]). Thus, specific studies with Lebanese samples are required to understand how these otherwise well-translated and validated measures work.

The inadequate management of pain in Lebanon and the limited number of published studies [20] might be in part due to the political, financial and occupational instability that has been taking place in the country for more than 30 years now, as suggested by Abu-Saad (2010). Lebanon is a country that has recurrently suffered from wars (the most recent in 2006), therefore, individuals living in Lebanon might be at an increased risk to suffer from chronic pain, mainly due to the association between chronic pain and PTSD [63]. This is particularly true for the most vulnerable individuals in society, which is the case of children.

An important barrier to improve the care of children with pain in Lebanon is the shortage of specialized health care providers [42,64]. In the country, only a few health care providers have specialized training and knowledge on the management of pain in young people [52] which is why pain is treated by general practitioners [21].

However, working with this population is challenging, particularly with children whose ability to express pain is limited or impaired [65]. In fact, this problem has been associated with an increased risk of developing chronic pain in other countries like the U.S. [66-68]. Studies conducted in Lebanon have shown that general non-specialized nurses tend to sometimes underestimate the pain of children, and even avoid its regular assessment due to their lack of knowledge [53], which has been identified as a potential risk factor in the development of chronic pain problems among children [69].

Inadequate training and education of professionals has been identified as an important barrier to proper pain management worldwide (e.g. [36,70-71]). There are no specific reports on how training of professionals is provided in Lebanon (number of hours, training model, etc.), but granted that there is a shortage of well-trained professionals, it is highly likely that education and training of future professionals is limited. Therefore, improving the training of professionals could help to positively change the situation of the treatment of children with pain in Lebanon.

In addition, children and their families as well could benefit from education on pain-related issues. For example, teaching children to report pain adequately and use appropriate coping strategies (e.g. distraction) would likely make them feel more involved [72]. On the other hand, educating parents about care options would help increase the use of evidence-based practices. Interestingly, the International Association for the Study of Pain Global Year 2019 was devoted to raise awareness, as well as to improve pain assessment and management for the most vulnerable, including pain in infants and young children, by promoting education and training to improve pain care worldwide [10].

Another important barrier for a proper pain management in children in Lebanon is the limited access to some pharmacological treatments (e.g. opioids). For example, in 2001, only 465 children (most of them with cancer) in Lebanon benefited from pain relief and palliative care when around 15000 children were in need of palliative care [64]. This shortage of potentially effective pharmacological treatments could help to explain, in part at least, the widespread use of non-pharmacological and CAM-related approaches among families living in Lebanon [65].

To summarize, the studies reviewed showed that chronic pain is a problem for young people living in Lebanon. This is no different to the situation in other countries.

However, specific contextual factors might increase its negative societal impact in Lebanon, for example, massive budget deficits [64] resulting in the inability to afford medical expenses [52] or the fact that healthcare

is almost restricted to suburban areas [21]. Although some important studies have been published since the work of Abu-Saad in 2010, additional works to help improve the treatment provided to young people suffering from chronic pain in Lebanon are warranted. Research is needed in order to help take informed decision, on what to do and how to best use the limited resources. As described previously, epidemiology works are of most importance. In addition, assessment and treatment-related studies addressing specific cultural factors are also essential. Education is also crucial in order to improve the treatment that professionals are currently providing. Furthermore, education is of most interest to increase the awareness that pain in children, particularly chronic pain, is a public health problem, one deserving close attention and in need of additional resources.

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