REVIEW ARTICLE

Pain in children with cerebral palsy and implications on nursing practice and research: integrative review*

Dor em crianças com paralisia cerebral e implicações na prática e pesquisa em enfermagem: revisão integrativa

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ABSTRACT

BACKGROUND AND OBJECTIVES: Due to physical impairment, cerebral palsy (CP) children have pain related to several hospital admissions and multiple knowingly painful procedures. This study aimed at identifying in the literature aspects related to pain in CP children and at evaluating implications for nursing practice and research.

CONTENTS: The keywords *nursing, pain, children* and *cerebral palsy* were queried in Medline, Pubmed, LILACS, Scielo and Cochrane Library databases. Starting date was not limited and final date was October 30, 2011. Among 69 publications, 19 have met the inclusion criteria. The analysis has resulted in four categories: CP children acute pain management; CP children chronic pain management; use of validated tools for pain evaluation; and family participation in CP children's care. Results reflect the complexity of CP children pain management and the need for specialized nursing care and multidisciplinary approach.

CONCLUSION: Notwithstanding the scarcity of publications on this subject, we have identified major aspects of nursing practices for CP children pain management. Faced to complex CP children damages, the evaluation of the painful process should permeate not only the physical dimension, but also psychological, social and spiritual dimensions, which are still seldom discussed in clinical settings. The nursing team should be equipped, should adopt evidence-based practices and translate them into clinical and managerial indicators.

Keywords: Cerebral palsy, Pain, Pediatric nursing.

RESUMO

JUSTIFICATIVA E OBJETIVOS: Em decorrência do comprometimento físico, a criança com paralisia cerebral (PC) é acometida por processos dolorosos, relacionados às diversas internações e múltiplos procedimentos reconhecidos como álgicos. Os objetivos do estudo foram identificar na literatura aspectos relacionados à dor das crianças com PC e avaliar as implicações para a prática e a pesquisa de enfermagem.

CONTEÚDO: Os descritores utilizados foram *nursing, pain, children* e *cerebral palsy* nas bases de dados Medline, Pubmed, LILACS, Scielo e Biblioteca Cochrane. A data inicial não foi limitada e a data final foi 30 de outubro de 2011. Dentre as 69 publicações, 19 atenderam aos critérios de inclusão. A análise resultou em quatro categorias temáticas: manuseio da dor aguda na criança com PC; manuseio da dor crônica na criança com PC; utilização de instrumentos validados para a avaliação da dor; e participação da família no cuidado à criança com PC. Os resultados refletem a complexidade do manuseio da dor em crianças com PC, bem como a necessidade de cuidado especializado de enfermagem e de abordagem multiprofissional.

CONCLUSÃO: Apesar da escassez de publicação referente a essa temática, identificaram-se aspectos importantes da prática de enfermagem mediante a dor da criança com PC. Frente à complexidade de agravos da criança com PC, a avaliação do processo doloroso deve permear não somente a dimensão física, como também as dimensões psicológica, social e espiritual, ainda pouco discutidas na clínica. A enfermagem deve se instrumentalizar, adotar práticas baseadas em evidências e transformá-las em indicadores clínicos e gerenciais.

Descritores: Dor, Enfermagem pediátrica, Paralisia cerebral.

INTRODUCTION

Cerebral palsy (CP) definition is reviewed and modified since 1964 as a function of improved knowledge about this condition. The latest change dates from 2004 and defines CP as a group of posture and movement development disorders leading to limitation of activities, being attributed to non progressive brain disorders during fetal development or childhood. CP motor disorders are often followed by sensory, cognitive, communication and perception disorders, in addition to potential identification of behavioral disorders and epileptic crises[1].

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Pre, peri and postnatal periods are considered critical for encephalic development impairment[2].

In developed countries, the incidence of CP is 2 to 3:1000 liveborns, and evidences point to a higher incidence of this morbidity among premature low weight children. In developing countries, the incidence of CP is higher as compared to developed countries[3-5].

In general, CP is classified in three groups: spastic, considered the most common presentation with prevalence of 80% to 90%; dyskinetic, with prevalence of 5% to 10% and ataxic, with prevalence of 2% to 5%[6].

CP is often diagnosed later, when children present motor development delay, persistence of primitive reflexes and abnormal behaviors and postural reactions[2], which result in late children and families follow up and, as a consequence, in the rehabilitation process, thus impairing their quality of life.

In addition, the stigma attributed to CP children is another relevant aspect to be considered, since it may generate discomfort and social isolation of children and their families, negatively impacting their clinical evolution[7,8].

Due to physical impairment, CP children are affected by painful processes, be them related to several hospitalizations and knowingly painful procedures, be it by the level of musculoskeletal impairment leading to movement limitations and inadequate posture[3,9].

Children with neurological deficits are at higher risk for experiencing pain, because they have additional clinical problems which may induce pain; they are often submitted to painful procedures; have idiosyncrasies which may mask the expression of pain; have already some pain indicators, such as change in facial expression and sleep pattern as a function of their condition, which make difficult the evaluation of the painful phenomenon; have their comfort not so valued as compared to other children without neurological deficits[10].

Advances in studies on painful perception of neonates and children reinforce that verbal communication inability does not reflect the absence of pain, which justifies the need for adequate pain relief. This way, all individuals who, for any reason, cannot verbalize their pain, such as children in pre-verbal development stage, those clinically severe and those with some neurological deficit, should be adequately and specifically assisted[11].

In this context, nursing interventions to evaluate pain become critical, in addition to the implementation of pain perception prevention, of proposed treatment and revaluation of applied therapy.

This study aimed at identifying in the literature aspects related to pain in CP children and at evaluating its implications on nursing practice and research.

CONTENTS

This is an integrative literature review on pain in CP children and its implications on nursing practice and research.

Integrative review is a research method which allows the incorporation of evidences to the clinical practice. It also allows the inclusion of different experimental, quasi experimental and non experimental study designs in the investigation. The development of the integrative review is defined by six steps: identification of the subject and selection of the research question; definition of inclusion and exclusion criteria for the studies; definition of information to be extracted from selected studies; evaluation of studies included in the review; interpretation of results; and presentation of the review[12,13]. All six steps were considered in the development of this study.

The research question was defined as: Which nursing strategies may contribute to the management of CP children's pain?

Keywords used in the query were *nursing, pain, children* and *cerebral palsy*. Queried databases were: Medline, Pubmed, LILACS, Scielo and Cochrane Library. Initial date was not limited for the query and final date was October 30, 2011.

Inclusion criteria were texts in English, Portuguese or Spanish, abstract and/or title with questions or words indicating pain management in CP children, as well as actions suggesting some direct or indirect nursing assistance.

The combination of keywords has resulted in a total of 69 texts and after applying inclusion criteria 50 were excluded resulting in a total of 19 texts.

All 19 texts were read in full and descriptive data are shown in table 1 in order of text citation.

As to the origin of studies, eight were developed in the United States, three in Northern Ireland, three in the United Kingdom, two in Spain, one in The Netherlands, one in Canada and one in China.

From 19 recovered texts, five have authorship of other professional categories except for nurses[14-18]. However, direct or indirect nursing actions were identified.

Knowledge areas identified in recovered journals were: Nursing, Medicine, Social Sciences and health professionals in general.

It could be observed that pain in CP children permeates the discussion in different knowledge areas, which makes necessary a multidisciplinary approach.

Primary discussions about pain identified in the texts were consolidated in four categories: management of CP children acute pain; management of CP children chronic pain; use of validated pain measurement tools; and participation of the family in the whole context of CP children care.

ACUTE PAIN MANAGEMENT

Parents, when qualified, are able to evaluate their children's pain, be it related to procedures or to the clinical condition itself, and contribute in an important way for the adequate therapy[16,17].

Among painful procedures, the use of puncture needles was the most mentioned by the studies. Daily situations identified by parents as painful were walking, stretching during rehabilitation, placement of orthosis and daily hygiene activities. In this context, CP children often experience acute pain due to therapeutic procedures, and chronic pain due to problems secondary to CP. One of the most frequent and painful problems is muscle spasm[16].

Surgical procedures, more specifically the postoperative period, were also described as painful. CP children, especially those with more severe neurological deficits, have a higher chance of being submitted to surgical procedures, such as joint luxation correction, application of botulinum toxin, rhizotomy, tenotomy, fasciotomy, correction of scoliosis and other deformities,

Table 1 – Description of selected texts

Authors	Types of Studies and Populations	Objectives
Moberg-Wolff et al.[14]	Experience report	To refine learning and knowledge of family-centered care of children with chronic impairment such as pain, spasticity and cognitive deficit.
Vles[15]	Prospective: 55 CP children between 3 to 18 years of age	To evaluate the reliability and efficiency of the visual analog scale (VAS) to evaluate spasticity management, which is considered painful, before and after botulinum toxin application.
Hadden and Von Baeyer[16]	Descriptive: 43 children between 1 and 19 years of age	To evaluate common behaviors of CP children when in pain.
Geiduschek et al.[17]	Retrospective: 55 CP patients between 3 to 22 years of age	To present the postoperative pain evaluation, as well as clinical management.
Cassidy et al.[18]	Retrospective: 37 children with CP and scoliosis from 11 to 27 years of age (20 without surgery for spinal stabilization and 17 with surgery)	To identify whether children with scoliosis submitted to spinal stabilization surgery have functional gain; to verify whether spinal stabilization surgery helps decreasing the amount of care to these children with regard to caregivers; to verify whether children submitted to spinal stabilization surgery have less pain and lung problems.
Hunt and Franck[19]	Experience Report with five families of CP children from 5 to 16 years of age.	To describe the experience if a CP children unit in the postoperative period, being evaluated with regard to pain with the Paediatric Pain Profile scale (PPP).
Ou et al.[20]	Descriptive, retrospective with documental evaluation: 27 CP children from 3 to 9 years of age.	To compare two surgical techniques with regard to postoperative pain control, time for mobilization in the postoperative period and hospital stay length.
Parkes et al.[21]	Descriptive transversal with home visit and interview: 99 children between 8 and 12 years of age.	To describe the health of CP children (evaluating the presence of pain, motor function, vision, hearing, communication, feeding and use of drugs) and to investigate stress predictors for their parents.
Zier et al.[22]	Randomized, double-blind and placebo controlled: 50 children randomized in two groups (nitrous oxide and midazolam citrate) aged between one and 16 years.	To compare the efficacy of inhaled nitrous oxide and enteral midazolam citrate for sedation of CP children submitted to muscular botulinum toxin A injection, by pain evaluation during the procedure and parents' satisfaction with the comfort of their children after the procedure.
Mckearnan et al.[23]	Literature review.	To observe subjects related to pain experience in cerebral palsy children.
McArthur and Dooley[24]	Experience report. Children with 17 years of age.	To discuss the clinical experience of adequate pain management of cerebral palsy children.
Mason[25]	Experience report	To describe recommendations about adequate pain management in children with neurological deficits.
Villarreal and Johnson[26]	Descriptive	To describe the psychological impact on the family of children with severe neurological deficits, including pain management during daily care.
Roscigno[27]	Literature review	To discuss the significance of pain in spasticity in children with spastic cerebral palsy, as well as possible mechanisms, agreements and limitations of evaluated studies.
Yu et al.[28]	Controlled randomized. 60 children between 2 and 12 years of age divided in two groups (30/30) for intervention (acupuncture) with and without music.	To evaluate the effectiveness of music on the expression of anxiety and pain in cerebral palsy children receiving acupuncture.
Riquelme, Cifre and Montoya[29]	Descriptive transversal by means of interview and observation of two groups from 6 to 35 years of age, with CP (86 participants) and without CP (115 participants),	To verify whether there is difference in pain intensity (using pressure in different body areas) and sensitivity to touch (using a test to evaluate sensitivity with Von Frey with monofilaments) in three age groups (6 to 10; 11 to 17; and 18 to 30 years of age) in individuals with and without CP.
Riquelme and Montoya[30]	Descriptive, transversal with observation of two groups: 5 to 55 years of age with CP and 5 to 42 years of age without CP, by means of interview, touch and pressure application.	To verify whether there is difference in proprioception, sensitivity to touch, pain intensity under pressure using a dynamometer (measures kgf in the pressed site) and somatosensory evoked potential (evaluation of brain wave by means of tactile and painless stimulation in dark environment) in individuals with CP (4 to 14 and 22 to 55 years of age) and without CP (5 to 14 and 22 to 42 years of age).
Donnelly et al.[31]	Descriptive transversal. 251 children from 4 to 25 years of age	To present a protocol to establish the prevalence of orthopedic problems and their impact on pain, motor function, social participation and health of children and adolescents with severe CP.
Dowling[32]	Experience report.	To describe the experience with pain evaluation of cerebral palsy children.

gastrostomy, among others. The postoperative period becomes more complicated for these children, especially for those unable to verbally communicate, being important the qualification of professionals for the adequate assistance of this population[17-26].

It was also observed the importance of the anesthetic process in the perioperative period of children submitted to botulinum toxin injections since this procedure requires several muscle punctures and is referred as painful. A study has compared the use of nitrous oxide and midazolam citrate in two groups of CP children during the toxin application. Sedation level was mea-

sured with the modified numerical scale with scores from zero to four, from the University of Michigan, where the higher the number the deeper the sedation.

Pain was evaluated by nurses using the Face, Legs, Activity, Cry, Consolability scale (FLACC) during the procedure. Results have pointed to the higher efficacy of nitrous oxide with regard to pain intensity during the procedure. When asked about their children's comfort after the procedure, parents have reported being happy with both therapies. Botulinum toxin aims at helping the management of spasticity[22]. It is worth stressing that the study compares sedation and analgesia for the same procedure.

CHRONIC PAIN MANAGEMENT

Another important aspect of chronic pain management reported by the studies was the importance of the evaluation of children's spasticity by the nursing team, since the success of spasmodic pain management depends on the understanding of pain mechanisms. It was also emphasized the importance of including in nursing assistance practices non pharmacological therapies such as heat, cold, physical movement and other exercises as pharmacological treatment adjuvants[27].

It is important to stress that one study has evaluated the use of non pharmacological therapies (acupuncture and music) for chronic pain relief. The study aimed at evaluating the effectiveness of music on anxiety and pain of CP children receiving acupuncture in a specialized clinic. Acupuncture was routinely used in the clinic under musical hearing of children's or parents' preferred songs aiming at knowing whether it would decrease anxiety and pain caused by needling during therapy.

Authors have previously selected 112 songs and, the day before, parents and children would choose 10 to be used during the procedure[28]. Although results have shown higher significance in decreasing anxiety as compared to pain, it is worth highlighting that a single nurse has evaluated anxiety and pain with different scales at the same moment. Other observation for further studies is that the musical selection should be determined by the investigator as from defined criteria related to his/her therapeutic intention.

Important characteristic was observed in the difference in pain perception among individuals with and without CP in different age groups. To recruit CP-free individuals, criteria were age compatible with the CP group and preserved cognitive level to answer simple questions (Yes or No). CP participants had preserved verbal expression.

Test for touch stimulation was Von Frey with monofilaments, often used in chronic pain patients to identify the presence of allodynia. The test used to identify pain was pressure with a dynamometer. No pain evaluation scales were used; confirmation was by participants' verbal expression. After applying pressure in different body regions, it was possible to observe that CP individuals (children, adolescents and adults), showed higher sensitivity to pain as compared to CP-free individuals and, topographically, have reported a higher number of painful body regions during tactile stimulation. CP children had lower sensitivity to painless stimulations and higher sensitivity to painful stimulations as compared to the CP-free group[29,30.]

USE OF VALIDATED PAIN EVALUATION TOOLS

Validated tools are critical for the evaluation of pain (acute or chronic) in CP children. Among studies systematically evaluating pain, the most widely used evaluation tools were Paediatric Pain Profile (PPP), Children's Hospital of Eastern Ontario Pain Scale (CHEOPS), Faces Visual Analog Scale (Wong Baker), Non-Communicating Children's Pain Checklist, Revised Faces Pain Scale, Visual Analog Scale (Williamson) and Face, Legs, Activity, Cry, Consolability (FLACC)[15,16,19,20,22,23,28,31,32]. Three studies have used more than one scale to compare results[15,20,28].

Authors have emphasized that professionals at bedside or giving care to the family should be clinically and scientifically prepared to recognize pain signs and to apply adequate tools. Scales used by the studies presented validity and reliability tests developed by their original authors.

More than evaluating pain, professionals should be sensitized by the pain of others, especially children with severe neurological deficits, since they are unable to verbalize their pain and are at higher risk for having their evaluation underestimated and their pain undertreated, as compared to children without neurological deficits[32].

PARTICIPATION OF THE FAMILY IN THE WHOLE CONTEXT OF CEREBRAL PALSY CHILDREN CARE

All texts selected by this review mentioned the family as integral part of the care-giving process.

CP children are at higher risk for experiencing the impairment of their health, especially in terms of physical functionality, body pain, general perception of health and family well-being, and stress lived during daily activities is a major factor. It is important to recognize the impact of family-centered care with regard to psychological, financial and physical capacity. For such, training programs for professionals are recommended[14,21].

Major implications for the nursing practice are: nursing evaluation of CP children with routine discussions about pain management and psychological disorders which are common; the use of tools which may guide clinical and family evaluation of assisted children with the development of strategies to keep family-centered care, since parents of CP children have a higher need for health professionals support to cope with the daily care of their children[21].

Results have shown a higher number of nursing studies in the area of pain evaluation, especially in the validation of tools/scales for this purpose. In addition, care of children and families was also observed as nursing practice and object of research.

It was also observed in clinical trials a trend toward nurses' participation being limited to the capturing of individuals with the Free and Informed Consent Term and to the management of protocols.

CONCLUSION

The literature recovered by this review was scarce, since the proposed query period was not limited in its initial date and the first text found dates from 1994. So, there are major implications for nursing research, since the survival of increasingly premature children is a reality, which is a risk factor for the increase in the

number of children with disorders, such as CP.

Even so, it was possible to identify important nursing practices with regard to CP children pain. In light of the complexity of disorders to which children and families are subject, pain evaluation should permeate not only the physical dimension, but also psychological, social and spiritual dimensions still seldom discussed in the clinical practice. For such, nurses should be equipped with tools, should adopt evidence-based practices and translate them into clinical and management indicators.

It should be also highlighted that the multidisciplinary work should be considered by the nursing clinical practice as a collaborative resource to manage pain, which requires thorough evaluation and not only directed to the painful focus.

No studies were found about pain management in CP children hospitalized for long periods (residents) or even children under the legal custody of the institution they are in. In such cases, the closest relation of the children is with their caregivers (institution's professional), which is a reality in the Brazilian health system.

Further studies are needed to understand the environment experienced by these children, the professionals' perception faced to prolonged hospitalization periods of children and the impact in their daily practice.

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