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Complementarity of pain assessment instruments in children with central nervous system impairment

Complementaridade de instrumentos de mensuração de dor em crianças com comprometimento do sistema nervoso central

Complementariedad de instrumentos de medición del dolor en niños con compromiso del sistema nervioso central

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ABSTRACT

Objective: To evaluate the complementarity of the revised Face, Legs, Activity, Cry, Consolability scale and of the Inventory of Pain Behavior in Neurological Disability for the assessment of pain in children with severe neurological impairment.
Method: Cross-sectional study conducted in pediatric units of a university hospital in the southern region of Brazil. The sample consisted of 26 children with severe neurological impairment, hospitalized from January to August 2019, and their caregivers. The data were analyzed by descriptive statistics; Kappa Coefficient, Fisher's Exact Test and Spearman's Coefficient were used ($p \leq 0{,}05$).
Results: Most children primary diagnosis was cerebral palsy (80.8%). Pain was present in 50.0% of children with the application of the scale and in 34.6% with that of the inventory. Considering the two instruments, there was good agreement (84.6%) between respondents ($k=0.692$; 95% CI 0.437-0.967; $p=0.000$).
Conclusion: The instruments can be used complementarily to assess pain in children with this profile.
Keywords: Brain damage, chronic. Central nervous system. Pain. Pediatric nursing. Pain measurement.

RESUMO

Objetivo: Avaliar a complementaridade da Escala *revised Faces, Legs, Activity, Cry and Consolability* e do Inventário de Comportamentos da Dor na Deficiência Neurológica para mensuração da dor em crianças com comprometimento neurológico severo.
Método: Estudo transversal, realizado em unidades pediátricas de um hospital universitário da região Sul do Brasil. Amostra de 26 crianças com comprometimento neurológico severo, internadas de janeiro a agosto de 2019, e seus cuidadores. Dados analisados por estatística descritiva; Coeficiente de Kappa, Teste Exato de Fisher e Coeficiente de Spearman foram utilizados ($p \leq 0{,}05$).
Resultados: Maioria das crianças apresentou diagnóstico primário de paralisia cerebral (80,8%). Presença de dor foi pontuada em 50% das crianças com a aplicação da escala e, em 34,6%, com inventário. Considerando os dois instrumentos, houve boa concordância (84,6%) entre os respondentes ($k=0{,}692$; IC 95%0,437-0,967; $p=0{,}000$).
Conclusão: Os instrumentos podem ser utilizados de forma complementar na avaliação da dor neste perfil de crianças.
Palavras-chave: Dano encefálico crônico. Sistema nervoso central. Dor. Enfermagem pediátrica. Medição da dor.

RESUMEN

Objetivo: Evaluar la complementariedad de la Escala *revised Faces, Legs, Activity, Cry and Consolability* y del Inventario de Comportamientos del Dolor en la Deficiencia Neurológica para la medición del dolor en los niños con severo compromiso neurológico.
Método: Estudio transversal, realizado en las unidades pediátricas de un hospital universitario de la región sur de Brasil. Muestra de 26 niños con severo compromiso neurológico, internados desde enero a agosto de 2019, y sus cuidadores. Datos analizados por estadística descriptiva; se utilizó el coeficiente Kappa, la Prueba Exacta de Fisher y la Coeficiente de Spearman ($p \leq 0{,}05$).
Resultados: La mayoría de los niños tenía un diagnóstico primario de parálisis cerebral (80,8%). La puntuación indicó presencia de dolor en 50% de los niños por la aplicación de la escala, y en 34,6%, por el inventario. Considerando los dos instrumentos, hubo una buena concordancia (84,6%) entre los encuestados ($k=0{,}692$; IC 95%0,437-0,967; $p=0{,}000$).
Conclusión: Los instrumentos se puede utilizar de forma complementaria para evaluar el dolor en este perfil de niños.
Palabras clave: Daño encefálico crónico. Sistema nervioso central. Dolor. Enfermería pediátrica. Dimensión del dolor.

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INTRODUCTION

Pain is defined as an unpleasant, sensory, and emotional experience, associated with a real or potential damage to tissues, or described in the same terms of this type of damage(1). Children who experience hospitalizations have to deal with a new environment, where they are exposed to procedures that cause fear and pain(2).

Pain in populations of children takes place through the analysis of three factors: physiological, behavioral, and/or self-reported. The self-report is seen as the golden standard to measure pain in children from four years old onwards(3). However, the evaluation of pain is complex when it must be done with children with severe neurological impairment (SNI). These children have a considerably damaged central nervous system (CNS), leading to chronic and limited intellectual disability, often accompanied by diminished motor abilities(4). This population cannot report pain, since motor or sensory disturbances, generated by the SNI, can lead to a poor interpretation of pain on the part of health professionals. The inadequate and/or neglected management of pain may bring physical and emotional consequences for these patients(5–7).

Therefore, it is essential to use appropriate tools according to the age and the clinical state of the child, to optimize the treatment of pain(8). For patients with SNI, who have cognitive and speech impairments, the aid of parents and/or reference caregivers is essential to provide a good assessment of the pain(7).

The Inventory of Pain Behavior in Neurological Disabilities (*Inventário de Comportamento de Dor na Deficiência Neurológica* – ICDDN), developed to evaluate the pain in children with SNI, is a scale to assess behavior, which encourages the participation of caregivers for its completion(9). The ICDDN is a product of the validation of the Pediatric Pain Profile in Brazil and is considered to be the golden standard for children with SNI. However, its applicability requires a caregiver to be present for reference(9).

The FLACC scale (Face, Legs, Activity, Cry, Consolability) was elaborated as a method for health professionals to identify pain in children who cannot put in words its presence or severity(10). In 2006, the scale went through a revision, the new version being named revised FLACC (rFLACC). In this version, descriptors were added to help assessing the pain of children with SNI. Furthermore, the rFLACC scale considers additional information of the reference caregiver with regard to the behavior of the child(11). Both instruments, the rFLACC Scale and ICDDN are validated for Brazilian Portuguese(9,12).

Although there are instruments to evaluate the pain in children with SNI in the international environment, there are still few studies about this theme, and pain is often evaluated by instruments used in healthy and responsive children, disregarding their particularities. The rFLACC Scale and the ICDDN are adequate for this group of children (9,11), but they are used separately, due to their different approaches and indicators. However, considering the particularities of children with SNI, in whom the evaluation of pain is a challenge, applying the rFLACC scale with the ICDDN could minimize the subjectivity of this evaluation.

This study aimed at evaluating how rFLACC Scale and the ICDDN complement each other to assess pain in children with SNI.

METHOD

Cross-sectional study carried out in a Pediatric Hospitalization Unit and in a Pediatric Intensive Care Unit from a teaching hospital in the South of Brazil. These units receive children with clinical, surgical, gastroenterological, orthopedic, psychiatric, pneumological, and neurological issues.

The study included children from both sexes, who had not completed their 12th year of life and were hospitalized from January to August 2019 with a diagnosis related to severe cerebral impairment, being unable to communicate by speaking or in any other way. The exclusion criteria were: using vasoactive drugs or continuous endovenous sedoanalgesia, due to the severity of the clinical state of the child. The study also included a caregiver of reference for each child, all 18 years old or older. The reference caregiver is a person who declares to be and/or is recognized by the family as the responsible for the daily care to the child, who knows completely their behaviors in the different situations of daily life.

The sample was by convenience and formed by 26 children. The researchers went to the hospitalization units of the appropriate location, contacted the Nurse directly, and reviewed the new admissions to identify the patients with the clinical characteristics needed by the study.

For the sample calculation, the software *WinPepi*, version 11.43, was used, considering a 10% loss, a correlation coefficient of 0.6, 90% of power and 4% of margin of error, and using as a reference the study by Pedersen et al.(5). The sample size was calculated considering 43 children with this profile in 2018 and the inclusion criteria established by this study.

The data collection was only carried out after the researchers responsible for the application of the instrument were trained (rFLACC Scale and ICDDN). The training was provided by a specialist in the field of pain, in addition to the theoretical studies of the researchers.

At first, the rFLACC Scale was applied by the researcher without the aid of the caregiver. Then, immediately, the ICDDN was applied through an interview given by the reference caregiver to the researcher.

The rFLACC Scale presents the following categories: face, legs, activity, cry, and consolability. Filling it in requires from 2 to 3 minutes of observation. For each category, the score varies from 0 (zero) to 2, according to the description of the category evaluated, generating partial scores. The total score, from 0 to 10, is the sum of the partial scores. It is categorized as follows: 0 (no pain); 1 to 3 (mild pain); 4 to 6 (moderate pain); and 7 to 10 (severe pain)(11). The rFLACC Scale is recommended for the use in children from 3 to 15 years old(5).

The ICDDN is an instrument formed by 20 items, with a score from 0 to 3. The score of the items is added, with a result from 0 to 60. A score of 14 or more suggest that there is pain. To use the ICDDN, the reference caregiver was asked at first whether the child, during collection, was in a "good day" (a behavior that typically indicated wellbeing, calm) or in a "bad day" (a behavior that typically indicated not feeling well, unrest). The Pediatric Pain Profile, which was the source of the ICDDN, suggests that the instrument should be used in patients in the age group from 1 to 18 years old, with a severe neurological diagnosis, with no possibility of communication(9).

The instruments were applied with a distance from one hour or more of any technical procedures the child went through. The sample considered all invasive procedures that were carried out six hours or less from the application of the instruments.

Sociodemographic (age, sex, lives with whom) and clinical data (main diagnosis, drugs used, use of assistive technology, and time of hospitalization) of the child were found in the electronic history.

Data was analyzed using the statistical software *Statistical Package for the Social Sciences*, version 21.0. The results were described using descriptive statistics, through medians and quartiles (25-75) and frequencies (relative and absolute). The Kappa Coefficient was used to analyze the degree of agreement (<0.10: no agreement; <0.40: weak agreement; 0.40-0.70: good agreement; and >0.75: excellent agreement) between respondents, in the comparison between the instruments. Fisher's Exact was used for the association between the variables "use of assistive technology" and "hospitalization time", with scores obtained from the rFLACC Scale and the ICDDN. Considering that the rFLACC Scale has categories (Face, Legs, Activity, Cry, and Consolability) that allow for partial scores, Spearman's correlation was used to analyze the correlation of these categories with the total score of the scale. The results were found to be statistically significant when $p \leq 0.05$.

The reference caregivers signed two copies of the Free and Informed Consent Form (FICF), which guarantees the anonymity of the information collected. This project was approved by the Research Ethics Committee of the institution under opinion No.3.265.771/2019 and CAAE: 08329518.7.0000.5327. The procedures used for data collection followed all national regulations for researches with human beings.

RESULTS

A total of 26 children with a median age of 2.5 (1-4) years old, mostly male and living with their families, participated in the study. Cerebral palsy, genetic pathologies, and epilepsy were the main diagnosis. The most common hospitalization time was up to 7 days. The use of anticonvulsants; continuous oxygen therapy through nasal catheters, mechanical pulmonary ventilation, or non-invasive ventilation; and feeding via gastrostomy were mentioned as the main assistive technologies used during hospitalization. For 10 (38.4%) children, there were descriptions of airway aspiration as the only procedure carried out one hour before the rFLACC Scale and the ICDDN, as Table 1 shows.

The rFLACC Scale was the first instrument to be used. 50% of children presented a score of pain of 13. Among these, 9 (34.6%) expressed mild pain, while 4 (15.4%) expressed moderate pain. No child showed a score that indicated intense pain. For the children with pain during the evaluation, the nurse was asked to manage it, according to the protocol of the institution.

Furthermore, the scores of each category in the rFLACC Scale (Face, Legs, Activity, Cry, Consolability) were compared to the total score. The correlation between the scores was more evident for the category face (rs=0.821), when compared to the others (p=0.000), as Table 2 shows.

After the rFLACC scale was used, and immediately before the ICDDN was applied, the reference caregivers were asked about the emotional state of the child. Most (20; 76.9%) caregivers stated that the child was painless and calm, which corresponded to the state of a "good day".

The ICDDN was the second instrument applied. 9 children (34.6%) had a score consistent with the presence of pain, considering the total score of the instrument.

Considering the rFLACC Scale and the ICDDN, they were in accordance with 84.6% of cases. According to the Kappa index, there was a good level of agreement between respondents (k=0.692; CI 95% 0.437-0.967; p=0.000).

The time hospitalized and the use of assistive technology were not associated with the presence of pain, neither according to the rFLACC Scale nor to that of the ICDDN (p>0.05), as Table 3 shows.

Table 1 – Demographic and clinical data of children with severe neurological impairment (n=26). Porto Alegre, RS, Brazil, 2019

Variables	n	%
Sex		
Female	9	34.6
Male	17	65.4
Lives with whom		
Family	25	96.2
Institutionalized	1	3.8
Main diagnosis*		
Cerebral palsy	21	80.8
Genetic pathologies	20	76.9
Epilepsy	19	73.1
Microcephaly	4	15.4
Hydrocephalus	3	11.5
Stroke	2	7.7
Hospitalization time		
Up to 7 days	14	53.9
From 8 to 14 days	3	11.5
From 14 to 30 days	5	19.2
More than 30 days	4	15.4
Drugs being used*		
Anticonvulsants	22	84.6
Antibiotics	19	73.1
Constant analgesic	2	7.7
None	1	3.8
Invasive procedures		
Airway aspiration	10	38.5
None	16	61.5
Use of assistive technologies*		
Gastrostomy	16	61.5
Enteric/gastric catheter	9	34.6
Tracheostomy	8	30.8
Nasal catheter	13	50.0
Pulmonary / Non-invasive mechanical ventilation	4	15.4

Source: Research data, 2019.
*Aspects observed simultaneously for some children in the sample.

Table 2 – Categories of the revised Face, Legs, Activity, Cry and Consolability Scale (rFLACC) in the assessment of pain in children with severe neurological impairment (n=26). Porto Alegre, RS, Brazil, 2019

rFLACC	Presence of pain	Absence of pain	rs*	p-value
Categories	n (%)			
Face	10 (38.5)	16 (61.5)	0.821	0.000
Legs	9 (34.6)	17 (65.4)	0.719	0.000
Activity	6 (23.1)	20 (76.9)	0.708	0.000
Cry	3 (11.5)	23 (88.5)	0.467	0.016
Consolability	9 (34.6)	17 (65.4)	0.709	0.000

Source: Research data, 2019.
***** Spearman's correlation coefficient.

Table 3 – Relation between hospitalization times/assistive technology and the revised Faces, Legs, Activity, Cry, and Consolability Scale (rFLACC)/Inventory of Pain Behavior in Neurological Disabilities (ICDDN). Porto Alegre, RS, Brazil, 2019

Variables	rFLACC	ICDDN
	p-value*	
Hospitalization time	0.312	0.753
Use of assistive technologies		
Gastrostomy	0.344	0.210
Enteric/gastric catheter	0.500	0.635
Tracheostomy	0.673	0.063
Nasal catheter	0.500	0.654
Pulmonary / Non-invasive mechanical ventilation	0.075	0.236

Source: Research data, 2019.
*Fisher's exact text

DISCUSSION

Most children had a primary diagnosis of cerebral palsy, were below five years old, male, hospitalized for one week or less, and were receiving assistance for diagnosis compatible with SNI. The pain assessment scores found by the researcher through the application of the rFLACC scale and by the caregiver in the application of the ICDDN showed a good agreement between respondents. Considering the categories of the rFLACC Scale, the expression of pain was more present in the evaluation of the facial expression. The time of hospitalization and the use of assistive technologies were not factors associated to the presence of pain in the sample studied by the application of the Scale and the Inventory.

A systematic review(12) regarding the prognosis of cerebral palsy found that one in four of these children have epilepsy, which corroborates the main diagnosis presented in this study: cerebral palsy secondary to genetic pathologies and epilepsy. As a result, the continuous and prolonged use of anticonvulsants is necessary, as well as the use of therapies with antibiotics to deal with the comorbidities associated(13). Patients with neurological impairments are the most vulnerable to diseases, especially those that affect the respiratory tract. This is due to factors such as recurring aspirations, inefficient coughs, and alterations in the thoracic walls and/or spinal column, which prevent the maximum expansion of the thorax(14). Gastrointestinal disorders also stand out among comorbidities caused by cerebral palsy, including constipation, gastroesophageal reflux associated with vomit episodes, swallowing disorders, and abdominal pain(14).

Therefore, most children with SNI need to use some type of assistive technology, so they can receive safe therapy and be provided with adequate care. In this context, the gastrostomy, tracheostomy, and non-invasive ventilation are the most used among children with SNI(15–16), which is accordance with the data found in this study.

The evaluation of the pain in individuals with SNI was measured, in this study, by the simultaneous application of the rFLACC scale and the ICDDN, with a level of agreement of 84.6% among respondents. This reinforces the complementary use of the instruments in the assessment of pain in children with SNI. Likewise, a research(17) carried out to select the most adequate tool to evaluate pain in children with delayed neurodevelopment showed that most nurses (74%) preferred the rFLACC Scale, while parents were divided, 54% preferring he ICDDN while 46% preferred the rFLACC Scale. When asked about the applicability of the instruments, respondents stated that the descriptors of the ICDDN were more detailed, which meant it took longer to fill in. Also, it contained words that were considered offensive by some and was hard to interpret. The rFLACC scale, on the other hand, had a selection of individualized behaviors, easier to use, more precise and concrete. Both nurses and parents agreed that if the pain descriptors form the ICDDN were included in the rFLACC Scale, it would be the ideal tool(17).

The advantages seen in the use of the rFLACC Scale include the assessment of consolability, the possibility of including pain behaviors particular to the individual, and the fact that it can be applied without the presence of parents and caregivers. Its disadvantages include the fact that it requires caregivers and health professionals to undergo a training process. The ICDDN has as an advantage the fact that it can be used to evaluate children with severe disabilities, making it possible to monitor pain and the effectiveness of the treatment. As for its disadvantages, the ICDDN is not useful in specific clinical settings due to its length, not to mention that parents and caregivers need to develop the necessary capacity to use it correctly(6).

In this study, considering the rFLACC Scale in the evaluation of the researchers for signs of pain, the category with the highest score was the face. The facial expression is the main indicator of pain when there can be no self-report of pain(18). From this perspective, the evaluation of the face is an important tool in the evaluation of the pain in pediatrics, since many children are impaired with regard to verbal communication(19). However, the facial expressions present in children with SNI is idiosyncratic, and it may often mask expressions of pain or lead to an overestimation in the assessment(20). This shows the relevance of the complementary use of the ICDDN, to increase the power of the pain assessment in these individuals.

CONCLUSIONS

The rFLACC Scale and the ICDDN may be instruments used complementarily to evaluate the pain in children with SNI, since they had good agreement among respondents in this study. Both instruments can be used independently; however, when the evaluation includes the interpretation of both the professional and the caregiver, and these instruments are used in tandem, the assessment of the pain is more precise.

The authors propose the joint use of these instruments. The ICDDN has a role in providing an "anamnesis of pain" with the reference caregiver at the moment of admission, while the rFLACC Scale has a role in the daily assessment of pain. Therefore, this study can contribute substantially to standardize the evaluation of pain in children with SNI.

The limitations of this study are related to the fact that the children were evaluated a single time, whether regarding the assessment by the researcher or that by the reference caregiver, and there was no routine follow up or reevaluation of cases in which there was a score that indicated pain. Another limitation is the size of the sample, its potential to show associations with a higher statistical power.

This study suggests the performance of future multicentric studies, applying both the rFLACC Scale and the ICDDN during the hospitalization of children, to develop adequate algorithms to provide humane care to children with SNI, as well as an analysis of the instruments in the several environments of the hospitalizations.

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