

## ORIGINAL PAPER

## USE OF SPECIFIC METHODS FOR ASSESSMENT OF PAIN IN CHILDREN WITH SEVERE MULTIPLE DISABILITIES

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**Abstract**

**Aim:** The main objective of the study was to compare the intensity of pain in children with severe multiple disabilities assessed with three specific scales. **Design:** A cross-sectional study using the quantitative research methods was conducted. **Methods:** The study comprised 43 children with severe multiple diseases experiencing pain. The data were collected between March 2013 and November 2013 in hospital and institutional care facilities. **Results:** The intensity of pain was compared using the Paediatric Pain Profile (PPP), the revised Face, Legs, Activity, Cry, Consolability (rFLACC) scale and the Non-Communicating Children's Pain Checklist – Revised (NCCPC-R). At the same time, pain intensity in children with severe multiple disabilities was tested with respect to age and gender. The comparison showed that older children (8–18 years of age) perceived pain more intensely than their younger counterparts. The mean score of pain intensity assessed with the rFLACC scale was 7.19, corresponding with severe pain or discomfort. The results clearly show significant correlations between the scales. The only exception was no statistically significant correlation between the rFLACC and PPP ( $p = 0.267$ ). To a certain extent, this may be explained by the relatively small sample. **Conclusion:** Pain intensity in children with severe multiple disabilities assessed with three standardized scales was compared, with the scores obtained by individual scales being similar. The psychometric properties of the PPP and NCCPC-R have not been tested so far.

**Keywords:** child; pain; severe multiple disabilities; Paediatric Pain Profile; Non-Communicating Children's Pain Checklist – Revised; revised Face, Legs, Activity, Cry, Consolability.

**Introduction**

The birth of a child with severe multiple disabilities represents a huge burden for the entire family. It also brings great tension to the family environment, that may last for a very long time (Matějček, 2001, p. 27). What all severely disabled individuals, irrespective of their age, have in common is that due to their impairment, they have special needs for their own development and interactions with other people (Hanák, 2005, p. 15). This group of children places increased demands on their parents' time as well as physical and financial resources (Matějček, 2001, p. 28). In children with severe disabilities, the integrity of a human being in their life performances is so severely impaired that in most areas, it barely reaches the border of what in our interpersonal interactions is considered normal in the broadest sense of the word (Vítková, 2003, p. 152).

These children with severe multiple disabilities represent a group with diverse etiology of their impairments and a higher risk for the development of pain (Dowling, 2004, p. 37–38). They experience pain more frequently than the normal pediatric population (Hauer, 2010, p. 198; Perguin et al, 2000a, p. 51). Disabilities affect numerous families throughout the world. Today, disabled individuals account for about 10% of the global population, that is, approximately 650 million people (Taormina-Weiss, 2011). In the Czech Republic, indicators of morbidity in the pediatric population include the rates of congenital disorders. Out of 118,348 live births in 2009, congenital defects were detected in 4,653 infants before their first year of age. That means 393 children with congenital disorders per 10,000 live births, or 1 in 25 children (Zdravotnická ročenka, 2010). In 2010, 8,431 children with cerebral palsy, 98,629 children with visual impairment, low vision or blindness, and 6,256 children with hearing impairment, hearing loss or deafness were followed in the Czech Republic. For congenital disorders and deformities, a total of 36,708 children were followed in the country in 2010 (ÚZIS, 2011).

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Pediatric pain is a phenomenon that until recently had not been perceived as a specific problem by medical practitioners. According to Mareš (1997, p. 43) or Fendrychová et al. (2001), pain used to be associated with many myths and untruths. It was not until the 1980s and 1990s that research on pain in childhood started to receive increased attention (Palyzová, 2004, p. 264). Experiencing pain, its manifestations, consequences, adaptive behavior, coping and assessment vary in different phases of childhood (Sedlářová, 2008, p. 120). An individual approach to all disabled children is of crucial importance. Pain assessment in children with severe multiple disabilities is particularly difficult. These children are unable to verbalize the level of pain experienced and this must be ascertained from their parents/caregivers. Every disabled child expresses pain in a different way. The specific issue of pain assessment in children with severe multiple disabilities has been dealt with only few authors. At present, only six standardized tools in for assessing pain in children with severe multiple disabilities are available in the English language. In the Czech Republic, no specific method for pain assessment in children with severe multiple disabilities has been developed as yet.

## Aim

The study aimed at comparing the intensity of pain in children with severe multiple disabilities assessed with three specific scales and analyzing selected pain scoring systems that may be used in children with severe multiple disabilities, namely the Paediatric Pain Profile, the revised Face, Legs, Activity, Cry, Consolability scale and the Non-Communicating Children's Pain Checklist – Revised.

## Methods

### Design

A cross-sectional study using the quantitative research methods was conducted.

### Sample

The study comprised children with severe multiple disabilities experiencing pain.

The inclusion criteria were as follows:

- children with severe multiple disabilities experiencing pain;
- children unable to communicate and verbalize their pain;
- children aged 3 to 18 years;
- children living in the Czech Republic; and
- consent from a parent/guardian to participation in the study.

Every parent/guardian was individually informed about the purpose and meaning of the survey and as well as its anonymity. The survey was only carried out after their written consent was obtained.

### Data collection

The data were collected between March 2013 and November 2013 in hospital and institutional care facilities that remain anonymous. In the first phase of data collection, respondents' identification data (age, gender) were obtained for further analysis of the data. Subsequently, pain assessment was carried out with the following three specific measurement tools: the Paediatric Pain Profile (PPP), the revised Face, Legs, Activity, Cry, Consolability (rFLACC) scale and the Non-Communicating Children's Pain Checklist – Revised (NCCPC-R).

The instruments were used with permission from their authors and in accordance with the strictly defined methods. The rFLACC scale has been routinely used in Czech nursing care since it was first introduced to Czech professionals by Fendrychová (2004, p. 55). The PPP and NCCPC-R instruments were translated from English into Czech and subjected to linguistic validation. The translation process comprised four steps as follows: (1) translation from English to Czech was made independently by two translators whose mother tongue was Czech; (2) both translations were analyzed by a small working group, mainly to discuss differences and ambiguities between the two versions and to reach a consensus on the first draft translation; (3) the first draft was back-translated into English by two translators whose mother tongue was English and who were neither involved in preparing the first draft nor acquainted with the original English document; (4) differences between the original English document and the back-translated version were analyzed to identify and explain all ambiguities in either the translation or the original version.

### Paediatric Pain Profile

This pain assessment tool (Hunt et al., 2004, p. 9–18) was specifically developed for use in children with severe disabilities, in particular those who have difficulties verbalizing their pain and are dependent on their caregivers. Its aim is to facilitate the description and recording of pain-related behavior, monitoring of pain and treatment effectiveness, and communication with professionals in case of any concerns about pain of a child. The tool comprises 20 behavioral items, each of which may be evaluated on a 4-point Likert scale (from 0 – not at all to 3 – very much) (Table 1). The PPP is a reliable and valid tool to be used in both clinical and interventional research. Its internal consistency is 0.75–0.89

(Cronbach's alpha) and reliability is 0.74–0.89 (intraclass correlation) (Hunt et al., 2004, p. 9–18).

#### *Non-Communicating Children's Pain Checklist – Revised*

The NCCPC-R (Breau et al., 2002) is meant to be used in children unable to communicate verbally due to their cognitive (mental) impairment. The tool was developed for assessing both short-term and long-term pediatric pain. It includes 7 subscales: vocal (4 items), social (4 items), facial (5 items), activity (2 items), body and limbs (6 items), physiological (6 items), and eating/sleeping (3 items). Each item is evaluated on a 5-point Likert scale (0 – not at all, 1 – just a little, 2 – fairly often, 3 – very often, and NA – not applicable) (Table 1). Once again, this tool showed very good reliability and validity, with a Cronbach's alpha of 0.93 (Breau et al., 2002, p. 354).

#### *Revised Face, Legs, Activity, Cry, Consolability*

This assessment scale (Merkel, 1997, p. 293) is concerned with five categories (face, legs, activity, cry and consolability). Individual reactions of a child are evaluated on a scale from 0 to 2, with a total score of 7–10 points suggesting severe pain and discomfort. The scale is reliable and valid for pain assessment in children with cognitive impairment (Voepel-Lewis et al., 2002, p. 1224). The revised version (Malviya et al., 2006, p. 258) is beneficial in that it includes individual pain behaviors for particular scores in children with severe multiple disabilities. The internal consistency of the rFLACC may be considered excellent, with a Cronbach's alpha of 0.86 for all the items (Malviya et al., 2006, p. 263).

**Table 1** The measurement tools Non-Communicating Children's Pain Checklist – Revised, Paediatric Pain Profile and revised Face, Legs, Activity, Cry, Consolability

Scale	NCCPC-R	PPP	rFLACC
Age	3–18	0–18	children/adults
Evaluated parameters	vocal (4 items), social (4 items), facial (5 items), activity (2 items), body and limbs (6 items), physiological (6 items), eating/sleeping (3 items)	vocal, social, facial, activity, body and limbs, physiological, eating/sleeping (no categories)	vocal, facial, limbs, activity, consolability
Number of items	30	20	5
Scoring	5-point Likert scale (0 – not at all, 1 – just a little, 2 – fairly often, 3 – very often, NA – not applicable)	4-point Likert scale (0 – not at all, 1 – a little, 2 – quite a lot, 3 – a great deal)	3-point scale (0 – 1 – 2 points, according to specific pain behaviors)
Total score	0–90	0–60	0–10
Appendices	none	Pain history Summary graph Ongoing assessments Professionals helping with pain	none

#### *Data analysis*

The data were processed with the Microsoft Excel spreadsheet editor and the Stata v. 10 statistical software. Basic descriptive statistics was used to describe the subjects (frequency tables with absolute and relative counts, arithmetic means, standard deviations, and medians). The dependence of individual variables between the pain assessment scales was measured with Spearman's rank correlation coefficient. The basic characteristics were compared using the chi-squared test and Fisher's exact test. For evaluation of quantitative values with respect to pain intensity, the Wilcoxon two-sample

test was used. The statistical tests were evaluated at a significance level of 5%. The results were entered into MS Excel spreadsheets.

#### *Results*

The study comprised a total of 43 participants (22 girls and 21 boys) with severe multiple diseases experiencing pain. The mean age of the participating children was 8.1 years.

In the literature, theoretical descriptions and classifications of individual types of disabilities are usually stated separately. In practice, however, two or more conditions may be combined in a single child.

This group of children is so heterogeneous that a uniform classification system cannot be developed for them (Slowik, 2007, p. 147). Multiple disabilities may have numerous forms and degrees of severity (Langer, 2006, p. 69–77). Many authors (Bartoňová, Vítková, 2007, p. 116; Pipeková, 2010, p. 35; Vašek, 2003, p. 37) use the following classification of children with multiple disabilities into three groups: (1) intellectual disability combined with other impairments, (2) dual sensory impairment – most frequently deafblindness, physical disabilities and speech disorders, and (3) autism spectrum disorders, autism combined with other impairments. This classification was used in the present study to divide the respondents according to their main diagnosis. The largest group were children with intellectual disability combined with other impairments ( $n = 25$ ;

58%), followed by those with dual sensory impairment – most frequently deafblindness, physical disabilities and speech disorders ( $n = 10$ ; 23%) and with autism spectrum disorders combined with other impairments ( $n = 8$ ; 19%).

Individual items of the rFLACC scale were scored to compare the intensity of pain in children with severe multiple disabilities divided into two age categories (Table 2), younger (3–7 years of age) and older (8–18 years) children. The comparison showed a statistically significant difference ( $p = 0.023$ ), meaning that older children perceived pain more intensely than their younger counterparts. Additionally, variations in pain intensity between the two genders were analyzed with no statistically significant difference.

**Table 2** Pain intensity assessment with the rFLACC scale according to age and gender

Characteristics	rFLACC	Moderate pain (%)	Severe pain (%)	p-value
Age	Younger children	10 (50)	10 (50)	0.023
	Older children	4 (17)	19 (83)	
Gender	Girls	7 (32)	15 (68)	0.961
	Boys	7 (32)	14 (67)	

Furthermore, pain behaviors in children with severe multiple disabilities were studied. The individual scales mapped how often the participants showed the following behaviors: vocal, social, facial, activity, body and limbs, physiological and eating/sleeping. In the present study, pain was most frequently manifested by facial expressions. This subscale comprised 5 items – a furrowed brow; a change in eyes, including squinching of eyes, eyes opened wide and eyes frowning; turning down of mouth, not smiling (very often shown in 30% of the respondents); lips puckering up, tight, pouting or quivering (very often seen in 14% of the children); and clenching or grinding teeth, chewing or thrusting

tongue out (very often noticed in 16% of the subjects).

The benefit of the PPP is that, unlike the other assessment scales, it includes sheets to describe up to three sources of pain, ongoing pain assessment sheets and other appendices such as a summary graph to record the progression of pain or a sheet for notes made by professionals who were consulted.

The results suggest that (pharmacological or non-pharmacological) pain management results in reduced pain intensity as seen from the PPP scale and its sheet for ongoing pain assessment. The intensity of pain decreased from a mean of 30.72 to 14.49 (Table 3).

**Table 3** Comparison of pain intensity assessed with individual scales in the entire group of children

	n	median	mean	SD	min	max
Age	43	8	8.09	4.04	3	18
rFLACC – total	43	7	7.19	1.40	5	10
NCCPC-R – total	43	31	33.30	7.44	22	57
PPP – Pain A	43	30	30.72	9.28	12	54
PPP – Pain B	19	28	28.58	9.58	14	49
PPP – Pain C	5	28	30.20	11.52	21	49
PPP – ongoing pain assessment	43	13	14.49	7.75	2	33

The main objective of the study was to compare the intensity of pain in children with severe multiple disabilities assessed with three specific scales. The PPP and NCCPC-R were translated into the Czech

language and results obtained with these tools in children with severe multiple disabilities were compared with those obtained with the rFLACC scale commonly used in Czech nursing practice.

The Wilcoxon two-sample test was used to analyze individual parameters of the PPP and NCCPC-R and compare them with the rFLACC moderate (4–6 points) and severe (7–10 points) pain categories. For these parameters, statistically significant differences were found (NCCPC-R,  $p = 0.001$ ; PPP,  $p = 0.036$ ). Correlation of the assessment scales was performed

using the Spearman's rank correlation coefficient. The results clearly show significant correlations between the scales (Table 4). The only exception was no statistically significant correlation between the rFLACC and PPP ( $p = 0.2674$ ). To a certain extent, this may be explained by the relatively small sample.

**Table 4** Pain intensity assessment with individual scales

Scale	rFLACC	NCCPC-R	PPP	PPP – ongoing pain assessment
rFLACC	1.0000			
NCCPC-R	0.5444	1.0000		
PPP	0.2674	0.3940	1.0000	
PPP – ongoing pain assessment	0.4832	0.3155	0.3989	1.0000

The psychometric properties of the PPP and NCCPC-R have not been tested so far. Such evaluation should be carried out in further research so that the instruments could be recommended for use in Czech nursing practice.

## Discussion

According to authors of several studies (Breau et al., 2003a, p. 335; Hunt et al., 2007, p. 276; Oberlander, O'Donnell, 2001, p. 38), pain is an everyday experience for children with severe multiple disabilities. Similarly, everyday pain in children with impairments was confirmed by 71% of 50 professionals working in a Vancouver health center (Oberlander, O'Donnell, 2001, p. 38). Breau et al. (2003a, p. 340) reported that as many as 52% of children experienced everyday pains over a 4-week period. This frequency of pain was somehow higher than 50% of children experiencing pain during a 3-week period in a study by Perguin et al. (2000a, p. 51). To a certain extent, however, the comparison of these two studies may be limited by the fact that they used different methods for pain measurement. A comparative study performed in children cared for in a day-center found higher levels of pain in children with severe multiple disabilities (72%) than in those without disabilities (25%) (Leland, 1994, p. 402). According to a study by Hunt et al. (2004, p. 14), parents reported that 42% of children with severe multiple disabilities had pain on a daily basis and 20% of children had pain rated as severe or very severe. In another study, as many as 73% of children with severe impairments had at least one pain episode over a period of 2 to 4 weeks (Stallard et al., 2001, p. 460).

Although pediatric pain behavior is complex, the predominant manifestations may change with the children's development (Palyzová, 2004, p. 265). In children with severe multiple disabilities, the

manifestations of pain behavior may vary depending on the type of pain. Whereas acute pain is more frequently associated with crying, intense facial expressions or immobility, chronic pain is typically characterized by moaning, appetite loss and non-cooperation (Breau et al., 2000, p. 609). In many children with severe multiple disabilities, pain is atypically manifested (Masterson, 2011, p. 1–6). While some disabled children, such as those with Prader-Willi syndrome, have an increased pain tolerance (Priano et al., 2009, p. 829), others have an increased sensitivity to pain (Defrin et al., 2004, p. 58). Children and adolescents with disabilities show higher levels of emotional and behavioral problems than their healthy peers (Dekker et al., 2002, p. 1087; Emerson, Einfeld, 2010, p. 583). Children with disabilities due to similar causes tend to respond to pain in a similar way. Solodiuk et al. (2013, p. 1043) pointed to a significant association between the pain response and the cause of mental impairment. Children with disabilities caused by prenatal or perinatal complications mainly express pain by facial expressions, less commonly by social and vocal behaviors, as compared with those with mental impairments due to other causes. Pain behaviors are also influenced by gender. Whereas physiological and social responses to pain are more frequently seen in girls, boys tend to express pain by vocal behaviors. Physiological and social changes in behavior are less common in boys. However, these differences are difficult to interpret in children with severe multiple disabilities. Since both biological and behavioral factors may play a role, more research is needed that is specifically focused on the association between gender and pain in children with severe multiple disabilities.

Pain behaviors in children with severe multiple disabilities may be less pronounced and are often identified mainly by parents/caregivers (Hunt et al.,

2003, p. 171; Terstegen et al, 2003, p. 187). The most frequently observed manifestations of pain in children with severe multiple disabilities are motor changes, facial expressions and grimaces, stereotypical movements, vocalization, changes in eating or sleeping patterns, social behavior, and changes in physiological, immune, endocrine and humoral functions (Knegt, 2013, p. 894; Palyzová, 2004, p. 265; Solodiuk et al., 2013, p. 1042). In the present study, pain was most frequently manifested by facial expressions, namely in 19% of children with severe multiple disabilities.

Many authors claim that the more severe is the child's disability, the more severe and frequent is the pain (Breau et al., 2001, p. 721–727; Breau et al., 2003b, p. 1219–1226; Hunt et al., 2007, p. 276; Houlihan et al., 2004, p. 305; Stallard et al., 2002, p. 460–462).

The results in the present study are consistent, for instance, with those in a study by Voepel-Lewis et al. (2005, p. 168) reporting a total score of pain intensity assessed with the FLACC of 6.4, corresponding to severe pain or discomfort. In a validation study of the PPP, the mean intensity of pain in 140 nonverbal children was 31.3 for Pain A and 26.9 for Pain B. In a group of 168 children with severe multiple disabilities aged 3 to 18 years, the mean intensity of pain assessed with the NCCPC-R was 35.6 (Breau et al., 2003c, p. 499).

Information concerning the association between pain intensity and age and gender is rather inconsistent. For example, Perguin et al. (2000b, p. 230) reported a high prevalence of severe chronic pain in girls aged 12 or more. A study by Breau et al. (2003a, p. 335) found no differences in family and demographic characteristics between children with acute and chronic pain, suggesting that the environment did not greatly influence the type and intensity of pain. The results also showed that in children with severe multiple disabilities, pain is independent of age or gender. Similarly, Hunt et al. (2007, p. 278) stated no differences in pain intensity depending on demographic characteristics such as age and gender. However, the present study showed an association between pain intensity and age of children with severe multiple disabilities, with older children perceiving pain more intensely.

Children with severe multiple disabilities have considerably impaired motor function and cognitive and communication skills, requiring support and help in most aspects of everyday life (Petry et al., 2008, p. 15). Therefore, care for these children should be focused on active search for and satisfaction of biological, mental and social needs so that as the

highest quality of their life possible may be achieved. Good quality nursing care is the main goal of current nursing.

## Conclusion

Pain assessment should reflect the development of a child with severe multiple disabilities. Pain behaviors of these children are different and often problematic due to their social communication deficits (Gilbert-MacLeod et al., 2000, p. 301). It is therefore important that all these aspects are considered in the nursing diagnosis using standardized scales for pain assessment in children with severe multiple disabilities.

It is essential that health professionals are familiar with specific issues related to pain in children with severe multiple disabilities. They must understand how pain affects these children as well as their families to provide them with services that better meet their needs and have a potential to improve their health and quality of life. At the same time, every nurse should know more than just one measuring instrument for assessing pain in children. And she should be able to select and recommend an adequate tool to the parents, depending on the child's type of pain or developmental stage of communication and cognitive functions.

## Ethical aspects and conflict of interest

All the questionnaires were supplemented with informed consent forms so that parents/guardians could agree with their children's participation in the study. The survey was initiated following approval from the University in Ostrava Faculty of Medicine and University Hospital Ostrava ethics committees. Prior to its initiation, the survey had been approved by the managements of individual institutions.

The study complied with the Charter of Fundamental Rights and Basic Freedoms, Convention on the Rights of Persons with Disabilities, Convention on the Rights of the Child, Nuremberg Code, Declaration of Helsinki, Declaration of Tokyo, International Ethical Guidelines for Biomedical Research Involving Human Subjects and IASP Declaration of Montreal stating that access to pain management is a fundamental human right.

## Author contribution

Conception and design (JC, LS), data analysis and interpretation (JC, LS), draft of the manuscript (JC), critical revision of the manuscript (JC, LS), final version of the manuscript (JC, LS).

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