



<http://www.diva-portal.org>

Postprint

This is the accepted version of a paper published in *Disability and Rehabilitation*. This paper has been peer-reviewed but does not include the final publisher proof-corrections or journal pagination.

Citation for the original published paper (version of record):

Adolfsson, M., Johnson, E., Nilsson, S. (2018)

Pain management for children with cerebral palsy in school settings in two cultures:

Action and reaction approaches

Disability and Rehabilitation, 40(18): 2152-2162

<https://doi.org/10.1080/09638288.2017.1327987>

Access to the published version may require subscription.

N.B. When citing this work, cite the original published paper.

Permanent link to this version:

<http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-35597>

Pain management for children with cerebral palsy in school settings in two cultures: Action and reaction approaches

Authors: Margareta Adolfsson^{1,2,3}, Ensa Johnson⁴, Stefan Nilsson^{1,5}

¹ CHILD, Jönköping University, Jönköping, Sweden

² School of Education and Communication, Jönköping University, Jönköping, Sweden

³ Swedish Institute of Disability Research, Jönköping University, Jönköping, Sweden

⁴ Centre for Augmentative and Alternative Communication, University of Pretoria,
Pretoria, South Africa

⁵ Institute of Health and Care Sciences, University of Gothenburg, Gothenburg, Sweden

Correspondence author

Margareta Adolfsson, School of Education and Communication, Jönköping University,

Box 1026, SE-551 11 Jönköping, Sweden

Phone: +46 (0) 70 787 64 64

email: margareta.adolfsson@ju.se

Pain management for children with cerebral palsy in school settings in two cultures: Action and reaction approaches

Abstract

Background. Children with cerebral palsy face particular challenges, e.g. daily pain that threaten their participation in school activities. This study focuses on how teachers, personal assistants, and clinicians in two countries with different cultural prerequisites, Sweden and South Africa, manage the pain of children in school settings.

Method. Participants' statements collected in focus groups were analyzed using a directed qualitative content analysis framed by a Frequency of attendance–Intensity of involvement model, which was modified into a Knowing-Doing model.

Results. Findings indicated that pain management focused more on children's attendance in the classroom than on their involvement, and a difference between countries in terms of action-versus-reaction approaches. Swedish participants reported action strategies to prevent pain whereas South African participants primarily discussed interventions when observing a child in pain.

Conclusion. Differences might be due to school- and healthcare systems. To provide effective support when children with cerebral palsy are in pain in school settings, an action-and-reaction approach would be optimal and the use of alternative and augmentative communication strategies would help to communicate children's pain. As prevention of pain is desired, structured surveillance and treatment programs are recommended along with trustful collaboration with parents and access to "hands-on" pain management when needed.

Implications for Rehabilitation

- When providing support, hands-on interventions should be supplemented by structured preventive programs and routines for parent collaboration (action-and-reaction approach).
- When regulating support, Sweden and South Africa can learn from each other;
 - In Sweden, the implementation of a prevention program has been successful.
 - In South Africa, the possibilities giving support directly when pain in children is observed have been beneficial.

Key words

Intervention, involvement, participation, prevention, strategy

Introduction

All children should have the opportunity to be active participants in school settings. However, children with cerebral palsy (CP) face particular challenges that may reduce such opportunities. Many of these children experience recurrent pain on a daily basis, which affects their ability to pay attention and decreases their focus on school activities [1, 2]. Because pain in early childhood can also decrease participation later in life [3, 4], it is important to identify the environmental conditions that impact participation in terms of attendance and probably engagement. This study focuses on how teachers, personal assistants, and clinicians in two countries with different cultural pre-requisites, Sweden and South Africa, report on strategies to manage the pain of children with CP in school settings.

Children with CP

CP is a permanent impairment with an estimated prevalence of 2–3 infants per 1000 live births. About one out of three children with CP has severe self-mobility limitations and cannot walk

independently [5]. Pain, such as musculoskeletal or gastrointestinal, is the most common secondary condition associated with CP and is caused by spasticity combined with an inability to change position and reduce pressure on certain body parts. When trying to cope with pain, the children use extra energy, which causes fatigue and distracts them from the activity at hand [6, 7, 8, 9]. This might lead to learning challenges for these children because their efforts to minimize the pain affect every aspect of their daily lives [2, 5, 10, 11]. A strong association between pain in early years and low levels of participation and quality of life in adolescents with CP has recently been reported [3, 4, 12]. This underlines the importance of identifying the pain management strategies that could be provided to reduce children's negative pain experiences and enable involvement in school activities.

Pain management

Pain management comprises a combination of pharmacological, non-pharmacological, and technical strategies aimed at reducing pain and facilitating participation. Examples of such strategies for children with CP are medication [5], physiotherapy [13], occupational therapy [14], technical aids [15], and psychological and social interventions [14].

An important part of pain management is preventing as much pain as possible. According to Novak [5], three out of four children with CP experience pain regardless of the level of physical disability, but the risk increases if a child cannot walk or has contractures. Musculoskeletal pain is often associated with hip displacement (one in three children) and a progression to hip dislocation increases the pain experience [5]. Progression can be prevented by frequent hip surveillance combined with treatment such as orthopedic surgery, botulinum toxin, and physiotherapy [5]. Unfortunately, a comprehensive review on safe and effective interventions for children with CP published by Novak [2, 5] showed that pain is the most under-recognized secondary condition, although it is treatable. The goal of pain management is not necessarily to

remove pain, but rather to establish a level at which children can be active participants, enjoy their life situations, and comfortably engage in everyday activities.

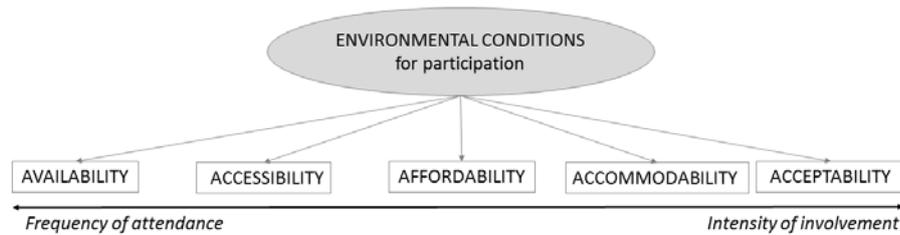


Figure 1. Environmental conditions along a continuum from frequency of attendance to intensity of involvement.

Environmental conditions for child participation in school activities

Involvement in school activities means participation that goes beyond only classroom attendance [16]. Opportunities for an individual child's participation require support at both system (regulating) and professional (providing) levels [17]. Both levels include environmental conditions that should match the individual needs of a child and that can be defined in terms of five A-dimensions [18, 19, 20]. *Availability* and *Accessibility* reflect the influence of regulations, which in this study include support aiming to enhance the child's attendance in classroom. *Accommodability* and *Acceptability* reflect how professionals act and consequently include support aiming to enhance the child's engagement in classroom activities. The fifth A-dimension is *Affordability*, which includes, for example, financial resources. Definitions of the dimensions are presented in Table 1.

According to Maxwell [21], these five environmental conditions for participation can fit into a **Frequency-Intensity model** (Figure 1) that mirrors a continuum from frequency of attendance (a

child's "being in the classroom") to intensity of involvement (that is "being engaged while being in the classroom"). In this study, the model is trialed in an analysis of intervention support in terms of pain management which, as far as we know, is the first time it has been used in such a way.

Table 1 *Environmental conditions for the participation of children with CP in school activities*

Environmental condition	Definitions as presented by Maxwell [21, p21-22]	Special meanings in this study	Rules for the coding in this study
Availability	“The objective possibility to engage in a situation. In terms of services it refers to the objective provision of facilities or resources.”	Possible methods for the professionals to handle children’s pain are mentioned, i.e. to assess and manage pain.	Talking about a method but not referring to the effects or doing it with the child. Methods do not necessarily exist in the participating schools.
Accessibility	“Describes whether you can, or perceive that you can, access the context for the situation.”	Possible, familiar methods. The effect is known by the professionals and also that they know how to use the methods to handle children’s pain.	Knowing or asking about/referring to an available method but not doing anything with the child. All kinds of information and collaboration that provide access for the child to interventions including informing others on how to do.
Affordability	“Covers not only financial constraints but also whether the amount of effort in both time and energy expenditure is worth the return to engage in the situation.”	The use of methods depends on how professionals perceive the value for the child related to time, energy and effect on the child’s situation in school.	A method that could be provided but is not worth it because the price is perceived as too high for a child in terms of e.g. stigmatization or alienation. The school has money to obtain resources needed and/or the professionals have time and energy to learn about methods on how to handle children’s pain.
Accommodability	“Describes whether a situation can be adapted.”	The professionals adapt the methods used to match individual children’s needs.	Adaptions of a situation including the demands, methods, procedures, and equipment for the child. Means to do something in the environment.
Acceptability	“Covers people’s acceptance of a person’s presence in a situation. If there is an expression of values or common beliefs which are of a subjective nature, then this is also acceptability.”	The professionals acknowledge the appropriate methods/ interventions to manage individual children’s pain.	Includes what the professionals actually do with the child. Includes communication with and information to the child about methods and pain.

Two cultures

The environmental conditions for engagement of children in school settings are largely dependent on cultural issues. These include regional and national regulations, attitudes, and beliefs in society and among professionals, available knowledge, suitable schools, integration opportunities, transportation, technical aids, and curricula [22]. The participation of children with disability, e.g. CP, is considered a product of the environment in which it takes place, which implies that both children's attendance and involvement depend on where they live and hence the availability of resources rather than the type or severity of CP by which they are affected [23, 24]. Another contributing factor may be the type of school the child attends, for example, a mainstream school or a school for children with special education needs. As the most typical barriers are attitudes, policies, and the lack of support from staff and service providers [22], one can expect variations in how professionals support children in different types of school settings.

In the current study, Sweden and South Africa represent two countries on different ends of a spectrum of cultural and socio-economical prerequisites. For example, Sweden is considered a developed, high-income country with a population of around 10 million with one official language, whereas South Africa is classified as a developing, middle-income country with a population of approximately 55 million that speaks 11 official languages [25]. The Gross Domestic Product reflects the size of an economy and in 2013, the Swedish economy was four times that of South Africa [26].

In both countries, the right to free healthcare and education for children should be guaranteed according to the Convention on the Rights of the Child [27]. The opportunities to attend school do not differ by law in the two included countries and schooling is mandatory from 7 up to 16 years of age [28, 29]. Most South African children with typical development attend school, but despite the law, only 30–50% of children with disability do. As they usually go to schools for learners with special education needs, school-based clinicians are available on a daily basis [26,

30]. In Sweden, 99% of all children attend school and most children with disability go to mainstream schools. Children with severe disability, such as severe CP, usually attend special schools where clinicians are available as external consultants [31], which results in less frequent collaboration between teachers/personal assistants and clinicians compared to South Africa.

A major issue that differentiates developed countries from developing countries is pain management. This difference depends on factors such as healthcare resources, the ability to manage pain pharmacologically, and people's tendency to seek healthcare assistance [32].

Another important factor concerns the expressions of pain that are learned from early childhood through mechanisms, such as modelling, explanations and instructions [33]. For example, in some African cultures, children (particularly boys) learn to endure pain with stoicism and resilience because men are considered weak if they show physical or emotional pain [32]. Although children do not necessarily express pain in the same way as adults, the culturally accepted pain behaviors need to be considered.

As presented above, several cultural issues are assumed to influence the environmental conditions for child participation. However, it is not known which pain management strategies professionals working with children with CP use to manage the children's recurrent pain in school settings.

Aim

The aim of this study was to explore how professionals in two countries with different cultural prerequisites, namely Sweden and South Africa, manage pain in children with CP in school settings. In addition to teachers and personal assistants, "professionals" include internal or external clinicians, such as nurses, and occupational-, physio-, and speech/language therapists, who are present in school settings to treat the children and/or advise teachers and personal assistants. For the purpose of this study, pain management refers to all different strategies for pain relief with the goal of supporting the children to attend school and to actively engage in

school activities, and thereby, to become successful learners. This means a focus on environmental conditions in terms of regulating (system level) as well as providing (professional level) support with child engagement and learning as the desired outcome. In cases where substantial similarities or differences between the countries are identified, they will be discussed. A secondary aim of the study was to determine how the Frequency-Intensity model works for the analysis of pain management strategies to support children's engagement.

Method

This study is descriptive in nature with a qualitative, exploratory approach. Focus groups were conducted in Sweden and South Africa. The professionals' statements were analyzed using the Frequency-Intensity model [18, 21] and the utility of the model was reviewed.

The present study is part of a larger project aimed to facilitate discussions about best practices, which might improve pain management in children with CP and induce children's progress in school activities despite their pain [34, 35]. Ethics approval was obtained from the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria and the Gauteng Department of Education in South Africa.

Table 2 *Demographic data of participants in the focus groups*

	Sweden	South Africa
Number of participants	25	38
Age of participants (years)	23-66 M=48.3	22-64 M=44.4
Years of experience working with children	6-40 M=19.8	0:2-40 M=16.6
Years of experience working with children with CP	0:8-38 M=15.8	0:1-34 M=11.8
Teachers	3	11
Personal assistants	5	1
Clinicians	17	26
Dieticians	1	0
Nurses	2	5
Occupational therapists	5	8
Physiotherapists	4	6
Psychologists	1	1
Social workers	2	1
Speech/language therapists	2	5

Participants

A convenience, purposive sample included professionals at schools and habilitation services within easy reach of the researchers' universities. The researchers relied on their own judgment when selecting the participating institutions, including participants from both rural and densely populated areas, and the sample was deemed representative based on the cultural prerequisites. The participants included all the professional groups that could be part of an interdisciplinary team, except physicians. Participants represented a broad range of ages; and they had extensive experience working with children both with and without CP (Table 2). Principals or directors from schools or habilitation centers in both countries provided consent

for the participation of the professionals. Informed consent letters were then provided to the participants who submitted the consent forms before the focus groups commenced.

In Sweden, the participants were recruited by the directors of four habilitation centers in two smaller towns (20,000–55,000 inhabitants) in rural areas and in two larger cities (135,000–550,000 inhabitants) in the south-western part of the country (the regions of Gothenburg and Jönköping). The directors pointed out appropriate interdisciplinary teams working with the target group and asked principals at local government schools to recruit teachers and personal assistants. As the personal assistants were near one specific child across the schooldays, they knew the child well and were usually the person who observed and discussed needs with clinicians and parents.

In South Africa, all teachers, personal assistants and clinicians were employed at government schools for children with special education needs that accommodated children with CP. The schools were situated in big city environments (500,000–4.5 million inhabitants) in Gauteng province in the area of Pretoria and Johannesburg in the north-eastern part of the country. Three out of five participating schools were boarding schools including children from rural areas because of the unavailability of schools for children with special education needs accommodating children with CP in rural areas. The principals of the schools identified and invited potential participants (teachers, personal assistants and clinicians) for the focus groups at their schools.

Detailed information on the children with CP was not gathered. However, based on participants' descriptions of the children's needs, it was understood that they all had severe self-mobility limitations.

Data collection

Focus groups were conducted to identify a broad spectrum of strategies for pain management. During the focus group sessions, participants were directly involved in the research process, ideas for possible improvements could be generated, and member checks could be performed immediately to ensure validation of the analysis of data [36, 37, 38].

Interview guides and demographic information questionnaires were developed in both Swedish and English. The guides directed the introduction of the topic and the performance of the focus groups. The first sessions in each country were planned as pilots. However, because the procedures worked well and required only minor revisions to the guide, both pilots constituted full data collections. Five sessions were planned in each country, but as saturation occurred after four Swedish groups, the fifth was cancelled.

To generate trust among the participants and get them to share their thoughts and experiences, the focus group method was introduced. It was described as starting with an empty frame, wherein statements from each focus group provided elements of a picture to supplement the others' views, with some overlapping information. At the end, a whole picture was expected to appear in the frame. Participants were insured that there were no right or wrong statements and that they would have opportunities to immediately revise their statements.

One open ended question was raised: *How can you manage to support the children to become active participants in the school despite their persistent pain?* Two sub-questions were added to support the discussions: 1) How do you act when a child with CP is in pain? 2) What other options have you tried to manage pain in children with CP? These questions were provided in print to the participants for further referral during the discussions. Some additional sub-questions were prepared to direct the answers to the concrete strategies used by the participants. The construct of pain was kept on an overall level without focusing on any specific type of pain.

In South Africa, all three authors of this paper participated in the five focus groups conducted during one week in February 2014. In Sweden, the first and last author participated in the four focus groups spread over one year (February 2014–March 2015). The procedures across focus groups were followed as consistently as possible [36, 37]. The first author, a Swedish physiotherapist having experience with children with disability as well as with conducting focus groups, acted as the moderator. The second author, a South African special educator who specializes in pain communication, typed on a laptop word for word all South African statements about pain management strategies. In Sweden, this was the responsibility of the first author. The third author, a Swedish pediatric nurse who specializes in pain management, audio-recorded the discussions, reflected on the statements, and concluded the sessions by asking for more information about possible missing data. The discussions lasted about 30 minutes.

The statements were projected onto a wall as they were typed. This method enabled participants to reflect on what others said, be reminded of strategies, and to check the formulation of their own statements. To clarify and validate the data, member checks were conducted at the end of the focus group sessions [39, 40]. All statements were jointly reviewed and revised where necessary and participants given the opportunity to confirm the truth and coherence of their statements. According to a validation technique reported by White and Verhoef [40], two final questions were asked after the revision of the statements: 1) Do these findings accurately represent your experiences? 2) Is there anything we have missed that you feel should be included? The audio-recorded material was not transcribed afterward but used to update researchers on the discussions during their analysis [39].

Data analysis

For data analysis, all written statements were saved and considered in their entirety. In the content analysis, a directed approach framed by the Frequency-Intensity model was used [18,

21, 41]. The directed content analysis had two main outcomes: 1) describing the incidence of codes representing a theory; and 2) describing different dimensions of a theory, that is, for the purpose of finding new directions.

As preparation for the analysis, all statements relating to each focus group were merged into one single spreadsheet per country. The Swedish data were translated into English by the first author. The three authors met and jointly analyzed the data. In cases where the Swedish translated comments were unclear, the authors reread the original wording and listened to the recorded statements to clarify inaccuracies by putting them into context. Because of this, a blind back-translation was deemed unnecessary [42, 43]. All statements were reviewed and reductions made due to the deletion of duplications, statements that were too general, or those not related to children with CP or pain management. Statements including two or more meaning units were divided into codes representing pain management strategies. The researchers discussed differences and deviations in detail until consensus was reached.

In the first step of the directed content analysis, the original, operational definitions of the five A-dimensions were considered [21]. The special meanings for this study were discussed and formulated, after which special rules for the coding were developed (see Table 1). This represented addition to the original model and were continuously reviewed and revised during the analysis process. Before the codes were assigned an A-dimension, they were carefully examined to determine their meanings as environmental conditions for a child's opportunities to participate in school activities. To ensure that the rules were followed, this step was iterated after assorting the codes into the A-dimensions. Thereafter, the researchers examined all codes for each A-dimension and determined, based on the special meanings for the study and the rules for coding, that no sub-dimensions were needed.

To explore how the professionals in the two countries described their pain management strategies, descriptive statistics were used. Percentages displayed the incidence of codes and

their distribution across the five A-dimensions. Substantial similarities and differences in pain management strategies were listed related to each of the five A-dimensions. To examine how the data supported the Frequency-Intensity model of child participation, codes were respectively summarized for Availability-Accessibility and Accommodability-Acceptability. Due to few statements, the dimension of Affordability was not further considered.

Results

The four Swedish focus groups included 4-8 participants (n=25) and generated 84 statements from which 91 codes were identified. The five South African focus groups included 6-10 participants (n=38) and generated 164 statements including 175 codes. The codes represented all three pain management strategies (pharmacological, non-pharmacological, and technical).

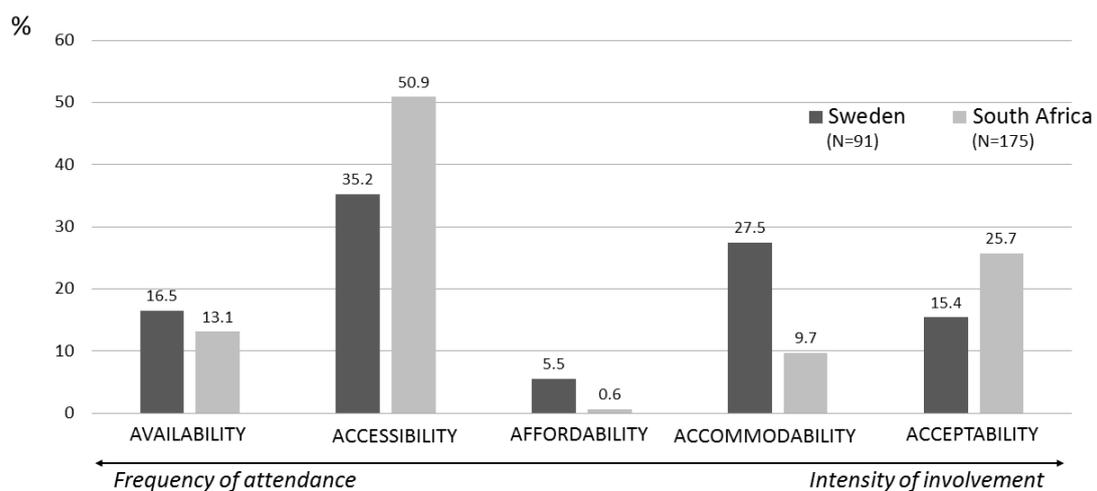


Figure 2. Distribution (%) of codes across the five A-dimensions in the Frequency-Intensity model.

The incidence of codes representing the Frequency-Intensity model

Figure 2 shows the distribution (%) of codes across the Frequency-Intensity model. Examples from each country are presented in Supplementary Table S1 along with the most significant similarities and differences relating to each of the A-dimensions.

The majority of the participants' statements included pain management strategies related to children's attendance in the classroom, that is, their "being there" (Σ 52%; 64% of statements). Other statements included strategies relating to involvement, that is, "being engaged while being there" (Σ 43%; 35%). They showed that the Swedish participants described firsthand adaptations of procedures and equipment (Accommodability), whereas the South African participants more often described the methods used to manage the pain of individual children (Acceptability).

New direction of the Frequency-Intensity model

The analysis showed that the original Frequency-Intensity model with five A-dimensions reported by Maxwell and colleagues [18, 21] was not the optimal model for displaying professionals' descriptions of pain management strategies with the purpose of supporting children's participation in classrooms. Rather, it demonstrated the participants' knowledge about methods (knowing) and their practices (doing). The directed content analysis, therefore, resulted in a change of the dimensions of the model. The new direction is displayed in Figure 3—a *Knowing-Doing model*. The summary of the participants' adaptations of procedures and equipment (Accommodability), and what they told us they were doing, that is, methods used (Acceptability), suggest that professionals in Sweden used strategies for *actions* aimed at preventing pain more than the professionals in South Africa, who more often expressed *reactions*, that is, how they intervened when they observed that children with CP were in pain. In addition to the quotes given below, examples of the professionals' descriptions of pain management strategies are displayed in the Supplementary Table S1.

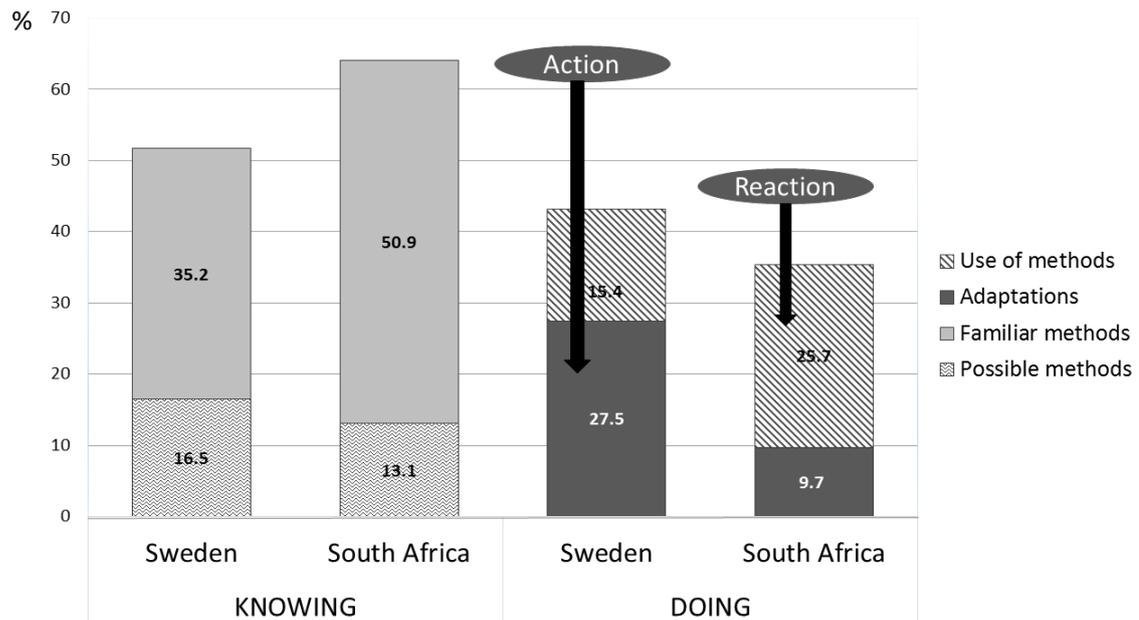


Figure 3. Distribution (%) of codes across the Knowing-Doing model indicating Action-versus Reaction approaches of performed pain management (Doing)

Knowing

The high proportion of codes related to Knowing indicated that all participants had the knowledge of a wide range of methods to manage children’s pain. However, information was lacking about how these methods were actually used. The participants expressed knowledge about the children’s needs related to the demands in school environments: *In schools, there is a complicated balance between considerations about the child’s body and the need for academic learning. Considering everything around these children takes a longer time.* They also mentioned collaboration, such as between professions, with external services, and with parents. Both countries acknowledged team collaboration with colleagues: *Discuss the child with the team, since different professions may have different perspectives on solutions.* However, there was a difference regarding collaboration with parents. In Sweden, parents were seen as partners in the team: *Collaboration is needed in certain situations, such as sports, needlework, and other practical topics.* South African participants referred to parents more as trainers of the child: *Try to train them on a specific topic – practical session, show how to handle, position, transfer to toilets, etc.*

Doing

The distribution of codes related to Doing revealed a different percentage distribution of statements (Figure 3). A high percentage of Swedish codes about adaptations included how the professionals undertook actions to prevent the emergence of pain by keeping the child comfortable in school situations, prescribing technical aids, scheduling interruptions in school work, and frequently following up on children with the most severe disabilities. A follow-up surveillance program for children with CP (CPUP) was implemented followed by pharmacological treatment with baclofen or botulinumtoxin aiming to prevent pain by decreasing spasticity.

A high percentage of South African codes about methods included how the professionals used a wide range of methods in daily practice, that is, they react when they notice a child in pain (Supplementary Table S1). They mentioned methods for relieving hip pain and how a child could be supported by clinicians in the classroom: *Assistance from therapists depending on how the child presents – pain in hip joints – PT (physiotherapist) attempts to treat, minimize, or eliminate the pain.* Alternatively, a child could be sent out of class to be supported by clinicians in the school or back home to see an external doctor. The pharmacological treatment consisted of drugs prescribed by external physicians but administered and followed up in the school setting or of non-prescription medications administered by the school nurses. Preventive pharmacological treatments were rarely available in South Africa where pain-relieving medication was used instead.

All participants reported using strategies to distract children from pain by, for example, making jokes or focusing on something nice, to prepare a child for activities by explaining: *that is what we will do, what you will feel, anticipate what to expect and will happen – mentally prepare and show them, demonstrate the activity;* to show empathy during painful sessions by saying, for example: *I am empathetic, but you must try to get through this stretching* or *We know what you*

are going through. It is tough. We are here to assist, but you need to finish the activity; to use “tender loving care” such as putting the child on the lap, or holding him close; and to provide encouragement during activities by praising the child for standing in a frame or talking about his capability. All of them also reported how they worked to ensure the correct positioning to minimize pain (see Supplementary Table S1).

Discussion

This study focused on environmental conditions for children with CP in pain in school settings, such as opportunities available on different levels with child participation as the desired outcome. Findings show how teachers together with internally or externally employed clinicians in two countries with different cultural pre-requisites provide pain management and how regulations differ due to culture. The participants in both countries knew about a wide range of possible methods to support children with CP to become active participants in school activities. Analysis of what they reported doing showed differences in the use of pain management strategies suggesting “action versus reaction” approaches. The general conclusion was that professionals in Sweden described *actions* (strategies to prevent children’s pain), whereas in South Africa, professionals more often described *reactions* (strategies to intervene when a child is already experiencing pain). According to the participants’ descriptions, the “action-versus-reaction” approaches to pain management in the school settings could not only be explained by different strategies but also by the occurrence of severe pain in children, access to healthcare resources, kind of school system, and prerequisites for collaboration with parents.

Occurrence of pain in school settings

Despite the fact that in none of the focus groups participants were oriented to think about hip pain specifically, findings suggest a difference between the countries in the occurrence of such pain. Chronic pain in children with CP is often related to hip dislocations [44], which was pointed out in six of the South African statements, whereas in Sweden, it was not mentioned at all. In

accordance with the clinical prognostic messages published by Novak [2], this difference can probably be explained by the systematic, preventive CPUP surveillance that was introduced in Sweden two decades ago and which, since 2005, has been designated as a National Quality Register [45]. In South Africa, no such surveillance has been implemented but clinicians in schools support the children when expressions of pain are observed. In Sweden, such immediate interventions in the school environment were rare as children were monitored on a continuous basis.

It is not confirmed to what extent pain is a distractor for learning, especially as children with CP also experience other difficulties, such as communication challenges related to their disability. Despite this, professionals sometimes expect the children themselves to express how they feel and what they need [46]. However, this could prove challenging for a child that cannot communicate verbally and, as a result, their pain is misunderstood and not appropriately supported [34]. As it is mostly teachers or personal assistants who affect children's involvement in school settings, their attitudes and support are essential environmental factors. If they misunderstand or ignore the children's pain communication efforts, the children's engagement and learning could be impeded [17]. This could be because no pain relieving strategies were employed and the children still experienced pain [47]. Therefore, professionals can use facilitating strategies, such as augmentative and alternative communication (AAC) to enable children to express their pain in such a way that the professionals understand. These AAC strategies should be adapted to a child's individual needs and should be implemented to help children with CP to communicate their pain.

Healthcare resources

Although the access to healthcare resources might be a matter outside the school, the focus groups showed how it clearly affected the children's opportunities to participate actively in school activities. The statements concerned all kinds of healthcare opportunities for the

children at hand and external opportunities could not be overlooked. For example, pharmacological pain management strategies are dependent on access, costs, and legislation. For children with CP, medication intended for the reduction of spasticity and recurrent pain is typically needed [48, 49]. Access to such medication was rare in South African schools where pharmacological treatment could not be offered without a doctor's prescription [50]. Instead, pain treatment in South Africa included analgesics more feasible for acute pain, such as paracetamol and ibuprofen and, because clinicians were of the opinion that children experienced side effects with these drugs, they alternatively provided the child with a glass of water as a placebo.

The occurrence of pain in Swedish school settings is most likely limited due to a planned and continuous spasticity-reducing treatment with pharmacological strategies combined with non-pharmacological interventions and others. Botulinumtoxin is a drug injected into overactive spastic muscles and used for children with CP from the age of 2 years [5, 51, 52]. Combined with non-pharmacological interventions, it has demonstrated significant improvements in joint motion and spontaneous hand and arm use [53, 54, 55]. Unfortunately, there is a lack of evidence as to whether this also means improved participation. In addition, the effect of botulinumtoxin can decrease over time [55, 56]. Another medication is baclofen that intends to manage global spasticity and can be administered orally or via intrathecal injections [5, 57]. Continuous intrathecal baclofen therapy is reported to reduce spasms [48, 58], improving the ability of children with intractable spastic CP and severe self-mobility limitations to sit.

In South Africa, these medications are not available, but non-pharmacological interventions in the schools, such as physiotherapy, play an important role in pain management; many different strategies were reported. In general, there is a gap between the use of pain management and the evidence of its effects [10, 13, 59] and in this study, the participants did not state how effective their pain relief methods were. Also in Sweden, physiotherapists play a significant role

in the treatment of children with CP. Together with occupational therapists they are active in the implementation of the CPUP to prevent pain by following up on range of motion and other measures [45]. As the prevention of hip dislocation is a preferred treatment, a structured follow-up program is of great value. It includes needs assessment from other perspectives, such as technical or other strategies, for example assistive technology, custom schedules, or other adaptations. In addition to the implementation of the CPUP and botulinumtoxin, adaptations are meant to prevent, as far as possible, unpredictable pain occurrences. However, procedural pain might occur during therapy aiming to correct or prevent orthopedic problems, such as standing in frames, assisted stretching, or needle injections [13]. This further strengthens the need for professionals to pay attention to the children's reactions and facilitate communication strategies.

School systems

The two countries' school and support systems, in addition to socioeconomic prerequisites, are environmental conditions that would explain parts of the action-versus-reaction approaches while affecting children's involvement in classroom activities. According to Ullenhag and colleagues [60], the systems might influence the participation of children with disability more than other children among countries with vast different cultural prerequisites. The findings in the present study established that the systems differ between countries.

In Sweden, children are provided consultative interventions by external, not school-based clinicians. The children are typically integrated into mainstream schools, although there are debates in Sweden and in other countries about the effects of inclusive education and what factors make schools and classrooms more inclusive [61]. The clinicians act as consultants to the teachers, and as such, focus on the impact of the environment. Opportunities for environmental adaptations that match the needs of an individual child are discussed in collaboration with

teachers and parents. The preventive actions are extra important because as consultants, the therapists cannot show up immediately when pain is observed.

In South Africa, children with CP are accommodated in schools for children with special education needs, which seems to be more typical than being included in mainstream schools [30]. As the clinicians are based at the schools, they know each child and can provide “hands-on” pain management through treatment on a daily basis. The clinicians are available for support when teachers observe unpredictable pain occurrences and can focus on immediate improvement of the child’s pain and bodily functions rather than on the impact of the environment. This reactive approach requires close cooperation between teachers and clinicians and is labor intensive. Should clinicians become centralized, in other words, no longer school-based, the access to “hands-on” treatment would most likely decrease and a change of strategies would be required. Preventive pain management strategies are assumed to be less expensive while they are also confirmed to be more effective than reactive approaches [10, 62]. This suggests that the “action approach” could have benefits besides supporting the children directly. However, as the Swedish participants highlighted limited pain management resources in schools, the action approach seemed perceived as insufficient. Extended resources in terms of healthcare professionals or personal assistants were mentioned as opportunities to manage the children’s pain when it occurs unpredictably. Likewise, the South African participants talked about limited resources in terms of personal assistants, but they also saw benefits with an improved collaboration with parents.

Collaboration with parents

From a school perspective, parents with knowledge and economic resources to support the children with effective pain management would mean prevention as the child could attend classroom activities with a better pain status. Therefore, parents’ involvement in the pain management of their children is essential. It can, for example, prevent children from becoming

“extra stiff” during holidays, as frequently mentioned by the South African clinicians. The participants discussed opportunities to introduce parent training programs focusing on CP and referred to how, as an example, the use of educational films could be a successful action for involving the parents in pain management [63, 64].

Collaboration with parents can be supported if they are included as part of the child’s professional team. During team discussions, parents and professionals share information about a child’s specific needs and jointly decide how to implement pain management strategies. Joint planning meetings were frequently performed in Sweden [65], but in South Africa, parents were seldom involved in their children’s treatment. Participants perceived it challenging to find means for informing parents about the child’s needs. They explained that some parents had a low level of education or experience problems coming to the school for team meetings due to, for example, lack of transportation or transport money. Some children also lived with grandparents who were illiterate. Nevertheless, various effects can be achieved when parents learn how to maintain their child’s health status during holidays. Not least are the parents’ own feelings of being in control and self-worth, which exerts a positive effect on their enhanced competence in pain management [66]. These insights reinforced the participants' idea to devote time to parental training, which did not currently exist but was deemed important.

The impact of pain on child participation and learning

Many children with CP experience daily pain, which often affects their attention and decreases their focus on school activities [1]. Already 30 years ago, a high level of engagement was proven to be a critical precursor for learning and development [67]. As the most fundamental prerequisite for engagement is attendance, [20], children must be supported as much as possible to remain in the classroom. The time children spend engaged in stimulating activities correlates with learning, both at present and in the future, and children can sometimes perceive missed time in the classroom as worse than the disability itself [68, 69]. This was an aspect

raised in the South African focus groups [34] where participants reported that they not always knew about a child's pain. The children sometimes tried to mask their pain because they were worried about being sent away from the classroom or sent home for a longer period of time.

To optimize the opportunities for children with CP to both attend and engage in classroom activities, the findings suggest that a combination of action and reaction approaches is necessary. Because participation is influenced by intrinsic factors, not only environmental conditions [17], it promotes children's desire to learn if the professionals are open to their "state of the day" and not bound "to always do as they always do". This reactive approach was reflected by participants and shows how they were aware of the benefits of providing support by paying attention to a child's preferences. An example of action approach was the use of botulinumtoxin combined with non-pharmacological treatments, which are evidence-based and has become an effective alternative to orthopedic surgery in many countries [59]. Thereby, children with CP do not need to stay home for long periods for rehabilitation.

The study shows that participants in both countries knew what impact neglected pain could have on the individual child. Moreover, other studies have reported that pain and the impact of disability not only negatively affect learning but also the quality of life of children and young people with CP [3, 70]. Therefore, even though few interventions focus on participation as the primary outcome [71], it is important to frequently evaluate pain management strategies so that they are perceived effective for the individual child. Nevertheless, as this study did not investigate how neither pain management nor attendance enhances engagement, the hypothetical relationship is based on previous studies.

Knowing-Doing model

Related to the Knowing-Doing model suggested in this study, the participants frequently mentioned methods and strategies they were aware of, but they less often indicated how they actually implemented these strategies. This indicates that they were well aware of the needs of

the children as well as the potential that might exist; however, they did not clearly state the interventions [35]. Affordability can be a possible reason because financial resources are important in several aspects. The exclusion of Affordability from the Knowing-Doing model is in line with the thoughts of Maxwell [21], who stated that it did not appear to be especially aligned to either frequency of attendance or intensity of involvement. However, in discussions about potential strategies, affordability might be critical.

Trustworthiness

To achieve trustworthiness in this study focusing on how professionals manage pain in children with CP in school settings with different cultural prerequisites, the study design and the context have been described in detail [72]. The participants were selected to represent various experiences based on demographic and background characteristics, which enabled them to deal with the research questions from a variety of aspects and the focus groups were conducted in the participants' familiar, everyday context. The three researchers represented various cultural and clinical backgrounds, which ensured a broad understanding of statements. Furthermore, member checks were performed immediately to guarantee the credibility of the data analysis and the meaning units were most often narrow. Although data were collected at different timepoints, they were all analyzed simultaneously and by the three researchers together, striving to minimize the modification of data during the analysis process.

Limitations

Our intention to try to use the Frequency-Intensity model in the analysis resulted in limitations because it did not appear to map onto the pain management strategies in the focus of this study. Even though the dimensions of the model were changed, the findings revealed overlaps between the Knowing and Doing perspectives. The distinction between the perspectives was vague, most likely because there were not enough clarification questions during the focus groups. In addition, the professionals' statements included not only successful methods but also

those they considered to be less successful, and the same method could be assigned more than one A-dimension depending on how a statement was formulated. Nevertheless, the analysis of the Doing perspective provided the picture of action-versus-reaction approaches with positive implications of both.

The results must be interpreted with caution. The samples varied in size, the statements were gathered in different cultural contexts, and the recruitment strategies differed for organizational reasons. This might explain the imbalanced number of teachers/personal assistants versus clinicians and the uneven incidence of codes that could have affected the perspectives submitted. The different number of participants is firsthand explained by saturation and the lower number of Swedish teachers were compensated by more personal assistants who were each responsible for specific children. In addition, the different number of participants/focus group might have influenced the number of statements collected during each occasion. To compensate for the uneven numbers of codes, percentage distribution was the basis for the analyses. Furthermore, focus groups, as alternative interview forms, are challenging because participants tend to respond in a way that they think the researchers expect—the so-called Hawthorne effect [73]. For this reason, the introductions were thoroughly prepared to generate trust among the participants in an effort to get them to respond honestly.

In the future, research should include a triangulation of data by adding on the children's own perceptions and also participation observations [38] to determine how professionals actually perform in practice. Another suggestion for future research is to conduct a longitudinal intervention study with the implementation of a follow-up program including hip surveillance and predetermined treatment to prevent hip dislocations in some South African provinces to investigate if it will be as successful as the CPUP has been in Sweden.

Conclusion

New directions for the Frequency-Intensity model used in analysis were found. The modified Knowing-Doing model supported the finding that professionals had knowledge about a wide range of pain management strategies but that they did not necessarily have access to them or use them. The Doing perspective highlighted similarities and some differences between countries in terms of action-versus-reaction approaches. Explanations were found on system level, such as healthcare resources and school systems; and on professional level, such as routines for the collaboration with parents, professionals' attitudes to the children, possibilities to communicate pain experiences and provide pain management on a daily basis.

When reactions are necessary, clinicians should be able to provide support for children in the classroom. In addition, access to structured surveillance and treatment programs are desirable along with trustful collaboration with parents. However, even though a prevention program is beneficial, the action approach might not be enough. An action-and-reaction approach would be optimal, meaning that the children are also provided with "hands-on" pain management when needed. To supplement the professional's observation of children, the implementation of AAC strategies is recommended to help the children communicate their pain.

Despite a focus on environmental conditions in terms of regulating as well as providing support in school settings with child engagement and learning as a desired outcome, the correlation between the variables is still hypothetical.

Conflict of interest

The authors report no conflict of interest. The authors alone are responsible for the content and writing of the paper.

Acknowledgements

We thank the participants in the focus groups who generously shared their experiences. We

also thank the principals of the South African schools and directors of the Swedish habilitation centers who gave consent for their staff to participate in these focus group discussions.

References

- [1] Vargus-Adams JN, Martin LK. Domains of importance for parents, medical professionals and youth with cerebral palsy considering treatment outcomes. *Child Care Health Dev.* 2011;37:276-81.
- [2] Novak I, Hines M, Goldsmith S, Barclay R. Clinical prognostic messages from a systematic review on cerebral palsy. *Pediatrics.* 2012;130:e1285-312.
- [3] Colver A, Rapp M, Eisemann N, Ehlinger V, Thyen U, Dickinson HO, Parkes J, Parkinson K, Nystrand M, Fauconnier J, Marcelli M, Michelsen SI, Arnaud C. Self-reported quality of life of adolescents with cerebral palsy: a cross-sectional and longitudinal analysis. *Lancet.* 2015;385:705-16.
- [4] Dang VM, Colver A, Dickinson HO, Marcelli M, Michelsen SI, Parkes J, Parkinson K, Rapp M, Arnaud C, Nystrand M, Fauconnier J. Predictors of participation of adolescents with cerebral palsy: A European multi-centre longitudinal study. *Res Dev Disabil.* 2014;36C:551-64.
- [5] Novak I. Evidence-based diagnosis, health care, and rehabilitation for children with cerebral palsy. *J Child Neurol.* 2014;29:1141-56.
- [6] Breau L. A reminder that pain hurts. *Dev Med Child Neurol.* 2011;53:974-5.
- [7] Castle K, Imms C, Howie L. Being in pain: a phenomenological study of young people with cerebral palsy. *Dev Med Child Neurol.* 2007;49:445-9.
- [8] Berrin SJ, Malcarne VL, Varni JW, Burwinkle TM, Sherman SA, Artavia K, Chambers HG. Pain, fatigue, and school functioning in children with cerebral palsy: a path-analytic model. *J Pediatr Psychol.* 2007;32:330-7.
- [9] Breau L, Stevens B, Grunau RE. Developmental issues in acute and chronic pain in developmental disabilities. In: Oberlander TF, Symons FJ, editors. *Pain in children and adults with developmental disabilities* Baltimore, Maryland: Paul Brookes Publishing Company; 2006. p. 89-107.
- [10] Fowler EG, Kolobe THA, Damiano DL, Thorpe DE, Morgan DW, Brunstrom JE, Coster WJ, Henderson RC, Pitetti KH, Rimmer JH, Rose J, Stevenson RD. Promotion of Physical Fitness and Prevention of Secondary Conditions for Children With Cerebral Palsy: Section on Pediatrics Research Summit Proceedings. *Phys Ther.* 2007;87:1495-510.
- [11] Westbom L, Hägglund G, Nordmark E. Cerebral palsy in a total population of 4-11 year olds in southern Sweden. Prevalence and distribution according to different CP classification systems. *BMC Pediatrics.* 2007;7:41.
- [12] Kingsnorth S, Orava T, Provvidenza C, Adler E, Ami N, Gresley-Jones T, Mankad D, Slonim N, Fay L, Joachimides N, Hoffman A, Hung R, Fehlings D. Chronic Pain Assessment Tools for Cerebral Palsy: A Systematic Review. *Pediatrics.* 2015;136:e947-60.
- [13] Swiggum M, Hamilton ML, Gleeson P, Roddey T. Pain in Children with Cerebral Palsy: Implications for Pediatric Physical Therapy. *Pediatr Phys Ther.* 2010;22:86-92.
- [14] Kent RM. Cerebral palsy. *Handb Clin Neurol.* 2013;110:443-59.
- [15] Rivi E, Filippi M, Fornasari E, Mascia MT, Ferrari A, Costi S. Effectiveness of standing frame on constipation in children with cerebral palsy: a single-subject study. *Occup Ther Int.* 2014;21:115-23.
- [16] Imms C, Granlund M. Participation: Are we there yet... *Aust Occup Ther Journal.* 2014;61:291-2.

- [17] Imms C, Granlund M, Wilson PH, Steenbergen B, Rosenbaum PL, Gordon AM. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Dev Med Child Neurol*. 2016;Early online.
- [18] Maxwell G, Alves I, Granlund M. Participation and environmental aspects in education and the ICF and the ICF-CY: Findings from a systematic literature review. *Dev Neurorehabil*. 2012;15:63-78.
- [19] Simeonsson RJ, Bailey DB, Scandlin D, Huntington GS, Roth M. Disability, health, secondary conditions and quality of life: Emerging issues in public health. In: Simeonsson RJ, McDevitt LN, editors. *Issues in disability & health The role of secondary conditions & quality of life*. Chapel Hill: NC: University of North Carolina; 1999. p. 239-55.
- [20] Granlund M. Participation – challenges in conceptualization, measurement and intervention. *Child Care Health Dev*. 2013;39:470-3.
- [21] Maxwell G. Bringing more to participation. *Participation in school activities of persons with disability within the framework of the ICF-CY*. Jönköping: School of education and communication; 2012.
- [22] Anaby D, Hand C, Bradley L, DiRezze B, Forhan M, DiGiacomo A, Law M. The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disabil Rehabil*. 2013;35:1589-98.
- [23] Colver A, Dickinson HO. Study protocol: Determinants of participation and quality of life of adolescents with cerebral palsy: a longitudinal study (SPARCLE2). *BMC Public Health*. 2010;10:280.
- [24] Hammal D, Jarvis S, Colver A. Participation of children with cerebral palsy is influenced by where they live. *Dev Med Child Neurol*. 2004;46:292-8.
- [25] GEOHIVE. Global Population Statistics 2015 [cited 2015 June 21]. Available from: <http://www.geohive.com>.
- [26] OECD. OECD Economic Surveys: South Africa 2013 2013 [cited 2015 June 22]. Available from: http://dx.doi.org/10.1787/eco_surveys-zaf-2013-en.
- [27] UN Convention on the Rights of the Child, (1989).
- [28] Saloojee G, Phohole M, Saloojee H, Ijsselmuiden C. Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child Care Health Dev*. 2007;33:230-5.
- [29] SFS. The Swedish Education Act (2010:800). 2010.
- [30] Donohue D, Bornman J. The challenges of realising inclusive education in South Africa. *S Afr J Educ*. 2014;34:01-14.
- [31] Skolverket. Elever i obligatoriska skolan läsåret 2012/13 [Pupils in compulsory education 2012/13]. Dnr 71-2013:299. 2013.
- [32] Nortjé N, Albertyn R. The cultural language of pain: a South African study. *S Afr Family Practice*. 2015;57:24-7.
- [33] Finnström B, Söderhamn O. Conceptions of pain among Somali women. *J Adv Nurs*. 2006;54:418-25.
- [34] Johnson E, Nilsson S, Adolfsson M. Eina! Ouch! Eish! Professionals' Perceptions of How Children with Cerebral Palsy Communicate About Pain in South African School Settings: Implications for the use of AAC. *Augment Altern Comm*. 2015;31 325-35.
- [35] Nilsson S, Johnson E, Adolfsson M. Professionals Perceptions about the Need for Pain Management Interventions for Children with Cerebral Palsy in South African School Settings. *Pain Management Nursing*. 2016;17:249-61.
- [36] Brod M, Tesler LE, Christensen TL. Qualitative research and content validity: developing best practices based on science and experience. *Qual Life Res*. 2009;18:1263-78.
- [37] Wibeck V, Abrandt Dahlgren M, Öberg G. Learning in focus groups: an analytical dimension for enhancing focus group research. *Qual res*. 2007;7:249-67.
- [38] Brotherson MJ. Interactive Focus Group Interviewing: A Qualitative Research Method in Early Intervention. *TECSE* 1994;14:101-18.
- [39] Obert C, Forsell M. Fokusgrupp - ett enkelt sätt att mäta kvalitet [Focus groups - an easy method to measure quality]. Helsingborg: Kommunnlitteratur; 2000.

- [40] White MA, Verhoef MJ. Toward a Patient-Centered Approach: Incorporating Principles of Participatory Action Research Into Clinical Studies. *Integr Cancer Ther.* 2005;4:21-4.
- [41] Hsieh H, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005;15:1277-88.
- [42] Bornman J, Sevcik RA, Ronski MA, Pae HK. Successfully Translating Language and Culture when Adapting Assessment Measures. *J Policy and Practice in Intellectual Disabil.* 2010;7:111-8.
- [43] Pena E. Lost in translation: Methodological considerations in cross-cultural research. *Child Dev.* 2007;78:1255-64.
- [44] Jóźwiak M, Harasymczuk P, Koch A, Kotwicki T. Incidence and risk factors of hip joint pain in children with severe cerebral palsy. *Disabil Rehabil.* 2011;33:1367-72.
- [45] Hägglund G, Alriksson-Schmidt A, Lauge-Pedersen H, Rodby-Bousquet E, Wagner P, Westbom L. Prevention of dislocation of the hip in children with cerebral palsy: 20-year results of a population-based prevention programme. *Bone & Joint J.* 2014;96-B:1546-52.
- [46] Twycross A, Collins S. Nurses' views about the barriers and facilitators to effective management of pediatric pain. *Pain Management Nurs.* 2013;14:e164-72.
- [47] Johnson E, Bornman J, Tönsing KM. An exploration of pain-related vocabulary: implications for AAC use with children. *Augment Altern Comm.* 2016;32:249-60.
- [48] Vles G, Soudant D, Hoving M, Vermeulen R, Bonouvrie L, van Oostenbrugge R, al. e. Long-term follow-up on continuous intrathecal Baclofen therapy in non-ambulant children with intractable spastic Cerebral Palsy. *Eur J Paediatr Neurol.* 2013;17:639-44.
- [49] Ramstad K, Jahnsen R, Skjeldal OH, Diseth TH. Characteristics of recurrent musculoskeletal pain in children with cerebral palsy aged 8 to 18 years. *Dev Med Child Neurol.* 2011;53:1013-8.
- [50] RSA. Republic of South Africa. No. 59 of 2002: Medicines and Related Substances Amendment Act, 2002., (2003).
- [51] Patil S, Willett O, Thompkins T, Hermann R, Ramanathan S, Cornett E, al e. Botulinum Toxin: Pharmacology and Therapeutic Roles in Pain States. *Curr Pain Headache Rep.* 2016;20:15.
- [52] Pavone V, Testa G, Restivo D, Cannavo L, Condorelli G, Portinaro N, al e. Botulinum Toxin Treatment for Limb Spasticity in Childhood Cerebral Palsy. *Front Pharmacol.* 2016;7.
- [53]. Karaca B, Unlu E, Kose G, Gonen E, Cakci A. Outcomes of Botulinum Toxin Type A Injection Followed by Rehabilitation in Cases of Cerebral Palsy With Upper Extremity Involvement. *J Child Neurol.* 2016;31:357-63.
- [54] Pin T, Elmasry J, Lewis J. Efficacy of botulinum toxin A in children with cerebral palsy in Gross Motor Function Classification System levels IV and V: a systematic review. *Dev Med Child Neurol.* 2013;55:304-13.
- [55] Lidman G, Nachemson A, Peny-Dahlstrand M, Himmelmann K. Botulinum toxin A injections and occupational therapy in children with unilateral spastic cerebral palsy: a randomized controlled trial. *Dev Med Child Neurol.* 2015;57:754-61.
- [56] Schwabe A. Botulinum Toxin in the Treatment of Pediatric Upper Limb Spasticity. *Semin Plast Surg.* 2016;30:24-8.
- [57] Overgard T, Kjaersgaard-Hansen L, Soe M, Illum N. Positive experience with intrathecal baclofen treatment in children with severe cerebral palsy. *Dan Med J.* 2015;62:A4999.
- [58] Gray N, Morton R, Brimlow K, Keetley R, Vloeberghs M. Goals and outcomes for non ambulant children receiving continuous infusion of intrathecal baclofen. *Eur J Paediatr Neurol.* 2012;16:443-8.
- [59] Papavasiliou AS. Management of motor problems in cerebral palsy: A critical update for the clinician. *Eur J Paediatric Neurol.* 2009;13:387-96.
- [60] Ullenhag A, Bult MK, Nyquist A, Ketelaar M, Jahnsen R, Krumlinde-Sundholm L, Almqvist L, Granlund M. An international comparison of patterns of participation in leisure activities for children with and without disabilities in Sweden, Norway and the Netherlands. *Dev Neurorehabil.* 2012;15:369-85.
- [61] Göransson K, Nilholm C. Conceptual diversities and empirical shortcomings – a critical analysis of research on inclusive education. *Eur J Spec Needs Educ.* 2014;29:265-80.

- [62] Noel M, Chambers CT, McGrath PJ, Klein RM, Stewart SH. The influence of children's pain memories on subsequent pain experience. *PAIN®*. 2012;153:1563-72.
- [63] Karande S, Patil S, Kulkarni M. Impact of an educational program on parental knowledge of cerebral palsy. *Indian J Pediatr*. 2008;75:901-6.
- [64] Arora SK, Aggarwal A, Mittal H. Impact of an Educational Film on Parental Knowledge of Children with Cerebral Palsy. *Int J Pediatr*. 2014;2014:573698.
- [65] Björck-Åkesson E, Granlund M. Early intervention in Sweden. A developmental systems perspective. In: Guralnick MJ, editor. *The Developmental Systems Approach to Early Intervention*. Baltimore, MD Paul H. Brookes 2005. p. 571-92.
- [66] Dunst CJ, Dempsey I. Family-Professional Partnerships and Parenting Competence, Confidence, and Enjoyment. *Int J Disabil, Dev & Educ*. 2007;54:305-18.
- [67] McWilliam RA, Triveffe CM, Dunst CJ. Behavior engagement as a measure of efficacy of early intervention. *Anal and Interv in Dev Disabil*. 1985;5:33-45.
- [68] UNESCO. Open file on inclusive education: support materials for managers and administrator. Paris: UNESCO; 2003.
- [69] Shikako-Thomas K, Shevell M, Lach L, Law M, Schmitz N, Poulin C, Majnemer A, tQg. Are you doing what you want to do? Leisure preferences of adolescents with cerebral palsy. *Dev Neurorehabil*. 2015;18:234-40.
- [70] Böling S, Varho T, Kiviranta T, Haataja L. Quality of life of Finnish children with cerebral palsy. *Disabil Rehabil*. 2016;38:683-8.
- [71] Adair B, Ullenhag A, Keen D, Granlund M, Imms C. The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review. *Dev Med Child Neurol* 2015;57:1093–104.
- [72] Graneheim Hällgren U, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*. 2004;24:105-12.
- [73] Kottner J, Audige L, Brorson S, Donner A, Gajewski BJ, Hróbjartsson A, Roberts C, Shoukri M, Streiner DL. Guidelines for Reporting Reliability and Agreement Studies (GRRAS) were proposed. *Int J Nursing Studies*. 2011;48:661-71.

Figure legends

Figure 1. Environmental conditions along a continuum from frequency of attendance to intensity of involvement.

Figure 2. Distribution (%) of codes across the five A-dimensions in the Frequency-Intensity model.

Figure 3. Distribution (%) of codes across the Knowing-Doing model indicating Action-versus-Reaction approaches of performed pain management (Doing)

Supplementary Table S1 *Statements about pain management strategies and intervention methods related to the modified Knowing-Doing model and to the five A-dimensions in the Frequency-Intensity model*

	A-dimension	Pain management strategy	Reported intervention method		Substantial similarities and differences Sweden - South Africa
			Sweden	South Africa	
KNOWING	Availability	Pharmacological	<i>Baclofen or Botulinumtoxin.</i>	<i>Panado (paracetamol) or Brufen (ibuprofen).</i>	<p><i>Similarities:</i> Physiotherapy was mentioned in both countries as an available pain reducing strategy.</p> <p><i>Differences:</i> Different pharmacological substances were emphasized: Sweden: Baclofen and Botulinum toxin to prevent pain South Africa: paracetamol and ibuprofen to relieve pain.</p>
		Non-pharmacological	<i>Tactile massage, movement techniques.</i>	<i>Heat therapy, massage, mobilization.</i>	
		Technical	<i>Technical aids, adapted chairs.</i>	<i>Standing frames, cushion to lie on.</i>	
		Other	---	<i>Parents not really interested in support groups or training at the school.</i>	
KNOWING	Accessibility	Pharmacological	<i>Botulinumtoxin makes a big difference.</i>	<i>Only medication for headaches/pain, e.g. Brufen (ibuprofen) when needed, because medication has side effects such as tiredness, dizziness.</i>	<p><i>Similarities:</i> Children's need of good positioning. Team collaboration acknowledged (between teachers and clinicians or with experts from external medical resources).</p> <p><i>Differences:</i> Sweden: professionals identified CPUP as an important source of pain information and also that due to the CPUP, hip locations had become rare. South Africa: treatment related to hip dislocation was frequently mentioned.</p> <p>The collaboration with parents reflected different perspectives. Sweden: parents were seen as partners in the team. South Africa: parents were seen as trainers of the child.</p> <p>Knowledge about the effects of medication.</p>
		Non-pharmacological	<i>CPUP gives information about pain. Scheduled time in the white room* relieve the pressure on the body.</i>	<i>Positioning help children with hip dislocations. Heat packs – makes children comfortable for a time.</i>	
		Technical	<i>Children use walker or other walking aids.</i>	<i>Putting them on a mat or a standing frame. Computer helps a lot to focus in class despite pain.</i>	
		Other	<i>Discuss the child with the team, since different professions may have different perspectives on solutions. Collaboration between parents, habilitation services, school</i>	<i>Teachers can always ask clinicians about a specific child in their class on how to support them. Train parents to manage their children's pain</i>	

Not included in the Knowing-Doing model	Affordability	Pharmacological	---	---	<p><i>Similarities:</i> Overall few statements</p> <p><i>Differences:</i> Sweden: statements referred to resources and reflected a child perspective on how management could affect the child's situation in school. South Africa: the only code reflected the need to take cultural views and attitudes into consideration.</p>
	Non-pharmacological	<p><i>Find time for recovery, for example, for children who do not have the most difficult disabilities but still want to be involved in everything that their friends are doing.</i></p>	<p><i>The cultural frame of reference should be taken into consideration during treatment as it can be totally different from the professionals' beliefs.</i></p>		
DOING	Accomodability	Pharmacological	---	<p><i>Try to steer away from medication as many are at sister every day – medication last option.</i></p>	<p><i>Similarities:</i> Positioning important</p> <p><i>Differences:</i> Sweden: professionals frequently adapted the methods to match the needs of an individual child. This implied a focus on strategies to prevent pain South Africa: codes included what to do when observing pain reactions, e.g. teachers sent the child to the clinician to become supported.</p>
	Non-pharmacological	<p><i>Children with impaired gait patterns will get more follow ups in school environments than children with for example unilateral impairments.</i></p> <p><i>Confirm with the child that it is not possible to do an activity the way you have planned but it may be done later.</i></p>	<p><i>Children with poor posture brought to physiotherapist from classroom – out of wheelchair, more comfortable position to lie down, heat, ice, changing the pattern – sit badly, sliding through in their chairs – posture not supported enough – reposition – help with their posture.</i></p>		
	Technical	<p><i>Special shoes or other minimal adaptations. Be inventive and open to new solutions.</i></p>	<p><i>Special wheelchair</i></p>		
	Other	<p><i>Schedule moments for children to relax and offload the body. Adapt the environment and the demands based on the child's state of the day.</i></p> <p><i>Negotiate with the teachers about lockers at comfortable height and maybe double sets of books to prevent pain.</i></p>	<p><i>When the child shows a pain reaction – stop the treatment.</i></p>		

DOING	Accept-ability	Pharmacological	<i>Planned and continuous treatment with Baclofen or Botulinumtoxin.</i>	<i>Can't keep on giving Panado (paracetamol) or Brufen (ibuprofen) – refer to doctor or clinic; Doctor prescribe Diazepam (valium) – but children may be sleepy – can't concentrate in class.</i>	<p><i>Similarities:</i> The importance of ensuring the correct positioning to minimize pain was highlighted. Ways to distract/encourage the child to change focus.</p> <p><i>Differences:</i> Sweden: strategies to provide interventions in advance, to prevent pain, for example Botox. South Africa: Clinicians made class visits to respond to the children's needs, referred to rules on restraint medications and were not sure that Botox was suitable as pain medication.</p>
		Non-pharmacological	<i>You have to make interventions without asked by the child.</i> <i>Change position.</i>	<i>Clinicians go to classroom when teacher inform them child is not sitting properly.</i> <i>Pain in hip joints – physiotherapist treat it, minimize or eliminate pain.</i>	
		Technical	<i>Vary sitting positions by using different types of chairs.</i>	<i>Occupational therapists fit the chair with proper inserts and support structure.</i>	
		Other	<i>Talk to children about how much they can do before it becomes too painful.</i> <i>Try to distract the pain. For example, sit on the walking aid and get a ride instead of going himself.</i>	<i>Prepare children – i.e. will do a stretch, this is what we will do, what you will feel, anticipate what to expect and will happen – mentally prepare and show them, and demonstrate the activity.</i> <i>Tries to distract them from pain, positive motivational strategies to get them to participate and not focus on the pain.</i>	