

RESEARCH ARTICLE

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

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ABSTRACT

Most children with severe cerebral palsy experience daily pain that affects their school performance. School professionals need to assess pain in these children, who may also have communication difficulties, in order to pay attention to the pain and support the children's continued participation in school. In this study, South African school professionals' perceptions of how they observed pain in children with cerebral palsy, how they questioned them about it and how the children communicated their pain back to them were investigated. Thirty-eight school professionals participated in five focus groups. Their statements were categorized using qualitative content analysis. From the results it became clear that professionals observed children's pain communication through their bodily expressions, behavioral changes, and verbal and non-verbal messages. Augmentative and alternative communication (AAC) methods were rarely used. The necessity of considering pain-related vocabulary in a multilingual South African context, and of advocating for the use of AAC strategies to enable children with cerebral palsy to communicate their pain was highlighted in this study.

KEYWORDS

Augmentative and alternative communication, children with cerebral palsy, Complex communication needs, pain communication, school settings

HISTORY


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Introduction

Most children with cerebral palsy experience pain every day and this may affect their attention to and participation in schoolwork. Owing to their communication difficulties, children with cerebral palsy and complex communication needs participate and communicate less than their peers with typical development (Clarke, Newton, Petrides, Griffiths, Lysley, & Price, 2012). Professionals in schools should, therefore, be particularly cognizant of when and how these children express their pain (Engel & Kartin, 2006). They should also be aware that the proxy reports by parents, caregivers, or teachers cannot replace children's self-reports during pain assessment (Chang, Versloot, Fashler, McCrystal, & Craig, 2015; Zhou, Roberts, & Horgan, 2008). In addition to observation strategies, children's own communication and self-reports of pain experiences are essential to ensure appropriate treatment. These considerations, focusing

on children with cerebral palsy in South African school settings, were explored in this study.

Cerebral palsy is a non-progressive developmental disorder caused by damage to specific areas of the brain before, during, or shortly after birth. It affects between 1.5 and three children per 1000 live births in the world (Berrin et al., 2007; Johnson, 2002; Yeargin-Allsopp et al., 2008). Muscle functioning is affected, resulting in specific neurological signs such as spasticity, dystonia or ataxia, ranging from mild to severe (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). This abnormal muscle tone influences fine motor abilities, movement, posture, and speech functions. Musculoskeletal and gastrointestinal pain typically appears because of spasticity and the inability to change from one position to another (Engel & Kartin, 2006). Furthermore, children with severe cerebral palsy often have additional impairments such as epilepsy, visual disturbances, hearing difficulties,

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communication problems, or learning disabilities (Beckung & Hagberg, 2002).

Pain in children with cerebral palsy may be severe and may influence their daily activities, including sleeping, positioning, and walking (Breau, 2011); this, in turn, may affect their communication and social skills. The majority of young children with cerebral palsy have high episodes of recurrent and intense persistent pain at levels of above 5 on a 10-point visual analogue scale (Engel & Kartin, 2006; Parkinson et al., 2013; Ramstad, Jahnsen, Skjeldal, & Diseth, 2011). Persistent pain in children may be a result of hormones, the circulatory system, or physiological stress reactions in muscles (Alfven & Nilsson, 2014). Most often, persistent pain refers to conditions where the pain lacks an obvious biological value and is beyond normal tissue healing (Harstall & Ospina, 2003). In contrast, acute pain appears in combination with trauma and will decrease when the body tissue is healed. Acute pain, therefore, supports the definition of pain as “An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (International Association for the Study of Pain [IASP], 1994, Pain section, para. 1). Communication and self-reports of pain experiences are of the utmost importance in the assessment of children with cerebral palsy, to ensure appropriate pain treatment. Gathering this information requires that children with cerebral palsy who have communication difficulties use alternative ways, such as augmentative and alternative communication (AAC), to self-report and communicate their pain.

Children’s social, emotional, personal, biological, and linguistic backgrounds influence their experiences and expressions of pain. They can be neglected, uncared for, and inadequately treated, owing to poor social or communication skills (Dubois, Capdevila, Bringuier, & Pry, 2010). If professionals repeatedly ignore or misread children’s attempts to express pain, they may no longer attempt to communicate their need for pain management (Craig, 2009). Pain assessment can be performed using speech or self-reports. When children cannot speak or self-report, professionals in school settings can only guess the children’s pain by interpreting bodily signs (Kortesluoma & Nikkonen, 2004; Stähle-Öberg & Fjellman-Wiklund, 2009). Such strategies might result in pain being underestimated if, for example, children’s unique behavioral responses to pain are misinterpreted (Beyer, McGrath, & Berde, 1990; Bottos & Chambers, 2006; Dubois et al., 2010; Gilbert-MacLeod, Craig, Rocha, & Mathias, 2000; Hadjistavropoulos & Craig, 2002). Misinterpretation of pain can occur even when the professionals know the children well. Therefore, the implementation of self-reports is regarded as the gold

standard in assessment (McCaffery & Ferrell, 1997), in order to ensure that professionals are aware of and do not misinterpret the magnitude of the pain.

Children with disabilities rely on others for assistance and become vulnerable to and dependent on professionals’ competence (Thunberg, Buchholz, & Nilsson, 2015). Supporting children’s self-reports with the use of AAC gives professionals access to children’s perspectives of their own pain experiences. By knowing more about the occurrence and specific nature of children’s experiences of pain and distress, adults can make more accurate decisions about how to address the pain (Hadjistavropoulos, Von Baeyer, & Craig, 2011; Nilsson et al., 2013). Improper pain management can occur if children do not have access to AAC or prefer not to use it as a means to express their pain or discomfort (Versloot & Craig, 2009). When it comes to managing AAC, children might also be dependent on others.

There is evidence that AAC is under-utilized in school settings (Connelly & Neville, 2010; Raghavendra, Olsson, Sampson, Mcinerney, & Connel, 2012), despite successful implementation of AAC strategies in various hospital settings aimed at determining children’s perspectives (Banerjee, Bennett, & Luke, 2012; Mesko, Eliades, Christ-Libertin, & Shelestak, 2011). Environmental barriers, such as individual characteristics, class structure, teacher attitudes, language of learning and teaching at the school, and collaboration with teachers and speech-language pathologists (SLPs), are some of the reasons for the under-utilization of AAC in the school environment (De Bertoli, Arthur-Kelly, Marhisen, & Balandin, 2014). As a result, professionals often prefer to rely mainly on their own observations in making decisions about the pain experiences of a child. Nonetheless, it remains the responsibility of professionals to try and obtain some type of self-report from the child in pain, in order to ensure proper pain assessment and management (Schiavenato & Craig, 2010).

In some countries, children with complex communication needs (including children with cerebral palsy) often need to attend schools where the language of learning and teaching is not their first language, because there are no schools that offer instruction in their first language (Pickl, 2011). These children have insufficient vocabulary of the language spoken to be able to communicate their pain (Ncoko, Osman, & Cockcroft, 2000). Attempts to implement AAC strategies in these multilingual school contexts have been reported (Pickl, 2011), where teachers provided children with AAC strategies such as communication boards or books that portrayed culturally sensitive picture symbols. Where applicable, the teachers also gave the children speech-generating devices with recorded messages (Pickl, 2011).

The researchers highlighted the importance of teachers' experience with AAC as well as teaching children with severe disabilities to ensure the successful implementation of AAC strategies in multilingual contexts (Pickl, 2011). They also emphasized the strength of supportive teams, for example, speech-language pathologists who assist teachers to implement AAC in the classroom.

When assessing pain, professionals cannot obtain a child's perspective merely by interpreting bodily signs, which may be inadequate reflections of the child's pain experience. Instead, it is advisable that professionals communicate directly with the child (Nilsson et al., 2013), otherwise they run the risk of limiting their understanding (Briggs, 2010) of the pain. It is suggested that an investigation of the use of AAC would be helpful for school professionals who need to deal with the pain-relieving needs of children. To date, no research has specifically attempted to investigate how pain in children with cerebral palsy is communicated in South African school settings.

The aim of this study was to explore how professionals in South African school settings assess pain in children with cerebral palsy, that is, how they observe a child in pain, how they address and investigate children's perceptions of their own pain, and how they interpret children's pain communication, in order to support them to continue with school activities. An additional purpose was to gather information (as reported by professionals) on children's use of pain-related vocabulary in a multilingual South African context that could be considered when selecting vocabulary for AAC systems of children with cerebral palsy. The following research questions are addressed:

- (1) How do professionals observe pain in children with cerebral palsy?
- (2) How do professionals communicate about pain to children with cerebral palsy?
- (3) How do children with cerebral palsy communicate pain to professionals?

Method

Research Design

This qualitative study is descriptive. Interactive focus groups provided information on the situation of children with cerebral palsy in schools. Before recruitment commenced, ethical approval was obtained from various authorities, such as the Research Ethics Committee of the university, the Department of Education, and the principals of the five schools involved in this study.

The study forms part of a larger project aimed at comparing the prerequisites and practices for pain

management in children with cerebral palsy in two cultural school settings: South Africa and Sweden. The overall aim is to facilitate discussion about best practices that might advance pain management in children with cerebral palsy by eliciting their active engagement in reporting the pain so that they can continue to participate in school activities despite their pain.

Participants

Professionals from five government schools for children with special education needs that also accommodate children with cerebral palsy participated in five focus groups conducted in February 2014. The schools differed in size, percentage of children with cerebral palsy, and number of children in hostels (Table I). Hostels are boarding facilities at the schools where children can stay during the school term. The classes accommodated 12–16 children, and each school had different types of clinicians (e.g., speech-language pathologists, occupational therapists, and physiotherapists). Detailed information about the children with cerebral palsy was not available; however, because the professionals described the children's performance in terms of gross motor function, we assumed that most of the children were limited in their ability to move themselves around. Per the Gross Motor Functional Classification System Expanded and Revised (GMFCS-E&R), the children most likely would be assigned to Level IV–V (Palisano, Rosenbaum, Bartlett, & Livingston, 2007) status, that is, they need support to sit, have limited mobility, and often need a wheelchair. Some children might also have limitations in head and trunk control and so may have required assisted technology and physical assistance. Such severe mobility limitations often include communication difficulties. The clinicians worked with the children in the school classrooms and therapy rooms.

In the five focus groups, 38 professionals (aged 22–64 years; $M = 44.4$) participated, of whom 26 were clinicians, 11 were educators, and one was a personal assistant. The 26 clinicians represented six professions: nurses (5), occupational therapists (8), physiotherapists (6), psychologists (1), social workers (1), and speech-language therapists (5). With the exception of one male participant (a personal assistant and the sibling of a child with severe cerebral palsy), all participants were women. The professionals had a mean of 11.8 (years;months) of experience working with children with cerebral palsy, attesting to their knowledge of this condition. They were highly educated: 76% had 4 or more years' university education and 11% had additional training in neurodevelopmental treatment.

Table 1. Characteristics of the participants and their schools.

	School A	School B	School C	School D	School E
Type of school					
Government school	X	X	X	X	X
School for specialized education	X	X	X	X	X
Ages of children					
Younger than 6;0 (year;months)		X		X	X
6;0–9;11		X	X	X	X
10;0–12;11		X	X	X	X
13;0–15;0	X	X	X	X	X
16;0–18;0	X	X	X	X	X
18;0–21;11	X	X		X	X
Distribution of children					
No. of children in school	506	403	329	372	270
Maximum children per class	14	16	12	12	15
No. of children with CP	16	106	126	241	100
Percentage of children with CP	3%	26%	38%	65%	37%
Skill levels of children					
Gross motor skills level according to GMFCS-E&R	Range from Level I–V	Range from Level I–V	Range from Level I–V	Range from Level I–V	Range from Level I–V
Hostel					
Availability	Yes	Yes	No	Yes	No
No. of children in hostel	506	23	0	102	0
Proportion of children in hostel	100%	6%	—	27%	—
Staff					
No. of teachers in the school	53	49	28	34	20
No. of children/teacher	9.5	8.2	11.8	10.9	13.5
No. of class assistants per class	0	2	0.33	1 - 2	1
No. of clinicians in school	7	21	6	?	8
No. of children/clinician	72.3	19.2	54.8	?	33.8
Type of clinician					
Audiologist	X			X	
Nurse	X	X	X	X	X
Occupational therapist	X	X	X	X	X
Physiotherapist	X	X	X		X
Psychologist		X		X	
Psychometrist		X			
Social worker	X	X	X		
Speech language therapist	X	X	X	X	
Other support disciplines	Orthotics prosthetics	Orthopedic surgeons, GP, pediatrician, seating expert, orthotist	ENT, orthopedic surgeon, plastic surgeon	Pediatric and orthopedic surgeon	Orthopedic surgeons, speech therapy students, oral hygiene students

CP, cerebral palsy; GMFCS-E&R, Gross Motor Functional Classification System Expanded and Revised; GP, general practitioner (medical doctor); ENT, ear, nose, and throat surgeon.

Procedure

The principals of the schools were contacted and, after receiving written information about the project, consented in writing and identified suitable participants for the focus groups. All of the participants received written information about the study and provided written informed consent to participate.

The decision to conduct focus groups was based on the fact that group dynamics can stimulate discussion and help participants to conceptualize issues in more depth than through other methods, such as surveys or individual interviews (White & Verhoef, 2005; Wibeck, Abrandt Dahlgren, & Öberg, 2007). The participants also became involved in the research process; ideas for possible improvements were generated, and member checks were able to be performed immediately to guarantee the validation of the data analysis.

For the purposes of the larger project, the focus group sessions addressed two major issues: pain assessment and pain management. To address the aim of the study reported here, data about pain assessment was considered and collected mainly during the first part of the focus group sessions.

Before the focus groups commenced, the researchers agreed on the procedure. Interview guides and demographic information questionnaires were developed in English and Swedish. Both were pilot tested in Sweden with six experienced clinicians. After the pilot testing, minor amendments were made to the interview guide, for example that discussions should focus primarily on pain assessment and pain management in children with cerebral palsy and not the diagnosis in general (Nilsson, Johnson, & Adolfsson, 2014).

The duration of the focus group sessions varied between 70 and 110 min. During the first part of the

discussion (on pain assessment), one main question was asked: What are your experiences of persistent pain in children with cerebral palsy in your school? Three supporting sub-questions were (a) How do you observe a child with cerebral palsy in pain? (b) How do you communicate pain to the child with cerebral palsy? and (c) How do children with cerebral palsy communicate their pain? These sub-questions were intended to solicit the professional's perspective of the child and the child's own perspective (Nilsson et al., 2013). Anticipated responses included the use of proxy-report tools for observation, the use of AAC as a self-reporting tool to indicate pain location or degree of pain, and professionals' interpretation of the children's body language. Information about the children's use of pain-related vocabulary in multilingual contexts was also anticipated.

One of three researchers, a Swedish physiotherapist with experience in conducting focus groups, acted as the moderator (Wibeck et al., 2007). Another researcher, a South African special educator who specializes in pain communication, typed all comments on a laptop and supported the participants in Afrikaans where necessary. The comments were projected on a wall to enable the participants to check and revise the formulation of their statements. The third researcher, a Swedish pediatric nurse who specializes in pain management, audio-recorded the discussions and asked for more information about possible missing data. In each focus group, all statements were jointly reviewed and revised where necessary. As part of this process, participants indicated that the statements truly represented their experiences and added more information where applicable.

Data Analysis

Conventional qualitative analysis was used to describe how professionals in South African schools assess pain in children with cerebral palsy (Hsieh & Shannon, 2005). According to Hsieh and Shannon (2005), the codes are determined after multiple readings of the text, and are then sorted into categories based on how the codes are related and linked to each other.

Statements were entered on a spreadsheet and divided into meaning units grouped according to the perspectives of the three sub-questions: observation, professional communication, and child communication. Following the completion of the five focus groups, all data was merged onto one spreadsheet. Reductions were made due to duplication, overly general meaning units, and statements that were not related to cerebral

Table II. Coding categories and subcategories of professional observations that children with cerebral palsy were in pain.

Main category	Subcategory
Bodily expressions	<ul style="list-style-type: none"> Physiological effects Unintentional facial changes Positioning
Behavioral changes	<ul style="list-style-type: none"> Altered participation Clown behavior Escape
Message	<ul style="list-style-type: none"> Non-verbal Spoken Use of devices

Table III. Coding categories and subcategories of professional methods for communicating about pain with children.

Main category	Subcategory
Verbal questions	<ul style="list-style-type: none"> General questions Specific questions Clarifying questions
Symbols	<ul style="list-style-type: none"> Drawings Communication boards with mainly body parts
Pain scale	<ul style="list-style-type: none"> Faces pain scales No pain scale

Table IV. Coding categories and subcategories of methods used by children to communicate pain.

Main category	Subcategory
Verbal expressions	<ul style="list-style-type: none"> Vocalizations Words Phrases Talk about something else
Non-verbal communication	<ul style="list-style-type: none"> Intentional facial expressions No complaints
AAC strategies	<ul style="list-style-type: none"> Communication boards Drawings/symbols Spoken Speech generating devices Computer

palsy or pain experiences. Similar meaning units were combined and coded. The codes were inductively sorted into main categories (meaningful clusters of codes related to each of the three sub-questions), where after, subcategories were identified (see Tables II, III and IV). The first author completed this procedure supported by the other two authors. Thereafter, all three authors discussed the categories via an Internet supported audio-video conferencing tool until consensus was obtained. Recorded audio material was used to ensure credibility during the data analysis.

Results

The manner in which professionals communicate about pain with children with cerebral palsy is reflected by observation, professional communication, and child communication. Where applicable, a selection of citations is used to explain the results.

Observation

Professionals perceived that they knew when a child with cerebral palsy was in pain, because they observed the child's expressions of pain. Expressions of pain were divided into three main categories: bodily expressions, behavioural change, and messages (Table II). Professionals mainly used children's bodily expressions to determine if a child was in pain.

Bodily expressions were observed as physiological effects. These included sweating or fast and shallow breathing, as well as unintended facial changes such as frowning, expressions that were atypical of the child's customary behavior, and positioning. Positioning refers to changes in the manner in which the children typically moved or positioned themselves (e.g., assuming uncomfortable positions or refusing to use the affected body part), which indicated to the professionals that the children were in pain. For example, some children avoided the painful side and sat differently compared to their usual manner, some children with dislocated hips did not want to be positioned when being moved from the wheelchair to a chair, and some did not want to be moved during physical examinations.

As reported by the professionals, behavioural changes in the children were observed as altered participation due to mood changes resulting from their pain (e.g., "...when in pain, they act differently"). Participation in classroom activities decreased in children with pain, who did not wish to continue with activities that they would usually have enjoyed. For example, children who were typically happy and active participants in the classroom (i.e., those who normally raised their hands and were excited to answer questions) became quiet and depressed observers, worked very slowly, became fixated on their pain, or tried to find excuses not to work. They also struggled with the work content, as they could not concentrate because of their pain. Other children developed clownish behavior in the classroom: "...children get 'silly', adopt clowning behavior, giggle, laugh to mask the pain (non-verbal), become aggressive, irritable..." The third type of behavioral change was when children tried to evade responsibilities in the classroom due to their pain, such as often wanting to go to the school nurse or the toilet.

The professionals could observe messages from the children in pain. An example was non-verbal expressions: "The therapists know that children, who usually speak, are in pain when these children are quiet." Other examples included verbal expressions that were not directed towards the professionals: "Older children who

were verbal told their friends when they were in pain or went to a specific therapist to ask for assistance." There was also the use of AAC such as communication boards: "...they move their bodies to the relevant side on the communication board to point to vocabulary to indicate where they are in pain."

Professional Communication

Professionals mainly communicated verbally with the children by using various kinds of oral questions to determine if a child was in pain, whether a movement caused pain, and where the pain was located (Table III). For the same reasons, professionals sometimes used symbols; they infrequently used faces pain scales.

Verbal questions were used by professionals to communicate about pain with the children. First, they asked general questions such as, How do you feel today? How are you doing today? and What do you mean by fine? Usually, when working with younger children, professionals did not use the word pain to determine if a child was in pain, but rather referred to "feeling sore" – *Do you have eina?* (Eina is an Afrikaans word for pain that is used by children from various South African language groups to refer to physical pain). Specific questions were used when talking to older children about pain or manipulating the children during treatment: Do you have pain? or Are you in pain? Clarifying questions such as those about pain location gave the professionals more specific information. They also confirmed the children's responses by touching the area, and asking, *Is it here?*

Professionals mentioned that, due to the multilingual context in South African schools, children often have a different language than the language of learning and teaching at the specific school, resulting in their not being able to understand the language(s) the professionals spoke. Therefore, professionals used picture symbols to enhance children's understanding. For example, the use of picture symbols, typically of body parts, supported professionals' questions about the pain location. Other professionals drew pictures that the child could use to show where the pain was. In one of the schools, one type of pain scale (Wong-Baker Faces Pain Rating Scale) was part of the routine to determine pain intensity. The Wong-Baker Faces Pain Rating Scale is a 6-point faces scale ranging from a smiley to a crying child's face, with the child pointing to the level of pain (Wong & Baker, 1988). No pain scales were used in the other four schools, because the professionals perceived that the children did not understand them. As one participant noted "(we) do not use standardized pain

scales at the school – it would be wrong to ask a learner: ‘On a scale of 5, where do you think your pain is?’ It might not be a true reflection because the children do not understand the abstract concept.” In one of the schools, the professionals admitted that they had pain scales, but added that the children “. . . usually don’t understand a faces scale.”

Child Communication

Professionals reported different examples of children’s ability to communicate pain, as portrayed in Table IV. The responses of the children varied. They used verbal and non-verbal expressions or alternative communication devices to communicate their pain. As one participant noted, these efforts were not always successful: “They can’t tell you where it is sore, because they don’t have the same language as the therapist.”

Verbal expressions varied when children communicated their pain. Vocalizations such as *ouch* were common, as well as words such as *eina*; *esh* (an isiZulu exclamation that indicates disapproval or surprise) or hurt. Phrases such as *I’m not well*, *It’s painful*, *You are hurting me*, *sore tummy*, *sore here*, *kiss better*, *It is sore*, not *lekker* [nice] were used to express pain.

Professionals noted that sometimes children would attempt to change the topic of conversation, or the activity, and that this was interpreted as evidence the child was in pain. One participant described the behavior of a particular child as an example, saying, “She is tired – not always saying that she has pain – wants to talk about something else, talk about problems at home.” Other child excuses reported by participants included *I am tired*; *I want to go back to class* or *I have to take a break*. The professionals also mentioned that some children masked their physical pain by presenting with emotional problems. As one professional noted:

They might say, “I feel rejected, I’m unhappy because the children don’t want to play with me”, when they actually want to say: “My problem is my pain, not emotional pain, really. Pain makes it difficult for me to deal with socialization.”

Non-verbal communication was another way in which children communicated their pain directly to the professionals. Particular facial expressions by the children were indications to the professionals that the children were in pain: “. . . the therapist will ask, ‘Should I stop?’ – (and then) look at (the child’s) facial reaction and stop the treatment; . . . (when you) look at her face – you can see this child is really in pain. . . ; her eyes show it to you.”

Only a few children used AAC strategies to communicate their pain. One such strategy was the use of communication boards, which were used mainly to

show body parts. Some children used low-tech communication boards such as alphabet boards. One child with complex communication needs, who understood the symbol systems and knew how they worked, could indicate that she was uncomfortable and gave different options to explain her discomfort. Some professionals drew pictures and the children used them to point to where the pain was. Others indicated that if the children had no speech, picture communication symbols were employed. Speech-generating devices were introduced in one of the schools to help the children express themselves more effectively. Only one child used a computer to communicate pain.

Discussion

The present study explored how professionals in South African school settings assessed pain in children with severe cerebral palsy and possible communication difficulties. From the results, it became clear that professionals observed pain in children through their bodily expressions, behavioral changes, and non-verbal and verbal messages.

It is the responsibility of professionals to determine if a child with cerebral palsy is in pain, what the pain intensity might be, and where the pain is located. Healthcare professionals often attempt to determine pain intensity by observing facial expressions of their pediatric patients, but often misinterpret these expressions because the children actually have higher pain intensity than they express (Chang et al., 2015). It is interesting to note that the professionals in the South African schools indicated that they knew when children with cerebral palsy were in pain by observing their facial expressions or body language, and said that this may have been because they had worked closely with the children from as young as 3 years of age. The children also received special one-on-one attention from the professionals on a daily basis, which helped the adults to get to know the children well. Accordingly, the professionals regarded any changes in the behavior of the children, such as poor positioning resulting in general body discomfort, as indicators of pain. Because the professionals believed that their interpretations of the children’s pain experiences were correct, they did not query the accuracy of their conclusions. They should therefore be made aware that their interpretations might have been inaccurate and that they should rather depend on other ways to enable children to self-report their pain.

Professionals also mentioned that they struggled to identify pain in children who would never complain about it (“She can’t express herself”, “The children don’t

complain”), which might have led to misunderstandings. Dubois et al. (2010) found that many children with complex communication needs prefer not to complain about their pain or become reluctant to communicate when they are in pain either because previous attempts were ignored or they did not have appropriate methods, such as AAC, to communicate the pain. The professionals in this study had similar experiences (i.e., children did not communicate about pain) however they were of the opinion that some children did not complain about their pain because they “got accustomed” to the pain – once again indicating that they did not question whether the reason for children not alerting them about their pain was due to being previously ignored.

AAC strategies could also play a useful role in helping children with complex communication needs to communicate pain (Costello, Patak, & Pritchard, 2010). The low occurrence of AAC implementation in the South African schools that was found in this study could possibly have hampered children with cerebral palsy who have communication difficulties to self-report their pain by alternative means such as AAC. These findings were similar to other studies indicating that external complex factors such as deficient skills, attitudes, and experiences of teachers and therapists, hampered the implementation of AAC in school settings (Bornman & Donohue, 2013; De Bertoli et al., 2014). For example, teachers’ perceptions of children’s ability to learn are contributing factors in their decisions regarding the use of AAC in their classrooms (Soto, 1997). Most likely, the use of AAC strategies would increase if professionals learned more about the benefits of the implementation of these strategies for children with complex communication needs (Pickl, 2011).

Multilingual Context

AAC strategies had been implemented on a small scale to address the multilingual context of the five participating schools. In South Africa, children often receive instruction in a language other than their first language (Ncoko et al., 2000). Therefore, some of the children might not have understood the language the therapists spoke (usually English) and so would not have known how to tell the therapist that they were in pain (Ncoko et al., 2000). In those cases where communication boards were not available, professionals improvised by drawing pictures (symbols) to assist the children’s receptive and expressive understanding, while asking questions about their pain. The children then used the same symbols to answer the questions. When communication boards were available, they were used mostly to portray body parts and to ask the children about their pain location. It

is important to note that these communication boards were mainly used to indicate pain location. The children were not given symbols indicating words or phrases to describe their pain (Johnson, Boshoff, & Bornman, 2015). Descriptive words and phrases such as sore, eina, I am not well, and eish were typically used by other children with cerebral palsy who could speak and should be considered for inclusion on communication boards. Words and phrases should be provided on the communication boards to allow the children to express how they cope with their pain, just as their peers with typical development would do (Johnson et al., 2015).

The use of words borrowed from other languages to communicate pain (e.g., eina and eish), was recently found in another South African study on the pain vocabulary of children with typical development whose home-language was English (Johnson, Bornman, & Tönsing, 2014). This phenomenon, known as *code switching*, is a characteristic of the multilingual South African context, where vocabularies of different languages influence one another (Moodley, 2007; Ncoko et al., 2000). The fact that the same pain words are used in a country where most children are multilingual should be taken into account in the selection of words and phrases that express pain for an AAC pain-related communication board.

Speech-Generating Devices

During the focus groups, professionals referred to speech-generating devices. It was not clear if the children had access to them in the classrooms or if this represented a vision for possible best practices for pain management for these children (Nilsson et al., 2014). It might also have been possible that the professionals tried to impress the researchers by talking about AAC devices because they knew that the researchers were associated with the field of AAC. Even though professionals felt that the use of low-tech communication boards was “not ideal,” they agreed that it was functional in eliciting information from the children.

AAC Implementation in School Settings

AAC support for children with cerebral palsy in school settings is of the utmost importance in order to ensure effective communication and participation in classrooms. Although the findings of the current study revealed limited AAC implementation in South African schools where children with cerebral palsy were accommodated, there was evidence that some professionals realized that AAC use might assist the children’s receptive and expressive abilities to understand and

communicate their pain (Pennington, 2008). However, external factors, such as the lack of skills and knowledge of professionals, seem to be hampering the implementation of AAC in school settings – a phenomenon that appears to be a challenge reaching beyond South Africa, as reported in other studies (De Bertoli et al., 2014; Kent-Walsh, Stark, & Binger, 2008; Pickl, 2011; Soto, 1997). Professionals must be supported in taking steps to use AAC in school settings to assist children's pain communication (Zisk-Rony, Lev, & Haviv, 2015), because South African professionals did not use other approaches (e.g., pain scales) for pain assessment. It is therefore the researchers' responsibility to provide support and training which will assist professionals in school settings with the employment of AAC strategies to empower children with cerebral palsy and complex communication needs to self-report their pain effectively.

Limitations and Future Research

Some limitations of this study should be noted. For example, only government schools in the Pretoria and Johannesburg areas were included; data regarding potential differences at schools in other areas of the country was not taken into account. Nevertheless, the study does contribute information about the possible implementation of AAC strategies as well as the selection of pain-related vocabulary to be provided on communication devices in multilingual contexts. Future research should investigate the implementation of AAC for children with complex communication needs who must communicate pain in multilingual environments in schools in both South Africa and other parts of the world. This would raise awareness among professionals working with children with cerebral palsy who have communication difficulties about how to implement AAC to communicate pain.

Conclusion

Effective communication is essential for full participation in society, and is especially important in issues related to health and medical services (Costello et al., 2010). This study provides evidence that pain in children with cerebral palsy in South African schools was communicated non-verbally and verbally. Professionals observed and interpreted the children's bodily expressions, behavioral changes, or messages, and spoke to the children about their pain. The messages were either non-verbal (by means of facial expression or changes in body position) or verbal (Eina; I'm not well, It's painful; It's not lekker). In some instances, AAC strategies such as

communication boards or speech-generating devices were used. The multilingual context influenced the use of pain-related vocabulary by verbal children with cerebral palsy as code-switching took place. Professionals seemingly chose not to implement children's self-report during pain assessment, but preferred to focus on their observations of children's non-verbal messages, which could result in misinterpretation and under-treatment of children's pain experiences. This enhances the importance of offering AAC strategies to children with cerebral palsy and complex communication needs to self-report their pain experiences.

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Declaration of interest

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

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