An Exploration of Pain-Related Vocabulary: Implications for AAC Use with Children

Ensa Johnson, Juan Bornman, and Kerstin Tönsing

University of Pretoria

Author Note

Ensa Johnson, Juan Bornman, and Kerstin Tönsing, Centre for Augmentative and Alternative Communication, University of Pretoria, Pretoria, South Africa.

Correspondence concerning this article should be addressed to Ensa Johnson, Centre for Augmentative and Alternative Communication, University of Pretoria, Private Bag X20 Hatfield, Pretoria 0028; E-mail: ensa.johnson@up.ac.za

Abstract

Children with significant communication difficulties who experience pain need appropriate means to communicate their pain in order to receive appropriate treatment. Augmentative and alternative communication (AAC) strategies could be used to enable children to self-report pain. The aim of this research study was to identify the common vocabulary children with typical development use to describe physical pain experiences and develop and socially validate an appropriate pain-related vocabulary list for children who use or could benefit from using AAC. A sequential, exploratory, mixed-method design was employed. This paper focuses on the quantitative phase. A set of scenarios was developed to gather pain-related vocabulary appropriate for children aged 6;0 – 7;11 (years;months) and children aged 8;0 – 9;11, from 74 children, 61 parents, and 56 teachers. Some 629 pain-related words or phrases were suggested and then classified into seven categories. A composite list of the 84 most frequently occurring pain-related vocabulary items was compiled and socially validated by three adults who used AAC. They emphasized the need to individualize vocabulary and provided suggestions for vocabulary organization for display on any type of AAC system. Despite similarities in the categories of words offered by the various respondent groups, the differences underscore the importance of more than one perspective (particularly that of children and adults) in generating a comprehensive vocabulary list.

Keywords: Augmentative and alternative communication; AAC system; AAC Category; AAC word lists; Pain communication; Pain-related vocabulary; Significant communication difficulties

An Exploration of Pain-Related Vocabulary: Implications for AAC Use with Children

Every 3 hours on average, young children with typical development experience minor pain from bumps and bruises caused by small accidents during daily activities such as running around (Fearon, McGrath, & Achat, 1996; Von Baeyer, Baskerville, & McGrath, 1998). These children use crying, vocalizations, or words to communicate their painful experiences and typically only start to use the word "pain" by the age of 6 years (Stanford, Chambers, & Craig, 2005). Children with disabilities may experience more frequent pain episodes than their peers with typical development. For example, children with cerebral palsy need more frequent treatments such as physiotherapy to stretch their stiff muscles, with potential associated discomfort or even pain (Johnson, Nilsson, & Adolfsson, 2015); while children with other disabilities may experience frequent needle procedures such as drawing blood or receiving blood transfusions to maintain their health (Bottos & Chambers, 2006). Some children with disabilities may even need to undergo surgery more often than their peers with typical development (Ramstad, Jahnsen, Skjeldal, & Diseth, 2011). For these children, it is essential to be able to effectively communicate their pain.

Communicating Pain

The inability to communicate pain verbally can be stressful and frightening for any individual (Costello, Patak, & Pritchard, 2010), and may lead to the pain not being treated. This can be true for children with severe disabilities and associated communication difficulties that are temporary (e.g., in some cases of children with developmental apraxia of speech) or permanent (e.g., cerebral palsy; Johnson, 2015); as well as children with typical development who experience temporary communication difficulties due to medical interventions such as tracheotomies or other procedures influencing their expressive and receptive communication

abilities (Costello et al., 2010). In a study by Zhou, Roberts, & Horgan (2008) healthcare staff used observations, physiological assessment, and proxy reports by parents or caregivers to assess the children's pain but remained unsure about the children's pain experience. Bottos and Chambers (2006) found that healthcare staff often overlooked non-verbal communication attempts (such as a behavioral change) used by children with severe communication difficulties to indicate that they were in pain. These changes were often interpreted as instances of challenging behavior and not necessarily as attempts to communicate pain experiences. Sadly, if healthcare staff ignore these changes in behaviour it might lead to the non-treatment of pain (Zhou et al., 2008).

Self-report is regarded as the gold standard to retrieve information about a patient's pain (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). Apart from communicating the occurrence, nature, and intensity of pain for treatment purposes, children typically also communicate causes of pain, strategies to avoid pain in the future, and self-comfort messages to calm themselves in order to cope with pain (Johnson, Boshoff, & Bornman, 2016).

Alternative Means for Communicating Pain

Obtaining verbal self-reports from children with significant communication difficulties is challenging. Without alternative methods it is difficult to determine if they are in pain and if so, the nature, intensity, and location of the pain. The way these children display pain nonverbally may also differ from other, more common expressions (such as frowning or crying), which may result in their not receiving the essential pain treatment they require (Beyer, McGrath, & Berde, 1990). It therefore seems that children who experience significant communication difficulties, on either a temporary or permanent basis, may require additional or alternative means of expressing their pain, such as aided communication options, to ensure they receive appropriate and effective

pain treatment. Access to appropriate, preselected, pain-related vocabulary on an augmentative

and alternative communication (AAC) system represents such an alternative.

Informants for Vocabulary Selection

AAC interventionists should consult multiple informants when selecting and compiling

the best possible vocabulary to be placed on an AAC communication system (Beukelman &

Mirenda, 2013). Although evidence shows that adults (such as parents, teachers, and therapists)

are often asked to suggest the typical vocabulary children would need for activities such as

playing or eating (Roulstone, 2015), there is evidence that children often use different words or

phrases than those suggested by adults (Beukelman & Mirenda, 2013).

Identifying Pain Vocabulary

In selecting vocabulary for aided AAC systems, emphasis is often placed on the inclusion

of core vocabulary. These words, which occur with high frequency in typical language samples,

have been deemed useful across various settings and activities (Banajee, Dicarlo, & Buras

Stricklin, 2003; Marvin, Beukelman, & Bilyeu, 1994; Trembath, Balandin, & Togher, 2007).

Low-frequency fringe vocabulary is added according to the needs of the individual and his or her

contexts (Beukelman & Mirenda, 2013). However, there is a lack of information on determining

vocabulary for sensitive topics such as pain. For example, currently available core vocabulary

lists for toddlers and children (Banajee et al., 2003; Marvin et al., 1994; Trembath et al., 2007),

do not include any pain-related words, perhaps in part because recordings of activities that were

unlikely to result in painful experiences were used to compile these lists. Alternatively, the

infrequent occurrence of pain-related utterances may have precluded them from being designated

as core words, and they may have been regarded as fringe vocabulary. Activity-based

approaches, in turn, have resulted in vocabulary lists applicable to specific activities (e.g.,

Goossens', Crain, & Elder, 1994). The result is that such approaches focused mainly on activities

of daily living (e.g., eating, dressing) or fun activities (e.g., book reading or play) due to their

motivational value (Banajee et al., 2003; Da Fonte, Pufpaff, & Taber-Doughty, 2010; Goossens'

et al., 1994; Trembath et al., 2007). More unpleasant or sensitive topics, such as pain, were often

not considered in activity-based approaches. The absence of pain-related words on aided AAC

systems may limit opportunities for children with severe communication difficulties to

communicate their pain. Accordingly, the aim of this study was to identify the common

vocabulary that children with typical development use to describe physical pain experiences and

to develop and socially validate an appropriate pain-related vocabulary list for children who use

or could benefit from using AAC. The availability of such a list may assist AAC interventionists

to include appropriate pain-related vocabulary on AAC systems as a first step towards

encouraging self-report of pain. Pain-related vocabulary was gathered from younger and older

children, as well as parents and teachers. The vocabulary of the informant groups was then

compared, to assist in understanding the influence of age as well as informant group on

suggested vocabulary.

Method

Design

The original study (Johnson, 2015) made use of a sequential, exploratory, mixed-method

design (Creswell, 2014) with a qualitative development phase, during which materials (scenarios

and vignettes) were developed for the second phase, which entailed quantitative data collection

of pain-related vocabulary. The focus of this paper is the quantitative phase of the study, during

which semi-structured interviews and questionnaires were used to determine pain-related

vocabulary from parents, children, and teachers. This vocabulary was then validated by four

adults who used AAC.

Recruitment

Ethics approval for this study was obtained from the relevant authorities and participants

from schools in the Tshwane South region, Gauteng, South Africa were recruited by means of

convenience sampling of an area that included both schools for English-speaking children and

hospitals. Principals from 10 of the possible 16 schools with English as the language of learning

and teaching were contacted (seven government and three independent private schools) and gave

informed consent. English-speaking children who were hospitalized during the time of data

collection were recruited from two private hospitals in the identified region because they were

information-rich participants regarding the specific topic and hence their experiences would

enhance the study. Although the aim was to recruit more pediatric patients for the study, the

researcher was not always informed by medical social workers when new potential participants

were admitted.

Participants

Four participant groups were involved in the study. Group 1 consisted of 74 English-

speaking children with typical development who represented all ethnic groups in South Africa

(African, Mixed race, Indian, and White). The group was divided into two age subgroups:

children aged 6;0 to 7;11 ($n=39$; $M=6;4$) and children aged 8;0 to 9;11 ($n=35$; $M=8;3$). Only 18%

of children in the younger-age subgroup and 12% in the older-age subgroup had experiences of

hospitalisations during the previous 2 years. The Hypothetical Physical Pain Scenario-Children

(HPPS-C) was implemented with these two groups of children because it was important to obtain

the child's perspective of his or her experiences (Nilsson et al., 2015). Furthermore, two age

groups were included because research has indicated that children's pain-related vocabulary progresses as they grow older (Johnson et al., 2016).

Group 2 consisted of 61 parents of children from the same two age subgroups. Parents also represented all ethnic groups. Parents of the younger children ($n=29$) were aged 29–49 years ($M=34.3$). Parents of the older children ($n=32$) were aged 30 to 49 years ($M=39.5$). Five fathers (14% in the younger group and 3% in the older group) were included, while the rest of the parent participants were mothers. Although it would have been ideal to include the parents of the children from Group 1 in Group 2, some parents were only willing to consent that their children participate in the study, whereas others were only willing to participate in the study themselves and did not consent to their children participating. The Hypothetical Physical Pain Scenario-Parents (HPPS-P) was used to gather data from parents.

Group 3 consisted of 56 female teachers who either taught children in Grade 1 (typically 6;0 – 7;11 year olds) or Grade 3 (typically 8;0 – 9;11 year olds). Of the group, 30 teachers taught Grade 1 children and were aged 22 – 60 years ($M=39.9$), with teaching experience ranging from 1–34 years ($M=15.2$). The others ($n=26$) taught Grade 3 children and were aged between 24 – 62 years ($M=39.5$) with 1–40 years of teaching experience ($M=15.7$). Four teachers (one from the younger group and three from the older group) were African and the other teachers were White. The teachers were from the same schools as the children in Group 1, as well as from additional schools to ensure minimum numbers for statistical calculations. The Hypothetical Physical Pain Scenario-Teachers (HPPS-T) was implemented with teachers who taught children representing the younger group and the older groups.

Group 4 consisted of literate adults who used AAC (one African female aged 28 years and two White males, aged 30 and 35 years, respectively) and with whom the Hypothetical

Physical Pain Scenario-Stakeholders (HPPS-S) was used in an attempt to socially validate the

vocabulary list. A pain-related communication board, with the composite list of pain-related

words or phrases in the seven categories derived from the study, was presented to the adults who

used AAC. The same vignettes that were used in three of the scenarios (see Table 1) with the

children were shared with the adults, who used the communication board to answer the

questions. Afterwards, the adults were asked to give suggestions on how the pain-related words

or phrases could be adapted for use by children (Johnson, 2015).

        Insert Table 1 about here

Materials

        A set of 10 Hypothetical Physical Pain Scenarios (HPPS) was compiled to use in

interviews and questionnaires with the four participant groups following a thematic analysis and

discussions with 50 children with typical development around drawings made by them depicting

painful experiences (this was the qualitative phase of the study; see Johnson, 2015). An expert

panel comprising five teachers, two occupational therapists, one nurse, one SLP, one doctor, and

one medical social worker who represented all ethnicities in South Africa and who worked with

children on a daily basis, confirmed the set of hypothetical scenarios (e.g., The child had an

operation; The child runs into a thorn bush; see Table 1 for a list of the scenario themes in the

HPPS used by the different participant groups). Vignettes were then developed based on the

hypothetical scenarios, and were illustrated by a graphic artist.

        To enhance the comprehensiveness of child and adult responses, the measuring

instrument based on the HPPS was adapted for four participant groups. The four versions

differed slightly from each other in terms of the number and list of scenarios presented and also

in the presentation method, as shown in Table 1. The HPPS was piloted on 12 participants: five

children, five parents, and two teachers. Based on this pilot stody (Johnson, 2015) changes were made to the instrument before it was implemented (e.g., to the vignettes and the format of presentation). The option to complete the HPPS-T either online or in hard copy format was incorporated because three of the potential five teachers cited lack of access to the Internet as their reason for not participating. Finally, a shorter version of the questionnaire for parents and teachers was suggested.

Data Collection Procedures

Data collection commenced once parental informed consent as well as child assent had been obtained. Children provided written assent using a symbol-based assent form on which they could indicate whether they wanted to participate in the study or not. For the child participants (Group 1), in-depth interviews were conducted at their school or hospital setting using the HPPS-C. A scripted interview guide (Johnson, 2015) was used during the interviews to heighten the procedural reliability of the study. Parent participants (Group 2) were contacted via email to request participation. Once they indicated their willingness to participate and signed the online consent forms, they received a link via email to the online questionnaire (HPPS-P), which they could complete at a time suitable to them.

Teachers (Group 3) received letters outlining the study and requesting their consent for participation. The teachers had the option of completing online or hard copy versions of the HPPS-T (a copy of which was attached to the original letter). Of the 56 teachers who consented, 13 (23%) chose to complete the online HPPS-T. The remaining teachers (77%) completed the hard copy version.

Three adults who used AAC (Group 4) provided informed consent to socially validate the list of words or phrases for use by children who may or could benefit from AAC. One participant

was interviewed at her workplace and the other two at their homes. All three adults had an acquired disability and were competent users of AAC. They had all experienced one or more hospitalizations during the previous 4 years.

Validity and Reliability

For procedural reliability, a scripted interview guide and procedural checklist were developed to guarantee that the same script and procedures were followed (Boyce & Neale, 2006; McMillan & Schumacher, 2010) for data collection from Groups 1 and 4. All interviews were video-recorded. An independent observer watched 22 randomly selected video recordings (30% of recordings) and scored adherence to each of 97 procedural steps on the checklist. To calculate procedural reliability, the number of steps scored as correct was divided by the total number of steps and then multiplied by 100 to express the percentage of procedural reliability (McMillan & Schumacher, 2010). The coder determined that the percentage of adherence to the proposed procedures for the in-depth interview process was 94%, indicating good procedural reliability.

Data Analysis

First, all of the recorded in-depth interviews with the children were transcribed verbatim (Poland, 1995), adhering to a predetermined set of transcription rules (Johnson, 2015). For example, these rules stated that contractions (e.g., *don't, won't*) and colloquial substitutions (e.g., *gonna for going to*) were typed as they were spoken and that exclamations (e.g., *ouch*, *ow*) related to pain were included. Then, the first author and second coder identified pain-related words and phrases within all verbatim transcriptions of the children's data. A pain-related word or phase was defined as a word or phrase that resembles a response or reaction to pain, coping with pain, or describing the pain (e.g., *put on plaster* [adhesive bandage]*, ow, lie in bed, I am*

fine, blood). A unique number was allocated to each unique phrase or word. Identical numbers were given if the phrases or words were identical. In this way, the total number of unique pain words and phrases could be determined. A total of 549 words or phrases were identified within the children's data set. Inter-rater reliability was acceptable at 86% (Heilmann et al., 2008).

Next, the written responses given by the parents and teachers were copied into an Excel spreadsheet and identical procedures were followed to identify pain-related words or phrases. The same numerical codes assigned to the children's data set were allocated to the same pain-related words or phrases in the parents' or teachers' data sets. New pain-related words or phrases within the parents' or teachers' data sets that did not appear in the children's data received additional numerical codes. In this way, 80 new words or phrases in the parents' and teachers' data sets were identified, which brought the total number of words or phrases to 629.

Directed content analysis based on Hsieh and Shannon (2005) was done using the following five themes or categories identified in the literature:

1. Vocabulary to describe pain (Azize, Endacott, Cattani, & Humphreys, 2013; Franck, Noble, & Liossi, 2010; Johnson et al., 2016);

2. Vocabulary to direct the actions of others in response to the pain or injury (Azize et al., 2013; Ely, 1992);

3. Vocabulary to describe the location of the pain (Ely, 1992; Franck et al., 2010);

4. Vocabulary to describe the causes of pain (Franck et al., 2010); and

5. Vocabulary to describe strategies to cope with pain (Johnson et al., 2016).

Words or phrases that could not be categorized into any of the five categories above were allocated to a sixth category, labelled Other. The words in the Other category were then coded by means of consensus (Hsieh & Shannon, 2005). The two coders agreed that these words could be

categorized into two new pain-related categories: Vocabulary to reflect on strategies of how the pain could have been prevented, and Vocabulary to indicate the consequences of the pain or injury or its influence on activities and participation, for a total of seven pain-related categories. These seven main categories were further subdivided into 23 subcategories by mutual agreement between the two coders in order to categorize the words or phrases more easily. Table 2 provides a detailed layout of the seven categories and 23 subcategories.

Insert Table 2 about here

Inferential statistics were calculated using the Statistical Analysis Software (SAS®) programme (SAS Institute Inc., 2011). The data were compared between children and parents (Group 1 and Group 2), children and teachers (Group 1 and Group 3), or parents and teachers (Group 2 and Group 3). Pearson's Chi-Square Test or Fisher's Exact test (Field, 2013) were used to determine if the frequency with which words in the categories and subcategories occurred across the two age cohorts of the three participant groups differed significantly from each other. Because Group 4 was used to socially validate the vocabulary list, this group was not included in the inferential statistical analysis.

Results

In order to develop the pain-related vocabulary list, all three participant groups proposed pain-related vocabulary that children would use in specific scenarios. From the 629 pain-related words or phrases that were categorized according to the seven pain-related categories and 23 subcategories described earlier, those that occurred 10 times or more within each of the various age subgroups in the three participant groups were included in the composite list. The decision to include words or phrases from subcategories that were mentioned with a frequency of 10 or more

by any group was an arbitrary decision in an attempt to shorten the list to words that were more frequently used.

Next, the differences in the use of pain-related words or phrases among age subgroups and also participant groups were explored and the percentage of respondents per group who offered words in the seven categories was determined. These were compared across (a) age subgroups, and (b) participant groups. Table 3 shows the percentage of the three participant groups -- children, parents, and teachers -- who used or suggested the use of words or phrases in the seven main pain-related categories, as well as the inferential statistical test used and the p-values. A distinction was made between the younger-age (6;0 – 7;11) and the older-age (8;0 – 9;11) subgroups. Where no *p*-values are indicated, 100% of participants in both child age groups used vocabulary in that specific category. Pearson's Chi-Square Test was used where possible to test for homogeneity of age groups across subcategories for all six age or informant subgroups. In some cases, Fisher's Exact Test was preferred over Pearson's Chi-Square Test because 50% of the cells had expected counts of less than five, rendering Pearson's Chi-Square Test invalid (Field, 2013).

<div align="center">Insert Table 3 about here</div>

Based on the findings detailed in Table 3, there were statistically significant differences in the child participant groups for Categories E, χ^2 (1, $N = 74$) = 2.8061, $p =.047$), F, χ^2 (1, $N = 74$) = 3.6356, $p =.028$) and G, χ^2 (1, $N = 74$) = 3.4564, $p =.032$) where, on average, a greater percentage of children in the older-age subgroup (8;0 – 9;11) used more words in these three categories than did the children in the younger-age subgroup (6;0 – 7;11). No statistical differences were noted for the two adult participant groups (parents and teachers). In order to determine the statistically significant differences between the percentage of responses in the six

subgroups in the use or suggested use of words or phrases within the seven main and 23

subcategories, pairwise comparisons were done (children compared to parents; children

compared to teachers and parents compared to teachers). Table 4 provides a summary of the

number of main and subcategories where the pairwise comparisons yielded statistically

significant differences between participant groups for the two age subgroups.

<div align="center">Insert Table 4 about here</div>

In summary, Table 4 shows that in the younger-age subgroup, only two of the seven main

categories differed statistically significantly, for only one pair namely for children and teachers.

No other pairs showed significant differences. Of the 23 subcategories, 13 differed significantly

between the children and teachers, 10 showed differences between the children and parents, and

five showed differences between the parents and teachers. In the older-age subgroup, the

differences between children and parents (five main categories and 15 subcategories) and

children and teachers (three main categories and 13 subcategories) were larger than those in the

younger-age subgroups. These findings suggest that the older the children are, the larger the

differences become between children and adults (parents or teachers). Smaller differences were

reported between parents and teachers (no main category and three subcategories) in comparison

to the younger-age subgroup (no main category and five subcategories).

To illustrate the commonality between groups, a composite list of pain-related words or

phrases was compiled. This composite list was used to select pain-related words or phrases that

could be socially validated by the adults who used AAC. Table 5 represents the composite list of

pain-related words or phrases in their respective pain-related subcategories that occurred 10

times or more. Table 5 also shows in which of the six respondent groups each word or phrase

occurred. The total in the table indicates the number of respondent groups in which each word or

phrase occurred, with a higher number indicating that the specific words or phrases were provided or suggested in more respondent groups. The composite list comprised 87 pain-related words or phrases, covering all main categories and 21 of the 23 subcategories; only Comparisons or metaphors (A6) and Secondary gain (G2) were not represented.

Insert Tables 5 and 6 about here

Finally, the social validation of the composite list of pain-related words or phrases was done. During this social validation, input from three adults who used AAC (Group 4) was sought to determine how appropriate the compiled list would be for use by children who used or could benefit from AAC. All of the participants suggested that words rather than sentences or phrases should be included in the list. For example, they suggested using a core word such as put and to add to it different options like cast, cream, ice, and so forth, for the child to choose from. Participant 3, who used a speech-generating device, emphasized: "*Make messages short and effective, as a person like me does not want to struggle to find the word, because it takes so much effort*." As a result, the first author determined the single words that occurred in the composite list by means of ATLAS.ti word cruncher (Johnson, 2015). Next, the researchers determined which words were classified as being either core or fringe, using the published core word lists for children (Banajee et al., 2003; Marvin et al., 1994; Trembath et al., 2007). A total of 78 different core words (45%) appeared in the composite pain-related list, whereas 98 (55%) were categorized as fringe words (of which 23% were pain-related words and 32% were other words; Johnson, 2015). Table 6 provides the list of core words, pain-related fringe words, and other fring words that originated from this study. The adults who used AAC also proposed that a body figure should be included on the communication board to enable the child to indicate where the pain is physically.

Discussion

Children with significant communication difficulties need to communicate about pain experiences associated receiving appropriate pain-relieving treatment, coping with pain, and the like. However, they struggle to do so because they may not present their pain in typical ways (e.g., expected facial expressions, crying, spoken words; Beyer et al., 1990). Therefore, it is vital that pain-related vocabulary be included on AAC systems so that they are able to communicate pain by selecting prestored messages.

The suggestion that children use different words or phrases when compared to adults (Beukelman & Mirenda, 2013) was confirmed in the present study. There were statistically significant differences in the pairwise comparisons between the responses of the children and those of the parents and teachers, respectively, for specific categories and subcategories for both age subgroups, which indicates that children provided different words or phrases than did the two adult participant groups. For example, children from both age subgroups suggested *make it better* (subcategory B1) or *medicine* (subcategory B3), whereas adults from all four adult subgroups indicated that the children would say *I am okay* (subcategory E1) or *the sore was burning* (subcategory A4). This finding supports the importance of including the children's viewpoint, the so-called "child's perspective" (Nilsson et al., 2015, pp. 162-167), as opposed to simply employing a child perspective, which refers to adults' reflections on children. In order to gain understanding of how children use language to express pain, speech-language pathologists should never rely only on input from adults (Ely, 1992). Obtaining a child's perspective by talking directly to children about their pain could thus reveal the rich and descriptive language children use to express their pain experiences (Ely, 1992; Nilsson et al., 2015). It is interesting that, in the current study, the differences between children and adults seemed more marked for the older participant group. This finding was unexpected, given that one may expect children to

use vocabulary that is more like that of adults as they get older. However, it must be remembered that parents and teachers did not offer vocabulary they would use, but rather vocabulary they expected the children to use. This suggests that these adults were more in tune with the vocabulary used by younger children. It is possible that younger children seek adult comfort after a painful experience more often than older children, which could lead to adults being more attuned to the vocabulary these younger children use.

Both parents and teachers were included as respondents in this study because it was hypothesized that they could potentially contribute unique data based on their different experiences and perspectives on the topic. The teachers were included because of their experience dealing with children's bumps and bruises resulting from minor injuries at school. They were asked to complete five scenarios (Scenarios 1, 4, 6, 7, 9) relevant to their experience. Parents, in contrast, could comment on the pain their children experienced from minor as well as severe injuries (e.g., needle procedures and surgeries); however, data from these groups was very similar. This finding suggests that it may be more important to include both adult and child perspectives when asking for suggestions about pain-related vocabulary; however, this may not be applicable when selecting vocabulary on other topics.

Evidence-based practice advocates attention to social validation of study results by means of stakeholder reviews to gather information from consumers such as individuals who use AAC (Schlosser, 1999). In this study, the social validation process was designed to ensure that the pain-related vocabulary suggested by the participant groups would be appropriate for children who either use or could benefit from using AAC to express pain. Valid suggestions from the adults who used AAC were that single words rather than phrases should be offered to children. The researchers therefore categorized all individual words that occurred in the composite word

list into core words, pain words, and other fringe words, using existing core vocabulary lists for

children (Banajee et al., 2003; Marvin et al., 1994; Trembath et al., 2007).

The suggestion from the adults who used AAC that a body figure of a child be included

in the layout of the pain-related communication board could eliminate the need for some of the

words and phrases suggested in Category C (Describe pain location). Body figures were also

included on the Vidatak EZ boards developed by Patak and colleagues (Patak et al., 2006), the

child version of which comprises a body figure and symbols.

During the social validation process, the adults who used AAC supported the use of

various pain-related categories, though every pain-related communication board should suit the

individual needs of each child (Johnson, 2015). Furthermore, because vocabularies of different

languages influence one another in multilingual contexts such as South Africa, words from

languages other than English (also referred to as code-switching), for example, *eina* and *eish*

should be incorporated on the board (Johnson et al., 2015; Moodley, 2007). Eina, equivalent to

ouch, is an original Afrikaans word used to express physical pain. Eish is an isiZulu exclamation

indicating surprise or disapproval.

The use of hypothetical scenarios to determine vocabulary was successful. The vignettes

and accompanying illustrations with a character developed with input from children participating

during the qualitative phase ensured that the children could easily relate to the character and

vignettes. Given the success with which the use of hypothetical scenarios elicited appropriate

pain-related vocabulary, the same method could be appropriate for the selection of vocabulary

for other sensitive topics, such as sexual, physical, or emotional abuse. The use of custom-

designed hypothetical scenarios (relevant to the specific topic) to share information about

sensitive topics has been shown to be less invasive and stressful than talking about actual

experiences (Hughes & Huby, 2002; Jenkins, Bloor, Fischer, Berney, & Neale, 2010). In this study, the use of hypothetical scenarios helped to elicit a large pool of potentially appropriate vocabulary items all the while not adding to secondary stress that would have occurred had participants been required to relive the painful events (Hughes & Huby, 2002; Jenkins et al., 2010).

Limitations and Future Research

Limitations in the study should be acknowledged. The fact that parents in Group 2 were not the parents of the children in Group 1 resulted in the children not being matched with their parents, and instead a comparison between the two groups had to be done. Few children in hospital settings were included, thus the influence of hospital experiences on pain-related vocabulary could not be determined. Ideally, children with significant communication disabilities would have been recruited to validate the suggested vocabulary list, as this study highlighted that children may suggest other words than adults. However, because many children with severe communication difficulties are not fully literate, it was difficult to recruit an appropriate group. Relying on graphic symbols such as Picture Communication Symbols to represent the vocabulary would have necessitated teaching all of the symbols first, because many of the words and phrases in the list were abstract and difficult to represent with a transparent graphic symbol.

For future research, the use of the list of pain-related words by various healthcare staff to ask children with significant communication difficulties to self-report their pain could be investigated. A follow-up study could be done to determine the best-suited visual representation (photographs or line drawings) of the words identified and presented in the pain-related vocabulary list. It is also important to determine whether the pain-related vignettes are appropriate for children whose demographic profiles differ from those of the children included in

this study, such as other language groups and children from other socioeconomic backgrounds. As the current study found that there were more marked differences between the responses of older children and adults than between those of younger children and adults, a follow-up study could be done to determine the extent to which the responses between the children and adults change as the age of the children increases.

Conclusion

Children with temporary or permanent communication difficulties need ways to communicate their pain in order to receive effective and appropriate pain-relieving treatment (Costello et al., 2010). This study explored the pain-related vocabulary that could be stored in an AAC system to enable children to express their pain. A socially validated, pain-related vocabulary list that included core words, pain-related fringe words, and other fringe words, was developed. AAC interventionists may use this list as a basis for selecting appropriate pain-related words for inclusion on electronic or nonelectronic AAC systems for young children with communication disabilities in order to afford them the opportunity to report on any painful experiences they may have. As far as possible, input from both the child as well as significant adults should be used to inform the exact choice of words to be included.

The study also highlights the importance of obtaining input from children on appropriate vocabulary items, rather than relying on adult input only. The use of vignettes may be a particularly useful way of eliciting vocabulary about specific sensitive topics from children.

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End Notes

[1] Picture Communication Symbols is a product of Mayer-Johnson, a Tobii Dynavox Company.

www.mayer-Johnson.com

[2] iPad is a product of Apple Computers Inc., Cupertino, CA, www.apple.com

[3] SurveyMonkey is an online survey development cloud-based founded in 1999 by Ryan Finley.

www.surveymonkey.com

Table 1

The Measuring Instrument (HPPS) Adapted for the Four Participant Groups

Aspect	HPPS-C	HPPS-P	HPPS-T	HPPS-S
Target participant group	Group 1 Children (*N*=74) age 6;0 – 9;11	Group 2 Parents (*N*=61) of children aged 6;0 – 9;11	Group 3 Teachers (*N*=56) who teach children aged 6;0 – 9;11	Group 4 Literate adults (*N*=3) who use AAC
Number of scenarios	10	8	5	3
List of scenario themes	Falls out of a tree Operation Falls from bicycle Car accident Ball against body part Thorns Bodily pain Burn wound Bee sting Needle procedure (drip or intravenous line)	Child falls Ball against body part Operation Thorns Bodily pain (e.g., head or stomach pain) Burn wound Bee sting Needle procedure (drip or intravenous line)	Child falls Ball against body part Thorn/splinter gets into a body part of learner Bodily pain (e.g., head or stomach ache) Bee sting	Operation Bodily pain Needle procedure (drip or intravenous line)
Method	In-depth interviews using a scripted interview guide; iPad© with illustrations for vignettes	Self-administered online questionnaire via SurveyMonkey	Self-administered questionnaire available online (SurveyMonkey) or in printed format	In-depth interviews using a scripted interview guide; iPad with illustrations for vignettes; communication board with words/phrases according to categories

Table 2

Categories, Definitions, Subcategories, Definitions of Pain-Related Vocabulary

Main categories of pain-related vocabulary and their definitions	Definition of main category	Subcategories	Definition of subcategory
Category A: Vocabulary to describe pain	Words or phrases that explain the physical feeling of how the pain is experienced	A1: Exclamations	A sudden cry or remark, to specifically express surprise, anger, or pain
		A2: Vocalizations and verbalizations	Utterances or noises to express pain
		A3: Descriptors	Vocabulary used to describe a pain experience or feelings of pain
		A4: Sensory words	Vocabulary related to sensation or the physical senses; transmitted or perceived by the senses
		A5: Intensifiers	Vocabulary that indicates the intensity or severity of the pain experience
		A6: Comparisons or metaphors	Vocabulary used to compare the feeling of pain with something else, for example, *like ... or feels as if ...*
		A7: Evaluative words	Vocabulary to evaluate or assess the pain experience
Category B: Vocabulary to direct others' actions in response to the pain or injury or illness	Words or phrases that specify to others what to do or not do when the child is in pain. These include requests for help or assistance, specifications of how treatment should be carried out, protests from the child, and remedies to be given to ease the pain	B1: Actions	Vocabulary to indicate to others' what to do or not to do when child is in pain
		B2: Places	Vocabulary to indicate where the child wants to or should go when in pain
		B3: Remedy	Vocabulary to indicate what medicine or treatment should be

			provided when child is in pain
Category C: Vocabulary to describe the pain location and visible signs to the actual tissue damage as a result of the physical injury	Words or phrases to give an account of all characteristics or features of the place of injury, both internally and externally, as well as what the injury looks like and how this injury affects the body structure and functions of the child	C1: Site of injury	Vocabulary to indicate the place of injury on the body
		C2: Visible signs of injury	Vocabulary to give an account of the characteristics and features, both internally and externally, of the actual tissue damage as a result of physical injury
Category D: Vocabulary to describe the cause of the pain	Words or phrases that describe the incident that led to the pain experience, including reasons and explanations of actions that resulted in the injury	D1: Internal causes of pain	Vocabulary to describe the incident due to own mistake that led to the pain experience (could have avoided injury or cause of pain)
		D2: External causes of pain	Vocabulary to describe the incident inflicted by others, thus outside of own control, that led to the pain experience (could not have avoided injury or cause of pain)
Category E: Vocabulary to describe strategies used to cope with pain	Words or phrases of attempts or actions to deal with pain	E1: Self-talk	Vocabulary used as a form of self-regulation to deal better with pain
		E2: Actions to cope with pain	Vocabulary used to indicate what to do to deal effectively with pain
		E3: Positive outcomes	Vocabulary to affirm that the pain will become better
		E4: Distractions	A thing or action that deflects attention away from pain
Category F: Vocabulary to reflect on strategies of how the pain could have been prevented	Words or phrases that show that the child thought carefully about how the pain could have been avoided or about lessons learnt for the future	F1: Reflect on what happened (past)	Vocabulary to reflect on how what happened to cause the pain could have been prevented
		F2: Reflect on how to prevent pain	Vocabulary to indicate how the pain can be avoided in the future

Category G: Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	Words or phrases that indicate the outcome(s) or results of the pain or injury that affect (a) the child's participation in activities, (b) rewards received as a result of the injury, and (c) emotional responses and reflections as a result of the pain or injury.	G1: Physical outcome	Vocabulary to indicate the physical consequences or influence of participation in activities as a result of pain (cannot do something as a result of pain or pain denies child of something)
		G2: Secondary gain	Vocabulary to explain the extra rewards received as a result of the pain experience (such as getting attention or receiving some consolation as a result of pain)
		G3: Emotional response as result of pain	Vocabulary to describe emotions due to pain experience

Table 3

Percentage of Child, Parent, or Teacher Participants in Two Age Subgroups who Proposed Words or Phrases in the Seven Pain-related Categories

Pain-related main category	% of participants offering words/phrases		Test used	*p*-value
	Younger group (6;0 – 7;11) (*n*=39)	Older group (8;0 – 9;11) (*n*=35)		
Children				
Vocabulary to describe pain	100.0	100.0	-	-
Vocabulary to direct others' actions	100.0	100.0	-	-
Vocabulary to describe pain location	71.8	82.9	P	.1294
Vocabulary to describe the causes of pain	97.4	97.1	F	0.5
Vocabulary to describe strategies used to cope with pain	92.3	100.0	P	.047*
Vocabulary to reflect on strategies of how the pain could have been prevented	43.6	65.7	P	.028*
Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	79.5	94.2	P	.032*
Parents				
Vocabulary to describe pain	100.0	100.0	-	-
Vocabulary to direct others' actions	100.0	100.0	-	-
Vocabulary to describe pain location	58.6	43.8	P	.2460
Vocabulary to describe the causes of pain	96.6	93.8	P	.613
Vocabulary to describe strategies used to cope with pain	100.0	90.6	P	.239
Vocabulary to reflect on strategies of how the pain could have been prevented	34.5	28.1	P	.5923
Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	58.6	59.1	P	.952
Teachers				
Vocabulary to describe pain	100.0	100.0	-	-
Vocabulary to direct others' actions	100.0	100.0	-	-
Vocabulary to describe pain location	33.3	30.8	P	.838
Vocabulary to describe the causes of pain	100.0	100.0		-
Vocabulary to describe strategies used to cope with pain	93.3	88.5	P	.524
Vocabulary to reflect on strategies of how the pain could have been prevented	16.7	11.5	F	.711
Vocabulary to indicate the consequences of pain or injury and its influence on activities and participation	56.7	50.0	P	.618

Note. P = Pearson's Chi-Square Test; F = Fisher's Exact Test.
*p<.05.

Table 4

Summary of Number of Main and Subcategories Where the Pairwise Comparisons Yielded Statistically Significant Differences Between Participant Groups Within the Two Age Subgroups

Younger group (6;0 – 7;11)				Older group (8;0 – 9;11)			
Pairwise comparison		Main	Subcategories	Pairwise comparison		Main	Subcategories
Children *(n=39)*	Parents *(n=29)*	0	10	Children *(n=35)*	Parents *(n=32)*	3	15
Children *(n=39)*	Teachers *(n=30)*	2	13	Children *(n=35)*	Teachers *(n=26)*	3	13
Parents *(n=29)*	Teachers *(n=30)*	0	5	Parents *(n=32)*	Teachers *(n=26)*	0	3

Note. Pairwise comparisons were done to detect statistical significant differences in percentage of responses given by the three participant groups (children, teachers and parents) per main and subcategory.

Table 5

Composite List of All Pain-Related Words or Phrases Across Respondent Groups

Main and sub pain-related categories	Pain-relate words and/or phrases	YC	OC	PYC	POC	TYC	TOC	Total
B1	call/tell (mommy/daddy/teacher)	1	1	1	1	1	1	6
A2	cry/cries/crying	1	1	1	1	1	1	6
A3	hurt (my body part)	1	1	1	1	1	1	6
D1	I fell	1	1	1	1	1	1	6
D2	ball hit me	1	1	1	1	1	1	6
A3	it is sore	1	1	1	1	1	1	6
A1	ouch	1	1	1	1	1	1	6
A1	ow	1	1	1	1	1	1	6
B1	please help	1	1	1	1	1	1	6
B1	take it (thorns/splinter) out	1	1	1	1	1	1	6
D2	the bee stung me	1	1	1	1	1	1	6
A5	very sore/really sore/so sore	1	1	1	1	1	1	6
A3	it pains/paining	1	1	1	0	1	1	5
E3	it will feel better/will be better	1	1	1	1	1	0	5
B3	put on plaster	1	1	1	1	1	0	5
A3	blood/bleeding (there is blood all over/the sore is bleeding)	1	1	0	0	1	1	4
A1	eina	0	0	1	1	1	1	4
E1	I am okay	0	0	1	1	1	1	4
A2	I screamed	0	1	1	1	1	0	4
B1	make it better	1	1	1	1	0	0	4
B3	medicine/medication	1	1	1	1	0	0	4
A4	the sore was burning	0	0	1	1	1	1	4
B2	go to sickroom/office/principal	0	1	0	0	1	1	3
A7	I don't feel well	0	1	0	1	0	1	3
E2	I hold (it)/hold on hurt	0	0	1	0	1	1	3
A5	it was painful	1	1	0	1	0	0	3
G1	point at/show (the place of injury)	0	0	1	1	1	0	3
B3	put on something	1	0	0	0	1	1	3

B3	put some cream/special cream (on)	1	1	1	0	0	0	3
E2	do nothing/don't do anything (when in pain)	0	0	1	0	1	0	2
B2	go to the doctor	1	1	0	0	0	0	2
B2	go to the hospital	1	1	0	0	0	0	2
B1	hold my hand	0	0	1	1	0	0	2
A5	hurts very bad/hurt a lot	1	1	0	0	0	0	2
A3	I feel sick	0	0	1	0	1	0	2
D1	I have a headache	0	1	0	1	0	0	2
E2	I rub it	0	0	1	1	0	0	2
E2	I want to go home	1	1	0	0	0	0	2
G1	I want to vomit	1	1	0	0	0	0	2
E1	I'm fine/ it is fine	0	0	0	1	0	1	2
C2	it is swollen	1	1	0	0	0	0	2
D2	it was him (blame somebody else)	0	0	0	0	1	1	2
E2	lie down (when in pain)	0	0	0	1	1	0	2
E2	lie in bed	1	1	0	0	0	0	2
A1	owie	0	0	1	1	0	0	2
B3	put cold water on it	1	1	0	0	0	0	2
B3	put on bandage	1	1	0	0	0	0	2
B3	put on ice/ice pack	1	1	0	0	0	0	2
A5	really hurt	1	1	0	0	0	0	2
A4	the sore sting(s)/is stinging	0	0	1	1	0	0	2
D2	there is a splinter in my skin	0	0	0	1	0	1	2
A5	very painful/so painful	1	1	0	0	0	0	2
A5	very, very sore/ extremely sore/really, really sore	1	1	0	0	0	0	2
G1	facial expressions/grimace (show they are in pain)	0	0	1	0	0	1	2
D2	a dog ran across the street	0	1	0	0	0	0	1
F2	be more careful	0	1	0	0	0	0	1
C2	break (body part)	0	1	0	0	0	0	1
G1	can't move (body part)	0	1	0	0	0	0	1
B1	clean it	0	1	0	0	0	0	1
E3	doctor will help to make it better	0	1	0	0	0	0	1
B3	drink water/put water on the sore	0	1	0	0	0	0	1

B1	give me a/I need a hug	1	0	0	0	0	0	1
A4	hot	0	0	1	0	0	0	1
G3	I am sorry Mom (that I got hurt)	0	0	0	0	1	0	1
G1	I can't talk/speak (because it is sore)	0	1	0	0	0	0	1
C2	I have a blister	0	1	0	0	0	0	1
D2	I touched the warm pot/kettle/iron	0	1	0	0	0	0	1
E2	I want to sleep/go to sleep (when in pain to feel better afterwards)	1	0	0	0	0	0	1
D2	I was hit by a ball	0	0	0	0	1	0	1
A7	it feels not nice/ don't feel nice	0	1	0	0	0	0	1
E1	it is not sore at all/wasn't that sore	0	1	0	0	0	0	1
F1	I've pulled the brakes too hard	0	1	0	0	0	0	1
E4	let's play	1	0	0	0	0	0	1
A2	moan	0	0	0	1	0	0	1
C2	my skin has scratches	0	1	0	0	0	0	1
A1	ouchie	1	0	0	0	0	0	1
A1	owa/owie	0	0	0	0	1	0	1
A5	pain/sore feels really bad	0	1	0	0	0	0	1
E3	pray to God/Allah* to make it better	1	0	0	0	0	0	1
B3	put on cast	1	0	0	0	0	0	1
B3	put on ointment	1	0	0	0	0	0	1
E2	rest for a little bit	0	1	0	0	0	0	1
B1	stop hurting/poking me	0	1	0	0	0	0	1
A3	the sore aches/aching	0	0	0	1	0	0	1
C1	there are thorns in my body part (head/skin/leg/hand	0	0	0	0	1	0	1
D2	they gave injection/inject	1	0	0	0	0	0	1
B1	wait until it is better	0	1	0	0	0	0	1

Note. YC = younger children; OC = older children; PYC = parents of younger children; POC = Parents of older children; TYC = teachers of young children; TOC = teachers of older children

*Children used either God or Allah

Table 6

List of Core Words, Fringe (Pain-Related) and Fringe (Other)

Core vocabulary			Fringe (pain-related)	Fringe (other)	
a	hot	take	aches/aching	across	principal
all	I	tell	bandage	Allah/God*	pulled
am	I'm	the	bleeding	anything	ran
an	in	there	blister	ball	rest
are	is	they	blood	bee	rub
at	it	to	burning	brake	sickroom
bad	I've	too	cast	break	skin
ball	let's	very	cry/cries/crying	by	sleep
be	little	wait	eina	careful	speak
bed	lot	want	headache	clean	special
better	make	was	hospital	cold	splinter
bit	me	water	hurt/hurts/hurting	cream	street
call	mommy	well	inject	daddy	talk
can't	more	will	injection	expressions	teacher
do	move		medication	extremely	thorns
doctor	my		medicine	facial	touched
dog	need		moan	feel/feels	until
don't	not		ointment	fine	warm
down	okay		ouch/ouchie	gave	
drink	on		ow/owa/owie	grimace	
fell	out		pain/pains/paining	hard	
for	play		painful	hit	
give	please		plaster (adhesive bandage)	hug	
go	put		poking	ice	
hand	really		scratches	lie	
has	show		scream	nothing	
have	so		sick	office	
help	some		sore	pack	
him	something		stings/stinging/stung	point	
hold	sorry		swollen	pot/kettle/iron	
home	stop		vomit	pray	

*Children used either Allah or God