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Exploring children's preferences for graphic symbols to represent pain-related words

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Abstract

Children who are hospitalized may sometimes not be able to communicate verbally to self-report their pain or other symptoms due to medical conditions, medical interventions, or communication difficulties. As such, these children may need other means, such as augmentative and alternative communication (AAC) strategies, in this case, graphic symbols, to express their pain-related experiences and receive applicable treatment. Choosing suitable graphic symbols to represent pain-related words contributes to the effective use and implementation of visual support. This study explored the preferences of 6.0–9.11-year-old (years; months) children with typical development regarding graphic symbols to represent pain-related words. These symbols were selected from two commonly used and widespread symbol resources: Picture Communication Symbols (PCS®) and Aragonese Portal of Augmentative and Alternative Communication (ARASAAC) symbols. A descriptive, quantitative study design was employed, including a total of 30 typically developed South African children. Data were collected by means of an electronic questionnaire and analyzed using descriptive and inferential statistics. Probability values were determined and predictions, as well as inferences, were implemented. The results showed that the children preferred ARASAAC symbols to represent most pain-related words ($p < 0.001$). It is important to consider stakeholders' (in this case, children's) input on their preferences in designing communication support to enable participation during the clinical decision-making process.

KEYWORDS
Aragonese Portal of Augmentative and Alternative Communication symbols, communication vulnerable, hospital, pain, participation, Picture Communication Symbols

1 | INTRODUCTION

Children who are hospitalized may at times not be able to communicate verbally. These children are referred to as communicatively vulnerable.[1] Communicative vulnerable children may be unable to adequately express themselves verbally or hear, understand, read, remember, or write.[2] These communication difficulties could either be permanent (e.g., due to disability) or temporary (e.g., due to critical illness or medical intervention).[1] Several factors, including noisy environments and language and cultural barriers, could increase

children's communication difficulty resulting in more time and effort to convey feelings of pain and discomfort, which in turn, may delay or hinder adequate or prompt support related to their pain experiences.[2,3]

Augmentative and alternative communication (AAC) strategies are frequently considered when there is limited or no functional speech to communicate efficiently and effectively with communication partners.[4] AAC refers to a variety of communication strategies used to express meaning or support comprehension in communication.[5] AAC systems are divided into unaided AAC systems that involve methods of communication that do not require external material apart from the body (e.g., facial expressions, signs and gestures) and aided AAC systems that include external material (e.g., communication boards with graphic symbols, speech-generating devices or communication apps).[4,6]

Symbols are used as a means to represent something (i.e., an object, action or feeling).[7] Practitioners often need to identify a suitable graphic symbol collection for their clients in need of AAC, and in the past, research often focused on iconicity of symbols as the most possible reason for symbol selection.[8–11] Iconicity refers to the relationship between the symbol and what it represents.[7] The iconicity of symbols is further described as being on a continuum starting with transparent, then translucent and opaque symbols.[11]

On the other hand, Ogletree et al.[12] warn that assumptions, such as the ease of recognizing a symbol (iconicity) is not supported by evidence-based practice and may place a burden on practitioners and clients. Schlosser and Raghavendra[13] underlined the importance of adhering to evidence-based practice in decision-making regarding AAC, including choices concerning symbol inclusion. For example, the assumption that "adults and children see symbols in the same way"[12] is not founded by evidence. Therefore, the input from children with regard to what graphic symbol they choose to represent a specific word or concept should be considered as practitioners often opt easily available graphic symbols that are iconic or frequently used without any evidence that it may be the best option.[7,12–14]

The selection of graphic symbols should focus on their design and physical attributes as well as their linguistic characteristics.[6] In turn, symbol characteristics should be matched with the needs and preferences of the stakeholder (client).[6,7] Therefore, clinicians should consider and utilize visual materials that are preferred by the stakeholder (client)—in the current study, a child with a temporary or permanent communication difficulty.

The study by Pampoulou and Diamanti,[15] for example, found that stakeholders (young adults with autism spectrum disorder or with intellectual disabilities) preferred colored symbols and not iconic symbols per se. The authors proposed that children may also prefer colored symbols above symbols without color.[15] These participants regarded colored symbols as "happy symbols" and the authors believed that children may also prefer the colored symbols as such.[15] On the contrary, in another study conducted in Cyprus and Texas, Pampoulou and Fuller[7] found that clinicians tend to choose symbols based on the availability of specific symbol collections, their intelligibility for the clients including their abilities, needs and culture. No mention was made of color as an option for clinicians when selecting symbols. Furthermore. clinicians often prioritize symbol characteristics (e.g., design, linguistic and physical attributes) and match them with the needs and skills of the clients they support, whilst children may have other priorities when selecting symbols.[7] Due to the differences in perspectives of adults and clinicians, it is important to consider a child's input as a direct stakeholder.[15–18] Since children have the right to express their views and participate in their care,[19,20] it is crucial to obtain children's voices concerning the choice of symbols used to support communication.

Children who temporarily lack access to verbal communication may not have prior exposure to an AAC collection of symbols, nor do they require a long-term linguistically functional symbol collection. Since the linguistic functionality of symbols may not be required for these stakeholders (children with temporary communication difficulties), it is necessary to select symbol collections that do not only focus on linguistic features of symbols.[7] One earlier study with this focus has been identified. This study by Nilsson and colleagues[21] studied 103 children's preferences of pictures for communicating emotions using the visual framework Talking Mats. In this study, the children tended to choose symbols inconsistently and independent of system (PCS® and Widgit symbols), only some older children (7–8 years of age) tended to choose pictures from one system to represent different words in a category or a dimension (visual scale in this case).[21]

This study made use of symbols from two systems: PCS®[22] and Aragonese Portal of Augmentative and Alternative Communication (ARASAAC) symbols.[23] Refer to Appendix A to see the symbols that were included in this study. PCS® is a commercially available symbol system including more than 45 000 symbols mainly used to support communication with children and adults with cognitive and/or communicative disabilities.[10,24–26] PCS® symbols are usually made available as part of an application in a speech-generating device or through the software Boardmaker, aimed at designing printed symbol material such as communication boards or schedules (Tobi Dynavox, 2022). PCS® was found to have high iconicity compared to alternative aided symbol collections such as Picsyms and Bliss symbols.[27] ARASAAC symbols are freely available for download from different online platforms such as the ARASAAC portal (https://arasaac.org/) and the Bildstöd platform (bildstod.se). The ARASAAC symbols were introduced in 2007 as a government-funded project in Spain[23] and have since been used as a graphic symbol system for AAC intervention.[28] Results from a study by Cabello and Bertola[28] confirmed that ARASAAC symbols were more iconic and translucent compared to PCS® and Bliss symbols. The only exception was for the transparency of PCS® and ARASAAC symbols with linguistic features where no differences were reported.[28]

Shifting the attention to the pain-related vocabulary, children, who experience significant communication difficulties temporarily or permanently, need to have access to alternative means of self-reporting the nature, location and intensity of their pain to ensure they receive appropriate treatment.[29] Self-report is regarded as the

gold standard of gaining information regarding pain and other symptoms.[30] For children, pain is a difficult concept to describe due to the personal, intrinsic and subjective nature of the pain-related experience.[29] As such, suitable pain-related vocabulary is necessary to enable clinicians to develop appropriate AAC systems to encourage children to self-report their pain-related experiences.[16] In response to a lack of research on the vocabulary of sensitive topics such as pain, Johnson[31] identified a pain-related vocabulary to be used by South African typically developed children aged 6. 0–9. 11 years.

A growing number of studies are available that describe the use of AAC with pediatric populations to enable them to participate in their medical intervention.[18,32–37] Making use of AAC to self-report their pain essentially improves children's participation in life situations, which is considered to be a fundamental intervention goal.[38] Moreover, the ability to self-report allows children an active role in decision-making processes, which is essential according to the United Nation's Conventions on the Rights of Children.[20]

Since the importance of recognizing children's own voices together with the successful implementation of AAC and/or visual support in pediatric healthcare settings were confirmed in literature, the aim of the current study was to explore 6.0–9.11-year-old children without disabilities' choices between visual representations of PCS® and ARASAAC symbols based on the pain-related vocabulary as identified by Johnson et al.[16,31] An additional aim was to explore factors, such as gender, age and ethnicity that may influence children's preferences.

2 | METHOD

2.1 | Design

The study used a non-experimental descriptive, quantitative design[39] to describe the preferences of children without disabilities relating to the representation of symbols for pain and symptom communication. This quantitative design was chosen because the relationship between dependent (i.e., graphic symbol preference) and independent (i.e., age, gender, ethnicity) variables were examined as well as a description of possible factors which may influence the quantitative results.

2.2 | Participants, setting and recruitment

Non-probability, purposive, convenience sampling was conducted.[40] Participants were chosen based on specific selection criteria, namely children without disabilities aged 6.0–9.11 years attending a mainstream school in the Cape Metropole, Western Cape, South Africa, where English is the language of teaching and learning. The likelihood of such a sample to be representative is low, although generalization is possible to similar participants.[40] Purposeful sampling allows the researcher to concentrate on participants with certain characteristics who are able to answer the relevant research questions.[41]

Of the potential 34 participants who received letters of informed consent, 3 did not return their reply slip (91% response rate) and one did not pass the screening test as this participant achieved a "borderline impaired or delayed" score on the test of Auditory Comprehension of Language (4th Edition) (TACL-4).[42] The final sample of 30 participants had a mean age of 8.0 years. Participants did not have visual impairments which could interfere with graphic selections.

More boys (57%) than girls (43%) participated, with a boy–girl ratio of 1.3:1. A total of 67% of participants ($n = 20$) identified as colored (mixed race) and 33% ($n = 10$) as Black African. The ethnic distribution of the sample is representative of the school's ethnic distribution of mainly Colored and Black African learners and to some degree correlates with the census data from Statistics SA,[43] which indicated that the largest ethnic population in the Cape Metropole was Colored (42.4%), followed by Black African (38.6%). However, this is not representative of the larger South African population, with the largest ethnical group being Black African (79.2%) and the second largest being colored (8.9%) and White (8.9%). Altogether, 20% of participants only spoke English, while 67% of participants spoke at least two languages with 13% being able to speak three or more languages. The official South African languages other than English include Afrikaans, isiXhosa, isiZulu, and Sesotho—languages that typically spoken in the Western Cape. Two participants (7%) spoke Lingala (a Congolese language) and French (an European colonial language also spoken in some African countries), respectively—indicating that children from diverse cultures attended this mainstream school.

2.3 | Materials

The questionnaire was displayed electronically via a PowerPoint presentation (see Appendix B) on a Lenovo laptop. It was decided to display the questionnaire electronically as it was found in the study by Johnson[31] that the electronic display of symbols contributed to the children being engaged and focused on the task at hand. The electronic questionnaire consisted of 32 pain words based on the pain-related core vocabulary of South African children identified by Johnson et al.[16,31] and reduced by means of the symbol selection criteria. The original study aimed to include all 32 pain words identified by Johnson et al.[16] All words were available on the PCS® platform at the time, compared to 26 of the words on the ARASAAC platform. Originally, in the electronic questionnaire (see Appendix B), the authors utilized other graphic symbols on the Bildstöd platform to represent the five words that were unavailable in ARASAAC at the time of symbol selection. This work is part of a larger study, but for this paper, we only focused on the 26 common symbols or words found in PCS and ARASAAC at the time of symbol collection. Some of the questions in the original questionnaire (see Appendix B) included no ARASAAC symbols (i.e., "sting", "upset") and were thus excluded during data analysis for this paper. In cases where there was an ARASAAC symbol and another symbol from the Bildstöd platform (i.e., "headache", "medicine", "plaster", "vomit"), the other symbol was removed during

data analysis. Data were re-analyzed after removal of these questions or symbols relating to these pain words ("headache", "medicine", "plaster", "sting", "vomit", "upset") to keep only the PCS® and ARASAAC symbols. (See Appendix A for a detailed example of the symbols that were included and excluded for data analysis.) All the options per pain word were included in color as well as black-and-white versions of each graphic symbol. Care was taken to ensure randomized order per pain word and equal size distribution of symbols to limit the potential effects on participants' preferences. Only the graphic symbol options of a single pain word were presented on the screen at a time, in a circle to discourage potential subconscious ranking from occurring. The order of pain words as well as the order of symbol options were random because in any fixed order of pain words, earlier words can anchor the responses to later words in unpredictable ways.[44] An interview script and procedural checklist was employed during data collection and a GoPro Hero 5 Black video camera was used to record all interviews to confirm procedural reliability.

Two platforms were used to identify the symbol collections: PCS® symbols were retrieved from the commercially available PCS® platform, while ARASAAC symbols were retrieved from the Bildstöd platform (bildstod.se). ARASAAC symbols are available for download without cost and accessible via various online platforms, which is a reason why ARASAAC was chosen as another option in the current study in the low socio-economic South African context.

2.4 | Data collection procedures

Permission from the Western Cape Department of Education, South Africa and ethics approval (GW20171134HS) from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria were obtained before data collection commenced. Each participant was taken to a private room and assent was sought using a child-friendly visual assent form to explain the procedures and participant rights and created awareness that the session would be video recorded. For confidentiality purposes, the video-recorder was positioned towards the researcher (second author) and material, avoiding the face of the child. The researcher and participant were both seated at a child-sized table in a room that had no distractions and had adequate lighting. No data collection commenced before caregiver consent and child assent had been obtained. For the purposes of this study, a meticulous interview script and procedural protocol was followed to ensure that all participants were exposed to the exact same questions so as to limit a varying of results depending on external variables such as time of contact sessions.[39] Thereafter, the TACL-4 was conducted as a screening tool to determine inclusion or exclusion based on the participants' vocabulary and/or composite performance and not to identify language problems. The laptop with the electronic questionnaire was positioned in front of the participant to ensure good access and a clear view of the graphic symbols. Before the symbols for a specific pain word were presented, participants who scored below average on the TACL-4 had to describe the meaning of each pain word before the word was included in the study. Therefore, different totals were calculated per pain word as words were excluded if not comprehended. Upon confirming the comprehension of the pain word, participants were asked to point to their preferred symbol for each pain word and explain why they chose the specific symbol. Each response made by each participant was recorded using a paper-based data collection sheet. After data collection, results were transferred to Excel spreadsheets to facilitate statistical analysis and the drawing of tables and figures.

2.5 | Validity and reliability

For procedural reliability, an interview script and procedural protocol was used when interviewing each participant.[39] (See supplementary material for an example of the interview script and procedural checklist.) An independent observer observed nine sessions (30%) of the video-recorded material and marked each completed or missed step according to the interview script and procedural checklist. An adherence percentage was calculated based on the following formula: (steps correctly completed ÷ total number of steps) × 100 = % adherence. An 80% adherence score was calculated, which supports good procedural reliability.[45]

2.6 | Data analysis

In this study, the following data set is analyzed. The data were collected from 30 participants. There were 27 variables with a nominal kind of data set where gender, ethnicity and age group were used as demographical variables of the participants.

Symbols compared were between PCS® and ARASAAC for the following pain-related words: "backache"; "bandage"; "blood"; "bottom ache"; "burn"; "cry"; "earache"; "headache"; "hurt"; "pain"; "sad"; "sad"; "scared"; "scratch"; "scream"; "sick"; "sore"; "sore chest"; "sore finger"; "sore throat"; "stomach ache"; "tickle";* "upset", and "vomit".

Descriptive analysis and analysis of variance (ANOVA) was applied to analyze the data. Participants' preferences were compared between the different symbols by their demography that is, gender, ethnicity, and age group. Comparisons were between the preferred symbol that is, PCS® and ARASAAC. Chi-squared test was used to test association between the preferred symbols and the geographical information of the participants. Data were analyzed using cross tabulation and then derived the means and applied analysis of variance for informed results. A p-value of 0.05 was used to test the level of significance.

3 | RESULTS

Figure 1 displays all participants' preferences ($N = 30$) for the individual pain words. Results indicate that children aged 6.0–9.11 years significantly preferred ARASAAC above PCS® to visually represent pain-related words ($p < 0.001$)—all except for three pain words ("burn", "sad", "sore finger"). The pain word "burn" presented two

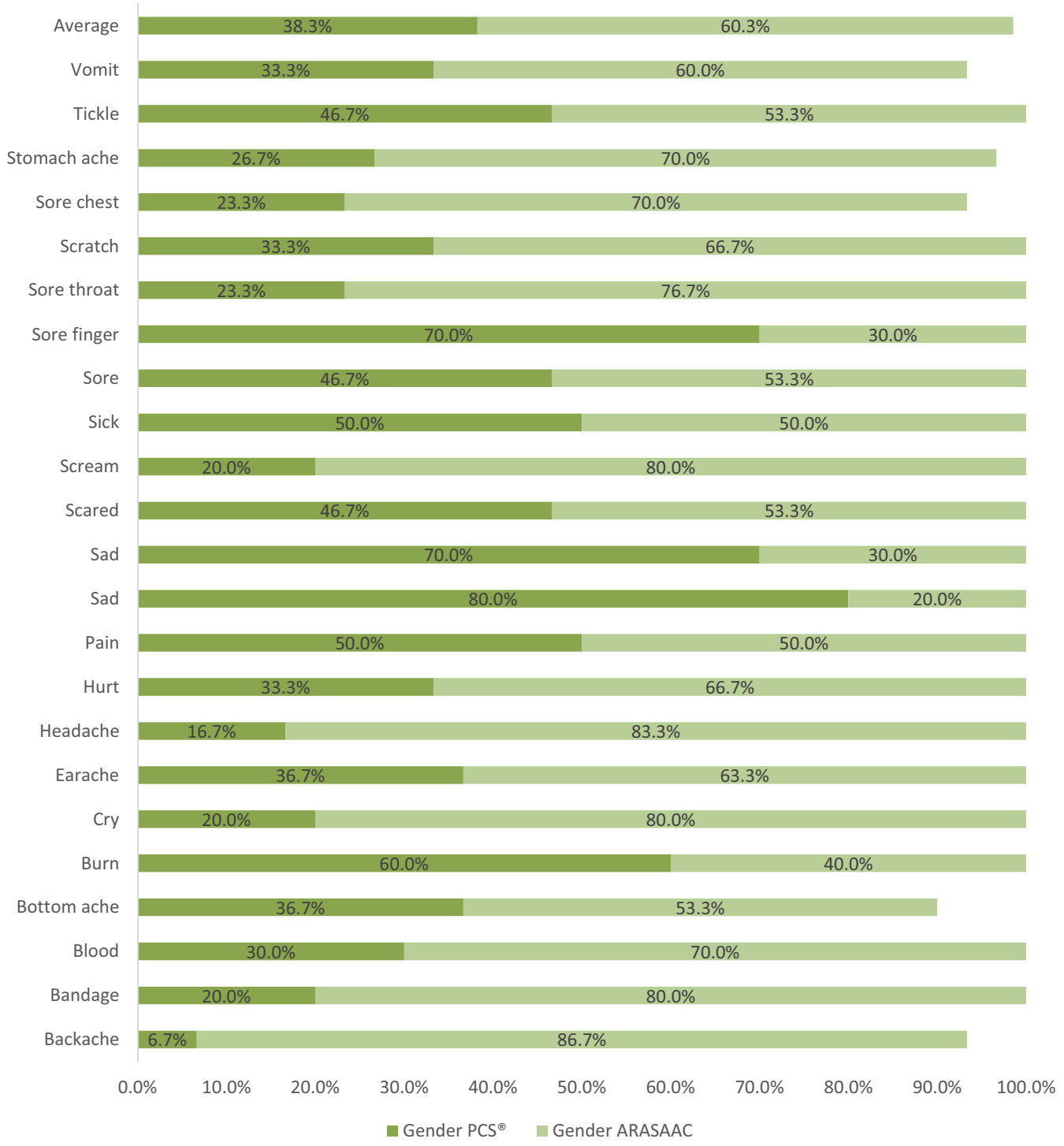

FIGURE 1 Participants' preferences ($N = 30$) for the individual pain words. PCS is a trademark of Tobii Dynavox LLC. All rights reserved. Used with permission.

different contexts—PCS® displayed burning from an open fire, while ARASAAC displayed sunburn. The word "sad" was represented twice in the questionnaire and used as a check for the children's responses. Interesting to note is that in both presentations of the word (with the symbols presented in two different orders), the children preferred the PCS® symbol to visually represent the word with scores of 70%–80%, respectively. The words "pain" and "sick" were equally preferred and participants overwhelmingly favored ARASAAC symbols for pain words "injection" (93%), "backache" (87%), "headache" (83%), bandage (80%), cry (80%), and "scream" (80%).

To gain more insight in terms of the reasons why participants preferred symbols retrieved from ARASAAC over PCS®, preferences for each pain word were examined, comparing PCS® and ARASAAC symbols. According to qualitative responses by the children, three

TABLE 1 Preferences by gender.

Summary				
Groups	**Count**	**Sum**	**Average**	**Variance**
ARASAAC female %	30	8.1	27.1%	0.0076
ARASAAC male	30	10.4	34.6%	0.0116
PCS® female	30	4.2	14.0%	0.0076
PCS® male	30	5.8	19.4%	0.0136

ANOVA						
Source of variation	**SS**	**Df**	**MS**	***F***	***p*-value**	***F* crit**
Between groups	0.724963	3	0.241654	23.94979	**<0.00001**	2.683
Within groups	1.170444	116	0.01009			
Total	1.895407	119				

Note: Bold values denote statistical significance at the $p < 0.05$ level.

TABLE 2 Preferences by age group.

Groups	Count	Sum	Average	Variance
ARASAAC 6.0–7.11 years	30	8.4	28.0%	0.0097
ARASAAC 8.0–9.11 years %	30	9.37	31.2%	0.0150
PCS® 6.0–7.11 years	30	5.43	18.1%	0.0081
PCS® 8.0–9.11 years	30	4.6	15.3%	0.0131

ANOVA						
Source of variation	**SS**	**df**	**MS**	***F***	***p*-value**	***F* crit**
Between groups	0.525519	3	0.175173	15.25614	**<0.00001**	2.6828
Within groups	1.331926	116	0.011482			
Total	1.857444	119				

Note: Bold values denote statistical significance at the $p < 0.05$ level.

main features that they appreciated of the ARASAAC symbols were highlighted, namely the colourfulness of symbols, the iconicity and intelligibility of the symbols ("the symbols look so real"), as well as added features, namely lightning and a medical red or green cross included in the symbols.

Participants preferred the ARASAAC "backache" symbol as it was pink/red with red lightning indicating the aching area and not a side-view of the back as the PCS® version. They also found ARASAAC symbols to be more realistic (intelligible) than PCS® versions and often related to the symbols out of personal experience. For example, one participant mentioned that he preferred an ARASAAC symbol to represent "cry", the reason being that "the boy cries so much that it makes me want to cry".

Participants remarked that they liked the color of the ARASAAC symbols for all except two pain words ("sore finger", "tickle"), whereas color was not included as reasons for their preference in 20 of the PCS® pain words. The only critique provided on the use of color was that the PCS® "sore throat" symbol resembled the color orange and that the PCS® "sick" symbol looked "brown with a little bit of silver" and that it can therefore not be real.

It was noted that the word "vomit" received the most reaction with participants commenting that the ARASAAC symbol for "vomit" is "disgusting" and the vomit is being "splashed on the floor". However, 67% of participants all preferred the symbol that caused such responses and only a small number of participants (33%) preferred the PCS® symbol, where "vomit" was portrayed as happening in a toilet.

For two ("sad", "sore finger") of the three pain words where participants highlighted their preference of the PCS® symbol, they regarded the ARASAAC symbols as "too sore/painful" and observed the PCS® symbols as "less sore/painful" than the ARASAAC symbols. The ARASAAC symbol for "sore finger" shows a needle prick whereas the PCS® symbol displays a throbbing thumb. The ARASAAC symbol for "sad" includes tears in both eyes while the various PCS® options displayed more facial expressions indicating sad. On the contrary, for the pain word, "burn", participants preferred the fire-burning PCS® symbol (compared to the sunburn ARASAAC symbol) and explained that they liked the blood dripping from the hand, the facial expression, and the yellow fire.

3.1 | Possible factors influencing symbol preference

3.1.1 | Gender

It was hypothesized that gender may have an impact on children's preferences of symbols to represent pain words. With regards to participants' preferences by gender, the results indicated that most boys preferred ARASAAC than girls, represented by the average of (34.6% vs. 27.1%) respectively. Majority of the boy participants preferred ARASAAC when the word "back ache" was expressed. However, most girls preferred ARASAAC with words like "sick", "burn", and "sore finger".

Overall, most participants preferred ARASAAC than PCS®, except for "burn", "sad" and "sore finger". Results in Table 1 show that there is a significant difference between participants that preferred ARASAAC compared to those that preferred PCS®. Thus, most boys preferred ARASAAC compared to the girls ($p<0.00001$).

3.2 | Age

It was hypothised that there would be no difference between participants that prefer ARASAAC and PCS® by age group. Table 2 provides a summary of children's preferences by age group.

Results from Table 2 shows that there is a significant difference between participants that preferred ARASAAC and PCS® by age group. Most participants preferred ARASAAC were 8.0–9.11 years compared to similar age group that preferred PCS. ($p<0.0001$).

3.3 | Ethnicity

The hypothesis was that there is no difference between preferences by ethnicity. Results indicated that the majority of participants preferred ARASAAC by ethnicity. Words associated with this preference were "backache"; "bandage", "blood", "cast", "cry", "earache", "hurt", "stomach ache", "scream", "pain", "sore chest", "tickle", "vomit", and "headache" (>50%). Table 3 provides a summary of children's preferences according to ethnicity.

Table 3 shows a significant difference between preferences by ethnicity ($p<0.0001$). Most of the participants identified as colored preferred ARASAAC compared to PCS® preference.

Results further showed a significant difference in color preferences between ethnic groups. Children identified as colored mostly preferred color ARASAAC symbols compared to children identified as Black African ($p<0.0001$). Furthermore, results show that children identified as colored also preferred color PCS® symbols as opposed to Black African children ($p<0.0001$).

4 | DISCUSSION

This study aimed to explore which symbols (PCS® or ARASAAC) children prefer as representing pain-related words. Results showed that children aged 6.0-9.11 years significantly ($p<0.001$) preferred the ARASAAC symbols compared to the PCS® symbols to represent most pain-related words identified by Johnson et al.[16,31] Even though children's understanding and use of pain vocabulary develops with age and experience, it had no significant impact on the participants' preference for symbols to represent pain words in this study.[46,47]

The three key features of the symbols from the ARASAAC symbols which the participants appreciated, included the color scheme; how "real" it looks (relating to iconicity and intelligibility) as well as the added features including lightning and a red medical cross. The reasons for the participants' preferences were provided to gain insight regarding factors which may potentially influence children's selection of symbols. For example, participants preferred the ARASAAC "backache" symbol because pink/red color as well as lightning was included, indicating the aching area and it was not a profile of the back as portrayed in the PCS® version. This finding might be that the added lightning and red color used in the ARASAAC "backache"

TABLE 3 Difference between preferences by ethnicity.

Summary						
Groups	Count	Sum	Average	Variance		
ARASAAC Black African %	30	5.4	18.0%	0.00503		
ARASAAC Colored	30	13.1	43.7%	0.01780		
PCS® Black African	30	4.0	13.3%	0.00536		
PCS® colored	30	5.9	19.8%	0.01992		
ANOVA						
Source of variation	**SS**	**Df**	**MS**	***F***	***p*-value**	***F* crit**
Between groups	1.662028	3	0.554009	46.058371	**<0.0001**	2.682809
Within groups	1.395296	116	0.012028			
Total	3.057324	119				

Note: Bold values denote statistical significance at the $p<0.05$ level.

symbol might have helped to inform the children about the intensity of the pain as it corresponds to elements of reality.[7,48] These findings correlate with a study by Pampoulou and Diamanti[15] where end users—participants (young adults with disabilities)—preferred photos as the people were more realistic and human. In a study by Norré et al.,[23] it was proved that if the added feature of lightning is used continuously to indicate pain, users recognize that lightning does not refer to "electricity", but to "pain". This goes in line with recent research within the AAC field pointing to the importance of use and exposure as central and primary in understanding and learning to use graphic AAC, as well as other AAC forms.[49] Consequently, it was found that stimuli with conceptual familiarity and higher values of image agreement could be named and identified sooner.[28] If the visual field of symbols is more comprehensible, the symbols are more comprehendible.[23] The latter is an important finding confirmed by the current study as clinicians often use a tick or a cross symbol to indicate "yes" or "no", however, it might be that the symbol is not as iconic for children due to the lack of contextuality.[23,28]

The fact that most children preferred the PCS® symbol for "sore finger" (throbbing thumb) above the ARASAAC symbol indicating a needle prick, may also be significant. Research has shown that children often experience needle-related distress due to previous negative experiences during needle-related procedures including immunizations and blood draws.[35,50] This may be a reason for participants' preference for the PCS® symbol for "sore finger" (throbbing thumb).

From infancy and early childhood, children without disabilities learn how pictures relate to real-world references.[51] Children find it easier to recognize symbols with realistic colors as they can use semantic associations and it is the main characteristic which separates an object from its environment.[52] Results from the current study confirmed that both age groups preferred colorful options compared to grayscale versions, correlating with the preferences of young adults with ASD or intellectual disability.[15] In the study by Rossion and Pourtois,[53] it was also found that colored line drawings were selected quicker than black-and-white versions. The reason for this may be that children prefer color symbols rather than black-and-white or grayscale symbols. For example, in this study, the participants commented that they liked the coloring of ARASAAC symbols, which influenced their preferences.

The current study's findings on gender correlate with research indicating that even though boys and girls may have similar experiences of pain, research suggests that pain vocabulary differs depending on gender, which may thus have an impact on their choice of symbols to represent certain words.[54–56] This finding is contradictory to what Haupt and Alant[8] established, namely that Zulu-speaking boys and girls experienced a similar level of iconicity. These authors suggested that a possible explanation for a lack of gender influence was ascribed to equal educational exposure and experience.[8] However, the current study included participants from two cultural backgrounds and one educational context, and the investigation still revealed that gender does have a significant impact on symbol preference.

The results on ethnicity correlate with South African and international studies conducted on different cultural populations, which confirmed variation in symbol choice between typically developing children from different languages and life experiences, with clinical implications for symbol selection in AAC intervention.[8–10,57,58] Despite PCS® allowing ethnical variations unlike symbols from ARASAAC at the time, children still preferred the ARASAAC symbols overall, where coloring emphasizes the place of pain (e.g., red finger) and added features (e.g., red cross).

4.1 | Implications for AAC intervention

The findings of the study could have a direct impact on clinical practice and decision-making in pointing to the differences between individuals and groups. On the other hand—what is well-known and familiar to staff and significant others is used more often—and use and exposure is central for understanding of AAC symbols. A compromise between these two perspectives may be to develop a universal board/application that could be adjusted to individual needs and preferences if needed. Children with temporary communication difficulties' personal preferences should be considered a vital component in AAC assessment and symbol selection. Clinical decision-making requires careful consideration of the needs and preferences of the end-user, respecting their voice throughout the process, as it determines the success of the intervention. Clinicians need to be aware that there are many symbol systems available. Although PCS® are used often in South Africa, this study confirmed that ARASAAC symbol collection may be viable for use in clinical settings as children indicated they prefer it opposed to PCS®. The bonus of the ARASAAC symbols being freely available in a context where access to finances pose a challenge also contribute to the potential use of ARASAAC in developing countries such as South Africa.

In AAC, for children with temporary communication difficulties, tailor-made, individualized communication boards can be made with a variety of symbols from different symbol collections, according to the child's preference and understanding. To enable children to indicate pain intensity and pain location, it is proposed that a faces thermometer scale and body figure be added to the communication board. It should, however, be mentioned that the study by Esplana et al.[59] found that older children (above 10:00 years) regarded a faces thermometer scale easy to understand, while younger children (similar age of the children in the current study) thought it was more difficult—as such, children's perceptions on the use of faces thermometer scale should be further investigated.

4.2 | Critical evaluation and recommendations for future research

Since the study had a small sample, results should be taken with caution, and it should not be assumed that results are applicable to the entire population. The participants were selected from a

closed set, in particular learners of one school, which limits generalisability of results.

Graphical representation of only *pain*-related words was examined, whereas children's preferences may change depending on the fringe vocabulary set presented. Furthermore, PCS® and ARASAAC continue to develop symbols and expand their vocabularies, which may affect children's preferences.

At the time when the symbols were selected for the study (April 2018), only PCS® symbols had ethnic variations available, although it did not increase participants' preference for PCS®. Some of the pain-related words were unavailable in ARASAAC symbols at the time and were removed from the study during data analysis (e.g., "sting", "upset"). New ARASAAC symbols may be available currently as the symbol collections continue to evolve, which might influence children's preferences when the study is replicated. Words such as "cast" might have multiple variations (e.g., "cast leg", "cast arm"), which may also influence children's preferences depending on their lived experiences. For some symbols there were more options from one symbol collection (i.e., PCS® symbols for "hospital", "medicine", "sad" and "scared") which might have influenced the preferences of the participants. For future research, it is thus suggested that a similar study be conducted with a different group of children without disabilities using the latest ARASAAC symbols and PCS® symbols available.

Based on the clinical implications and limitations of the study, it is recommended that further research can be conducted in which more than two collections of symbols are investigated. In addition, the investigation should also focus on other vocabulary required in different settings, for example, home and playground.

A follow-up study can be conducted with a graphic board for children with temporary communication difficulties, displaying the identified preferred ARASAAC symbols, or mixed collections. A similar study could be conducted with a larger sample, including children from various ethnic and age groups.

5 | CONCLUSION

Children may need to make use of symbols or aided AAC when they temporarily cannot rely on natural speech for communication due to medical conditions, intervention or cognitive or communicative difficulties or temporary medical conditions leading to communication difficulties. Choosing the most suitable symbols as preferred by the end-user (in this case, children) is one of the most important steps to ensure effective communication of pain-related experiences as well as overall success of AAC intervention.

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CONFLICT OF INTEREST STATEMENT

The authors report no conflict of interest.

COPYRIGHT CLEARANCE

The authors requested approval from the owners of PCS® for the use of the symbols in this article.

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REFERENCES

1. Costello J, Santiago R, Blackstone SW. Pediatric acute and intensive care in hospitals. In: Blackstone SW, Beukelman DR, Yorkson KM, eds. *Patient Provider Communication: Roles for Speech-Language Pathologists and Other Health Care Professionals*. Plural Publishing; 2015:187-215.
2. Costello J, Patak L, Pritchard J. Communication vulnerable patients in the pediatric ICU: enhancing care through augmentaitve and alternative communication. *J Pediatr Rehabil Med*. 2010;3:289-301.
3. Blackstone SW, Pressman H. Patient communication in health care settings: new opportunities for augmentative and alternative communication, augmentative and alternative communication. *Augment Altern Commun*. 2016;32(1):69-79.
4. Santiago R, Howard M, Dombrowski ND, et al. Preoperative augmentative and alternative communication enhancement in pediatric tracheostomy. *Laryngoscope*. 2020;130(7):1817-1822.
5. Bornman J, Tönsing KM. Augmentative and alternative communication. In: Landsberg E, Kruger D, Swart E, eds. *Addressing Barriers to Learning: A South African Perspective*. 4th ed. Van Schaik; 2019.
6. Pampoulou E, Fuller DR. Introduction of a new AAC symbol classification system: the multidimensional quaternary symbol continuum (MQSC). *J Enabling Technol*. 2021;15:252-267.
7. Pampoulou E, Fuller DR. Exploring AAC graphic symbol choices: a preliminary study. *J Enabling Technol*. 2020;14:171-185.
8. Haupt L, Alant E. The iconicity of picture communication symbols for rural Zulu children. *S Afr J Commun Disord*. 2002;49(1):40-49.
9. Basson M, Alant E. The iconicity and case of learning of picture communication symbols: a study with Afrikaans-speaking children. *S Afr J Commun Disord*. 2005;52(1):4-14.
10. Dada S, Huguet A, Bornman J. The iconicity of picture communication symbols for children with English additional language and mild intellectual disability. *Augment Altern Commun*. 2013;29(4):360-373.
11. Fuller DR, Lloyd LL. Toward a common usage of iconicity terminology. *Augment Altern Commun*. 1991;7(3):215-220.
12. Ogletree BT, McMurry S, Schmidt M, Evans K. The changing world of augmentative and alternative communication (AAC): examining three realities faced by today's AAC provider. *Perspect ASHA Spec Interest Groups*. 2018;3(12):113-122.
13. Schlosser RW, Raghavendra P. Evidence-based practice in augmentative and alternative communication. *Augment Altern Commun*. 2004;20(1):1-21.
14. Tsai M. Adults' preferences between picture communication symbols (PCSs) and gus communication symbols (GCSs) used in AAC. *Res Dev Disabil*. 2013;34(10):3536-3544.

15. Pampoulou E, Diamanti I. Graphic symbol preferences of adults with disabilities in one non-profit foundation in Greece. *J Enabling Technol*. 2020;14:157-169.
16. Johnson E, Bornman J, Tönsing KM. An exploration of pain-related vocabulary: implications for AAC use with children. *Augment Altern Commun*. 2016; 32(4): 249-261.
17. Beukelman DR, Mirenda P, Augmentative and Alternative Communication. *Supporting Children and Adults with Complex Communication Needs*. 4th ed. Paul H. Brookes; 2013.
18. Thunberg G, Johansson M, Wikholm J. Meeting the communicative rights of people with autism—using pictorial supports during assessment, intervention and hospital care. *Autism Spectrum Disorder—Recent Advances*. IntechOpen; 2015:289-309.
19. Nilsson S, Björkman B, Almqvist AL, et al. Children's voices—differentiating a child perspective from a child's perspective. *Dev Neurorehabil*. 2015;18:162-168.
20. United Nations. Convention on the rights of the child. 1989.
21. Nilsson S, Holstensson J, Johansson C, Thunberg G. Children's perceptions of pictures intended to measure anxiety during hospitalization. *J Pediatr Nurs*. 2019;44:63-73.
22. Johnson R. *The Picture Communication Symbols*. Mayor-Johnson LLC; 1981–2011.
23. Norré M, Bouillon P, Gerlach J, Spechbach H. Evaluating the Comprehension of Arasaac and Sclera Pictographs for the BabelDr Patient Response Interface. *Proceedings of the 3rd Swiss Conference on Barrier-Free Communication (BfC 2020)*. ZHAW Zürcher Hochschule für Angewandte Wissenschaften; 2021.
24. Bornman J, Nelson Bryen D, Kershaw P, Ledwaba G. Reducing the risk of being a victim of crime in South Africa: you can tell and be heard! *Augment Altern Commun*. 2011;27(2):117-130.
25. Visser N, Alant E, Harty M. Which graphic symbols do 4-year-old children choose to represent each of the four basic emotions? *Augment Altern Commun*. 2008;24(4):302-312.
26. Naidoo M, Singh S. A dental communication board as an oral care tool for children with autism spectrum disorder. *J Autism Dev Disord*. 2020;50(11):3831-3843.
27. Mizuko M. Transparency and ease of learning of symbols represented by Blissymbols, PCS, and Picsyms. *Augment Altern Commun*. 1987;3(3):129-136.
28. Paolieri D, Marful A. Norms for a pictographic system: the Aragonese Portal of Augmentative/Alternative Communication (ARASAAC) system. *Front Psychol*. 2018;9:2538.
29. Johnson E. Supporting communication vulnerable children to communicate their pain. In: Waisundara WY, Banjari I, Balkić J, eds. *Pain Management: Practices, Novel Therapies and Bioactives*. IntechOpen; 2021:139-158.
30. Herr K, Coyne PJ, McCaffery M, Manworren R, Merkel S. Pain assessment in the patient unable to self-report: position statement with clinical practice recommendations. *Pain Manag Nurs*. 2011;12(4):230-250.
31. Johnson E. *An Exploration of the Common Pain-Related Vocabulary Typically-Developing Children Use: Implications for Children Who Use AAC, in Centre for Augmentative and Alternative Communication*. University of Pretoria; 2015.
32. Santiago R, Costello JM. AAC assessment and intervention in pediatric ICU/acute care: from referral through continuum of care. *Perspect Augment Altern Commun*. 2013;22(2):102-111.
33. Patak L, Wilson-Stronks A, Costello J, et al. Improving patient-provider communication: a call to action. *J Nurs Adm*. 2009;39(9):372-376.
34. Costello J. AAC intervention in the intensive care unit: the children's hospital Boston model. *Augment Altern Commun*. 2000;16(3):137-153.
35. Vantaa Benjaminsson M, Thunberg G, Nilsson S. Using picture and text schedules to inform children: effects on distress and pain during needle-related procedures in nitrous oxide sedation. *Pain Res Treat*. 2015;1-6.
36. Thunberg G, Johnson E, Bornman J, Öhlén J, Nilsson S. Being heard–supporting person-centred communication in paediatric care using augmentative and alternative communication as universal design: a position paper. *Nurs Inq*. 2022;29:e12426.
37. Thunberg G, Törnhage CJ, Nilsson S. Evaluating the impact of AAC interventions in reducing hospitalization related stress: challenges and possibilities. *Augment Altern Commun*. 2016;11(1):143-150.
38. Organization, W.H. *International Classification of Functioning, Disability and Health—Children and Youth Version*. World Health Organization; 2007.
39. McMillan JH, Schumacher S. *Research in Education. Evidence Based Inquiry*. 7th ed. Pearson; 2014.
40. Leedy PD, Ormrod JE, eds. *Practical Research-Planning and Design*. 9th ed. Merrill Prentice Hall; 2010.
41. Etikan I, Musa SA, Alkassim RS. Comparison of convenience sampling and purposive sampling. *Am J Theor Appl Stat*. 2016;5(1):1-4.
42. Carrow-Woolfolk E. *Test for Auditory Comprehension of Language*. DLM Teaching Resources Allen; 1985.
43. Africa SS. In: Statistics D, ed. *General Household Survey 2013*. Statistics South Africa; 2014.
44. Hammond JL, Iwata BA, Rooker GW, Fritz JN, Bloom SE. Effects of fixed versus random condition sequencing during multielement functional analyses. *J Appl Behav Anal*. 2013;46(1):22-30.
45. Heilmann J, Miller JF, Iglesias A, Fabiano-Smith L, Nockerts A, Andriacchi KD. Narrative transcription accuracy and reliability in two languages. *Top Lang Disord*. 2008;28(2):178-188.
46. Franck L, Noble G, Liossi C. From tears to words: the development of language to express pain in young children with everyday minor illnesses and injuries. *Child Care Health Dev*. 2010;36(4):524-533.
47. Versloot J, Veerkamp JSJ, Hoogstraten J. Children's self-reported pain at the dentist. *Pain*. 2008;137(2):389-394.
48. Hartley C, Allen ML. Iconicity influences how effectively minimally verbal children with autism and ability-matched typically developing children use pictures as symbols in a search task. *Autism*. 2015;19(5):570-579.
49. Beukelman D, Light J. *Augmentative & Alternative Communication: Supporting Children and Adults with Complex Communication Needs*. 5th ed. Paul H. Brookes Publishing; 2020.
50. Birnie KA, Noel M, Chambers CT, Uman LS, Parker JA. Psychological interventions for needle-related procedural pain and distress in children and adolescents. *Cochrane Database Syst Rev*. 2018;10:1-165.
51. DeLoache JS, Burns NM. Early understanding of the representational function of pictures. *Cognition*. 1994;52(2):83-110.
52. Johnson CJ, Paivio A, Clark JM. Cognitive components of picture naming. *Psychol Bull*. 1996;120(1):113-139.
53. Rossion B, Pourtois G. Revisiting Snodgrass and Vanderwart's object pictorial set: the role of surface detail in basic-level object recognition. *Perception*. 2004;33(2):217-236.
54. Briggs E. Assessment and expression of pain. *Nurs Stand*. 2010;25(2):35-38.
55. Fearon I, McGrath PJ, Achat H. 'Booboos': the study of everyday pain among young children. *Pain*. 1996;68(1):55-62.
56. Huguet A, Miró J, Nieto R. The inventory of parent/caregiver responses to the children's pain experience (IRPEDNA): development and preliminary validation. *Pain*. 2008;134(1):128-139.
57. Nakamura K, Newell A, Alm N, Waller A. How do members of different language communities compose sentences with a picture-based communication system?—a cross–cultural study of picture–based sentences constructed by English and Japanese speakers. *Augment Altern Commun*. 1998;14(2):71-80.
58. Quist RW. Lloyd LL, van Balkom H, Welle-Donker GM & Vander BK. Translucency values of Blissymbols across cultures. Poster presentation at the 8th Biennial Conference of the International Society

for Augmentative and Alternative Communication, 1998;Dublin, Ireland.
59. Esplana L, Olsson M, Nilsson S. 'Do you feel well or unwell?'A study on children's experience of estimating their nausea using the digital tool PicPecc. *J Child Health Care*. 2022;27:654.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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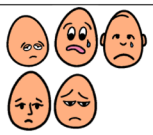
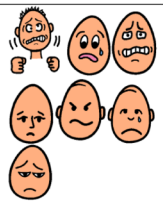
APPENDIX A

SYMBOL SOURCES OF SYMBOLS USED IN THE QUESTIONNAIRE

"backache"; "bandage"; "blood"; "bottom ache"; "burn"; "cast"; "cry"; "earache"; "headache"; "hospital"; "hurt"; "injection"; "ointment"; "pain"; "plaster"; "sad"; "sad"; "scared"; "scratch"; "scream"; "sick"; "sore"; "sore chest"; "sore finger"; "sore throat"; "stomach ache"; "swollen"; "tickle"; "tooth ache", and "vomit".

Word	PCS®	ARASAAC	OTHER SYMBOLS included in original questionnaire*
Backache			
Bandage			
Blood			
Bottom ache			
Burning			
Cast			
Cry			
Earache			
Headache			
Hospital			

			
Hurt			
Injection			
Medicine			
Ointment			
Pain			
Plaster			
Sad			
Scared			
Scratch			
Scream			
Sick			
Sore			

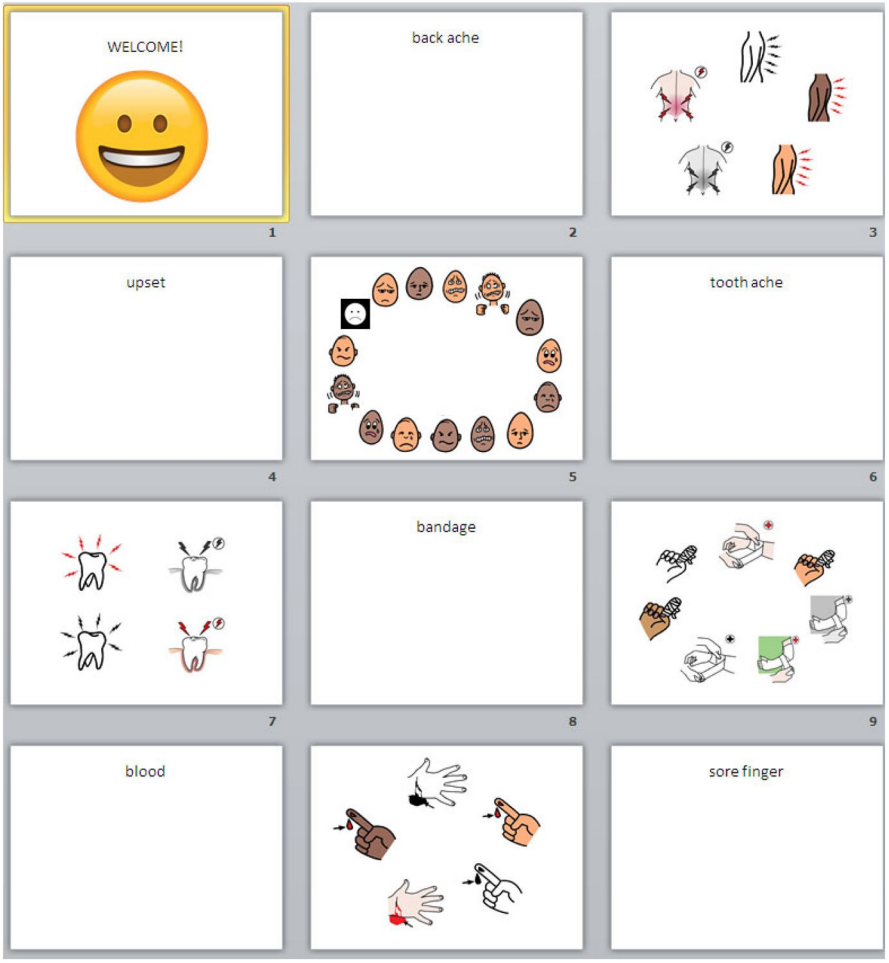
Sore chest			
Sore finger			
Sore throat			
Sting			
Stomach ache			
Swollen			
Tickle			
Tooth ache			
Upset			
Vomit			

*Note: Questions which included no ARASAAC symbols (i.e., “sting” and “upset”) were excluded during data analysis. In cases where there was an ARASAAC symbol and another symbol (i.e., “vomit”), the other symbol was removed during data analysis.

APPENDIX B

ELECTRONIC QUESTIONNAIRE

(Note: for data analysis only PCS® and ARASAAC symbols were analyzed)

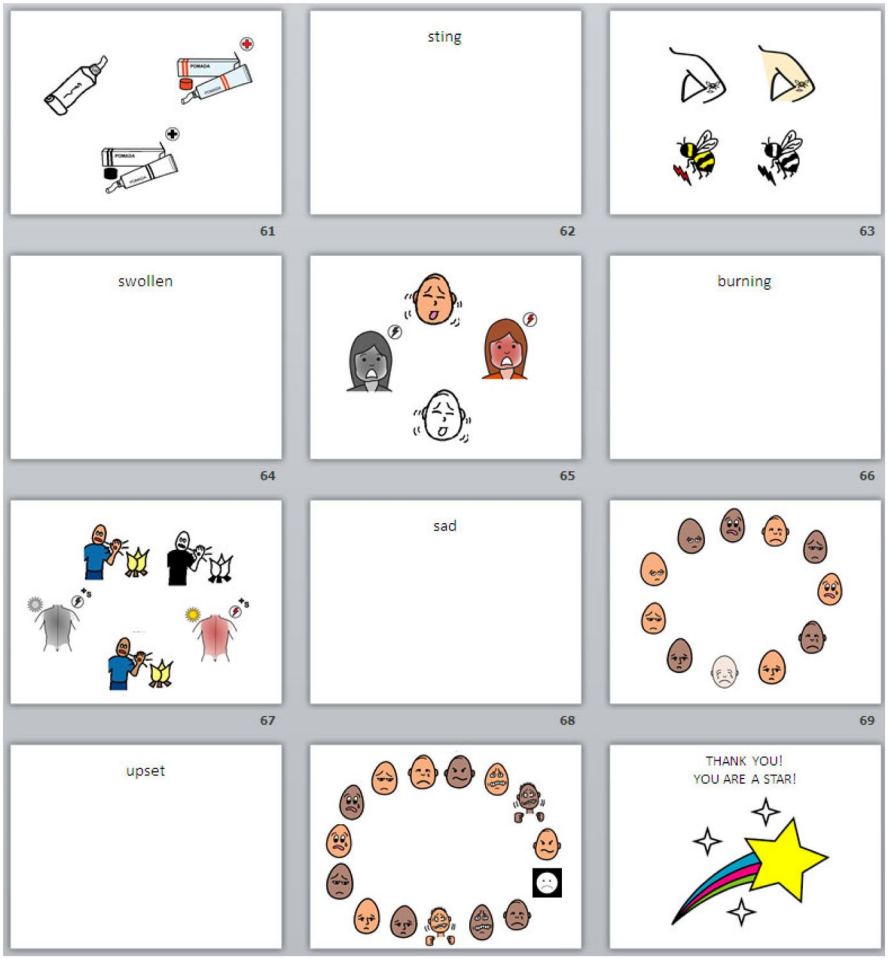



13
cast
14
15
cry
16
17
ear ache
18
19
hospital
20
21
hurt
stomach ache


25
injection
26
27
sore throat
28
29
bottom ache
30
31
medicine
32
33
pain
plaster


scratch
scream
sick
sore
sore chest
sad
37
38
39
40
41
42
43
44
45


49
scared
50
51
head ache
52
53
tickle
54
55
upset
56
57
vomit
ointment


61
sting
62
63
swollen
64
65
burning
66
67
sad
68
69
upset
THANK YOU!
YOU ARE A STAR!