



Scoping Review of Children's Pain Vocabulary: Implications for Augmentative and Alternative Communication



Revue exploratoire sur le vocabulaire utilisé par les enfants pour exprimer la douleur : implications pour les systèmes de communication augmentée et alternative

KEYWORDS

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SELF-REPORT

Ensa Johnson
Kobie Boshoff
Juan Bornman

Ensa Johnson
University of Pretoria,
Pretoria, SOUTH AFRICA

Kobie Boshoff
University of South Australia,
Adelaide, AUSTRALIA

Juan Bornman
University of Pretoria,
Pretoria, SOUTH AFRICA

Abstract

The goal of this study was to conduct a scoping review to determine the words that children use to express pain. In the past, children's verbal expression of pain was overlooked during pain assessment. A scoping review was conducted of research publications by means of keyword searches in six individual journal databases (CINAHL, Medline ProQuest, PsycINFO, PubMed, Scopus, and Web of Science). A general browser was also used to ensure that all available literature was consulted. Seventeen articles met the selection criteria, and from this literature, two core themes were identified regarding the use of children's pain vocabulary: description of pain and coping with pain. Original words and phrases from the literature were divided into single words using the ATLAS.ti Word Cruncher. This resulted in a list of 60 pain-related words. These words may assist healthcare staff (e.g., speech-language pathologists), parents, and researchers to select pain-related vocabulary to incorporate into augmentative and alternative communication systems to allow children with severe communication difficulties to express painful experiences.

Abrégé

L'objectif de la présente étude était d'effectuer une revue exploratoire de la littérature pour déterminer les mots que les enfants utilisent pour exprimer la douleur. Dans le passé, les expressions verbales utilisées par les enfants pour exprimer la douleur étaient souvent négligées lors des évaluations de la douleur. Une revue exploratoire d'articles scientifiques a donc été effectuée au moyen d'une recherche par mots-clés dans six bases de données (CINAHL, Medline ProQuest, PsycINFO, PubMed, Scopus et Web of Science). Un moteur de recherche général a également été utilisé afin de s'assurer que toute la littérature disponible avait été consultée. Dix-sept articles respectant les critères de sélection ont été identifiés et ceux-ci ont permis l'identification de deux thèmes principaux pour décrire le vocabulaire utilisé par les enfants pour exprimer la douleur : description de la douleur et gestion de la douleur. Les mots formant les expressions et les syntagmes provenant des articles scientifiques ont été divisés et isolés à l'aide du logiciel ATLAS.ti Word Cruncher. Au total, soixante mots associés à la douleur ont été identifiés. Ces mots ont le potentiel d'assister le personnel de soins de santé (tel que les orthophonistes), les parents et les chercheurs dans la sélection du vocabulaire associé à la douleur pour que celui-ci soit incorporé dans les systèmes de communication augmentée et alternative d'enfants présentant des difficultés de communication sévères, et ainsi, leur permettre d'exprimer des expériences douloureuses.

Using words to describe pain is a significant developmental milestone for children, as it enables them to communicate their painful experiences in such a way that healthcare practitioners and parents can better understand their discomfort and react accordingly (Craig, Stanford, Fairbairn, & Chambers, 2006). Language and cognitive development influence this skill (Hay, Oates, Giannini, Berkowitz, & Rotenberg, 2009). Young children have not yet mastered the language and cognitive skills to explain the bodily sensations that they experience during pain (Dubois, Bringuier, Capdevila, & Pry, 2008). As cognition develops, children's concept of pain becomes increasingly abstract and also incorporates psychological aspects (Hay et al., 2009).

Children with disabilities often experience more acute pain episodes than their typically developing peers. This is due to the fact that they have to undergo numerous medical procedures such as needle injections and blood-drawing procedures or surgery in order to maintain their health (Davies, 2010; Dubois, Capdevila, Bringuier, & Pry, 2010; Ramstad, Jahnsen, Skjeldal, & Diseth, 2011). Sadly, many children with disabilities experience co-morbid communication and language difficulties that make it difficult for them to express their pain verbally (Barney, Feyma, Beisang, & Symons, 2015).

Self-report is regarded as the gold standard for assessing pain in patients (Hay et al., 2009). However, self-report by children with disability—in particular those who have severe communication challenges, such as little or no functional speech (LNFS)—is a challenge. It might be difficult to determine if these children, who cannot rely on oral communication to make their needs known, are in pain and, if so, the location, type, and intensity of the pain. As a result, healthcare practitioners, such as doctors and nurses, typically rely on proxy reports (e.g., asking parents or caregivers who know the child well), observational tools (e.g., temperature or heart rate measurements), or physical examinations when assessing these children's pain (Barney et al., 2015; Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). Discrepancies between proxy reports and children's self-report are widely documented. Furthermore, with the implementation of all these proxy methods, healthcare practitioners often tend to overlook non-verbal communication attempts by children with LNFS, such as a change in behaviour to indicate pain (Bottos & Chambers, 2006; Gilbert-MacLeod, Craig, Rocha, & Mathias, 2000; Zhou, Roberts, & Horgan, 2008). Failure to notice the child's attempts at communicating pain might result in non-treatment.

One way of assisting children with LNFS to communicate

their pain is by means of an augmentative and alternative communication (AAC) system that includes a vocabulary set for expressing pain. This paper therefore aims to identify a vocabulary set for children to express pain from children's own accounts available in literature.

A deeper understanding of children's use of language to express the subjective experience of pain could assist healthcare practitioners to understand children's pain and intervene when necessary (Craig et al., 2006). It is the responsibility of healthcare practitioners to ensure that they recognize and accommodate the needs of all children including those with LNFS, and that they assist these children to communicate, for example, through the use of AAC systems (American Speech-Language-Hearing Association, 2005). Speech-language pathologists (S-LPs) typically focus on building both receptive and expressive language skills of children with LNFS to enable them to communicate about age-appropriate topics. This implies that S-LPs should consider introducing a range of vocabulary to ensure that all children, irrespective of age or developmental level, have the ability to communicate painful experiences effectively. This could be done through the use of unaided AAC strategies (e.g., manual signs) or aided AAC strategies (e.g., pictures, graphic symbols, or spelling systems that can be displayed on low technology communication boards or books or on high technology devices such as speech generating devices).

All S-LPs who provide services to communication vulnerable children should be made aware of the importance of exposing these children to vocabulary that can be used to communicate pain. S-LPs who work in pediatric hospital settings may work in intensive care, acute care, or rehabilitation settings, but regardless of the specific setting, they are extremely likely to see children with communication needs who would need to communicate about painful experiences (Costello, 2000). If communication support for children is to be successful, it should be integrated into the overall care plan in medical settings and be simple to use, and should also require minimal training and learning (Costello, 2000; Costello, Patak, & Pritchard, 2010).

Identifying and Selecting Pain Vocabulary

Within the AAC literature there has been considerable interest in vocabulary selection for children (Banajee, Dicarolo, & Buras Stricklin, 2003; Carlson, 1981; Fallon, Light, & Page, 2001; Fried-Oken & More, 1992; Marvin, Beukelman, & Bilyeu, 1994; Trembath, Balandin, & Togher, 2007). For example, researchers have identified words most commonly used by preschoolers in an effort to inform the selection of vocabulary for similarly aged children who required AAC (Fried-Oken & More, 1992; Marvin

et al., 1994; Trembath et al., 2007). Studies of this type have generally involved observing and recording the vocabulary used in different contexts (e.g., home or school) and with different samples (e.g., toddlers or preschoolers) to identify the most frequently used words. The rationale is that AAC systems might be more functional for the child if they contain vocabulary that is frequently used. However, pain words occur infrequently in children's general vocabulary lists (Banajee et al., 2003; Fried-Oken & More, 1992; Marvin et al., 1994; Trembath et al., 2007). The usual methods for identifying vocabulary for AAC systems for children that focus on frequency or commonality are not appropriate for the identification of pain vocabulary words, which tend to be produced infrequently. Therefore, the existing lists from prior studies were not informative in this respect, and another approach was necessary.

Aim of the Study

The aim of this scoping review was to scope the pain-related vocabulary used by children themselves in published literature. This was done to compile a list of pain-related vocabulary that could be used by S-LPs and parents to identify words suitable for the individual needs of their children with communication challenges. Scoping reviews are regarded as a practical and popular alternative approach for reviewing, synthesizing, or mapping evidence on a specific topic (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010; McKinstry, Brown, & Gustafsson, 2014; Pham et al., 2014). Scoping reviews are further described by Grant and Booth (2009, p. 95) as a "preliminary assessment of potential size and scope of available research literature." Although scoping reviews do not analyze the quality of the research evidence, they can provide an overview of existing knowledge and information gaps for further research (McKinstry et al., 2014). Identifying and listing the pain-related vocabulary used by children themselves through this scoping review might be a helpful vocabulary selection strategy for children with temporary or permanent communication challenges. Exposing these children to the vocabulary on this list might enable them to express their pain in an effective and less frustrating way, thus providing more information to healthcare providers, which could lead to better treatment (Costello, 2000; Costello et al., 2010). The following review question guided the literature search: "What is the vocabulary that children themselves use to express pain?"

Method

Design and Steps in Review Process

Based on the framework proposed by Arksey and O'Malley (2005), an interpretive scoping literature review methodology was followed. The five steps were to (a) identify the initial research question (to facilitate the

most appropriate search), (b) identify the relevant studies to answer the central research question, (c) select studies, (d) use a narrative descriptive analytical framework, and (e) collate and summarize the data using a framework approach.

A scoping review is broad in nature, as its focus is on summarizing breadth of evidence (Levac et al., 2010). Therefore, it is important to combine a broad research question with a clearly articulated scope of inquiry. The scope includes, for example, defining the concept (pain vocabulary), the target population (children), and the outcomes of interest to clarify the focus of the scoping study (self-reported pain-related words) and establishing an effective search strategy (Levac et al., 2010). Thus, clear inclusion and exclusion criteria were set and agreed on by all reviewers prior to the review, and are shown in Table 1 with a theoretical justification for their use. This prevented selection bias when articles were found and ensured that only relevant studies were identified and included in the review (Gough, Oliver, & Thomas, 2012). Due to time and resource constraints, accurate translation of what the children themselves said (i.e., the children's own words) was not possible, and hence only studies published in English were included. A typical procedure followed during the development of vocabulary lists for specific individuals with communication disorders is to first examine the vocabulary use of peers with typical development (Beukelman & Mirenda, 2013). Therefore, studies on typical development were included. However, studies in which children with disabilities reported pain words themselves (e.g., Craig et al., 2006) were also included. Due to the communication difficulties often experienced in this population, it should be noted that the number of studies including children with disabilities themselves reporting on pain vocabulary was low.

Once all of the articles had been retrieved, the inclusion and exclusion criteria were applied to ensure that articles were relevant to the study. Although unpublished master's and doctoral theses were considered, only two theses that met the criteria for this review were available online (i.e., Azize, 2012; Johnson, 2015). In both cases, published research articles resulted from the specific studies (i.e., Azize, Endacott, Cattani, & Humphreys, 2013; Johnson, Bornman, & Tönsing, 2016). The reviewers therefore focused on the published articles of said studies, as they provided sufficient information on the specific data required for this review.

Table 1. Selection Criteria of the Review with Corresponding Justification

Criteria	Inclusion	Exclusion	Justification
Defining the concept: Pain vocabulary	Include full-text publications on children's pain vocabulary including pain-related words and/or phrases.	Exclude if only the abstracts of publications were available or duplications (e.g., theses and publications of the theses) were identified.	The aim of this review is to determine pain vocabulary children use to express pain.
Target population: Children	Include children 1;0 to 17;11 years.	Exclude children < 1;0 year and > 18;0 years.	Typically, children begin to speak at around the age of 1;0 to 1;6. The skill to use spoken words to describe pain is a significant developmental milestone for children (Craig, Stanford, Fairbairn, & Chambers, 2006).
Outcomes: Children's self-reported pain words	Include articles that portray examples of children's own voices of pain-related vocabulary and answer the review question: "What is the vocabulary that children use to express pain as reported by themselves?"	Exclude articles on children's pain vocabulary, as suggested by proxies, such as adults (parents, caregivers, or healthcare practitioners). Exclude articles describing other issues around children's pain (i.e., pain management).	Children provided different words than adults suggesting words that children may use (Fried-Oken & More, 1992; Johnson, Bornman, & Tönsing, 2016). It may therefore be best for children to voice their own experiences of pain (Nilsson et al., 2015).
Types of articles	Include qualitative, quantitative, or mixed study designs.	No specific research design was excluded.	Due to the descriptive nature of the research question, different study designs were included.
Other	Include articles published in or after 1980.	Exclude articles published before 1980.	More literature was prevalent since the 1980s, when healthcare practitioners started acknowledging that children with communication difficulties do experience pain and are in need of appropriate pain-relieving treatment (Bottos & Chambers, 2006)
Other	Only articles published in English were included.	Exclude articles written in foreign languages not available in English.	Time and resource constraints rendered translation problematic (Gough, Oliver, & Thomas, 2012)

Searches Undertaken

An inclusive, systematic search was performed in January 2017. To ensure that all possible available literature was accessed, the following three strategies were adopted (Davis, Drey, & Gould, 2009): (a) online database searches (b)

hand searches, and (c) a general Internet browser (Google Scholar). In Figure 1, an adapted PRISMA flow diagram is displayed (Moher, Liberati, Tetzlaff, Altman, & PRISMA-P Group, 2010) that illustrates the search and article selection process.

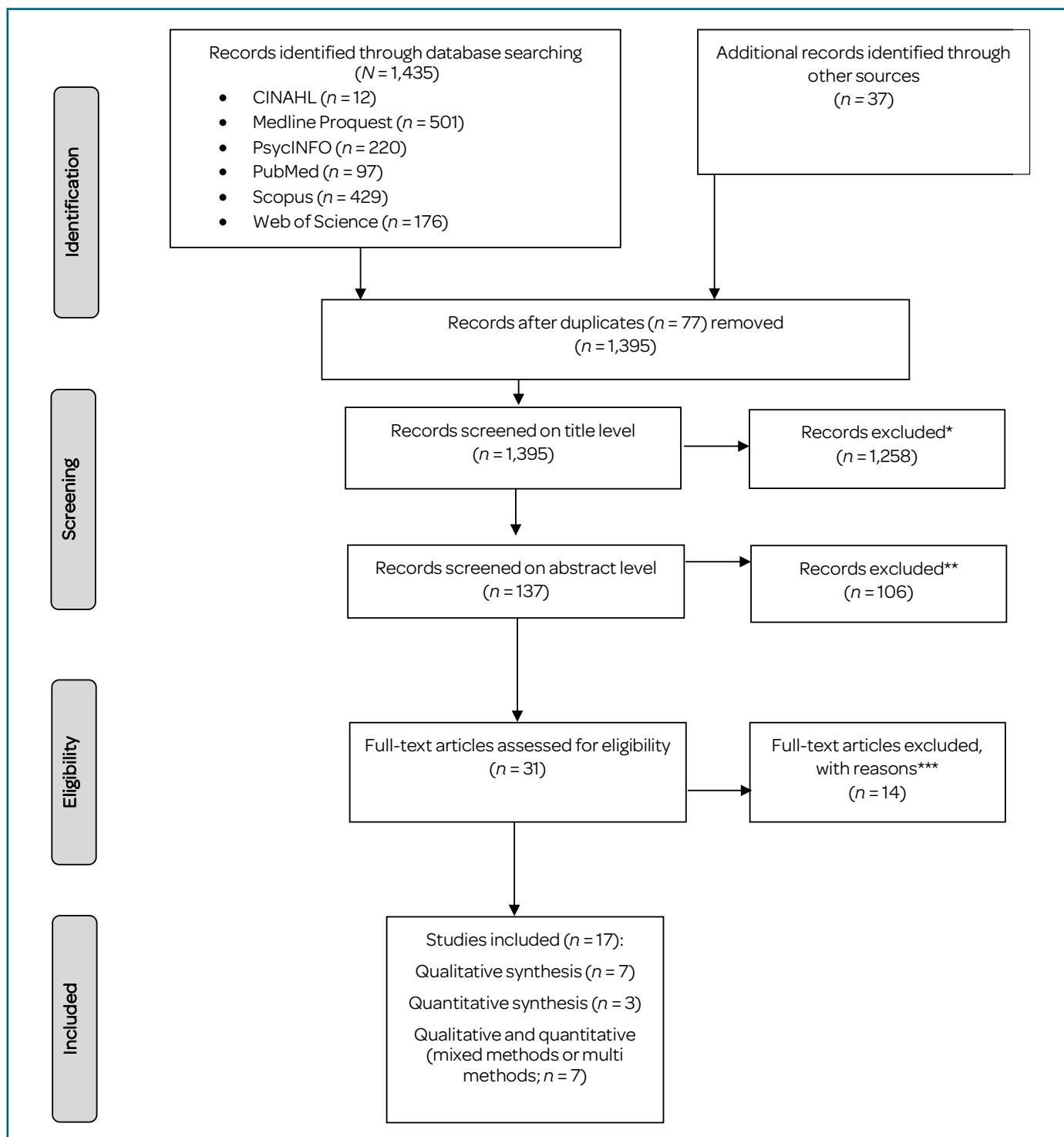


Figure 1. Adapted PRISMA flow diagram of literature selection process (Moher et al., 2010). Reasons for exclusion: * = did not deal with children’s pain vocabulary [1,251], not written in English [7], ** = did not meet criteria for this review [104], excluded as full text of conference presentation was not available [2], *** = did not contain children’s own voices about pain.

First, searches were done using electronic databases with keywords that addressed the review topic and question. A Boolean search using the keywords "pain" AND "child*" OR "young child*" AND "vocabulary" OR "words" OR "express*" was performed in six individual journal databases (CINAHL, Medline ProQuest, PsycINFO, PubMed, Scopus, and Web of Science). From the six databases, a total of 1,435 possible articles were identified.

Second, a hand search was undertaken in *Pain*, the peer-reviewed official journal of the International Association for the Study of Pain to ensure that current relevant articles were not missed. This journal, which is published in 12 issues per year, contains original research on the nature, mechanisms, and treatment of pain. The literature search was further supplemented by a hand search in which the reviewers screened through the reference lists of identified studies and used Google Scholar to ensure that all possible studies on the topic had been identified (Levac et al., 2010). Another 37 possible articles were identified through the additional searches. From the total of 1,472, there were 77 identified as duplicates that were therefore removed.

The three authors—who acted as the reviewers—each have different professional backgrounds, namely teaching, occupational therapy, and speech-language therapy. They have all worked with children with disability for at least 25 years, and have experience in conducting research with this population.

When author 1 screened the 1,395 articles on title level, 1,258 were excluded, as it was clear that these articles did not fit the inclusion criteria of children's self-reported pain vocabulary. Furthermore, seven of these articles were published in other languages: four in French, and one each in Polish, Spanish, and German. Thus, a total of 137 records were identified to match the inclusion criteria as set out in Table 1.

Next, authors 1 and 3 screened abstracts of the identified 137 records to confirm their potential suitability in answering the review question. Altogether, 106 were excluded after a closer examination of the abstract, as 104 of them did not meet the inclusion criteria as stipulated in Table 1 and the full texts of the two other records (conference presentations) were not available. The three reviewers subsequently performed an independent screening of the remaining 31 full-text articles and agreed on 90% (28) of the articles. After discussion between the reviewers, 100% agreement was reached resulting in the inclusion of 17 articles that all contained specific pain words as reported by the children themselves. As per scoping review methodology, no critical appraisal of the articles was done as it would not serve the purpose of this review, which

was to scope the children's own words to express pain.

Data Extraction and Analysis

The review question—"What is the vocabulary that children themselves use to express pain?"—also guided the reviewers in the extraction of data from the articles. Data that were not applicable to the review question were excluded. For example, in one article, the results of older participants (aged 18;0 to 23;11) were excluded (i.e., Harbeck & Peterson, 1992).

The children's direct quotes of their pain vocabulary in the selected 17 articles were uploaded into ATLAS.ti for an inductive qualitative analysis. Based on the work by Thomas and Harden (2008), the inductive qualitative thematic synthesis was done in two stages: (a) the line-by-line coding of the direct quotations and (b) the organization of these codes and categories into related areas to construct themes.

For the first stage, two reviewers (authors 1 and 3) familiarized themselves with the data from the 17 articles and independently identified each line in the text of each article that reflected direct quotations of children's pain vocabulary. They then individually coded the words inductively according to their content and meaning. In this process, categories were generated (e.g., "interjections," "to indicate location of pain," or "distractions"). At least one category was applied to each quotation, although some quotations were categorized using more than one category (e.g., "rest; sleep; relaxation" were coded as "distractions" or "secondary gain," depending on the context). After independent coding of the data, the two reviewers met and discussed any discrepancies regarding categories until 100% agreement was reached.

In stage two, all of the reviewers worked together to mutually agree and identify similarities and differences among the categories in order to group them into two descriptive themes, namely codes that refer to description of pain (theme 1) and coping with pain (theme 2; see Figure 2). Throughout the process, no themes changed, but categories were reviewed and refined, which resulted in more subtle nuances compared to the initial ones. Figure 2 portrays the two identified themes, as well as the different categories (4 and 6, respectively) associated with them.

The pain words or phrases were then divided into single words using the ATLAS.ti Word Cruncher. In total, 403 individual words were calculated. Various forms of a given word (e.g., single or plural nouns or various forms of a given verb) were regarded as a single entry from a vocabulary standpoint, resulting in a total of 360 single

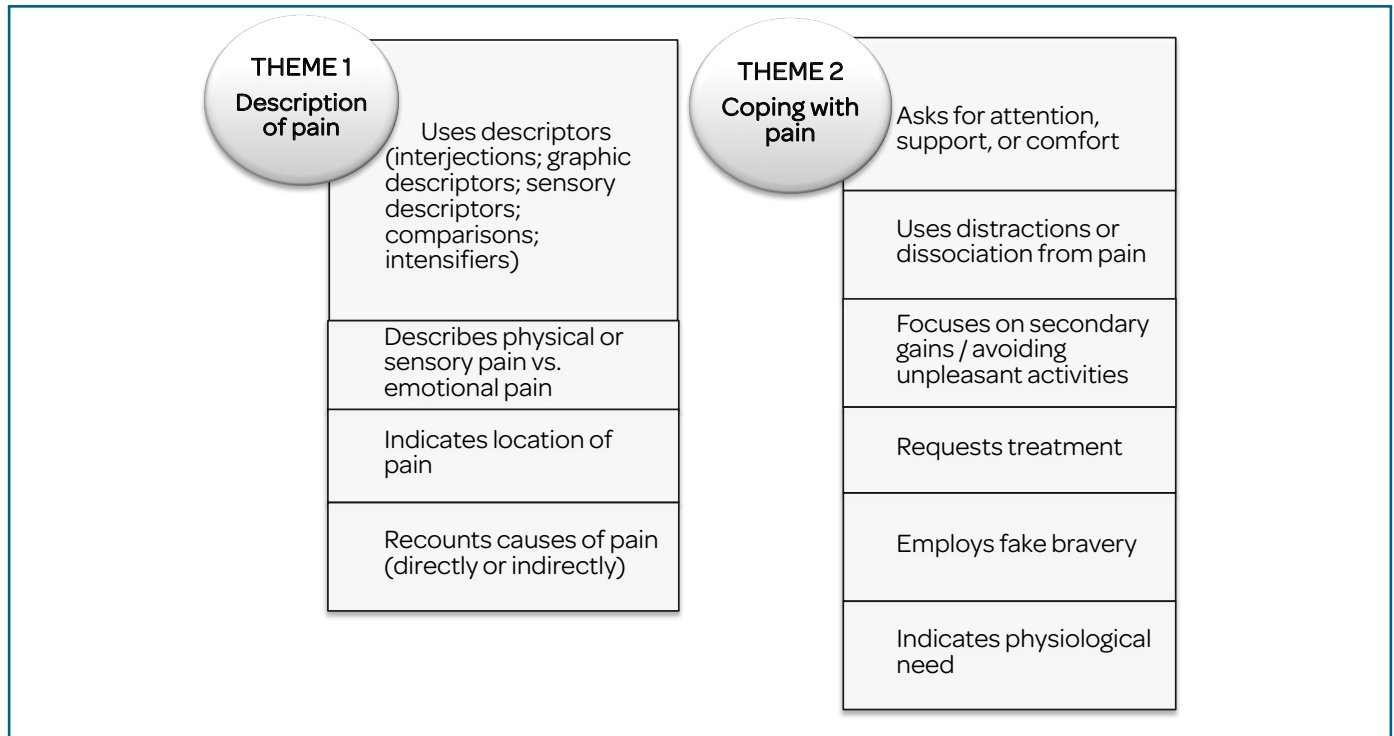


Figure 2. Themes identified within the pain vocabulary

words. Next, the first author and a second coder mutually separated the single words into core and fringe vocabulary. In the AAC literature, core vocabulary refers to frequently used words that can be used across environments and activities (e.g., “a,” “get,” and “want”) to communicate a range of communicative functions (Beukelman & Mirenda, 2013). Prominent researchers in the field, namely Banajee et al. (2003), Fried-Oken and More (1992), Marvin et al. (1994), and Trembath et al. (2007), have published lists of children’s core vocabulary. All of the words published in these lists were combined to form a comprehensive core vocabulary list. These published core vocabulary lists varied with regards to the number of words. For example, Banajee’s list contained 23 words, as it was focused on toddlers aged 24 to 36 months, while Trembath’s list contained 263 words and focused on preschoolers aged 3 to 5 years. To be representative of children’s core vocabulary across all age ranges, all core word lists were included, irrespective of how many times a specific word appeared on the lists. Some core words (e.g., “I,” “some,” “you”) appeared on all four published vocabulary lists, while other core words (e.g., “okay,” “sad,” “take”) were not represented in all four of these lists. The words from the current study were compared to the combined list of core vocabulary to determine if they were core or fringe. The purpose of identifying core vocabulary was to determine which single vocabulary items could be incorporated in a

pain-related AAC communication board that could also be used to communicate other messages apart from pain.

Fringe vocabulary, on the other hand, refers to context-specific words (e.g., “injection,” “medicine,” “hurt”) that are unique to the individuals’ specific interests, and that are influenced directly by their immediate environment and specific activities in which they are engaged, for example expressing pain (Beukelman & Mirenda, 2013). In the current study, the first author identified all of the fringe vocabulary related to the theme of expressing pain. She then presented the list of words to an independent reviewer (a journalist) who was blind to the purpose of the study, to verify the suggested categories (pain-related vs. other words). Initial agreement was 97% as the independent reviewer identified 10 out of the 360 words (3%) originally categorized as pain-related, but that should actually be considered other fringe words not related to pain. All differences were discussed until 100% agreement was reached. The Appendix includes core, pain-related, and “other” words, although the rest of the discussion will only focus on the pain-related words, as the “core” and “other” categories are beyond the scope of this paper.

Results

Characteristics of the Included Studies

An overview of the characteristics of the 17 articles that

met the inclusion criteria as stipulated in Table 1 is provided in Table 2. Table 2 shows that the ages of the children in the 17 studies range from one year (12 months) to 17;11. A total of 2,683 children participated in the 17 studies.

Seven of the 17 selected studies portrayed in Table 2 were qualitative, five studies were classified by the reviewers as multi-method (since they included both quantitative and qualitative components), two were mixed-method studies, two were questionnaire/word list development studies, and one was a quantitative study.

From these 17 studies, seven originated from the United States of America, three from Canada, two from Finland, and one each from Kuwait, South Africa, Spain, Sweden, and the United Kingdom (UK), which speaks to the diversity of the cultures presented. Five studies were published between 1981 and 1990, three between 1991 and 2000, five between 2001 and 2010, and four between 2011 and 2017, showing that the number of studies is quite consistent for each decade.

Themes and Vocabulary List

Two main themes of children's use of pain vocabulary were identified, namely description of pain and coping with pain (Figure 2). Within the theme description of pain, four categories were identified: (a) Uses descriptors (subdivided in interjections, graphic word descriptors, sensory descriptors, comparisons, intensifiers); (b) Describes physical or sensory pain rather than emotional pain; (c) Indicates location of pain; and (d) Recounts causes of pain (directly or indirectly). For theme 2, coping with pain, six categories were identified: (a) Asks for attention, support, or comfort; (b) Uses distractions or dissociation from pain; (c) Focuses on secondary gains or avoiding unpleasant activities; (d) Requests treatment; (e) Employs fake bravery; and (f) Indicates physiological need.

By classifying the 360 words into core and fringe (pain-related and other) words as described earlier, 147 (40%) were determined to be core words, 60 (17%) pain-related fringe words, and 153 (43%) other fringe words for this pain vocabulary list. The complete list is provided in the Appendix with the list of 60 pain-related words shaded in grey.

Discussion

This scoping review provided a list of 60 pain-related words that children with typical development, aged 1;0 to 17;11, use to express and talk about their pain. This list could be used by S-LPs and parents to select relevant vocabulary to be used in an AAC pain-related communication system for children who may not be able to communicate their pain experiences verbally.

A positive outcome of this review is that the identified list of pain-related vocabulary was obtained from children from various cultures on four different continents. By gathering vocabulary from children from different continents and cultures, this study indicates the specific pain-related words children may use globally (despite their language or culture). In some cultures (e.g., the Mi'kmaq in Canada or various African cultures in South Africa), children—especially boys—are expected not to express their pain so as not to be regarded as cowardly (Latimer et al., 2014; Nortjé & Albertyn, 2015). In other cultures, it is, for example, considered disgraceful to ask for pain relief, and some people believe that a godly intervention will relieve pain when it is appropriate (Briggs, 2010; Nortjé & Albertyn, 2015). The result is that children from these cultures cannot express their pain or ask for pain relief medication. Nevertheless, despite the impact that culture could have on children's expression of pain, this review identified a list of at least 60 pain-related words from which words could be selected to be used on AAC pain-related communication boards for children to express and talk about their pain experiences.

An interesting aspect regarding the similar usage of children's pain words further means that, although the children in the different studies spoke different languages (e.g., Arabic, Finnish, Mi'kmaq, Spanish, and Swedish), the meaning of the words in the native language generally translated to the same words or word meanings in English (Alwugyan, Alroumi, & Zureiqi, 2007; Latimer et al., 2014). However, some translation challenges were noted by the original authors. For example, Alwugyan and colleagues (2007, p. 5) stated: "There was a problem in grouping Arabic words according to their corresponding English meanings. A wide variety of Arabic words is available for describing different aspects of pain." In the Canadian study by Latimer and colleagues (2014, p. E135), it was also indicated that "many derivatives of the Mi'kmaq word *kesa'si* (meaning "I'm hurting") were noted in the transcripts." This could mean that "I'm hurting" in English could have had various words in the original language (Mi'kmaq). Nevertheless, it seems as if the findings from the current review could be used by clinicians from various countries where languages other than English are spoken as a starting point to determine vocabulary for the children of that specific country or context. Children from different countries could thus benefit from this word list should it be translated into their native language.

Development of Pain-Related Language

Although the authors acknowledge that the age groups of children included in this review cover quite a large range (from 1;0 to 17;11), it is important to allude to

Table 2. Summary of Articles

Author(s) (Year); Country	Research aim	Age of children (N = 2,683)	Design and methodology
1) Abu-Saad (1984a); USA	To determine children's self-assessment of their pain experience	9;0 – 15;11-year-olds admitted to hospital for surgical procedures (n = 10) 9;0 – 12;0-year-olds (n = 24)	Multi-method*
2) Abu-Saad (1984b); USA	To explore how school-aged children from an Asian-American cultural background perceive, describe, and respond to painful experiences	9;0 – 12;0-year-olds (n = 24)	Qualitative
3) Alwugyan, Alroumi, and Zureiqi (2007); Kuwait	To study the ability of children to describe, localize, and assess the intensity of their current pain and to compare their evaluation with those of their parents	6;0 – 12;0-year-old native Arabic-speaking children presented with acute pain to the emergency room (n = 281)	Cross-sectional survey design with quantitative analysis
4) Azize, Endacott, Cattani, and Humphreys (2013); UK	To use drawings from the Pediatric Pain Inventory to capture the language used by children to describe pain; and to observe the children's placing of pain drawings on red/amber/green paper to denote perceived severity of pain	4;0 – 7;0-year-olds (typically developing; n = 34)	Mixed-method
5) Craig, Stanford, Fairbairn, and Chambers (2006); USA	To examine healthy young children's early spontaneous use of pain language	1;0 – 9;11-year-olds (typically developing; n = 246); 3;0 – 12;3-year-olds (Down Syndrome; n = 57)	Multi-method*
6) Ely (1992); USA	To examine words and their meaning when used by children describing their experiences with pain	6;6 – 8;6-year-olds (n = 8)	Descriptive qualitative
7) Esteve and Marquina-Aponte (2011); Spain	To investigate the developmental progression of children's pain perspectives	4;0 – 14;11-year-olds (n = 180)	Cross-sectional descriptive (stated by authors) / multi-method*
8) Harbeck and Peterson (1992); USA	To determine if the increasing age and developmental level increases the specificity and accuracy of children's descriptions of pain; reasons why pain hurt, and degree of pain	3;0 – 4;11-year-olds (n = 20); 6;0 – 7;11-year-olds (n = 20); 8;0 – 10;11-year-olds (n = 20); 11;0 – 12;11-year-olds (n = 20; typically developing) [Data for 18;0 – 23;11-year-olds (n = 20) were omitted for this review on children's pain vocabulary]	Qualitative
9) Jerrett and Evans (1986); Canada	To examine how school-aged children view their pain	5;0 – 9;11-year-olds (children with acute health problems at outpatient clinic; n = 40)	Qualitative (stated as "descriptive" by authors, not as "qualitative")
10) Johnson, Bornman, and Tönsing (2016); South Africa	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	6;0 – 9;11-year-olds (typically developing; n = 74)	Mixed method
11) Kortessluoma and Nikkonen (2006); Finland	To obtain children's voice on how they describe their pain and the purpose of pain	4;0 – 11;11-year-olds (hospitalized children; n = 44)	Qualitative*
12) Latimer et al. (2014); Canada	To understand how Mi'kmaq children express pain and how others interpret it	6;0 – 10;11-year-olds (n = 39); 11;0 – 15;11-year-olds (n = 19); 16;0 – 18;11-year-olds (n = 18)	Qualitative
13) Pölkki, Pietilä, and Rissanen (1999); Finland	To describe children's pain experiences in the hospital	7;0 – 11;11-year-olds (n = 20)	Qualitative
14) Savedra, Gibbons, Tesler, Ward, and Wegner (1982); USA	To determine how children describe their experience of pain	9;0 – 12;11-year-olds (n = 100 children in four hospitals and 114 children from one church and one private school)	Questionnaire development
15) Stanford, Chambers, Craig, McGrath, and Cassidy (2005); Canada	To describe verbalizations of pain among children during immunizations	4;8 – 6;3-year-olds (who receive routine preschool immunizations; n = 58)	Multi-method*
16) Wennström and Bergh (2008); Sweden	To determine how young boys describe bodily pain; verbal expressions of postoperative symptoms	3;0 – 6;11-year-old boys (who underwent elective surgery of retentiotestis; n = 14)	Multi-method*
17) Wilkie et al. (1990); USA	To develop and examine the validity and reliability of a word list for measuring pain quality	8;0 – 17;11-year-olds (multi-ethnic children in school and hospital settings; n = 1,223)	Development of word list

literature to provide background of how the use of pain-related vocabulary develops as the children grow older. This discussion on the use of children's pain vocabulary is therefore based on the two main themes identified in this review and refers to the development of language according to children's chronological age. Table 2 indicates the ages of the children who participated in each study.

Theme 1: Description of pain. Children's use of the different pain descriptors changes as they grow older. Younger children ($\leq 3;11$), for example, mainly use interjections, such as "ouch" or "ow," and words like "ache" to describe their pain. Literature indicates that children start to use the word "pain" for the first time at the age of 3;0 to 3;11 (Craig et al., 2006) and continue to use interjections and descriptors to describe their pain as they grow older (Craig et al., 2006; Ely, 1992; Wennström & Bergh, 2008).

When younger children do not yet have the cognitive and language skills to explain the bodily sensations that they experience during pain (Dubois et al., 2008), they try to explain pain with concrete phrases like "I lose my smile and feel bad" (Jerrett & Evans, 1986) or "I'm not feeling well" (Kortessluoma & Nikkonen, 2006). Some use comparisons such as "I had a real bad – kinda like a scar" (Ely, 1992) or "Feels like someone hit it with a sledge hammer" (Abu-Saad, 1984a). Other children explain what caused the accident that resulted in the pain experience, such as "I was playing too rough..." (Harbeck & Peterson, 1992) or "I touched the warm pot" (Johnson et al., 2016).

As children's thinking develops on a more symbolic level, they start to describe their pain by using more graphic descriptors, such as "terrible, disgusting," "aching and hurting" (Kortessluoma & Nikkonen, 2006), and "beating or pounding in my head" (Harbeck & Peterson, 1992). Older children tend to include intensifiers when using descriptor words: "really bad;" "pain was radiating...;" "pounding, stabbing, throbbing" (Kortessluoma & Nikkonen, 2006); "horrible; annoying; pin-like; sharp; shooting" (Abu-Saad, 1984a; Harbeck & Peterson, 1992; Savedra, Gibbons, Tesler, Ward, & Wegner, 1982; Wilkie et al., 1990); or "aching; stinging; itching" (Abu-Saad, 1984b; Johnson et al., 2016; Kortessluoma & Nikkonen, 2006; Pölkki, Pietilä, & Rissanen, 1999).

From approximately 8 years of age, children start to think in a more abstract way to describe pain: "Sometimes it is worse and sometimes more like stabbing" (Savedra et al., 1982). Building on these skills, older children ($> 10;0$) use comparisons ("Like there was a fire inside my head;" "Feels like someone hit it with a sledge hammer") and define pain as a psychological state based on emotions ("Pain is really

upsetting no matter where the pain is;" Kortessluoma & Nikkonen, 2006).

Theme 2: Coping with pain. Younger children prefer to seek emotional support from their parents ("I want to sit on Mummy's knee") or wish to be distracted from the pain ("I want to play;" "I want to go home;" or "I want to drink...;" Johnson et al., 2016; Wennstrom & Bergh, 2008). These children also refer to concrete treatment or action to lessen the pain: "Put on plasters/Band-Aid" (Esteve & Marquina-Aponte, 2011; Johnson et al., 2016) or "put on something;" "put on cream/ointment" (Johnson et al., 2016; Wennström & Bergh, 2008). Examples of self-comforting words to indicate their pride of being able to cope with pain include "I wasn't afraid..." (Wennström & Bergh, 2008); "it is not sore at all" (Johnson et al., 2016); "you get better" (Kortessluoma & Nikkonen, 2006); "this will be over in just a little while;" and "I can take it" (Pölkki et al., 1999).

Children older than 8;0 also prefer distraction by others or they "try to ignore" the pain in an attempt to help them forget about it (Ely, 1992; Esteve & Marquina-Aponte, 2011). Interesting to note is that older children also start to realize that while experiencing pain, they may have secondary gains such as "escaping" from responsibilities at home or school (Johnson et al., 2016; Kortessluoma & Nikkonen, 2006), for example "you can stay at home when there is an exam" (Esteve & Marquina-Aponte, 2011). This option should thus also be included when deciding upon vocabulary for the older child.

Since it acknowledges the development of children's pain vocabulary as they mature, the pain-related vocabulary list obtained from this review may assist S-LPs and parents to select pain-related vocabulary for children who may benefit from AAC to express their pain. In the past, children's pain verbalizations had often been overlooked in terms of their potential value during pain assessment. Therefore, it is the responsibility of the S-LP to provide a means of communicating pain to children with communication disorders relying on AAC methods (American Speech-Language-Hearing Association, 2005). Providing children who experience communication challenges with a means to express their pain could assist other healthcare staff when assessing children's pain, as the children can now self-report their pain (Stanford, Chambers, Craig, McGrath, & Cassidy, 2005). In determining children's pain-related words, words from different developmental language inventories should be considered, since younger children and adolescents appear to utilize different vocabularies to describe their painful experiences and what they do to cope with the pain.

Limitations

Only full-text English articles were considered for this review. English studies had to be excluded when only the abstracts and not the full text were available, despite the fact that their aim might have been relevant. Although only studies published in English were included, the studies were not all conducted in English and translated versions of children's self-reported vocabulary were provided by the original authors. Possible translation errors by the original authors in reporting the children's vocabulary should therefore be acknowledged. Only studies that portrayed examples of children's own voices of pain-related vocabulary were included (see Table 1). Although this considerably narrowed down the number of studies reported, it strengthened the modern notion of including children's own voices in research about them (Nilsson et al., 2015).

Conclusion and Future Directions

This review of children's pain-related vocabulary revealed a relatively small research base of 17 studies for understanding the vocabulary that children themselves use to express their pain. An analysis of the data pertaining to children's self-reported vocabulary concluded that children mainly use pain words to describe and to cope with physical pain. Furthermore, this scoping review provided a list of pain-related words ($n = 60$). It is important to note that the vocabulary should be selected for each individual child by considering his/her individual context and needs. Furthermore, children who use AAC include both pre-literate and non-literate individuals and future research should be done to determine how these pain-related concepts could be visually represented, and to determine which of the commonly used symbol sets or systems have existing visual representations available of the vocabulary on this pain-related vocabulary list. This will determine if new graphic symbols will need to be developed for vocabulary items that do not have visual representations in such symbol sets or systems. The pain-related vocabulary list can be used by children who suffer a temporary loss of speech (e.g., children in intensive care units), as well as children with disabilities and LNFS to express their pain. In addition, AAC systems could be set up with pain vocabulary for a group of children with LNFS. The effectiveness of including pain-related vocabulary in AAC systems to increase these children's ability to draw attention to their pain and the subsequent effect to communicate their pain (e.g., the impact thereof on assessment and treatment of pain) should also be analyzed.

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Correspondence concerning this article should be addressed to Ensa Johnson, Centre for Augmentative and Alternative Communication, University of Pretoria, Communication Pathology Building, Lynnwood Road, Pretoria, 0002, South Africa. Email: ensa.johnson@up.ac.za

Declaration of Interest

The authors report no conflicts of interest.

Appendix. List of Vocabulary Categorized as Core, Pain-Related Fringe, and Other Fringe Words From all 17 Studies

Core vocabulary		Pain-related fringe	Other fringe	
a/an	like	ache	across	mood
about	little	Band-Aid/ plaster	alone	mosquito
all	look	bandage	angry	movie
am	lot	bang	animals	needle
and	make	blister	annoy	nerves
another	mom	blood	anxious	nervous
around	more	boo	anything	nothing
at	most	burn	area	nuts
away	move	cast	arms	office
back	much	cramp	ask	pack
bad	my	cry	avoid	palm
ball	need	discomfort	awful	part
be	next	disgust	bear	point
because	new	dizzy	beat	position
bed	no	eee	bee	pot
being	not	eina*	blame	pray
better	of	headache	body	presence
big	off	healthcare	bothers	pressure
bit	okay	hospital	brakes	principal
but	on	ill	brave	pull
by	one	injection	break	punch
call	only	itch	breathe	real
can/could	or	medicine	bump	relax
can't	other	miserable	careful	rest
cause	over	moan	certain	restrict
cold	play	nauseous	cheer	road
come	please	numb	cheers	rough
could	put	ointment/ cream	clap	rub
cut	really	ooh	clean	sample
dad	say/tell	ouch	clothespin	scary
different	school	ow	comfort	sharp
do/does	she	pain	crazy	shock
doctor	show	painful	crush	shoot
dog	sick	paralyzing	cymbals	sickroom
done	sleep	pill	dance	skateboard
don't	so	pin	deadly	skin
down	some	pinch	depends	sledge
drink	somebody	poke	die	smile
drive	someone	pounding	difficult	somehow
eat	something	puke	dirt	sorrow
else	sometimes	radiating	distract	sorry
even	somewhere	sad	dull	sort
fall	stay	scared	ears	speak
fire	take	scratch	easier	special
first	that	scream/ shout	elephant	split
for	the	sore	enough	squeeze
friend	then	sting	eventually	stab
get	there	stretch	exam	staff
give	they	suffer	exhausting	start
go/goes	think	suffocate	expect	stiff
good	this	swollen	extremely	stomach
hand	time	throbbing	failure	strength
has/have	to	tickle	family	stress
head	too	tingle	fear	strong
help	try	unhappy	feel	swallow
here	up	unwell	fight	sweet
him	use	upset	fine	talk
hold	very	vomit	fix	teacher
home	want	yell	forget	tear
hot	was/were	yuckie	frightening	terrible
how	water		fun	terrify
hug	way		funny	thumb
hurt	well		God/Allah	tight
I/me	what		guilty	touch
I'll	when		hammer	tummy
if	where		hard	understand
in	while		harm	useless
inside	whole		hit	usually
is/are	will/would		hobby	vacation
it	with		horrible	vessel
just	you		ice	warm
kind	your		lead	weird
know			left	whenever
let			lie	willie
let's			lose	worry
			matter	worse
			might	

Note. *Although "eina" is an Afrikaans word (meaning "ouch"), it is also used extensively by English-speaking South African children (code switching).