

Supporting communication vulnerable children to communicate their pain*

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Abstract

Communication vulnerable children need an alternative way to express their pain to receive appropriate pain management. In this chapter, the concept of communication vulnerability will be explained by using the social-communication model of pain as a theoretical framework. The concept of pain is difficult to describe due to its subjective nature and individuals' different experiences to pain. Clinicians and researchers find it challenging to understand the dynamic interplay between the biological, psychological and social determinants of pain. Understanding any episode of acute or chronic pain therefore necessitates considering the holistic pain picture to analyse the essentials at biological, psychological and social levels. The chapter concludes with suggestions to use augmentative and alternative strategies to support communication vulnerable children to communicate their pain.

Keywords: augmentative and alternative communication (AAC), disabilities, care, healthcare professional, paediatric patient, social-communication model of pain.

1. Introduction

Pain is intrinsically private, and the concept of pain is difficult to describe and assess due to its subjective nature and individuals' unique experiences of pain [1, 2]. Up until the mid-1980s, clinicians believed that infants, toddlers and persons with disabilities, specifically those with significant communication difficulties, either do not have pain or may have very high pain thresholds [3-5]. These myths and beliefs

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were reinforced by McCaffery's widely accepted definition of pain at that time that stated that "pain is what the person says it is and exists whenever he or she says it does" [6, p.95]. By default, McCaffery's definition therefore suggested that all persons with the inability to communicate their pain verbally (including the aforementioned) may not have pain.

In addition to their limited verbal ability to express pain, communication vulnerable children's neurology may also impact on their ability to show other tell-tale signs of pain that transform the parts of the brain responsible for the expression of pain [5]. For this reason, clinicians repeatedly overlooked other signs of pain [4], such as changes in the children's behaviour (withdrawal, acting clownish, having mood changes, displaying aggressive behaviour or exhibiting extreme tantrums) or changes in positioning (refusing to use the body part where pain is). This is because children with communication challenges may not display pain in the typical ways such as by crying or through facial changes [7-10]. Clinicians often mistakenly regard these kinds of "different reactions to pain" as challenging behaviour and not as children's alternative attempts of trying to express their pain [11].

Lately, clinicians have started to acknowledge that the inability to communicate pain verbally does not negate the likelihood that a person is in pain or that they require applicable pain-relieving treatment [3, 10]. The International Association for the Study of Pain (IASP) updated the definition of pain in July 2020 [2, p.2] to: "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage". According to Raja et al. [2] the IASP also added six key notes as an expansion to the definition and to provide further context to the definition and the etymology of the word "pain". Additional notes to the latest pain definition for example highlight that a person's report of their pain should be acknowledged and respected and that verbal expressions of pain is only one of many behaviours to express pain [2]. Nevertheless, irrespective of patients' ability or inability to verbally self-report their pain, it remains the ethical obligation of all clinicians to acknowledge and relieve the most vulnerable patients' pain [12].

2. Communication vulnerability

Children with severe physical, sensory and/or cognitive disabilities affecting their receptive and expressive communication may not be able to verbally communicate their pain and other pain-related experiences [10, 13]. Children with

languages or cultures different to those of the treating clinicians or with limited proficiency in the latter's language often do not have the vocabulary to express their pain [14]. Furthermore, children who are receiving treatment in intensive care units – where medical intervention such as sedation, intubation or tracheotomy can influence their ability to verbally communicate – as well as children receiving palliative end-of-life support may also not be able to communicate verbally [13]. Authors refer to these groups of children as communication vulnerable [13-15]. Communication vulnerability is defined as a reduced ability in respect of expressive and/or receptive communication and can involve permanent vulnerability (such as children with severe communication disabilities) or temporary vulnerability (such as patients in critical care units receiving medical interventions that may influence their ability to speak) [16, 17].

The inability to express pain verbally may result in communication breakdowns between the child and the clinician, which could result in risks such as non-treatment, adverse medical outcomes and increased anxiety for both patients and clinicians [18]. Clinicians often find it demanding to assess pain in communication vulnerable children [7, 19], as they have to attempt to interpret the children's bodily movements, facial expressions and physiological signs [7]. As mentioned earlier, children with communication disabilities may express their pain in atypical ways that could influence clinicians' interpretation of the children's pain [10, 11, 19]. In the latest recommendations for clinicians to follow during pain assessment of those unable to self-report, Herr et al. proposed that as a first step, clinicians should become aware of potential causes of pain [20]. The second step in pain assessment is to try to obtain self-report from all patients [20]. Therefore, it is vital that alternative means of communication should be investigated to enable children with severe communication difficulties to self-report their pain.

Hay et al. [21] promoted the use of self-reporting as the primary method for measuring the intensity and other features of pain. Thus, it was recommended that parents' proxy reports of their children's pain should only be used once the children's reports were in doubt [21, 22]. Research has confirmed that speaking children themselves can give a clear self-report of their pain experience by verbally expressing their pain or using various pain assessment tools such as the Colored Analogue Scale or the Faces Pain Scale-Revised [23]. However, Schiavenato and Craig [24] are of the opinion that pain assessment tools do not do justice to a patient's pain experience as they oversimplify the demands for rating pain intensity without taking the type of pain into consideration. For this reason, a possible

solution should be found for how communication vulnerable children can self-report their pain in ways other than by verbal accounts.

Clinicians' expertise to support communication vulnerable children in pain depends on the availability of reliable and valid information about the existence and precise nature of the child's distress [25]. Self-report and observational measures of pain can be reviewed from the perspective of a model of human communication [26]. Therefore, to gain a better understanding of this complex pain communication process, clinicians and researchers need to grasp the challenges that children with disabilities – and particularly those who are communication vulnerable – may encounter when trying to express their pain. The social communication model of pain [26, 27] offers an inclusive theoretical framework to be used in this chapter, because it explains the dynamic interaction between the biological, psychological and social determinants of pain [28]. An adapted social communication model of pain for communication vulnerable children based on the model proposed by Craig [27, 28] warrants further discussion in this chapter.

3. Social communication model of pain

Communication plays an important part in any action that aims to improve health [29]. Communication is a social, dynamic and interchanging reciprocal process that involves persons (acting as a sender or receiver) [30]. Communication comprises verbal (speech) as well as non-verbal modes (gestures, a shared glance, facial expression) (31). Symbols (abstract or concrete) are used to convey a from the sender to the receiver in order to achieve a shared meaning in a specific context or environment [30]. In other words, communication involves sender(s) and receiver(s) conveying information through a communication channel. Effective communication occurs when the intent and meaning of one person (e.g. the sender) is understood by another person (e.g. the receiver) [31]. For communication vulnerable children, this communication process poses a serious challenge, due to their inability to communicate verbally (i.e. the communication intent is lost if the receiver does not understand the communication channel used by the sender). Although these children may have the desire to communicate their pain, research indicates that communication vulnerable children often opt not to communicate their pain because their previous communication attempts were ignored, or simply because it takes too much physical effort trying to communicate their pain [32].

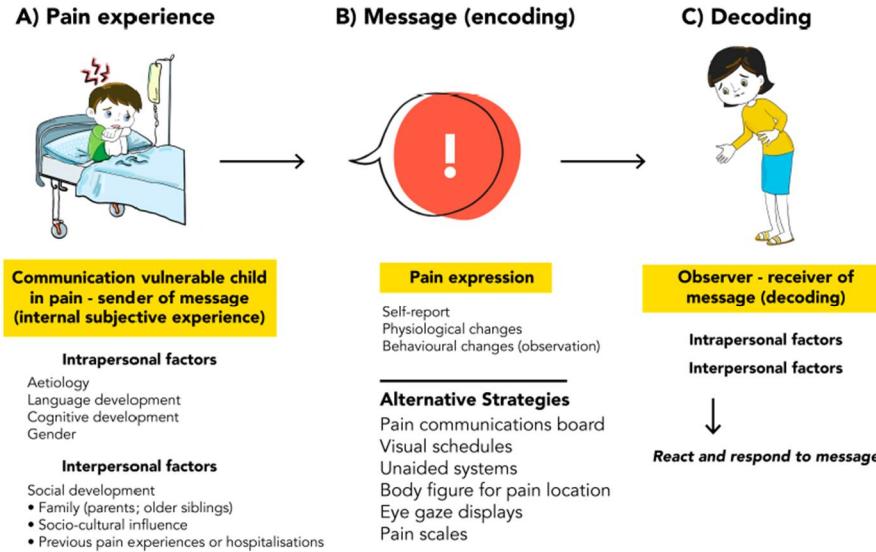


Figure 1: Adapted social communication model of pain for communication vulnerable children (as based on Craig, 2009, 2015).

The social communication model of pain was developed as a framework to explain how pain is experienced and to describe the multifaceted communication process required to adequately express and interpret pain and to have pain understood by others [26, 27]. The social communication model of pain underlines both the role of the sender who is the person in pain (e.g. the communication vulnerable child) and the ability of the receiver as the observer of the pain (e.g. clinicians) in understanding the experience of pain. Biomedical models, in contrast, focus on the sensory characteristics of pain, with no emphasis on the social factors of pain [26, 27, 33]. Since this chapter will proceed to focus on pain communication of communication vulnerable children, Figure 1 depicts the suggested adaptations to the social communication model of pain (based on Craig [27, 28]) as it relates to communication vulnerable children's expression of pain.

A proposed three-step pain communication process altered for communication vulnerable children highlights the different factors that may intervene in the children's pain expression, the pain assessment and the accompanying treatment ([10, 27, 28]):

(A) *Pain experience* – the inward personal painful pain experience that happens over time and is stimulated by both interpersonal and intrapersonal (biological and psychological) factors involves the status of the child before the event;

(B) *Message* – the encoding of the pain experience (e.g. the child's understanding or making sense of the pain) and the expression of pain through expressive

behaviours such as crying, exclamations or (verbal) self-report to make the pain known to observers (e.g. clinicians or parents);

(C) *Observer (receiver of message)* – the process whereby observers decipher or decode pain behaviours to react and respond by providing appropriate pain management or pain-relieving treatment [34].

This model also highlights the possibility that observers' own perceptions and responses to pain as based on their own pain experiences may influence their understanding of pain as well as how they will respond to the child's pain experience. Although researchers and clinicians should be aware of their own bias towards pain, it will not be dealt with in further detail in this chapter.

In short, the adapted social communication model of pain proposes that the communication of pain begins with the communication vulnerable child who experiences pain (A); it continues to describe how this experience influences the child to make sense of the pain (B) and to express it in atypical ways or by means of augmentative and alternative communication (AAC) modes. These pain expressions are made known to the observers (C), who decode the child's pain to take appropriate pain management actions. The adapted social communication model of pain can thus be used to help researchers and clinicians to understand the pain in communication vulnerable children. Examples are children with a variety of disabilities such as Down syndrome, intellectual disabilities, autism spectrum disorder (ASD) or cerebral palsy (CP), or children who experience temporary communication vulnerability due to medical interventions such as intubation.

The model considers that there are many ways that a child can encode (B) their pain experience (A). Thus, when decoding the child's pain, observers (C) need to be open to other modes that children may use to communicate their pain. A child's self-report of pain is influenced by the pain context as well as their emotional, sensory, cognitive, developmental and cultural composition [2, 35, 36]. The social factors and reciprocal, repeating and dynamic effects of pain communication are acknowledged during this pain account within human beings [28]. In the social communication model of pain, a clear distinction is made between historical and current biological and social factors. For example, intrapersonal factors refer to a person's temperament to react based on their biological, psychological and social histories. Craig [28] highlights that, during the pain event (A), the immediate social and physical environment has a powerful effect on both the person in pain (e.g. the communication vulnerable child) and on the observers (C). The internal subjective pain experiences of communication vulnerable children will now be discussed based

on the adapted social communication model of pain for communication vulnerable children (Figure 1).

3.1 The internal subjective pain experiences of communication vulnerable children

The way persons express pain can give insight into their pain experiences. Pain *expressions* involve the person's observable response (such as their pain behaviours) to a noxious stimulus, whereas a person's pain *experience* is private and internal and involves severity of discomfort [27]. Based on their own experiences with pain, each individual displays different potential behavioural reactions to pain [27]. For example, children who have had negative pain experiences during needle procedures may exhibit more severe responses to pain because of their previous negative experiences. Additionally, their individual biological capabilities trigger their complicated expressions of pain [2]. Children with significant communication difficulties have different disability diagnoses with unique pain-related experiences related to these disabilities (e.g. children with CP or ASD).

3.1.1 *Intrapersonal factors*

Along with biological capabilities, the constructs behind pain expression are the impact of language and cognitive development as well as social interaction and experiences. The expansion of pain-related vocabulary progresses along a similar sequence as does natural language development [37, 38]. The theoretical constructs that underlie pain expression within communication vulnerable children with various aetiologies will now be discussed in more detail.

Aetiologies

All children experience pain on a regular basis. Young children with typical development may respond to everyday pain such as bumps and bruises by crying, verbalisations or spoken words to express their pain experiences. They usually start to use the word "pain" by the age of six years [37]. On the contrary, children with disabilities might have more pain incidents more often than their peers without disabilities. For example, children with disabilities may experience more acute pain incidents due to needle procedures (such as blood drawing or receiving blood

transfusions) and recurring medical procedures and treatments (such as range-of-motion manipulation during physiotherapy for children with CP) to maintain their health [3, 39, 40].

Young children with CP experience high occurrences of chronic and acute pain [19, 41]. In an Australian study conducted by Ostojic and colleagues [19] to determine the prevalence of pain in children with CP, they found that two in three children with CP experienced acute pain and one in three children had chronic pain. Furthermore, the study revealed that children with CP, functioning on levels IV and V of the Gross Motor Function Scale (GMFCS), have a bigger risk of suffering from chronic pain [19]. This group also has communication challenges and may need alternative means to communicate their pain [19, 41]. Multi-factorial reasons for pain in children with CP could include spasticity, contractures and the incapacity to walk [19, 41, 42]. Spasticity and the inability to change their positioning to decrease pressure on certain body parts may also lead to contractures, musculoskeletal and gastrointestinal pain [43]. In a study among children with CP in South African schools, Adolfsson and colleagues [44] found that South African children with CP often experience hip dislocations– resulting from spasticity that caused hip displacements and ultimately lead to hip dislocations. As such, persons with CP have to undergo constant surgical procedures and medical interventions throughout their life span in an attempt to correct or rehabilitate orthopaedic problems associated with their condition [41, 43, 45]. All these procedures, including range-of-motion manipulation and assisted stretching, are painful experiences [44]. Communication through the use of AAC communication strategies is therefore crucial for children with CP to ensure that they can express their pain and receive appropriate pain treatment [41].

Children with intellectual disabilities are at risk of experiencing a variety of painful somatic conditions due to comorbidities such as contractures, gastro-oesophageal refluxes, and epilepsy [11, 46]. These children with intellectual disabilities often experience socio-communicative deficits typical of children with ASD, for example they may not use facial expressions or make eye contact to display pain or other emotions [11, 46, 47]. Children with intellectual disabilities also express their pain consistent with their level of cognitive and physical development and not necessarily consistent with their chronological age [46]. Some atypical expressions, such as hand flapping or hand rubbing, smiling or freezing has been observed when children with intellectual disabilities were not able to verbalise their pain [5]. Yet, according to Doody and Bailey [9], children with intellectual disability

who are unable to communicate their pain in a typical manner seem to have less opportunity to receive pain treatment.

Children with Down syndrome also fall in the group of children with intellectual disability who can be expected to experience pain as a result of their disability. They are at high risk of secondary pain-related experiences such as the development of hip abnormalities and oral health issues [3, 48]. Children with Down syndrome have higher occurrences than their peers with typical development of dental problems due to frequent incidence of periodontal disease and chronic facial pain disorders [3]. They may also experience chronic pain due to congenital heart anomalies, bone fractures due to osteoporosis, or eczema – to name a few conditions [5]. Davies [48] reported that, compared to their siblings with typical development, children with Down syndrome have a decreased tendency to react to pain – but that does not mean that they are unresponsive to pain. Due to lower cognitive functioning, children with Down syndrome may not have the ability to localise the painful stimulus, because their pain-related vocabulary only tends to develop at a later stage. Their limited pain-related vocabulary may thus influence their ability to communicate pain [38].

As with children with CP, children with intellectual disabilities such as Down syndrome or ASD also experience a large number of pain incidents and they are sometimes two to three times more at risk of an injury than their peers with typical development [10, 49]. Children with ASD often display challenging and self-injurious behaviour, as well as extreme tantrums that could lead to injury and pain [10]. Some children with ASD may also have trouble expressing their pain, due to their typical delay in language development and possible cognitive impairment [10, 50]. If children with ASD do use speech, they struggle to convey their emotions and the intensity of their pain experiences due to their monotone intonation. In addition, they do not usually use the same facial expressions and gestures that their peers with typical development would do to express their feelings. The pain expressions of children with ASD are distinctively individual and may differ from those of the larger population, considering the fact that children with ASD experience socio-communicative impairments and therefore may not understand social closeness as their peers with typical development would do [3].

Besides the communication difficulties of children with disabilities, this chapter also focuses on children who experience a temporary communication vulnerability due to medical procedures (such as intubation) or life-threatening conditions (such as cancer). For example, critically ill children who have been admitted to paediatric

intensive care units suffer a temporary loss of their expressive or receptive communication [13]. These communication vulnerable children show stress, frustration and anxiety, and are at a greater risk of being treated incorrectly by clinicians who wrongly decode the children's pain message [15, 51]. Even clinicians such as nurses often mention their feelings of frustration when they find it difficult to grasp what their paediatric patients are trying to communicate [7]. The vast significance of efficient alternative means of communication to ensure safe treatment of paediatric patients is therefore emphasised [15].

Language development

Spoken language is seen as the ultimate means of communicating pain [52]. Language and cognitive development influence children's use of words to describe their pain experiences in such a way that observers (clinicians) can decode the message correctly and respond appropriately with pain-relieving treatment [53]. Language learning occurs within a physical and social context determined by actual people, objects, activities and events in the child's environment [54]. Children learn about new concepts in the world while interacting with their physical environment, which forms the foundation for their lexical development [54]. For example, the words parents use to communicate with their children during painful experiences enable children to acquire new pain-related vocabulary [38]. Parents tend to talk to their children about pain on an age-appropriate level, thus enlarging their children's pain-related vocabulary. For example, when a child cries when injured, the parent might respond with exclamations or words such as "Ouch! You got hurt!" thereby enabling the child to add meaning to the painful experience and to expand their repertoire of pain-related vocabulary [55].

However, since children with severe communication difficulties do not have the same contact with their social environment as their peers with typical development, they may find the language-learning process challenging [54]. Whereas children with typical development gain new knowledge about the world they live in through their encounters with their environment, children with disabilities have reduced access to their environment. This makes it more challenging for them to acquire new concepts without having the relevant previous knowledge to build on [54]. It is consequently the adults' responsibility to guarantee that children with severe communication difficulties are exposed to a social environment that includes people, objects and possible pain experiences. This exposure to facilitate children's

language development can be achieved for instance through play activities like doctor-doctor play with peers [54].

Cognitive development

Language development corresponds with cognitive development and as children mature cognitively, they can describe their pain more successfully [52]. Younger children tend to explain the bodily sensations they experience during pain in a more concrete manner (such as 'my stomach hurts') due to their limited cognitive and language skills [56]. As children's thinking develops on a symbolic level, they start to use more graphic descriptors such as "terrible" or "beating", while older children start to add intensifiers, such as "really bad" when describing their pain [53]. Since children with severe communication difficulties may not be able to verbally express their pain, Johnson et al. [57] proposed that clinicians such as speech-language therapists provide these children with preselected pain vocabulary that can be added to their AAC system to enable them to express their pain appropriately.

Apart from disability aetiology, language or cognitive development, gender is another intrapersonal factor that might have an impact on the development of children's pain-related vocabulary [37, 38, 58, 59].

Gender

Gender differences in pain expression and pain-related vocabulary – despite similar pain experiences – are often highlighted in literature [38, 60-62]. As girls typically develop expressive vocabulary sooner than boys, Frank et al. [38] found a slight advantage in girls' pain-related vocabulary, which may imply that pain-related language acquisition could be related to other factors. For example, girls tend to be more emotive and more expected to complain and also report their pain experiences more frequently than boys [52]. Contrary to girls, boys tend to be more passive or have more anger-related vocabulary in response to pain due to an injury [38]. In the event of communication vulnerable children, the differences between the reactions to pain by boys and girls are not clear [8]. However, it was found in literature that adult observers' responses to children's pain experiences tend to be influenced by gender-stereotyped attitudes, and that girls were treated in a different way than boys [62-64]. Clinicians are often biased and expect girls to experience more pain than boys [63-65].

3.1.2 Interpersonal factors: Social development

According to the adapted social communication model of pain, interpersonal factors such as family settings, children's social and cultural environment, as well as previous hospitalisations may further influence children's experience and expression of pain [27].

Family

Though some characteristics of pain-related language seem to be universal, substantial influences of family and ethnic contexts are also repeated in the specificity of pain-related language due to the nature of the social setting in which children are growing up [55, 66]. The entire family is affected by children's chronic pain experiences and these experiences are often stressful for other family members as well. The treatment prescribed to manage the child's pain can result in interferences in planned family events, thus upsetting or disrupting the overall family system [66].

From the perspective of the family systems theory, family dynamics influence the way children understand and talk about their pain [22, 62]. Parents are the role models for their children to learn words to express pain [55]. As children's cognitive and social skills develop, they learn to talk about pain by observing how their parents respond to and talk about their children's pain experiences [66]. Parents' socio-economic background, education and age may influence the way in which they respond to their children's pain. For example, in an American study by Rowe [67] – who investigated why parents from different socio-economic statuses communicate in different ways with their children – it was found that more educated parents and parents from advantaged backgrounds tended to talk more often to their children and use a bigger variety of words and longer utterances thereby expanding their children's language ability and pain-related vocabulary. Younger parents also tended to use different pain words in comparison with older parents [68].

Birth order also impacts on children's development of pain-related vocabulary [38]. Younger children observe their older siblings' use of pain words, which stimulates their own development of pain-related vocabulary [38]. It was reported that the presence of one or more older siblings has an impact on children's use of pain words compared to those children without older siblings [38]. Moreover, children with siblings who had previously been hospitalised had a larger vocabulary

than those with siblings who had never been hospitalised before. This suggests that experience plays a role in the learning of pain language because these children had to deal with the illness or hospitalisations of their sibling(s) [38].

Socio-cultural influence

Apart from family practices, children develop an understanding of pain-related language within their sociolinguistic environment [66, 69]. Children's language is influenced by their cultural beliefs, social groups and communities [69]. There are differences between the beliefs of diverse cultures and their views on parents' roles in their children's language development. In some cultures, parents may not react to their children's utterances: they are of the opinion that adults must not teach children to talk, as they will eventually learn to talk on their own [67]. Some family and cultural beliefs can also result in disparities in the way children learn about pain and react to pain [36]. In some Nguni and Sotho cultures in South Africa, for example, boys are taught that they may not express their pain, because showing or expressing pain is a sign of weakness or lack of courage [70].

Clinicians should therefore acknowledge cultural differences and try to understand the culture of the communication vulnerable child. They should ask detailed questions to help understand the child's pain condition and to prevent any misunderstanding [52]. Clinicians should for instance be aware of the fact that in some cultures it is considered disgraceful to ask for pain relief, while people in other cultures believe that a godly intervention will relieve pain when necessary [62, 70].

Previous pain experiences and hospitalisations

Children's understanding (and the significance) of their first painful experience due to tissue injury will intensify with experience – either through positive or negative contextual associations [2]. Children learn the use of the word "pain" through their experiences related to injury [58]. Hospitalisations help children to develop pain vocabulary based on their personal experiences with pain. Therefore, children with previous hospitalisations who experience pain events more often and who have learnt and processed the concept of pain (and pain management) tend to have a larger pain-related vocabulary than those who have never been admitted to hospital before [38].

4. Alternative means to communicate pain

From the discussion above, it is clear that communication vulnerable children experience challenges to express their pain and need alternative means – such as AAC strategies and systems – to communicate their pain. AAC involves a variety of communication strategies that can be used to aid communication attempts of persons with communication challenges to either augment their speech or to be used as an alternative means to speech ([31]. Regarding the adapted social communication model of pain, one can agree that when the communication vulnerable child is offered the use of AAC to express their pain (A), the form (or communication mode used) is less important than ensuring that the message (B) is understood by the observer (C). AAC systems are classified as either unaided or aided. Unaided AAC systems are defined as the use of only body parts to convey messages such as by pointing, making gestures, body language movements, facial expressions, and manual signing [31]. Aided AAC systems include low-technology aids that need no electronic programming (e.g. pen and paper, and symbol-based communication boards), as well as high-technology aids such as speech-generating devices [71]. Clinicians should be encouraged to incorporate AAC strategies and tools to enable communication vulnerable child patients to communicate their pain.

AAC strategies and systems have been successfully used with communication vulnerable children in various settings, including hospital settings [13, 16-18, 71-73]. Next, some potential AAC strategies are proposed to support communication vulnerable children to express their pain in order for observers (C) to understand the messages (B). The suggested AAC strategies will focus mainly on low-technology systems although all these strategies could also be incorporated in apps on digital mobile devices (smart phones or tablets) to enable communication vulnerable children as well as clinicians and researchers to gain a history of pain communication and subsequent pain treatment [74].

4.1 Pain-related communication boards

Communication boards are low-technology AAC systems used to display pictures (photographs, line drawings or graphic symbols) to enable communication vulnerable persons to communicate [31]. When designing a communication board, aspects such as the type of symbol (photograph, type of line drawing, graphic symbols or written words), the symbol size (to best accommodate the child's visual

and motor skills), symbol colour (to ensure contrast and increase the ease of finding a word within a particular word class), board layout and display (e.g. using the left-to-right Fitzgerald-key outlay as a precursor to reading), as well as the child's vocabulary need should be taken into consideration [71]. For example, children with physical disabilities or limited range of movement may not be able to access symbols that are too far apart.

Johnson, Boshoff and Bornman [53] conducted a scoping review to compile a list of children's pain-related vocabulary in an attempt to provide clinicians and parents with possible pain words that children would typically use to express their pain. In this scoping review, 17 studies from diverse cultures in countries such as the United States of America, Canada, Finland, Kuwait, South Africa, Spain and Sweden were included. It was interesting to note that the meaning of children's pain-related words in the native language translated to the same English word or words [53]. The study also showed that clinicians from different countries could use this list of pain-related words to compile basic pain-related communication boards that could be further individualised for their communication vulnerable paediatric clients [53].

In a follow-up pilot study by Gerber [75], 6- to 9-year-old children were asked to choose which symbols from two symbol sets, namely Picture Communication Symbols [PCSTTM] and Bildstöd symbols (www.bildstod.se) that they perceived as capturing the meaning of the pain-related words identified by Johnson et al. [53] most effectively. They were also asked which symbols they prefer, and why they made this choice. The children predominantly chose the Bildstöd symbols (an open source symbol library) because they perceived these symbols as looking more "real", being colourful, and with extra features to show the intensity of the pain experienced and they looked more real. Hence it is recommended that clinicians familiarise themselves with the pain-related word list compiled by Johnson et al. [53] and that they use the freely available symbols from the Bildstöd platform to develop a pain-related communication board for communication vulnerable children. A further recommendation is that the pain-related words should be representative of different categories of pain-related words, namely vocabulary that can be used to (i) describe pain; (ii) direct other's actions; (iii) describe pain location; (iv) describe causes of pain; (v) describe strategies to cope with pain; (vi) reflect on strategies for pain prevention, and (vii) strategies to indicate consequences of pain or injury [57]. These categories will enable children to search quickly through the options. Adults who use AAC suggested that a body figure of a child should be included on the communication board to eliminate the use of words

to describe the pain location (category (iii)) [57]. Body figures were also included in the child version of a communication board developed by Patak and colleagues [73] to be used with communication vulnerable children in intensive care settings.

4.2 Visual schedules

The discussion earlier in this chapter makes it clear that children's previous negative pain-related encounters influence how they perceive new pain experiences. Furthermore, since children with ASD and intellectual disabilities need routine to function optimally, visual schedules can be used to great benefit to prepare them for specific medical procedures. This preparation could reduce their anxiousness due to unfamiliarity with the procedure or previous negative experiences [15, 76]. A visual schedule should include a step-by-step and easily understandable format with pictures accompanied by written words (See Figure 2 for example). These will provide children with the necessary information to help them feel that they are in control of the imminent frightening procedures [77]. Visual schedules can be offered either in paper format (low-technology) or, where applicable, in a video story-based format.



Figure 2: Visual schedule of a needle procedure.

4.3 Eye gaze displays

Children with severe physical disabilities and limited movements may not be able to use their fingers to point to choices on a low-technology communication board. Therefore, the use of eye gaze displays is proposed. With eye gaze, the child is instructed to use their eyes to look at a picture or word on the display and then glance at the communication partner (observer), who will then verbally confirm the child's selection [15]. Figure 3 is an example of an eye-gaze flipchart display.

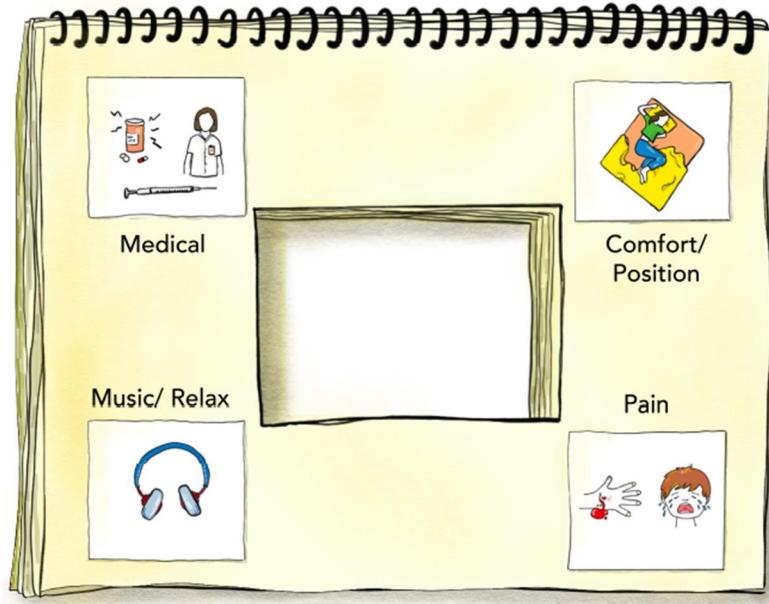


Figure 3: Eye gaze flip chart.

4.4 Unaided systems

During pain assessments of communication vulnerable children, clinicians or researchers can also ask the child pain-related questions providing them three options: "Yes", "No", "Not sure". Communication vulnerable children often have clear yes/no responses (e.g. head nodding to indicate "Yes"). Should communication vulnerable children have no typical yes/no responses, the clinician can ask the child to blink their eyes ("Yes"), close their eyes ("No"), or to look away to indicate that they are not sure what to answer. In this case, the clinician should refrain from asking more than one close-ended question at a time (e.g. "Does it hurt?" and "Do you hurt in your [body part]?""). The clinician should rather ask only one question (e.g. "Does it hurt?") to ensure that the child can give an appropriate response.

4.5 Pain scales

Appropriate pain management relies on the ability to accurately assess pain. For children, a common method to communicate pain is the use of pain scales [13]. Pain scales that are often used in clinical and research practice typically depict faces, colours or numeric grading [13]. An example of faces pain scales that are built on how children communicate their feeling(s) in a facial expression is the Faces Pain

Scale-Revised (FPS-R) [78]. Colours and numeric grading are typically used in analogue scales that are based on increments to indicate pain severity, and these allow children to show that a somewhat larger or smaller pain is experienced (examples are the Color Analogue Scale (CAS) [79]; and the Numeric Rating Scale (NRS) [80]). In a systematic review by Birnie et al. [23] on recommendations for the selection of children's self-report rating scales for pain intensity, the FPS-R, CAS and NRS were recommended for self-report of acute pain. However, though these self-report scales are freely available, clinicians and researchers should keep in mind that they may not be effective for everyone [13]. For example, while some of these scales may not need expressive language, receptive language skills are crucial, as children are expected to comprehend and know the meaning of words such as "hurt" or "pain" when using these scales [26].

5. CONCLUSION

This chapter aimed to address communication vulnerable children's experiences of pain and their need for alternative ways to express their pain so as to receive appropriate pain treatment. The concept of communication vulnerability was explained framed in the context of the adapted social communication model of pain for communication vulnerable children. According to this model, there are many ways in which communication vulnerable children can encode (B) their pain experience (A). The model also emphasises the need for observers (C) to be open to other communication modes that children may use to communicate their pain. The discussion centred on the pain experiences of communication vulnerable children such as children with Down syndrome, with intellectual disabilities, autism or cerebral palsy, as well as of children in intensive care settings who experience temporary communication vulnerability. The chapter concludes with suggestions on how AAC strategies can be used to support communication vulnerable children in communicating their pain.

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Conflict of Interest

The author declares no conflict of interest.

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