

**AAC Adapted Pain Scale Populations: Preliterate Children, Intellectually/Developmentally Disabled, and Memory Impaired.
Review of populations' sizes, needs, and suggested application of an Augmentative and Alternative Communication (AAC)
adapted pain scale tool**

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BACKGROUND :

Several populations are shut out of direct participation in their pain management by the vocabulary and memory demands of the common 10-point pain scale: preliterate children, Intellectually and developmentally disabled (ID/DD), and memory impaired patients (within Dementia, Stroke and TBI populations). Before COVID restrictions family caregivers stayed with these patients to interpret their needs. Medical personnel have seen very young and impaired communicators traumatized by being caught in pain, and unable to elicit its end. These populations are sizable and growing. Augmentative Alternative Communication (AAC) technology is evolving.

Does the standard 10-level pain rating require too much processing for communication handicapped patients? Is trial and error pain medicating based on observation the only solution for communication disabled patients? Are the current pain scales, discriminatory to individuals with communication issues because they require a pain rating based on the patient's recall of their pain history? Are lay people horrified at the thought of little ones and disabled communicators being taught, and/or practicing pain management words? Maybe, but this solution is promising. Augmentative and Alternative Communication (AAC) tools can meet patient expression concerns with pain vocabulary word banks. Caregivers can help individuals learn to communicate their levels of pain. Patients who have learned pain care vocabulary prior to a projected pain experience, request the appropriate help without prompts. Action apparent pain levels, expressed several ways, are useful to efficiently provide care to these populations.

METHODS:

This study presents size estimates of these populations, research on their communication challenges, and potential for AAC supported pain care. Recommendations are made for use, within current medical practices, of an existing commercially available AAC pain scale with training. Training of this pain vocabulary tool, is designed for family facilitation through story book reading (*My Pain Alert® Book* ,!SBN 978-0-9981610-2-0), and daily use in home settings.

Preliterate children- birth through age 6 +/- . Population Percentage: 11.9% 945,964,000 globally (UN, 2019). "Pediatric Pain is commonly undertreated and overlooked." "30% experience chronic pain." (SPPM, 2021). TBI is a leading cause of morbidity and mortality in children, both in the United States and throughout the world. (Appavu, 2019 Abstract)

Children, who will or are experiencing pain, need pain vocabulary learning presented by familiar, trusted people. Applying the word “more” to sensations (pains) rather than things (food) is expecting abstract concept comprehension of little ones. That skill may not be developed. (Vigliocco, 2017) “In addition to their limited verbal ability to express pain, communication vulnerable children’s neurology may also impact on their ability to show other telltale signs of pain.”(McGuire, B. as cited in Johnson, E., 2020, pg.1) A child’s learning and remembering vocabulary requires practice and regular reinforcement. (Komesidou, 2015) (Gevarter,2017). Studies show that some parents can reliably rate their child’s pain. (Voepel-Lewis, 2005). The question then becomes: Is the child without a preceptive parental pain-rater doomed to suffer? Supporting the child’s pain communication effort with AAC is positive. “AAC does not hinder and actually aids speech in...young children with developmental delay.” (Ronski, 2010 pg.350)

Recommendation: Parent reads short narratives about a character with pain which introduce each pain level. Author trialed this approach with My Pain Alert® Scale Communication Tool. (Goldstein, 2016) All 15 field trial families given the book with instruction: “Try this,” reported less stress with subsequent pain events. Some children started using pain level vocabulary immediately. Field trial parents reported being able to choose efficient action in response to their child’s spontaneous expression of their pain level. One family reported less days of hospitalization after a surgical procedure. (Goldstein, 2020, Bibliography) The story book can be introduced at the Primary Care Physician patient examining room. While family waits for medical personnel: Parent reads and child responds by pointing to pictures, making sounds, repeating words, and/or imitating sign language. My Pain Alert® Book e-book (<7mB), can be a download to parents’ cellphone, available as needed, for subsequent family pain events. (Goldstein, 2020)

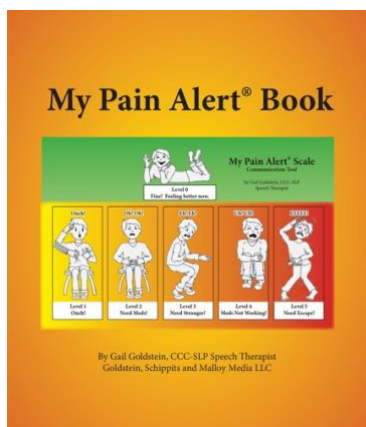


Figure 1

icon for book downloadable in iOS or Android

Intellectually Disabled/Developmentally Disabled (ID/DD) Patients- “Developmental disabilities are a group of lifelong conditions due to an impairment in physical, learning, language, or behavior areas.”(Zablotsky, 2019 pg. 2)
USA Population Percent: 17% (Zablotsky, 2019) Population estimates: globally 52.9 million under age five (Olusanya, 2018)

Characteristic memory and comprehension reductions make FACES pain scale aurally given directions a poor choice for care of these patients. They need accommodated learning, sensitive to their dignity, and modifications such as word banks to support interaction with others. ID/DD patients often present with other physical disabilities.(Zablotsky, 2019) “Aided AAC input may reduce input-output asymmetry and enhance expression and comprehension” (O’Neill, 2018 pg.1743) “Use of AAC does not decrease speech production, 89% of (ID/DD) individuals demonstrated gains.”(Millar, 2006 pg.248) “Positive effects of AAC intervention on speech production were observed across children and adults, ranging in age from 2 to 60 years.”(Millar, 2006 pg.257) Most developed countries have expectations of accommodations being made for these individuals. (Global, 2020)

Recommendation: Use each pain level’s brief story format presented aurally/visually, requesting responses to pictures and text. Use of sign language is offered as a response option. Low-tech AAC such as My Pain Alert Scale + (MPAS+) card or digital book cover and first page (MPAS+ word scale side) provides familiar and relatable pain level words which can be regularly reinforced with daily activities. Are You Hurting? My Pain Alert® Song has a verse for each pain level with a distinct paired vowel sound. (Goldstein, 2020) Pain management is an activity of daily living which should be supported with appropriate vocabulary and reinforced with tools which enhance the individual’s personal care participation. The individual’s participation in their pain care can be a daily “How are you?” home routine with frequent review of pain level words in family, as well as, social, educational, and medical settings.

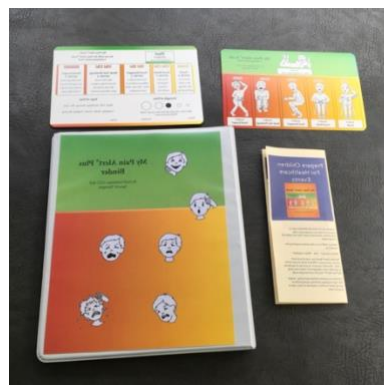


Figure 2

word and picture side MPAS+, plastic paged MPA binder, brochure

Memory Challenged- People experiencing a brain impacting event or disease process need supported communication to convey their pain care needs from the start of their medical event.

Dementia: current estimate 50million, expected to double every 20 years. (WHO, 2021)

Traumatic Brain Injury: 69 million/year worldwide.(Dewan, 2018)

Stroke: 2nd leading cause of death worldwide, adding 5.5million/year (Stroke Facts-CDC,2021) 795,000/yr. USA (Stroke Facts-CDC,2021)

Prior language and cognitive manipulative function are disrupted. Pain scale Instructions, given orally, may not be retained or understood. (Dietz, 2020) (Doyle, 2011) (Swan, 2018) (Johnson, L., 2021) “Preliminary evidence was found to support communication interventions for people with moderate-severe dementia.”(Swan, 2018, pg.836) “AAC...dual purpose tool...drives intersystemic reorganization resulting in improved language performance - and perhaps restoration of language function – while offering communicative alternative during anomic events.” (Dietz, 2020, Conclusions). Smart phone memory aids were found to aid TBI patients. (Wong, 2017) Vocal music can help language recovery. (Sihvonen, 2021) Some progressive communication disorders are supported with AAC. (Utianski, 2020) (Bourgeois, 2010) Patients receiving End-of -Life care should also have access to simplified pain needs communication. (Kinder, 2021) (Bourgeois,2010) Continued use of supports is individual case and time dependent. (Jokel, 2021)

Recommendation: Provide card (MPAS+) modelling response by reading level description, then pointing to level depicted on picture or words side of plastic MPAS+ card. (Goldstein, 2020) My Pain Alert Scale materials include methodology for sorting between two pain levels. (Goldstein, 2020, First Use) Encourage family and staff to use level stories to help patient differentiate their pain care needs on a routine basis. Patient group discussion (of pain, using the MPAS+ cards) will maximize ability of patient to participate in their care over time in residential care settings. (Comer, 2022, Abstract) Provide musical reinforcement with My Pain Alert® Song pain level verses. (Goldstein, 2020) Provide pain management vocabulary supports in palliative care. These methodologies can be paired with awareness of an observational pain rating such as PASLAC-II (Chan, 2021) to achieve a continuity of best practice pain management for those with dense or progressive disease processes.



Figure 3 front and back MPAS+ card showing medication response dots and pain descriptors

Preliminary Research Efforts: 50 two-sided MPAS+ cards (figure 3) and a binder (figure 2) which included My Pain Alert® Scale Communication Tool and update pages in wipe-clean plastic page protectors were sent to SLP at large Washington state hospital in May of 2021 to use, as needed. The ID/DD COVID patients there were without home caregivers to communicate pain management needs. Here are the SLP’s impressions as of February 2022 taken from direct correspondence:

“Obviously this is close to my heart, but I regularly see acute care staff frustrated and feeling powerless to help those who cannot clearly communicate with them about their pain or any of their internal symptoms. Both nurses and MD's express frustration and I often find that when I arrive at bedside RN's are very relieved that "someone" who deals with communication may be able to make things easier for everyone concerned. Call lights are ignored when they are constantly activated by patients who are not getting their needs met because they cannot communicate them clearly! This is awesome. I think an SLP will need to facilitate the program for many institutions, but perhaps if MD's and RN's get the chance to see what the possibilities are, they will be the ones to bring it to their SLP or rehab staff's attention.”

Barbara Coven-Ellis, MA CCC-SLP

RESULTS:

Preliminary and informal assessment of the effect of AAC pain management supports and training for special populations suggest this approach can be effective and stress reducing for patients and family, as well as, cost-effective and stress reducing for healthcare personnel. Americans with Disabilities Act has existed for 30 years without disability adapted pain management communication. It is time to get this right.

CONCLUSIONS:

The pain communication methodology offered for these populations should be: direct, flexible, include vocabulary learning or refreshing, and support improved patient pain care communication. The methodology should also be time and cost effective, reducing stress for all communication partners.

This Poster is offered to heighten awareness of communication challenged patient populations; and support their individual right to provide input directly for their pain care management.

Author is retirement age, not academically affiliated. Author and family published the original : My Pain Alert® Scale Communication Tool in 2016 based on over 40 years SLP experience. Field test of this book was by 15 families: 10 families included a child with serious medical conditions, and 5 families with children of average health. All field test families reported reduced stress with subsequent medical care (Presented as a poster at IASP 11th Forum on Pediatric Pain). My Pain Alert® Book was revised and offered as FLEPub in 2020. MPAS+ card is low-tech wipe-clean AAC. MPAS+ card was printed in 2020 for a presentation to long-term care administrators, addressing pain care with memory impaired adults. MPAS+ Images can be downloaded by individuals *for their use only* from website as a fringe vocabulary with blue background for robust vocabulary AAC methodology or device.

Inquiries about gifts of products for research with special populations may be directed to info@mypainalert.com Research on use by each of the three communication challenged populations would enhance its acceptance and use.

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