

Communication vulnerability in South African health care:

the role of augmentative and alternative communication

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The term 'communication vulnerability' covers long-term communication disabilities, temporary communication disabilities (e.g. while on ventilation), language disparities, cultural differences, and low literacy levels.

The right to health is enshrined in the South African Constitution, yet in the presence of communication vulnerability, equal access to health care of acceptable quality is frequently not realised. Individuals with communication vulnerability are at risk for decreased participation in the healthcare system, leading to increased risk of lack of treatment adherence and adverse events.

The term 'communication vulnerability' covers long-term communication disabilities, temporary communication disabilities (e.g. while on ventilation), language disparities, cultural differences, and low literacy levels. A possible mechanism to reduce the effect of communication vulnerability in the healthcare context is the use of augmentative and alternative communication (AAC). AAC uses a range of techniques to supplement language comprehension and replace speech, and may also assist persons with disabilities to express their healthcare needs.

A systematised review was done of the recent literature on use of AAC for persons with communication vulnerability in the healthcare system. The review identified 24 studies, half of which reported on the perceptions of AAC training, use, or systems. Most studies included health professionals as participants. The studies reported positive perceptions of AAC among healthcare professionals, and the effectiveness of both low- and high-technology AAC in intensive care, general health care, and dental health care. The effectiveness of unaided and low-technology AAC is most promising for South Africa. The results of the studies are considered in the context of the South African healthcare system, and policy, management and practitioner-level recommendations are suggested for the implementation of AAC.

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Introduction

Health care is a fundamental right.¹ This includes access to basic and preventive health care, rehabilitation, physical and psychosocial support, and health care that is acceptable and of good quality.²

In South Africa, individuals with disabilities face barriers when accessing health care, for example, challenges with transport and access to buildings, and disparities in the quality of services received compared with peers without disabilities.³⁻⁸ In particular, these individuals face higher risks in relation to healthcare quality and safety,⁹⁻¹³ with preventable adverse events reported three times more frequently than for peers without communication vulnerability.^{8,11,14,15} This chapter aims to identify strategies that could facilitate communication participation among individuals with communication vulnerability in the South African healthcare system.

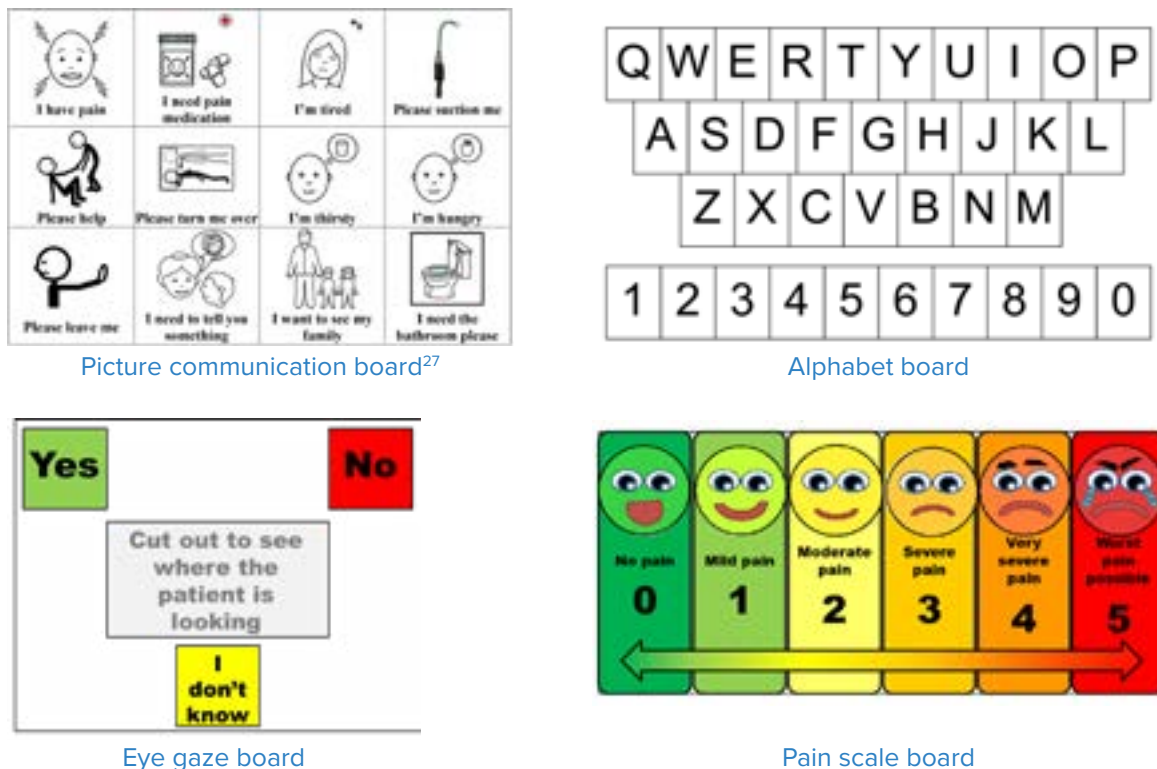
Where communication is difficult, the caring philosophy of healthcare professionals can be eroded, and physical-based care can replace psychosocial and communication-based care.¹⁶ A physical care philosophy increases reliance on objective assessments and decreases communication with the individual.¹⁶ However, best practice in health management supports the sharing of information between providers and individuals, in a “process of mutual influence among people, where information serves as the content”¹⁶

In the absence of mutual communication, declines are seen in treatment adherence and outcomes,¹⁷ empowerment, and participation in health care.¹⁸

Communication vulnerability in health care is not limited to individuals with established disabilities such as speech, language, hearing, cognitive or visual impairments. Temporary communication vulnerability also arises when a person is intubated or ventilated, such as during the COVID-19 pandemic, or when s/he has had a tracheostomy,^{15,16} a stroke, or traumatic brain injury (among other conditions). Although temporary communication vulnerability may resolve, the person’s immediate communication needs cannot be ignored.^{7,8,19,20} Disparities in language between the individual and the health professional may also result in communication vulnerability.^{3,21-23} Similarly, individuals with cultural, ethnic, gender, sexual or religious diversity (cultural and linguistic diversity (CALD)), and individuals with low literacy may experience communication vulnerability.²⁴ For these individuals, both understanding and expression may be impacted, particularly in relation to asking questions and expression of concern and consent.^{21,24}

Augmentative and alternative communication (AAC), however, provides a range of techniques and resources that facilitate non-functional communication.^{24,25} AAC includes aided techniques (alphabet boards, picture communication boards, picture-supported text, and speech-generating devices (SGDs) (Figure 1), as well as unaided techniques (including gestures and signs from sign language).²⁶

Figure 1: Examples of AAC tools



According to researchers in the field, use of AAC in health care can decrease the need for sedation and time in intensive care²⁸ (thus reducing strain on the health system during times such as the COVID-19 pandemic), improve treatment adherence,²⁵ and increase patient satisfaction^{15,24,25,28,29} and feelings of empowerment associated with increased participation in health care.²⁹

In South Africa, a minimum of two and a half million people are at risk for communication vulnerability in the healthcare system,⁶ and many additional individuals encounter language disparities, CALD, and literacy difficulties. Yet, recent reviews on the use of visual communication aids among individuals with low literacy levels found few studies from low-and middle-income countries.^{25,a}

This chapter aims to highlight evidence-based recommendations for the health care of individuals with communication vulnerability, with a view to informing policy and practice in South Africa. A systematised review was done to identify the existing literature on AAC interventions in health care. The results and recommendations are presented in relation to the South African context.

A systematised review has a narrow but detailed focus, rather than the broad overview of a scoping review.³⁰ It has similar search and quality-evaluation processes to a systematic review, but can be applied where a limited number of studies preclude statistical synthesis and meta-analysis.³⁰

This review included AAC interventions among individuals with communication vulnerability or their healthcare professionals, in healthcare settings. Perceptions of health care not related to AAC intervention, and experiences independent of AAC intervention, were excluded. Search terms and databases were identified using the population, intervention and outcomes methodology,³¹ followed by piloting. The reference lists of included articles were also hand searched. Title and abstract screening, and full-text screening were conducted by both authors independently. Disagreements were discussed until consensus was reached. Reliability of 97% was found for the title and abstract, and 100% at full-text level. Quality screening of studies was conducted using the National Service Framework for long-term conditions;³² this was done by the first author and confirmed by the second author (100% agreement). Studies of poor quality were excluded.

Twenty-four articles were identified for review: 20 from high-income countries and four from middle-income countries (Botswana 1, India 2, and Brazil 1). Data were extracted and synthesised using thematic analysis.³³ Themes relating to where the intervention occurred (e.g. intensive care, dental care), or with whom (e.g. adults with amyotrophic lateral sclerosis (ALS), children), and the type of AAC implemented, are reported in Table 1 below. Additional themes relating to perceptions of AAC, and the effects and type of AAC, are reported in key findings.

Table 1: Type of AAC intervention and results

Type of AAC	Intervention	Results
Communication in the ICU		
LT-AAC	Training of ICU nurses in AAC. ^{34,35}	Nurses reported: <ul style="list-style-type: none"> Increased knowledge, skills and confidence. A need for management support. An appreciation of AAC. Attitude changes. The need for ongoing skill sharing.
HT-AAC	Introduction of HT-AAC to patients in the ICU and clinical staff. ³⁶⁻³⁸	Patients reported that: <ul style="list-style-type: none"> HT-AAC was significantly better than no access. Pre-programmed messages were most successful, but additional strategies were needed as time progressed. The device was often placed out of reach. Nurses reported that: <ul style="list-style-type: none"> The app was easy for nurses and patients to use. The app facilitated patient communication.

a Mbanda N, Dada S, Bastable K, Gimbler-Berglund I, Schlosser RW. A scoping review of the use of visual aids in health education materials for persons with low-literacy levels. Manuscript submitted for publication.

Type of AAC	Intervention	Results
LT-and HT-AAC	Training of ICU nurses. ³⁹⁻⁴¹	<p>Researchers reported an:</p> <ul style="list-style-type: none"> • Increase* in communication acts. • Increase* in clarification acts. • Increase* in successful communication of pain. • Increase* in the quality of positive communication from nurses. <p>Nurses reported that:</p> <ul style="list-style-type: none"> • Challenges were related to patient fatigue, cognitive impairment, reduced muscle strength, time constraints, and the limited number of staff trained. • AAC was not always necessary. • The best way to facilitate communication was through a systematic strategy initiated by the nurse. • Training was helpful for basic communication strategies, but advanced strategies were not always useful.
Communication in general healthcare settings		
LT-AAC	Training of nurses/EMS personnel. ^{42,43}	<p>EMS personnel and nurses reported:</p> <ul style="list-style-type: none"> • Increased confidence communicating with individuals with communication vulnerability. • That the supports were helpful and needed.
HT-AAC	Information videos and pictorial supports. ⁴⁴⁻⁴⁶	<p>Patients reported:</p> <ul style="list-style-type: none"> • Increased knowledge, skills and satisfaction. • Concerns regarding information access and security on electronic devices. • That a visual application can provide fast, intuitive communication options in emergency situations.
Communication and compliance in dental health care		
Unaided AAC	Training of dentists in sign language. ⁴⁷	<p>Researchers reported:</p> <ul style="list-style-type: none"> • An increase* in understanding after training.
LT-AAC	PECS visual schedule provided to children with ASD. ⁴⁸	<p>Researchers reported:</p> <ul style="list-style-type: none"> • An increase in the number of steps, and speed of completion when PECS was used. • Lower levels of distress when PECS was used.
LT-and HT-AAC	<p>Pre-dental visit information provision for children with special needs, HT- and LT-AAC.⁴⁹</p> <p>A comparison of PECS and HT-AAC for visual schedule presentation to children with ASD.⁵⁰</p>	<p>Researchers reported:</p> <ul style="list-style-type: none"> • Improvements* in behaviour and dental health care when either HT- or LT-AAC were used. • Children using HT-AAC acquired skills faster.
Communication for individuals with neurological impairments		
Unaided AAC	KWS training for caregivers. ⁵¹	<p>Researchers reported that:</p> <ul style="list-style-type: none"> • Direct training resulted in increased* use of keyword signing and was more accurate than secondary training. • Attitude did not correlate with KWS usage.

Type of AAC	Intervention	Results
HT-AAC	HT-AAC implementation. ^{52,53} HT-AAC device training remotely for facilitators. ⁵⁴	Researchers reported that: <ul style="list-style-type: none"> Participants were able to use and enjoy the HT-AAC systems in various situations. Facilitators were successfully trained using the remote training programme.
Anxiety and behaviour management for children		
LT-AAC	Symbol-supported story intervention prior to intervention to explain procedures. ⁵⁵⁻⁵⁷	Nurses reported: <ul style="list-style-type: none"> Use of the LT-AAC as a positive distraction during procedures. Anxiety reduction, behaviour calming and increased co-operation during assessments and procedures. An objective measure of cortisol levels did not show differences with the use of the LT-AAC, but methodological challenges were reported.

* A significant difference was reported in the study.

ASD = autism spectrum disorder; EMS = emergency medical services; HT-AAC = high-technology-aided AAC; ICU = intensive care unit; KWS = key word signing; LT-AAC = low-technology-aided AAC; PECS = picture-exchange communication system.

Key findings

The interventions in this review were implemented in the ICU,^{34,35,37-41} general health care settings,⁵⁵⁻⁵⁷ and in pre-hospital EMS.⁴² The studies primarily targeted nursing staff for training in the use of AAC.^{34,35,38-40,55,58,59} One study considered the efficacy of remote training for AAC facilitators.⁵⁴ Other interventions focused on information sharing,^{43,46} and patient-provider communication^{44,45} with individuals with communication vulnerability. Communication also targeted individuals with amyotrophic lateral sclerosis^{52,53} or intellectual disabilities.⁵¹ Four studies concluded that AAC improved the compliance of and communication with children who were deaf,⁴⁷ or who had autism spectrum disorder,^{48,60} or special needs,⁴⁹ during dental health care.

Perceptions of AAC

Perceptions of high-and low-technology AAC were positive in 12 studies. Nurses reported increased confidence in using AAC to communicate with patients.^{34,35,38-43,55} Dependence on management support and lack of time were identified as barriers to the use of AAC.⁴¹ Similarly, individual limitations were identified, including fatigue and low levels of alertness.^{34,37,40,41}

Effects of AAC

Use of AAC increased compliance and decreased distress among children with special needs during dental procedures,^{48,49,59} but was inconclusive in a day hospital setting.⁵⁵⁻⁵⁷ Studies involving adults with communication vulnerability provided evidence of successful use of high-technology AAC among participants.^{36,37,52,55}

High- or low-technology AAC

Studies comparing the efficacy of low-technology AAC (PECS, symbol-supported stories) and high-technology AAC (iPad apps, interactive videos), reported that high-tech AAC was more effective than low-tech AAC in the ICU⁴⁰ and dental health clinics.^{49,60} However, the studies also reported that low-tech AAC was more effective than no AAC.^{39,49}

Discussion

AAC could improve communication in health care for persons with communication vulnerability. However, for communication to be enhanced through AAC it is imperative that mutual sharing of information be facilitated.²¹ Studies in this review reported on the success of mutual information sharing across settings and types of AAC.^{36,43-45,47-49} The results were primarily from high-income countries, and half of the studies reported only on perceptions of AAC. Although perceptions of healthcare professionals and users can influence the success or abandonment of an AAC system,⁶¹ further clarity on the efficacy of interventions is required.

This review highlighted the ongoing challenge of physical care taking precedence over psychosocial and communication care, as doctors and rehabilitation professionals (who set the tone for patient care^{62,63}) were found to be largely excluded from AAC training and studies. In South Africa, where systemic challenges also include ineffective communication and financial and staff shortages,⁶⁴ the support of management is particularly relevant, as the pressure exerted on the system drives behaviour in the system. For example, limited staff reduces the time available for each patient and may lead to a physical care focus.^{16,34,37,40,41}

This review also highlighted successful training in basic communication skills^{36,39} using low- and high-tech AAC,^{34,35,42} but emphasised the need for ongoing training,³⁵ supported by communication professionals.⁴¹

In the South African setting, basic communication skills training could be conducted and supported by speech or occupational therapists who have received AAC training, and these interventions should include a range of unaided and low-tech AAC strategies.^{37,39-41} Unaided and low-tech AAC interventions have been found to be effective in improving patient-provider communication⁴⁷⁻⁴⁹ and require generic materials that are cost-effective and available in most healthcare settings (e.g. pen and paper, a printer, photographs or real objects).

Although resource-friendly unaided low-tech AAC may be preferred in South Africa, higher-efficacy high-tech AAC^{37,39,41} should not be overlooked. Specifically, the efficacy of universal technology (e.g. commercially available tablets or phones) and downloadable applications has been highlighted.^{38,40,46} Approximately 51% of South African adults are reported to own a smart phone.⁶⁵ Hence it may be feasible to implement high-tech AAC with an individual's personal phone/tablet, which s/he can then take home. Use of an individual's personal device may be particularly applicable for individuals with permanent communication vulnerability. Conversely, the suitability of applications needs to be considered, as most are in English and are developed in high-income countries.

In South Africa, training of professionals in the use of AAC and the provision of materials with AAC supports (e.g. picture communication) could increase the mutual

sharing and understanding of information between individuals with communication vulnerability and healthcare professionals, leading to improved participation in health care, better health outcomes, and increased empowerment. Nevertheless, this recommendation is made with the caveat that communication varies across cultures, which may impact the perception of symbols⁶⁶ or the acceptability of an AAC system, hence a one-size-fits-all model cannot be applied in South Africa.

Recommendations on use of AAC in the South African healthcare setting

The following recommendations were developed in alignment with the results of the systematised review and the mission of the National Department of Health, namely to facilitate the development of a culture of communication participation in health care.⁶⁷ Management/leadership recommendations are given in Table 2, and provider education recommendations in Table 3. It is recommended that individuals with communication vulnerability be included in all stages of training and implementation.

Policy recommendations

It is recommended that national policy be developed on communication vulnerability and the facilitation of communication participation in health care. This should help to guide budget and resource allocation.

Management/leadership recommendations

Table 2: Management/ leadership recommendations – AAC implementation

Aims	Personnel	Intervention
Institutional level		
Facilitate a culture of communication.	Healthcare facility management: financial, medical, nursing, allied health professional, communication, patient-care and support-service managers.	<p>Training on communication vulnerability:</p> <ul style="list-style-type: none"> • Who has communication vulnerability? • Risk of adverse events, treatment adherence, participation. <p>Staff to drive the culture of communication.</p> <p>Needs identification for AAC:</p> <ul style="list-style-type: none"> • Training • Materials • Support • Local languages and cultures • Specialised units (ICU,¹⁶ paediatric ICU (PICU),⁶⁸ surgical,¹⁵ neurological²⁴). <p>Allocation of budget.</p>
Unit level		
Provide training and a support system to grow the culture of communication.	<p>Unit management, healthcare professionals and support services.</p> <p>All staff who come into contact with patients in the unit. Medical doctors should be trained with their unit.</p>	<p>Direct (in person) basic communication skills training with all staff (all shifts).</p> <p>Identification of an individual to lead AAC implementation, encouraging others and ensuring availability of materials (liaise with management).</p> <p>Unit guidelines:</p> <ul style="list-style-type: none"> • Who determines communication vulnerability? • How will this be recorded? • Where will materials be stored? (in and out of use) <p>Identification of a clearly defined communication support and referral process.</p> <p>Evaluation of training and future needs identification.</p>

Practitioner recommendations

The aim of AAC is “to facilitate communication through a systematic communication strategy”.³⁸ Santiago and

Costello⁶⁸ describe three phases of AAC need. An additional ‘pre-need’ phase has been added here. The phases are described in Table 3.

Table 3: Practitioner recommendations – AAC education

<p>Phase 1: Pre-need identification of at-risk individuals, and communication needs assessment Communication needs: Training in AAC tools; AAC resources; recording tools for current preferences and needs.</p> <p>Screen all individuals on entry to the units for communication vulnerability risks, including:</p> <ul style="list-style-type: none"> Established communication vulnerability (e.g. ASD, ALS). Acute-onset speechlessness (e.g. neurological conditions, pulmonary or airway disease, trauma, spinal injury). At risk (e.g. postoperative intubation or tracheostomy, head and neck surgery). Individuals with CALD (e.g. language disparities, low literacy). Individuals receiving palliative care and end-of-life support. <hr/> <p>Identify communication needs:</p> <p>Current AAC user:</p> <ul style="list-style-type: none"> What is the individual's current communication system? How will the individual access his/her system in the healthcare setting? For example, direct access, partner-assisted scanning, eye gaze, switch access. Ensure that this communication system is noted and available in the ward. <p>User at risk for short-term communication disability:</p> <ul style="list-style-type: none"> Introduce individuals to AAC and train them in the use of the system that will be available when they are unable to speak. Discuss communication preferences with individuals and their families. Identify additional needs the individual might want to communicate, but that are not available on the standard board. Adapt the communication board to meet those needs.
<p>Phase 2: Emerging from sedation Communication needs: To gain attention. AAC for basic communication, and an option to indicate 'what I want to say is not here'.</p> <p>Ensure that individuals are able to communicate the following needs:</p> <ul style="list-style-type: none"> Gain attention, e.g. a communication button or noisemaker. Express yes/no answers to basic questions. Express pain. Express basic needs.
<p>Phase 3: Increased wakefulness Communication needs: Extend communication boards, including mechanisms to format individual communication options or topics.</p> <p>Provide for:</p> <ul style="list-style-type: none"> More complex communication with healthcare providers using symbols and text. Communication with family, expression of personality, including humour and non-medical communication.
<p>Phase 4: Diverse and broad communication access Communication needs: A complex communication system including multiple modes of communication and the ability to create and use novel messages independently.</p> <p>A broad communication system is able to support communication across multiple life situations and includes:</p> <ul style="list-style-type: none"> Broad vocabulary. Multiple pages. A range of communication topics. Individuals may have multiple systems for use across different settings. Access methods may change across different environments and over time as a person becomes fatigued.

Limitations of the review

Limitations of this review include use of a limited date range for the search, and restriction on chapter length.

A further limitation was use of studies from high-income countries to guide the development of recommendations for South Africa.

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