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Personalization of Patient-Provider Communication Across the Lifespan

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Abstract

People with disabilities are more likely to be hospitalized and use healthcare services relative to people without disabilities. They also report experiencing negative experiences interacting with health care providers during these encounters placing them at risk for preventable adverse medical events, poor quality of life, and dependence on others. Fortunately, providers and people with communication disabilities can take steps to improve these interactions by personalizing and implementing communication supports to empower people with communication disabilities to actively participate in these interactions and improve outcomes. The purpose of this article is to describe strategies that health care providers can use to develop and implement personalized communication supports for children and adults with communication disorders during health care interactions. Additional strategies are provided to guide people with disabilities as well as their community/school providers and families to prepare for health care interactions. Case examples are provided to illustrate use of these strategies in acute care, inpatient rehabilitation, and outpatient settings. The use of emerging training tools (e.g., video visual scene displays) and AAC partner training formats (e.g., just-in-time training) are also presented as future directions to expedite learning and implementation of communication supports in fast-paced and time-limited health care interactions.

Introduction

Regardless of their age or disability status, all people have the right to an accessible environment and healthcare as well as the freedom of expression using a communication method of their choice (United Nations, 2006). To achieve these rights and freedoms within the healthcare environment, patients and providers must be able to effectively exchange information and actively participate in healthcare interactions. Further, these exchanges which typically occur during patient-provider interactions should be patient-centered in nature meaning care provision is “respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical

decisions” (Institute of Medicine, 2001, p.6). Patient-provider interactions may include patients sharing information about their medical history, symptoms, and preferences as well as asking questions about these topics. Providers may share information about diagnoses and results, answer questions about patient symptoms, and ask questions to patients. Typically, patient-provider communication occurs using speech; however, people with communication disabilities, including those who have language disorders and/or limited functional speech, rely upon and prefer to use augmentative or alternative communication (AAC) strategies (e.g., use of picture symbols, speech-generating devices, gestures) to participate.

Unfortunately, current evidence suggests that people with communication disabilities experience poorer health and health outcomes relative to people without communication disabilities (Stransky et al., 2018). In many countries (e.g., the United States), health care organizations are expected to provide the necessary personnel, training, and tools to support patients to actively participate in their care and communicate with staff (The Joint Commission, 2010). However, despite existing mandates for organizations to provide communication supports, people with communication disabilities, have repeatedly reported negative patient-provider communication experiences (Blackstone et al., 2015). Specifically, people with communication disabilities have reported: (a) a higher level of dissatisfaction with the quality of their care relative to those without communication disabilities (Hoffman et al., 2005), (b) limited access to effective communication tools (e.g., Hemsley & Balandin, 2014; Hemsley et al., 2013), and (c) interactions with staff who either are untrained (e.g., Hemsley et al., 2013) or do not use the patient’s preferred communication strategies (e.g., Morris et al., 2014). Ultimately, these factors suggest that people with communication disabilities are not receiving optimal patient-centered care and, instead, are at heightened risk for preventable adverse medical events (Bartlett et al. 2008), poor quality of life, and dependence on others (Hemsley & Balandin, 2014).

In general medical units, nurses have reported that 40% of their patients experienced difficulties communicating about their healthcare (O’Halloran et al., 2017) and, in the United States, it is estimated that approximately 14% of hospitalized patients cannot summon help using a nursing call system, an important skill necessary to initiate the communication process (Zubow & Hurtig, 2013). Without use of communication supports tailored to meet patient needs, effective patient-provider communication involving patients with communication disabilities is difficult to achieve. Fortunately, providers and people with communication disabilities can take steps to improve healthcare interactions by creating and implementing personalized communication supports to empower active patient participation in these interactions and ultimately improve outcomes.

General communication supports such as standard alphabet boards or picture boards (e.g.,¹EZ Board by Vidatek,²Talk to Me Technologies, Medical Communication Boards) are prevalent in health care facilities. Patients, clinicians, and healthcare organizations can now easily download or purchase excellent communication supports containing vocabulary

¹EZ Board™ by Vidatek, <http://www.vidatak.com/ezboards.html>

²Talk to Me Technologies, Medical Communication Boards, <https://www.talktometechnologies.com/pages/communication-boards-free-download>

content related to patient-provider interactions (e.g., Patient Provider Communication Network, 2020). However, clinicians must be cautious not to use the same materials with all patients with communication disabilities, as these tools do not fully meet each patient's needs. Instead, providers should tailor communication supports to meet the patient's unique skills and needs and integrate these supports within across all facets of the healthcare continuum. The challenges to creating and implementing communication supports are well documented in the literature based (e.g., time constraints, Gormley & Light, 2019); however, providers and patients can take steps to mitigate the effects of these constraints during interactions.

Purpose

The purpose of this article is to describe: (a) factors that are important to consider when developing and implementing personalized communication supports in health care settings, and (b) strategies that providers can use to develop and implement personalized communication supports for children and adults with communication disorders during health care interactions. This article will also provide strategies to guide people with disabilities as well as their community/school providers and families to prepare for health care interactions. As communication supports are considered AAC tools, the Participation Model (Beukelman & Light, 2020) was used to frame the factors to consider and the strategies recommended to use with people who have communication disabilities in health care settings. The Participation Model outlines “a systematic process for conducting AAC assessments and designing interventions based on the functional requirements for participation in life activities” (Beukelman & Light, 2020, p. 29). The factors considered in this paper are all encompassed within this model (i.e., identifying patient participation patterns and communication needs, assessing opportunity barriers and supports, assessing patient capabilities and access barriers, planning and implementing interventions for today and tomorrow, and evaluating intervention effectiveness; Beukelman & Light, 2020). The specific strategies and recommendations provided in this paper are informed by existing patient-provider communication and AAC literature as well as the authors' clinical experiences.

Factors to Consider When Personalizing Communication Supports for Health Care Interactions

As designing healthcare communication supports is not a “one-size fits all” approach (Gormley & Light, 2019), unique factors related to the patient and the environment must be considered for use in patient-provider interactions (Marshall & Hurtig, 2019). The following sections briefly highlight patient and environmental factors that influence the design and implementation of communication supports for patients with communication disabilities.

Patient Factors Impacting Patient-Provider Communication

Patient Age.—Children and adults with communication disabilities must actively participate in their healthcare; however, their active participation and the content of the interactions may look different based on the patient's age. The ultimate goal is for adults with communication disabilities to self-direct their care and independently engage in

shared decision-making with their provider, express their preferences and values to the provider, and fully understand the information providers present. To do so, they require the medical vocabulary to ask and answer questions about their care (e.g., “how long with the operation take?”, “what are the possible side effects?”), request assistance (e.g., ask for pain medication), communicate their preferences from routine activities (e.g., “I would like the head of my bed raised”) to serious decisions (e.g., advanced directives). Further, providers may need to use visual or written communication supports that supplement their spoken instructions, explanations, and information, especially when discussing complex medical topics and information.

For children, their parents and guardians must be fully involved in all aspects of care while children learn essential self-determination, decision-making, and communication skills. For children with communication disabilities, it may be difficult to acquire these and other language development skills in the healthcare environment despite lengthy or frequent hospital stays (Gormley & Williams, 2019; Burns et al., 2010). In a recent observational case study, Gormley and Light (2020) found that healthcare staff tended to dominate healthcare interactions with young children with communication disabilities and seldom used AAC supports in these interactions. Adolescents with communication disabilities who use AAC have also been noted to be passive participants in healthcare interactions; however, these same individuals reported wanting to actively participate in these interactions despite reporting limited opportunities to do so (e.g., Hemsley et al., 2014). To ensure active participation in health care interactions, children and adolescents also require medical vocabulary to request assistance (e.g., “I need suction”), make age-appropriate choices (e.g., when taking vitals, choose what happens first getting their temperature checked or blood pressure taken), and ask questions (e.g., “where is my mom?”). Further, integrating play activities and play-based vocabulary within healthcare interactions can be a powerful tool to increase child engagement, help them cope with stressors associated with the medical environment, and potentially increase compliance for new and potentially frightening tasks (e.g., blood draws; Burns-Nader & Hernandez-Reif, 2016).

Patient Needs, Skills, and Level of Recovery.—Every person with a communication disability has a unique set of needs, skills, and preferences that requires a unique set of communication supports to promote their full participation in healthcare encounters. Clinicians can best identify these needs, skills, and preferences through a thorough AAC assessment, which then can be matched to appropriate AAC options (Beukelman & Light, 2020). However, in the healthcare environment, this assessment may be challenging to complete due to time constraints, patient fatigue, and busy schedules (Gormley & Light, 2019) thus placing quick, efficient, and effective assessment techniques paramount. To assist clinicians with the AAC assessment in medical contexts see Tables 1 and 2, which are comprised of questions and materials that can be used to assess opportunity barriers and supports as well as patient participation patterns, unmet communication needs, communication level, skills, and preferences during healthcare interactions.

One way to identify appropriate and meaningful communication strategies for a patient is to consider their level of recovery (if a new onset communication need is present) and/or their level of communication development. For example, to prepare for interactions with a

person with aphasia, use of Garrett and colleagues (2005) aphasia classification system may be useful to determine if the person best falls within one of the following categories of AAC communicators – emerging, contextual choice, transitional, stored-message, generative, and specific need. For people recovering from a traumatic brain injury, knowledge of the patient’s level on the Ranchos Los Amigos Scale (Ylvisaker & Szekeres, 1998) may also be useful to understand the patient’s cognitive-linguistic skills that influence their use of communication supports. Similarly, for children who are recovering from illnesses in the pediatric intensive care unit, clinicians can use the framework described by Costello and colleagues (2010) to identify the phases of recovery and common communication needs related to the phase. These phases include: (a) Emerging from sedation: getting attention and responding to yes/no questions, (b) Increased wakefulness: communicating basic information with staff and family, and (c) Needing broad and diverse communication access: communicating about and beyond the hospital environment (Costello et al., 2010).

Young children with a new onset communication difficulty and many individuals with developmental disabilities are considered *beginning communicators* (i.e., they are in the early stages of communication development; Beukelman & Light, 2020). Patients who are in the early levels of recovery or who are beginning communicators may have limited opportunities to interact with staff (e.g., Gormley & Light, 2020; Gormley & Light, 2019). This may lead staff to not provide consistent communication opportunities, direct less speech to the patient, or feel frustrated or helpless when caring for patients. Use of personalized communication supports and vocabulary also provides an opportunity to increase patient engagement during health care interactions. When designing and using communication supports for beginning communicators to participate in healthcare interactions, clinicians should consider the stages of communication development (i.e., preintentional, intentional but presymbolic, early symbolic, and combining symbols) to ensure that the supports match the communicator’s existing communication level and promote ongoing learning and participation.

Patient Preferences.—Although patients may overlap in terms of their age, skills, and level of recovery, ultimately their preferences and choices should dictate the way in which they express themselves and participate in health care interactions. Unfortunately, patients with communication disabilities report that providers do not frequently ask about their communication preferences (Iezzoni et al., 2004) nor did they use preferred communication strategies to interact with patients with communication difficulties (Law et al., 2005). Morris and colleagues (2014) completed a study investigating patient-centered communication involving patients with aphasia, their companions, and their physicians. In this study, all groups identified strategies that were consistent with patient-centered communication (e.g., providing opportunities for the patient to speak, adapting information to the patient’s level of comprehension); however, patients and their companions identified other strategies (e.g., writing down key words, using gestures, using visual aids) that they viewed as essential to use with people with aphasia. Unfortunately, during recorded patient-provider communication interactions, physicians did not use the aphasia-specific strategies leaving much room for growth in the implementation of patient-centered communication with this population.

Environmental Factors Impacting Patient-Provider Communication

Staff Knowledge and Skills.—Unfortunately, many health care providers such as nurses (e.g., Finke et al., 2008; Simmons et al., 2019), physicians, and allied health professionals (e.g., Burns et al., 2017) do not have the necessary pre-service or in-service opportunities to learn how to interact with patients with communication disabilities. Without providers having a foundation of knowledge about effective communication strategies, it is not surprising that they have difficulty using these strategies with patients with communication disabilities and those who require AAC. Creating a healthcare workforce that is knowledgeable about patient communication needs requires time, resources, and the creation of a “culture of communication” (Marshall & Hurtig, 2019). However, providers who are experts in supporting patient communication (e.g., speech-language pathologists) as well as patients and their families can take steps to teach unfamiliar healthcare providers to interact effectively with patients with communication disabilities. These providers can also take steps to ask patients and their families about their preferences and effective communication supports. Further, patients, their families, and/or speech-language pathologists (SLPs) should identify and share information about the patient’s communication skills, needs, and preferences with unfamiliar providers to optimize patient involvement in their care.

Availability of Communication Materials.—Stans and colleagues (2017) completed a scoping review of environmental factors that influence communication between patients with communication difficulties and health providers. The results of this review suggest that the availability of AAC tools that are tailored to meet individual patient needs played a positive role on the effectiveness of patient-provider communication interactions. However, recent observational studies suggest that providers rarely used picture, visual, or written communication supports during interactions (e.g., Gormley & Light, 2020; Morris et al., 2014) despite these modes being the preferred method of communication for the patient. Healthcare providers such as SLPs and nurses also have reported not having access to communication materials that meet patient needs (e.g., Gormley & Light, 2019). Before communication supports can be used, patients and providers must first have ready access to a diverse set of options to match the patient and environmental needs. Healthcare organizations should have a range of equipment that can be used to support patients with a wide variety of language, cognitive, and motor needs, especially in the event that patients are not able to bring their own communication supports with them (e.g., in an emergency situation) or if there is a new communication difficulty. Lists developed by researchers and clinicians of suggested communication equipment for hospitals are also available to healthcare providers when starting to build their resource bank (e.g., Blackstone et al., 2015).

Healthcare Continuum.—Another factor that impacts the development and use of communication supports in patient-provider interactions is the setting that the interactions occur in. Each setting presents with unique priorities of care, routines, time constraints, and environmental demands that need to be considered when developing and implementing personalized communication supports and training efforts. For example, in acute care settings, patients are often recovering from significant or even life-threatening illness or

injuries requiring substantial medical and pharmacological intervention. Typically, the focus in this setting is providing life-sustaining measures and ensuring the patient's medical stability. Patients in this setting may interact with many providers and be significantly fatigued, limiting their alertness and amount of time they can tolerate interactions. However, in this setting, patients may be faced with making serious decisions (e.g., end of life), need to communicate their preferences during their cares, and communicate their pain, symptoms, and comfort level to others. As patients transition to rehabilitation, their opportunities for participation expand as they engage in activities focusing on recovery and preparing for transitions into home and community environments. A patient's recovery at this time can be dynamic and rapidly change requiring frequent monitoring and updating of communication supports to continue to meet their developing needs. See Blackstone and colleagues (2015) for a comprehensive review of the difficulties, priorities, and potential communication solutions associated with patient-provider communication in the following settings - adult and pediatric acute and intensive care hospitals, rehabilitation settings, long-term care, outpatient clinics, and hospice.

Strategies to Personalize Patient-Provider Communication

Regardless of health care setting, patient age, patient developmental level, and patient skills/needs, providers must offer frequent opportunities for patients to participate in health care encounters, make their needs and preferences known, ask and answer questions, and summon assistance. To ensure that children and adults are actively involved in their care, providers should talk directly to the patient, offer age-appropriate choices (e.g., distractor items, order of vitals), provide sufficient wait time for the patient to understand and express themselves, and offer personalized communication supports containing appropriate vocabulary to engage in the interaction. The next sections discuss strategies that providers, patients, and their families can use to personalize communication supports for healthcare interactions. Case examples are also presented to illustrate how strategies can be incorporated in healthcare situations involving children and adults with communication disabilities.

Customization and design of communication supports

Many pre-made low-tech communication boards exist and are often available in hospital settings (e.g.,¹EZ Board by Vidatek). These boards can provide a starting point to support communication, have been designed to support a wide range of users, and often include a content to support general medical and basic communication content. However, this generic approach may not fully meet the communication needs of some individuals as these boards: (a) may not include specific content required to discuss the individual's condition, (b) may not include the kinds of messages the individual needs to communicate in their daily routines, (c) may be too cluttered or difficult for the individual to use due to visual and cognitive processing issues, or (d) may not be accessible for those with motor deficits (e.g., paresis, paralysis, or weakness that makes pointing with their hands difficult).

Personalization of communication supports is first dependent upon the specific needs of the individual with communication disabilities. Personalization can include tailoring the content

of specific messages/vocabulary, the organization and layout of communication content to support alternative access, the way messages are represented (words, icons, digital images), and the layouts and size of communication content to accommodate for visual and cognitive processing challenges (Beukelman & Light, 2020). Not only does personalization support the patients' expressive communication, but it can also support their comprehension by augmenting the mode that information is received (e.g., visually). Effective personalization considers all of the expressive and receptive components of the interaction and seeks to design supports that meet these needs in a way that can substantially improve the quality of patient-provider communication. See Table 3 for a list of personalization strategies for patient-provider interactions.

Personalizing messages.—When personalizing communication content for patients, several factors should be considered. First, providers should ask what are the specific, most urgent needs that might need to be expressed related to the individual's current condition? In a study by Fager and colleagues (2019), adults who have recently received care in a healthcare setting selected specific vocabulary and content related to their condition (e.g., suctioning for those on a ventilator, mouth cares for those who were unable to eat for a period of time) to be included in communication supports. However, in the same study, healthcare staff often selected a wider range of general messages that could meet the basic needs of several patients yet the patients themselves preferred more targeted messages that were personalized to their condition. Additionally, Fager and colleagues (2019) found that patients selected a wider range of messages related to asking questions about their specific condition, prognosis, and questions related to the management of their care compared to healthcare professionals. While AAC supports in medical settings typically focus on the expression of urgent medical care needs, finding ways to personalize these supports so that patients can engage in their care by being an active participant in care-planning and medical decision-making should not be overlooked.

When personalizing vocabulary to be included in AAC supports, clinicians should identify what information is most useful, relevant, and important to the patient that may serve as a way to reduce the amount of extraneous information presented in communication supports which, in turn, could reduce the overall visual and cognitive processing required to find messages to communicate urgent basic needs. Providers must take time to investigate the patient's priorities; however, providers often cite time constraints as a barrier to personalizing communication tools. Fortunately, many tools are available to assist providers with programming personalized vocabulary onto high-tech and low-tech communication supports. One option is to create and maintain a bank of communication vocabularies with text, photo, and/or picture options to help expedite the personalization process. The pre-made communication banks can easily be saved, modified with the patient's preferred vocabulary, and printed/uploaded as a new copy for quick use in an interaction. Many existing AAC software programs also allow for cloud-based storage which may make setting up and personalizing vocabulary more efficient. For instance, instead of starting from "scratch" each time a patient needs a communication system, a set of vocabulary that is commonly used on an intensive care unit can be created, saved on the cloud, downloaded

to the patient's bedside tablet, and then modified at bedside to incorporate their personalized content.

Further, existing communication technology (e.g., Snap Scene by Tobii Dynavox) also allows for *just-in-time programming* - the addition of new vocabulary "on the fly" during daily interactions (Beukelman & Light, 2020, p. 222). Just-in-time programming can be completed by quickly taking a photo or video during interactions with people with communication disabilities and adding text and/or audio output to represent a concept embedded within the image. Research suggests that beginning communicators take more turns when using technology that allows for just-in-time programming (e.g., Holyfield et al., 2017) and communication partners can quickly learn how to program such technology (e.g., Caron et al., 2016). Although research has not directly evaluated the effects of technology that incorporate just-in-time programming in healthcare settings, use of this feature may mitigate the environmental demands associated with the setting by quickly allowing patients, their families, and providers to quickly add new, personalized vocabulary for medical encounters. Future research should be completed to apply these techniques to support patient-provider communication.

Personalizing access and layout.—For patients who are unable to temporarily (e.g., due to weakness/fatigue or paresis) or permanently (e.g., due to paralysis) point to communication displays using their hands, content layout may need to be personalized to accommodate an alternative access method. For example, displays spaced out into quadrants and placed upon clear, plexi-glass board might be useful for individuals who require eye gaze to access communication messages. For others, content may need to be semantically organized and placed within a format so that communication partners can auditorily scan options for the patient to signal yes/no in order for a message to be communicated (e.g., partner-dependent scanning; Beukelman & Light, 2020).

Sedation and early recovery may also affect an individual's ability to visually and cognitively process communication content presented to them. Communication displays may require changes in size and number of communication targets, spacing of content, and to accommodate visual and cognitive processing challenges (Brown et al., 2015; Light, et al., 2019; Wilkinson & Jagaroo, 2004). Selecting displays that are likely to be familiar to the patient may also facilitate successful use of the display if the patient experiences cognitive changes. For example, the onscreen keyboards in mobile technologies often default to QWERTY layouts. Preliminary research by Gormley & Fager (2020) has indicated that the QWERTY layout may be preferred and easier to visually process compared to alphabetic layout by individuals with and without brain injury. Alleviating extraneous cognitive and visual processing required to use an AAC support by carefully considering the size, spacing, and number of targets as well as the likelihood of general familiarity with the display will help patients benefit from these supports when cognitive and visual process issues are present.

Personalizing message representation.—After determining the content of communication supports, providers should ask - how should the communication content be represented? AAC layout and display decisions requires careful consideration given

specific diagnoses. For example, research demonstrates strong support for the use of visual scene displays – integrated scenes (e.g., photos) that depict a meaningful and motivating event (Blackstone, 2004) - versus photographic images versus line-drawing to represent communication content for individuals with aphasia (McKelvey et al., 2010; Brock et al., 2017; Hux et al., 2010) and young children who are typically developing (e.g., Drager et al., 2003). Further, recent studies demonstrate that beginning communicators increase the frequency of their communication turns and express a larger number of vocabulary concepts when using high-tech or low-tech communication supports that incorporate VSDs (e.g., Drager et al., 2019; Holyfield et al., 2019; Muttiah et al., 2019). Research also suggests that personalized photographs may be more intuitive for individuals with TBI to identify (Thiessen & Brown, 2017). When personal photos are not accessible, new research (Beukelman et al., 2021) has indicated digital images that contain elements of age and gender similar to the individual with using the communication support may be of benefit. For individuals with traumatic brain injury, Brown and colleagues (2015) have found that using icons only compared to icons with text or text only might be easier for some to visually process.

New AAC software (e.g.,³GoVisual™ by Attainment Company) is currently available that incorporates videos with embedded VSDs (video VSDs). Using this technology, video-content can be quickly captured, and individuals can program hotspots, written text, and voice output to support patient communication. Research using video VSDs has focused primarily on supporting children during play tasks (e.g., Laubscher et al., 2019) and adolescents with development disabilities (e.g., Babb et al., 2018); however, the use of this technology may also be useful to support patient-provider communication. While limited information exists as to the application of video VSDs for adults with acquired conditions (e.g., aphasia, TBI), these new tools demonstrate potential to also benefit patients by providing content to augment their understanding of medical encounters and quickly capture communicative opportunities to promote patient participation in healthcare interactions. For example, videos can be captured of medical routines (e.g., the patient and nurse completing morning cares) or activities that are motivating to the patient (e.g., play tasks for children, videos of family members). Then hotspots and audio output can be programmed at relevant pauses in the video to promote patient understanding and expression during the task.

As mentioned in an earlier article in this issue (Beukelman et al., 2021), preliminary research supports that, when given the option, people with aphasia select photos that contain people that had similar features to themselves. To quickly generate personalized AAC supports for this population, SLPs can complete simple online searches of photos that align with the patient's age and gender. Further, as patients transition to long-term care environments, they may require personalized content that is more specific due to the numerous and changing caregivers over time. This content can be quickly created by taking photos or videos of the patient (or another person) completing each step of the target activity and uploading it to an app that supports VSDs or video-VSDs (e.g.,⁴ Snap Scene by Tobii/Dynavox). Paper-based communication boards using these photos may also be created if

³GoVisual™ by Attainment Company, <https://www.attainmentcompany.com/govisual>

⁴Snap Scene by Tobii/Dynavox, <https://www.mytobiidynavox.com/Store/SnapScene>

technology is not available in the facility or if the patient prefers to not use communication technology. The following example demonstrates the utility of developing personalized vocabulary and vocabulary representation of an older adult with aphasia.

Case Example: Adult with Aphasia in Long-Term Care

Hattie had severe receptive and expressive language deficits and resided in a long-term care facility. Hattie used a speech-generating device (SGD) with AAC displays developed for her that utilized personalized photos or visual scenes displays (VSDs). Her SGD served a dual purpose in that it not only helped her to express her needs, it also helped her to understand communicative interactions with care staff. For example, Hattie had been unable to follow verbal or written directions to participate in her morning routine with staff (e.g., getting dressed, taking her medications before breakfast, going to the facility dining room for breakfast) due to the severity of her receptive language deficits. Hattie's SLP developed a series of VSDs using the⁵Snap Core First Aphasia Page Set by TobiiDynaovx depicting Hattie performing the care tasks she needed help with every day (e.g., getting dressed, taking her medications before breakfast, going to the facility dining room for breakfast). Hattie's SLP directly trained care staff to support her communication and use VSDs as a part of her intervention. Staff were instructed to "just-in-time" by the SLP to show her the associated VSD to give her time to understand and process the activities she was being asked to complete. Use of these visual supports helped to decrease Hattie's refusal to complete daily tasks. To ensure that all staff were able to be trained to support Hattie's communication, simple checklists and a video of the SLP demonstrating the communication recommendations were created and available at the nurses station and in Hattie's room. The long-term care staff also created personalized VSDs for Hattie to communicate information about herself to new staff and she used these displays to generate communicative topics when friends and family members came to visit her.

In this example, personalization for Hattie included not only using message representation strategies that are known to be intuitive for individuals with aphasia (e.g. VSDs), but also using communication supports to *augment* her understanding of what others around her were attempting to communicate. Using VSD communication supports to help Hattie understand her daily care routines allowed her to control the interaction and participate in her care. Additionally, personalization of VSDs in a way that allowed Hattie to communicate information about herself (e.g., introductory content for new communication partners, hobbies/interests, important life milestones, family) motivated her to engage in meaningful communicative interactions with staff, family, and friends.

Case Example: Adult with an Acquired Brain Injury in an Acute Care Hospital.

Following an acute bout of encephalitis with seizures, Elena woke up in the ICU intubated and confused. When staff attempted to ask her yes/no questions, she continually shook her head 'no'. Nursing staff tried to use a standard, pre-made communication board (i.e., an

⁵Snap Core First Aphasia Page Set by Tobii/Dynavox, <https://us.tobiidynavox.com/pages/snap-corefirst-aphasia>

alphabet board and picture board with over 50 items on it) to find out what she needed. When they showed the board to Elena, she looked perplexed and shook her head. Upon further evaluation, it was determined that Elena could not visually and cognitively process the extensive number of messages represented on the pre-made communication board. Her encephalitis had affected her ability to visually scan and identify salient messages if more than six symbols were presented at a time. She was able to communicate her basic needs (e.g., “pain”, “sick/nausea”, “uncomfortable/reposition”, “dry mouth”) when simplified communication boards of four to six messages were presented to her both visually and auditorily. As Elena became more alert and was able to sustain her attention for more than 5-minute interactions, she was offered an alphabet board containing letters in a QWERTY configuration, a space button, and a backspace button to spell messages via pointing. She began asking questions about where she was and what had happened to her. Elena did not remember the answers to these questions throughout the day due to the cognitive deficits she continued to exhibit early in recovery from her encephalitis which often caused extreme agitation. Elena’s SLP added these questions to her communication boards so that she could quickly select them. Elena’s SLP provided direct training during therapy sessions to primary care staff on how to use the boards to visually and auditorily orient Elena throughout the day, which decreased her agitation and confusion.

This example highlights the importance of matching the layout and content of communication materials to the patient’s fluctuating cognitive-linguistic skills in the acute care environment. Many patients in the acute care setting experience delirium and new onset cognitive-linguistic deficits which negatively affects the patient’s alertness, orientation, visual processing, and memory skills (Blackstone et al., 2015). In this level of recovery, providers should minimize auditory and visual distractors, provide ample time for patients to process new information, offer repetitions of information, and address the patient’s immediate concerns by including messages that are urgent or highly important to the person. In this stage of the recovery process, patients may become fixated on a certain topic (e.g., asking questions to where their family members are). During this stage, SLPs and other health care providers should create communication supports containing messages that allow patients to express these concerns and allow providers to also validate these concerns (e.g., orientation information). Supports that contain such information may be a useful tool to calm the patient and may positively impact other aspects of their medical care such as reducing the use for sedation, restraints, and one-to-one supervision.

Case Example: Adolescent with Brain Injury at a Rehabilitation Hospital.

Luke is a 15-year-old who was in a motor vehicle accident and experienced a significant traumatic brain injury, leaving him in a coma for 12 days. Since his accident, he uses a feeding tube for nutrition and hydration, a tracheostomy to support his breathing, and a specialized wheelchair to support his positioning. He is able to tolerate wearing a speaking valve; however, he is not able to phonate. He transferred to a rehabilitation hospital after a three-month acute care stay. Upon admission, the team completed the Ranchos Los Amigos Scale (Ylvisaker & Szekeres, 1998) and he performed at Level 3, meaning that he responds inconsistently to stimuli but can follow simple commands. When in physical therapy, Luke frequently shuts his eyes when asked to complete exercises; however, he becomes more alert

and looks towards objects when his favorite music artists and videos are played. Luke's SLP and physical therapist decided to co-treat to work towards sustaining Luke's alertness and establishing consistent communicative intent, given his severe motor and cognitive-linguistic deficits. The SLP asked Luke's family and friends what his favorite musicians and Internet videos were and from this list made a series of large photo symbols representing these preferences. She presented photos of two options to him and encouraged him to use eye pointing to make his selection. Given head and trunk support provided by the physical therapist, Luke made his selections. The next day, the SLP presented a switch connected to a laptop computer via a switch interface. After he made his choice using eye pointing, the SLP and physical therapist found the optimal position for him to access the switch, queued his video, and encouraged him to press the switch to turn on the video. Using this method, Luke was able to participate in his therapy session for a full 60-minutes. Soon thereafter, the SLP was able to replace picture symbols with text and trial use with a high-tech eye gaze device so Luke could communicate a wider range of concepts to others.

In this example, the SLP and physical therapist collaborated with the patient's family to create personalized communication supports based on patients' interests that drastically increased his participation in treatment tasks. The SLP considered the patient's current level of recovery using the Ranchos Los Amigos Scale which informed her decision-making to create simple, personalized communication supports to match his current cognitive, visual, and motor skills. She also presented a motivating activity (i.e., selecting preferred music and videos) which allowed Luke to actively control aspects of his treatment which, in turn, increased his compliance and participation in treatment.

Communication Partner Training Considerations

Many healthcare providers receive little to no training on techniques to communicate effectively with patients with speech, language, and communication deficits (e.g., Finke et al., 2008; Simmons et al., 2019); however, they can learn to use techniques during their daily job duties following specialized training. An emerging body of research exists suggests that communication partner training in healthcare settings can increase provider knowledge and skills (e.g., Baylor et al., 2019) and the quality of patient-provider communication (e.g., Happ et al., 2014) when interacting with patients with communication difficulties. Healthcare communication trainings exist in many formats including: (a) online modules training general communication techniques (e.g., SPEACS-2; Happ, 2013), (b) face-to-face trainings that address general communication topics (e.g., Baylor et al., 2019), (c) face-to-face in-service trainings to teach a patient-specific strategy to direct service providers, (d) use of electronic medical orders sets that describe the patient's communication system use (e.g., Beukelman & Nordness, 2017), and (e) bedside signs describing patient communication needs. Unfortunately, many healthcare trainings require extensive time commitments, face-to-face learning which may be difficult for all staff to complete (e.g., night shift), and have not been evaluated during naturally-occurring healthcare interactions. Conversely, a risk of using solely written information is that staff may not refer to the signs or notes when interacting with patients.

Due to the large number of healthcare providers that patients may need to interact and the time constraints imposed on many health care interactions, *just-in-time* training formats may be useful for teaching personalized communication strategies to staff in the moment. Gormley (2019) used video VSD technology to develop a just-in-time training to teach pediatric rehabilitation providers to offer choices to children with communication disabilities during routine healthcare interactions. The training was 15-minutes in length and was viewed on a tablet with pre-programmed pause points to outline steps of a checklist to train the technique. After the training, providers offered more choices to children during naturally occurring interactions taking on average 45 seconds to complete the procedure during the interactions and patients were able to effectively communicate their preferences. Future research should evaluate the effects of additional just-in-time trainings addressing different patient populations (e.g., adults with communication difficulties), different settings (e.g., acute care), and training targets (e.g., establishing yes/no signals, providing written choice).

Case Example: Child in an Acute Care Hospital Following an Organ Transplant.

Imani is a four-year old girl with a rare genetic disorder who required a multiorgan transplant and currently uses a tracheostomy to help with her breathing. She is not able to tolerate wearing a speaking valve on her trach and, instead, uses sign approximations, gestures, and simple photo symbols to interact with others. She has spent a large percentage of her life in the inpatient setting and due to geographic and time constraints, her family is not able to stay at her bedside throughout her entire hospitalization. Imani is typically happy to interact with familiar staff members; however, becomes scared when unfamiliar staff members enter her room, when respiratory therapy needs to complete her tracheostomy change, and when nursing gives her injections. When she becomes upset she produces her sign approximation for “stop” repeatedly and if staff are not able to understand this sign, she pulls her feeding tube, tracheostomy, and IV lines causing them to be dislodged and replaced. When family is not bedside and when she does not have access to toys, she attempts to get out of bed leading to repeated falls and the need for one-to-one supervision.

To help staff members understand Imani’s communication signals, her SLP created a video and paper signal inventory which depicts Imani’s signs and their meaning. Digital copies of these signs were uploaded to Imani’s medical chart and physical copies were printed and posted at the nurse’s station and Imani’s ante-room to be easily visible to staff. The video signal inventory was created using the GoVisual™³ app and uploaded onto a bedside tablet and available in Imani’s room for staff to view and for Imani’s parents and SLP to add new content as Imani’s development progressed.

A bedside sign was also posted reminding staff to not leave the room without providing Imani with access to toys or her favorite movies to ensure she stays in bed. The SLP also took pictures of Imani’s favorite toys so staff could offer her choices of preferred activities. A “First, then” board was also left at bedside, so that staff can prepare Imani for the upcoming activity (e.g., trach care) and she can select a toy/activity to work for

after the activity. When staff used these communication supports and better understood her idiosyncratic signs, a drastic increase in Imani's participation in the medical routine was observed and she no longer required one-on-one supervision at bedside.

This case example illustrates a number of communication partner training formats to support the patient's effective communication and safety through her hospitalization. Just-in-time trainings were created to demonstrate models of the patient's unique signs. This technique has been effectively used to teach communication partners to interpret children's communicative behaviors in the school setting (Holyfield et al., 2018). In addition to the video training, paper signage also was useful to remind staff to provide the patient access to toys and motivating activities to increase her participation and compliance in medical routines.

Preparing for health care interactions

Patients, their families, and their community providers that are experts in supporting the patient's communication (e.g., their school-based or outpatient SLPs) can take steps to ensure that the patient has ready access to the necessary communication supports to fully participate in healthcare interactions. To prepare for a planned healthcare interactions or unplanned hospitalizations, these groups can collaborate to write down or record information that included the patient's preferred communication strategies, their medical information, medical vocabulary, and other important information related to the individual. Methods to document this information include: (a) creating a communication passport (e.g., Widgit Health, available for download at https://widgit-health.com/download-files/aande/2013/A-E_Communication_Passport_2013.pdf), (b) creating paper or mobile identification cards, and (c) creating and/or saving high-tech or paper communication materials specifically created for medical interactions on the patient's everyday communication system (Blackstone et al., 2015).

Case Example: Adult with Cerebral Palsy in Community Care Home.

Rick is a 28-year-old adult with cerebral palsy and is non-speaking. He uses an SGD with switch scanning and a low-tech alphabet board with partner-dependent scanning to communicate and lives in a community care home. Rick has a long history of respiratory issues and is often hospitalized due to ongoing bouts of pneumonia. Rick and his staff have developed a communication support plan for when Rick is hospitalized. First, Rick and his care staff developed a communication passport where important information about Rick's condition (e.g., medications, diagnoses), personal information (e.g., his family and facility contact information), preferences, daily routine, and methods of communication are briefly described. Second, Rick and his staff developed a series of laminated, paper communication boards that contain his alphabet board, a board of health-related questions, and pre-set messages that Rick frequently uses throughout the day. Each of these messages were printed in large-font to meet his visual needs. These materials were created so that Rick can use partner-dependent scanning to efficiently communicate urgent medical information, especially if he is too fatigued to use his SGD or if it is unavailable. Third, a brief 2-minute video using the GoVisual app was developed by Rick and his care staff that describes and

demonstrates how to implement partner-dependent scanning so that unfamiliar healthcare providers can help Rick communicate when hospitalized. Each of these materials help Rick to communicate his needs with care staff who are unfamiliar with him and for situations where he may not have ready access to his SGD (e.g., an emergent hospitalization) and needs assistance with communication (e.g., using partner-dependent scanning).

This example illustrates the need to prepare individuals for times where communication is critical (e.g., being able to communicate needs while hospitalized) but complicated by lack of familiarity of the communication partner. This becomes particularly important when caregivers and familiar communication partners are not able to be present to support the individual who uses AAC (e.g., COVID restrictions on visitation for hospitalized individuals). Providing information that gives new communication partners knowledge of the individual's pertinent medical information as well as the communication capabilities (e.g., through a communication passport or other tool) sets the stage for effectively supporting communication. Because use of a high-tech SGD may be hindered in an environment where no familiar communication partners are present, developing effective low-tech solutions that the individual has practiced using is essential. Further supporting new communication partners through video illustration of communication strategies (e.g., partner-dependent scanning) is now a reality given the fact that so many individuals now carry cell phone and tablet technologies. A comprehensive plan, much like the one Rick and his caregivers devised, can support the needs of individuals who use AAC regardless of context and familiarity of communication partners.

Case Example: Child with Autism Preparing for Outpatient Visit

Alberto is a nine-year old child with autism-spectrum disorder. He uses an SGD containing picture symbols and basic sight words to communicate at home and at school. He is highly sensitive to loud noises, bright lights, and tactile stimuli to his face and arms. When faced with situations containing these stimuli, he engages in self-injurious behaviors and attempts to elope from the situation. It is extremely difficult for Alberto to participate in toothbrushing routines and dental visits, as a result, he requires an outpatient procedure to clean his teeth and receive multiple dental fillings. Last time Alberto participated in a dental visit, he uncontrollably cried, hit his head against the wall when the care tech attempted to take his vital signs, and needed to be physically restrained before the procedure. He also did not have any communication materials or his SGD during this interaction.

To prepare for this appointment, Alberto's parents asked his outpatient SLP to provide materials for the dental and medical staff. The SLP worked to make a high-tech communication pages using the language software on his SGD (i.e.,⁶Snap Core First by Tobii Dynavox) that contain vocabulary about the dental visit and a visual schedule of activities to be completed. She also linked his preferred toy page to the new content so he could easily make choices between toy items known to calm him. She printed screenshots of these pages and put them in plastic sleeves so Alberto's mother could easily bring the boards to the appointment. Alberto's mother and the SLP also worked together to make a one-page

⁶Snap Core First by Tobii/Dynavox, <https://us.tobiidynavox.com/pages/snap-corefirst>

“About Me” page to be emailed to the office providers before the appointment. This page described Alberto’s sensitivities and communication techniques to calm him and participate better in the interactions.

The day of the appointment, Alberto’s mother brought the communication materials, “About Me” page, and a small bag of Alberto’s preferred toys. The office staff read through the “About Me” page, spoke in quiet voices, and brought Alberto to a room that could be dimly lit. They showed him the visual schedule before each new activity (e.g., sitting on the dental chair, taking vitals) and used his communication board to ask him which toys he would like to play with before each activity. Alberto picked watching a preferred video on his tablet each time. When staff used these strategies, Alberto was able to participate in the appointment without requiring physical restraints or engaging in self-injurious behavior.

This case example illustrates the positive impact that communication preparedness can have on patient-provider communication involving a child with communication disability. The patient’s mother collaborated with his medical providers and familiar partners to generate a plan that considered: the patient’s needs, the demands of the setting, and solutions that helped Alberto understand what is happening to him and simultaneously empowering him to actively control some aspects of the interaction. Communication supports were personalized to his unique developmental, sensory, and communication needs while being readily available during healthcare interactions. Further, the patient’s mother was able to quickly share important information to unfamiliar providers to train them in strategies to make the interactions a success.

Conclusion

While a range of generic, pre-made communication supports exist, they often fall short in fully supporting the communication needs of patients during patient-provider interactions. Considering the Participation Model (Beukelman & Light, 2020), this paper has highlighted the complexity of patient and environmental factors that influence the effectiveness and personalization of patient-provider communication. There are a wide range of strategies that patients, their families, and their providers can use to personalize communication supports to meet the unique needs of these patients today and in the future. New technologies and software have been developed and are emerging that will make the personalization process easier and more intuitive for patients and providers in the near future.

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Table 1.

Assessing patient participation patterns and unmet communication needs in healthcare settings prior to personalizing communication supports. Adapted from AAC Assessment recommendations guided by the Participation Model (Beukelman and Light, 2020)

Assessment Strategy	Questions to Ask and Existing Tools	Strategies Patients with Communication Difficulties
Conduct interviews with the patient, family, and staff	Ask: <ul style="list-style-type: none"> • What were the patient's pre-existing needs? • What are the patient's new needs? 	<ul style="list-style-type: none"> • If patient is not able to participate, ask family members and staff • If family members are not present, contact them via phone or email as appropriate • Use the needs, activities, and partners to guide the patient's treatment plan and intervention
Investigate the patient's social networks	Ask: <ul style="list-style-type: none"> • Who does the patient need/want to communicate with? • Who is on the patient's team? • How often do these team members interact with the patient? For how long? 	<ul style="list-style-type: none"> • Of these needs, prioritize based on: <ul style="list-style-type: none"> – Patient safety – Patient and partner preference – Patient communication level and/or phase of recovery
Administer communication needs surveys and tools	Examples of existing communication needs assessment tools: <ul style="list-style-type: none"> • "Intensive Care Unit Communication Needs and Constraints Checklist" (Beukelman, et al., 2007) • "(Traumatic Brain Injury) Communication Needs Assessment" (Beukelman, et al., 2007) • "AAC-Aphasia Needs Assessment" (Beukelman, et al., 2007) • Inpatient Functional Communication Interview (O'Hallorhan et al, 2020) Create your own communication needs checklist that contains: <ul style="list-style-type: none"> • A list of the patient's daily/weekly activities • The following information about each activity: With whom, when, where, why, how, and about what does the patient need to communicate about? • Of these activities, what needs are met and unmet? 	

Table 2.

Assessing patient skills and preferences for personalizing patient-provider communication supports

Assessment Domain	Questions to Ask
Assess patient's hearing and vision skills	<p>Ask:</p> <ul style="list-style-type: none"> • Does the patient use hearing aids or glasses? • If so, are these supports present at bedside or during the interaction? • Has there been any recent changes in the patient's vision/hearing? • Do providers need to wear personal protective equipment (e.g., masks, face shields, etc.) when interacting with the patient?
Determine the patient's communication level and/or phase in their recovery process	<p>Ask:</p> <ul style="list-style-type: none"> • What communication phase/level is the patient's current skills most consistent with? <p>Examples:</p> <ul style="list-style-type: none"> • Aphasia: Categories of communicators with aphasia (Lasker et al. 2007) • Beginning Communicators: Stages of Communication Development (Beukelman & Light, 2020) • Traumatic Brain Injury: Ranchos Los Amigos Scale Levels (Ylvisaker & Szekeres, 1998) • ICU continuum (Costello, Patak, & Pritchard, 2010)
Consider the patient's receptive communication skills	<p>Ask:</p> <ul style="list-style-type: none"> • Is the patient experiencing any of the following that may make it difficult to understand daily events? <ul style="list-style-type: none"> – Sedation level, medication effects – Delirium – New/chronic neurological disorder (e.g., stroke, brain injury)
Consider the patient's expressive communication skills	<p>Ask:</p> <ul style="list-style-type: none"> • How does the patient communicate "yes", "no", and "I don't know"? • How does the patient gain attention from others (e.g., nurse call)? • How does the patient answer questions? • How does the patient ask questions? • How does the patient communicate basic/medical needs?

Table 3.

Strategies to Personalize Patient-Provider Communication

Domain	Strategies
Personalizing Messages	<ul style="list-style-type: none"> • Include content pertinent to diagnosis and eliminate unrelated content • Include messages to support patient asking questions about care and inclusion in decision-making • Ask patient to indicate preferences for kinds of messages and breadth of topics to include • Add vocabulary that is highly motivating and relevant to topics the patient and provider would like to discuss during interactions
Access	<ul style="list-style-type: none"> • Consider physical access capabilities (e.g., pointing with hand, eye gaze, partner dependent scanning with physical signal) • Design content layout to accommodate access method (e.g., quadrant layout for eye gaze, row/column layout for partner dependent scanning)
Display, Layout, and Representation	<ul style="list-style-type: none"> • Match the communication display and layout to the patient's cognitive, motor, developmental, and visual skills • Consider options such as: Grids, visual scene displays, video visual scene displays • Consider patient preferences and past experiences when selecting a keyboard layout (e.g., QWERTY vs alphabetic; Gormley & Fager, 2020) • Reduce the number of items to aid in visual search • Consider spacing or clustering items to increase ease of processing and navigation
Ensure that communication tools are available	<ul style="list-style-type: none"> • Create communication toolkits to ensure that a variety of tools at the following categories are available to meet the diverse needs of patients including: low-tech tools, high-tech equipment, nurse call bells • Create a shared computer drive to quickly access, customize, and print communication boards based on patient and interaction needs • Consider use of just-in-time programming to add new vocabulary
Provider trainings	<ul style="list-style-type: none"> • Consider using the following provider training methods: In person training, video trainings, just-in-time trainings, written instructions • Consider using the following strategies to inform staff about the patient's communication needs and setting up the system: Bedside signs, electronic order sets