

**AUGMENTATIVE-ALTERNATIVE COMMUNICATION ACCESS FOR  
INDIVIDUALS WITH COMMUNICATION DISORDERS IN MEDICAL  
SETTINGS**

by

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## **ABSTRACT**

This study surveyed speech-language pathologists (SLPs) working in medical settings in the state of Florida in order to: (a) assess the availability of AAC devices, related materials, and services in acute, sub-acute, long-term care, and outpatient medical facilities, (b) examine barriers and supports in providing AAC services to patients with complex communication needs (CCN) in the aforementioned settings, and (c) determine perceived levels of AAC knowledge of health care practitioners.

One of the study's major findings was that 97.59% of SLPs served at least one patient they identified as having CCNs, and 94.1% of respondents indicated that their patients could benefit from increased access to AAC devices and service delivery. A notable finding relating to the need for increased AAC-related communication partner instruction (CPI) is as follows: 97% and 100% of respondents indicated that increased CPI for medical practitioners/staff and family members, respectively, were important elements in order to ensure functional communication for individuals with AAC needs in the medical setting. Major barriers to providing AAC services related to device access (i.e., lack of AAC supports / devices, lack of funding for equipment, length of time of device funding). Other barriers were related to the nature of medical settings (i.e., frequently changing caseloads, limited time with patients) and demands of the job (i.e., lack of time to prepare AAC materials / devices). Supports to providing AAC services included low-tech AAC options and mobile technologies. In terms of practitioner knowledge, 57.6% of respondents rated themselves not at all or somewhat knowledgeable regarding AAC. Physicians, nurses, and other rehabilitation professionals were rated as less than knowledgeable by 95%, 97%, and 84.3% of participants, respectively. Overall, the findings of this study suggests there is

a high prevalence of patients in medical settings with AAC needs, and some face unmet communication needs resulting from barriers related to the setting itself, lack of access to AAC devices and materials, and limited time spent on AAC service delivery.

In memory of my grandfather, Leonard Nicholas Schregardus, who continues to inspire me academically, professionally, and personally, and who has taught me that people with complex communication needs have a voice.

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## LIST OF ACRONYMS

AAC	Augmentative-alternative communication
ALS	Amyotrophic lateral sclerosis
AOS	Apraxia of speech
ASD	Autism spectrum disorder
ASHA	American Speech-Language Hearing Association
CAS	Childhood apraxia of speech
CCN	Complex communication needs
CNS	Central nervous system
CP	Cerebral palsy
CVA	Cerebral vascular accident
FLASHA	Florida Association of Speech-Language Pathologists and Audiologists
HD	Huntington's disease
HNC	Head & neck cancer
ICU	Intensive care unit
ID	Intellectual disability
IV	Intravenous therapy
MS	Multiple sclerosis
MSD	Motor speech disorder
NG	Nasogastric tube
OT	Occupational therapist
PD	Parkinson's disease

PPEC	Prescribed pediatric extended care
PT	Physical therapist
RT	Respiratory therapist
SGD	Speech-generating device
SLP	Speech-language pathologist
SSD	Speech sound disorder
TBI	Traumatic brain injury
TEP	Tracheo-esophageal speech

## CHAPTER ONE: INTRODUCTION

### Background

Communication is an essential human function that is closely entwined with quality of life. The ability to communicate is necessary to carry out various functions including: (a) expressing needs and desires, (b) exchanging information, (c) fostering social closeness, and (d) carrying out social routines (Light & McNaughton, 2014; Light, 1988). Unfortunately, with 2.8 million Americans aged 16 and older reporting communication disabilities, including 523,000 individuals classified as having severe communication disabilities, a staggering number of individuals in the United States are unable to realize the aforementioned communicative functions (United States Census Bureau, 2010). In fact, recent numbers indicate that 1.4% of all people, including 4.05 million Americans, have communication needs severe enough to warrant a recommendation for augmentative and alternative communication (AAC) (Beukelman & Mirenda, 2013).

**Augmentative-alternative communication (AAC).** AAC is defined by the American Speech-Language Hearing Association (ASHA) as “attempts to study and, when necessary, temporarily or permanently compensate for the impairments, activity limitations, and participation restrictions of individuals with severe disorders of speech-language production and / or comprehension. These may include spoken and written modes of communication” (ASHA, 2004, p. 1). An individual may use AAC when their speech, writing, or gesture-system is not sufficient to meet all their communication needs, which may be permanent or temporary (Beukelman & Mirenda, 2013). AAC service delivery has fallen within the scope of practice for

speech-language pathologists (SLPs) for many years (ASHA, 2005) and has continued as a required area of competency within ASHA certification standards (ASHA, 2013a).

Therefore, SLPs must demonstrate the knowledge and skills required to provide assessments for individuals with complex communication needs (CCN) (ASHA, 2013a). Additionally, SLPs must be able to adapt speech-language assessment procedures to make them accessible for individuals who may use or require the use of AAC (ASHA, 2013a). Furthermore, they must possess the ability to provide intervention services for individuals with AAC needs (ASHA, 2013a). This may entail therapy using the device for functional communication, communication partner instruction, and / or technical assistance.

**Categorization of AAC options.** AAC options can be divided into two main categories: unaided and aided. Unaided communication is accomplished without the use of anything external to the individual (Beukelman & Mirenda, 2013). These options include gesturing, vocalizing, or using manual sign systems such as American Sign Language, Signed English, and Signing Exact English (Beukelman & Mirenda, 2013). Aided communication systems utilize supports which are external to the individual with CCN (Beukelman & Mirenda, 2013). Aided communication systems can be further divided into low-tech, mid-tech, and high-tech.

***Low-tech AAC options.*** Low-tech devices do not use sophisticated electronic programming or equipment (Hurtig & Downey, 2009). Therefore, they do not offer voice output. Examples of low-tech devices include alphabet boards, communication books / boards, remnant books, line drawings, picture symbols, real objects, memory books / boards, and writing notebooks. Individuals either point to or exchange symbols to communicate intended messages.

Some benefits of low-tech AAC devices or supports are that they are inexpensive and easy to use.

**Mid-tech AAC options.** Mid-tech options, on the other hand, do offer voice output features - typically with digitized voice (i.e., recorded message representation). Depending on the device, a varied number of messages can be recorded. For example, the *Big Mack* and *Little Mack* devices allow recording of only one high frequency message (e.g., “Hello!” “My name is Sally.”) per device. Other mid-tech devices, such as the *iTalk* or the *Step-by-Step*, allow several different messages to be recorded. The *Go Talk* allows up to 163 messages. While these devices are much more cost-effective than high-tech devices, a disadvantage is that they can only support static message displays. In other words, end users are limited to accessing messages currently available on the device unless someone updates the device.

**High-tech AAC options.** High-tech devices, however, are dynamic, meaning they allow end users to create novel messages by activating touch screen computer interfaces. Most high-tech devices utilize synthesized voice output (i.e., computer-generated speech), and some allow for digitized (recorded) voice output as well (Hurtig & Downey, 2009). They are also referred to as speech-generating devices (SGDs) within the category of Durable Medical Equipment (DME). High-tech SGDs fall into two categories: dedicated and non-dedicated devices (Hurtig & Downey, 2009). A dedicated device has been designed specifically for communication purposes, whereas a non-dedicated device has been designed with other purposes in mind, but has been adapted to meet the needs of individuals with CCN. Examples of dedicated high-tech devices include the *Dynavox T10*, *Tobii i12*, *Lightwriter*, *PRC Accent 800*, or *NovaChat 7*. Examples of non-dedicated devices include iDevices (i.e., *iPhone*, *iPad*, *iPod*), *Samsung*, or *Windows* tablets

with speech-generating apps such as *Proloquo2Go*, *TouchChatHD*, *Predictable*, or *Proloquo4Text*; or computers with special software fostering access for people with CCN. Many SGDs are picture-based, meaning individuals select a picture symbol representing what they want to say, for example choosing a picture of food that is used to represent the message, “I’m hungry.” Examples of picture-based devices include *Dynavox T10*, *NovaChat 7*, and *Tobii i12*. Other SGDs are orthography-based, meaning end users type or select what they want to say using a keyboard and then press a button to have their message delivered via synthesized voice output. Examples of orthography-based high-tech AAC choices include the *Lightwriter* and an *iPad* with the *Predictable* app.

***AAC access options.*** Many AAC devices are designed for direct selection. This means end users select their target words / letters / pictures by pointing, touching, blinking, or using a mouse to make selections (Beukelman & Mirenda, 2013). Eye gaze is a direct selection method appropriate for people who do not have the use of their extremities, such as those with spinal cord impairment, cerebral palsy, or those in advanced stages of amyotrophic lateral sclerosis (ALS) (Beukelman & Mirenda, 2013). Additional alternative access direct selection methods include using head pointers or a head mouse (Beukelman & Mirenda, 2013).

For individuals who are unable to directly select on a device, such as someone who is visually and motorically impaired, indirect selection involves narrowing groups of choices presented via scanned / highlighted sections on the device display (Beukelman & Mirenda, 2013). End users activate a switch when the group of choices includes their target. For example, individuals using indirect selection may have the device highlight each row (linear scanning) on the screen until the row with their choice is highlighted (Beukelman & Mirenda, 2013). Then, the

users activate a switch to demonstrate their target is in that group. Next, the device highlights each stimulus in the chosen row until the target is highlighted. Then, users activate the switch again to indicate their choice. Scanning can be visual, auditory, or both. Although indirect selection is utilized on SGDs, it can also be used with low-tech AAC systems. Partner-assisted scanning is a low-tech form of scanning in which the communication partner points to various choices on a communication or alphabet board until the individual with CCN needs makes a selection via some form of positive indication.

**Complex communication needs in medical settings.** Patients with CCN in medical settings comprise a group of individuals with unique needs. Such individuals require access to AAC not only because they have a right to access effective communication modes to meet the above-mentioned communicative functions, but because reliable communication is “an essential component of quality care and patient safety” (The Joint Commission, 2010, p. 1).

When examining patient demographics, it is reported that over 6.7 million individuals in the United States alone present to ICUs each year (Angus, 2004). Many individuals admitted to ICUs are rendered non-verbal due to a variety of medical reasons including – but not limited to – oral intubation, tracheostomy, and mechanical ventilation (Garrett, Happ, Costello, & Fried-Oken, 2007). The inability to communicate via natural speech may be short-term, long-term, or permanent. Roughly 36 percent of individuals admitted to ICUs are dependent on mechanical ventilators (Dasta, McLaughlin, Mody, & Piech, 2005) and, upon transferring to other acute care units or health care facilities, more than one-fourth of these patients continue to require mechanical ventilation (Eskildsen, 2007). In addition, patients present to the ICU, long-term acute medical facilities, sub-acute, outpatient, and rehabilitation facilities with CCN secondary to



a variety of disorders and diagnoses. Traumatic brain injury (TBI) and other trauma; stroke / cerebral vascular accident (CVA) and cardiac issues; head and neck cancer; respiratory distress; and progressive degenerative conditions (e.g., dementia, amyotrophic lateral sclerosis, muscular dystrophy, late stage Parkinson's disease (PD), Huntington's disease (HD), myasthenia gravis, and supranuclear palsy) are some of the illnesses represented by individuals in such settings (Beukelman & Mirenda, 2013; Garrett et al., 2007; Yorkston & Beukelman, 2007).

Due to limitations in verbal output imposed on such individuals, including decreased intelligibility, disruptions in access to symbolic language, and incoordination of respiration and phonation among others, communicating with health care professionals and participating in decision-making become problematic (Beukelman & Mirenda, 2013; Garrett et al., 2007; King, Simmons-Mackie, & Beukelman, 2013).

Given this information, SLPs working in medical facilities are responsible for providing AAC services to patients. Due to the nature of medical settings, SLPs must receive orders – typically from a physician – to provide speech-language services to individuals with CCN (Beukelman & Mirenda, 2013). Therefore, physician, physician assistant, and nurse knowledge regarding AAC and CCN is a crucial first step in access to AAC services.

In some hospitals, protocols are in place for individuals with planned surgeries who will be rendered non-verbal due to intubation or tracheostomy. One particular protocol has been in place at Children's Hospital in Boston since 1994 (Costello, 2000). Using this model, AAC assessment and training is provided prior to the procedure, and the device is introduced immediately following the procedure (Costello, 2000). This model reportedly has been effective at decreasing patient feelings of frustration, isolation, and anxiety due to the inability to communicate (Costello, 2000).

It should be noted that this model necessitates device access in order for SLPs to provide meaningful AAC services. It is recommended that, at a minimum, SLPs should have access to the following communication devices and supports in medical settings: (a) various electrolarynx options, (b) alphabet, word, and picture type communication boards along with the resources to devise them, (c) boards for writing / drawing messages, and (d) mounting options for communication boards (Garrett et al., 2007).

Despite the vast communication needs of patients in medical settings, it is unclear: (a) how many patients with CCN in medical settings in the United States face unmet AAC needs, (b) exactly what barriers and supports patients may encounter to functional communication in medical settings, and (c) the availability of AAC supports and training in medical settings.

## **Literature review**

Given the number of individuals with CCN in the United States, it is no surprise that SLPs working across the full range of clinical settings encounter individuals who would benefit from AAC. A survey conducted by ASHA (2002) revealed that 50.3% of SLPs encountered clients with AAC needs in hospitals, 45.6% in schools, 43.2% in nonresidential health care, and 38.4% in residential health care. However, more recently, Beukelman (2012) indicated an increasing prevalence of individuals across the lifespan requiring AAC due to increasing lifespans of the general population, longer life expectancies of individuals with developmental disabilities, and increased diagnoses of disabilities.

**Influence of mainstream mobile technologies on AAC clinical services.** Along with the growing number of individuals requiring AAC, the availability of speech-generating options has increased with the growth of mobile technologies (i.e., smartphones and tablets), such as

iDevices (i.e., *iPods*, *iPhones*, and *iPads*), and *Android* and *Windows* mobile systems (McNaughton & Light, 2013). With individuals spending roughly four hours on smartphones per day (Barrabee, 2013), it is no surprise that mainstream use of these devices has increased social acceptance of the use of mobile devices for communication purposes, improving access to high-tech AAC options (McNaughton & Light, 2013). In fact, with voice options on speech-generating apps sounding more natural as the technology continues to improve, some total laryngectomy patients prefer mobile technologies over electrolarynges due to the artificial-sounding voice quality inherent in electrolarynx technology (V. Lewis, personal communication, April 22, 2014). Not only has access improved, thanks to mobile technologies, but acceptance of AAC has improved as well (McNaughton & Light, 2013). Whereas a traditional SGD might be branded as evidence of a disability, a mobile device is considered ubiquitous and a speech-generating “app” is considered innovative (McNaughton & Light, 2013).

With a wealth of AAC “apps” available (Gosnell, Costello, & Shane, 2011), there are a number of benefits to using them on mobile devices versus traditional high-tech SGDs, which make them an exciting possibility for use in medical settings. For instance, purchasing a mobile device with an AAC app is much less expensive than purchasing a traditional SGD, and end users and families / caregivers are more empowered as decision-makers as they can browse “app stores” to choose their app and make the purchase without an SLP’s involvement if desired (McNaughton & Light, 2013). As a result, many clients / families make app purchases without an AAC evaluation with an SLP (Meder, 2012). This essentially forgoes the need to engage in the lengthy and laborious third-party device funding process. In fact, it has been reported that many AAC app purchases are made through private pay (Meder, 2012). Seemingly, these benefits would lead to an increased use of AAC on mobile technologies in medical settings.

Unfortunately, as the use of mobile devices for functional communication requires client and family training, this potential benefit also contributes to the challenge of using them (McNaughton & Light, 2013). Despite the wide use of mobile technologies, it is not always the best choice for each patient, and without an AAC assessment, other potential devices are overlooked (McNaughton & Light, 2013).

The draw of technological advances has the danger of taking the focus away from establishing functional communication (Hershberger, 2011; McNaughton & Light, 2013). First and foremost, the goal of choosing a particular device must be to meet the communication needs of the individual. Getting side-tracked by technology alone can detract from this.

Even when SLP support is sought, many SLPs lack the knowledge to provide the needed AAC assessment (Binger et al., 2012). Therefore, many end users lack much-needed support (McNaughton & Light, 2013). Furthermore, in rehabilitation settings, several barriers exist to providing AAC mobile technology services, which include the cost of purchasing devices, logistics, and time (Chen & Bode, 2011). Again, despite the potential for the use of AAC apps on mobile devices, these barriers inhibit access to training and support in medical settings (Brandenburg, Worrall, Rodriguez, & Copland, 2013).

Another limitation of mobile devices relates to access. Most mobile technologies utilize touch screen access, although access methods are being advanced in the cases of some mobile devices (Fager, Bardach, Russell, & Higginbotham, 2012; McNaughton & Light, 2013). As the development of new technologies is fueled by mainstream consumers, alternative access methods required for individuals with CCN are often overlooked (Beukelman, 2012). Individuals who lack the fine-motor skills necessary to activate a touch screen are subsequently excluded from using AAC apps on mobile devices (Light & McNaughton, 2012). As a result, individuals with

various muscular, coordination, and cognitive deficits are not often candidates for such AAC choices. There is a fear that the growing reliance on mobile technologies for AAC will further marginalize those not appropriate for them unless alternative access is improved. Despite the exciting possibilities for AAC that mobile technologies offer, the limitations they present demonstrate the continued need for traditional forms of AAC as well as the need for skilled assessment and intervention from a well-trained SLP.

### **Prevalence of AAC needs / service-delivery & related service delivery trends.**

Various survey studies have documented the prevalence of AAC needs and barriers in a number of settings. Kent-Walsh, Stark, & Binger (2008) surveyed school-based speech-language clinicians in a large metropolitan school district in Florida and found that 57.8% of participants served clients with AAC needs, with an average of eight individuals using AAC per assigned clinician caseload. These findings demonstrate an increase from an earlier study conducted by Simpson, Beukelman, & Bird (1998), which reported that 47.4% of school-based speech-language clinicians served students with AAC needs.

In the Kent-Walsh et al., (2008) study, a number of barriers to effective AAC service delivery were identified by respondents in the context of high demand for services. Respondents reported that a majority of their clients with AAC needs would benefit from more time spent on AAC intervention. However, increasingly high caseloads reportedly made this unrealistic (Kent-Walsh et al., 2008). Respondents also reported difficulty collaborating with other professionals, not enough time to provide AAC services, and low levels of expertise as significant barriers to providing effective AAC services (Kent-Walsh et al., 2008).

As it pertains to preschoolers, Binger & Light (2006) found that approximately 12% of preschoolers already receiving special education services in Pennsylvania had AAC needs. Further, preschool speech-language service providers in Pennsylvania served an average of seven children with AAC needs on their caseloads, with an average caseload of 29; close to one-third of their caseloads were comprised of children with CCN (Binger & Light, 2006). A survey conducted in Australia indicated that 0.15% of individuals aged 21 or younger had CCN (Sutherland, Gillon, & Yoder, 2005).

Siu and colleagues (2010) examined AAC service delivery and personnel AAC training in school-based and adult settings in Hong Kong. Similar to the results of Kent-Walsh et al. (2008), Siu et al. (2010) discovered that the lack of AAC training was a barrier to AAC service delivery. In their study, Siu et al. (2010) sought to examine AAC expertise amongst various professionals (i.e., occupational therapists, social workers, nurses, physical therapists, “center-in-charges,” health/welfare workers, and SLPs) and discovered that 72% of the respondents working in pediatric or adult settings indicated dissatisfaction with their AAC training. As a result, a relationship between AAC experience and AAC service delivery was suggested (Siu et al., 2010). Additionally, low availability of AAC devices and a lack of funding was noted (Siu et al., 2010). These studies outline significant barriers for providing effective AAC services.

AAC needs within adult populations have been examined to a limited extent. King (1998) surveyed SLPs working in health care settings (e.g., outpatient clients, acute care, private practice) and found that 69% had at least one client with AAC needs on their caseload. However, the participants reported spending limited time providing AAC services throughout their work week (King, 1998). Sutherland et al. (2013) examined the use of AAC with adults with intellectual disabilities (ID) in group homes and assisted living facilities in New Zealand. Their

findings indicated that 28.8% of the adults with ID represented in the study were candidates for AAC, some of whom relied merely on “informal behaviors” for communication (Sutherland et al., 2013, p. 119). These studies clearly indicate that adults with AAC needs are underserved.

A recent survey by ASHA reinforced this alarming trend of limited AAC service provision. In 2013, ASHA reported that minimal time is dedicated to AAC intervention with adult clients (ASHA, 2013b). Across settings with adults, SLPs reported devoting only 3% of intervention time to AAC strategies when compared with other areas of speech-language intervention (e.g., swallowing, voice, traumatic brain injury, aphasia, and dementia services) (ASHA, 2013b). Traditional aphasia (23%) and traumatic brain injury (TBI) (19%) rehabilitation dominated intervention provided in rehabilitation facilities despite findings that traditional speech-language rehabilitation for aphasia remains largely ineffective (Nicholas & Helm-Estabrooks, 1990; Porch, 1981; Robey, 1994), and approximately 40% of individuals with aphasia have chronic and severe aphasia (Beukelman, Fager, Ball, & Dietz, 2007). Regarding TBI, a study by Dongilli and colleagues (1992) found that 19 percent of participants failed to regain functional natural communication despite significant gains in cognitive functioning. Dementia (27%) services were most represented in skilled nursing facilities (SNFs) (ASHA, 2013b). These findings imply that many adults with CCN in various facilities face unmet AAC needs and SLPs continue to target ineffectual therapeutic goals.

Various barriers impeding AAC services for adults with CCN have been suggested. Siu et al. (2010) discovered that nearly one half (i.e., 45.7%) of professionals working in adult settings in Hong Kong lacked AAC experience. As previously mentioned, the respondents reported they were dissatisfied with their level of training in AAC (Siu et al., 2010). Unfortunately, the poor response rate (i.e., 18%) amongst professionals serving adult populations was a serious limitation

of this investigation (Siu et al., 2010). More comprehensive research with SLPs working with adults was identified by this group of researchers as critically important to further document service delivery trends and to ameliorate AAC services for adults with CCN (Siu et al., 2010).

**Facilitating AAC service delivery in medical settings.** The importance of AAC “finders” and “facilitators” has been discussed in AAC literature. Finders are those who identify individuals who are candidates for AAC services (Beukelman, Ball, & Fager, 2008). Finders are vital in order to refer individuals with CCN to SLPs and, thus, AAC services (Beukelman et al., 2008; Binger et al., 2012). Finders are especially important in medical settings as SLPs require doctors’ orders before they can provide services. In these settings, nurses and physicians serve as finders. Nurses spend a significant amount of time with patients, especially in acute care, and they communicate with physicians regarding patient needs, including AAC needs. This is of utmost importance as physicians are responsible for ordering speech-language and AAC services. Hence, without nurse and physician knowledge of AAC, service delivery is compromised.

Facilitators serve as common communication partners for individuals using AAC (Beukelman et al., 2008). In health care settings, nursing professionals have extensive interaction with patients with CCN (Beukelman & Mirenda, 2013). Respiratory therapists and physicians also make frequent contact with patients, especially in acute care settings (Beukelman & Mirenda, 2013). Thus, these health-care professionals commonly fill the role of facilitators. Both finders and facilitators require knowledge about AAC, yet, limited information is available as to how these two groups commonly function in adult-focused medical settings. Given that physicians and nurses must oftentimes serve as both finders and facilitators, their role in AAC



service delivery is vital (Hurtig & Downey, 2009), but, reportedly, they rarely possess the AAC knowledge to do so effectively (Beukelman et al., 2008). To date, no study that specifically examined the level of AAC knowledge of other professionals in medical facilities has been conducted. In fact, there is little research on finders and facilitators in general. Studies examining this barrier are needed in order to improve the rate and quality of service delivery in medical settings.

**The role of communication on quality of life in medical settings.** A key reason for the need to provide patients in medical settings with a reliable form of communication is to positively influence their quality of life. Research has shown that patient quality of life is compromised without a communication system. For example, secondary to being temporarily intubated, patients have reported feeling helpless when unable to communicate (Fowler, 1997; Stovsky, Rudy, & Dragonette, 1988). Patients on mechanical ventilation have reported that the main source of their fear and anxiety while on a ventilator was the inability to communicate (Fornataro-Clerici & Roop, 1997). Family members, as well, tend to feel more anxious when their loved-one, especially if it is a child, is unable to communicate their needs (Hurtig & Downey, 2009). In the case of non-verbal pediatric patients, parents are more likely to defer sleep and not leave their child's side if the child is unable to communicate, thus compromising their own health and well-being (Hurtig & Downey, 2009).

Unfortunately, the lack of a reliable means of communication also has negative effects on the quality of medical care received (Fornataro-Clerici & Roop, 1997). The ability to communicate with nursing staff has immediate implications on patient quality of life. On the

most basic level, patients must have access to a nurse call button to insure the patient is able to alert medical staff in situations of distress (Hurtig & Downey, 2009).

Nurses spend a significant amount of time caring for patients (Beukelman, Garrett, & Yorkston, 2007). It has been suggested that nurses communicate more positively and effectively with patients who they feel are more communicative (Ashworth, 1984; Happ, 2001; Leathart, 1994). Nurses can become increasingly frustrated when patients have difficulty communicating (Appel-Hardin, 1984; Cronin & Carrizosa, 1984). Due to the demanding nature of their job, they have limited time to interpret non-verbal messages (Ashworth, 1984). Training on lip reading and interpreting gestures is rarely included in nurses' training (Happ, 2001). A nurse's inability to interpret a patient's non-verbal message, in turn, increases the frustration level of the patient (Ashworth, 1984).

Being provided with a reliable form of communication can also allow patients to participate in making decisions regarding their medical care. Quality of life is increased when patients are able to communicate end-of-life and comfort measure wishes (Happ, Swigart, Tate, Hoffman, & Arnold, 2007; Hurtig & Downey, 2009; Sorensen & Iedema, 2011). In addition to allowing the patient to be involved in this decision-making process, it allows them the opportunity to communicate with loved-ones prior to initiating comfort measures, giving the patient and family feelings of closure (Hurtig & Downey, 2009).

**AAC service delivery and health disparity issues.** In line with the communicative function of exchanging information, access to a reliable form of communication is of utmost importance in medical settings in order to involve patients in making decisions regarding their health care. Patients need to be involved in all stages of decision-making (Happ et al., 2007).

According to Happ et al. (2007), health care decision making involves initiating, continuing, or discontinuing treatment, diagnostics, or therapeutic care activities. These choices may involve vent weaning, surgical procedures, PEG tubes, discharge, rehabilitation, or even end-of life / comfort care decisions (Happ et al., 2007; Sorensen & Iedema, 2011). Without current guidelines regarding decision making in ICU settings (Happ et al., 2007), decisions are often made by family members and even health care professionals (Sorensen & Iedema, 2011). This is disconcerting as patient and family wishes do not always coincide (Haddad, 2004) and the relationships between family members may be complicated (Way, Back, & Curtis, 2002).

Happ et al. (2007) examined the health care decision making process with non-verbal patients requiring mechanical ventilation in an ICU. They found that: (a) only 6 out of 31 health care decisions were patient-initiated, (b) patients were directly involved in only 12 of 31 health care decisions, and (c) patients were more likely to initiate decision-making discussions when it came to withdrawing or withholding treatment (i.e., initiating comfort care / palliative measures) (Happ et al., 2007). Seymour (2000) discovered that patients with CCN often feel their emotions are ignored when making decisions regarding palliative care. Similarly, Worrall et al. (2011) found that individuals with aphasia wish to communicate regarding medical diagnoses and therapeutic options. Instead, they often feel “left out” due to communication disparities (King et al., 2013).

**Acute care facilities, intensive care units (ICUs) & AAC.** Patients present to acute care settings and ICUs with serious, often unexpected, traumatic injuries or illnesses (Hirshon et al., 2013). Acute care includes emergency, trauma, and urgent care centers, as well as surgery and short-term inpatient services (Hirshon et al., 2013). Individuals in these settings may have CCN

secondary to stroke, TBI, brainstem impairment, or surgery for head and neck cancer. In such cases, a reliable communication system is vital for involving these patients in their plan of care.

Depending on the nature of the patient's illness, they may be rendered non-verbal for a short- or long-term duration (Beukelman, Garrett, et al., 2007). This could be a result of the patient's injuries / illness, such as stroke, brainstem injury, traumatic brain injury, and laryngeal or facial trauma, or even a result of a surgical procedure, such as laryngectomy or glossectomy (Beukelman, Garrett, et al., 2007). In addition to the patient's etiology or surgery contributing to CCN, the need to implement life-saving medical equipment including oral endotracheal tubes, tracheostomy tubes, and mechanical ventilators, leaves patients unable to speak.

Acute care facilities present barriers to AAC service delivery that are unique to this setting. One obvious barrier includes the patient's medical condition. Especially in an intensive care unit (ICU), patients' conditions may require extensive medical intervention (Beukelman, Garrett, et al., 2007). Therefore, SLP services may be delayed until a patient's condition improves. Additionally, patients with neurological deficits often present with impaired cognitive skills, which can eliminate the appropriateness of certain AAC devices which require various attentional and cognitive skills (Hurtig & Downey, 2009). Patients with significant physical and motor deficits present the need for alternative access to AAC devices (Hurtig & Downey, 2009). As mentioned earlier, this limits the possibility of these patients utilizing mobile technologies for communication purposes (Fager et al., 2012; McNaughton & Light, 2013). Moreover, many patients in acute care and ICU settings wear restraints on their hands or wrists in order to prevent them from displacing important medical equipment such as nasogastric (NG) feeding tubes, oral endotracheal tubes, or intravenous therapy (IVs), again, complicating access (Beukelman, Garrett, et al., 2007; Hurtig & Downey, 2009).

Hurtig and Downey (2009) observed that acute care settings lack sufficient types of AAC supports and devices, making establishing viable communication options for patients in this setting challenging. Traditionally, acute care centers tended to rely more on low-tech AAC choices rather than mid- or high-tech (Fried-Oken, Howard, & Stewart, 1991). A major pitfall of low-tech AAC is that it can be taxing on the communication partner (Hurtig & Downey, 2009). Although low-tech AAC provides many useful options in acute care, it has certain drawbacks. The partner must pay close attention to the individual who is communicating with low-tech AAC in order to interpret the message. The partner must also provide significant assistance when using options such as partner-assisted scanning. Another limitation of low-tech communication is that the patient is not able to alert someone in another room if they need help or are in distress. In acute care, all patients should have access to a nurse call button, and low-tech AAC cannot sufficiently provide this (Hurtig & Downey, 2009)

Due to the more recent development of mobile technologies, the preference for low-tech AAC in acute care is transforming as attitudes toward high-tech AAC devices are becoming more positive (Hurtig & Downey, 2009). Despite increased openness to high-tech options, access to sufficient equipment (i.e., low-, mid-, or high-tech) has been perceived as a significant barrier to providing patients with AAC services in acute care and ICUs, although no particular study has closely examined this (Beukelman, Garrett, et al., 2007; Hurtig & Downey, 2009).

One-way speaking valves offer tracheostomy and ventilator patients a way to vocalize, however, they are not appropriate for all clients in the ICU or acute care. First of all, in order to be a candidate for a one-way speaking valve, a patient must have a cuffless tracheostomy tube, or a tracheostomy tube, in which the cuff is able to be deflated (Fornataro-Clerici & Roop, 1997). In addition, the patient must be able to handle their secretions (Beukelman, Garrett, et al., 2007;

Fornataro-Clerici & Roop, 1997). Even if a patient meets those requirements, they may not initially be able to tolerate a one-way speaking valve for more than short periods of time.

Therefore, other forms of AAC are necessary until a patient can, if ever, build up tolerance for using a speaking valve for an extended period of time. Overall, few studies have been conducted on AAC service delivery in acute care; therefore, it is difficult to estimate how many individuals in this setting have unmet AAC needs (Hurtig & Downey, 2009) (Hurtig & Downey, 2009).

**Sub-acute facilities & AAC.** Sub-acute services are “more intensive than those typically received in skilled nursing facilities but less intensive than acute care” (ASHA, n.d.-b, p. 1). SLPs may provide sub-acute services in specific units in SNFs or rehabilitation hospitals. Individuals in such settings who may present with AAC needs include the same individuals found in acute care, but who are further along in the rehabilitation process. Therefore, they may have been recently discharged from acute care. There are currently no reports regarding the role of AAC in sub-acute facilities.

**Rehabilitation hospitals, skilled nursing facilities (SNFs) & AAC.** SLPs working in inpatient rehabilitation facilities often serve individuals following CVA, head injury, respiratory illness, CNS impairment, or a hemorrhagic event (ASHA). SLPs in these settings report most commonly targeting swallowing, expressive and receptive communication, and cognition (ASHA, n.d.-a). Based on this information, it is likely that SLPs encounter individuals with CCN and AAC needs in this setting.

SNFs may serve patients with similar etiologies, but SNFs are unique as SLPs in these settings are more likely to serve individuals with brainstem impairment and individuals who need ventilator support (Beukelman et al., 2008). Those with brainstem impairment often

transition directly from acute care to a long-term care facility (i.e., they are not appropriate for rehabilitation settings) (Beukelman et al., 2008). These individuals often rely on partner-assisted scanning, however, they could benefit from eye-tracking or head-tracking access options (Beukelman et al., 2008). In the SNF setting, it is important to get AAC recommendations early, such as when the patient arrives. If individuals with brainstem impairment are there too long without the SLP initiating the device funding process, they could lose the possibility of funding (Beukelman et al., 2008). Some individuals with brainstem impairment regain natural speech, but it may not be for several years, and may still not be sufficient to realize all communication needs (Culp & Ladtkow, 1992).

### **Etiologies Contributing to Complex Communication Needs (CCN) in Medical Settings**

Individuals with CCN comprise a heterogeneous group. They may present with developmental disabilities, acquired disorders, degenerative conditions, or short-term / temporary conditions. The medical conditions most often contributing to CCN include stroke, TBI, amyotrophic lateral sclerosis (ALS), and multiple sclerosis (MS) (Beukelman & Mirenda, 2013). In addition, the growing prevalence of head and neck cancer can be attributed to individuals with CCN.

**Developmental disabilities.** Individuals with CCN may be born with a congenital etiology or develop the need for AAC early in childhood (Beukelman & Mirenda, 2013). The most common of these etiologies includes severe intellectual disability, autism, childhood

of speech (CAS), and cerebral palsy (CP). Although the developmental disorders mentioned most commonly contribute to CCN, other developmental disorders such as deaf-blindness, Down syndrome, and other disorders contribute as well (Beukelman & Mirenda, 2013).

***Intellectual disability (ID).*** ID has been defined as “limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical skills” and it is diagnosed prior to the child turning 18 (Schalock et al., 2010, p. 1). It is estimated that approximately one to three percent of individuals throughout the world have ID (World Health Organization, 2001). ID encompasses a wide range of disabilities impairing cognition (Beukelman & Mirenda, 2013). Individuals with various forms of ID often benefit from various types of supports, including AAC (Beukelman & Mirenda, 2013). In fact, it has been reported that in Florida, 34% of school-aged children needing AAC presented with ID (Kent-Walsh et al., 2008).

***Autism spectrum disorders (ASD).*** ASD refers to a range of social and communication disorders with varying degrees of severity (Wing, 1996). The Centers for Disease Control and Prevention (2012) reports that approximately one in every 88 persons has ASD. Among those individuals, an estimated 40% are non-verbal, while 25-30% develop a limited number of words at a young age before attrition of those words (Johnson, 2004; Schneider, 2004). Given these statistics, AAC is necessary to establish functional communication, and SGDs have proven to be effective at improving communication skills in many individuals with ASD (Schlosser, Sigafos, & Koul, 2009; Schlosser, 2003).

***Childhood apraxia of speech (CAS).*** CAS, like acquired apraxia of speech (AOS), is a speech sound disorder (SSD) (Bauman-Waengler, 2012). ASHA, (2007a) defines CAS as “a



neurological childhood (pediatric) speech sound disorder in which the precision and consistency of movements underlying speech are impaired in the absence of neuromuscular deficits (e.g., abnormal reflexes, abnormal tone)” (p. 1). The origins of CAS are neurologic in nature, and it can occur as the result of a known neurologic event, as a characteristic of a neurologic / developmental disorder, or for unknown reasons (i.e., idiopathic etiology) (ASHA, 2007a). Characteristics of CAS include inconsistent articulatory errors, impaired prosody, unusual errors compared to children with other SSDs, omissions, voicing errors, vowel errors, sequencing errors, prosodic errors, and groping behaviors, all seriously affecting intelligibility (ASHA, 2007a; Bauman-Waengler, 2012). Estimates indicate that roughly one to two in every 1,000 children presents with CAS (Shriberg, Aram, & Kwiatowski, 1997).

Although intensive and frequent speech sound therapy is recommended for children with CAS, AAC is often recommended as well (Beukelman & Mirenda, 2013). ASHA (2007b) supports this approach to CAS treatment – implementing AAC so the child can communicate until speech intelligibility improves through intensive treatment. Providing the child with a language output system may mitigate possible language delays by providing them the opportunity to form language (Binger, 2008; Cumley & Swanson, 1999), and AAC has no negative effect on developing speech abilities in children with CAS (Bornman, Alant, & Meiring, 2001).

***Cerebral Palsy (CP)***. CP is a disorder effecting movement and posture (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). An estimated one out of 500 children born in developed countries have CP (Pakula, Van Naarden Braun, & Yeargin-Allsopp, 2009). It causes

deficits in motor function, and the various types of CP, including spastic, dyskinetic, and ataxic, affect musculature differently (Beukelman & Mirenda, 2013).

CP is commonly associated with a diagnosis of spastic dysarthria, a motor speech disorder (MSD) which negatively affects movement patterns needed for speech (Duffy, 2013). Because motor functioning is affected, the various systems required for speech are impaired (Duffy, 2013). As a result, individuals with CP not only have difficulty articulating speech sounds, but they also have impairments in respiration, laryngeal, and velopharyngeal functioning, making it difficult to coordinate these systems for speech (Bauman-Waengler, 2012; Beukelman & Mirenda, 2013; Duffy, 2013). Ashwal et al. (2004) found that roughly 38% of children born with CP have decreased speech intelligibility. As individuals with CP often live into adulthood, SLPs can expect to serve these individuals in a variety of settings across the lifespan (Beukelman & Mirenda, 2013).

**Acquired disorders.** Individuals with acquired disorders had developed speech and language abilities, but lost them with gradual or sudden onset (Beukelman & Mirenda, 2013). Acquired disorders contributing to complex communication needs include aphasia, AOS, dysarthria, or TBI.

**Aphasia.** Aphasia is a language disorder causing impairments in receptive and expressive language. Approximately one in every 300 Americans has aphasia with roughly 80,000 new cases per year (Garrett & Lasker, 2013). It is most commonly caused by a cerebral vascular accident (CVA) (Garrett & Lasker, 2013). However, it can also result from TBI, neoplasm, or epilepsy (Garrett & Lasker, 2013). Aphasia can be devastating to functional communication as it can affect one or all modalities to varying degrees: (a) speaking, (b) comprehension, (c) reading,

and (d) writing (Garrett & Lasker, 2013). There are many different types of aphasia resulting in different types of language impairments. The various forms of aphasia include Broca's, Wernicke's, global, transcortical motor, transcortical sensory, conduction, and anomic aphasia.

Following acute onset of aphasia, many important medical decisions are made regarding surgery, medication, and treatment. The importance of these decisions underlies the role of the SLP in immediately establishing a reliable, functional communication system for the individual with aphasia (Garrett & Lasker, 2013). In many cases, low-tech, easily accessible AAC systems are often most appropriate, as aphasia causes a disruption in the individual's linguistic system and may also coincide with physical impairments. Possibilities for low-tech AAC may include manual gestures, writing, drawing, photo albums, written choices, communication books or boards, eye gaze, and / or alphabetic boards, depending on the nature of the individual's impairment (Garrett & Lasker, 2013).

As recovery progresses and the individual transitions into sub-acute care, decisions regarding long-term use of AAC and upgrading to mid- and high-tech options must be made (Garrett & Lasker, 2013). Most often, however, speech-language therapy for aphasia focuses on traditional aphasia rehabilitation (Beukelman, Fager, et al., 2007). Traditional aphasia intervention attempts to restore natural communication to levels commiserate with functioning before the neurologic event (Beukelman, Fager, et al., 2007). Unfortunately, traditional speech-language rehabilitation has remained vastly ineffective. Porch (1981) found that roughly half of individuals receiving traditional speech-language intervention for aphasia were not competent communicators in conversational settings. In addition, Nicholas & Helm-Estabrooks (1990) examined the effectiveness of traditional aphasia intervention and deemed it an impractical approach for a number of adults with aphasia.

On a more positive note, traditional aphasia intervention is often sufficient for restoring functional communication in individuals with mild to moderate impairments (Robey, 1994). On the other hand, it is most often unsuccessful for those with severe aphasia (Robey, 1994). According to Beukelman, Fager, et al. (2007), approximately 40% of individuals with aphasia have chronic and severe aphasia. As studies illustrate, restoration of functional, natural communication is unrealistic in many cases. Thus, AAC strategies must be considered not only in the acute phase of recovery, but also as a long-term solution for certain individuals in outpatient, home health, or long-term care settings (Garrett & Lasker, 2013; Hux, Beukelman, & Garrett, 1994). Despite such findings, traditional aphasia therapy continues to dominate adult intervention (ASHA, 2013b).

***Apraxia of speech (AOS).*** AOS is most commonly caused by CVA (Duffy, 2013). It is an SSD that often coincides with aphasia and dysarthria (Duffy, 2013). AOS is distinct from aphasia and dysarthria, however, as AOS is a disorder of motor planning. In other words, when AOS occurs in isolation, there are no associated deficits in the speech musculature, and no language-based impairment (Duffy, 2013). According to Yorkston, Spencer, & Duffy (2003), individuals with AOS may have limitations in speech intelligibility to varying degrees.

***Dysarthria.*** Duffy (2013) defined dysarthria as “a group of neurologic speech disorders that reflect abnormalities in the strength, speed, range, steadiness, tone, or accuracy of movements required for the breathing, phonatory, resonatory, articulatory, or prosodic aspects of speech production” (p. 4). It can arise from a number of conditions, including stroke. In addition, it is always neurologic in nature (Duffy, 2013).

There are several types of dysarthria including flaccid, spastic, ataxic, hypokinetic, hyperkinetic, unilateral upper motor neuron, and mixed. The varying forms and severities of dysarthria can affect the intelligibility of a speaker in different ways. Although dysarthria is presented in this section on acquired disorders, it can result from onset of progressive-degenerative disease processes as well.

***Traumatic brain injury (TBI).*** TBI may cause deficits in speech, language, and cognition (Beukelman, Fager, et al., 2007). Each year, 1.7 million individuals experience TBI, although cases commonly go unreported (Centers for Disease Control and Prevention, 2010). In the United States, 80,000 to 90,000 individuals who experience TBI annually have impairments severe enough to cause a decline in independent functioning (Fager, 2013). Certain groups of individuals sustain TBI more commonly than others. For instance, males are twice as likely to sustain TBI as females (Centers for Disease Control and Prevention, 2010; Fager, 2013). Further, children under age five, teenagers, and adults over age 65 are more likely to experience TBI than other age groups (Centers for Disease Control and Prevention, 2010; Fager, 2013). Falls (35.2%) are to blame for the majority of TBIs, with motor vehicle crashes (17.3%) coming in second (Centers for Disease Control and Prevention, 2010; Hux, 2011).

TBI can lead to a decrease in cognitive functioning, but can also cause aphasia and dysarthria (Fager, 2013; Garrett & Lasker, 2013). Regarding dysarthria with TBI, researchers have identified three patterns of recovery: (a) speech is restored rapidly parallel to an increase in cognitive functioning, (b) functional speech is regained in conjunction with intensive motor speech treatment, or (c) functional speech is not regained, even after several years of treatment (Fager, Hux, Beukelman, & Karantounis, 2006). Pertaining to cognition, Dongilli, Hakel, &

Beukelman (1992) found that 22 percent of participants with TBI did not progress to levels of cognitive functioning commiserate with regaining communication. Furthermore, 19 percent of participants failed to regain functional communication even if cognitive functioning resolved to levels in which communication re-emerges or higher (Dongilli et al., 1992).

With regards to the use of AAC with individuals with TBI, the patient was traditionally provided a single communication support / device (Fager, 2013). This approach is now considered outmoded as individuals with TBI often continue to progress cognitively, making them better suited for different types of AAC at different periods during their recovery (Fager, 2013). Therefore, AAC assessment and intervention with individuals with TBI often take a multimodal approach while still targeting natural speech (Fager, 2013). As the recovery process may be protracted for some with TBI, they may find themselves transitioning to different care settings (Fager, 2013). As a result, SLPs must be involved in providing AAC services to individuals with TBI in a range of settings including acute care, rehabilitation facilities, home health, and outpatient clinics. Moreover, individuals with TBI require considerable support from facilitators due to cognitive factors (Fager, 2013), and unfortunately, in some instances, patients with TBI have abandoned AAC due to lack of facilitator support (Fager et al., 2006).

***Head and Neck Cancer (HNC).*** The three most common types of HNC include lingual, maxillary, and laryngeal cancer (Sullivan, Gaebler, & Ball, 2007). In the United States alone, it was reported that in 2006, there were 30,990 cases of oral or pharyngeal cancer, and 9,510 cases of laryngeal cancer (Jemal et al., 2006). Additionally, HNC sites may include the mandible, soft or hard palate, and nasopharynx.

*Lingual cancer.* Unfortunately, the incidence of lingual cancer is on the rise, especially amongst young adult males (Myers, Elkins, Roberts, & Byers, 2000). While some surgical procedures to remove lingual cancer tumors are likely to have only minimal disturbances on speech, the effects of total glossectomy will be devastating (Sullivan et al., 2007). While prosthetics can lead to increases in speech and swallowing function, speech intelligibility often remains impaired (Sullivan et al., 2007). In fact, those with lingual cancer following glossectomy comprise the largest group of patients with HNC to derive benefit from AAC (Sullivan et al., 2007).

*Maxillary cancer.* Maxillary cancer, cancer of the upper jaw, usually involves surgical removal of the tumor, often with portions of the hard and soft palate removed, which can cause articulatory impairments (Sullivan et al., 2007). In many cases, a prosthesis called an obturator is utilized to conceal the palatal opening (Sullivan et al., 2007). The use of an obturator can increase speech intelligibility (Sullivan et al., 2007). However, for individuals who may not use or may not derive benefit from an obturator, other communication options must be considered.

*Laryngeal cancer.* Laryngeal cancer may be supraglottic (above the vocal folds), subglottic (below the vocal folds), or glottic (on the vocal folds). Currently, laryngeal cancer is treated with radiation, chemotherapy, surgery, or a combination of chemotherapy and radiation (Sullivan et al., 2007). Radiation or radiation plus chemotherapy may be chosen to preserve the larynx, although vocal quality may still be compromised (Sullivan et al., 2007). Surgical options include total laryngectomy, in which the entire larynx is removed, or partial laryngectomy, in which a portion of the larynx is removed. In cases of total laryngectomy, another means of communication must be sought.

A common communication choice for individuals post total laryngectomy often involves alaryngeal speech, including options such as electrolarynx / artificial larynx, esophageal speech, or tracheo-esophageal speech (TEP) (Sullivan et al., 2007). There are advantages and disadvantages to using each type of alaryngeal speech. For instance, intelligibility appears to vary as consequence of speaking environment / situation with these types of speech (Sullivan, Beukelman, & Mathy-Laikko, 1993). Furthermore, because of certain drawbacks of alaryngeal speech, such as a mechanical-sounding quality, some individuals post total laryngectomy actually prefer speech-generating apps for mobile devices due to more natural-sounding voice output options (V. Lewis, personal communication, April 22, 2014).

Additionally, immediately following surgery, alaryngeal speech is not typically an option due to the medical condition of the post-operative patient (Sullivan et al., 2007). Tracheostomy tubes for respiration and NG tubes for nutritional intake are often placed, and the patient may experience significant pain, making alaryngeal speech inappropriate at this time (Sullivan et al., 2007). At this stage during recovery, these patients often rely on unaided (e.g., gesturing, mouth words) and low-tech (e.g., communication boards, writing, alphabet boards) forms of communication, which they should be educated on pre-operatively (Sullivan et al., 2007). Because HNC patients most often have intact fine motor skills and cognition, speech-generating mobile devices may be a viable option.

For individuals status post laryngectomy, AAC decision making is an ongoing process as communication needs evolve. When individuals who use alaryngeal speech contract certain illnesses such as respiratory infections, bronchitis, or pneumonia, or have to undergo additional surgical procedures, alaryngeal speech may not be possible and alternative forms of communication are necessary (Sullivan et al., 2007). Furthermore, individuals may find they



need supplements to alaryngeal speech in certain situations. Additional AAC options are recommended for individuals using alaryngeal speech in the following situations: (a) if the cancer reoccurs, (b) if another operation is needed, or (c) if the individual is less than 80% intelligible (Sullivan et al., 1993, 2007; Yorkston, Beukelman, & Tice, 1996).

**Degenerative conditions.** Degenerative conditions are long-term, progressive conditions (Beukelman, Fager, et al., 2007; Yorkston & Beukelman, 2007). Individuals with degenerative conditions generally transition to different facilities as the disease progresses. Therefore, SLPs may encounter these individuals in outpatient clients at the onset of the disease, and in SNFs in later stages as the disease necessitates the need for long-term care (Yorkston & Beukelman, 2007). Individuals with these conditions may also be seen in acute care due to complications from the disease process (Yorkston & Beukelman, 2007). Degenerative conditions, which can lead to CCN include ALS, Parkinson's disease (PD), and Huntington's disease (HD), among others (Yorkston & Beukelman, 2007).

***Amyotrophic lateral sclerosis (ALS).*** ALS – also referred to as motor neuron disease or Lou Gehrig's disease – is a degenerative neuromuscular disease that progresses rapidly and has no known cure. Types of ALS include bulbar (initially affecting the cranial nerves), spinal (initially affecting the spinal nerves), and mixed (Ball, Beukelman, & Bardach, 2007). One of the first symptoms of ALS is manifested in speech, and individuals with ALS usually acquire mixed flaccid-spastic dysarthria (Duffy, 2013).

There is a dire need for AAC amongst individuals with ALS as roughly 95% of individuals with the disease lose the ability to speak (Ball, Beukelman, & Pattee, 2004). In fact, traditional speech therapy techniques such as oral motor exercises or articulatory exercises are

contraindicated for individuals with ALS as they increase fatigue (Ball et al., 2007). With this in mind, AAC services are of utmost importance for individuals with ALS. Due to the rapid progression of the disease, timing of AAC referral is essential. It is recommended that referral for AAC take place when the individual's speaking rate drops to 100 to 125 words per minute (Yorkston et al., 1996). Fortunately, AAC has a high rate of acceptance among individuals with AAC. In a study by Ball et al. (2004), approximately 96% of individuals with ALS who received an AAC recommendation accepted it.

***Multiple sclerosis (MS).*** While the exact cause of MS is unknown, theories suggest this acquired central nervous system (CNS) disease may have auto-immune, viral, and / or genetic origins (Boyden, 2000). It is an inflammatory, demyelinating, progressive condition which affects women more than men and is the leading neurological diagnosis for young adults and middle-aged individuals (Yorkston & Beukelman, 2007).

Many individuals diagnosed with MS present with speech-language symptoms. The majority of these individuals present with dysarthria (usually ataxic, spastic, or ataxic-spastic) (Duffy, 2013; Yorkston & Beukelman, 2007), while some have aphasia (Devere, Trotter, & Cross, 2000; Lacour et al., 2004; Trinka, Unterberger, Luef, Benke, & Berger, 2001). While many individuals with MS do not have speech symptoms in the early stages of the disease, many have some need for AAC during the later stages (Yorkston & Beukelman, 2007).

According to research by Darley, Aronson, & Brown (1975), those who presented with speech disturbances may have difficulties with respiration, loudness control, vocal quality, and articulation. Beukelman, Kraft, & Freal (1985) and Hartelius & Svensson (1994) found that 23%

and 44%, respectively, of individuals in various stages of MS reported communication difficulties.

Clearly, there is a need for communication supports for individuals with MS, especially in the late stage when natural speech may not be functional (Yorkston & Beukelman, 2007). Unfortunately, there is a paucity of research on AAC use with individuals with MS (Yorkston & Beukelman, 2007). Limited research demonstrates that few individuals with MS utilize high-tech AAC (Beukelman et al., 1985; Yorkston et al., 2003), and access is an issue at the later stages of the disease process as vision and motor problems begin to manifest (Yorkston & Beukelman, 2007).

***Parkinson's disease (PD)***. PD is a progressive neurologic disease which involves the basal ganglia. PD is often characterized by presence of tremors, bradykinesia (slow movements), and rigidity (Yorkston & Beukelman, 2007). PD is often a cause of hypokinetic dysarthria (Duffy, 2013). Many individuals with PD report speaking difficulty with weak voice as a chief complaint (Hartelius & Svensson, 1994). In addition, the speech of an individual with PD may be characterized by monopitch, monoloudness, short rushes of speech, breathy voice, and imprecise articulation (Duffy, 2013; Yorkston & Beukelman, 2007). Although PD is often managed pharmacologically, prescription drug-use for PD has had little effect in improving speech, and during the late stages of the disease, AAC may be necessary (Yorkston & Beukelman, 2007). During early phases of PD, the individual may be introduced to different forms of AAC (Yorkston & Beukelman, 2007). In the middle stages, delayed auditory feedback or other strategies might be introduced to slow the rate of speaking (Yorkston & Beukelman, 2007). In the final stages of the disease, when speech is much less intelligible, the individual with PD

might use alphabet boards to supplement speech; pointing to the first letter of the word the speaker is using also serves to slow the rate of speech (Yorkston & Beukelman, 2007). Others in this stage may utilize orthography-based SGDs (Yorkston & Beukelman, 2007).

***Huntington's disease (HD)***. HD is a hereditary degenerative disease with neurologic origins. HD affects four to seven people in every 100,000 (Hunt & Walker, 1991), and death typically occurs between 15 and 20 years post onset (Yorkston & Beukelman, 2007). HD causes cognitive, emotional, and movement impairments, and is linked to hyperkinetic dysarthria (Duffy, 2013; Yorkston & Beukelman, 2007). The hyperkinetic dysarthria caused by HD is characterized by chorea-like movements, which are involuntary movements. They affect respiration, phonation, and articulation (Yorkston & Beukelman, 2007). Deficits in cognition also negatively impact communication (Yorkston & Beukelman, 2007). Therefore, supports for topic maintenance, and scripts may be helpful in supplementing the communication of individuals in the early stages of HD, and cognitive supports may be beneficial in the middle stages (e.g., a visual schedule displaying the steps of an activity) (Yorkston & Beukelman, 2007). In the late stages of the disease, previously learned, simple techniques are best, and communication partner training is essential (Yorkston & Beukelman, 2007). Partner-assisted scanning, alphabet boards, memory supports, and a reliable yes / no system are appropriate during this stage, although there is little research on the implementation of AAC with individuals with late stage HD (Yorkston & Beukelman, 2007).

**Short-term / temporary conditions.** Although it seems intuitive to provide AAC service delivery for individuals with long-term CCN, the needs of those with temporary CCN should not be ignored. Individuals who present to acute care for planned surgeries may be temporarily

unable to speak due to mechanical ventilation, the nature of the surgery, intubation, or tracheostomy. Without the ability to communicate, these individuals become frustrated or anxious (Fried-Oken et al., 1991). Some hospitals have implemented protocols in which patients with planned surgeries are provided AAC pre-operatively (Costello, 2000). Costello (2000) has reported on the model used at Children's Hospital in Boston, and has found that this model is effective at decreasing frustration, feelings of isolation, and anxiety associated with being unable to speak (Costello, 2000). According to this model, before the operation, the SLP meets with the patient to assess and provide treatment using aided and unaided AAC strategies, to select vocabulary, to use voice banking, and to train families and caregivers (Costello, 2000). It is at this stage that patients choose the forms of AAC that best fit their needs (Costello, 2000). Following the operation, when the patient is alert enough, the nurse calls the SLP to immediately bring the chosen device, reassess the patient, and commence treatment (Costello, 2000). This protocol has been used with patients undergoing surgery for HNC, respiratory distress, subglottic stenosis, laryngeal malformation, lung transplant for cystic fibrosis, venous malformation, and jaw reconstruction, among surgeries (Costello, 2000). Similarly, Sullivan et al. (2007) advocated a multi-step approach for working with individuals undergoing laryngectomy, which includes a "getting ready phase," a post-surgical phase, a restorative phase, and a long-term AAC phase.

## **Purpose**

The purpose of this study was to: (a) assess the availability of AAC devices, related materials, and skilled AAC services in acute, sub-acute, long-term care, and outpatient medical facilities in Florida, and (b) examine any barriers and supports that may exist for SLPs in

providing AAC services to patients with CCN in the aforementioned settings. Specifically, this study aimed to answer the following research questions:

**Research question 1:** What are the prevalence and characteristics of patients with AAC needs in medical settings?

**Research question 2:** What is the availability of AAC devices and related materials in medical settings?

**Research question 3:** What major barriers to AAC service delivery are prevalent in medical settings?

**Research question 4:** How do SLPs perceive their own level of knowledge regarding AAC?

**Research question 5:** From the SLP's point of view, what is the perceived level of knowledge that other health-care professionals including physicians, nurses, and other rehabilitation professionals (e.g., physical therapists (PTs), occupational therapists (OTs), and respiratory therapists (RTs)) demonstrate regarding AAC?

## **Hypotheses**

Based on the extant literature, the following hypotheses were developed:

- 1) Individuals with CCN face unmet communication needs in medical settings.
- 2) From the perspective of SLPs working in medical settings, the availability of AAC devices and related services are limited in medical settings.

- 3) Major barriers to AAC service delivery in medical settings include limited availability of AAC devices / services, high caseloads, and lack of time to prepare devices / materials.
- 4) The majority of SLPs will rate their own level of AAC expertise as “less than knowledgeable.”
- 5) The majority of SLPs will rate the level of AAC knowledge of other health care professionals including physicians, nurses, and other rehabilitation professionals (e.g., PTs, OTs, and RTs) to be “less than knowledgeable.”

## **CHAPTER TWO: METHOD**

### **Study Design**

This study is a descriptive study using an email-based online survey. An email-based approach was chosen for benefits of cost and timeliness of responses. A non-probability sampling method was used to target a closed population; all members in the closed population were included in the email list.

### **Participants**

To obtain information on the AAC services in medical settings, surveys were distributed to SLPs in Florida between September and October of 2014. Possible respondents were chosen on the basis of meeting the following criteria: (a) SLPs listed in the membership directory of the Florida Association of Speech-Language Pathologists and Audiologists (FLASHA) in September 2014, and (b) SLPs with identified work settings or e-mail domains listed in the FLASHA membership directory that were indicative of employment in medical settings (i.e., acute care, sub-care, sub-acute care, long-term care, or outpatient medical clinics) in the state of Florida. Emails were sent to 264 possible respondents who matched the above-mentioned criteria.

Each respondent provided informed consent for participating. Upon clicking or copying and pasting the survey link, respondents were directed to a page informing them about the study's purpose, anticipated risks, and confidentiality. By clicking "next" to begin the survey, they provided informed consent.

### **Materials**

An email-based online survey method was chosen for cost-effectiveness and timeliness of distribution and receiving responses (Dillman, Smyth, & Christian, 2009). Materials included a



32-question online survey (see Appendix B), an invitation email (see Appendix C), two reminder emails (see Appendices D & E), and a thank you email (see Appendix F).

The survey was created using the tailored design method (Dillman et al., 2009). The survey consisted of multiple choice, open-ended, Likert-scale (i.e., ordinal), true-false, and check-all-that-apply questions. Five-point bipolar scales were used for ordinal scale questions because they allow for two distinction levels on both the left and right of the middle choice (Dillman et al., 2009).

The survey included three sections targeting information regarding respondent demographics; caseload information; and AAC knowledge, training, and resources. The demographic section consisted of items pertaining to the SLP, including gender, employment, setting, and years of practice. Caseload questions related to age of patients, disability / classification of patients, patients' AAC use, and patients' AAC needs. The AAC knowledge, training, and resources section provided a definition and examples of AAC prior to the questions. The questions in this section asked the respondent about their own experience and knowledge using AAC, the availability of AAC at their setting, the barriers to AAC at their setting, and the perceived AAC knowledge of other medical professionals at their facility.

The invitation email explained the purpose of the survey, the survey incentive, and included a URL to access the survey. A material incentive was offered to respondents who completed surveys as this has a positive effect on response rates (Görizt, 2006; Sauermann & Roach, 2013). Respondents were initially offered a \$1.00 Amazon.com credit for completing the survey.

The wording in the reminder emails varied as recommended by Dillman et al. (2009). An opt-out link was provided in the invitation and subsequent reminder emails. Upon clicking the

survey URL or cutting and pasting it in their browser, participants were directed to the survey. Before beginning the survey, they were shown an informed consent statement detailing the survey procedures, study purpose, research contact information, and an informed consent statement. Participants' responses remained confidential.

## **Procedures**

**Survey development.** The survey was constructed using a multiple stage procedure as suggested by Dillman et al. (2009). The stages utilized included: (a) drafting, (b) obtaining feedback from a panel, (c) piloting the survey, and (d) developing a final draft (Dillman et al., 2009).

Following creation of the initial survey draft, an expert panel including three university professors, who are SLPs and have experience with survey research, convened to provide feedback on survey items. Feedback was incorporated and a pilot study was conducted.

The pilot study was conducted by sending the survey via email to 11 SLPs working in ICUs, short-term acute care hospitals, rehabilitation hospitals, and outpatient medical clinics in the state of Florida. The pilot respondents took the survey, and provided feedback to the author about the ease of taking the survey and any unclear items. Several respondents expressed that asking SLPs in medical settings to report precise numbers of patients on caseloads was problematic in light of frequent fluctuations in caseload sizes in medical settings. Instead, it was suggested that respondents be asked to provide an average number of patients seen per week. Additionally, respondents suggested that one-way speaking valves be added to the list of possible AAC devices. These changes were made to the survey and a finalized version was created.

***Survey distribution.*** Online surveys were distributed via email directly to FLASHA members identified as working in medical settings. Surveys were emailed using Qualtrics.com. Each survey respondent received a unique URL to prevent respondents from taking the survey more than one time. With the unique URL, each participant was assigned a code. Therefore, the author was able to send reminder and thank you emails and the material incentive to the correct individuals.

One week following the initial invitation email, to maximize response rates, a reminder email was distributed (Dillman et al., 2009). Following a low response rate after the first distribution, the incentive amount was increased to \$5.00. Changing distribution procedures is consistent with a dynamic design approach, which allows the researcher to maximize responses (Sauermann & Roach, 2013). Sending multiple emails is a proven method for increasing responses (Cook, Heath, & Thompson, 2000). The reminder email used wording which varied from the original email, as this is a suggested way to decrease the possibility the email will be flagged as “spam” (Dillman et al., 2009). Lastly, a second reminder email with novel wording was sent two weeks following the initial email distribution.

## **CHAPTER THREE: RESULTS**

This study sought to examine: (a) the prevalence and characteristics of individuals with CCN in acute care, sub-acute care, rehabilitation hospitals, SNFs, outpatient medical settings, and home health care, (b) the availability of AAC devices, related materials, and skilled AAC services in medical settings in Florida, and (c) barriers and supports to providing effective AAC services in these settings.

The survey elicited responses pertaining to three sections including: (a) respondent demographic information, (b) caseload / patient demographic information, and (c) AAC knowledge, training, and resources.

### **Response Rate and Demographics**

Of the 264 emails sent, 16 emails bounced, yielding 248 successfully delivered e-mails. Of the remaining 248 emails, 92 individuals responded, for a response rate of 37%. The responses of six participants were not included in data analyses as these respondents indicated they did not work in medical settings; this yielded a final count of 86 respondents. It should be noted that respondents were permitted to skip questions, so some questions were not answered by every respondent.

Of the 86 respondents, 81 (94%) were female and 5 (6%) were male. This gender distribution is similar to demographic information from ASHA (ASHA, 2013); 3.7% of SLPs who are ASHA members are reported to be male. Respondents had worked in the field of speech-language pathology from a range of less than one to 40 years with a mean of 13.6 years in the field and a median of 10 years. Table 1 displays the breakdown of years of experience in the field of speech-language pathology of the respondents.

Respondents worked in cities (65%), large towns (24%), and small towns (11%). Thirty-two percent of them reported working part-time in a medical setting, and 68% reported working full-time. They worked in ICUs, short-term acute medical care hospitals, transitional / post-acute hospitals, rehabilitation hospitals, SNFs, and home health. Table 2 displays the number of respondents working in each setting. Many respondents worked in multiple settings. Twenty-five percent of respondents were the only SLP working in their facility. Respondents worked with patients across the lifespan. Table 3 presents the patient age groups that respondents worked with. Respondents reported seeing a range of 3 to 50 different patients per week with a mean of 22 patients and a median of 20. Table 4 depicts the average number of different patients that respondents saw in a week.

*Table 1: Respondents' Years of Experience Employed as SLPs*

Range in Years	Percentage of Respondents
<1-5	23.3%
6-10	27.9%
11-15	16.3%
16-20	9.3%
21-25	9.3%
26-30	5.8%
31-35	1.2%
36-40	7.0%

n=86

*Table 2: Respondents' Work Settings / Facilities*

Setting	Percentage of Respondents
ICU	29.4%
Short-term Acute Medical Care Hospital	34.1%
Transitional / Post-Acute Hospital	5.9%
Rehabilitation Hospital	11.8%
Skilled Nursing Facility	34.1%
Home Health Care	17.6%
Outpatient Clinic	38.8%

n=85

*Table 3: Age Ranges of Respondents' Patients*

Age Ranges in Years	Percentage of Respondents*
0-2	25%
2-4;11	27%
5-12	30%
12-18	33%
19-59	58%
60+	82%

n=84

\*most respondents work with more than one age range

*Table 4: Average Number of Different Patients Seen in one Week*

Number of Patients	Percentage of Respondents
1-5	3.7%
6-10	17.1%
11-15	20.7%
16-20	15.9%
21-25	9.8%
26-30	9.8%
31-35	6.1%
36-40	8.5%
41-45	4.9%
46-50	3.7%

n=82

## Caseload Information / Demographics of Patients with CCN

**Prevalence of patients with CCN.** The vast majority (97.59%) of respondents indicated their patients had AAC needs. The percentage of patients with whom respondents worked in any given week who were unable to meet all of their communication needs using natural speech are displayed in Table 5.

*Table 5: Percentage of Patients on Respondents' Caseload Unable to Meet all Communication Needs using Natural Speech*

Percentage of patients	Percentage of Respondents
0%	2.41%
1-25%	62.65%
26-50%	15.66%
51-75%	14.46%
76-99%	2.41%
100%	2.41%

n=83

The majority of respondents (80%) indicated that between 1% and 25% of the patients on their caseload uses AAC or receives AAC services. Table 6 displays the percentages of patients on respondents' weekly caseloads who use AAC or receive AAC services.



*Table 6: Percentage of Respondents' Current Caseload Receiving AAC Services*

Average percentage of patients	Percentage of Respondents
0%	9%
1-25%	80%
26-50%	4%
51-75%	3%
76-99%	4%
100%	0%

n=76

Data revealed that 94.1% of respondents indicated that their patients could benefit from increased access to AAC technologies or services. Table 7 presents the percentages of patients on respondents' caseload who they indicated would benefit from increased AAC access.

*Table 7: Percentages of Patients who would Benefit from Increased AAC Access*

Percentage of Patients	Respondents, n=51
0%	5.9%
1%	13.7%
2%	2.0%
3%	11.8%
5%	9.8%
10%	7.8%
15%	9.8%
20%	19.6%
25%	7.8%
30%	2.0%
40%	5.9%
50%	3.9%

**Primary disabilities of patients with CCN.** Table 8 provides information regarding the etiologies represented on respondents' caseloads.

*Table 8: Etiologies, Diagnoses, and Disorders Represented on Respondents' Caseloads*

Etiology, diagnosis, or disorder	Percentage of respondents working with this population
Amyotrophic lateral sclerosis (ALS)	32%
Aphasia	73%
Apraxia of speech	69%
Brainstem impairment	29%
Dementia	73%
Dysphonia	33%
Dysarthria	80%
Head and neck cancer	44%
Huntington's disease	20%
Locked-in syndrome	16%
Multiple sclerosis	33%
Myasthenia gravis	25%
Parkinson's disease	68%
Primary progressive aphasia	17%
Tracheostomy	55%
Traumatic brain injury	60%
Other complex neurological	37%
Other*	13.7%

\*Other responses included autism (4.1%), speech sound disorders (2.7%), expressive and receptive language disorders (2.7%), cerebral palsy (1.4%), intellectual disability (1.4%), and Down syndrome (1.4%).

n=75

## AAC Service Delivery in Medical Settings

Direct AAC services included AAC assessment, intervention, or implementation activities with patients; 79.8% of respondents provided direct services on average each week. Indirect services included device programming, educating families or caregivers, researching AAC options, or completing online training to learn to operate AAC devices for patients; 68% provided indirect services weekly. Table 9 presents the number of hours respondents spent providing direct and indirect AAC services.

*Table 9: Average Number of Hours per Week Respondents Spent Providing Direct and Indirect AAC Services*

	Respondents – <i>Direct services</i> <i>n=75</i>	Respondents – <i>Indirect Services</i> <i>n=75</i>
0 hours	20.3%	32.0%
0.1-1 hours	35.1%	36.0%
1.1-2 hours	13.5%	14.67%
2.1-3 hours	9.5%	4.0%
3.1-4 hours	6.8%	4.0%
4.1-5 hours	4.1%	5.33%
>5 hours	10.8%*	4.0%**

\*Answers included 8, 10, 15, 20, and 25 hours

\*\*Answers included 7.5, 15, and 20 hours

The majority of respondents (i.e., 75%) claimed that there was not an SLP at their facility whose primary responsibility was to provide AAC services.

## AAC Device and Resource Availability in Medical Settings

Figure 1 displays the types of AAC devices which respondents indicated their patients were using. It also displays types of AAC that patients on respondents' caseloads were not using, but would benefit from.

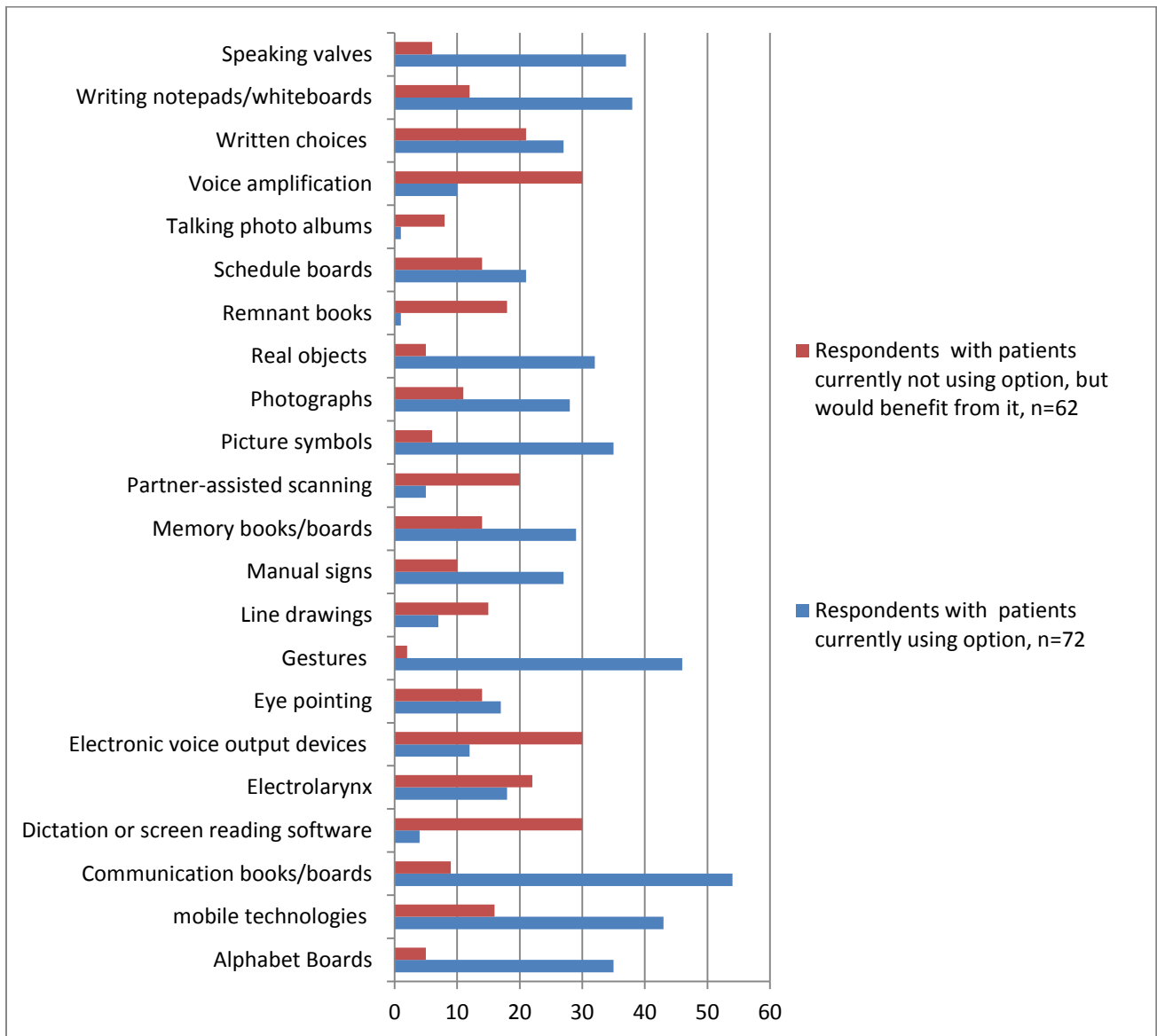


Figure 1: AAC Options Utilized & Not Utilized by Patients despite Probable Benefit

In response to the availability of AAC resources available in their settings, many respondents indicated that they were “somewhat available” (i.e., 67%). Table 10 displays the SLPs’ ratings of availability of AAC resources in their work settings.

*Table 10: Availability of AAC Resources in Medical Settings as Rated by Respondents*

Availability	Respondents
not at all available	13.7%
somewhat available	67.1%
available	16.4%
very available	1.4%
plentiful	1.4%

n=73

The vast majority of respondents (97%) indicated that AAC partner communication training for medical professionals (e.g., physicians, nurses, other rehabilitation professionals, social workers) would be beneficial in their settings. This type of training would include providing information regarding available AAC options and services, and supporting individuals with CCN communicate via AAC. Additionally, 100% of participants indicated that AAC training for families / caregivers of patients with CCN would be beneficial.

Table 11 presents barriers that respondents identified as inhibiting AAC service delivery in their settings. The most commonly identified barriers included: (a) frequently changing caseloads (73%), (b) the patient’s medical condition (e.g., unstable medical condition) (55%), (c) lack of AAC supports or devices (55%), (d) limited time to work with the patient (55%), (e) lack of time to prepare AAC materials / devices (51%), (f) lack of funding to purchase equipment (63%), and (g) the length of time of the device funding process (51%).

*Table 11: Barriers to AAC in Medical Settings*

Barriers	Respondents, n=71
Patients on caseload change frequently	73%
Lack of funding to purchase equipment	63%
Lack of AAC supports or devices	58%
Patients' medical condition (e.g., unstable medical condition)	55%
Limited time to work with patient	55%
Lack of knowledge about AAC from other staff members	37%
Length of time of device funding process	51%
Lack of time to prepare AAC materials/device	51%
Lack of access to technology	48%
Limited time to work with patient's family/caregivers	46%
Large caseload	15%
Lack of funding to purchase other AAC materials (e.g., laminator, printer, Boardmaker)	38%
Limitations with my own training/experience with AAC	38%
Lack of training of other professionals	28%
Lack of access to technology to prepare AAC materials	20%
Challenges with referral, recommendations, and assessments for AAC	20%
Patient/family acceptance	17%
Lack of administrative support	13%
Other (please explain)*	3%

\*Responses included acuity of patients' condition, and the priority of other needs

## AAC Knowledge and Training

**Respondents' AAC knowledge.** Pertaining to respondents' self-ratings of AAC expertise, most rated themselves as “somewhat knowledgeable” (56.2%) or “knowledgeable” (34.2%). Table 12 displays the SLPs' self-ratings.

*Table 12: Respondents' Self-Ratings of AAC Expertise*

Self-rating	Respondents
not at all knowledgeable	1.4%
somewhat knowledgeable	56.2%
knowledgeable	34.2%
very knowledgeable	8.2%
expert in AAC	0.0%

n=73

**Respondents' AAC training.** In terms of AAC training, most respondents had taken one to three credits dedicated to AAC at the graduate level while most had not taken AAC courses at the undergraduate level. Table 13 depicts the number of credit hours respondents had taken dedicated to AAC.

*Table 13: Number of Undergraduate and Graduate AAC Credits taken by Respondents*

	Undergraduate Credits n=72			Graduate Credits n=73		
	0	1-3	>3	0	1-3	>3
Number of Credits						
Respondents	61%	35%	4%	12%	74%	14%



In addition to courses dedicated to AAC, roughly half of respondents had clinical experience with AAC assessment or intervention. Fifty-four percent of respondents had experience conducting AAC assessment activities as graduate students, while 46% did not. Fewer respondents (i.e., 40%) received clinical experience with AAC intervention as graduate students compared to assessment.

In terms of professional AAC training outside of undergraduate and graduate education, 72.3% of respondents had attended professional workshops or training dedicated to AAC while 22.2% had not. Of those who had attending training, one individual received 200 hours of professional AAC training, and one received over 100 hours. The individual with 200 hours reported that in a previous job in the schools, s/he received monthly technology training. The individual who reported completing over 100 hours of AAC professional training had been working as an SLP for 40 years, and explained that there were no university AAC courses when s/he attended college. Table 14 provides information regarding the hours dedicated to professional AAC training respondents had received.

*Table 14: Hours of Professional AAC Training Received by Respondents*

Hours	0	1-5	6-10	11-15	16-20	21-25	26-30	>31*
Respondents	22.2%	30.6%	20.8%	5.6%	5.6%	2.8%	0.0%	12.5%

\*Responses included, 40, 48, 50, more than 50, 75, more than 100, and 200 hours

n=75

**The perceived AAC knowledge of other health care professionals.** Table 15 depicts the perceived AAC knowledge (e.g., available technologies, services, appropriateness of referral) of other health care professionals in respondents’ work settings. Other health care professionals

included physicians, nurses, and other rehabilitation professionals (i.e., PTs, OTs, and RTs).

Overall, most respondents rated physicians “not at all knowledgeable” (53%), nurses “somewhat knowledgeable” (53%), and other rehabilitation professionals as “somewhat knowledgeable” (75.7%).

*Table 15: Perceived Level of AAC Knowledge of Health Care Professionals as Rated by Respondents*

Rating	Physicians n=72	Nurses n=72	Other rehabilitation professionals n=70
not at all knowledgeable	53%	44%	8.6%
somewhat knowledgeable	42%	53%	75.7%
knowledgeable	4%	3%	15.7%
very knowledgeable	1%	0%	0.0%
expert in AAC	0%	0%	0.0%

Following completion of the survey, some respondents chose to provide additional comments, which they indicated were relevant. Some commented on access to and funding for devices:

I have found that the eye scanning device can be very useful in acute care. It would be great to have one dedicated to our facility, but funding is an issue.

I use an iPad and apps, [and] sound amplification for my Parkinson’s patients when needed, but do not have access to any electronic devices, other than referring out to a local university or calling Dynavox, but reimbursement is a problem for my HMO patients and Medicare patients.

We need more reasonably priced devices for families with limited funds to have access.

One participant commented on the increasing popularity of mobile devices:

Although I am in favor of dedicated SGDs, I believe we must capitalize on using iDevices (iPads, iPhones) as a viable AAC method as these are becoming more affordable and accepted by society.

One respondent commented on the importance of low- and mid-tech devices and difficulty using high-tech devices with a particular population:

I work with geriatrics. I have attempted to use devices such as Dynavox with minimal success. I found that if the geriatric individual does not have computer experience, then they are very apprehensive about using it and have a very difficult time understanding the flow of the device. With the Dynavox, I now believe that it is not the best use of finances to pursue a device that expensive. I use alphabet boards and patient specific communication papers consisting of words and pictures. I recently found the GoTalk and am beginning to try that with greater success. It can be functional and is cost effective.

One respondent touched on the importance of collaboration with other professionals to provide AAC services:

AAC is a wonderful tool for therapy. I need more OT support to assist with adapted stylus, positioning, etc.

## CHAPTER FOUR: DISCUSSION

This study aimed to understand AAC service delivery in medical settings, including acute care, sub-acute care, rehabilitation hospitals, SNFs, outpatient medical clinics, and home health settings in terms of the availability of AAC devices, and barriers and supports to AAC service delivery. Specifically, this study sought to examine the prevalence of individuals with CCN in these settings, and evaluate whether those needs are being met. Further, this study investigated the knowledge and training of SLPs in these settings. Additional information was sought to examine the perceived level of AAC knowledge of other health care professionals working in these settings (e.g., physicians, nurses, PTs, OTs, RTs). Another major focus of this study was to better understand the challenges to providing AAC service delivery in medical settings.

### **Prevalence of Patients with CCN in Medical Settings**

**Prevalence of patients with AAC needs.** Survey respondents shared information regarding the communication needs of their current caseloads. A major finding of this study was that 97.59% of respondents indicated that they had individuals on their current caseload whose natural speech was not sufficient for meeting all of their communication needs. While little information is available regarding the prevalence of individuals with CCN in medical settings (Hurtig & Downey, 2009), this finding represents a considerable increase compared to the study by King (1998) which found that 69% of SLPs working in health care settings in Nebraska had one or more patient with AAC needs. The findings of the current study are similar to a report by Beukelman (2012) which revealed that 95% of nurses surveyed in an ICU setting worked with patients who could benefit from AAC.

Despite 97.59% of respondents reporting they had clients who could not meet all of their communication needs via natural speech, only 91% reported their patients used AAC or received AAC services. This discrepancy between needs and services supports the hypothesis that patients in the aforementioned settings have unmet communication needs. In the case of the 91% of patients who used AAC or received AAC services, it should not be assumed that all their AAC needs were met. Most respondents reported dedicating minimal time per week on AAC service delivery. Only 79.8% of respondents said they provided direct AAC services on a weekly basis, and only 68% said they provided indirect AAC services each week. Despite only 68% of respondents indicating they dedicated time to indirect AAC services, 100% of respondents indicated family / caregiver communication partner training would be beneficial in their settings. These data further support the hypothesis that individuals with CCN in medical settings have unmet communication needs.

### **AAC Access for Individuals with CCN in Medical Settings**

The findings of this investigation indicated that not all patients had access to appropriate AAC options. A central finding was that 94.1% of respondents indicated their patients could benefit from increased access to AAC technologies or services, which was, again, demonstrative of the presence of unmet communication needs of individuals with CCN in medical settings.

Roughly 80% of participants rated availability of AAC devices and related resources as “less than available” (i.e., either “not at all available” or “somewhat available”). These findings support the hypothesis that SLPs in medical settings lack access to AAC devices. The lack of AAC devices and resources contributes to patients having unmet communication needs, and is a major barrier to AAC service delivery.

**Under-utilized AAC options for patients with CCN in medical settings.** Specifically, numerous AAC options were identified as unavailable to respondents' patients despite potential benefits. While each AAC option listed on the survey (see Results) was identified at least one time as being unavailable despite potential benefits to respondents' patients, clear trends were identified. Forty-eight percent of respondents' patients were not using electronic voice output devices / SGDs, voice amplification, or dictation / screen reading software even though they indicated patients would derive benefit from them. These findings support the claim that low-tech AAC options dominate medical settings (Fried-Oken et al., 1991; Hurtig & Downey, 2009). Possible reasons for the lack of access to high-tech (e.g., SGDs, screen reading software), and mid-tech devices include lack of availability of such devices in medical settings, site policies, and SLP knowledge of AAC (Hurtig & Downey, 2009). For the respondents, device funding was a common concern. One respondent commented that device funding via insurance was an issue; therefore, s/he gravitated toward recommending mobile technologies. Another respondent commented that an SGD with eye gaze technology would be beneficial to her / his facility, but funding was problematic. A third respondent shared the desire for more affordable devices. Overall, findings suggest funding barriers were paramount to limited access to SGDs in medical settings.

It was somewhat surprising that 35% of respondents claimed that their current patients could benefit from an electrolarynx, but were not using one. This is alarming since Garrett et al. (2007) identified that, at a minimum, acute care settings should be equipped with various electrolarynx options in addition to alphabet / communication boards, writing options, and communication board mounting equipment. Furthermore, it has been recommended that protocols for AAC provisions be put in place for patients undergoing planned surgeries for HNC

or other etiologies, and that these protocols increase patients' quality of care (Costello, 2000; Sullivan et al., 2007). Therefore, the communication needs of laryngectomy or HNC patients, including electrolarynx options, should be addressed prior to surgery (Costello, 2000; Sullivan et al., 2007). The fact that this was overlooked for 35% of respondents' patients demonstrates a major discrepancy between best practice and actual procedures. At first glance, it was unexpected that 34% and 32% of respondents indicated their patients could benefit from written choices and partner-scanning, respectively, but were not using them because these are affordable low-tech AAC options. However, the challenges of these AAC options, like other low-tech options, is that they place a significant burden on the communication partner (Hurtig & Downey, 2009). Thus, communication partners must be trained to use them. This finding emphasizes the importance of involving family / caregivers in AAC training. Further, nurses are frequent communication partners for patients in hospital settings (Beukelman et al., 2008; Beukelman, 2012; Garrett et al., 2007; Hurtig & Downey, 2009). However, because of the demands of their job, they are not able to spend prolonged periods of time communicating with each patient. Therefore, partner-assisted scanning may be difficult to implement with nurses. These data suggest that although a communication option is affordable, it is not necessarily easily implemented.

#### **Commonly utilized AAC options for individuals with CCN in medical settings.**

Interestingly, many respondents (i.e., 60%) reported patient use of communication apps on mobile devices. This relatively high rate of AAC use via mobile devices is consistent with reports by McNaughton & Light (2013), Light & McNaughton (2012), and Beukelman (2012), which detailed technological advances that have made mobile technologies more ubiquitous, in

turn leading to increased AAC availability and acceptance. The availability of mobile devices can be seen as a support to AAC service delivery. In medical settings, mobile technologies offer exciting possibilities for individuals who may have CCN over a short-term or long-term period. The danger in the push toward mobile technologies, however, is that it can further marginalize certain individuals (Beukelman, 2012). For example, elderly individuals for whom mobile technology may be difficult to learn, or individuals with motor impairments may not be candidates for AAC on mobile technologies. These individuals need other AAC solutions which fit their own needs. AAC options must be based on individual needs, and not on the appeal of technology alone (McNaughton & Light, 2013).

Additionally, speech-generating apps are readily available for download from “app stores.” Thus, patients and families / caregivers, can readily make AAC app purchases without consulting an SLP. While this streamlines the device acquisition process by not going through insurance, the patient also often foregoes services of the SLP, who is able to provide not only AAC assessment and training, but technical assistance (McNaughton & Light, 2013). Meder (2012) found that many families making AAC app purchases for their children did not seek the assistance of an SLP. Similar trends might be present in medical settings.

Another major finding of this study supported previous findings (Fried-Oken et al., 1991) and observations (Hurtig & Downey, 2009) regarding the wide use of unaided and low-tech AAC options in medical settings. Commonly used unaided forms of communication included gestures (64%) and manual signs (38%). Regarding low-tech AAC, many respondents reported their patients using communication boards (75%), writing notepads / whiteboards (53%), alphabet boards (49%), pictures symbols (49%), and real objects (44%). The availability of these forms of AAC in medical settings serve as supports. There are many benefits of using



unaided and low-tech communication. Some of these benefits include cost, availability, and ease of learning. One of the study participants mentioned that ease of use was an important factor in considering AAC options for geriatric populations. Despite the benefits of low-tech AAC, there are limitations.

First, low-tech AAC places a burden on the communication partner (Hurtig & Downey, 2009). Secondly, patients in ICUs, acute care hospitals, sub-acute hospitals, rehabilitation hospitals, and SNFs must be able to call a nurse in times of discomfort (Hurtig & Downey, 2009). Without voice output or a switch attached to a call button, low-tech options cannot provide this basic patient right for those with motor deficits. Moreover, low-tech devices do not allow for novel message generation, so patients are limited to using what is on their communication board. Many hospital-issued communication boards only include information regarding patients' basic needs, such as hunger, bathroom use, and need for suction. This is clearly not sufficient for meeting all communication needs. Lastly, the author recently worked with a nonverbal patient who chose not to use his hospital-provided communication board because it did not have a voice. Instead, he preferred using gestures to answer yes / no questions until mobile technology was introduced.

Speaking valves were another commonly used communication option with 51% of respondents indicating their patients used them. One-way speaking valves are a good option for tracheostomy patients or patients on ventilators if they are able to tolerate them. Not all patients on ventilators are on settings conducive to using speaking valves (Fornataro-Clerici & Roop, 1997). Also, due to the life-threatening danger of wearing a one-way valve with an inflated cuff, many hospitals have precautions in place preventing the use of speaking valves unless an SLP or RT is present. For example, in the author's current ICU and acute care setting, speaking valves

are not allowed to be left in the rooms of trauma patients. Therefore, when the SLP or RT is not present, the patient is unable to voice using the speaking valve. In these cases, speaking valves cannot possibly meet the communication needs of patients, and an additional form of communication is necessary.

### **Major Barriers to AAC in Medical Settings**

Participants selected several barriers which inhibit AAC service delivery in medical settings. The most frequently indicated barriers to AAC in respondents' work settings included caseloads frequently changing (73%), lack of funding to purchase equipment (63%), lack of AAC supports or devices (58%), patients' medical conditions (55%), limited time to work with patients (55%), lack of access to technology (48%), lack of time to prepare AAC materials / device (51%), and length of time of the device funding process (51%). Many of the barriers selected (i.e., lack of funding, lack of AAC supports / devices, lack of access to technology, and length of device funding process) indicate access to and availability of AAC devices and related resources are significant challenges to AAC service delivery in medical settings. This supports the hypothesis that availability of devices in medical settings is problematic.

In medical settings, the stability of the patient and their basic health needs are the priorities. For this reason, SLPs in these settings spend the most time providing swallowing services (ASHA, 2002, 2013b) to address patients' nutritional intake. Furthermore, depending on the severity of the patients' conditions, it may not be appropriate from a medical perspective for the SLP to provide communication services. Also, as patients in acute care are often only admitted for a short period of time, the SLP's caseload in this environment is constantly

changing. These barriers cannot be easily changed as they are secondary to the health of the patient and nature of the acute care environment.

The presence of barriers related to access to devices, technology, and funding make it difficult to provide patients with the AAC supports they need. These barriers lead to the unmet communication needs of individuals with CCN in medical settings, as evidenced by the aforementioned need for high-tech SGDs, voice amplification, and electrolarynges in medical settings. Clearly, device availability inhibits AAC service delivery.

These findings support the hypothesis that the major barriers to AAC service delivery in medical settings include: (a) availability of AAC devices / equipment, (b) high caseloads, (c) and lack of time to prepare devices / materials.

### **AAC Knowledge and Training**

**SLPs' self-ratings of AAC expertise.** SLPs' AAC knowledge has been postulated as a barrier to AAC service delivery in medical settings (Hurtig & Downey, 2009). When asked to self-rate their level of expertise with AAC, the majority of respondents (57.6%) rated themselves as "less than knowledgeable" (i.e., either "not at all knowledgeable" or "somewhat knowledgeable"). Although this finding is slightly more encouraging than the finding of Siu et al. (2010) that 72% of respondents indicated their AAC training was inadequate, it still demonstrates that the majority of SLPs feel they have limitations based on their own knowledge in their ability to provide AAC service delivery. This supports the findings of Kent-Walsh et al. (2008) that discovered low SLP expertise was a major barrier in providing AAC service delivery in educational settings.

**Respondents' AAC training and preparation.** The above findings are notable in light of 88% of respondents indicating that they took between one and three graduate credits dedicated to AAC; this may suggest a need for more extensive or specific types of pre-service and in-service education in this particular area of clinical practice. Interestingly, the few respondents (i.e., 8.2%) who rated themselves as very knowledgeable regarding AAC were set apart from the respondents who did not based on their reported graduate clinical experiences as follows. Of the respondents who indicated they were “very knowledgeable” about AAC, 86% indicated they had graduate clinical experience with both AAC assessment and intervention despite similarities amongst other respondents in undergraduate and graduate credits taken. Eighty percent of the respondents who reported they were “knowledgeable” about AAC, reporting having graduate clinical experience with AAC intervention. Of those who rated themselves “somewhat knowledgeable” about AAC, only 39% had graduate clinical AAC assessment experience, and 44% had graduate clinical AAC intervention experience. Perhaps AAC coursework is not sufficient for preparing SLPs to provide AAC service delivery, and graduate clinical experience is the key element in affecting self-perceptions of expertise. Overall, these findings support the hypothesis that the majority of SLPs view their own expertise regarding AAC as “less than knowledgeable.”

**SLPs' perceptions of other health-care professionals' AAC knowledge.** Respondents also provided ratings based on their perceptions of the knowledge of physicians, nurses, and other rehabilitation professionals pertaining to AAC. Regarding physicians, 95% of respondents indicated they were “less than knowledgeable” about AAC (i.e., “not at all knowledgeable” or “somewhat knowledgeable”) and 97% rated nurses as “less than knowledgeable.” The majority

of respondents indicated that of the medical professionals listed, rehabilitation professionals (e.g., PTs, OTs, RTs) were more knowledgeable than physicians and nurses as only 84.3% of participants rated them as “less than knowledgeable.” Therefore, it is not surprising that 97% of respondents indicated that AAC communication partner training would be beneficial for the health care professionals in their work settings.

Given that physicians make referrals for SLP services in medical settings, these findings are troubling. Physicians and nurses play significant roles in medical settings as finders and facilitators for AAC for individuals with CCN (Beukelman et al., 2008; Hurtig & Downey, 2009). The role of nurses is especially important as they spend a significant amount of time with patients (Beukelman & Mirenda, 2013; Beukelman, 2012). Unfortunately, these findings align with the belief that physicians and nurses often do not possess the knowledge to be effective AAC finders and facilitators. The data from this study support the researcher’s hypothesis that physicians, nurses, and other healthcare professionals are perceived by SLPs as less than knowledgeable regarding AAC.

### **Study Limitations**

Despite the interesting findings of this study, several limitations should be noted. First, although the response rate was higher than that of Siu et al. (2010), this study could have been strengthened by reaching more respondents. Possible respondents were chosen for being members of FLASHA who were SLPs working in medical settings. Compared to ASHA membership, there are fewer FLASHA members as ASHA encompasses SLPs in all 50 states. This study only sampled SLPs currently working in the state of Florida. A larger scale study

reaching more respondents in states throughout the country is suggested to add to the findings of the current study.

While the response rate of this survey (37%) is acceptable for web- and email-based surveys (Dillman et al., 2009; Schonlau, Fricker, & Elliot, 2002), surveys utilizing a mail-based distribution technique are known to have higher response rates (Dillman et al., 2009). Due to funding limitations and speed of distribution and response, email-based distribution was selected for this study despite notoriously low response rates reported for web- and email-based questionnaires (Sauermann & Roach, 2013). To increase responses, a future study would utilize mail-based distribution.

An additional limitation of this study was that other health-care professionals, nurses, and rehabilitation professionals were not directly sampled. It should be noted that survey findings relating to other professionals' AAC knowledge were based solely on SLP perceptions. SLPs sometimes have limited interaction with these health-care professionals, especially physicians. Therefore, their perceptions may not be accurate. Beukelman (2012) recently reported that in a sample of 135 nurses working in an ICU, 100% reported working with patients with CCN, and 99% reported using AAC strategies. Therefore, nurses may possess more AAC knowledge than might be suggested within the results of the current investigation.

Finally, this study focused on a variety of medical settings. ICUs and rehabilitation hospitals may differ widely in the types of patients they serve, and many SLPs who took this survey reported working in more than one setting. Therefore, to get a more comprehensive perspective regarding AAC service delivery, AAC availability, and AAC barriers, additional studies targeting these settings individually may be indicated.

## **Future Research**

The findings of this study have identified interesting directions for future research regarding AAC in medical settings. One suggested direction of future research in medical settings would be to closely examine the use of, possibilities for, and challenges of using mobile technologies for AAC in light of 60% of respondents reporting having patients who currently use mobile technologies for AAC. Although traditionally unaided and low-tech forms of AAC were popular options in medical settings (Fried-Oken et al., 1991), mobile technologies are emerging as another widely used option in general for AAC users (McNaughton & Light, 2013). Meder (2012) explored the needs and desires of families with children using communication apps on mobile technologies as well as the role of the SLP. Similar studies with adult populations in medical settings are warranted to examine the unique role mobile technology could play in these settings.

Another interesting finding of this study was that respondents who rated themselves as “very knowledgeable” regarding AAC had experience with both AAC assessment and intervention in a clinical setting as graduate students, despite taking a similar number of AAC course credits at the graduate and undergraduate level. Future studies would be instrumental for exploring the roles that service learning and AAC student clinical experience play in preparing SLPs for providing AAC service delivery in medical settings.

Respondents reported that the majority of physicians, nurses, and rehabilitation professionals they worked with were “less than knowledgeable” regarding AAC. A limitation of this study was that it did not reach these populations directly. Because of the importance these two types of medical professionals play as finders and facilitators, a study directly targeting these groups regarding their AAC knowledge and use would provide more valid findings.

## **Conclusion**

The findings of this study demonstrate that there was a high prevalence of individuals with CCN in medical settings with unmet communication needs as the vast majority of respondents indicated their patients could benefit from increased access to AAC devices and services. In addition, the data showed that SLPs in medical settings spent scant time providing direct and indirect AAC services. In addition, as 80% of respondents indicated that AAC devices and related materials were either not at all available or only somewhat available, device access was problematic. This is also supported by the indication that many patients who would benefit from voice amplification, SGDs, electrolarynges, and dictation / screen reading software did not have access to them.

Respondents identified major barriers to AAC service delivery in their settings, which included frequently changing caseloads, patients' medical conditions, lack of AAC supports / devices, limited time to work with patients, lack of access to technology, lack of time to prepare AAC materials / devices, lack of funding to purchase equipment, and the length of time of the device funding process.

Mobile technologies emerged as a support to individuals with CCN in medical settings as 60% of respondents reported having patients who used mobile devices for communication. Other widely used supports available to individuals with CCN in medical settings included unaided and low-tech AAC options, such as gestures, manual signs, writing notepads / whiteboards, picture symbols, communication boards / books, and alphabet boards. These AAC options are cost effective and relatively easy to implement. In addition, many respondents reported availability of one-way speaking valves, which are of great benefit to individuals status post tracheostomy.



Finally, respondents shared ratings of their own expertise regarding AAC and the perceived expertise of the health care providers they work with. Most SLPs rated their AAC expertise as “somewhat knowledgeable.” Respondents indicated that physicians, nurses, and other rehabilitation professionals were less than knowledgeable regarding AAC. These findings should be further explored in studies directly targeting these health care professionals as their role in the referral process and as communication partners plays an indispensable role in health-care settings.

## **APPENDIX A: IRB APPROVAL LETTER**



University of Central Florida Institutional Review Board  
Office of Research & Commercialization  
12201 Research Parkway, Suite 501  
Orlando, Florida 32826-3246  
Telephone: 407-823-2901 or 407-882-2276  
[www.research.ucf.edu/compliance/irb.html](http://www.research.ucf.edu/compliance/irb.html)

### Approval of Exempt Human Research

From: UCF Institutional Review Board #1  
FWA00000351, IRB00001138

To: Stephanie E. Amundsen

Date: August 20, 2014

Dear Researcher:

On 8/20/2014, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination  
Project Title: Augmentative-alternative Communication Access for Individuals with Acquired Communication Disorders in Acute and Sub-acute settings  
Investigator: Stephanie E. Amundsen  
IRB Number: SBE-14-10510  
Funding Agency:  
Grant Title:  
Research ID: N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual

On behalf of Sophia Dziegielewska, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 08/20/2014 03:40:35 PM EDT

IRB Coordinator

**APPENDIX B: SURVEY**

## Welcome to the Florida Acute and Sub-acute Care Speech-Language Pathology Survey!

This survey is designed to be completed by speech-language pathologists working in acute care and sub-acute care settings in Florida. We will ask about your current overall caseload and will then move on to additional questions relating to your work history, your training background, and any patients you may work with whose natural speech is not highly intelligible and/or is insufficient to meet all of their communication needs.

We estimate that this survey will take you approximately 10 minutes to complete. There are no anticipated risks to you participating in this study. You may refuse to participate in the study and are free to discontinue the survey at any time. All answers that you provide are completely confidential. We will never ask you to identify your name, work facility, or contact information. It should also be noted that your computer IP address will not be recorded when your survey is submitted through Qualtrics.com.

By participating in this survey, you will help us to gauge the following:

- a) the number of patients who have natural speech that is insufficient to meet all of their communication needs in medical settings
- b) available resources for patients and their speech-language pathologists in medical settings
- c) speech-language pathologists' training background
- d) perceived level of knowledge of other practitioners in medical settings relating to patients who have natural speech that is limitedly intelligible
- e) what type of help or additional supports you might like to have when working with patients who cannot meet all of their communication needs using natural speech

There are 32 questions in total in this survey. Please answer each question to the best of your knowledge, without taking too much of your time to check your files before responding. Please note that any SLP working in an acute or sub-acute setting is a candidate to complete this survey – no matter the composition of your caseload.

Research at the University of Central Florida (UCF) involving human participants is carried out under the oversight of the Institutional Review Board (IRB). Questions or concerns about research participants' rights may be directed to the UCF IRB Office at the UCF Office of Research and Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246. The phone numbers are 407-823-2901 or 407-882-2276.

If you have any specific questions or comments about this survey, which I am conducting in partial fulfillment of my master's thesis requirements, please feel free to contact me – Stephanie Amundsen, M.A. by e-mail ([steph.bruining@knights.ucf.edu](mailto:steph.bruining@knights.ucf.edu)) or phone (616-502-5756) or my

supervising professor/researcher - Dr. Jennifer Kent-Walsh by e-mail (jkentwalsh@ucf.edu) or phone (407-823-4800).

Thank you for your interest and participation.

IF YOU HAVE ALREADY COMPLETED THIS SURVEY, PLEASE DO NOT COMPLETE IT AGAIN.

Sincerely,

Stephanie Amundsen, M.A.  
M.A. Candidate, Communication Sciences & Disorders  
University of Central Florida

Jennifer Kent-Walsh, Ph.D., CCC-SLP, S-LP(C)  
Associate Professor, Communication Sciences & Disorders  
University of Central Florida

Consent: By completing this survey, I confirm that am at least 18 years of age. I understand that I will not receive any compensation for completing this survey and that clicking the “Next” button below and completing this survey constitutes my informed consent.

## **I. EMPLOYMENT INFORMATION**

1. Gender

- Male  
 Female

2. How many years have you been practicing as an SLP, regardless of the setting(s) in which you have worked?

3. Describe your current position in your setting.

- Part-time
- Full-time

4. Who is your employer?

- Acute care or sub-acute care facility
- Contract company
- I am an independent contractor
- Private practice
- Rehabilitation facility
- Residential / Long-term care facility

5. In what type of setting/facility do you currently work? Unless you select "None of the above," you can select more than one setting as applicable. After making your selection(s), please respond to the remaining questions in this survey with the selected setting(s) in mind (even if you also work in a non-medical setting not listed below).

- Intensive Care Unit
- Short-term Acute Medical Care Hospital
- Transitional/Post-Acute Hospital
- Rehabilitation Hospital
- Skilled Nursing Facility
- Home Health Care
- Outpatient Clinic
- None of the Above (\*Please make this selection ONLY if you do not work in a medical setting at all.)

6. Describe your primary work setting.

- City (population >20,000)
- Large Town (10,000-20,000)
- Small Town (<10,000)
- Rural Town (located outside of a city or town)
- Other (Please Specify)

7. Are you the only SLP working in your facility?

- Yes
- No

8. If you are not the only SLP working in your facility, how many other SLPs work in your facility?

9. What is the age range of patients for whom you provide speech-language services? (Select all that apply within the acute or sub-acute facilities you selected above).

- Birth - 2 years
- 2 - 4.11 years
- 5 - 12 years
- 12 - 18 years
- 19 - 59 years
- 60+ years



## II. CASELOAD INFORMATION

10. What is the average number of patients you serve per week?

11. What percentage of the number of patients you indicated in Question #10 would you estimate CANNOT successfully meet ALL of their communication needs using natural speech alone?

In other words, please estimate the percentage of patients you serve on average in any given week who have natural speech deficits that lead to some communication breakdowns or confusion in one or more types of interactions.

Please select the percentage or percentage range that best corresponds to your estimate.

- 0%
- 1-25%
- 26-50%
- 51-75%
- 76-99%
- 100%

Many of the questions remaining in this survey will relate to augmentative and alternative communication (AAC). Please note that you do NOT need to have patients using AAC on your caseload to complete the remaining questions in this survey.

To help clarify what we are referencing in the remaining choices, please review the following definitions.

### DEFINITION OF AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC)

For the purposes of this survey, AAC is defined as the supplementation or replacement of natural speech through any strategy or approach, including alphabet boards, communication apps on mobile devices (e.g., iPads, iPods, iPhones, Samsung phones/tablets etc), communication books or boards, dictation or screen reading software, eye pointing, gestures, manual signs, memory boards/books, objects, partner-assisted scanning (e.g., provider/caregiver points to picture choices and client blinks his/her eyes to indicate the desired selection) photographs, picture symbols, real objects (e.g., patient points to toothbrush), remnant books, schedule boards, speaking valves, speech generating devices/voice output devices/electronic communication devices (e.g., Dynavox), talking photo album, voice amplifier, whiteboards, writing notepads.

Patients with a wide variety of disabilities/diagnoses may need low-tech or high-tech AAC

options in order to share medical information, needs, wants, feelings, and preferences with others, and/or to participate successfully in evaluations, interventions, or therapies in medical settings.

#### TYPES OF AAC THAT COULD BE BENEFICIAL TO PATIENTS

For the purposes of this survey, please consider any or all of the following forms of AAC as potential options for clients to use in a communication context or interaction.

Alphabet boards, communication apps on mobiles devices (e.g., iPads, iPods, iPhones, Samsung phones/tablets etc), communication books or boards, dictation or screen reading software, eye pointing, gestures, manual signs, memory boards/books, objects, partner-assisted scanning (e.g., provider/caregiver points to picture choices and client blinks his/her eyes to indicate the desired selection) photographs, picture symbols, real objects (e.g., patient points to toothbrush), remnant books, schedule boards, speaking valves, speech generating devices/voice output devices/electronic communication devices (e.g., Dynavox), talking photo album, voice amplifier, whiteboards, writing notepads.

12. Again referencing the patients for which you provided a count in #10, what percentage of those patients would you estimate use AAC or receive AAC services in the acute or subacute setting?

- 0%
- 1-25%
- 26-50%
- 51-75%
- 76-99%
- 100%

13. In some cases, positive impacts on health outcomes or ease of access to appropriate medical care could be seen with patients if the necessary supports were in place to afford consistent access to AAC options or services in their medical settings each day. What is the percentage of patients you see in an average week who you believe could experience such positive benefits with increased access to AAC technologies and/or services?

14. Indicate the average number of hours per week you spend providing DIRECT AAC services (e.g., AAC assessment activities, intervention/implementation activities) with patients.

15. Indicate the average number of hours per week you spend providing INDIRECT AAC services (e.g., device programming, consulting families or caregivers, researching AAC options, doing online training to learn to operate AAC devices) for patients.

16. Is there a clinician in your facility whose primary charge is to delivery AAC services (either yourself or someone else)?

Yes - Me: How many hours per week are allotted for AAC service-delivery?

Yes - Someone else: How many hours per week are allotted for AAC service-delivery?

No

17. Select all forms of AAC CURRENTLY BEING USED by patients on your CURRENT caseload with complex communication needs.

- Alphabet Boards
- Communication apps on mobile technologies (e.g., iPads, iPods, iPhones, Samsung phones/tablets)
- Communication books/boards
- Dictation or screen reading software
- Electrolarynx
- Electronic voice output devices / speech generating devices (SGDs) (e.g., Dynavox, TobiiATI devices, etc.)
- Eye pointing
- Gestures (e.g., pointing, head nodding, blinking)
- Line drawings
- Manual signs
- Memory books/boards
- Partner-assisted scanning (e.g., provider/caregiver points to picture choices and client blinks his/her eyes to indicate the desired selection)
- Picture symbols
- Photographs
- Real objects (e.g., patient points to toothbrush)

- Remnant books
- Schedule boards
- Speaking valves
- Talking photo albums
- Voice amplification
- Written choices (e.g., patient reads "tired, hungry, thirsty" and makes choice by pointing)
- Writing notepads/whiteboards

18. Select all forms of AAC NOT currently being used by patients on your CURRENT caseload that you believe could be beneficial for at least one of your patients.

- Alphabet Boards
- Communication apps on mobile technologies (e.g., iPads, iPods, iPhones, Samsung phones/tablets)
- Communication books/boards
- Dictation or screen reading software
- Electrolarynx
- Electronic voice output devices / speech generating devices (SGDs) (e.g., Dynavox, TobiiATI devices, etc.)
- Eye pointing
- Gestures (e.g., pointing, head nodding, blinking)
- Line drawings
- Manual signs
- Memory books/boards
- Partner-assisted scanning (e.g., provider/caregiver points to picture choices and client blinks his/her eyes to indicate the desired selection)
- Picture symbols
- Photographs
- Real objects (e.g., patient points to toothbrush)
- Remnant books
- Schedule boards
- Speaking valves
- Talking photo albums

- Voice amplification
- Written choices (e.g., patient reads "tired, hungry, thirsty" and makes choice by pointing)
- Writing notepads/whiteboards

19. Indicate the following disorders/diagnoses represented by patients on your caseload. Check all that apply.

- Amyotrophic lateral sclerosis (ALS)
- Aphasia
- Apraxia of speech
- Brainstem impairment
- Dementia
- Dysarthria
- Dysphonia
- Head and neck cancer
- Huntington's disease
- Locked-in syndrome
- Myasthenia gravis
- Multiple sclerosis
- Parkinson's disease
- Primary progressive aphasia
- Tracheostomy
- Traumatic brain injury
- Other complex neurological
- Other (please specify)

20. How would you rate your level of knowledge providing AAC services?

- not at all knowledgeable
- somewhat knowledgeable
- knowledgeable
- very knowledgeable
- expert in AAC

21. How many undergraduate credit hours dedicated to AAC have you had?

- 0
- 1-3
- More than 3

22. How many graduate credit hours dedicated to AAC have you had?

- 0
- 1-3
- More than 3

23. Approximately how many hours have you spent attending professional workshops, seminars, conference presentations, etc. dedicated to AAC?

24. How would you rate the availability of AAC devices available at your facility?

- not at all available
- somewhat available
- available
- very available
- plentiful

25. I completed clinical hours conducting AAC ASSESSMENTS as a graduate student.

- True
- False

26. I completed clinical hours conducting AAC TREATMENT/INTERVENTION as a graduate student.

- True
- False

27. How would you rate physician knowledge about AAC (e.g., available technologies, services, appropriateness of referral) in your work environment?

- not at all knowledgeable
- somewhat knowledgeable
- knowledgeable
- very knowledgeable
- expert in AAC

28. How would you rate nurse knowledge about AAC (e.g., available technologies, services, appropriateness of referral) in your work environment?

- not at all knowledgeable
- somewhat knowledgeable
- knowledgeable
- very knowledgeable
- expert in AAC

29. How would you rate other practitioner (e.g., PT, OT, respiratory therapist) knowledge about AAC (e.g., available technologies, services, appropriateness of referral) in your work environment?

- not at all knowledgeable
- somewhat knowledgeable
- knowledgeable
- very knowledgeable
- expert in AAC
- N/A

30. In your experience, what constraints exist in providing AAC services to patients in your facility? Check all that apply.

- Patients on caseload change frequently
- Patients' medical condition (e.g., unstable medical condition)
- Lack of AAC supports or devices
- Lack of knowledge about AAC from other staff members

- Limited time to work with patient
- Limited time to work with patient's family/caregivers
- Large caseload
- Lack of access to technology
- Lack of time to prepare AAC materials/device
- Lack of administrative support
- Lack of funding to purchase equipment
- Lack of funding to purchase other AAC materials (e.g., laminator, printer, Boardmaker)
- Lack of access to technology to prepare AAC materials (e.g., computer, printer, etc.)
- Lack of training of other professionals (e.g., physicians, nurses, etc.)
- Length of time of device funding process
- Patient/family acceptance
- Limitations with my own training/experience with AAC
- Challenges with referral, recommendations, and assessments for AAC
- Other (please explain)

31. Do you believe that increased AAC communication partner training for medical practitioners / staff is an important element in order to ensure functional communication for individuals with AAC needs in the medical setting (e.g., for physicians, nurses, social workers, other clinicians)? This training could include education on available AAC options / services and / or basic training in how to support an individual in communicating via AAC in the medical setting.

- Yes
- No

32. Do you believe that increased AAC communication partner training for family members/caregivers is an important element in order to ensure functional communication for individuals with AAC needs in the medical setting? This training could include education on available AAC options/services and/or basic training in how to support an individual in communicating via AAC in the medical setting.

- Yes
- No

Please provide below any comments you feel are relevant to this survey.



## **APPENDIX C: INVITATION EMAIL**

**Dear Speech-Language Pathologist:**

We are writing to **invite your participation in a survey study** we are conducting. This survey is designed to be completed by **any speech-language pathologists working in an acute care or sub-acute care setting in Florida**. We will ask about your caseload and will then move on to additional questions relating to your work history, your training background, and some other specific caseload questions.

We estimate that this survey will take you approximately **10 minutes** to complete. There are **no anticipated risks** to you participating in this study. You may refuse to participate in the study and are free to discontinue the survey at any time. All answers that you provide are completely **confidential**. It should also be noted that we will not ask for your name or the name of your employer, and that your computer IP address will not be recorded when your survey is submitted through Qualtrics.com.

By participating in this survey, you will help us to **better understand the nature of speech-language pathology practice and related supports in medical settings**.

Please **click on the link below** to visit the survey website (or copy and paste the survey link into your Internet browser). In appreciation for your participation in this research study, you will receive a code to redeem a \$1.00 **AMAZON.COM CREDIT upon completion of the survey**.

(Unique survey link)

**Thank you in advance for your interest and participation; we know we can learn a lot about speech-language pathology practice in medical settings with your input!**

Sincerely,

Stephanie Amundsen, M.A.  
M.A. Candidate, Communication Sciences & Disorders

Jennifer Kent-Walsh, Ph.D., CCC-SLP, S-LP(C)  
Associate Professor, Communication Sciences & Disorders

**University of Central Florida**

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Research at the University of Central Florida (UCF) involving human participants is carried out under the oversight of the Institutional Review Board (IRB). Questions or concerns about research participants' rights may be directed to the UCF IRB Office at the UCF Office of Research and Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246. The phone numbers are 407-823-2901 or 407-882-2276.

If you have any specific questions or comments about this survey, which I am conducting in partial fulfillment of my master's thesis requirements, please feel free to contact me – Stephanie

Amundsen, M.A. by email ([steph.bruining@knights.ucf.edu](mailto:steph.bruining@knights.ucf.edu)) or phone (616-502-5756) or my supervising professor/researcher - Dr. Jennifer Kent-Walsh by e-mail ([jkentwalsh@ucf.edu](mailto:jkentwalsh@ucf.edu)) or phone (407-823-4800).

## **APPENDIX D: FIRST REMINDER EMAIL**

Dear Speech-Language Pathologist:

We recently sent you an email asking you to respond to a brief survey about your experience as a speech-language pathologist working in acute, sub-acute care, or medical settings. Your responses to this survey are very important in helping us to **better understand the nature of speech-language pathology practice and related supports in medical settings.**

This survey is short and should only take you **10 minutes** to complete. **You do not need to have any specific type of caseload to complete the survey.**

Since we are trying to get as many responses as possible at the same time, **we are offering a special \$5.00 AMAZON.COM CREDIT incentive for completing the survey THIS WEEK!** Please click on the link below to visit the survey website (or copy and paste the survey link into your Internet browser). In appreciation for your participation in this research study, you will receive a code to redeem your \$5.00 AMAZON.COM CREDIT following completion of the survey.

(Unique survey link)

Your response is important. Getting direct feedback from SLPs is crucial in understanding service delivery in medical settings. Thank you for your help by completing the survey.

Sincerely,

Stephanie Amundsen, M.A.  
M.A. Candidate, Communication Sciences & Disorders  
University of Central Florida

Jennifer Kent-Walsh, Ph.D., CCC-SLP, S-LP(C)  
Associate Professor, Communication Sciences & Disorders  
University of Central Florida

## **APPENDIX E: SECOND REMINDER EMAIL**

Good Morning,

We recently sent you an email asking you to respond to a brief survey for speech-language pathologists (SLPs) working in acute, sub-acute, and medical settings. We are hoping you may be able to complete this short **10-minute** survey to help us collect important information regarding patients' needs in these settings. **You do not need to have any specific type of caseload to complete the survey.**

If you have already completed the survey, we greatly appreciate your participation. If you have not yet responded, **we have extended the \$5.00 AMAZON.COM CREDIT incentive until Friday, October 10<sup>th</sup>** in order to collect as many responses as possible. We would like to urge you to complete the survey. We plan to end this study shortly, so we wanted to email everyone who has not yet responded to ensure they have had a chance to participate.

Please click on the link below to visit the survey website (or copy and paste the survey link into your Internet browser). In appreciation for your participation in this research study, you will receive an email with a \$5.00 AMAZON.COM CREDIT following completion of the survey.

(Unique survey link)

Your responses are important to my thesis research! Thank you in advance for completing the survey. SLPs are the best source of information to help gauge information about speech-language service delivery.

Sincerely,

Stephanie Amundsen, M.A.  
M.A. Candidate, Communication Sciences & Disorders  
University of Central Florida

Jennifer Kent-Walsh, Ph.D., CCC-SLP, S-LP(C)  
Associate Professor, Communication Sciences & Disorders  
University of Central Florida

## **APPENDIX F: THANK YOU EMAIL**



Dear Speech-Language Pathologist:

Thank you for taking the time to complete my research survey. Your responses are important for helping us understand speech-language pathology in medical settings.

In appreciation of your participation, please accept this \$5.00 Amazon.com credit. Getting direct feedback from SLPs is crucial in improving access to AAC in medical settings.

Sincerely,

Stephanie Amundsen, M.A.

M.A. Candidate, Communication Sciences & Disorders  
University of Central Florida

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