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Identification of Opportunity Barriers and Supports for Individuals Using Augmentative and Alternative Communication (AAC) and Stakeholders

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IDENTIFICATION OF OPPORTUNITY BARRIERS AND SUPPORTS FOR INDIVIDUALS USING

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) AND STAKEHOLDERS

by

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ABSTRACT

IDENTIFICATION OF OPPORTUNITY BARRIERS AND SUPPORTS FOR INDIVIDUALS USING AUGMENTATIVE
AND ALTERNATIVE COMMUNICATION (AAC) AND STAKEHOLDERS

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Old Dominion University, 2021
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Individuals using augmentative and alternative communication (AAC) are supported by many

AAC stakeholders and communication partners. Clinical decision making and AAC assessment models

consider the capabilities and access needs of the individual using AAC, as well as opportunity barriers

and supports imposed by communication partners and environments. The purpose of this research was

to investigate opportunity barriers and supports identified by two critical AAC stakeholders: speech-

language pathologists and caregivers. The first study investigated characteristics of AAC service

provision reported by post-professional speech-language pathologists. Speech-language pathologists

reported lack of perceived knowledge related to AAC service delivery, inconsistent use of AAC

modalities, and persistent barriers to AAC service provision. The second study analyzed parent,

guardian, and caregiver perceptions of AAC interventions for school-aged children. Caregivers preferred

family-centered rather than patient-centered service delivery models to facilitate AAC use by their child.

The third study investigated experiences and contributing factors of stress in adult caregivers of children

using AAC. Caregivers' stress was impacted by the multiple enveloping systems. Within the family,

caregivers' experiences of stress were predicted by number of children and the caregivers' educational

level. Stress was mitigated by support systems which meet caregivers' needs and expectations. This

research reveals opportunity barriers and supports are a critical component to AAC service delivery and

clinical decision making as perceived by speech-language pathologists and caregivers. Sustainable and

adequate AAC service delivery requires AAC stakeholders to recognize opportunity barriers and

implement supports to facilitate the long-term participation and communication of individuals using

AAC. Augmentative and alternative communication service delivery in the absence of explicit

consideration for communication partners and environments does not address opportunity barriers for

the individual using AAC.

Keywords: augmentative and alternative communication, opportunity barriers, family systems

This dissertation is dedicated to the speech-language pathologists and caregivers of children using AAC

who participated in this research. Your time, effort, and energy are endlessly appreciated.

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NOMENCLATURE

AAC	Augmentative and alternative communication
ASHA	American Speech-Language-Hearing Association
AT	Assistive technology
CE	Continuing education
COVID-19	Coronavirus disease
FSS	Family Support Scale
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
PECS®	Picture Exchange Communication System
PODD	Pragmatic organization dynamic display
PSI™	Parenting Stress Index™
PSI™-4	Parenting Stress Index™ Fourth Edition
PSI™-4-SF	Parenting Stress Index™ Fourth Edition Short Form
QIAT	Quality Indicators for Assistive Technology Services
SLPs	Speech-language pathologists

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CHAPTER ONE

INTRODUCTION

Background

Overview of Augmentative and Alternative Communication

Augmentative and alternative communication (AAC) modalities are designed to support the communication of individuals who are unable to reliably achieve functional communication using verbal speech alone. AAC supports the needs of these individuals, offering temporary or permanent solutions across communication partners and environments (Beukelman & Mirenda, 2013). Individuals using AAC modalities are supported by a variety of AAC stakeholders, including direct caregivers, extended family, case managers, therapists, medical professionals, educators, and AAC vendors (Binger et al., 2012).

AAC systems are diverse and include both unaided and aided modalities (Figure 1.1) (Mirenda, 2003). Unaided AAC modalities, or no-technology modalities, are natural means of communication, including body language, eye gaze, facial expressions, signs, gestures, and vocalizations (Mirenda, 2003; Romski & Sevcik, 2005). Unaided modalities require nothing external to the communicator's body. Aided AAC modalities are characterized by external supports, which can be further categorized by low technology, mid-technology, and high-technology AAC (Light & McNaughton, 2012; Mirenda, 2003). Low-technology AAC modalities include pictures, objects, and symbol boards (Light & McNaughton, 2012b; Romski & Sevcik, 2005). Mid- and high-technology AAC modalities are electronic, speech-generating devices (Light & McNaughton, 2012b; Romski & Sevcik, 2005). The integration of communication modalities in a multimodal approach is critical, characterized by the individual's use of whichever modalities are effective in transferring an idea to a communication partner (Romski & Sevcik, 2005). Thus, individuals use multiple AAC modalities (aided and unaided) to meet communicative needs across communication partners and environments.

Figure 1.1

Classification of Aided and Unaided AAC Modalities

```
                    ┌──────────────────────┐
                    │   Communication      │
                    │   Modalities         │
                    └──────────┬───────────┘
          ┌────────────────────┴────────────────────┐
┌─────────────────────────┐              ┌─────────────────────────┐
│ Unaided (No-technology) │              │        Aided            │
└────────────┬────────────┘              └────────────┬────────────┘
                                                       │
┌─────────────────────────┐              ┌─────────────────────────┐
│  Body Language          │              │  Low-Technology         │
│  Sign language          │              └─────────────────────────┘
│  Gestures               │              ┌─────────────────────────┐
│  Facial expression      │              │  Mid-Technology         │
│  Vocalization           │              └─────────────────────────┘
└─────────────────────────┘              ┌─────────────────────────┐
                                         │  High-Technology        │
                                         └─────────────────────────┘
```
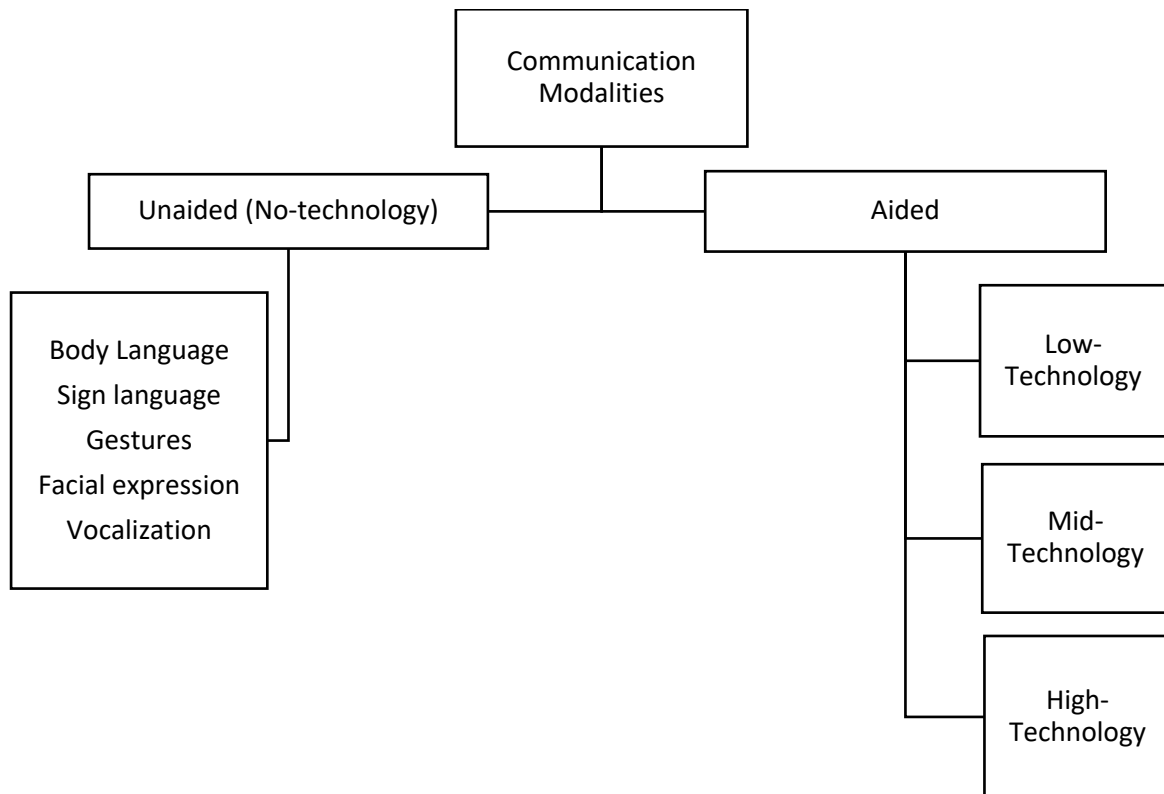
These modalities, the prevalence of AAC use, and AAC interventions have changed vastly over the last 30 years (Light & McNaughton, 2015). With recent technological developments, the use of mobile technologies has greatly advanced high-technology AAC systems (Light & McNaughton, 2012b). Development of AAC software and systems now includes the insight and skills of a variety of AAC stakeholders, including both families and professionals (Light & McNaughton, 2012b). The increasing use of AAC reflects the incidence of autism spectrum disorders, cerebral palsy, and the increased survival of children with developmental and acquired disabilities (Light & McNaughton, 2012b). The use of a candidacy model, characterized by specific characteristics deemed necessary for use of AAC, has been replaced by participation models and recognition of communication as a human right (Beukelman &

Mirenda, 2013; Brady et al., 2016). Evidence-based practices for AAC interventions have become more robust, resulting in the introduction of AAC earlier in development, rather than as a last resort intervention (Light & McNaughton, 2012b; Romski & Sevcik, 2005).

Participation Model

Beukelman and Mirenda (1988) outlined the Participation Model to reflect the participation patterns and communication needs of individuals using AAC. The purpose of this model is to systematically guide clinical decision making during both assessment and intervention in a cyclic process (Beukelman & Light, 2020; Moorcroft et al., 2019b). Since its inception, revisions to the Participation Model have elaborated the specific components necessary to guide AAC decision making and best practices (Beukelman & Light, 2020; Beukelman & Mirenda, 2013, 1988; Rosenberg & Beukelman, 1987). To make decisions, clinicians must assess the two elements of participation supports and barriers: 1) capabilities and access barriers and 2) opportunity barriers and supports (Beukelman & Light, 2020). For the individual using AAC, capabilities and access barriers are characterized by the individual's current abilities, constraints, and potential with respect to operational requirements and possible environmental adaptations (Beukelman & Light, 2020). This includes the assessment of current methods of communication and the individual's gross and fine motor, linguistic, cognitive, literacy, and sensory skills (Beukelman & Light, 2020).

Opportunity barriers and supports, however, exist and are imposed by others to include policy, practice, knowledge, skill, and attitude (Beukelman & Light, 2020). Policy barriers and supports reflect regulations in formal or informal contexts, such as hospital policies or family rules respectively (Beukelman & Light, 2020; Beukelman & Mirenda, 2013). Practice barriers and supports reflect procedures that are not policies (Beukelman & Light, 2020; Beukelman & Mirenda, 2013). This can include practices of professionals refusing to work with specific populations or school districts supporting inclusive practices (Beukelman & Light, 2020; Beukelman & Mirenda, 2013). Knowledge

barrier and supports are the communication partner's understanding of information to facilitate the

participation of an individual using AAC (Beukelman & Light, 2020; Beukelman & Mirenda, 2013).

Knowledge barriers and supports pair with skill barriers and supports, characterized by the

understanding of the technical aspect of implementation or intervention (Beukelman & Light, 2020;

Beukelman & Mirenda, 2013). Attitude barriers and supports reflect the beliefs of an individual, both at

the explicit and implicit level (Beukelman & Light, 2020; Beukelman & Mirenda, 2013).

Communication Partners

The communication ability of the individual using AAC, referred to as communicative

competence, is comprised by the linguistic, operational, social, strategic, and psychosocial skills to

effectively and efficiently communicate (Light, 1989, 2003; Light, McNaughton, & Caron, 2019; Light &

McNaughton, 2014). However, communication is characterized by a dual process with success

dependent not only upon the communicative competence of the individual using AAC, but the

communication partner as well (Kent-Walsh & McNaughton, 2005; Pino, 2000). Familiar communication

partners can include individuals with social, educational, or care relationships with the individual using

AAC (Kent-Walsh & McNaughton, 2005). To achieve successful communication, both individuals must

send and receive communicative messages to achieve interaction (Kent-Walsh & McNaughton, 2005;

Marra & Micco, 2019).

The Circle of Communication Partners (Figure 1.2) demonstrates the role of communication

partners in the act of communication through the use of concentric levels representing varying

relationships with an individual using AAC (Blackstone, 1999). Individuals with less familiar relationships

are represented in the circles more distant from the individual (Blackstone, 1999). Parents and sibling

may be in first circle, demonstrating an immediate relationship with the individual using AAC, whereas

service providers are in the fourth concentric circle (Blackstone, 1999). The model emphasizes the

interaction between an individual using AAC and people across the five circles. Traditional AAC

intervention is heavily directed toward the individual using AAC with a limited focus on the

communication partner and society (Light, McNaughton, & Caron, 2019; Light & McNaughton, 2015).

Therefore, traditional interventions only directly facilitate the communication between the individual

using AAC and the service provider, restricting intervention to the fourth circle of communication

partners (Blackstone, 1999).

Figure 1.2

Blackstone (1999) Circle of Communication Partners
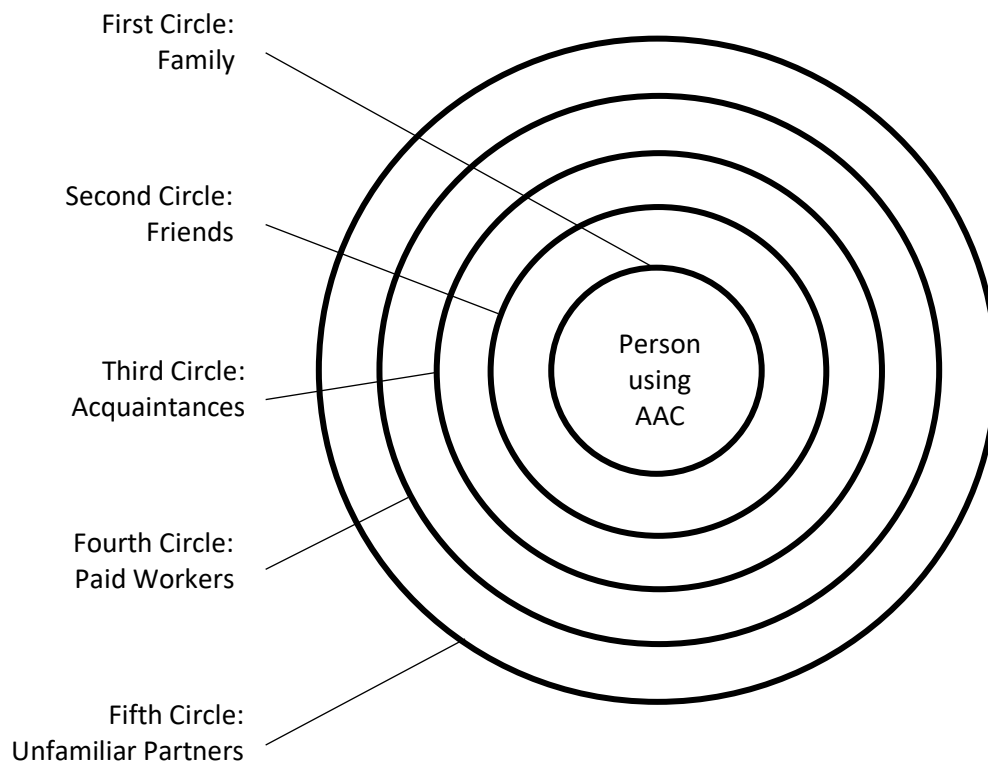
Interprofessional Service Provision

Intervention, education, and medical care for children using AAC requires many individuals across fields, including many therapeutic disciplines, educational professionals, and medical providers (O'Neill & Wilkinson, 2020). Interventions designed to develop communicative competence in individuals using AAC require "more hands-on deck" (Ogletree, 2012, p. 151). However, a culture of "the more, the merrier" (Beukelman & Mirenda, 2013, p. 105) does not yield an effective interprofessional team. Effective interprofessional teams require inventorying of expertise and interest across stakeholders (Beukelman & Mirenda, 2013). Each member must be able to work in a team, as well as understand the role of other team members (Chung & Stoner, 2016; Soto et al., 2001). Successful teaming can lead to positive outcomes, including learning and support among members of the team and improved AAC decision making (Batorowicz & Shepherd, 2011).

Speech-Language Pathologists

Under the guidance of the American Speech-Language-Hearing Association (ASHA) Scope of Practice in Speech-Language Pathology, speech-language pathologists in the United States are one critical member of the interprofessional AAC team and are responsible for AAC assessment, provision, and intervention (American Speech-Language-Hearing Association, 2016b). They are directly involved in provision of AAC services as critical AAC stakeholders, filling one or multiple personnel roles in the AAC assessment process (Binger et al., 2012). Speech-language pathologists may practice as general practitioners, providing speech and language services to individuals across practice settings, clinical populations, and diagnoses (Binger et al., 2012). In this role, speech-language pathologists can be responsible for the referral of individuals to AAC clinical specialists for assessment and intervention (Binger et al., 2012). In the absence of available AAC specialists, general practice speech-language pathologists deliver AAC services themselves (Binger et al., 2012). An AAC clinical specialist is a speech-language pathologist with a specific background, expertise, and training in AAC (Binger et al., 2012; Dietz

et al., 2012). However, the field of speech-language pathology lacks AAC clinical specialists to meet consumer needs in both adult and pediatric patient populations (Assistive Technology Industry Association, 2017). Speech-language pathologists may also fill the role of AAC facilitator and communication partner, responsible for "day-to-day AAC needs" (Binger et al., 2012, p. 283) and interaction with the individual using AAC (Binger et al., 2012).

American Speech-Language-Hearing Association (ASHA) certification changes in 2005 and 2014 specified the inclusion of instruction and clinical experience in AAC modalities during graduate studies. These certification standard changes may address the consistent reports of lack of preparation for AAC service delivery in preprofessional speech-language pathology students (Assistive Technology Industry Association, 2017; Dietz et al., 2012; R. K. Johnson & Prebor, 2019; Ratcliff et al., 2008). In the absence of adequate preparation at the undergraduate and graduate level, speech-language pathologists are unable to engage in confident and competent AAC service provision. During professional practice, speech-language pathologists report feelings of discomfort and limited expertise in AAC (Amundsen, 2014; De Bortoli et al., 2014; Kent-Walsh et al., 2010; Marvin et al., 2003; Sutherland et al., 2005). To fill knowledge gaps, they rely on post-professional training and continuing education (CE) (Amundsen, 2014; De Bortoli et al., 2014; Dietz et al., 2012; Kent-Walsh et al., 2008; Simpson et al., 1999; Sutherland et al., 2005; Wormnæs & Abdel Malek, 2004).

Caregivers

Parents, legal guardians, and adult caregivers ("caregivers") of children using AAC are embedded in naturalistic environments and fill the role of primary communication partner for their child regardless of prior training and education (O'Neill & Wilkinson, 2020). Evaluation of the communicative behaviors of caregivers, including mothers, foster mothers, and adult siblings, of children with physical disabilities using AAC revealed communication partners produce 68.1% of communicative turns and the children fulfill half of the remaining communicative opportunities (Light et al., 1985a). Thirty-three percent of

these caregivers' communicative turns are used to request information using closed, test-like questions (Light et al., 1985b). The linguistic input of mothers of children with physical disabilities is characterized by initiation of topics, questions, and directives (Pennington & McConachie, 1999). These communicative behaviors are predictive of the response of the child and the child's communication modality, as well as restrictive of the child's range of communicative functions (Light et al., 1985a, 1985c; Pennington & McConachie, 1999). In the absence of effective interventions over time, these caregiver-child interaction patterns become "fossilized" (Pennington & McConachie, 1999, p. 392).

The introduction of AAC, AAC service provision, and child outcomes require explicit collaboration between the clinical AAC team and families (Alant et al., 2012; Bailey, Parette, et al., 2006; Mandak et al., 2017; McNaughton et al., 2008). Appropriate family-centered AAC service provision requires a careful balance between the roles of the caregiver and the clinician (K. L. Anderson et al., 2014). This is accomplished by stepping away from a traditional, expert-driven model for the implementation of an interprofessional AAC team with explicit inclusion of caregivers (Mandak et al., 2017; Ogletree, 2012). Prior literature indicates caregivers prefer to be included as key AAC stakeholders, as well as active members of the AAC decision-making team on behalf of their child (Goldbart & Marshall, 2004). However, collaborative and interprofessional care continues to be a barrier for caregivers of children using AAC. Caregivers and children using AAC are often excluded from the teams making AAC-related decisions (Bailey, Parette, et al., 2006; S. Baxter et al., 2012; Goldbart & Marshall, 2004; McNaughton et al., 2008; Parette et al., 2000). An incohesive interdisciplinary team directly contributes to caregivers' negative experiences and the abandonment of AAC modalities (Moorcroft et al., 2019b). Further, without the inclusion of caregivers, decisions about AAC systems are made by service providers without insight to all of the child's communication needs, partners, and environments.

Qualitative studies have identified negative feelings in caregivers of children using AAC,

including stress, fatigue, isolation, guilt, and frustration (Goldbart & Marshall, 2004; Gona et al., 2014; Stadskleiv, 2017). The introduction of aided AAC systems results in feelings of intimidation, lack of confidence, and uncertainty (K. L. Anderson et al., 2016). Caregivers identify negative reactions and lack of support by unfamiliar communication partners (Crisp et al., 2014; Singh et al., 2017). Lack of public awareness results in the need to navigate negative reactions, lack of support, and lack of value for AAC from unfamiliar communication partners (Crisp et al., 2014; Donato et al., 2014; Glacken et al., 2019; Marshall & Goldbart, 2008; Singh et al., 2017). In response to AAC interventions, caregivers report barriers in the provision of appropriate training, support, and help across professional disciplines (Bailey, Parette, et al., 2006; Borg et al., 2015; Crisp et al., 2014; Donato et al., 2014; Glacken et al., 2019; Goldbart & Marshall, 2004; Moorcroft et al., 2019b; Singh et al., 2017). Caregivers report a need for technical training across operational, linguistic, social, and strategic competencies (McNaughton et al., 2008), including selecting vocabulary, programming and maintaining the AAC system, and troubleshooting (Alant et al., 2012). From service providers, caregivers report the need for accessible resources and family-centered and culturally-sensitive service provision, seeking the time to be both heard and understood (Parette et al., 2001). Without proper "graded supervision" (K. L. Anderson et al., 2014, p. 81), therapy can be overwhelming, resulting in caregivers fulfilling a passive rather than active role in an AAC intervention (K. L. Anderson et al., 2014, 2015).

Caregivers' judge AAC modalities with respect to the child's communicative competence, opportunities, and environment (Bailey, Parette, et al., 2006). If the modality met communication needs across these three domains, use of AAC increased. Ease of AAC use includes the specific aspects of the AAC system, voice quality, user-friendly design, personalization, immediate access to vocabulary, and physical size of the system (K. L. Anderson et al., 2016; Borg et al., 2015; Crisp et al., 2014; San & Abdullah, 2013). With increased availability of AAC on mainstream hardware, including tablets and smart phones, caregivers observe an increased awareness and familiarity across communication

partners and environments (Crisp et al., 2014). Familiarity with mainstream technology is motivating for both children and their caregivers (Hettiarachchi et al., 2019). However, the reliability of the AAC system, restricted vocabulary, and programming demands are barriers to AAC use (K. L. Anderson et al., 2016; Bailey, Parette, et al., 2006; Borg et al., 2015). The expense of aided AAC systems also inhibit AAC use (Borg et al., 2015; Hettiarachchi et al., 2019; Marshall & Goldbart, 2008; Singh et al., 2017). This can be compounded by caregivers' concerns that aided AAC systems are not safe due to the child's behavior (Hettiarachchi et al., 2019).

The benefit of AAC use is validated by caregivers, who report the use of AAC increases feelings of accomplishment and emotional fulfillment, as well as decreases feelings of frustration related to communication (Chung & Stoner, 2016). However, after introduction of AAC, caregivers often observe disconnection between initial expectations and the realities of their child's communication skills and demand of AAC systems (Allen et al., 2015). The introduction of AAC does not yield immediate communicative competence for pediatric users, resulting in specific demands placed on the child's most immediate communication partners (K. L. Anderson et al., 2016).

Not only are caregivers of children using AAC tasked with direct communication facilitation, but they also have multiple diverse responsibilities, including daily caregiving, guidance for clinical decisions, selection of interventions, negotiation and advocacy, and provision of AAC technical support (K. L. Anderson et al., 2016; Goldbart & Marshall, 2004; McNaughton et al., 2008; Serpentine et al., 2011). Parents of children using AAC experience the feeling of more demand for time and energy than the demand experienced by children without disabilities (Goldbart & Marshall, 2004). Time is a primary stressor related to AAC, characterized by caregivers' feelings of lack of preparation for the time necessary to program an AAC system and the presence of a cost of learning (Bailey, Parette, et al., 2006; Goldbart & Marshall, 2004; McNaughton et al., 2008). Lack of consistency and miscommunication between the multiple providers involved in the child's care results in strain on families (K. L. Anderson et

al., 2014).

Caregivers' perceptions and experiences have consequential impact. Uncertainty and underconfident feelings contradict caregivers' desire to be validated as experts in their child's care (Bailey, Parette, et al., 2006; Goldbart & Marshall, 2004). Frustrations with AAC systems and services, as well as lack of support, can ultimately lead to rejection and abandonment of the AAC system (K. L. Anderson et al., 2014; Moorcroft et al., 2019b). Additionally, strong family participation is associated with quality collaboration, improved child outcomes, and successful AAC use (Chung & Stoner, 2016; McNaughton et al., 2008).

Communication Partner Interventions

To support children using AAC, communication partners are tasked with understanding the child's modalities of communication, as well as appropriately modeling communication (Shire & Jones, 2015). However, communication partners' behaviors do not automatically facilitate the functional communication of individuals using AAC. Therefore, communication partner interventions have been designed to shape the behaviors of communication partners and equip them for these interactions with individuals using AAC (e.g., Binger et al., 2008; Kent-Walsh et al., 2010, 2015; Kent-Walsh & Mcnaughton, 2005). This disrupts predictive patterns that inhibit the communication opportunities for individuals using AAC, as well as abandonment of the AAC modality (J. M. Johnson et al., 2006).

Communication partner training can include strategy instruction, in which strategies are taught in a specific sequence (Kent-Walsh et al., 2015). Alternatively, it can include individual skill training, characterized by strategies taught with no prespecified sequence (Kent-Walsh et al., 2015). Interventions have been implemented across many communication partners, including caregivers, therapists, educators, and peers (Kent-Walsh et al., 2015; Shire & Jones, 2015). Outcomes suggest communication partner interventions not only change the communicative behaviors of the communication partner, but also the child (Kent-Walsh et al., 2015; Shire & Jones, 2015). Following

communication partner interventions, individuals using AAC demonstrate increased use of AAC, turn-taking, verbalization, as well as gains in pragmatic, semantic, and syntactic outcomes (Kent-Walsh et al., 2010, 2015; Lilienfeld & Alant, 2005; Senner et al., 2019; Shire & Jones, 2015).

Problem

The effectiveness of AAC modalities is driven by the interaction between intrinsic and extrinsic factors (Light & Drager, 2007). Therefore, introducing an AAC system with accompanying intervention does not effectively address the communication partner-driven opportunity barriers (Beukelman & Mirenda, 2013). The revised Participation Model (Beukelman & Light, 2020) outlines the impact of these external factors, including AAC stakeholders, as opportunity barriers and supports on the long-term outcomes of individuals using AAC.

The National Joint Committee for the Communication Needs of Persons with Severe Disabilities Communication Bill of Rights serves as a gold standard guideline for defining functional communication across individuals regardless of communication modality (Brady et al., 2016). This document outlines communication as a basic right and should be protected across environments, contexts, and communication partners (Brady et al., 2016). Currently, lack of evidence related to opportunity barriers and supports impedes AAC stakeholders' ability to consistently ensure protection of communication rights for individuals using AAC. Current and specific data related to stakeholders' perceptions and experiences is necessary to identify and address the opportunity barriers and supports that inhibit the participation and communication of individuals using AAC (Beukelman & Light, 2020).

Purpose

The purpose of this research is to thoroughly investigate the opportunity barriers and supports that impact the participation and communication of individuals using AAC in two critical members of the interprofessional AAC team: speech-language pathologists and caregivers. This dissertation includes three specific purposes to better understand these opportunity barriers. The first purpose was to

investigate characteristics of AAC service provision reported by post-professional speech-language pathologists. The second purpose was to analyze parent, guardian, and caregiver perceptions of AAC interventions. The third purpose was is to investigate experiences and contributing factors of stress in adult caregivers of children using AAC.

Aims and Hypotheses

The following aims were generated to guide this dissertation. Hypotheses have been generated for aims with quantitative methodologies.

1. Chapter 2:

   - Aim 1.1: Identify the characteristics of post-professional speech-language pathologists' perceived knowledge, use of AAC during service delivery, and feelings about AAC.

     o Hypothesis 1.1: Speech-language pathologists' perceived knowledge and use of AAC during service delivery will differ across competency areas and clinical populations.

   - Aim 1.2: Identify post-professional speech-language pathologists' perceived barriers to AAC service delivery.

     o Hypothesis 1.2: Speech-language pathologists will identify caseload, time, and knowledge as primary barriers to AAC service delivery.

   - Aim 1.3: Identify post-professional speech-language pathologists' learning preferences for AAC-related training.

     o Hypothesis 1.3: Speech-language pathologists will prefer an AAC intervention topic, interactive format, and on-the-spot dosage for AAC-related training and CE.

2. Chapter 3

   - Aim 2: Identify caregivers' perceived intervention barriers and facilitators to AAC use by school-aged children who use AAC.

3. Chapter 4

- **Aim 3.1**: Identify differences in level of stress reported by adult caregivers of children using AAC across frequency of aided AAC modality use.

    - **Hypothesis 3.1**: It is hypothesized that adult caregivers of children with more frequent use of aided AAC modalities will report more stress than adult caregivers of children with less frequent use of aided AAC modalities.

- **Aim 3.2**: Identify differences in level of stress reported by adult caregivers of children using AAC across differing microsystem and macrosystem characteristics.

    - **Hypothesis 3.2.1**: It is hypothesized that adult caregivers of a younger child using AAC will report less stress than those with an older child using AAC.

    - **Hypothesis 3.2.2**: It is hypothesized that adult caregivers with more family support will have less stress than those with less family support.

- **Aim 3.3**: Explore how adult caregivers of children using AAC describe their lived experiences of the phenomenon of stress.

Assumptions

The following assumptions were used throughout this dissertation:

1. Chapter 1:

- Reviewed literature was truthful and representative of the field of augmentative and alternative communication.

- The revised Participation Model (Beukelman & Light, 2020) is accurate and relevant to the research question.

2. Chapter 2:

- The quantitative research methodology was appropriate to answer the research question.

- Participants responded to surveys honestly and to the best of their ability.

- The survey instrument items accurately captured the specified variables.

- The study included an adequate number of participants to answer the research question.

- Participants were representative of the targeted population.

3. Chapter 3:

- The qualitative metasynthesis research methodology was appropriate to answer the specified research question.

- The included qualitative studies were representative of participants' perceptions.

- Participants were representative of the targeted population.

4. Chapter 4:

- The mixed-methods research methodology was appropriate to answer the research questions.

- Participants responded to surveys and interviews honestly and to the best of their ability.

- The family systems framework for family-centered AAC services (Mandak et al., 2017) is accurate and relevant to the research question.

- The survey instrument items accurately captured the specified variables.

- The power analysis was correct and the study was adequately powered.

- The assumptions of hierarchical linear regression were met, including additivity and linearity, independent errors, homoscedasticity, normally distributed errors, boundaries of predictors, collinearity, and non-zero variance (Field, 2018).

<div align="center">**Delimitations**</div>

The following delimitations were used throughout this dissertation:

1. Chapter 2:

- The study was focused on speech-language pathologists' perceptions related to characteristics of AAC service provision.

- This study used a quantitative research methodology.

- This study's specific variables were perceived knowledge, use of AAC modalities, feelings about AAC, barriers to AAC service provision, plans for future engagement in AAC training and CE, and learning preferences for AAC-related training and CE.

- Participants were speech-language pathologists with an ASHA Certificate of Clinical Competence with at least one year of clinical experience post-graduation.

2. Chapter 3:

- The study was focused on parent, guardian, and caregiver perceptions of AAC interventions

- This study used a qualitative metasynthesis research methodology.

- This study used a constructivist ontological assumption.

- Included studies included a research question related to reading, writing, and communication interventions using assistive technology (AT) and AAC.

- Included studies contained the caregiver perspective of intervention barriers or facilitators of a child's AAC use.

- Included studies had child participants are between 4 – 22 years.

- Included studies used qualitative methodology.

- Included studies were available in English as a full-text.

- Included studies were published between 2000 and July 2020.

Chapter 4:

- The study was focused on experiences and contributing factors of stress in adult caregivers of children using AAC.

- This study used a mixed-methods research methodology with a sequential explanatory implementation procedure.

- This study used a constructivist ontological assumption.

- This study's specific variables were child age, caregiver age, caregiver marital status,

caregiver education, caregiver employment, number of children with and without medical

and/or educational diagnoses, Family Support Scale total score, and Parenting Stress Index™,

Fourth Edition Short Form total score.

- Participants had no known speech, language, or hearing impairments.

- Participants were able to speak, understand, read, and write in English at a level of

    proficiency for participation in an interview without an interpreter present.

- Participants resided in the United States.

- Participants were adult caregivers of a child who: has AAC needs for communication; uses

    AAC; is between the ages of 3-9 years; has a developmental, congenital, or acquired medical

    or educational diagnosis.

Limitations

Limitations have been identified for each study and reported in Chapters 2-4.

CHAPTER TWO

REPORTED BARRIERS TO AUGMENTATIVE AND ALTERNATIVE COMMUNICATION SERVICE DELIVERY

AND POST-PROFESSIONAL LEARNING PREFERENCES AMONG SPEECH-LANGUAGE PATHOLOGISTS

Introduction

Augmentative and alternative communication (AAC) modalities are designed to meet an individual's communication needs across environments (Beukelman & Light, 2020). Tasked with the use of AAC to support individuals' communication, speech-language pathologists (SLPs) are directly involved in AAC service provision (American Speech-Language-Hearing Association, 2016b). Following certification standard changes in 2005 and 2014, the American Speech-Language-Hearing Association (ASHA) requires instruction and clinical experiences during graduate studies in the use of AAC modalities. The initial change increased the number of preprofessional programs reported to offer at least one AAC course from 62% (Ratcliff & Beukelman, 1995) to 72% (Ratcliff et al., 2008). The most recent report indicates 86% of all undergraduate and graduate preprofessional programs offer at least one dedicated AAC course (R. K. Johnson & Prebor, 2019). Strictly at the graduate level, more than 90% of speech-language pathology and speech and hearing science programs require an AAC course (R. K. Johnson & Prebor, 2019).

The dissemination of information in coursework during preprofessional training is through textbook and journal article readings, online learning modules, and webinars (R. K. Johnson & Prebor, 2019). Fifty-seven percent of the AAC course focuses on pediatric content and the remaining 43% is related to adult and geriatric populations (R. K. Johnson & Prebor, 2019). Current preprofessional training includes hands-on laboratory activities with requirements for operational competence in 44% of graduate programs (R. K. Johnson & Prebor, 2019). This is a reduction in the laboratory instruction with operational competency requirements since the Ratcliff et al. (2008) survey, in which 53% of programs had laboratory instruction with operational competency requirements. Currently, in 57% of graduate

programs, less than half of students graduate with clinical clock hours in AAC (R. K. Johnson & Prebor, 2019). Only half of programs reported at least 50% of students are prepared for AAC service provision at the time of graduation (R. K. Johnson & Prebor, 2019). The disparity between preparation and the required expertise for AAC service provision (Ratcliff et al., 2008) is consistent with reports of limited confidence in the competence among SLPs to provide AAC services. More than 70% of SLPs report inadequate preparation for AAC service delivery (Costigan & Light, 2010; Marvin et al., 2003). Sixty percent of SLPs report having limited or poor comfort with AAC (Marvin et al., 2003). To increase expertise, SLPs have an appreciation and desire for post-professional training related to AAC (Simpson et al., 1999; Sutherland et al., 2005; Wormnæs & Abdel Malek, 2004). In addition to preprofessional training, SLPs report training through on-the-job experiences, self-study, continuing education (CE), and other sources (Iacono & Cameron, 2009; Marvin et al., 2003; Sutherland et al., 2005).

Barriers

AAC is a complex area of clinical practice with heterogeneous patient populations, the need for interprofessional collaboration, and rapidly changing technology (Dietz et al., 2012). As Beukelman and Mirenda's revised participation model suggests, opportunity barriers negatively impact successful AAC use (Beukelman & Light, 2020). These opportunity barriers reflect characteristics of communication partners and environments surrounding the individual using AAC (Beukelman & Light, 2020). Communication partners' knowledge and skills, characterized by information, experience, technical ability, and interaction ability facilitate or inhibit the communication and participation of individuals using AAC (Beukelman & Light, 2020). Legislative and organizational policies can also impact the inclusion, participation, and communicative opportunities for individuals using AAC (Beukelman & Light, 2020). Practice and attitude barriers reveal organizational culture and personal beliefs (Beukelman & Light, 2020).

The five opportunity barriers are evident in past literature of SLPs' barriers to AAC service

delivery. Speech-language pathologists' reports of inadequate preparation and limited comfort are suggestive of knowledge and skill barriers. Caseload and documentation policies result in limited time to collaborate with both professionals and families of individuals using AAC (Bailey, Stoner, et al., 2006; Kent-Walsh et al., 2008). Time is necessary to program vocabulary on aided AAC systems (Bailey, Stoner, et al., 2006), educate other communication partners (Iacono & Cameron, 2009), prepare materials (Amundsen, 2014), and determine the most appropriate communication modality for a patient (Iacono & Cameron, 2009). Speech-language pathologists juggle these demands while maintaining high caseloads with diverse populations (Kent-Walsh et al., 2008) and demanding jobs (Alant et al., 2012; Amundsen, 2014). Lack of financial support limits the availability of aided AAC systems (Amundsen, 2014; Soto et al., 2001). Other barriers specific to the AAC system include availability, portability, extensive training requirements, and software limitations (Amundsen, 2014; Bailey, Stoner, et al., 2006; McNaughton et al., 2008). However, recent advancements to the field of AAC have also been observed. Updated and accessible technologies, expanded options for communication, and increased expectations for individuals using AAC may result in different barriers to AAC service provision for SLPs (Light, McNaughton, Beukelman, et al., 2019; Light, McNaughton, & Caron, 2019).

Practice Settings

Individuals using AAC receive services in multiple practice settings. Prior surveys related to service provision by SLPs often analyze the data by grouping participants by age of patient population or medical versus educational practice setting (e.g., American Speech-Language-Hearing Association, 2019, 2020; Assistive Technology Industry Association, 2017). In these studies, disparities are observed in SLPs' provision of AAC services. More than 60% of SLPs in the educational setting regularly serve patients using AAC modalities (American Speech-Language-Hearing Association, 2020). However, in medical settings, AAC service provision accounts for 2-5% of clinical services (American Speech-Language-Hearing Association, 2019).

Across caseload and setting characteristics, differences in SLPs' preferences for AAC-related training are present. A prior study of SLPs working with either adults or children identified preferences for post-professional training topics of AAC devices, device use and training, assessment, software, and working with patients (Sutherland et al., 2005). This group also reported preferences for seminar, workshop, written information, and training video formats (Sutherland et al., 2005). However, SLPs strictly practicing in the educational setting reported preferences for topics of general AAC intervention, AAC specific to language and literacy development, and AAC in the classroom (Kent-Walsh et al., 2008). Among those in the educational setting, format preferences included in-services, on-the-spot assistance within the classroom, and professional conferences (Kent-Walsh et al., 2008).

Learning preferences, paired with the specific characteristics of AAC service provision across practice settings, may be indicative of differing perceptions, preprofessional training outcomes, or overarching culture within a practice setting. Given the unequal distribution of time in preprofessional training across the lifespan, it is necessary to evaluate post-professional SLPs' perceived knowledge, use of AAC modalities, learning preferences, and barriers to AAC service provision across caseload characteristics and clinical practice setting. Differences may warrant modifications to exisiting preprofessional or post-professional training. Further, perceptions from SLPs in different practice settings may reveal setting-specific inhibitors or facilitators to patient care.

The purpose of this study is to investigate characteristics of AAC service provision reported by post-professional SLPs. Using a survey, the study examined post-professional SLPs' reports of current AAC service provision, barriers influencing AAC service provision, and learning preferences for post-professional instruction and training in AAC. This research examined three research questions:

1. What are the characteristics of SLPs' perceived knowledge, use of AAC during service delivery, and feelings about AAC?

2. What are the perceived barriers to AAC service delivery?

3. What are the learning preferences for AAC-related training among post-professional SLPs?

Three corresponding hypotheses were generated:

- Hypothesis 1.1: Speech-language pathologists' perceived knowledge and use of AAC during service delivery will differ across competency areas and clinical populations.

- Hypothesis 1.2: Speech-language pathologists will identify caseload, time, and knowledge as primary barriers to AAC service delivery.

- Hypothesis 1.3: Speech-language pathologists will prefer an AAC intervention topic, interactive format, and on-the-spot dosage for AAC-related training and CE.

Method

Participants

The participants for this study were SLPs with an ASHA Certificate of Clinical Competence with at least one year of clinical experience post-graduation. Invitations to participate in this study were disseminated through social media and the ASHA Community discussion groups. One reminder was posted to select social media and groups at least 2 weeks after initial information was shared. Invitations and reminders were staggered to reduce redundancy for individuals in multiple groups. Given the convenience and chain sampling technique used to recruit participants, it is impossible to determine the number of possible respondents. Participants were able to provide their e-mail addresses to receive a summary of the study and participate in a raffle as compensation for their time. Contact information remained independent from participant responses.

Instrument

No existing measure was identified, so literature related to preservice training (R. K. Johnson & Prebor, 2019; Ratcliff et al., 2008), AAC service delivery (American Speech-Language-Hearing Association, 2019, 2020; Amundsen, 2014; Assistive Technology Industry Association, 2017), barriers to practice (Beukelman & Light, 2020), and learning preferences (Assistive Technology Industry Association,

2017; Sutherland et al., 2005) was reviewed to develop the survey. Informed consent was obtained for voluntary participation in the research study in the first three survey questions. The survey included demographic questions, followed by three distinct sections for characteristics of service delivery, barriers, and learning preferences. The question format included a forced categorical response in a multiple-choice format with a write-in option and Likert-scale rating. Question types were primarily Likert-scale and categorical with free text boxes for select questions. A panel of four content-area experts were invited to participate in question testing. Feedback was received from two of the experts related to wording, clarification, and additions to the survey. The final 49 question survey (Appendix A) was distributed via Qualtrics survey software (Qualtrics, Provo, UT).

Recruitment and data collection began following the approval of the Old Dominion University Education Human Subjects Review Committee. Individual surveys electronically closed and submitted automatically 7 days following the participant's initiation regardless of the state of completion. Completion of the survey in its entirety was not a requirement for inclusion in analysis. For partially completed surveys, a criterion for inclusion in the data analysis was at least one answered question. Data collection occurred across five months.

Analysis Strategy

If participants did not work with the clinical population, responses were "not applicable" and were excluded from the specific analysis. Participants identified their feelings about AAC by selecting one of eight sections of a circumplex model of emotion (Figure 2.1) representing the pleasantness and intensity of emotions.

Figure 2.1

Circumplex Model of Emotions
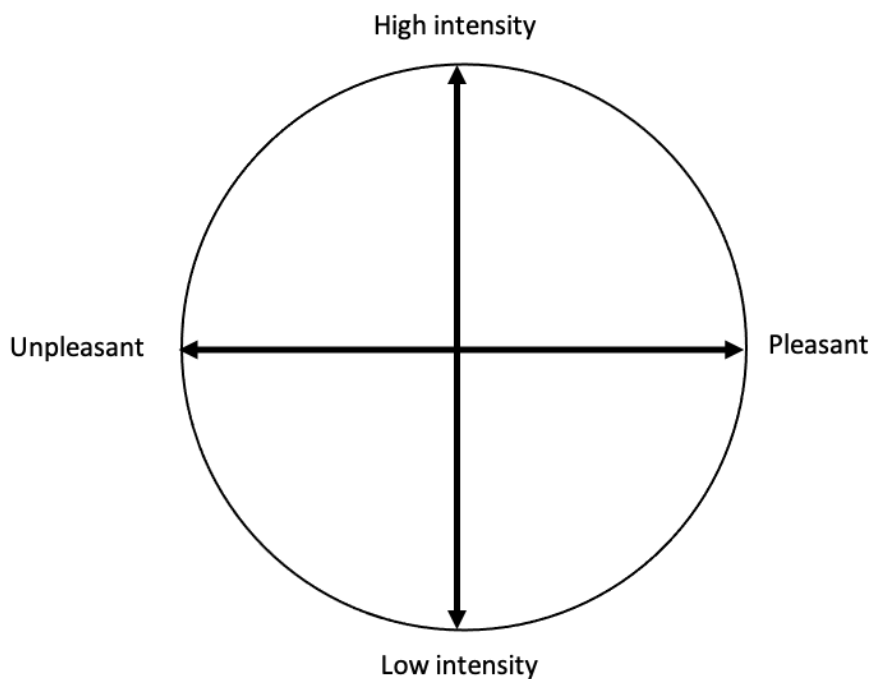
Participants reported primary barriers to AAC service provision across three primary categories: work setting, resources, and AAC systems. Participants rated their level of agreement using a 5-point Likert-scale (1 is strongly disagree, 5 is strongly agree) about personal benefit and plans for future engagement in AAC training and CE. They reported AAC-related training and CE learning preferences by selecting up to three responses related to topic, format, and dosage. Descriptive statistics were used to analyze participants' responses.

Results

Participant Flow

Five-hundred eighty-four individuals responded to at least one survey question. Fifty-one individuals did not complete the steps for voluntary consent and therefore, were excluded. Three

individuals were excluded due to <1 year of clinical experience. Five-hundred thirty participants were

included in analyses with a minimum response of three questions. Of these participants, 393 completed

the survey in its entirety, resulting in a completion rate of 74.15%.

Participant Characteristics

The participating SLPs were predominantly in the first 10 years of clinical practice and identified

schools as their primary work setting. A full description of participants demographic and clinical practice

settings are provided in Table 2.1 and Table 2.2, respectively.

Table 2.1

Demographic Characteristics of Post-Professional Speech-Language Pathologist Participants

Characteristic	*n*	%
Age	**522**	
≤34 years	235	45.0%
35-44 years	124	23.8%
45-54 years	92	17.6%
55-64 years	55	10.5%
≥65 years	16	3.1%
Number of years of professional practice	**437**	
1-5 years	126	28.8%
6-10 years	109	24.9%
11-15 years	57	13.0%
16-20 years	44	10.1%
21-25 years	41	9.4%
26-30 years	25	5.7%
≥31 years	35	8.0%
Highest earned degree	**436**	
Master's degree	416	95.4%
Clinical doctoral degree	3	0.7%
Research doctoral degree	17	3.9%
Professional role	**437**	
AAC finder	25	5.7%
General practice SLP	302	69.1%
AAC clinical specialist	80	18.3%
AAC facilitator and/or communication partner	16	3.7%
Collaborating professional	10	2.3%
AAC research and policy specialist	2	0.5%
Manufacturer/vendor	0	0.0%
AAC funding agency	0	0.0%
AAC technology training agency personnel	2	0.5%
Other	0	0.0%

Table 2.2

Characteristics of Post-Professional Speech-Language Pathologists' Clinical Practice Setting

Characteristic	*n*	%
Primary work setting	**517**	
General medical / Veterans Affairs / long-term acute care hospital	16	3.1%
Home health	15	2.9%
Outpatient clinic	57	11.0%
Pediatric hospital	12	2.3%
Rehabilitation hospital	24	4.6%
Skilled nursing facility	25	4.8%
School	239	46.2%
Early intervention	33	6.4%
Private practice	55	10.6%
University training clinic	27	5.2%
Other	14	2.7%
Region	**490**	
Northeast	116	23.7%
South	158	32.2%
Midwest	112	22.9%
West	103	21.0%
Territory	1	0.2%
Community	**501**	
City	199	39.7%
Suburban	220	43.9%
Rural	82	16.4%
Employment status	**512**	
Full time	406	79.3%
Part time	77	15.0%
PRN and per diem	19	3.7%
Unemployed / On leave of absence	10	2.0%
Number of employed SLPs in primary work setting	**510**	
1 - 2	172	33.7%
3 - 4	89	17.5%
≥5	249	48.8%
Professional team	**502**	
Multidisciplinary	121	24.1%
Interdisciplinary	279	55.6%
Transdisciplinary	42	8.4%
No team	57	11.4%
Not currently working	3	0.2%

Note. Northeast = New Jersey, New York, Pennsylvania, Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont; South = Alabama, Kentucky, Mississippi, Tennessee, Delaware, District of Columbia, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, West Virginia, Arkansas, Louisiana, Oklahoma, Texas; Midwest = Illinois, Indiana, Michigan, Ohio, Wisconsin, Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, South Dakota; West = Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Utah, Wyoming, Alaska, California, Hawaii, Oregon, Washington; Territory = other US territories (ASHA, 2019).

Current Characteristics

Only 64.6% (279 of 432) of SLPs reported dedicated AAC coursework during their graduate

education. The majority of surveyed SLPs (50.6%, 229 of 453) reported serving caseloads with between

1-25% of weekly patients unable to meet communication needs using unaided modalities alone (Figure

2.2). For SLPs with 26-100% of weekly patients unable to meet communication needs with unaided

modalities alone, a smaller percentage of patients receive AAC intervention (30.9%, 140 of 453) than the

percentage unable to meet communication needs with unaided modalities alone (44.2%, 200 of 453).

With more hours of direct AAC service provision, SLPs provided less indirect service provision (Figure

2.3).

Figure 2.2

Participants' Reported Weekly Caseload Characteristics
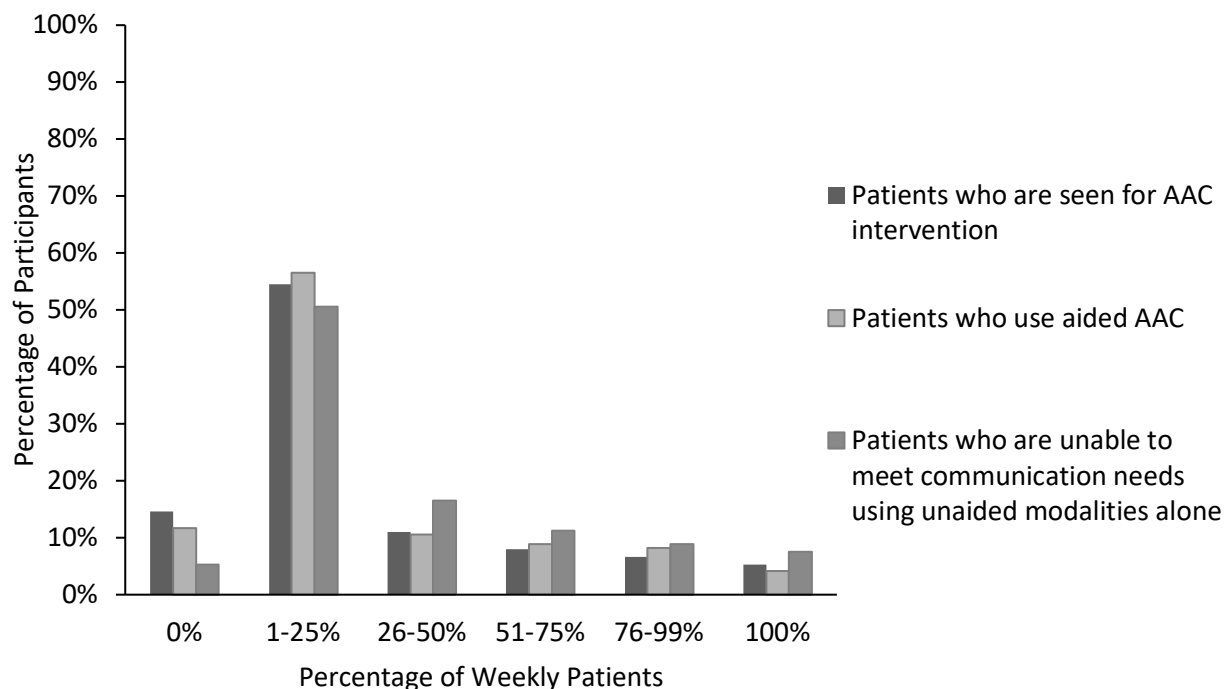
Figure 2.3

Participants' Reported Hours of AAC Service Provision
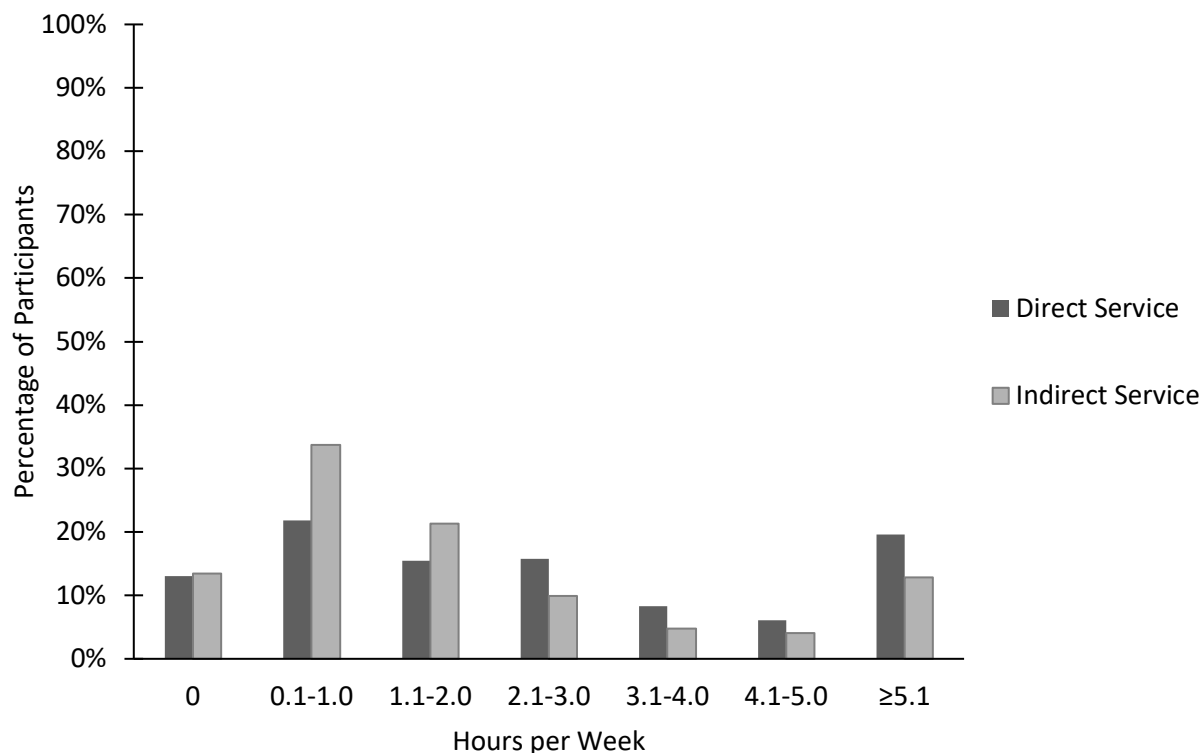
Service Provision

Knowledge

Using a 5-point Likert scale, participants rated their level of knowledge in 14 AAC-related areas

(1 is not at all knowledgeable, 5 is expert knowledge) and their use of AAC modalities for each of ASHA's

"Big 9" clinical topics and diagnoses (1 is never, 5 is always). In eight of the competency areas, more

than 60% of SLPs identify as at least knowledgeable: AAC intervention (67.8%, 272 of 401, M = 3.09),

AAC intervention with focus on language (69.6%, 279 of 401, M = 3.10), no-technology AAC modalities

(68.8%, 276 of 401, M = 3.13), low-technology AAC modalities (71.1%, 285 of 401, M = 3.20), high-

technology AAC modalities (62.1%, 249 of 401, M = 3.00), collaboration with professionals (72.3%, 290

of 401, *M* = 3.26), collaboration with families and caregivers (70.3%, 282 of 401, *M* = 3.20), and AAC

training and continuing education (61.8%, 248 of 401, *M* = 3.00). In two competency areas, only half of

SLPs identify as at least knowledgeable: AAC evaluation (52.6%, 211 of 401, *M* = 2.76) and programming

and maintenance of AAC (53.7%, 216 of 401, *M* = 2.82). However, the majority of SLPs identify as less

than knowledgeable in four competency areas. With respect to interventions, only 31.7% (127 of 401) of

SLPs identify as at least knowledgeable for AAC intervention with focus on literacy (*M* = 2.20). Less than

20% of SLPs identify as at least knowledgeable for AAC intervention with focus on aging (17.0%, 68 of

401, *M* = 1.70) and AAC intervention with focus on end of life (14.0%, 56 of 401, *M* = 1.57). Less than half

of SLPs (47.4%, 190 of 401) identify as at least knowledgeable in the area of collaboration with vendors

(*M* = 2.60).

Use

The frequency of use of AAC modalities across clinical topics and diagnoses varied greatly as

shown in Figure 2.4. Speech-language pathologists most frequently use AAC modalities during service

provision with individuals with cognitive communication disorders (*M* = 3.37), social communication

disorders (*M* = 3.44), receptive and expressive language disorders (*M* = 3.79), and those who

communicate using AAC modalities (*M* = 4.15). They sometimes use AAC modalities with individuals with

hearing impairment (*M* = 2.30) and articulation disorders (*M* = 2.49). Speech-language pathologists

seldom or never use AAC modalities with individuals with swallowing disorders (*M* = 1.42), fluency

disorders (*M* = 1.45), and voice and resonance disorders (*M* = 1.75). Due to the variation in SLPs'

perceived knowledge across competency areas and use of AAC modalities during service provision with

different clinical populations, Hypothesis 1.1 is supported.

Figure 2.4

Participants' Reported Use of AAC Modalities across Clinical Topics and Diagnoses
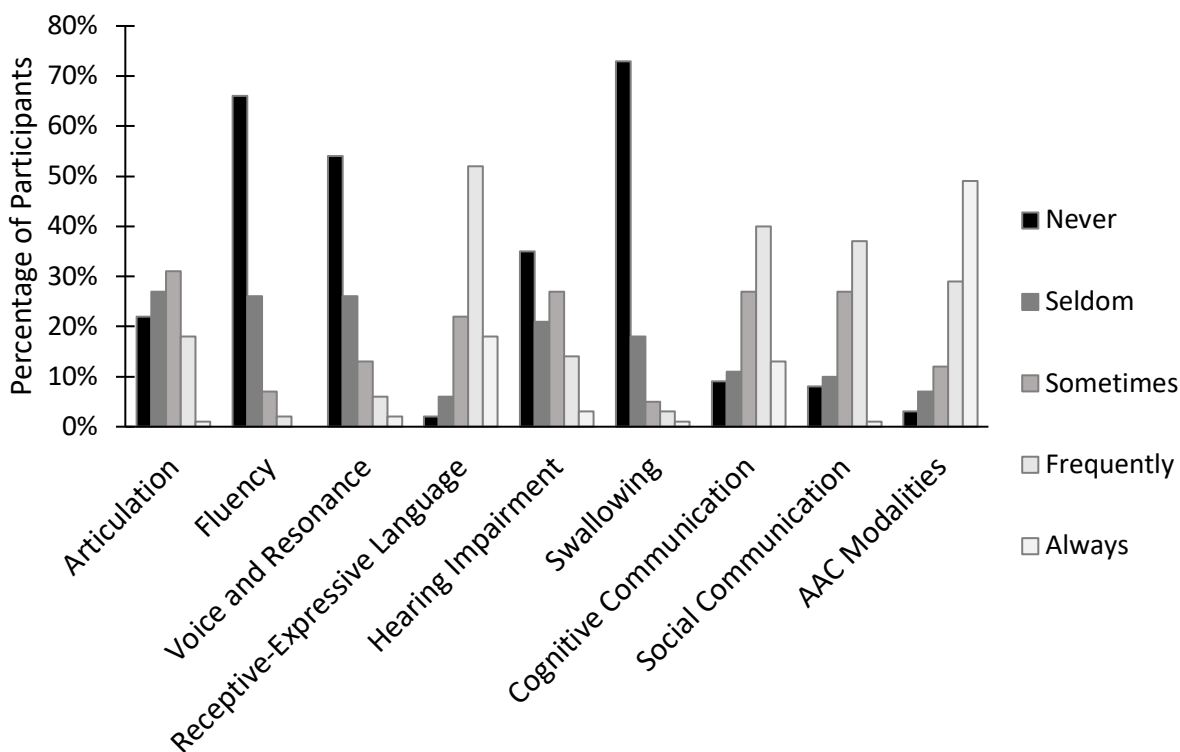
Feelings

Using a circumplex of emotion model, participants selected a one-eighth area of a circle

corresponding to the intensity of emotion (y-axis) and pleasantness of emotion (x-axis). Using this tool,

speech-language pathologists reported their general feelings about AAC with respect to (a) the patient

experience and (b) the clinician experience. More than sixty percent of SLPs reported pleasant feelings

about AAC related to patient (68.70%, 270 of 393) and clinician (66.16%, 270 of 393) experiences.

Speech-language pathologists reported feeling excited and happy, as well as sad and frustrated about

AAC related to patient experiences more than clinician experiences. Conversely, SLPs felt content, tired,

bored, and afraid more frequently about their own experience than the patient experience (Figure 2.5).

Figure 2.5

Participants' Reported Feelings about AAC across Patient and Clinician Experiences
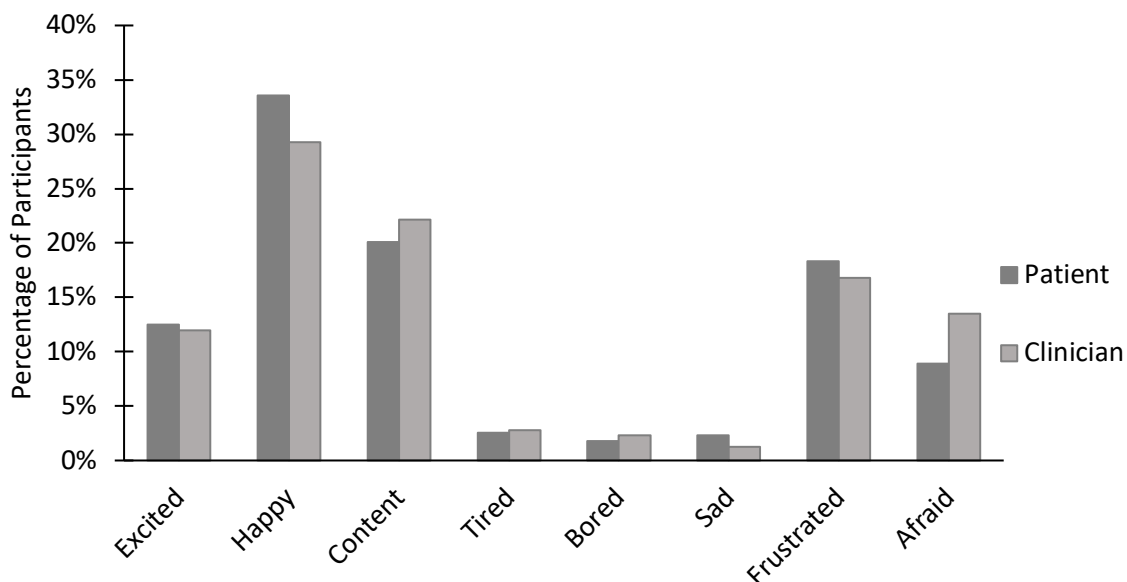
Barriers

Participants reported barriers to AAC service provision in three primary categories: work

settings, resources, and AAC systems. The work setting and AAC system primary categories were

characterized by two possible outcomes, whereas the resource category included three possible

outcomes. For each primary category, participants selected one barrier or wrote a unique response in

the text entry box. With respect to the work setting, SLPs reported both caseload (61.0%, 244 of 400)

and workplace (24.3%, 97 of 400) barriers to practice. Fifteen percent (59 of 400) of participants'

responses were characterized as other barriers. Barriers reported in the "other" category included: (a)

communication partner understanding, buy-in, carryover, and perceived value for AAC modalities (4.8%,

19 of 400), (b) the funding process and funding availability (2.5%, 10 of 400), (c) availability of aided AAC

modalities (1.8%, 7 of 400), (d) time for collaboration, documentation, and other duties (1.5%, 6 of 400),

(e) limited knowledge from pre- or post-professional training (0.8%, 3 of 400), (f) lack of collaboration (0.5%, 2 of 400), (g) service delivery models (0.3%, 1 of 400), and (h) professional philosophy (0.3%, 1 of 400). Some participants were unable to identify one primary work setting barrier to AAC service provision, either due to multiple barriers (1.5%, 6 of 400), no barriers (0.8%, 3 of 400), or lack of understanding of the response task (0.3%, 1 of 400). Overall, participants' other work setting barriers mirrored subsequent survey items related to primary barriers, including resource and AAC system barriers.

Resource barriers included time (53.3%, 213 of 400), financial resources (26.8%, 107 of 400), support (17.8%, 71 of 400), and other barriers (2.3%, 9 of 400). Other barriers included (a) communication partners' buy-in, knowledge, and availability (0.8%, 3 of 400), (b) SLPs' own knowledge of when and how to use AAC (0.3%, 1 of 400), and (c) lack of technology (0.3%, 1 of 400). Three participants (0.8%) reported a combination of time, financial resource, and support barriers to AAC service provision.

More than half of SLPs (52.6%, 210 of 399) identified knowledge as their most significant AAC system barrier to clinical practice. Thirty-nine percent of SLPs (157 of 399) identified availability as their most significant AAC system barrier, characterized by the availability of technical support, AAC systems, and AAC training and CE. Eight percent (32 of 399) of participants reported other primary barriers within the category of AAC systems. Other barriers included (a) communication partner buy-in, knowledge, and carryover (3.5%, 14 of 400), (b) time to program, train, troubleshoot, and complete documentation (2%, 8 of 400), (c) funding (0.5%, 2 of 400), (d) access to an assistive technology specialist (0.3%, 1 of 400), and (e) confidence (0.3%, 1 of 400). One participant (0.3%) reported a combination of knowledge and availability hindered AAC service delivery. Five participants (1.3%) reported no AAC system barriers to service delivery. These results support Hypothesis 1.2. Speech-language pathologists identified caseload, time, and knowledge as primary barriers to AAC service delivery.

Learning Preferences

Speech-language pathologists reported plans and preferences for AAC-related CE. Using a 5-point Likert scale (1 is lowest, 5 is highest), SLPs reported agreement for personal benefit and plans to engage in future AAC-related post-professional training. More than ninety percent of speech-language pathologists (92.73%, 370 of 399) agreed that they would benefit from AAC-related training and CE. Over eighty percent (81.2%, 324 of 199) agreed that they plan to engage in AAC-related training and CE.

Participants selected up to three responses to indicate preferences for AAC-related CE topic, format, and dosage. Speech-language pathologists reported a preference for AAC-related training with an intervention topic (82.71%, 330 of 399). The majority of speech-language pathologists did not report a preference for AAC-related training with the topics of communication modalities (49.12%, 196 of 399), evaluation (46.62%, 186 of 399), and collaboration (28.82%, 115 of 399). Participants preferred for this training to be delivered via course (77.83%, 309 of 397) and virtual (67.51%, 268 of 397) formats. Less than half of participants preferred an interactive format for AAC-related training and CE (49.12%, 195 of 397). Only 12.34% of SLPs reported preferences for a written format (49 of 397). Learning preferences for AAC-training dosage included both massed (69.52%, 276 of 397) and distributed (51.39%, 204 of 397). Conversely, the majority of SLPs did not report preferences for on-the-spot (46.60%, 185 of 397) or interactive guide (38.54%, 153 of 397) dosages.

The hypothesis is partially supported as SLPs did report preferences for AAC-related training and CE with an AAC intervention topic. However, most participants did not prefer an interactive format and on-the-spot dosage for their post-professional training.

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Discussion

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Summary

This study investigated the current state of AAC service provision as reported by post-professional SLPs. Based on the SLPs who responded, the survey revealed SLPs do work with individuals

unable to meet communication needs with unaided modalities alone. However, SLPs' caseloads are not characterized solely by individuals using AAC modalities or receiving AAC interventions. Therefore, the majority of SLPs are not practicing as AAC specialists, but as general practitioners. Despite working with fewer individuals using AAC modalities, general practitioners often spend more time preparing to serve individuals using AAC modalities than SLPs working as AAC specialists (Dietz et al., 2012). This preparation may occur off the clock during unpaid time (Iacono & Cameron, 2009).

Improvements to preprofessional education are not currently reflected among the practicing work force, characterized by inconsistent reports of participation in dedicated AAC coursework. These results are consistent with graduate programs' reports of lack of student preparation (R. K. Johnson & Prebor, 2019). Without laboratory instruction with operational competency requirements and the provision of clinical clock hours in AAC, students are not adequately prepared for competent and confident AAC service provision. To achieve this, preprofessional programs must provide adequate opportunities for diverse experiences with AAC and individuals with complex communication needs across clinical settings (Soto et al., 2001).

Service Delivery

Knowledge

Speech-language pathologists identified relative strengths in the areas of general AAC intervention and AAC intervention with a focus on language, all AAC modalities, collaboration with professionals, families, and caregivers, and access to AAC-related training. However, lack of perceived knowledge in aging and end of life interventions, as well as programming and maintenance of AAC systems reflects lack of AAC-related preprofessional instruction across the lifespan and operational skill competencies respectively. Disparities are also evident between SLPs' lack of perceived knowledge and areas of service provision with a growing body of evidence, including literacy interventions and AAC evaluations (e.g., Erickson & Koppenhaver, 2020; Light & McNaughton, 2012a). These results suggest

information other than general and language-focused AAC interventions, AAC modalities, and

collaboration is adequately disseminated to SLPs engaging in AAC service provision. Resources tailored

to areas of perceived lack of knowledge include RERC on AAC webcasts (https://rerc-

aac.psu.edu/dissemination/webcasts/), the AAC Learning Center Moodle (https://aac-learning-center-

moodle.psu.edu/), the AAC in the Cloud conference (https://www.aacconference.com/), and the Quality

Indicators for Assistive Technology Services (QIAT) Listserv (https://qiat.org/).

AAC Use

Use of AAC modalities during service provision varied greatly across clinical populations. This

variation mirrors differences in AAC use across clinical practice settings. Speech-language pathologists in

the medical setting report use of AAC modalities with patients accounts for only 3% of service provision

time (American Speech-Language-Hearing Association, 2019). In the educational setting, more than 60%

of SLPs regularly work with individuals using AAC modalities (American Speech-Language-Hearing

Association, 2020). These differences indicate a distinction in integration of AAC modalities during

service provision across practice settings. Differences in use may suggest limitations in the availability of

AAC modalities across practice settings. Changes in use, however, are of note when considering the

ethical responsibility of the SLP to provide adequate professional services (American Speech-Language-

Hearing Association, 2016a) and honor patients' right to communicate (Brady et al., 2016) regardless of

patient communication modality.

Feelings

Speech-language pathologists' general feelings about AAC with respect to the patient

experience mirrored their experiences as the clinician. However, responses varied with respect to

pleasantness and intensity, reflecting differences among speech-language pathologists' feelings about

AAC. Implicit biases toward individuals using AAC impact clinical decisions and behaviors (Arora, 2017).

Speech-language pathologists are involved in increasing the value for AAC modalities through

"successful and substantive" (J. M. Johnson et al., 2006, p. 95) instances of use, leading to the long-term use of AAC modalities (J. M. Johnson et al., 2006). This includes addressing family, professional, and society attitudes (S. Baxter et al., 2012; Iacono & Cameron, 2009) and myths (Romski & Sevcik, 2005) about AAC and individuals using AAC. Speech-language pathologists' implicit biases may present as low expectations, provision of inappropriate communication modalities, and lack of adequate communication opportunities and intervention.

Barriers

In the current study, SLPs reported knowledge, caseload, and time as primary barriers to AAC service provision. To equip SLPs for AAC service provision, knowledge barriers can be addressed through adequate pre- and post-professional training. This training includes both instructional and hands-on experiences across competency areas to improve SLPs' knowledge and skills related to AAC service delivery.

To adequately address caseload and time barriers to AAC service provision, however, policy and practice changes are needed. Speech-language pathologists are delivering AAC services with "less money for materials, less staff, larger caseload sizes, more responsibilities, and less time" (Alant et al., 2012, p. 178). These demands of lack of time, large caseloads, paperwork requirements, and lack of funding impede SLPs' use of evidence-based practices (Fulcher-Rood et al., 2020). Speech-language pathologists' identification of caseload barriers reflects the over 60% of SLPs in health care settings with productivity requirements (American Speech-Language-Hearing Association, 2019) and 79% of educational SLPs using a caseload approach (American Speech-Language-Hearing Association, 2020). Without the patient present, non-billable services do not count toward productivity requirements for 69% of SLPs in medical settings (American Speech-Language-Hearing Association, 2019). For AAC service provision, these non-billable components are important for effective collaboration and communication with other AAC stakeholders.

Time and support are necessary to facilitate effective collaboration, a necessary component to AAC service provision (Chung & Stoner, 2016; Kent-Walsh et al., 2008; Soto et al., 2001). With adequate support, SLPs navigate the complex dynamics between multiple care providers and members of the interprofessional AAC team (Dietz et al., 2012). This teaming promotes the provision of quality AAC services and encourages support within the team (Batorowicz & Shepherd, 2011). Additional time may also contribute to SLPs' engagement in mentorship (Assistive Technology Industry Association, 2017), regular supervision, and formal continuing education (De Bortoli et al., 2014), therefore addressing knowledge barriers to AAC service provision.

Continuing Education

The need for and desire for robust AAC training is well-documented (Amundsen, 2014; Dietz et al., 2012; Kent-Walsh et al., 2008; Marvin et al., 2003; Matthews, 2001; McNaughton et al., 2008; Sutherland et al., 2005). Speech-language pathologists identifying as AAC specialists have reported extensive participation in AAC-related training beyond preprofessional instruction (Dietz et al., 2012). Current post-professional AAC-related training does not adequately address the training needs of SLPs across clinical practice settings, experience levels, and patient populations. At the post-professional level, evidence-based continuing education must be developed to reflect SLPs' preferred topics, formats, and dosages. This specifically includes training to work with patient populations that lack consistent exposure to AAC modalities and interventions: (a) individuals with swallowing, fluency, and voice and resonance disorders, (b) individuals receiving services in medical settings, and (c) aging and end of life populations. Speech-language pathologists' lack of knowledge and use of AAC modalities across patient populations and the human lifespan contributes to a lack of ample mentorship opportunities for new clinicians to engage in on-the-job learning with seasoned mentors. With thorough consideration of SLPs' strengths and weaknesses related to AAC service provision, post-professional AAC-related CE and training can be tailored to these specific needs, therefore increasing the use of AAC modalities during

service provision across patient populations.

Conclusion

Despite documented advancements in ASHA certification standards, increased preprofessional coursework, and AAC-specific evidence-based practices and technology, post-professional SLPs continue to report lack of perceived knowledge related to AAC service delivery, inconsistent use of AAC modalities, and persistent barriers to AAC service provision. These characteristics reveal the lack of systematic, organizational, and informational mechanisms to support SLPs as vital members of the AAC team. To effectively manage heterogeneous patient populations, demands for collaboration, and changing technologies (Dietz et al., 2012), SLPs require time and support to increase their capacity to deliver AAC services. Further, AAC-related training and CE must reflect their daily practice, learning needs, and preferences.

This study reiterates the significance of Beukelman and Light's (2020) opportunity barriers of policy, practice, knowledge, skill, and attitude on the participation of individuals using AAC modalities. In addition to considering these barriers with respect to other communication partners and environments, SLPs must be aware of opportunity barriers during their own AAC service provision. Consideration of opportunity barriers will increase communication opportunities, therefore increasing the success of AAC interventions (Beukelman & Light, 2020).

Limitations

This study primarily used virtual correspondence to recruit participants. Despite dissemination to SLPs from varying practice settings, respondents predominantly worked with children in the educational setting. Participation required time and internet access to complete the survey. This may have resulted in a selection bias, inhibiting the participation of SLPs without time and internet access to complete the survey. The time to complete the survey may have contributed to the 74.15% completion rate. This study was also limited by its survey methodology. The survey instrument was created for the

purpose of this study with no prior use. The survey settings prevented multiple survey completions on

the same device. However, due to the method of recruitment, it is unknown whether participants with

submitted incomplete surveys later completed the survey in its entirety on a different device. It relied

on participants' self-report to identify and analyze knowledge, use, barriers, and learning preferences.

Perceptions of knowledge and use may not be accurate reflections of the participants' true

competencies and capacity for AAC service provision.

Future Research

Future research is necessary to expand this study and further evaluate AAC service provision.

Evaluation of preprofessional instruction is necessary to determine the specific attributes of didactic

coursework, laboratory experiences, and hands-on training that are most significant to the mastery of

introductory-level AAC intervention competencies. Investigation is also warranted to identify the specific

clinical competencies required for AAC service delivery in specific practice settings. Additional

information about the use of AAC modalities across patient populations is necessary to understand the

knowledge and skill needs of clinicians. This information can be used to steer the development of AAC-

related training to meet the needs of SLPs. Detailed analysis of adult learning principles, learning needs,

and AAC-related competencies with respect to implementation science is recommended for the

advancement of SLPs' AAC service provision.

CHAPTER THREE

CAREGIVERS' PERCEPTIONS OF INTERVENTION BARRIERS AND FACILITATORS TO AUGMENTATIVE AND ALTERNATIVE COMMUNICATION USE BY SCHOOL-AGED CHILDREN: A QUALITATIVE METASYNTHESIS

Introduction

Effective augmentative and alternative communication (AAC) assessment and intervention depends on a team of AAC professionals and stakeholders (Beukelman & Light, 2020; Binger et al., 2012; Mandak et al., 2017; Moorcroft et al., 2019b). Each AAC stakeholder is tasked with different responsibilities to fulfill the ultimate goal of effective AAC evaluation and interventions (Beukelman & Light, 2020). Speech-language pathologists, guided by a specific scope of practice and ethical guidelines (American Speech-Language-Hearing Association, 2016a, 2016b), support an individual using AAC in a different capacity than family members. Unlike some professional AAC stakeholders, family members fill a long-term role (Beukelman & Light, 2020). For a child using AAC, caregivers (i.e., parents, family members, and legal guardians) serve as "teachers, playmates, technical support personnel, and advocates" (McNaughton et al., 2008, p. 53) on behalf of the child using AAC. Caregivers are key decision-makers for AAC interventions, filling the critical role of "system selection, introduction and implementation" of AAC (Goldbart & Marshall, 2004, p. 194).

Caregivers' Perceptions of Aided AAC Modalities

Past research has thoroughly established caregiver's perceptions of specific AAC modalities. Caregivers' perceived strengths of AAC modalities, including vocabulary options, ease of programming, and the flexibility for games and other activities, facilitate integration of AAC modalities into daily life with their child (O'Neill & Wilkinson, 2020). However, the lack of intuitive characteristics, physical features, and inefficiencies of aided AAC systems inhibit integration into daily life (O'Neill & Wilkinson, 2020). Use is effortful, complicated further by technical breakdown and barriers to access (McNaughton et al., 2008). As a result, caregivers expect improvement of AAC systems over time (Borg et al., 2015;

Singh et al., 2017).

Service Delivery Models

Traditional direct service delivery models are designed to target discrete, measurable skills in

individuals using AAC (Light & McNaughton, 2015). Interventions with a traditional service delivery

model target communicative competencies, including linguistic, operational, and social competencies,

with limited generalization outside of a therapeutic setting (Light, 1989, 2003; Light & McNaughton,

2014, 2015). Research reflects the limitations of this service delivery model, characterized by lack of

family-centered and culturally-sensitive service provision (Mandak et al., 2017; Moorcroft et al., 2019b;

Parette et al., 2001). AAC service provision is further complicated by the limited availability of

professional members of the AAC team with the expertise, knowledge, and skills to provide adequate

services (Amundsen, 2014; Assistive Technology Industry Association, 2017; De Bortoli et al., 2014; Kent-

Walsh et al., 2008; Marvin et al., 2003; Sutherland et al., 2005). As a result, few AAC interventions

extend into naturalistic settings (Light & McNaughton, 2015).

Due to these factors, service provision for individuals using AAC increasingly reflects the training

and participation of stakeholders (Ogletree, 2012, p. 151). Consideration of both parties in indirect

service delivery models reflects the dual process of communication with success dependent not only

upon the communicative competence of the individual using AAC, but the communication partner as

well (Kent-Walsh & McNaughton, 2005; Pino, 2000). Indirect service delivery, including communication

partner intervention, targets the skills and ability to provide support during interactions with individuals

using AAC (Shire & Jones, 2015). It aims to address negative communicative patterns, such as control of

conversational turns, use of closed questions, interruptions, and a heightened focus on the AAC

modality rather than the individual using AAC (Blackstone, 1999; Kent-Walsh et al., 2015; Light et al.,

1985a, 1985b). Current communication partner interventions address the capacity, knowledge, and

skills of a variety of communication partners, such as educators, therapists, and caregivers (Kent-Walsh

et al., 2015; Shire & Jones, 2015).

Study Objectives and Research Goals

Caregivers are critical in the provision of reliable and natural communicative opportunities for children using AAC. Thus, solely addressing the communication needs of the child without explicit consideration for family needs does not result in an effective communication solution (O'Neill, 2019). Past research has thoroughly established caregivers' perceptions of AAC modalities and the quantity and quality of professional support. However, with an increase in the availability of AAC modalities and services, as well as the dispelling of AAC-related myths (Romski & Sevcik, 2005), current evidence related to the implementation of family-centered AAC services to match family goals, needs, and priorities is limited (Mandak et al., 2017).

Specifically, with an increased drive for the involvement of caregivers in the implementation of AAC interventions, caregivers' perceptions of AAC interventions remain largely unexplored. Relevant literature is predominantly characterized by small sample size or quantitative research methodologies with the use of open-ended questions for caregiver perceptions as a mechanism of external validity. Systematic review of the research is necessary for thorough understanding and interpretation of caregivers' perceptions. The purpose of this study is to answer the research question: What are intervention barriers and facilitators to AAC use by school-aged children as perceived by parents, guardians, and caregivers?

<div align="center">**Method**</div>

Research Design

Relevant data are often obtained through qualitative inquiry, which offers the flexibility to capture the complexity of a targeted phenomenon through a variety of data collection and analysis methods. As a result, qualitative metasynthesis was identified as the most appropriate method for systematic search and analysis of the relevant body of literature. This research method is appropriate to

inform both policy and practice (Thomas & Harden, 2008). Qualitative metasynthesis is not merely an aggregation of data, nor a narrative review (Grant & Booth, 2009; Thorne et al., 2004). Rather, qualitative metasynthesis serves to advance science through an emphasis on interpretation of the existing literature (Finlayson & Dixon, 2008; Thorne et al., 2004). This method of review reflects more than the sum of original parts (Thorne et al., 2004).

A qualitative metasynthesis was completed by determining specific search criteria, searching literature, appraising methodological quality, and conducting an analysis. This was completed with a constructivist approach. The constructivist approach was selected to reflect the individual's ability to construct meaning and truth (P. Baxter & Jack, 2008; Mack, 2010). With a constructivist approach, the researchers aimed to understand versus explain experiences (Mack, 2010).

Researcher Descriptions

The researchers involved in this study approached this qualitative metasynthesis with varying experience working with individuals using AAC and their caregivers. Three of the four researchers involved in this work are speech-language pathologists certified and credentialed by the American Speech-Language-Hearing Association. The remaining researcher is a speech-language pathology graduate student. To manage prior understanding and assumptions, engagement with the research team and peer debriefing was consistently used as a mechanism to reflect upon data, emerging themes, personal experiences, and expectations.

Search Criteria

Included studies met the following inclusion criteria: (a) research question related to reading, writing, and communication interventions using assistive technology (AT) and AAC, (b) contain the caregiver perspective of intervention barriers or facilitators of a child's AAC use, (c) child participants are between 4 – 22 years, (d) use qualitative methodology, (e) available in English as a full-text, and (f) published since 2000. Exclusion criteria are: (a) child participants younger than 4 years or older than 22

years, (b) full text unavailable in English, and (c) published prior to 2000. Caregivers were defined as parents or legal guardians responsible for the caregiving of a child using AAC. Due to the heterogeneity of educational and medical diagnoses among children using AAC (Dietz et al., 2012; Light et al., 2019), it was deemed appropriate to identify all relevant literature to allow for differences in caregivers' perspectives and experiences.

Search Procedures

A comprehensive search strategy was used to systematically search all existing research. Key terms were identified related to the guiding question and targeted population. Search terms included: ((parent) OR (caregiver) OR (guardian)) AND (("augmentative and alternative communication") OR ("assistive technology") OR ("complex communication needs")) AND ((feelings) OR (views) OR (experiences) OR (perspectives) OR (report) OR (rate) OR (survey) OR (impression) OR (knowledge) OR (identify) OR (perception)). Searches were conducted in PubMed, CINAHL Plus with Full Text, EBSCOhost Education Source, EBSCOhost Child Development & Adolescent Studies, SpeechBite, PsycBite, EBSCOhost Academic Search Complete, JSTOR, EBSCOhost Psychologist and Behavioral Science Collection, EBSCOhost PsycInfo, ERIC, Pearson Evidence-based Practice Briefs, and the Cochrane Database of Systematic Reviews. In addition, hand searches were completed of reference lists, as well as systematic reviews and meta-analyses of related populations.

The search was conducted in July 2020 and screening occurred in August through October 2020. Two reviewers consistently assessed titles, abstracts, and full-text articles for inclusion. When disagreements occurred, a third reviewer evaluated the applicable title and abstract or full-text article to determine inclusion. The search sequence is reported in Figure 3.1.

Figure 3.1

Flowchart for Systematic Search Completed in July 2020

```
┌─────────────────────────────────┐        ┌─────────────────────────────────┐
│ Records identified from:        │───────▶│ Duplicates excluded             │
│     Databased (n = 2503)        │        │ (n = 806)                       │
│     Hand search (n = 25)        │        │                                 │
└─────────────────────────────────┘        └─────────────────────────────────┘
              │
              ▼
┌─────────────────────────────────┐        ┌─────────────────────────────────┐
│ Records screened by title and   │───────▶│ Excluded based on title and     │
│ abstract                        │        │ abstract                        │
│ (n = 1722)                      │        │ (n = 1676)                      │
└─────────────────────────────────┘        └─────────────────────────────────┘
              │
              ▼
┌─────────────────────────────────┐        ┌─────────────────────────────────┐
│ Full-text articles assessed     │───────▶│ Full-text articles excluded     │
│ (n = 49)                        │        │ (n = 44):                       │
│                                 │        │                                 │
│                                 │        │ Population (n = 28),            │
│                                 │        │ Unrelated research question     │
│                                 │        │ (n = 9),                        │
│                                 │        │ Non-qualitative methodology     │
│              │                  │        │ (n = 4),                        │
│              ▼                  │        │ Caregiver data combined with    │
┌─────────────────────────────────┐        │ other AAC stakeholders' data    │
│ Eligible studies for inclusion  │        │ (n = 3)                         │
│ (n = 5)                         │        └─────────────────────────────────┘
│                                 │
└─────────────────────────────────┘
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Data Analysis

Two coders completed data extraction and analysis for all included studies. To extract relevant data, the results and conclusions related to caregivers' perceptions from the five included studies were extracted and imported into Microsoft Excel for analysis.

Thematic analysis was used to identify, analyze, and report patterns in the data (Braun & Clarke, 2006). This analytic strategy was selected due to the specificity of the process and rigor of the phases, as well as its flexibility to achieve the interpretive goal of qualitative metasynthesis (Finlayson & Dixon, 2008; Thorne et al., 2004). The thematic analysis process is characterized by six phases executed in a

recursive process (Braun & Clarke, 2006). In Phase 1, familiarization occurred through immersion and repeated reading with an active search for meaning and note taking. Phase 2 included the generation of initial codes for single sentence units of data with systematic attention to each aspect of the data. During this phase, the generation of codes was data-driven, reflecting the inductive purpose of this metasynthesis. Beginning with one randomly selected study, the two coders independently generated latent codes, resulting in the identification of ideologies rather than summaries (Braun & Clarke, 2006). Through discussion, the two coders then achieved consensus and generated an initial codebook. The two coders then independently coded the remaining data from the remaining four studies, using discussion to achieve coding consensus. During Phase 3, the coders generated themes and subthemes by sorting and collating of codes. A thematic map was also generated. Phase 4 included the refinement of themes in two steps. First, coded data extracts were reviewed for relevance and appropriateness for a given theme. Second, review of the entire data set occurred to determine the accuracy of the themes' representation of the data set. In Phase 5, themes were defined and named through a detailed analysis, specifying how the theme fit into the data set. Evidence has been reported in this manuscript as specified by Phase 6.

To increase trustworthiness and the overall rigor of the study, peer debriefing and discussion was consistently used to resolve disagreements between coders, track findings, and note impressions. Each coder maintained a reflexive journal for bracketing and recording of impressions, preconceptions, and ideas throughout the research process to increase credibility (Shenton, 2004; Tufford & Newman, 2010). The research rationale and procedure was also consistently documented to increase dependability and confirmability of these findings (Shenton, 2004).

Results

Description of Included Studies

The five studies included in this qualitative metasynthesis are characterized by variable methods

of qualitative data collection, data analysis, and number of caregiver participants (Table 3.1).

Table 3.1

Summary of Studies Included in Qualitative Metasynthesis

	Method of Data Collection	Method of Analysis	Number of Caregiver Participants
Marra & Micco (2019)	Pre- and post-training questionnaire	Not reported	1
Pickl (2011)	Observation, informal conversations, emails, memos, and semi-structured interviews	Strauss & Corbin (1990) grounded theory analysis	12
Serpentine et al. (2011)	Interview	Step 1-4 of McNaughton et al. (2001) five-step analysis	10
Travis & Geiger (2019)	Semi-structured interview	Thematic content analysis	2
Wadnerkar et al. (2012)	Not reported	Not reported	1

Quality Assessment

The included studies were evaluated using the Critical Appraisal Skills Programme (CASP) qualitative study quality appraisal tool (Critical Appraisal Skills Programme, 2018). This tool was selected due to wide use in comparable literature (Butler et al., 2016; Ferrer et al., 2014; Moorcroft et al., 2019b). Prior to independently assessing quality for the five included studies, two raters completed quality assessment using the CASP for one excluded study with similar methods. Nine of the ten CASP items were appraised using a "yes," "no," or "can't tell" response. The last item was appraised with a dichotomous "yes" or "no" response. Raters' independent responses were discussed until consensus was achieved (Table 3.2).

Table 3.2

Quality Appraisal of Studies Included in Qualitative Metasynthesis

	Pickl	Marra & Micco	Serpentine et al.	Travis & Geiger	Wadnerkar et al.
1. Was there a clear statement of the research?	Y	Y	Y	Y	Y
2. Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y
4. Was the recruitment strategy appropriate to the aims of the research?	Y	N	Y	CT	N
5. Was the data collected in a way that addressed the research issue?	Y	N	Y	CT	N
6. Has the relationship between researcher and participants been adequately considered?	Y	N	CT	N	N
7. Have ethical issues been taken into consideration?	Y	N	CT	N	CT
8. Was the data analysis sufficiently rigorous?	CT	N	CT	N	N
9. Is there a clear statement of findings?	N	N	Y	CT	N
10. How valuable is the research?	Y	N	Y	N	N

Note. CT = Can't tell; N = No; Y = Yes.

Results of Included Studies

Multifaceted

Caregivers' perceptions of AAC interventions for their children are complex, nuanced, and on a fluid continuum. AAC interventions are introduced and applied to multiple contexts, communication modalities, and communication partners. Caregivers navigate overlapping interventions across a wide scope of therapies and sources of information. Therefore, caregivers' perceptions of intervention barriers and facilitators to AAC use by school-aged children cannot be reduced to a strict dichotomy. Serpentine et al. (2011) identified this complexity in caregivers during interviews about communication

intervention decision-making. They reported, "…parents recognized various reasons for adding or discontinuing communication interventions rather than all identifying one or two consistent reasons" (Serpentine et al., 2011, p. 228). As a result of these complexities, four guiding characteristics were identified as primary influencers on AAC interventions and use of AAC modalities by school-aged children: relationships, intervention implementation, caregiver aspects, and resources.

Relationships

Meaningful relationships are a foundational step for AAC intervention and serve as the avenue for shared understanding of values, priorities, and needs. In the absence of meaningful relationships, caregivers lack support and communication with other AAC stakeholders. The impact of relationships is evident in caregivers' descriptions of support networks, value for connection, and collaborative partnership.

Support network. Support networks offer feelings of camaraderie versus isolation for caregivers of children using AAC. This support is often sought from other parents of children with disabilities, who are trusted sources of information due to the sharing of similar experiences, such as shared culture or child diagnosis. These support networks inform caregivers' general knowledge of AAC interventions, as well as influence caregivers' perceptions and experiences with AAC interventions. One parent reported, "he typically first learned of approaches 'most from other parents'" (Serpentine et al., 2011, p. 225). A knowledgeable and understanding support network facilitates AAC use through the sharing of information and experiences with AAC interventions. Support considerations are also evident with caregiver's own family members. While navigating AAC introduction and use, caregivers report, "You are always alone when you fight for something, or when you have to decide something. Sometimes you are even alone within your own family" (Pickl, 2011, p. 238). Without this support, caregivers are tasked with independently navigating AAC decision-making, as well as implementation of AAC in

naturalistic settings. Despite the importance of support networks, a disparity is observed

between the desire for a sense of community and caregivers' participation in that community.

Across the five reviewed studies, the cause of this disparity remains inconsistent.

Value for connection. Caregivers consistently value human connection in the delivery of AAC

interventions. With the service providers, this includes a sense of acceptance, understanding,

and mutual respect. Shared connection between the caregiver and service provider results in

the mutual participation and investment in the AAC intervention, facilitating more successful

AAC buy-in and use. Caregivers also appreciate AAC interventions that facilitate interaction

between themselves and their child. Interventions that prioritize the expression of feelings,

building of friendships, and development of meaningful interactions are preferred due to the

resulting connection between the caregiver and child, as well as the child and the world. In

response to a mother's experience with a video interaction guidance intervention, Wadnerkar et

al. (2012) reported, "Rather than seeing communication as a send/receive act of transmission,

we can also understand communication at a more fundamental level – it is the central energy

that binds humans into relationships of trust and security" (Wadnerkar et al., 2012, p. 95).

Interventions that are designed to target these skills are commensurate with caregivers'

prioritized value for connection.

Collaborative partnership. In addition to the appreciation for support and connection,

caregivers seek AAC intervention with collaboration between AAC stakeholders. This leads to a

mutual benefit of both the caregiver and service provider and therefore, the child using AAC.

Engagement in a collaborative partnership allows for contextually-sound AAC intervention

recommendations and feedback. It emphasizes understanding an individual's communication

needs before a service provider attempts to recommend an intervention. Collaboration is not

always complex, but serves as a welcoming invitation for the sharing of culture, tradition, and

expertise. Following interviews with 12 caregivers of children using unaided and aided AAC

modalities, Pickl (2011) reported, "One mother appreciated especially the possibility of being

able to send her homemade food to school, because her child preferred it to traditional Austrian

food" (Pickl, 2011, p. 236).

Intervention Implementation

The use of AAC is facilitated by AAC interventions that reflect family and user priorities. Interventions

must not only reflect the child using AAC, but are tailored to each family's specific needs and goals.

Components of the intervention include AAC integration, individualized approaches, family dynamics,

contextual application, language acceptance, cultural influence, and strength-based models.

AAC integration. Caregivers report the selection and use of AAC modalities must be

individualized for the specific child. The recommended AAC modalities must be robust against

both internal and external constraints, including the child's preferences, funding, and availability

of therapy. The use of AAC modalities requires caregivers' acceptance, as well as their

observation of the child's improvement. Improvements must match caregivers' expectations of

improved language development, behavior, attention, or overall communication. Additionally,

AAC use is facilitated by the explicit involvement of communication partner(s) during AAC

intervention through practice, feedback, and specific goals.

Individualized approach. Individualized approaches are characterized by the identification of

the family's goals, followed by the selection of an AAC intervention to facilitate achievement of

those goals. Marra and Micco (2019) recommended the use of questionnaires and interviews to

identify families' goals to determine the most appropriate AAC interventions. Serpentine et al.

(2011) reported, "It is unlikely that an intervention technique will be "one size fits all," and many

of the available interventions have similar goals (e.g., increased communication)" (Serpentine et

al., 2011, p. 228). To reflect families' goals, service providers are tasked with modifying AAC

modalities, preparing for specific scenarios, and providing opportunities for relevant practice

and feedback across settings. Most importantly, an individualized approach involves the explicit

inclusion of the individual using AAC as a decision-maker.

Family dynamics. Interventions must reflect the complexities of family relationships, attitudes,

and priorities. This includes differing perspectives between family members, such as spouses

and grandparents. One parent in the Pickl (2011) study reported, "My husband just wants him

to talk. He cannot see it as success when our son has learned new signs to tell us something…

For my husband communication is only verbal speech" (Pickl, 2011, p. 238). Consistent use of

AAC is facilitated by interventions that can accommodate differing expectations through

education, disability awareness, and involvement of the family in home carryover.

Contextual application. The use of AAC is facilitated in interventions that explicitly generalize

across environments and communication partners. This involves constant monitoring and

modification as a child's communication skills and opportunities change. One parent suggested

AAC intervention that can go "beyond the routine" (Travis & Geiger, 2010, p. 58) and reflect

varying scenarios, such as "going to the beach" (Travis & Geiger, 2010, p. 58). When AAC

interventions reflect flexibility for AAC use in novel settings and scenarios, caregivers identify

increased opportunities for AAC use.

Language acceptance. An attitude of acceptance for a family's home language(s) is a consistent

prerequisite for the adoption of an AAC intervention and sustained use of AAC modalities. This

includes the service provider's sharing of evidence-based information. One mother, who moved

to Austria, reported in the Pickl (2011) study:

> I was so insecure about what to do when our pediatrician told me to speak German with
>
> my son, because due to his Down syndrome he would be overwhelmed with both
>
> languages… The teacher reassured me that it is perfectly fine when I speak Polish with

him. (p. 237)

AAC interventions must accommodate differing home languages to facilitate the successful use of AAC modalities in naturalistic communication settings. In the absence of language acceptance, AAC interventions do not meet families' needs and therefore, do not facilitate AAC use across communication partners and opportunities.

Cultural influence. Similarly, AAC interventions must adequately integrate with a family's culture, characterized by a web of factors influencing the caregivers' expectations, involvement, trust, attitude, and information. Culture influences the sharing of information and interactions with service providers. A participant in the Pickl (2011) study reported, "In my culture [Pakistan] teachers are absolute authorities; you never question what they are doing. Interfering is not expected and not wanted, any parental input would be completely unusual" (Pickl, 2011, p. 234). Culture also influences caregivers' generation of goals and identified preferences in AAC interventions. For example, "Parents in Hungary viewed communication interventions as avenues to improvement rather than the potential path to a cure" (Serpentine et al., 2011, p. 228). When recommending AAC interventions, service providers must foster an environment in which families' experiences and backgrounds can inform AAC intervention recommendations. This includes responsivity to families' preferred collaboration styles, methods of communication, and long-term goals.

Strengths-based. A strengths-based approach builds from the strengths of the child using AAC, rather than from the magnification of weaknesses. Caregivers identify this as a critical quality that reflects communication modalities that are already successful for the child and family. This approach involves the recognition of nonspeaking communication modalities as equally valuable to spoken communication. It also requires a reframing of intervention away from a medical model, which emphasizes skills individuals cannot do. Regarding her child, B, one caregiver

stated in Wadnerkar et al. (2012):

> The emphasis from the services we have received for so much of B's life have been
> about identifying and trying to address things that B cannot do as well as she (and we!)
> would like. The terms communication impairment, language impaired, etc. have been
> and still are used frequently and clearly cast B's communicative attempts in a negative
> and "sub-standard" light. This medicalization has had a significant impact on all of us. (p.
> 90)

Caregiver Aspects

Caregivers' own background and experiences directly contribute to their perception of the AAC

intervention as helpful, neutral, or hindering for AAC use by their children. These aspects reflect the

ability for interventions to integrate with caregivers' knowledge, attitudes, and experiences. Specifically,

caregiver adaptation, intrinsic expertise, expectations, and the consistency of their experience impact

their perceptions of intervention barriers and facilitators on AAC use by children.

Caregiver adaptation. Caregiver adaptation reflects the constant change in perspective,

aptitude, and rationale based on experiences. These experiences can be formal or informal

mechanisms that result in change for caregivers. For example, through a process of acclimation,

caregivers adjust to a novel experience, such as a new culture or diagnosis. Acclimation differs

with past experiences and exposure. Thus, a caregiver with no prior exposure to an individual

using AAC will have different familiarity, understanding, and informational needs during the

introduction of an AAC modality. Caregivers' experiences serve as the foundation of the views

and attitudes, which inform their decision making and perceptions of AAC interventions.

An AAC intervention's ability to target the development of caregivers' skill also

influences the use of AAC in school-aged children. This process occurs with practice and

feedback, resulting in more knowledge of AAC strategies, increased confidence, and improved

ability to evaluate sources of evidence. In response to a communication partner intervention, one parent reported, "better understanding of how to help him (her son) using his iPad in communication" and using "communication enhancing strategies in conversation and using books to enhance comprehension" (Marra & Micco, 2019, p. 588). When given the tools to do so, caregivers participate as expert AAC stakeholders.

Intrinsic expert. In contrast to learned skills, caregivers have innate expertise related to their child based on intuition and proximity. Regarding communication interventions in Serpentine et al. (2011), one participant said, "I know what he can do, I know his competencies" (Serpentine et al., 2011, p. 227). Based on this intuitive knowledge, caregivers actively seek AAC interventions that align with their intrinsic expertise in the preferences, needs, and abilities of their child. This guides decisions about sustained AAC use, selection and discontinuation of AAC interventions, and steering of a child's long-term treatment.

Expectations. Caregivers define expected outcomes for AAC use for school-aged children. Expected outcomes contribute to selection of AAC modalities, interventions, and short- and long-term goals. High expectations for a child's communicative competence contribute to communication opportunities and therefore, the development of functional communication skills. Setting high expectations is complicated by duality of caregivers' desire for their child to develop verbal speech simultaneous to their presumption of competence and potential in the absence of verbal speech. Differences are observed between caregivers' expectations for the purpose of AAC interventions. Some caregivers expect a cure from a primary diagnosis, such as autism spectrum disorder, rather than better communication (Serpentine et al., 2011).

Consistency of experience. Caregivers' perceptions are influenced by comparison as a result of many unpredictable experiences. This includes inconsistencies across settings, communication partners, sources of information, recommended interventions, expectations, and observed

outcomes. Comparison facilitates AAC use through shared experiences and concerns, such as

when multiple caregivers identify "concerns about their children's difficulty expressing feelings

(e.g., when hurt) and sharing information about their day" (Travis & Geiger, 2010, p. 52).

However, lack of consistency between caregivers, AAC stakeholders, and settings can also inhibit

the use of AAC modalities. It contributes to discontinuity in the use of AAC, differing

expectations for the demands and time associated with a given AAC intervention, or lack of

access to robust AAC modalities and timely AAC interventions.

Resources

Resources reflect the informational and tangible materials that contribute to caregivers' perceptions of

AAC interventions and their ability to facilitate sustained use of AAC modalities by school-aged children.

For caregivers, this requires access to and acceptance of these resources. Caregivers' knowledge of

resources, as well as ability to use them are influenced by other AAC stakeholders (extrinsic experts).

Access to resources. Caregivers require access to adequate resources, training, and tangible

items to engage in AAC interventions. This includes mechanisms to meet informational needs,

such as written materials in a home language, courses to introduce AAC modalities, and training

to integrate AAC in the home setting. Informational needs are met through "(a) professional-

related resources, (b) parent related resources, and (c) public-related resources" (Serpentine et

al., 2011, p. 225). By meeting caregivers' resource needs, caregivers can better participate in

AAC interventions and promote their child's AAC use.

Acceptance of resources. In addition to having access to resources, caregivers must accept a

given resource, training, or tangible item. This is not a one-time event, but an ongoing process

related to personality, culture, cost, age, child characteristics, and anticipated outcomes. True

acceptance of resources also requires in-depth knowledge of alternatives. Serpentine et al.

(2011) reported, "Several of the Hungarian participants in this investigation indicated that they

agreed with the communication intervention recommendations… because they did not know of

any other methods" (Serpentine et al., 2011, p. 227). Through the acceptance of resources,

caregivers' informational and tangible needs are met. This informs their decision-making and

promotes agreement or disagreement with an AAC intervention's ability to meet the child's

needs.

Extrinsic expert. Extrinsic experts serve as gatekeepers between resources and caregivers,

steering AAC interventions and related recommendations. This role is usually filled by staff and

other professional service providers. They demonstrate this expertise through routine

interactions with caregivers and instruction, such as training and workshops. In response to one

form of communication partner training, Marra and Micco (2019) identified increased

understanding of the use of AAC across settings in both a caregiver and child using AAC. To

facilitate the use of AAC by school-aged children, caregivers seek professionals who are

invested, generous with their time, and provide ample information (Pickl, 2011).

Child Outcomes

Anticipated child outcomes serve as the driving force for caregivers' decisions. The four

characteristics identified in this study (relationships, intervention implementation, caregiver aspects,

and resources) are distinctly rooted in an assumption that AAC interventions directly or indirectly result

in change for school-aged children using AAC. This change can include improvements in aided AAC use,

increased confidence and comfort with AAC modalities, increased overall communication, improvement

in comprehension, and the development of conventional behaviors. Changes also include outcomes

identified solely by caregivers, such as the child's contentment and happiness. When caregivers identify

the child's improvement, such as use of a device "more effectively" (Marra & Micco, 2019, p. 588) and

use of communication methods "increasingly more confidently and effectively" (Wadnerkar et al., 2012,

p. 90), caregivers perceive AAC interventions as successful. This contributes to their investment in the

intervention and promotes sustained use of AAC by the child. Caregivers' beliefs about the intervention's ability to impact the child remains the underpinning of each of the four characteristics.

Discussion

This study reveals the complexity of caregivers' roles as key decision-makers for AAC interventions for school-aged children. Caregivers' perceptions of AAC interventions cannot be reduced to a dichotomous list of barriers and facilitators. Instead, caregivers' perceptions of AAC interventions are dependent upon four primary characteristics, relationships, intervention implementation, caregiver aspects, and resources, all with an underlying desire for identifiable change in the child's skills. The four characteristics of this study suggest patient-centered services cannot successfully accommodate caregivers' preferences for AAC interventions to facilitate AAC use by school-aged children. Further, indirect service delivery models which target the capacity, knowledge, and skills of various communication partners do not offer the specificity desired by caregivers in AAC interventions. Instead, caregivers' perceptions of AAC interventions suggest true family-centered AAC services, in which both the child and the family is identified and treated as the client (Cress, 2004), are preferred to facilitate AAC use. This reflects changes across the entire family as a result of the introduction of AAC (Bailey, Parette, et al., 2006; Mandak et al., 2017).

The importance of family-centered AAC service provision is not novel (Mandak et al., 2017). The relevance of family-centered principles for families of children using AAC has been identified and reported for at least two decades (e.g., Cress, 2004; Parette et al., 2000). However, actual AAC service provision practices lack a family-centered approach (Mandak et al., 2017). Lack of true family-centered AAC services is commensurate with the inadequacies in training and teamwork to meet families' needs across interprofessional disciplines (Bailey, Parette, et al., 2006; Crisp et al., 2014; Donato et al., 2014; Goldbart & Marshall, 2004; Gona et al., 2014; Mandak et al., 2017; Singh et al., 2017; Stadskleiv, 2017).

To facilitate use of AAC by school-aged children, relationships, intervention implementation,

caregiver aspects, and resources emerged as key influencers on caregivers' perceptions. Caregivers'

value for meaningful, supportive, and collaborative relationships reflects the significance of caregiver-

professional relationships in family-centered service provision (Dunst, 2002). Relationships with

professionals must steer away from the pressure to adopt a specific communication modality or

intervention (Moorcroft et al., 2019b). Instead, collaborative caregiver-professional relationships must

empower caregivers and build their confidence to fulfill the desired role of leadership of the AAC team

(Bailey, Parette, et al., 2006; Goldbart & Marshall, 2004). Due to caregivers' vital role as their child's

most immediate communication partner (O'Neill & Wilkinson, 2020), exclusion of caregivers on the AAC

team contributes to long-term AAC abandonment (Moorcroft et al., 2019b).

The availability of resources, often given by extrinsic experts on the AAC team, contributes to

the success or failure of an AAC intervention to facilitate the use of AAC. In the absence of adequate

resources, professional members of the AAC team can contribute to AAC abandonment through belief in

now-debunked AAC myths and lack of expertise (Moorcroft et al., 2019b). Family-centered services

emphasize information and resource sharing to facilitate caregivers' informed decision making (Dunst,

2002). This is achieved through a longitudinal process of engagement with a child and family, rather

than solely during the introduction of an AAC modality (Glacken et al., 2019).

Family-centered services are individualized to reflect families' needs and priorities (Dunst,

2002). Caregivers identify specific attributes for the intervention implementation, including responsivity

to family dynamics, culture, communication strengths, and varied communication contexts. Use of an

AAC modality requires an intervention that addresses a gap between the child's communication need

and ability (Moorcroft et al., 2019a). If current communication modalities successfully meet an

individual's communication needs, a novel AAC modality will not be successfully integrated into daily life

(Bailey, Parette, et al., 2006; Hettiarachchi et al., 2019; Moorcroft et al., 2019a). The intervention should

build upon current communication modalities, characterized by a strengths-based approach. At this

time, however, AAC interventions continue to lack a strengths-based model (Light & McNaughton, 2015). Caregivers can identify their child's strengths and weaknesses to inform AAC intervention planning and development of goals (Cress, 2004; Starble et al., 2005).

Interventions must also explicitly reflect communication demands in natural environments and scenarios (Light & McNaughton, 2015). During AAC intervention planning, professional AAC stakeholders require an understanding of communication needs and patterns across all of the child's settings, including school, home, and the community (Beukelman & Light, 2020). Caregivers also report the significance of social relationships between the child using AAC and their communication partners. This emphasizes the social closeness purpose of communication (Light, 1989). Interventions should facilitate these relationships through recognition of the goal of communication as more than behavior regulation (Light & McNaughton, 2015).

Caregivers report successful and sustained use of AAC requires emotional readiness and resilience, as well as consistent time and effort (Bailey, Parette, et al., 2006; Goldbart & Marshall, 2004; Moorcroft et al., 2019a). This metasynthesis reveals the complexities of caregivers' experiences, contributing to their role in seeking or discontinuing AAC interventions to facilitate their child's use of AAC. To best support caregivers, clinicians must integrate the tenets of family-centered services into their own practices. Caregivers identify the adoption of family-centered principles as the mechanism to facilitate the use of AAC modalities by school-aged children.

Limitations

The results of this metasynthesis are limited by the small sample of articles meeting inclusion materials. The body of evidence is characterized by research with a wide array of child participant ages, as well as a primary focus on AAC modalities versus AAC interventions. This study is also limited by the rigor of the included articles. Quality appraisal with the Critical Appraisal Skills Programme (CASP) qualitative study quality appraisal tool (Critical Appraisal Skills Programme, 2018) revealed inconsistent

quality for the included studies, limiting the trustworthiness of this metasynthesis. Additionally, the qualitative metasynthesis methodology has limitations. The product is three times removed from original participants' voices (Gewurtz et al., 2008) as the metasynthesis interprets other researchers' interpretations of participants' experiences. This results in increased susceptibility to the researchers' bias, especially in the absence of specific methods to increase trustworthiness.

Future Research

This area of research requires further investigation using robust and replicable qualitative methods with a continued focus on caregivers' perceptions of AAC interventions rather than AAC modalities. Despite the global lens of this study, it is necessary to expand future research to identify caregivers' perceptions and priorities for AAC interventions across race, ethnicity, cultural background, educational level, and home language. Further, consideration for differing service delivery models will contribute to the development of future AAC interventions, as well as the applicability of current AAC interventions with respect to families' needs.

CHAPTER FOUR

PREDICTORS AND EXPERIENCES OF STRESS IN ADULT CAREGIVERS OF CHILDREN USING

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION: A MIXED-METHODS STUDY

Introduction

For children using augmentative and alternative communication (AAC), AAC modality

recommendations are related to the characteristics of the child, as well as external factors, including

professionals' training and skills, funding, and family support and attitudes (Goldbart & Marshall, 2004).

Caregivers' support, attitudes toward AAC, and implementation of AAC directly contributes to a child's

sustained use of AAC modalities (Moorcroft et al., 2019a). Use of AAC modalities requires extra work,

time, and effort from caregivers, who are already taxed with many other responsibilities and daily

demands (K. L. Anderson et al., 2016; Goldbart & Marshall, 2004; McNaughton et al., 2008; Moorcroft et

al., 2019a; Serpentine et al., 2011). To navigate these challenges, caregivers of children using AAC do

need support (K. L. Anderson et al., 2014; J. M. Johnson et al., 2006; Moorcroft et al., 2019a, 2019b;

O'Neill & Wilkinson, 2020).

For challenges related to the AAC modality, caregivers seek support to implement AAC through

explicit planning, extensive training, and frequent interactions with speech-language pathologists and

other service providers (Moorcroft et al., 2019b). This support is an ongoing need and must continue

beyond the initial introduction of AAC (Glacken et al., 2019; Moorcroft et al., 2019b; Singh et al., 2017).

Caregivers supplement the support from service providers with AAC system vendors, AAC modality

manuals, and support websites (K. L. Anderson et al., 2014). Caregivers struggle with the availability of

community support, characterized by the lack of use of AAC modalities across settings and

communication partners, which contributes to feelings of isolation (Moorcroft et al., 2019b; O'Neill &

Wilkinson, 2020). Caregivers look for support from spouses, online forums, support groups, and

communities of other caregivers of children using AAC (K. L. Anderson et al., 2014; Moorcroft et al.,

2019a, 2019b; O'Neill & Wilkinson, 2020). The absence of support from service providers, family

members, and other AAC stakeholders contributes to AAC abandonment (J. M. Johnson et al., 2006).

The substantial role of family support also emphasizes the dual process of communication, dependent

on both the individual using AAC and the communication partner (Kent-Walsh & McNaughton, 2005;

Pino, 2000). To adequately address family support during AAC introduction and intervention,

consideration for the needs of the entire family, including caregivers, is necessary.

Family Systems Theory

The contextualization of children in a larger unit mirrors the long-established family system

theory. Family systems theory suggests children do not exist in isolation, but rather in the context of a

family system (Minuchin, 1985). Therefore, an understanding of the family system that contextualizes

and envelops the child is necessary (Cox & Paley, 2003; O'Neill & Wilkinson, 2020). With roots in family

therapy, family systems theory was originally applied to the parent-child relationship and the

socioemotional development of children (Cox & Paley, 2003).

Family systems, characterized by a hierarchical structure, include multiple organized

subsystems, including spouses, parents, siblings, grandparents, and extended family members (Cox &

Paley, 1997, 2003; Mandak et al., 2017; Minuchin, 1985; O'Neill & Wilkinson, 2020; Sutphin et al., 2013)

2013). Subsystems are separated by clear, yet flexible boundaries, learned through the process of

repeated family interactions (Cox & Paley, 1997). Each subsystem boundary has its own pattern, which

changes over time based on development or external influences (Minuchin, 1985). Together, integrated

subsystems make up a whole unit, determined to be greater than the sum of its parts, referred to as

wholism (Cox & Paley, 1997, 2003). This unit consists of interdependent elements, indicating that one

cannot consider decontextualized members of the family system without resulting in invalid data

(Minuchin, 1985).

The homeostasis of the family system requires a careful balance in the degree of dependence

between members of the family system (Sutphin et al., 2013). To maintain homeostasis, families

experience adaptive self-stabilization to compensate for changes within the family system, such as

deviations from established patterns (Cox & Paley, 1997; Minuchin, 1985). These adaptive self-

stabilization patterns are non-linear recursive feedback loops in which behaviors in the unexpected

range are controlled with corrective feedback to return to homeostasis (Minuchin, 1985). However,

when the system cannot self-stabilize, family systems respond to external challenges through adaptive

self-organization (Cox & Paley, 1997). External challenges disrupt existing patterns until new patterns

emerge (Cox & Paley, 1997). Though their respective responses may differ, individuals, subsystems, and

families all respond to challenges through adaptive self-organization (Cox & Paley, 2003). Additionally,

even if the challenge does not initiate with a specific member of the family system, all members must

participate in adaptive self-organization (Minuchin, 1985). Though adaptive self-organization can result

in new patterns, the result is not consistently a less vulnerable family system (Cox & Paley, 1997). These

adaptations can result in new patterns with new vulnerabilities, such as increased family rigidity (Cox &

Paley, 1997, 2003; Minuchin, 1985). This reorganization is inevitable in life (Minuchin, 1985). Self-

organization frequently occurs during instances of transition (Cox & Paley, 1997). These transitions can

be normative, such as a child's transition to school, or nonnormative, such as the death of a family

member (Cox & Paley, 1997). Presently, self-organization may reflect transition in families' patterns as a

result of the COVID-19 pandemic.

For families of children using AAC, Mandak and colleagues (2017) proposed the family systems

framework for family-centered AAC services, which integrates family systems theory and ecological

systems theory. This results in the positioning of the interconnected family system in the center of many

interdependent systems (Mandak et al., 2017). Family relationships and life experiences provide a

natural context for development through the earliest and most enduring social relationships across the

lifespan (Pino, 2000). For families of children using AAC, the interdependence between subsystems is

observed in family members' provision of support for children using AAC, as well as family-related

barriers and challenges (Mandak et al., 2017). The family-wide impact of the introduction and provision

of AAC services reflects the wholism property of the family unit (Mandak et al., 2017). Families of

children using AAC may experience different normative and nonnormative transitions than other

families, such as the receipt of a medical diagnosis or the recommendation for an aided AAC modality.

The proposed family systems framework for family-centered AAC services (Mandak et al., 2017)

also reflects the functioning and interaction of families with outside influences, including schools and

communities (O'Neill & Wilkinson, 2020). The ecological systems theory proposes each individual is

embedded in the center a network of interdependent systems, including the microsystem, mesosystem,

exosystem, and macrosystem (Bronfenbrenner, 1979). For a child using AAC, these interdependent

systems represent family members, friends, peers, and community members, as well as the many

service providers involved in the interprofessional AAC team.

Caregiver Stress

Extensive research has demonstrated the significance of caregivers in the communication of

children using AAC (Light et al., 1985a, 1985b, 1985c; Pennington & McConachie, 1999). Past research

has also reported caregivers' negative feelings and experiences of inadequate training from professional

AAC stakeholders (Bailey, Parette, et al., 2006; Borg et al., 2015; Crisp et al., 2014; Donato et al., 2014;

Glacken et al., 2019; Goldbart & Marshall, 2004; Gona et al., 2014; Moorcroft et al., 2019b; Singh et al.,

2017; Stadskleiv, 2017). However, literature related to caregivers' capacity for AAC introduction and

implementation is sparse. With an increased focus on communication partner interventions, this is

necessary for the development of effective interventions with robust treatment fidelity.

Specifically, no research has been identified related to the experience of stress in caregivers of

children using AAC in the last 20 years. Jones, Angelo, and Kokoska (Jones et al., 1999) previously

evaluated parental stress in caregivers of children using AAC modalities. Using the Parenting Stress

Index™ (Abidin, 1995), Jones et al. (Jones et al., 1999) identified only two areas of parental stress outside

of the normal range, characterized by the 80th percentile and above. Both of these areas,

demandingness and acceptability, are couched within the child domain (Abidin, 1995). Demandingness

reflects the child placing demands on the parent (Abidin, 1995). Acceptability is defined as the disparity

between child attributes and the caregivers' expectation (Abidin, 1995). Jones and colleagues reported

all remaining stressors in the child and parent domains, as well as total stress scores fell within the

normal range (Jones et al., 1999). However, further analysis revealed statistically significant differences

between mothers' and fathers' stress scores (Jones et al., 1999). Mothers reported significantly more

stress in the categories of relations with a spouse and depression (Jones et al., 1999). Similarly, mothers

had significantly higher total scores in the parent domain than fathers (Jones et al., 1999). When rating

people and groups' helpfulness to raise a child, fathers in this study reported their spouse/partner and

spouse/partner's parents and relatives as significantly more helpful than the helpfulness reported by the

mother participants (Jones et al., 1999).

　　　While informative, the participants in this study may not be representative of the majority of

families with children who use AAC. Participants were "White, middle class, well-educated, two parent

families from the State of Pennsylvania" (Jones et al., 1999, p. 42). These characteristics, combined with

the substantial changes in the field of AAC in the past 30 years limit the generalization of these findings

to clinical practice today. Further, this study did not identify the contribution of microsystem and

macrosystem factors on caregivers' experiences of stress, such as specific communication modality,

child and family characteristics, and support mechanisms. Since this study was conducted, no additional

research related to stress in caregivers of children using AAC has been identified. Instead, stress has

been studied in caregivers of children grouped by medical and educational diagnosis without specific

emphasis on communication modality (e.g., Arakkathara & Bance, 2019; Silva & Schalock, 2012; Smith et

al., 2001).

Effective interventions require a more complete picture of the multiple influencing elements on child development (Cox & Paley, 1997). For children using AAC, the interprofessional AAC team is unable to make the most appropriate decisions for AAC systems or interventions without awareness of the caregiver experience (Goldbart & Marshall, 2004; Gona et al., 2014). Identification of caregivers' shared and current experiences of stress will inform the delivery of family-centered services through in-depth knowledge of needs, priorities, and supports with a systems approach (Dunst, 2002). With increased understanding of caregivers' experiences and application of the proposed family system framework for family-centered AAC services, analysis of system characteristics may result in the identification of factors that increase or mitigate caregivers' stress. Additionally, with increased understanding of caregivers' experiences, family-centered AAC service provision will include improved collaboration between the interprofessional AAC team and caregivers.

Purpose, Aims, and Hypotheses

The purpose of this research is to investigate experiences and contributing factors of stress in adult caregivers of children using AAC. The proposed study investigated the stress of adult caregivers of children using AAC using mixed methodologies for broader interpretation of findings (Hays & Singh, 2012). This study examines two research questions: (1) Does stress reported by adult caregivers of children using AAC differ depending on characteristics of the family microsystem and macrosystem? (2) What are the shared experiences of stress of adult caregivers of children using AAC? To address these research questions, a constructivist ontological assumption was utilized to emphasize the direct experiences of multiple participants (Mack, 2010). As a result of this assumption, the researcher aimed to understand the experiences of participants versus explain the phenomenon (Mack, 2010). The following aims and hypotheses have been generated:

- Aim 3.1 (Quantitative): Identify differences in level of stress reported by adult caregivers of children using AAC across frequency of aided AAC modality use.

○ Hypothesis 3.1: It is hypothesized that adult caregivers of children with more frequent use of aided AAC modalities will report more stress than adult caregivers of children with less frequent use of aided AAC modalities.

● Aim 3.2 (Quantitative): Identify differences in level of stress reported by adult caregivers of children using AAC across differing microsystem and macrosystem characteristics.

○ Hypothesis 3.2.1: It is hypothesized that adult caregivers of a younger child using AAC will report less stress than those with an older child using AAC.

○ Hypothesis 3.2.2: It is hypothesized that adult caregivers with more family support will have less stress than those with less family support.

● Aim 3.3 (Qualitative): Explore how adult caregivers of children using AAC describe their lived experiences of the phenomenon of stress.

Method

Research Design

Mixed Methods

This research was executed using a mixed method design to explain and contextualize the phenomenon within participants' lived experiences. Mixed methods are characterized by implementation, priority, integration, and theory decisions (Hays & Singh, 2012). This research utilized a sequential explanatory implementation procedure, characterized by initial utilization of quantitative methods, followed by qualitative methods (Hays & Singh, 2012). Quantitative data determined participants' eligibility for further participation in the qualitative data collection. Despite the sequential implementation procedure, equal priority was given to each method to adequately and appropriately address each research question. Following data collection and analysis, quantitative and qualitative data were integrated for broader interpretation of the phenomenon (Hays & Singh, 2012) and to identify areas for future research. The proposed family systems framework for family-centered AAC services

served as the overarching theoretical perspective throughout both the quantitative and qualitative

portions of this study. The tenets of this framework were considered during the study design, including

developing the survey and interview protocol, as well as selecting quantitative predictor variables.

Quantitative

The quantitative portion of this study was exploratory using a non-experimental predictive

correlational design. This design is appropriate to identify relationships and predict outcomes based on

selected variables (Portney & Watkins, 2015).

Qualitative

The qualitative portion of this study was conducted with a phenomenological methodology. This

method is appropriate to examine lived experiences of participants and search for commonalities

related to the phenomenon (Hays & Singh, 2012; Moustakas, 1994; Sundler et al., 2019). In this

approach, there is no objective reality, but only the participants' many perspectives and experiences

(Bevan, 2014). In phenomenological studies, the researcher studies lived experiences from participants'

different perspectives, rather than from a strict theoretical standpoint (Bevan, 2014).

The phenomenological process includes four steps: epoche, phenomenological reduction,

imaginative variation, and synthesis. The epoche process prepares the researcher for new knowledge by

eliminating assumptions and biases (Moustakas, 1994). The researcher uses an open stance to reflect no

preexisting position and a lack of prior understanding of the participants' lived experiences (Brinkmann

& Kvale, 2015; Moustakas, 1994; Sundler et al., 2019). To adequately explore the phenomenon and gain

understanding, the phenomenological method requires the researcher to bracket prior knowledge

(Sundler et al., 2019). This technique brings awareness to the researcher's assumptions, theories, and

preconceptions, as well as facilitates increased transparency and self-consciousness (Bevan, 2014;

Moustakas, 1994; Tufford & Newman, 2010). The resulting openness to the phenomenon and process of

"perceiving, thinking, remembering, [and] judging" (Moustakas, 1994, p. 91) is phenomenological

reduction (Brinkmann & Kvale, 2015; Moustakas, 1994). During horizontalization, each statement receives equal value and consideration (Moustakas, 1994). In the phenomenological reduction phase, researchers generate textural descriptions, the "what" of the experience (Moustakas, 1994).

Imaginative variation uses imagination and multiple perspectives to identify themes in the data (Moustakas, 1994). Imaginative variation develops structural descriptions and the "how" of the experience (Moustakas, 1994). This is used to clarify the phenomenon (Bevan, 2014).

The process concludes with synthesis, characterized by the generation of a statement for the phenomenon (Moustakas, 1994). After this process, the researcher returns to prior literature to summarize and determine the implications of the study (Moustakas, 1994).

Researcher Description

The primary investigator and author is an American Speech-Language-Hearing Association certified speech-language pathologist. She has a clinical background in pediatric speech and language assessment and intervention in outpatient practice settings, working primarily with children using AAC. Related prior clinical and research experiences include the creation and execution of training events and social groups for caregivers of children using AAC. For completion of the qualitative aim of this study, the second coder is a speech-language pathology graduate student. During data collection and analysis, reactions, thoughts, hunches, comments and notes were consistently documented in a reflexive journal to mitigate prior understanding and assumptions, as well as to increase the rigor of the study (Hays & Singh, 2012; Shenton, 2004; Sundler et al., 2019; Tufford & Newman, 2010). Peer debriefing occurred between the two coders through routine meetings where research decisions, discussions, and impressions were documented for the audit trail (Nowell et al., 2017).

Participants

Quantitative

The following inclusion criteria were required for participation in the study. Participants: (a) had

no known speech, language, or hearing impairments, (b) were able to speak, understand, read, and write in English at a level of proficiency for participation in an interview without an interpreter present, (c) currently reside in the United States, and (d) are an adult caregiver of a child who: has AAC needs for communication, uses AAC, is between the ages of 3-9 years, and has a developmental, congenital, or acquired medical or educational diagnosis. Adult caregivers of children using AAC younger than 3 years and older than 9 years were excluded from this study. This age range was selected to reflect the beginning of special education service eligibility under the Individuals with Disabilities Education Act (IDEA) Part B at age 3 years (Individuals with Disabilities Education Act, 2004). As a result, eligible children transition from early intervention services to free and appropriate public education services. This age range also reflects the federal guidelines for the developmental delay diagnosis under IDEA (IDEA, 2004). This age range was selected to reflect the availability of school-based services for children using AAC, as well as the range of educational diagnoses under federal statute.

A power analysis using G*Power (Faul et al., 2007) revealed at least 81 participants were necessary to achieve sufficient power with $f^2 = 0.28$, $p = .05$, $\beta = 0.80$, and 15 predictors. Criterion and chain sampling techniques were used to recruit participants in the quantitative portion of this study. Information about the study was disseminated to pediatric therapy settings (e.g., schools, outpatient clinics, private practices), caregiver networks, AAC stakeholders, pediatricians' offices, preschools, and AAC vendors through social media, email, phone, and direct correspondence.

Qualitative

Participants were recruited for the qualitative portion of the study using stratified purposeful sampling from the participants who completed the quantitative portion of the study. Following quantitative data collection, the quantitative outcome measure distribution was analyzed and divided into deciles. Participants from the first, fifth to sixth, and tenth deciles were selected using a random number generator to participate in qualitative data collection. These deciles were chosen to elicit the

participation of individuals with quantitative outcomes at both extreme tails and the mean of the

distribution, achieving phenomenal variation with respect to the phenomenon of stress (Sandelowski,

1995). The inclusion of participants from high-, mid-, and low-stress group was also used to triangulate

data sources (Shenton, 2004). Five caregivers per stratified group participated in the qualitative portion

of this study. Recruitment of additional participants ceased for the qualitative portion of this study upon

reaching saturation. Due to the use of stratified groups, the largest number within the minimum range

of participants was included to reach informational redundancy (Sandelowski, 1995). Saturation was

determined when all new information confirmed the information shared by prior participants (Hays &

Singh, 2012; Sandelowski, 1995).

Data Collection

Following the approval of the college committee for human subjects research at Old Dominion

University, participants were recruited between December 14, 2020 and April 11, 2021. Informed

consent was obtained from each participant.

Quantitative

Data collection for the quantitative portion of the study used a two-part survey (Appendix B).

Part 1 (46 questions) included 5 distinct sections: consent and participant screening, child demographics,

child and family system resources, family system demographics, and contact information for other adult

caregivers in the family system, if applicable. One response was collected per family system. Part 2 (78

questions) included 6 sections: consent and participant screening, frequency of communication modality

use, caregiver demographics, Parenting Stress Index™ - Fourth Edition (Short Form) (PSI™-4-SF) (Abidin,

2012), perceptions of care team, and Family Support Scale (FSS) (Dunst et al., 1984). The PSI™-4-SF is a

screening tool designed to measure stress in parents of children from 1 month to 12 years (Abidin,

2012). A higher PSI™-4-SF score is indicative of more stress. The FSS was designed to measure social

support across varying systems of support in caregivers (Dunst et al., 1984). A higher FSS score is

indicative of more family support. Part 2 was open for participation for each adult caregiver listed in Part

1 of the survey. Both Part 1 and 2 were administered with Qualtrics (Qualtrics, Provo, UT).

Survey Research. The following are specific methods used to reduce coverage, sampling,

nonresponse, and measurement error during the survey construction and distribution (Lohr,

2008). Study information was disseminated across geographic regions, child populations, and

service providers to recruit an adequate number and variety of participants. Sampling error was

anticipated due to the voluntary nature of this study, potentially resulting in the self-selection of

participants who 1) have children currently using AAC modalities and receiving AAC services, 2)

have time to allot for participation and physical access to the internet, and 3) are embedded in

the disability community through social media pages or current medical, educational, or

therapeutic services. Though this could not be entirely eliminated, sampling error was reduced

through distribution of the study information to multiple AAC stakeholders and limitation of the

time necessary for study participation. Reminder emails and calls were used to decrease

nonresponse error. Contact was personalized, brief, and included pertinent links and contact

information. Measurement error was reduced through the analyses of the psychometric

properties of the existing measures integrated in the online surveys and is later discussed in

detail.

Qualitative

A semi-structured interview was appropriate to integrate the phenomenological approach,

flexibility for participants to share their experiences, and structure to focus on specific topics

(Brinkmann & Kvale, 2015). Data were collected during semi-structured interviews using password-

protected Zoom video conferencing (Zoom Video Conferencing, San Jose, CA) between April 14, 2021

and June 2, 2021. Interviews were 54 minutes – 93 minutes in duration. Notes were compiled during

and immediately following each semi-structured interview (Brinkmann & Kvale, 2015). During data

collection, probes were used as needed throughout each interview (Jacob & Furgerson, 2012). Probes were in direct response to participants' experiences and reflected the researcher's deliberate naiveté (Brinkmann & Kvale, 2015). Probes were also used to clarify and increase participants' specificity related to a given experience (Brinkmann & Kvale, 2015).

Bracketing could not entirely absolve the researcher from some role in the generation of knowledge (Høffding & Martiny, 2016). In phenomenological studies, researchers approach phenomenological interviews with some goal or anticipation of the participants' responses, therefore influencing the research process (Høffding & Martiny, 2016). Interviews are an interactional process, during which knowledge is produced within an interactional context (Brinkmann & Kvale, 2015). During the present study, the researcher maintained awareness of ethical boundaries and the power asymmetry (Brinkmann & Kvale, 2015). Empathy and integrity were necessary due to the sensitive nature of the phenomenon.

Interviews were transcribed verbatim within the Zoom video conferencing software and transcription errors were corrected by the primary researcher. Notations were made during transcription for pauses, hand movements, emphasis, and affect to capture tacit knowledge (Høffding & Martiny, 2016). Following transcription of interviews, each transcript was sent via email to the corresponding participant for member checking (Shenton, 2004). Participants were able to review interview transcripts for a two-week period to confirm the content authenticity (Hays & Singh, 2012; Nowell et al., 2017). Eleven participants did not elect to review transcripts within the two-week period. Four participants reported no revisions to the transcript.

Instrumentation

Quantitative

No comprehensive existing measure was identified related to caregiver stress and support for this clinical population. A 3-stage process, including the developmental, question testing, and dress

rehearsal stages, was used for the development of a 2-part survey (Campanelli, 2008). In the

developmental phase, a review of the literature and surveys used with related populations informed the

background information for the current study (Campanelli, 2008). Questions were constructed to reflect

the proposed family systems framework for family-centered AAC services tenets (Mandak et al., 2017).

Questions were also written to be understood by a variety of participants, characterized by familiar

verbiage, definitions for any technical terms, and clear response tasks (Fowler & Cosenza, 2008). Any

novel verbiage was defined where the information is needed for ease of access (Dillman et al., 2009). In

this development phase, the survey was also sent to the developer of the proposed family systems

framework for family-centered AAC services (Mandak et al., 2017) for feedback. Based on this feedback,

changes were made to improve clarity and question flow.

During the question testing phase, the survey was distributed to four speech-language

pathologists and two occupational therapists across school-based, specialty center, outpatient, and

higher education practice settings. With the exception of the standardized instruments, full drafted

surveys were distributed to question testers during this phase. Feedback and revisions were specific to

the clarity of wording, formatting, spelling, flow, and specificity of content. A progress bar was

integrated in the survey design to inform participants of their completion status to reduce participant

attrition.

The final stage was the dress rehearsal phase, in which the survey was sent to individuals

related to the targeted clinical population, including three parents of individuals using AAC and one

sibling of an individual using AAC. Feedback and subsequent revisions during the dress rehearsal phase

addressed the clarity of wording, flow, specificity of content, and the time needed to complete the

survey. The reviewers who met the inclusion criteria were eligible to participate in the study.

Parenting Stress Index™ – Fourth Edition (Short Form). The PSI™-4-SF is characterized by 36

items using a 5-point Likert scale and three subscales: parental distress, the difficult child, and

the parent-child dysfunctional relationship (Abidin, 2012). The PSI™-4-SF is one of the most

commonly used tools to measure parental stress (Holly et al., 2019). It was developed from

factor analysis using the Parenting Stress Index™ (PSI™) full-length version. Demographics of the

normative sample for the PSI™-4 full-length version include both mothers and fathers of varying

ethnicity, marital status, annual household income, and education. The PSI™-4-SF relies on this

normative sample data (Abidin, 2012).

The PSI™-4-SF test-retest reliability for total stress is good (r = 0.84) with all subtests'

coefficients in at least the acceptable range (r = 0.68) (Abidin, 2012). The internal consistency for

total stress is excellent (Cronbach's α = 0.95) with all subscales' internal consistency in at least

the good range (Cronbach's α = 0.88) (Abidin, 2012). This tool is widely used to evaluate stress in

caregivers in clinical populations related to this study, such as children with autism spectrum

disorders (Miranda et al., 2019). Evaluation of the prior version of the Parenting Stress Index™ -

Short Form revealed excellent content validity due to selection of items from the PSI™ full-length

version with independent replication of factors (Holly et al., 2019). Construct validity is judged

as excellent secondary to differentiation between clinical populations and correlations to

theoretical constructs (Holly et al., 2019).

Family Support Scale. The FSS measures family support with 19 items rated on a 5-point Likert

scale. Caregivers rate kinship, partner, informal, program, and professional service support.

Demographics of the normative sample include 224 parents of children participating in an early

intervention program (Dunst et al., 1984). The children either had disabilities or were at risk for

poor developmental outcomes (Dunst et al., 1984). Of the participating parents, 84% were

married (Dunst et al., 1984).

The prior edition of the FSS included only 18 predetermined items for rating, as well as

two open open-ended items in which participants were able to generate support systems for

rating. In addition to the two open-ended responses, the current edition of the FSS is

characterized by 19 support systems for rating. The "neighbor" support system has been added

since the previous edition. Psychometric properties of the FSS have been established using the

prior 18-predetermined item edition.

Test-retest reliability is acceptable ($r = 0.73 – 0.91$) for administrations less than one

month apart (Dunst et al., 1984; Hanley et al., 1998). With more than a year between

administrations, test-retest reliability decreases ($r = 0.47 – 0.59$) (Dunst et al., 1984; Taylor et al.,

1993). The internal consistency is good for the total score (Cronbach's $\alpha = 0.77 – 0.85$), with less

internal consistency for individual subscales (Cronbach's $\alpha = 0.60 – 0.78$) (Dunst et al., 1984;

Hanley et al., 1998). In this proposed study, however, subscale scores will not be used as

predictor variables. Split-half reliability is also acceptable ($r = 0.72 – 0.77$) (Dunst & Trivette,

1988; Hanley et al., 1998). Content validity has been established through use of this tool with

populations relevant to this proposed study, including parents of children with disabilities,

parent of children at risk for poor developmental outcomes, and kinship caregivers (Dunst et al.,

1984; Hanley et al., 1998; Hassall et al., 2005; Kondrat et al., 2015; Littlewood et al., 2012).

Criterion and construct validity have been established in research using the FSS with related

clinical measures, such as the Parenting Stress Index™, to measure characteristics of caregiver

stress and support in clinical populations (e.g., Hassall et al., 2005; Jones et al., 1999; Smith et

al., 2001).

Qualitative

Development of the interview protocol began with literature review. Interview protocols

relevant to this study were also identified to inform the generation of this study's interview protocol

(e.g., Bailey, Parette, et al., 2006; O'Neill, 2019). To gain insight to caregivers' lived experiences, the

interview protocol mirrored phenomenological principles: contextualization, apprehending the

phenomenon, and clarifying the phenomenon (Bevan, 2014; Jacob & Furgerson, 2012). The protocol

began with a script providing information about consent, confidentiality, and the purpose of the study,

as well as an invitation for participant questions (Brinkmann & Kvale, 2015; Jacob & Furgerson, 2012).

The interview began with initial questions to further introduce the topic to contextualize the

phenomenon of stress (Bevan, 2014). Open descriptive questions facilitated participants' descriptions of

their experiences (Brinkmann & Kvale, 2015). The questions were designed to orient participants

without targeting a specific opinion (Brinkmann & Kvale, 2015). To apprehend the phenomenon,

multiple descriptive questions were developed to increase the focus on the phenomenon of stress.

Follow-up structural questions were integrated at this stage to prevent any premature interpretation

(Bevan, 2014). The interview concluded by clarifying and stabilizing the phenomenon to increase

credibility (Bevan, 2014; Shenton, 2004). Imaginative variation was embedded at the end of the data

collection period based on participants' lived experiences (Bevan, 2014). By using this principle at the

end of the interview, questions were grounded in the participant's original expressed context (Bevan,

2014). Questions were organized to reflect both thematic and dynamic dimensions. The thematic

dimension relates to the research topic and overall concept, whereas the dynamic dimension relates to

a positive interaction between the researcher and the participant (Brinkmann & Kvale, 2015). The

interview concluded with a script to debrief participants by briefly discussing future contact for member

checking and the analysis process (Brinkmann & Kvale, 2015; Jacob & Furgerson, 2012).

The interview protocol was sent to two parents of an individual using AAC and one sibling of an

individual using AAC. The interview protocol was also pilot tested with the parent of the individual using

AAC. Feedback targeted the clarity of wording and content specificity. Revisions were made to the

interview protocol to reflect feedback. This reviewer did not meet inclusion criteria for the study. The

semi-structured interview protocol is included in Appendix C.

Analytic Strategy

Quantitative

For the first research question, quantitative analyses were used to identify predictors of stress

reported by adult caregivers of children using AAC as measured by the PSI™-4-SF. Linear regression uses

a linear model to determine the relationship between a continuous outcome and predictor variables

(Field, 2018). Therefore, it was used to identify the relationship between different levels of stress and

the frequency of aided AAC modality use (Aim 3.1) and differing microsystem and macrosystem

characteristics (Aim 3.2). Participants with completed PSI™-4-SF and FSS measures were included in the

quantitative analyses, which were completed with IBM SPSS Version 27 (IBM Corporation, Armonk, NY).

For both Aim 3.1 and Aim 3.2, the outcome variable is the caregivers' PSI™-4-SF score, a

continuous variable. Aim 3.1 predictor variables include the frequency of use of aided AAC modalities by

children using AAC. This predictor variable is continuous and was selected for the identification of the

impact of differing AAC modalities on caregivers' stress. For Aim 3.2, predictor variables were entered

using hierarchical methods (Field, 2018). The first step was FSS score secondary to past research with

this measure (Jones et al., 1999). The second step was exploratory and included: child age (continuous),

number of children without medical and/or educational diagnoses (continuous), number of children

with medical and/or educational diagnoses (continuous), caregiver age (continuous), caregiver marital

status (categorical), caregiver education (categorical), and caregiver employment (categorical). These

predictors were selected as a result of literature review, the overarching theoretical perspective of the

study, and the guiding research question. Dummy coding was used for all categorical predictors. The

reference levels for categorical predictors were: "married" marital status, "4-year degree" educational

level, and "full-time" caregiver employment.

Qualitative

Thematic analysis, designed to identify, analyze, and report patterns in data, was used as the

analytic method (Braun & Clarke, 2006; Sundler et al., 2019) for Research Question 2. This analytic

method is appropriate across epistemologies (Braun & Clarke, 2006; Nowell et al., 2017) and was

selected to identify shared life experiences across participants. Thematic analysis has previously been

applied to phenomenological studies, including related research investigating the integration of AAC

into everyday life as perceived by parents of children with cerebral palsy (O'Neill & Wilkinson, 2020).

Braun and Clarke outline six recursive phases for thematic analysis, including familiarizing with data,

generating initial codes, searching for themes, reviewing themes, defining and naming themes, and

producing the report (Braun & Clarke, 2006). These phases are outlined in Table 4.1.

Table 4.1

Braun & Clarke (2006) Thematic Analysis Phases

Phase	Description
1. Familiarization with the data	Transcription, repeated reading, note-taking, and active searching for meaning
2. Generation of initial codes	Data-driven generation of codes with systematic attention to each aspect of data
3. Search for themes	Sorting and collating of codes for creation of themes and subthemes with corresponding extracted data
4. Review of themes	Refining of themes with two-part review: (1) Review coded data extracts for relevance and appropriateness for the theme; (2) Review entire data set for accuracy of themes' representation of the data set
5. Define and name themes	Defining and naming of themes with analysis and specification of how themes fit within the data set
6. Produce the report	Generation of a concise scholarly report for publication

During Phase 1, two coders individually engaged in repeated reading of semi-structured

interview transcripts and review of video recordings. Significant quotations were noted and initial

impressions were documented in analytic memos (Saldana, 2009). In Phase 2, two coders completed

initial coding of one randomly selected transcript. Coding was characterized by line-by-line descriptive coding with single word and short phrase codes (Harding, 2019). The two coders then compared and discussed initial codes, resulting in the generation of an initial code list used during the coding of remaining transcripts (Harding, 2019). The primary researcher completed first cycle descriptive coding for each participant transcript. The second coder coded every third transcript for a total of five transcripts. The two coders met to resolve disagreements through discussion, achieve consensus, and modify the codebook as needed. In Phase 3, codes and corresponding primary data was sorted to develop initial themes. Together, the two coders created a thematic map to display relationships between codes, resulting in themes and sub-themes (Braun & Clarke, 2006). In Phase 4, the two coders independently completed the two levels of review as specified by Braun and Clarke (2006). This review determined if primary data fit within a given theme, as well as if themes fit within the data set. The audit trail, including notes, the interview protocol, interview transcripts, the codebook, the reflexive journals, and the timeline of research activities, was reviewed during the second review to facilitate the contextualization of the data set (Hays & Singh, 2012; Nowell et al., 2017). Following individual review, consensus was achieved between the two coders through discussion. In Phase 5, the coders determined theme definitions and examples. Themes were reorganized until consensus was achieved (Nowell et al., 2017). Phase 6 is the generation of this report (Braun & Clarke, 2006). To increase transferability, this report uses thick description of the phenomenon and the research context, including situations, participants, and data collection methods, to facilitate the readers' judgment of transfer of information to their own experiences (Nowell et al., 2017; Shenton, 2004). Microsoft Word, Nvivo (QRS International, LLC, Melbourne, Australia), and Jamboard (Google, Mountain View, California) were used during data analysis.

Results

Sixty-seven family systems completed Part 1, resulting in a 56.3% (67/119) completion rate

(Figure 4.1). Eighty-four participants completed Part 2, resulting in a 64.2% response rate (88/137) and

61.3% (84/137) completion rate. Saturation was achieved with fifteen participant interviews. During

dissemination of invitations for participant interviews, three participants declined and three did not

respond. Demographic data is reported in Table 4.2 (caregiver participants) and 4.3 (family systems).

Figure 4.1

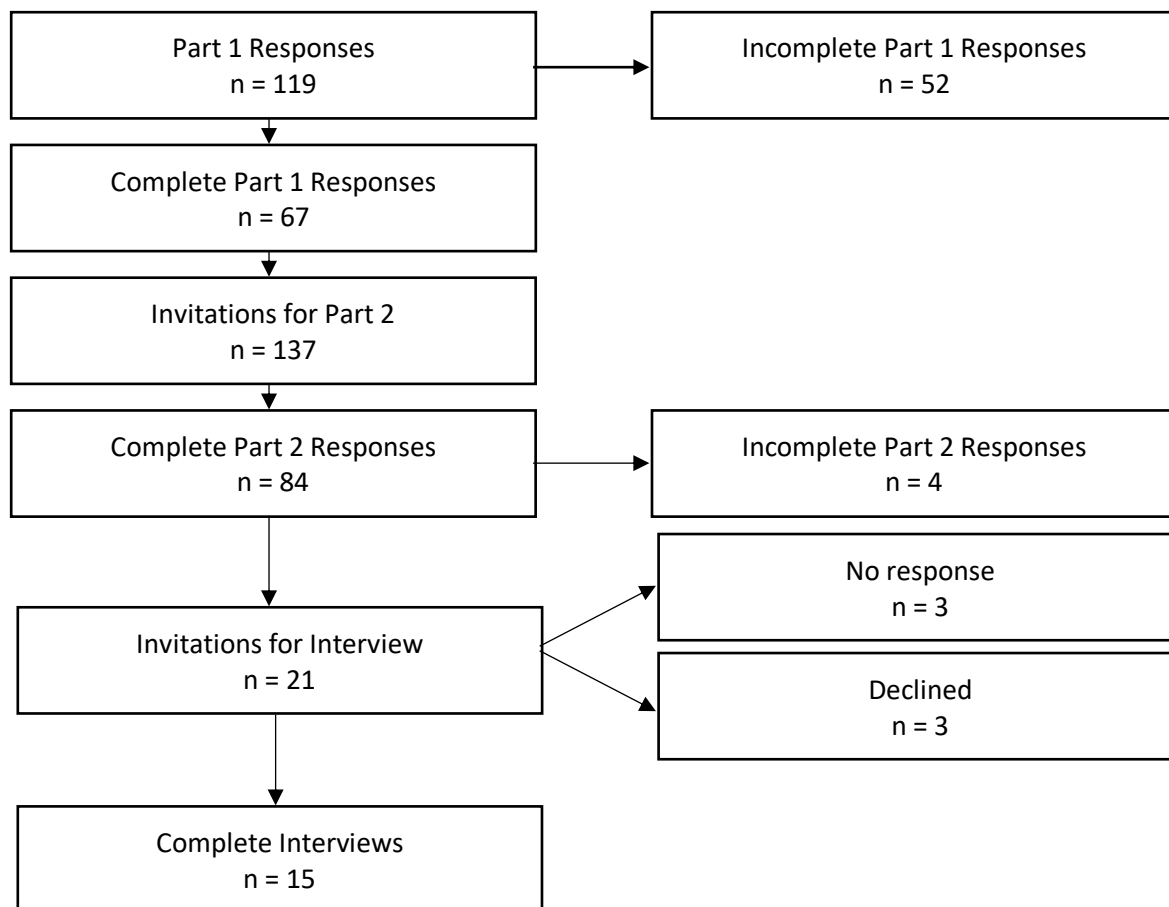*Participant Flow Chart for Mixed-Methods Investigation*

Table 4.2

Caregiver Demographic Characteristics of Survey Participants

Characteristic	Percent of Participants	*M*
Marital Status		
Married	89.3%	
Not married	10.7%	
Education		
Some college	13.1%	
Associate's degree and trade school	13.1%	
Four-year degree	32.1%	
Master's and professional degree	33.3%	
Doctoral degree	8.3%	
Employment Status		
Full-time	54.8%	
Part-time	15.5%	
Not employed outside of the home	28.6%	
Race		
White	89.3%	
Black or African American	1.2%	
American Indian or Alaska Native	1.2%	
Asian	2.4%	
Mexican	2.4%	
Multiracial	3.6%	
Age		41.70 ± 8.74
Language Used in Home Setting		
English	96.4%	
Multilingual	3.6%	
Geographic Region		
Northeast	10.7%	
South	39.3%	
Midwest	32.1%	
West	17.9%	
Communication with Child		
Communication using aided AAC modalities		71.82 ± 24.24
Communication using unaided AAC modalities		28.19 ± 24.24

Note. *n* = 84. Northeast = New Jersey, New York, Pennsylvania, Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont; South = Alabama, Kentucky, Mississippi, Tennessee, Delaware, District of Columbia, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, West Virginia, Arkansas, Louisiana, Oklahoma, Texas; Midwest = Illinois, Indiana, Michigan, Ohio, Wisconsin, Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, South Dakota; West = Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Utah, Wyoming, Alaska, California, Hawaii, Oregon, Washington; Territory = other US territories (ASHA, 2019).

Table 4.3

Family System Demographic Characteristics of Survey Participants

Characteristic	Percent of Family Systems	*M*
Children in Family System		
Children with medical or educational diagnoses		1.37 ± 0.71
Children without medical or educational diagnoses		0.88 ± 1.15
Child using AAC Age		6.11 ± 1.93
Exposed Languages in Home Setting		
English	92.3%	
Multilingual	7.7%	
Child using AAC Race		
White	76.9%%	
Black or African American	1.9%	
Asian	7.7%	
Other	1.9%	
Multiracial	11.5%	
Caregivers in Family System		
Mother/s	98.1%	
Father	86.5%	
Grandmother	13.5%	
Grandfather	5.8%	
Babysitter	5.8%	
Aunt	3.8%	
Great aunt	1.9%	

Note. *n* = 52.

Quantitative

Caregivers' PSI™-4-SF scores varied across participants with a range of 49 to 139 (*M* = 91.92 ±

19.79). Sixteen percent (14 of 84, 16.7%) of caregivers reported high or clinical levels of stress, defined

by above the 84th percentile on the PSI™-4-SF. Caregivers' FSS total scores varied with a range of 5 to 95

(*M* = 38.85 ± 13.53).

A simple linear regression was used to predict caregiver stress as a result of the child's AAC

modality (Aim 3.1). Assumptions were reviewed for the simple linear regression: continuous variables,

linearity and additivity, independence of errors, normality, homoscedasticity, multicollinearity, and non-

zero variance (Field, 2018). Both the predictor variable, frequency of aided AAC use, and the outcome variable, PSI™-4-SF total score, were continuous. Linearity and additivity were met using visual inspection of a linear relationship on a scatterplot with the two variables. No outliers were identified. Errors were independent, as evidenced by evaluation of the Durbin-Watson statistic, d = 1.68. Visual inspection of the histogram of residuals, the probability-probability plot, and the quantile-quantile plot was used (Field, 2018). Due to violations of normality and homoscedasticity, bias corrected accelerated bootstrapping was used for the analysis. Multicollinearity was met through review of correlations, r = .07. The predictors had variation in value, therefore meeting the assumption of non-zero variance.

Results of the simple linear regression indicate a nonsignificant relationship between caregiver stress and the child's AAC modality, $F(1, 82) = 0.34$, $p > 0.05$, $R^2 = 0.004$. These results do not support Hypothesis 3.1, indicating that adult caregivers of children with more frequent use of aided AAC modalities do not report more stress than adult caregivers of children with less frequent use of aided AAC modalities.

A multiple linear regression was used to predict caregiver stress as a result of microsystem and macrosystem characteristics (Aim 3.2). A review of assumptions include acceptable Cook's distance (<1) for all identified outliers on scatterplots. Errors were independent with an acceptable Durbin-Watson statistic, d = 2.34. The assumption of multicollinearity was met through review of correlations ($r \le .37$), tolerance (<.64), and VIF (≥ 1.00). Due to violations of normality and homoscedasticity, bias corrected accelerated bootstrapping was also used for this analysis. The microsystem and macrosystem predictors included in this analysis also had variation in value and met the non-zero variance assumption.

The first step of the hierarchical model was not significant, $R^2 = .04$, $F(1, 81) = 3.43$, $p = .068$. With the addition of the remaining predictor variables (see Table 4.4), the second step of the model was also not significant, $R^2 = .24$, $F(12, 70) = 1.86$, $p = .054$. However, the second step of the model did include three significant predictors: Family Support Scale total score ($p = .04$), number of children in the

family system without medical or educational diagnoses (*p* = .03), and Master's and professional degree

education (*p* = .03).

Table 4.4

Preliminary Multiple Linear Regression Results for Reported Caregiver Stress

Variable	*B*	95% CI for *B* LL, UL	*SE B*	β	R^2	ΔR^2
Step One					0.04	0.04
Constant	103.48***	86.23, 120.41	8.08			
Family Support Scale total score	-0.30	-0.66, 0.12	0.20	-0.20		
Step Two					0.24	0.20
Constant	80.18***	44.86, 124.16	17.69			
Family Support Scale total score	-0.44*	-0.85, -0.01	0.21	-0.30		
Child age	1.79	-0.54, 4.04	1.19	0.17		
Number of children with diagnosis	3.61	-1.88, 9.41	2.85	0.13		
Number of children without diagnosis	6.11*	0.84, 9.51	2.81	0.35*		
Caregiver age	0.11	-0.38, 0.64	0.30	0.05		
Marital status	2.30	-13.18, 17.49	7.41	0.03		
Some college education	0.54	-14.64, 16.41	8.04	0.01		
Two-year degree and trade school	7.95	-4.97, 20.95	6.54	0.14		
Master's and professional degree	12.16*	2.75, 21.63	5.07	0.29*		
Doctoral degree	-9.15	-26.02, 10.58	10.43	-0.13		
Part-time work	-1.42	-13.49, 9.03	6.22	-0.03		
Not employed outside of home	-3.99	-15.03, 5.38	5.64	-0.09		

Note. CI = confidence interval, *LL* = lower limit; *UL* = upper limit
*p < .05. ***p* < .01. ****p* ≤ .001.

Due to the exploratory nature of this analysis, the multiple regression was repeated with

backward stepwise elimination, characterized by removal of predictors from the full model with all

predictor variables included (Hocking, 1976). The nonsignificant predictors at the .05 alpha level were

individually removed based on the guiding theoretical approach. Backward stepwise elimination limits

suppressor effects (Field, 2018). This resulted in the models in Table 4.5. Since the first step of the

hierarchical model mirrored the initial multiple linear regression analysis, changes reflected only the

bootstrapping procedure. The first step explained 4% of the variance, $R^2 = .04$, $F(1, 82) = 3.55$, $p > .05$.

The additional inclusion of the number of children without medical or educational diagnosis and

educational levels resulted in a model which explained 19% of the variance, $R^2 = .19$, $F(6, 77) = 3.00$, p

$= .011$. With increased family support, caregivers' stress was predicted to significantly decrease, $p = .03$.

Caregivers' stress, however, significantly increased with the number of children in the family system

without medical or educational diagnoses, $p = .04$. Caregivers with a master's or professional degree

also reported more stress than caregivers with four-year degrees, $p = .03$. These results indicate

caregivers with more support experience less stress. As a result, Hypothesis 3.2.2 is accepted. However,

the age of the child using AAC does not significantly contribute to the explanation of the caregiver's

stress and therefore, Hypothesis 3.2.1 is rejected.

Table 4.5

Secondary Multiple Linear Regression Results for Reported Caregiver Stress

Variable	B	95% CI for B LL, UL	$SE\ B$	β	R^2	ΔR^2
Step One					0.04	0.04
Constant	103.49**	86.50, 118.15	7.88			
Family Support Scale total score	-0.30	-0.65, 0.11	0.20	-0.20		
Step Two					0.19	0.15*
Constant	99.39**	80.69, 113.28	8.24			
Family Support Scale total score	-0.41*	-0.73, 0.02	0.19	-0.28*		
Number of children without diagnosis	5.70*	-1.32, 9.19	2.64	0.33*		
Some college education	1.18	-11.95, 15.34	7.13	0.02		
Two-year degree and trade school	6.86	-4.31, 18.89	5.94	0.12		
Master's or professional degree	10.91*	1.41, 21.04	4.93	0.26*		
Doctoral degree	-10.29	-25.85, 13.01	9.71	-0.15		

Note. *CI* = confidence interval, *LL* = lower limit; *UL* = upper limit
*$p < .05$. **$p \leq .001$.

Qualitative

As described previously, multiple methods were utilized to maximize trustworthiness between the researcher and reader (Bevan, 2014; Nowell et al., 2017; Shenton, 2004). Interview participants' demographic data were collected during administration of the 2-part survey. Data for the 15 caregiver interview participants are reported in Table 4.6. The reported characteristics of each caregiver's child are reported in Table 4.7-4.9. All data have been deidentified and pseudonyms have been used.

Through the process of thematic analysis, five main themes were identified. Analysis included the construction of multiple iterations of thematic maps. The initial thematic map (Figure 4.2) and final thematic map (Figure 4.3) reflect the relationships between themes and subthemes throughout the analysis process. The five themes related to caregivers' shared experiences of stress are reported in Table 4.10.

Table 4.6

Demographic Characteristics of Interview Participants in Low-, Mid-, and High-Stress Groups

Stress Group	Caregiver	Age	Marital Status	Education	Employment	Funding Source for Child	Annual Household Income
Low-Stress	Jennifer	35	Married	Doctoral degree	FT	Private, public	>$100,001
	Heather	36	Married	4-year degree	FT	Private	>$100,001
	Elizabeth	34	Married	Doctoral degree	FT	Private, public	$80,001-$100,000
	James	38	Married	4-year degree	FT	Private, public	$80,001-$100,000
	Christine	39	Married	4-year degree	PT	Private, public	$80,001-$100,000
Mid-Stress	Kelly	38	Married	Associate's degree/trade school	FT	Private, public	>$100,001
	Danielle	39	Married	4-year degree	FT	Private	>$100,001
	Brian	35	Married	Some college	NE		
	Carol	65	Widowed	4-year degree	NE	Public	$40,001-$60,000
	Emily	39	Married	Master's/professional degree	PT	Private, public	$60,001-$80,000
High-Stress	Tina	36	Married	Associate's degree/trade school	NE	Private	$20,000-$40,001
	Angela	47	Married	Master's/professional degree	FT	Private, public	>$100,001
	Nicole	40	Married	Some college	PT	Private, public	>$100,001
	Michelle	38	Married	Doctoral degree	PT	Private, public	>$100,001
	Scott	49	Married	Master's/professional degree	FT	Private, public, self-pay	>$100,001

Note. Danielle and Brian are in the same family system. Their funding source for child and annual household income are shared.

FT = Full-time employment; NE = Not employed outside of the home; Private = Private insurance; PT = Part-time employment; Public = Public funding.

Table 4.7

Demographic Characteristics of Children of Interview Participants in the Low-Stress Group

Caregiver	Child Age	Words	Receptive Language	Diagnoses	Unaided AAC Modalities	Years of Unaided AAC	Aided AAC Modalities	Years of Aided AAC
Jennifer	6	>50	Single words Simple sentences Conversation Yes/no questions	CAS DD Down syndrome	Gestures, pointing, body language, physically leading, sign language, facial expressions, looking, sounds, words	1-2 years	Low-tech Mid/high-tech	1-2 years
Heather	6	21-30	Complex sentences Conversation Yes/no questions Complex questions	DD Genetic disorder	Gestures, pointing, body language, physically leading, sign language, facial expressions, sounds, words	2-3 years	Low-tech	<1 year
Elizabeth	4	>50	Simple sentences Complex sentences Conversation Yes/no questions Complex questions	CAS DD Down syndrome	Gestures, pointing, body language, physically leading, sign language, facial expression, looking, sounds, words	3-4 years	Low-tech Mid/high-tech	2-3 years
James	9	<10	Single words Simple sentences Complex sentences Conversation Yes/no questions	CP	Pointing, facial expression, looking with eyes	8-9 years	Low-tech Mid/high-tech	6-7 years
Christine	6	21-30	Single words, simple sentences	DD Genetic disorder ID LD Visual impairment	Gestures, body language, physically leading, sign language	2-3 years	Mid/high-tech	3-4 years

Note. AAC = Augmentative and alternative communication; ADHD = Attention-deficit/hyperactivity disorder; ASD = Autism spectrum disorder; CAS = Childhood apraxia of speech; CP = Cerebral palsy; DD = Developmental delay; ID = Intellectual disability; LD = Learning disability; Words = Number of words, signs, pictures, and other symbols used by child.

Table 4.8

Demographic Characteristics of Children of Interview Participants in the Mid-Stress Group

Caregiver	Child Age	Words	Receptive Language	Diagnoses	Unaided AAC Modalities	Years of Unaided AAC	Aided AAC Modalities	Years of Aided AAC
Kelly	6	>50	Single words Simple sentences Complex sentences Conversation Yes/no questions	CP CAS DD ID Pediatric stroke	Gestures, pointing, body language, looking sounds, words	4-5 years	Mid/high-tech	<1 year
Danielle and Brian	4	>50	Simple sentences	ASD DD	Body language, physically leading, facial expression, sounds	3-4 years	Low-tech Mid/high-tech	2-3 years
Carol	6	>50	Simple sentences Conversation Yes/no questions	Hearing impairment DD Genetic disorder	Gestures, pointing, body language, physically leading, sign language, facial expression, sounds, words	3-4 years	Mid/high-tech	2-3 years
Emily	4	>50	Single words Simple sentences Complex sentences Conversation Yes/no questions Complex questions	CAS Genetic disorder	Gestures, pointing, body language, physically leading, sign language, facial expression, looking, sounds	1-2 years	Low-tech Mid/high-tech	1-2 years

Note. Danielle and Brian are in the same family system. Their child characteristics are shared.

AAC = Augmentative and alternative communication; ADHD = Attention-deficit hyperactivity disorder; ASD = Autism spectrum disorder; CAS = Childhood apraxia of speech; CP = Cerebral palsy; DD = Developmental delay; ID = Intellectual disability; LD = Learning disability; Words = Number of words, signs, pictures, and other symbols used by child.

Table 4.9

Demographic Characteristics of Children of Interview Participants in the High-Stress Group

Caregiver	Child Age	Words	Receptive Language	Diagnoses	Unaided AAC Modalities	Years of Unaided AAC	Aided AAC Modalities	Years of Aided AAC
Tina	5	21-30	Simple sentences	DD Genetic disorder	Gestures, pointing, physically leading, sign language, sounds, words	2-3 years	Mid/high-tech	1-2 years
Angela	7	>50	Simple sentences	ASD CAS DD ADHD	Physically leading, facial expressions, looking with eyes, words	3-4 years	Low-tech Mid/high-tech	1-2 years
Nicole	8	41-50	Single words Simple sentences Conversation Yes/no questions	ASD CAS DD	Gestures, pointing, body language, physically leading, looking with eyes, sounds	3-4 years	Mid/high-tech	2-3 years
Michelle	8	11-20	Simple sentences	ASD DD	Gestures, pointing, physically leading, sounds, words	6-7 years	Mid/high-tech	3-4 years
Scott	8	31-40	Single words Simple sentence Complex sentences Conversation Yes/no questions	ASD Hearing impairment DD Genetic disorder Hypotonia Neurological disorder	Gestures, pointing, body language, physically leading, facial expressions, looking with eyes, sounds, word attempts	3-7 years	Low-tech Mid/high-tech	2-3 years

Note. AAC = Augmentative and alternative communication; ADHD = Attention-deficit/hyperactivity disorder; ASD = Autism spectrum disorder; CAS = Childhood apraxia of speech; CP = Cerebral palsy; DD = Developmental delay; ID = Intellectual disability; LD = Learning disability; Words = Number of words, signs, pictures, and other symbols used by child.

Figure 4.2

Initial Thematic Map of Themes and Subthemes for Caregivers' Shared Experiences of Stress
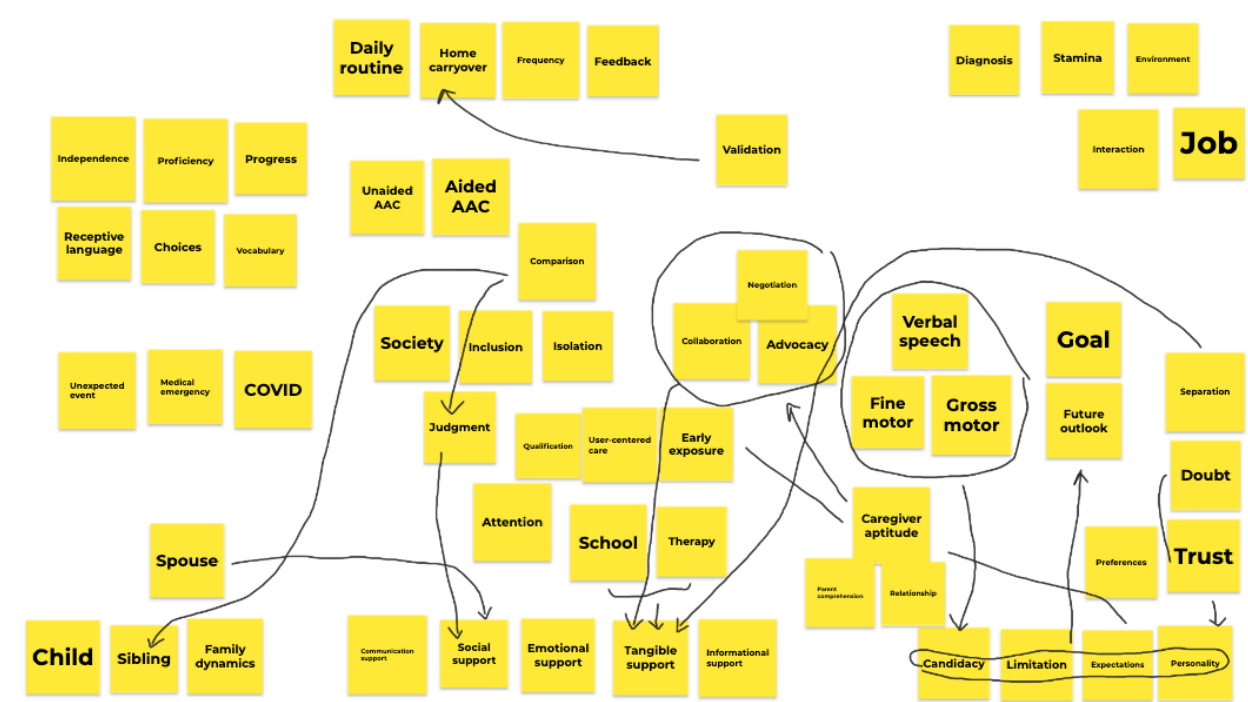

Figure 4.3

Final Thematic Map of Themes and Subthemes for Caregivers' Shared Experiences of Stress

Table 4.10

Identified Themes and Subthemes Following Thematic Analysis with Caregivers of Children using AAC

Theme	Sub-theme
People don't understand.	Judgment
	Isolation
Caregivers need to fill the role of expert.	Caregiver expertise
	Filling multiple roles
There is a mismatch between expectations and current realities.	Expectations
	Grief
	Comparison
Responsibilities are diverse, constant, and long-term.	Caregiver responsibilities
	Complex diagnoses
	Unexpected events
Support is often inadequate.	Qualifications
	Multifaceted
	Collaborative

People Don't Understand

Caregivers' experiences suggested society cannot accommodate the needs and experiences of caregivers of children using AAC. Caregivers shared the impact of judgment and isolation from outsiders who lack understanding of caregivers' experiences. The people who "get it" are often those with children with medical or educational diagnoses, including communication disorders.

Judgment. Caregivers described judgment as the sharing of opinions and perspectives from outsiders, often rooted in their expectations of what is deemed appropriate or normal. Opportunities for judgment were diminished by the COVID-19 pandemic, due to less overall time in public environments. Some caregivers, specifically those in the high-stress group, reported that judgment from others impeded their ability to go to public places regardless of the COVID-19 pandemic. Michelle described fear of judgment during experiences with her daughter during community outings:

She loves the pool, but I can't really take her because she'll go and just start grabbing

people randomly. And not just the pool, anywhere we go. If we go to the zoo, she'll just

run up to people and start grabbing people…

Many caregivers discussed experiences during which their efforts to work with their

child or intuitive knowledge were dismissed. This negatively impacted caregivers' feelings about

their knowledge, home environment, use of time, and expectations for their child. Judgment

also related to the child's current modalities of communication, such as non-speech

vocalizations. Caregivers described both adults and children observe the child's lack of verbal

speech and interpret it as something "wrong" (Christine).

For caregivers in the high-stress group, judgment was especially exacerbated during

stressful situations. In contrast, caregivers in the mid-stress group did note a positive side of

judgment, characterized by professionals', friends', family members', and strangers' recognition

of their expertise and close relationship with their child. However, this did not result in more

societal understanding. Emily reported that the lack of diminutive comments did not mean that

outsiders were able to fully understand her experiences.

Some judgments were related to the caregivers' ability to discipline their child for bad

behavior. For Carol, judgments suggested her discipline for her grandson is too strict:

These children need discipline. They do not need to be allowed, because they have

problems, to run wild and to disrupt everybody else's life. He does not have a free reign

to misbehave, no matter where we are or what we do and we have had people turn

around and say, 'Well you're awfully tough on him.'

Conversely, other caregivers experienced judgment due to their perceived inability to

discipline: "Even my dad sometimes will make comments like, 'Well, she does these things

because she's not disciplined… You need to discipline her.' It's like well I would love to do that,

but it's just different" (Michelle).

For some caregivers, outsider judgment provided a time to step into an advocacy role. This role wasn't always regarded as easy or welcomed, but necessary. For Danielle, advocacy in public was too emotional. Instead, she preferred advocating at home or with people she knew. She was able to approach advocacy without anger or emotion. Jennifer, however, described advocacy across settings:

> "I feel like I spend a lot of time and energy trying to fight for space for him, even with close friends. And that's probably the hardest thing about being his parent is just fighting for people to see him as a person who has value (nods)… That's hard. Whether we want to believe it or not, as a society, a person's ability to verbally communicate opens and closes doors for them."

Caregivers appreciated other people's openness to learn through asking questions. With less awareness of the child's diagnosis, skill set, or communication status, other people had more assumptions and judgments. For example, caregivers discussed times during which people were unable to distinguish a child's personality from their communication modality or diagnosis. In these situations, caregivers' children were called bratty, rude, and naughty. At a large scale, caregivers believed long-term engagement in the process of learning changes society's views of individuals with disabilities, including equality and discrimination. For example, Kelly desired that her family learn about her son's disability. She wanted them to "listen with an open mind and not having any preconceived notions of what disability is or how disabled individuals should be viewed in society."

Isolation. When no one was able to understand caregivers' experiences or accommodate their needs, caregivers reported feelings of isolation. This was overtly worsened by the COVID-19 pandemic, during which families' physical environment, activities, and childcare were restricted. Isolation also occurred due to the child's communication needs or the rarity of their diagnosis.

Angela stated, "You realize that you're a minority within a minority. So even within the autism

community, I feel like a minority, because my son has such huge communication challenges."

For caregivers of children with rare diagnoses, isolation included no available and qualified

people from whom to seek guidance or support.

Caregivers' experiences of isolation resulted in a desire for inclusion, characterized by an

acceptance and understanding to participate meaningfully in all of the opportunities available to

those without disabilities. Caregivers reported that this can be achieved through adequate

training and accommodations to support the success and participation of the child using AAC.

When asked about how inclusion looks for her son, Kelly reported, "It would be a school system

that includes him as much as they can, but also provides one-on-one individualized learning to

make sure he's supported and he's learning to the maximum extent possible." She expanded on

her thoughts about inclusion: "Not having inclusive education models really hinders society and

understanding disability." Some caregivers also shared the impact of exclusion on their own

participation in society.

Caregivers Need to Fill the Role of Expert.

Caregivers are tasked with filling an expert role. In this role, they are expected to have the

knowledge and ability to successfully navigate the best interest of the child. In some situations, the

expert role was welcomed. In other situations, however, caregivers felt ill-equipped to fill this role.

Caregiver expertise. Caregivers' expertise was characterized by focal strengths and weaknesses

that contribute to their confidence and competence in the role of the most primary caregiver to

a child using AAC. Intuitive expertise was attributed to a unique closeness between the caregiver

and child. Caregivers reported that some intuition could not be explained. However, it also

increased with proximity and time spent with the child, which increased during the COVID-19

pandemic. Expertise was also influenced by caregivers' personalities, the characteristics that

contribute to their confidence, decisions, and experiences. Caregivers reflected on their energy level and their willingness to accept help. Members of the low-stress group described themselves as "happy," "fulfilled," "low-stress," and "low-anxiety." Christine said, "I've been pretty laid back I think about all the diagnoses and all the things that came up or all the new things." In contrast, members of the high-stress group described themselves as "very direct" and "homebodies." Michelle said, "I'm like a really type A person so I'm a hard driver (laughs). That's part of the problem I think where I'm so tired (laughs)."

Caregiver expertise determined the best interest of the child. Angela reflected the best strategies to support her son: "I have a lot of experience with what's going to produce a better result for him." Caregivers' expertise also contributed to their recognition of their child's readiness for various AAC modalities. When a high-technology AAC system was suggested for her daughter, Emily pushed back. She described this interaction: "I said, "First of all, [Child] is not ready. She's a 2-year-old. She's not ready for device." On the other hand, Nicole pushed for use of a high-technology AAC system for her son:

> We were told over and over, 'He's not ready. He needs to start with one PEC.' I knew in
> my heart he was ready (points to self), so my husband and I decided just buy Proloquo
> and try it and see.

Caregivers applied their expertise to find services and support, as well as decide the value and quality of service providers. For example, they reflected on characteristics of silliness, patience, persistence, and physical touch to facilitate their child's success. Caregivers use this information to determine the worth of continued intervention for their child. They intentionally integrate professional recommendations with their in-depth knowledge. Emily stated, "Well, I relied on experts and the expertise, but also, it was our intuition (points to self), because we were suddenly nurses and doctors and all." This integration was effortful and resulted in an

approach that best fit each families' needs.

Expertise increased with multiple learning experiences. Time in close proximity to the child contributed to the caregivers' ability to understand the child regardless of intelligibility. To understand his son's communication, James reported, "My wife and I know that a different sound for whine, as opposed to him being hurt." This understanding included a knowledge to repair communication breakdowns. James continued: "You kind of have to take a step back and link things, right? We know some of the cues…" For some caregivers in the high-stress group, however, this expertise was complicated by the child's expectation that the caregiver always understood. When describing her daughter's requests, Tina said, "She yells and cries and (pause, exhales) I think she expects that I know what she wants. So she doesn't need to tell me."

Caregivers' employment experiences also contributed to their expertise, such as their ability to handle medical emergencies or prior familiarity with a diagnosis. Expertise increased with time with other "experts," such as members of the medical team, therapists, or other caregivers of children with disabilities. Caregivers described the development of caregiver expertise as a longitudinal process with intermittent, sudden changes. Heather described a recent experience, when she realized her daughter understood more than Heather expected:

It's that realization that like just because she can't talk, doesn't mean she's not listening and understanding and absorbing all the things around her and then she'll like respond to something and you're like whoa (leans back)! Like where did that come from?

Expertise also influenced the use of AAC modalities specifically. Caregivers contrasted their limited background knowledge and extensive training needs. Christine demonstrated this, describing how the amount of training was not enough to build an adequate amount of expertise with her daughter's high-technology AAC device: "I wasn't taught how to put stuff back on the core screen. So, it was a learn as you go." During the AAC evaluation and

intervention process, some caregivers felt unfamiliar with the capabilities and options of aided

AAC modalities. When service providers attempted to answer caregivers' questions, caregivers

didn't have the expertise to know what questions to ask. Caregivers felt that service providers

overestimated caregivers' knowledge to integrate use of new AAC modalities into daily life.

However, most caregivers identified home carryover as a learned skill, requiring extensive effort

and specific training to facilitate the use of AAC at home. Kelly described this lack of knowledge

about a high-technology AAC system for her son:

> I think the biggest thing, if I could go back and talk to myself back then, would be to ask,
>
> "How can I use this at home? If I were to introduce this into one activity at home, what
>
> can I do to make sure that this is carrying over?" Because I think the lack of exposure to
>
> AAC was probably a big reason why he never really took to any of it. It was lack of
>
> exposure and lack of understanding (gestures to self) on my part.

When learning to integrate AAC in the home setting, caregivers realized the frequency

needed to facilitate the child's successful use of an AAC modality. Some caregivers described

this frequency as "consistent" and "daily" with "no days off." Some caregivers reflected on their

realization that communication was more than verbal speech. Through her son's use of Picture

Exchange Communication System (PECS®) (Pyramid Educational Consultants, New Castle, DE),

Danielle described learning to "appreciate[e] communication in any way he can provide it."

Caregivers recommended that other caregivers be patient with themselves and their children

due to the time and energy needed to effectively learn to integrate AAC at home and build

expertise in this area.

Caregivers often recognized both the value and limitations of their expertise. Some

caregivers discussed experiences of doubt, characterized by second guessing whether they have

done enough to support their child, their ability to understanding, make future decisions, and

intervene during crisis situations. Caregivers also reported doubting the effectiveness of interventions. Nicole described doubt in her ability to care for her son: "I think a lot of times I second guess if I'm doing enough and that, if in the future he isn't able to be independent, then that's because I didn't do enough."

Caregivers shared a perceived threshold of ability, intelligence, energy, and patience. As a result of these limitations, caregivers generated different solutions to meet an identified need. Some caregivers discussed the need for a "middle man" to fill the role of case management. Scott described his desire for someone to fill the gaps in his son's care:

> They fill that gap between our doctors and our other therapists and his autism services
>
> and where he's going to pick up his new devices or who's going to help him use these
>
> new devices, who's going to do some physical therapy with him while he's learning his
>
> autism stuff. Families kind of need like a like a project manager on their side external to
>
> providers.

A few caregivers discussed the importance of asking for help and using self-care for rest and recovery. Heather described self-care in her advice to other caregivers beginning to navigate caring for a child who uses AAC:

> Figure out ways to take care of yourself, which again I don't do a great job of asking
>
> other people to do a lot of her care stuff, but I do work very hard to take care of myself.
>
> I know how important that is.

Recognition of the value and limitations of expertise was often recognized in the presence or absence of validation from others. After his son experienced a fall, Brian described an experience of validation when he sought medical care for his son after interpreting his cry:

> We ended up taking him into the hospital and they thought it was something wrong
>
> with a different part of his arm. It turned out to be a buckle fracture in his wrist, which

sucked. And so having the doctor confirm to us that we were right and he couldn't tell

us where it hurt or point it out, that felt pretty good, because (inhales) as parents of a

kiddo with special needs, who can't tell us if we're doing things right or wrong, it's

always good to find out that we don't suck as parents.

In contrast, Elizabeth reported recognition of her own expertise during her daughter's

Individualized Education Program (IEP) meeting. After the speech-language pathologist denied

more frequent therapy and recommended Elizabeth speak to her daughter more, Elizabeth

recalled: "I was like, 'What do you think we've been doing for the past 3 years?' (laughs)… We

have been working diligently on her being able to communicate in an observational way since

birth."

Fill multiple roles. Caregivers described experiences during which they needed to use their

expertise to fill multiple simultaneous roles. This included interpreting and facilitating their

child's communication at home and other therapeutic efforts, such as community participation,

fine and gross motor skills, behavioral compliance, feeding and oral motor skills, attention,

receptive language, and academic skills.

Specific to communication, caregivers interpreted their child's use of multiple

communication modalities. Caregivers described their child's use of multiple unaided AAC

modalities, including: physically leading and guiding, pointing, crying, whining, "tantrums,"

touching, gestures, sign language, body language, facial expression, eye gaze, vocalizations, and

verbalizations. They also described experiences with many aided AAC modalities, including:

Picture Exchange Communication System (PECS®) (Pyramid Educational Consultants, New Castle,

DE), picture supports, core board, visual schedule, iPad® and iPhone® (Apple, Inc., Cupertino,

CA), Proloquo2Go (AssistiveWare, Amsterdam, Netherlands) , LAMP Words for Life® (PRC-

Saltillo, Wooster, OH) , Accent®, (PRC-Saltillo, Wooster, OH), Tech/Talk (Advanced Multimedia

Devices, Inc., Farmingdale, NY), Tobii Dynavox (Tobii Dynavox, Pittsburgh, PA), Snap™ Core

First® (Tobii Dynavox, Pittsburgh, PA), TouchChat® (Saltillo, Wooster, OH), BigMack®

(AbleNet®,Roseville, MN) , pragmatic organization dynamic display (PODD), and real objects. Use

of AAC varied across access methods, including direct access via hands, eye gaze, and head

pointing.

Caregivers described many different barriers to the successful use of AAC modalities.

Unaided AAC modalities were limited by the understanding of unfamiliar communication

partners and the child's fine motor skills. For example, Emily described her daughter's use of

sign language:

But sign language is a little bit tricky for her just because of the fine motor dexterity that

it requires. So she has some signs, but to really be proficient at that is… the motor

planning piece comes into play… When she's just trying to say "help," like she kind of

goes through all her repertoire of signs…"

Emily concluded that sign language isn't an easy modality for her daughter as a result of

these fine motor deficits. Fine motor skills also impacted AAC use through the child's ability to

point or navigate a grid-based aided AAC device. Loose items, like pictures, lead to children

throwing or losing them. Successful use of aided AAC required physical proximity to the

modality. Often the caregiver or child forgot to bring the modality to each new environment.

Some caregivers described difficulties for their child to carry their aided AAC system due to size

and weight of the system. Mid- and high-technology AAC systems broke or didn't have enough

battery to support communication. Caregivers described the sorting for low-technology AAC

systems and programming for high-technology AAC systems as cumbersome and time-

consuming. Some caregivers reported their child's use of high-technology AAC was hindered by

the prolonged exposure to screens and stimming. For some caregivers, funding process or lack

of access to an aided AAC modality was a primary barrier. When barriers were identified, caregivers worked to resolve them. For example, in response to financial or availability barriers, caregivers bought aided AAC systems or made their own. When barriers could not be directly resolved, caregivers relied on their child's other successful communication modalities.

Using multiple communication modalities, caregivers were responsible for facilitating home carryover and using strategies to promote development and goal achievement during families' daily routines. Caregivers used yes and no questions, choices, and a variety of other unaided and aided AAC modalities to facilitate communication. Danielle described facilitating her son's communication following his recent transition from PECS® to a high-technology AAC system: "I can say 'use your words' and he can go to his PECS® book… I'm even moving from the PECS® book like 'No, I understand what you want, but can you tell me on your device?'" Many caregivers used choices as a sustainable option for the child's communication and involvement in routine decisions. During a morning routine, Kelly asked her son what he wants to wear: "We do, like I said, offering 2 choices (holds hands apart), or his AAC device. He helps pick out his clothes." Although AAC was often integrated in the home setting to determine the child's preferences, some families also described use of AAC for other communication functions, like Scott, who described his son's use of high-technology AAC system at home to make jokes.

The degree of support provided by caregivers varied. Caregivers mentioned providing direct instruction, modeling, verbal prompting, visual prompting, physical prompting, wait time, opportunities for repetition, and a reduced visual field with an aided AAC modality. In response to a child's communication, caregivers described their feedback, including natural reinforcements, consequences, or praise. To facilitate her daughter's verbal speech, Michelle reported: "I actually have to ask her to say it 3 or 4 times in a row, but she's not going to get the cheerios and so she says it the way she needs to say it." After Michelle felt her daughter

verbalized the word to the best of her ability, she was given the snack. Feedback was also given in the form of further instruction, conversation, or verbal redirection.

The effort required to fill the role of communication facilitator was often overwhelming for caregivers. However, despite the effort needed, caregivers identified carryover in the home setting contributed substantially to the child's progress. This was most frequently noted with respect to the COVID-19 pandemic. For many caregivers, COVID-19 resulted in the most difficult year, but most observed child progress. Progress contributed to a closer relationship between the caregiver and child, as well as a better understanding of the child's personality.

Caregivers' teaching and training was not limited to the home setting. Caregivers also reported the need to train others, including service providers, siblings, peers, and the public. Caregivers described situations when they instructed others to successfully interact with their child. Jennifer described teaching her friends how to interact with her son without infantizing him:

> In some of those moments it's a little bit awkward when I step in and kind of correct, for lack of better word, and had to explain like this is where he is with his speech. This is where he is with his cognitive ability. This is how you as an adult should talk to him and this is how he's going to talk back to you. Essentially trying to explain like, 'It's okay that you don't understand him. But it's not okay for you to talk to him like he's a baby.' Because he's not.

Jennifer and other caregivers also had to instruct people to handle unfamiliar interactions or communication modalities. Sometimes, caregivers needed to interpret their child's communication for other communication partners. Teaching also extended to advocacy efforts. Efforts to fight for the best interest of the child included adequate school accommodations, insurance authorizations, and medical and therapy services. Caregivers'

advocacy efforts also included their child's rights, such as the right to communicate and

participate in their community. Nicole described her son's right to communicate after his

teacher removed his high-technology AAC system: "Taking away the whole speaking device…

they didn't want to listen to him (waves hand away). That's another no-no… Just like you or me

talking, they have the right to talk." The timeframe of advocacy was important for caregivers.

Earlier advocacy led to more time with a desired outcome, including a diagnosis or intervention.

For some caregivers, advocacy came naturally. For others, advocacy was intimidating and

difficult. However, successful advocacy was often influenced by caregivers' knowledge and

ability to navigate educational, medical, and therapeutic systems.

There is a mismatch between expectations and current realities.

Caregivers described the complexities of managing a disconnection between what they

expected for their child's life and their current reality. Caregivers recognized these expectations and the

process of grief was necessary to cope with the mismatch.

Expectations. For most caregivers, expectations were realized through a deviation from the

"normalcy" that was anticipated for parenthood and the child. Caregivers established ideas of

what would or would not happen based on their perceptions of the child's potential for success,

opportunities, limitations, or entitlement of services. Many caregivers described the need to set

high expectations to maximize their child's abilities. In response to high expectations, some

caregivers were pleasantly surprised by their child's accomplishments. After introducing a low-

technology AAC system and visual schedule, Angela reported feeling surprised by her son's rapid

success:

> Early on in using the pictures and the picture schedule, there were a lot of those
>
> moments… Almost like a "Oh my gosh! Is this all it takes is showing him a picture of you
>
> know, something and then he understands it? Why didn't I think of this before?"

Some caregivers also described instances when their child was unable to keep up with high expectations. Emily expected that her daughter would have more independent play skills at an earlier age. Instead, her daughter needed support to engage in play: "She's almost 5 and then I don't want to always be engaged with her, because she has to learn how to [play]."

Some caregivers discussed expectations related to the development of verbal speech. For example, Danielle talked about her initial concerns about AAC hindering her son's future development of verbal speech: "I was nervous that it would stop progress with any verbalization." Scott continues to feel this concern about the impact of AAC on verbal speech:

> We got the Tobii Dynavox… still I'm like as a dad, why aren't you guys getting a speech pathologist in here and figuring out the ataxia (gestures to face) that caused this in the first place, right? Go back up chain and figure out where it is here, instead of just giving him an out, right? We don't want the crutch. We want to fix the ataxia.

Caregivers' expectations for the child often determined the quantity and quality of support that the child was anticipated to need, as well as the goals that the child was expected to achieve. Caregivers identified goals based on a desired benefit for the child. Some caregivers described goals related to happiness and well-being, like Nicole: "I don't want anything else, just as long as he's happy, I don't care what else." Other caregivers emphasized independence and life skills, including the use of AAC modalities. Christine reflected on her daughter's speech therapy sessions: "They work on concepts or work on a certain core word or whatever, but my biggest thing is helping [Child] develop into the most independent, happy person that we can." Regarding her daughter's high-technology AAC system, she said, "I just wanted [Child] to be successful and be able to use this." Other caregivers described goals for their child's verbal communication. Elizabeth described her daughter's recent progress with verbal speech:

> We don't hear anything about what happened during the day, so just the idea that like

maybe she'll get there to be able to like repeat back something about what she did for

the day is just really exciting to us.

Grief. Some caregivers described grief when coping with the mismatch between expectations

and current realities for themselves and their child. This was often characterized by worry and

fear of the future, often in regards to communication. A few families specifically described how

verbal speech was a pathway for success versus failure in life. Emily described her fears for her

daughter's future opportunities, friendships, and education. In contrast to the other facets of

her daughter's diagnosis, she said, "It's the speech that's just very stressful because it affects

everything in life." Some caregivers in the high-stress group specifically described fears and grief

related to the introduction and use of aided AAC modalities. Scott described this feeling:

We didn't want him to divert into the Stephen Hawking kind of lifestyle as brilliant as he

was. We didn't want to see that for [Child] when he's 30 years old is pushing the buttons

and it's really heartbreaking for a parent to see a baby doomed to that for 30, 40, 60

years. It's just heartbreaking.

Caregivers described a long-process to reach acceptance. To cope with grief and fear,

some caregivers sought information to diminish future unknowns. A new diagnosis did not

automatically result in resolution of fears through a clearer picture of the child's future. Danielle

wanted to see other children with the same diagnosis as her son, but she later identified that

each families' journey is different: "You're not going to find your son in the future or daughter in

the future through somebody else." Through the process of acceptance, some caregivers were

able reach feelings of joy.

Comparison. Most caregivers described many instances of comparison. Comparison included

times when caregivers' experiences of parenthood were compared to the experience of other

caregivers. Comparison also included when the child was compared to another child or a

hypothetical "norm." This was especially magnified in comparisons to siblings, resulting in the

identification of differences in each child's verbal speech development, parenting needs, and

energy demands. Comparisons related to diagnosis and severity of needs also occurred. This

comparison was often the impetus for the initiation of the diagnostic process.

Responsibilities are Diverse, Constant, and Long-Term

Caregivers' responsibilities are not isolated to strictly the tasks related to AAC and facilitating their

child's communication. Some caregivers emphasized the number of responsibilities they fulfill, while

other caregivers emphasized the long-term nature. Together, responsibility to fulfill these needs was

universal.

Caregiver responsibilities. Caregivers had additional responsibilities beyond communication-

related tasks. Responsibilities were often embedded in daily routines, such as assisting their

child with medical care and activities of daily living, stretches and exercises, and constant

attention due to safety, medical emergencies, the child's communication modalities, or the

child's desire for attention. Caregivers coordinated schedules, including school, therapy,

playtime, quiet time, family time, errands, time outdoors, and sibling activities. For some

families, the daily routine had less structure, new environments, and more community outings

on the weekends than weekdays, which brought different challenges. Many caregivers reported

their child appreciated a strict routine. However, the COVID-19 pandemic directly altered daily

routines, characterized by less change in environment or interaction, but allowed for

exploration of new preferred activities.

Caregivers also described a constant need to manage multiple demands, life

commitments, and stressful events. This included day-to-day family operation, including work,

household chores, and finances. For most caregivers, responsibilities also included multiple

children with their own unique needs, activities, and schooling. Like responsibilities, the

management of siblings' routines was altered by the COVID-19 pandemic. Some caregivers also cared for aging parents. When discussing educators' and therapists' understanding of her life, Angela reported:

> I feel like I have to explain to people that (laughs) I have a full-time job. You know, like I work. My husband works. We have an older son. We have a dog. You know, we have elderly parents. We have like all the same things that everybody else has…

Caregivers' decisions for their child's medical, therapeutic, and educational plan were often complicated by the presence of multiple concerns. Scott described the connected nature of these decisions for his son's therapy: "He needs that to build muscle to actually function and be able to sit up straight and walk and then, of course, that ties into OT, because you can't push a button unless you have a good core strength."

Caregivers' responsibilities were described as long-term, requiring stamina and a sustained effort. They discussed the lengthy process of speech and communication development, demanding patience and persistence. Heather described her advice for other families based on her daughter's recent progress in speech therapy: "…Stick with therapy (shakes head) no matter what. I mean we have gone to so much speech therapy where I've thought you know, what are we doing? So definitely like keep up with therapy."

Caregivers' current job and professional role also contributed to the number of competing demands. Employment impacts caregivers' time, flexibility, involvement, and physical proximity to their child's care. Like other facets of routines, the COVID-19 pandemic impacted many caregivers' employment status, hours, or physical location. Caregivers' employment also contributed to their expertise. For those in the educational and medical fields, additional knowledge was reported to be helpful, but also complicated their child's care. Jennifer, who had a background in the education field, reported: "I know what I'm talking about when it comes to

his education and even just little things like how he communicates and his teachers don't know

sign language." Heather, a nurse, stated, "It's definitely given me a better capability in terms of

medically managing [Child] with the caveat of I now know more, so there's also more to worry

about because sometimes ignorance is bliss." Some caregivers explicitly described their

employment as a valuable part of their identify beyond the role of caregiver of a child using

AAC. However, some caregivers, exclusively in the high-stress group, identified ways in which

their child or child's care impeded their ability to perform their job. Tina described the

experience of struggling to find adequate childcare during her workday:

> It's been extremely challenging kind of figuring out how I can stay employed and having
>
> somebody to take care of her. I can't go to work at 10 (laughs). There's no such work
>
> day like that. So, the option is do I leave my work or my job or what do I do? Because my
>
> job's really important to me too. Like I don't I don't want to have to give up my job.

Complex diagnoses. Caregivers discussed multiple diagnoses, often requiring the involvement of

multiple medical and educational professionals. Most caregivers suspected diagnoses before a

diagnosis was officially given. Regardless of prior knowledge, the diagnosis was frequently hard

to process. The diagnosis was a critical point (prenatal, perinatal, first months of life, or years

into life) during which caregivers process acceptance or determine next steps. Diagnosis was

also described as the gateway for services. Caregivers described experiences with many

diagnoses, including: autism spectrum disorder, apraxia of speech/movement, feeding disorder,

dysphagia, oral aversion, hearing loss, seizures/epilepsy, ataxia, transplant, visual impairment,

sensory impairment, medically fragile/complex, cerebral palsy, Down syndrome, syndrome, and

executive function impairment.

When discussing the impact of diagnoses on children, caregivers primarily described

their child's verbal speech, receptive language, and fine and gross motor skills. They discussed

the child's ability to verbally communicate, characterized by any attempts to verbalize, overall intelligibility, and use of verbal speech across communication functions. For Tina, this included restriction to primarily labeling. Angela's daughter predominantly used speech to request. Caregivers described the negative impact of their child's limited verbal speech on their own communication due to the one-sided nature of the interaction. Some families observed recent progress in their child's verbal speech, such as imitation and increased independence and confidence. When progress occurred, caregivers shared feelings of substantial excitement and celebration.

Unlike verbal speech, most caregivers identified the child's level of understanding or comprehension of communication as a relative strength. However, the child's understanding was a limiting factor during critical times, such as hospitalizations, being told "no," or understanding changes during the COVID-19 pandemic. Some caregivers described their child's receptive language as critical to their own recognition of the child's abilities. For example, Michelle described a bedtime routine with her daughter:

> One night, I remember saying, 'Scoot up in your bed.' Because I just talked to her when I was putting her to bed and she scooted up! I was like, 'Oh my gosh. You understood what I said to you.' I had no idea up until that moment that she understood anything that I said to her. There was no indication, because she would never talk to me.

> Similarly, Danielle reported a conversation with her husband near her son: "We were talking about autism in front of him once and he got a little sad. And I'm like 'Okay, we can't have these conversations in front of him anymore.'"

Some caregivers reported diagnoses were complicated by fine and gross motor concerns, such as difficulties with activities of daily living or mobility impairments. However, for a few caregivers, gross motor skills differed from communication skills due to substantial and

visible progress.

Unexpected events. Caregivers also managed unexpected events, characterized by deviation from a normal routine, resulting in a moment of crisis or increased stress. Many of these unexpected events were medically-related with a change in the child's level of function, such as seizures, critical illness, hospitalization, and surgery. Some caregivers felt that the risk of these medical emergencies and illness increased with COVID-19. Caregivers' experiences with crisis medical situations were often complicated by a change in the child's communication status, inhibiting the use of established communication modalities or impairing the caregiver's comprehension of the child. As a result, caregivers relied on intuition with variable levels of success.

Caregivers' experiences with unexpected events were frequently described as a loss of control. This included elopement, in which a child unexpectedly left an environment, such as running away from home. Other examples included the child crying or destroying property in a public place or during the caregivers' workday. Caregivers also described the loss of control that occurred with the COVID-19 pandemic.

Group differences emerged when caregivers described unexpected experiences. Every caregiver in the high-stress group discussed the overwhelming impact of judgment during a profoundly stressful situation. Angela recalled a recent trip to a store when her son became upset about a toy:

> I had to pick him up, try and carry him out of the store and it's just difficult to like get through aisles and open the door and people are staring at you. To have an end (laughs) so badly was disappointing and also to feel judged by other people (voice cracks). There were a lot of people staring at us and that's hard.

Michelle described a similar situation when her daughter unexpectedly left the house:

There's been a couple of instances when she ran away from home just because my kids

left the door open and then couldn't find her and the neighbors found her and brought

back and there was a lot of judgment.

The role of judgment during unexpected events was exclusively identified in the high-

stress group. The participants in the low- and mid-stress groups did not report judgment as an

impactful element during particularly stressful situations.

Support is often Inadequate

Caregivers shared many experiences during which mechanisms of support did not meet their

standards. Inadequate support resulted in additional demand on caregivers. In response, caregivers

have developed preferred characteristics for support systems. When support systems have all of the

desired characteristics, they were better able to meet the needs of children using AAC, as well as their

caregivers. For some caregivers, the stability of the entire support network was negatively impacted by

extrinsic factors, such as moving or the COVID-19 pandemic.

Qualifications. Caregivers shared specific qualifications that determined the adequacy of a

specific support. For some caregivers, the presence of these qualifications is determined based

on specific training, skills, or traits. However, other caregivers intuitively identified whether the

support met the expected qualifications.

Caregivers reported a shared emphasis on trust, characterized by the belief that their

child was safe when left alone with an individual or in a new environment. This trust related to

the ability to understand the child's communication modalities, handle medical emergencies,

and provide appropriate care for the child. For several caregivers, trust also required constant

attention, a critical element to notice the child's communication initiations, as well as keep the

child safe. Elizabeth included this qualification when describing her reluctance to accept help

with childcare: "I think our biggest worry is that she will put something in her mouth and choke

on it honestly and that you're not paying attention to her." Establishing trust was described as a long process with required training and testing. However, once trust was achieved, it diminished caregivers' worry for the well-being of their child.

Caregivers' preferred supports were timely, characterized by early access to a diagnosis, medical care, intervention, or AAC modality. Nicole described her desire for her son's earlier access to the iPad® with Proloquo2Go: "He does amazing but I kind of wish we would have started earlier, and (pause) I mean at least with a device." Jennifer also described wanting earlier access to AAC for her son based on his potential for success, stating, "I think he'll get there and so I wish that we had started earlier." Timely support also included someone "on-call" to meet urgent needs, such as behavior management on a particularly hard day.

Caregivers described adequate support as validating with explicit recognition of the caregivers' decisions, effort, knowledge, or expertise. For many caregivers, this was linked to the child's progress in various skill areas. Danielle described this feeling during her son's appointment with a developmental pediatrician:

But he was so complementary and like you know, went through all of the things that he would normally suggest for where we're at. We were doing them… And it felt really good to have that validation to know that we were on top of it. We were doing the right things. And just to have the validation and the advice for things that you know, maybe the path isn't 100% clear for us. Just to have that expert weigh in and encourage us and help direct us is really valuable.

Caregivers reported adequate supports were individualized. Often, this was in the form of individualized interventions designed specifically for a child, reflecting strengths and weaknesses, current communication modalities, personality, preferences, and diagnoses. Individualized supports were also evident in caregivers' discussions of the feature matching

process to determine the most appropriate AAC modality for their child. Individualized interventions explicitly worked toward progress and growth of the child. To deliver an individualized intervention, a service provider exerted visible effort, asked questions, and showed a willingness to learn. In the absence of an individualized approach, caregivers encountered the adoption of a candidacy model, in which criteria were used to determine eligibility for services. Children were described as too young, not ready, or not skilled enough to benefit from a specific intervention, frequency of treatment, or AAC modality.

Multifaceted. Caregivers' ideal support network met multiple support needs. Rather than standalone supports, caregivers described value for supports that met informational, social, tangible, and emotional needs. For example, some caregivers mentioned diagnosis-related foundations and symposiums as invaluable. During foundation symposiums, families were able to meet with medical providers who had a significant understanding and familiarity with a specific diagnosis, which met tangible and informational support needs. Symposiums also met social needs, as caregivers were able to interact with other caregivers and their children with the same diagnosis.

Informational support influenced caregivers' expertise and future decision-making. For most caregivers, informational support was needed to learn about AAC modalities and the integration of AAC in the home setting. For some caregivers, the most reliable informational support was from other caregivers of children with disabilities. To meet informational support needs, many caregivers felt they had to do their own research to access adequate information.

Caregivers received social support from friends, family, paid workers, neighbors, support groups, churches, and social media platforms. Interactions with inadequate social support required the caregiver to teach and navigate judgment, rather than receive social support. Many caregivers had less social support than they desired, especially with regard to family. Adequacy

of social support was facilitated by physical proximity, inclusion, and comfort with the child's

communication and diagnosis. Some caregivers continued to describe other caregivers of

children using AAC as the most understanding support, resulting in a feeling of camaraderie.

When describing his interactions with friends, Brian stated, "You just see that lack of

understanding mixed with discomfort mixed with 'I'm going to try to give a good platitude…'"

Each caregiver described the social support offered by a coparent. For some caregivers, this

relationship was a close partnership with constant communication. The roles of coparents

differed based on expertise, effort, or designated responsibilities in the child's care.

Tangible support included both people and resources that met a specific need or solved

a problem. However, caregivers continued to be responsible for managing and coordinating

tangible supports. Caregivers referenced care providers (i.e., pediatrician, developmental

pediatrician, audiologist, dentist, eye doctor, endocrinologist, geneticist, genetic counselor,

neurology, sleep neurologist, infectious disease doctor, childcare providers, masseuse), vendors

(wheelchair, technology, and AAC vendors), insurance, researchers, and case management as

tangible resources involved in meeting the child's needs. School was described as a tangible

support to address the child's educational and social skills, AAC modalities, and communication

support. Therapy included speech therapy, occupational therapy (OT), physical therapy (PT),

play therapy, hippotherapy, and behavior therapy (ABA). School and therapy changed

substantially during COVID-19, which impacted the setting, the child's participation, and in some

instances, the child's progress.

Other tangible supports included help with household tasks, like laundry pick-up and

grocery delivery. For some caregivers, tangible supports were related to their physical

environment, such as the size and accessibility of their home, locks and childproofing tools, and

their proximity to school or medical care. Heather and Angela discussed the importance of their

own mental health support to navigate anxiety and the feelings of isolation: "Thankfully, I have a wonderful therapist and she's also a psychiatrist so she helped. She prescribed an anti-anxiety med for me so that's helpful" (Heather).

Some caregivers reflected on the financial and knowledge barriers that impede access to adequate supports. Emily felt confident in her access to services for her daughter, but reflected on limitations other families may experience: "I think of families that that don't have, for X number of reasons, either why they don't or why they can't access all those resources and that's what makes me really sad and frustrated that the system isn't easier." For some families, caregivers had to "pull strings" to access adequate tangible supports.

Emotional support was described in tandem with informational, social, and tangible supports. Often, caregivers discussed the need for emotional support related to their child's diagnosis or feelings associated with caregiving of a child using AAC.

Collaborative. Caregivers felt that multiple parties needed to work together toward a shared goal for the child's communication and quality of life. Shortcomings in collaboration were amplified during multisystem processes, such as the AAC funding process or IEP meetings. Caregivers defined collaboration as effective communication between multiple providers. Brian described this: "It's really great to be able to have all of us communicate pretty much simultaneously, as opposed to them telling me, me forgetting half of it (laughs), and then communicating it to half of the people." Tina also described communication between care providers: "That was one of the most frustrating things was that like at school they're saying they want one thing, but her private speech therapist is wanting something else. And we want everybody to work together. So that was hard." Caregivers also desired communication between themselves and care providers. This included listening and recognizing caregivers' expertise, as well as providing instruction related to an intervention.

Discussion

The purpose of this study was to investigate contributing factors of stress in adult caregivers of children using AAC. Quantitative results suggest caregivers' stress differs with characteristics of the family microsystem and macrosystem. While caregivers' stress did not differ with the child's communication modality or the child's age, it did increase based on level of education and number of siblings without medical or educational diagnoses. Family support also did mitigate caregivers' stress. However, overall level of stress has changed in the last two decades. Jones and colleagues (1999) reported that caregivers of children using AAC did not have clinical levels of stress. In the current study, more than 15% of caregivers reported high or clinical levels of stress, suggesting a change in caregivers' experiences of stress over time.

When the quantitative and qualitative results are integrated to explain and contextualize the phenomenon (Bowen et al., 2017), caregivers' experiences of stress are better understood. As suggested by Mandak and colleagues (2017) in the proposed family systems framework for family-centered AAC, children using AAC are embedded within a family and multiple enveloping systems. In the most immediate system, caregivers have a critical role and impact on their child. Caregivers' expertise, characterized by intuitive and experiential knowledge, guides decision-making and intervention planning. Caregivers navigate decisions about readiness for AAC, their child's required level of support, and the adequacy of their services. Expertise also influences the patterns of interactions in the caregiver-child subsystem (Minuchin, 1985). Caregivers often communicate less with their child due to the one-sided nature of verbal interactions, contributing to restricting interaction patterns (Light et al., 1985a, 1985c; Pennington & McConachie, 1999). However, caregivers understand more of their child's communication than unfamiliar communication partners. They facilitate their child's communication both in the home and in the community as the most primary communication partner (O'Neill & Wilkinson, 2020). This can be overwhelming, especially with respect to the lack of training and support

caregivers receive (Bailey, Parette, et al., 2006; Borg et al., 2015; Crisp et al., 2014; Donato et al., 2014; Glacken et al., 2019; Goldbart & Marshall, 2004; Moorcroft et al., 2019b; Singh et al., 2017).

For clinicians delivering AAC services, incorporating caregivers' expertise into AAC interventions is a critical ingredient to success. The implementation of this approach requires clinicians to steer AAC interventions away from traditional service delivery models in which the child is decontextualized from their family system. Instead, sustainable AAC service delivery is informed by caregivers' intuitive and experiential knowledge and is embedded within natural environments. Caregivers are capable of guiding intervention planning and goal development through their familiarity with the child's strengths and weaknesses, family priorities and values, and expectations for the future. Clinicians are then responsible for the implementation of caregiver-specific training within AAC service delivery. With increased expertise over time, caregivers' training needs will shift, but clinicians must provide continuous guidance for caregivers to support their child's communication and remain an integral member of the AAC team longitudinally.

In other subsystems, caregivers receive or provide support to other family members, such as coparents, spouses, and other children (Minuchin, 1985). When these other family members are unable to provide support for the caregiver, the caregivers compensate. The caregiver supports that family member and their interaction with the child using AAC. This includes providing emotional support to help a spouse to cope with new diagnoses or teach a new AAC modality for interaction with the child. This experience mirrors the lack of significant impact of marital status on caregivers' stress identified in the quantitative aim of this study. Caregivers' support in other family subsystems may also include interpreting a child's communication for a sibling or providing instruction to the sibling on how to best interact. The demand associated with this responsibility was evident in the quantitative findings, as the number of children without medical or educational diagnoses added to caregivers' stress level. The inclusion of caregivers during AAC clinical decision-making not only creates the space to share their

expertise, but prepares caregivers for the additional responsibility to intervene in multiple family subsystems following the introduction of a novel AAC modality or intervention. Caregiver training requires the inclusion of AAC-specific strategies to successfully fill the intermediary role between subsystems.

Beyond the family microsystem, children are also impacted by other systems. This study suggests the support a family receives is a valuable mechanism to mitigate stress in caregivers of children using AAC. The most preferred support systems are able to meet multiple needs: informational, social, tangible, and emotional. Mechanisms of support are not preferred if they strictly address one need. For example, in the absence of emotional responsivity and support, information from medical providers is not optimum. Friends and family (social support) who feel comfortable to meet a tangible need through babysitting are more valuable than the social supports that do not. Lack of appropriate support leads to feelings of exclusion and isolation, which negatively impacts the participation of both children and their caregivers across environments. In both this study and past literature, caregivers have described other families of children with disabilities as a valued support network (K. L. Anderson et al., 2014; O'Neill & Wilkinson, 2020). Caregivers have a substantial value for support from people who can understand their lived experiences. Other caregivers of children with disabilities or using AAC are consistently able to meet multiple support needs with a unique understanding of caregivers' experiences.

Due to a lack of offered or available supports, caregivers must seek support (K. L. Anderson et al., 2014; Moorcroft et al., 2019a, 2019b; O'Neill & Wilkinson, 2020). This study identified inadequacies in the availability of support. Although many caregivers in the qualitative portion of this study shared they were able to successfully seek and receive desired services for their child, many shared frustrations with the complexity of the "system." Caregivers felt that other families who do not meet certain prerequisite criteria, such as higher education, extensive time to research, or thorough understanding of

medical care, cannot successfully access services for their child. These frustrations also reflect the

number of individuals involved in the care of children using AAC. The list of AAC stakeholders is

extensive (Binger et al., 2012). However, caregivers report that not all AAC stakeholders are qualified to

successfully accommodate families' needs. Caregivers constantly evaluate the effectiveness of an

intervention or the service provider's ability to provide a valuable service. Caregivers' mechanisms of

evaluation differ, but consistently include the qualifications of trust, timeliness, validation, and

individualization of services to their child's needs.

Caregivers' reflections on the value of support suggest a larger number of support systems is not

necessarily indicative of better support. Thus, for caregivers of children using AAC, the quantity of AAC

stakeholders is less impactful than their ability to provide support across multiple needs. To best

support caregivers, professional AAC stakeholders must refocus collaborative efforts on the

identification of caregivers' support needs and interprofessional practices to meet those needs. Notable

support needs included caregivers' foundational knowledge and ability to successfully navigate medical

and educational systems. This requires the provision of information for caregivers to navigate complex

systems in order to identify and receive desired services for their child, including referrals and funding

mechanisms. It also requires advocacy, research, and policies to reduce the substantial barriers to entry

that impede the identification and receipt of services. Caregivers also desire the information to

participate in the beginning stages of aided AAC introduction. Without this, they feel a lack of

competence and confidence to actively engage in this process by asking questions and problem solving.

This requires professional AAC stakeholders to provide information and resources, such as AAC vendor

websites, blogs, videos, and books, in enough time for caregivers to use them. Beyond professional AAC

stakeholders, caregivers' reports of feeling judged by others reveal a perception that society is unable to

appropriately accommodate the needs of children using AAC and their caregivers. For some caregivers,

this prevents many opportunities, such as community outings. Though macrosystem-level changes are

necessary to prevent the discrimination and exclusion of individuals with disabilities, the provision of the resources and tools for caregivers to successfully advocate for the inclusion of their child across settings may also contribute to this identified need.

Homeostasis is the adaptive self-stabilization and adaptative self-organization of family systems as a result of changes (Cox & Paley, 1997; Minuchin, 1985; Sutphin et al., 2013). In this study, interruption of homeostasis of the family system occurred frequently. To compensate for interruptions, caregivers described different strategies, which varied in effectiveness. The COVID-19 pandemic has substantially impacted families of children using AAC. With the sudden need to adapt to a new schedule with more time at home, virtual school and therapy, and working from home, some families effectively self-organized. They adopted new strategies, like more communication with their child or the engagement in new hobbies. Other families did not adopt effective strategies and therefore, caregivers and children alike were left frustrated and desperate to return to their pre-pandemic routines. A similar process was described following a new diagnosis or the introduction of a new aided AAC modality. Caregivers often needed to process and grieve after a new diagnosis to reach a point of acceptance. Without navigating feelings of grief and denial related to the child's disability, caregivers report lack of emotional resilience to consistently facilitate the child's use of AAC modalities (Moorcroft et al., 2019a). When aided AAC was introduced by therapists or educators, some caregivers immediately initiated adaptive self-organization, resulting in the acceptance of aided AAC modalities as a strategy to facilitate the child's independence. Other families described reluctance and concern about the impact of AAC modalities on existing family patterns, such as use of an unaided AAC modality and the long-term goal of strictly verbal speech. The role of counselors and social workers has not been thoroughly explored specific to AAC, but may play an integral role in the successful adaptation of family systems following the introduction of AAC modalities or interventions. The list of AAC stakeholders requires expansion to include mental health workers to support family's short-term and long-term needs.

Caregivers' shared experiences are unique and complex, but understanding is necessary to deliver true family-centered services. To integrate these findings into clinical practice, clinicians supporting children using AAC are responsible for adopting a holistic lens, contextualizing children within their family system (Minuchin, 1985). Historically, training has been reported as an area of weakness in clinical practice after the introduction of AAC (Glacken et al., 2019; Moorcroft et al., 2019b; Singh et al., 2017). Lack of appropriate support directly contributes to the risk of AAC abandonment (J. M. Johnson et al., 2006). Service providers can directly influence whether training needs are met for caregivers to successfully integrate AAC into the home setting. Members of the AAC team should aim to understand the family microsystem, as well as less immediate systems. Following the identification of barriers and supports, service providers can work with families to identify solutions (Mandak et al., 2017). With an understanding of families' needs, priorities, and current mechanisms of support, service providers are more equipped for adequate family-centered service delivery (Dunst, 2002). Caregivers who advocate, support the use of AAC modalities, and have high expectations are "perceived as a valuable input" (Chung & Stoner, 2016, p. 179). Service providers are responsible for the support and empowerment to help caregivers fulfill this role (K. L. Anderson et al., 2014; Parette et al., 2000).

Limitations

Participants in this study self-identified as caregivers of a child with AAC needs for communication who uses AAC. This may have resulted in a selection bias, limiting the participation of those who do not identify AAC needs due to lack of familiarity with AAC. Participation also required time and internet access to complete the survey and interview. Data for this study are characterized by participants' self-report. Participants' responses may not be a wholly accurate representation of their experiences of stress and support, characterized by modification of responses due to discomfort or emotional response. The FSS, an instrument used in this study, was used previously with this specific clinical population in only one identified, peer-reviewed study. The other instrument, the PSI-4-SF, was

not used in any identified study with this specific clinical population. The full-length Parenting Stress

Index™ was used by Jones et al. (1999) in the only known study of stress in caregivers of children using

AAC.

The research methods of this study also have limitations. The quantitative aim of this study is

exploratory. Based on the selected method of analysis, replication is necessary with a larger sample to

confirm the significance of the identified predictor variables on caregivers' stress. This study's qualitative

results cannot be generalized due to the goal of the qualitative methodology.

Future Research

Currently, caregivers' involvement as interventionists is increasing with the implementation of

communication partner interventions in the field of AAC. However, these interventions are not tailored

for specific communication partners' needs, background knowledge, and capacity. Caregivers' unique

experiences of stress suggests this universal design may not be the most effective approach. Future

research is needed to develop and investigate caregiver-specific communication partner interventions,

including experimental research of interventions across stress strata. Future research is also needed to

investigate race and class inequities in AAC service provision and the resulting impact on caregiver

stress.

Funding

CHAPTER FIVE

CONCLUSIONS

Augmentative and alternative communication (AAC) supports the communication and

participation of an estimated 97 million people in the world (Beukelman & Light, 2020). The discipline of

AAC identifies pathways to achieve communication, interaction, and participation (Loncke, 2022). In the

past three decades, technological developments have advanced AAC systems and myths inhibiting AAC

service delivery have been debunked (Light & McNaughton, 2012b, 2015; Romski & Sevcik, 2005). The

initial adoption of a candidacy model was replaced by a Participation Model (Beukelman & Light, 2020;

Beukelman & Mirenda, 2013, 1988; Rosenberg & Beukelman, 1987). The candidacy model limited access

to AAC modalities and interventions based on specific criteria (Beukelman & Mirenda, 2013). Individuals

that did not meet the criteria were deemed "too something" (Beukelman & Mirenda, 2013, p. 107) to

benefit from the introduction and use of AAC, resulting in the exclusion of individuals from AAC service

provision based on age, impairment, communication status, perceived readiness, and other criteria.

Conversely, in the Participation Model, communication is assessed in the context of the individual's life

experiences, including employment, education, and social interactions, to maximize participation

(Beukelman & Light, 2020; Beukelman & Mirenda, 1988). The Participation Model emphasizes

consideration of both (a) the individual's capabilities and access barriers and (b) opportunity barriers

and supports during clinical decision making (Beukelman & Light, 2020; Beukelman & Mirenda, 2013,

1988). Since its original development, the Participation Model has been revised to include five specific

opportunity barriers and supports, which reflect environmental and communication partner factors. The

current revised Participation Model (2020) reflects the impact of policy, practice, knowledge, skill, and

attitude opportunity barriers and supports (Beukelman & Light, 2020).

Past research related to AAC service delivery models, assessment, and clinical decision making

has identified the importance of collaboration between the many members of the AAC team (Alant et

al., 2012; Bailey, Parette, et al., 2006; Bailey, Stoner, et al., 2006; Mandak et al., 2017; McNaughton et

al., 2008). Collaboration relies on the identification and mitigation of opportunity barriers, including the

knowledge, skill, and attitude barriers that inhibit integrated work toward a shared goal. Documented

shortcomings are observed in the provision of collaborative AAC services (Alant et al., 2012; S. Baxter et

al., 2012; Delarosa et al., 2012; McNaughton et al., 2008). This includes lack of open communication and

ineffective teaming between AAC stakeholders (Bailey, Parette, et al., 2006; Bailey, Stoner, et al., 2006;

McNaughton et al., 2008). Effective collaboration requires a shared value for collaboration, respect,

communication, and environmental and organizational processes that foster a culture of collaboration

(Batorowicz & Shepherd, 2011; Chung & Stoner, 2016). Successful AAC teams operate with flexibility

around roles and boundaries, which may not adhere to traditional siloes (Soto et al., 2001). Each team

member has a clearly defined role and specific area of expertise to offer (Binger et al., 2012; Soto et al.,

2001). Collaboration facilitates the AAC team's ability to address the unique needs of individuals using

AAC, as well as to deliver AAC services at an appropriate intensity (Ogletree, 2012). The direct impact of

collaboration is observed in the increasing use of communication partner interventions, in which

multiple AAC team members can participate in service delivery. Through this service delivery model,

communication partners' behaviors are shaped to improve the child's communication and limit their

exposure to predictive and inhibiting interaction patterns (Binger et al., 2008; J. M. Johnson et al., 2006;

Kent-Walsh et al., 2010, 2015; Kent-Walsh & McNaughton, 2005; Shire & Jones, 2015).

Despite years since the development of the original Participation Model and its subsequent

revisions (Beukelman & Light, 2020; Beukelman & Mirenda, 2013, 1988; Rosenberg & Beukelman, 1987),

AAC stakeholders lack consistent implementation of each of the Participation Model components.

Specifically, the systematic consideration for opportunity barriers and supports has been overlooked in

both research and clinical practice. Without explicit consideration for opportunity barriers and supports,

past research reveals downstream effects, including AAC abandonment (J. M. Johnson et al., 2006;

Moorcroft et al., 2019a, 2019b).

The body of literature is limited by lack of specific evidence for the (a) identification of opportunity barriers and supports across AAC stakeholders and systems, (b) AAC stakeholders' knowledge to mitigate of opportunity barriers, and (c) the implementation of opportunity supports. This dissertation applied the revised Participation Model (Beukelman & Light, 2020) to examine opportunity barriers and supports that impact the participation and communication of individuals using AAC. Specifically, this research explored opportunity barriers and supports reported by speech-language pathologists and caregivers of children using AAC. Without current and thorough data for the identification and amelioration of opportunity barriers and supports for these critical members of the interprofessional AAC team, clinical decision making using the revised Participation Model (2020)) is hindered. This dissertation achieved this purpose through three studies.

In a survey, Study One investigated characteristics of AAC service provision reported by post-professional speech-language pathologists. This study explored three aims:

1. Aim 1.1: Identify the characteristics of post-professional speech-language pathologists' perceived knowledge, use of AAC during service delivery, and feelings about AAC.

   - Hypothesis 1.1: Speech-language pathologists' perceived knowledge and use of AAC during service delivery will differ across competency areas and clinical populations.

2. Aim 1.2: Identify post-professional speech-language pathologists' perceived barriers to AAC service delivery.

   - Hypothesis 1.2: Speech-language pathologists will identify caseload, time, and knowledge as primary barriers to AAC service delivery.

3. Aim 1.3: Identify post-professional speech-language pathologists' learning preferences for AAC-related training.

   - Hypothesis 1.3: Speech-language pathologists will prefer an AAC intervention topic,

interactive format, and on-the-spot dosage for AAC-related training and continuing

education (CE).

The findings of Study One supported Hypothesis 1.1 and 1.2. Post-professional speech-language pathologists' perceived knowledge and use of AAC modalities varied across competency areas and clinical populations, respectively. They also identified caseload, time, and knowledge as primary barriers to AAC service delivery. Speech-language pathologists readily identified the barriers that hinder their ability to provide quality AAC services. However, disparities between patients' communication needs and AAC service delivery suggests speech-language pathologists can also directly act as opportunity barriers or supports, therefore impacting the participation and communication of individuals using AAC. The results of Study One also partially supported Hypothesis 1.3, as post-professional speech-language pathologists reported preferences for an AAC intervention topic, but not an interactive format or on-the-spot dosage for AAC-related training and CE. Instead, speech-language pathologists prefer course and virtual formats, as well as massed and distributed dosages. The body of literature lacks detailed evidence applying AAC competencies and adult learning principles to the development of specific recommendations to build post-professional speech-language pathologists' competencies for AAC service delivery. The results of this study indicate a variety of training formats and dosages are necessary to meet post-professional speech-language pathologists' training needs.

Study Two used a qualitative metasynthesis methodology to identify intervention barriers and facilitators to AAC use by school-aged children as perceived by parents, guardians, and caregivers. This research had one aim:

Aim 2: Identify caregivers' perceived intervention barriers and facilitators to AAC use by school-aged children who use AAC.

In this study, caregivers' perceptions of AAC interventions could not be reduced to a dichotomous outcome. Caregivers identified relationships, intervention implementation, caregiver

aspects, and resources as primary influencers on AAC interventions. All caregiver perceptions were

rooted in an assumption of direct or indirect child outcomes. These themes support a family-centered

service delivery model, in which caregivers are decision-makers and the family is explicitly included in

the AAC intervention. This expands on the growing body of evidence in support of communication

partner intervention, in which strategies are taught to immediate communication partners to facilitate

the communication of individuals using AAC across settings (Kent-Walsh et al., 2015). However,

caregivers' perceptions of AAC interventions identified in this study are not reflected in current

communication partner interventions. This study reveals the components necessary to tailor

communication partner interventions for families, rather than the currently targeted broad audience of

caregivers, therapists, educators, peers, and other AAC stakeholders (Kent-Walsh et al., 2015; Shire &

Jones, 2015).

Study Three used a mixed-methodology research design to investigate experiences and

contributing factors of stress in adult caregivers of children using AAC. This study had three aims:

1. Aim 3.1: Identify differences in level of stress reported by adult caregivers of children using AAC

    across frequency of aided AAC modality use.

    • Hypothesis 3.1: It is hypothesized that adult caregivers of children with more frequent use

        of aided AAC modalities will report more stress than adult caregivers of children with less

        frequent use of aided AAC modalities.

2. Aim 3.2: Identify differences in level of stress reported by adult caregivers of children using AAC

    across differing microsystem and macrosystem characteristics.

    • Hypothesis 3.2.1: It is hypothesized that adult caregivers of a younger child using AAC will

        report less stress than those with an older child using AAC.

    • Hypothesis 3.2.2: It is hypothesized that adult caregivers with more family support will have

        less stress than those with less family support.

3. Aim 3.3: Explore how adult caregivers of children using AAC describe their lived experiences of the phenomenon of stress.

The results of Study Three did not support Hypothesis 3.1 or 3.2.1. Adult caregivers' stress was not predicted by the child's communication modality or age. The results, however, did support Hypothesis 3.2.2, as caregivers with more family support reported less stress than caregivers with less family support. Caregivers' experiences of stress were characterized by five main themes: (a) People don't understand; (b) Caregivers need to fill the role of expert; (c) There is a mismatch between expectations and current realities; (d) Responsibilities are diverse, constant, and long term; and (e) Support is often inadequate. This study reveals the direct impact of families' enveloping systems on caregivers' lived experiences. Caregivers of children using AAC share many barriers to the sustainable integration of AAC modalities and interventions in the home setting, including lack of time, energy, and stamina. However, opportunity barriers can be addressed through effective support systems. Similar to Study Two, this study contributes to the body of literature in support of family-centered AAC service delivery models and communication partner interventions. However, caregivers of children using AAC have unique training and support needs that cannot be adequately addressed without specificity of the training to their lived experiences, priorities, and expectations for the future.

Summary

Despite integration of the revised Participation Model (Beukelman & Light, 2020) in clinical practice and research, opportunity barriers and supports have not been considered as equal to the individual's access needs and capabilities in the success of an AAC modality or intervention. The results of this research oppose this partial implementation of the revised Participation Model (Beukelman & Light, 2020). Instead, opportunity barriers are identified as a critical component to AAC service delivery and clinical decision making.

Speech-language pathologists identify the opportunity barriers that inhibit their AAC service

delivery, including their own perceived knowledge, use of AAC modalities, and post-professional training needs. Despite an increase in dedicated AAC pre-professional coursework as a result of ASHA certification standard changes (R. K. Johnson & Prebor, 2019), pre-professional coursework alone does not mitigate these identified opportunity barriers. However, outside of the specific context of their direct service provision, speech-language pathologists do not routinely identify the opportunity barriers that inhibit the communication and participation of individuals using AAC. As a result, the many opportunity barriers and supports embedded within enveloping systems, representing the holistic life experiences of the individual using AAC, are not reflected in speech-language pathologists' clinical decision making.

To deliver AAC services, speech-language pathologists collaborate with multiple other AAC stakeholders, including families and caregivers. They identify collaboration with families and caregivers as a relative strength in their clinical practice. However, caregivers consistently identify collaboration as a weakness among members of the AAC team. This results in an important disparity between current AAC service delivery and families' education and training needs. Without caregivers' guidance, the professional AAC team members are unable to make informed AAC recommendations for children using AAC with a thorough understanding of communication patterns across settings (Beukelman & Light, 2020). However, caregivers require long-term and consistent training, education, and support that reflects their priorities, needs, and values. Caregivers also need support from other systems beyond professional service providers. This support is best delivered by individuals who understand their life experiences and from those who can meet multiple support needs.

Augmentative and alternative communication interventions cannot be reduced to simply the introduction of a novel AAC modality, but must explicitly reflect the many systems that support or inhibit the participation of the individual using AAC (Beukelman & Mirenda, 2013; Mandak et al., 2017). To successfully implement the revised Participation Model (Beukelman & Light, 2020), AAC stakeholders

must look beyond the capabilities and access barriers of the individual during AAC assessment and intervention. This research demonstrates the need for AAC stakeholders, including speech-language pathologists, caregivers, and researchers, to recognize opportunity barriers and implement supports throughout all phases of AAC service delivery to facilitate the long-term participation and communication of individuals using AAC.

Implications

Implications for Speech-Language Pathologists

Most speech-language pathologists do not currently work as AAC specialists, but as general practitioners. On-the-job training and post-professional CE are important mechanisms to increase competence in AAC service delivery. Participation in post-professional training to meet individualized learning needs diminishes the impact of speech-language pathologists' barriers of reduced knowledge. This contributes to speech-language pathologists' competence and confidence to deliver AAC services. Training needs include the skills to implement family-centered service delivery models. When collaborating with families, speech-language pathologists require understanding of the families' needs, support systems, and expertise.

Implications for Pre-Professional Training

Speech-language pathologists' perceived lack of knowledge in specific content area informs the content areas that require additional instruction at the pre-professional level, including AAC interventions targeting literacy, aging, and end phases of life. Additionally, due to the importance of post-professional training and CE on speech-language pathologists' perceived knowledge in AAC service delivery, students require the knowledge to expand their competence and use of AAC modalities upon entering the workforce. This includes (a) how to identify mentorship opportunities and meaningfully participate as a mentee and (b) how to identify evidence-based CE.

Implications for Families

Caregivers' experiences are unique and complex, but also characterized by commonalities with other caregivers of children with disabilities. To fulfill the role of expert, caregivers research and identify resources, an independent task which often lacks support from other AAC stakeholders. The identification of resources requires time, effort, and background knowledge, which can inhibit the success of caregivers who are not well-versed in the medical or educational "system." This research magnifies the capacity of caregivers to use their intuitive expertise to support the best interest of their children.

Implications for Policy

This research contributes to the explicit value of collaboration in AAC service delivery. Policy changes are necessary for AAC stakeholders to consistently participate in collaborative partnerships. Through policy changes in medical, educational, and legal systems, clinicians can engage in collaborative practices by abandoning individual siloes to engage in interprofessional practices. Current service providers are most frequently evaluated based on billable time, characterized by caseload or productivity standards. However, many critical elements of AAC service delivery, including elements of collaboration, are considered unbillable and cannot always be completed during direct patient care encounters. Current payer sources cannot accommodate truly collaborative practices, limiting clinicians' ability to integrate this model into professional practice. Revision of these policies is necessary to accommodate collaborative practices.

At a large scale, caregivers' reports of exclusion reflect a lack of consistent inclusivity. Despite legal mechanisms to prevent the discrimination of individuals with disabilities in the United States (e.g., the Americans with Disabilities Act), society is often not accommodating to individuals using AAC and their caregivers. Education and advocacy efforts are necessary to achieve AAC as a "common phenomenon" (Loncke, 2022, p. 262), characterized by true inclusion in education, work, and

community settings. Inclusion as a pathway to increased opportunities for individuals using AAC. This inclusion requires the acceptance of non-speaking communication modalities as equal, meaningful, and valid.

Implications for Research

These studies serve as a foundation for future investigations to identify and mitigate opportunity barriers that inhibit the full participation of individuals using AAC. The field of AAC requires intervention tools, intervention methods, and service delivery models that are contextually relevant for individuals using AAC. The opportunity barriers require equal consideration in the theoretical and clinical application of the revised Participation Model (Beukelman & Light, 2020). Current service delivery models do not reflect the impact of environmental and communication partner contexts on communication and participation of individuals using AAC. Therefore, research to develop AAC assessments and interventions cannot solely investigate efficacy, but also effectiveness in real-world contexts. Without consideration for the true complexities of real-world settings, research has not applied the full extent of the revised Participation Model (Beukelman & Light, 2020).

Advancement of evidence-based educational and training practices is necessary to prepare pre-professional speech-language pathologists for AAC service delivery. This includes education and training to deliver AAC services across patient populations, as well as strategies to identify implicit biases. Additionally, the counseling components of family-centered care remain largely unexplored in the field of AAC. Speech-language pathologists require education, training, and resources to better engage in collaboration with counseling and mental health services. Based on the results of these studies, future research is also necessary to develop communication partner interventions tailored to the needs of specific communication partners, such as caregivers. Studies are needed to explore the development of caregiver partner interventions with methods to explicitly integrate caregivers' expertise. This may include the co-development of intervention goals and measurement of treatment fidelity changes as a

result of a truly collaborative partnership.

REFERENCES

Abidin, R. (1995). *Parenting Stress Index*. Lutz: PAR.

Abidin, R. (2012). *Parenting Stress Index—Fourth Edition*. Lutz: PAR.

Alant, E., Champion, A., & Peabody, E. C. (2012). Exploring interagency collaboration in AAC

intervention. *Communication Disorders Quarterly*, *34*(3), 172–183.

https://doi.org/10.1177/1525740112455432

Allen, A. A., Jeans, C., Ball, L. J., & Guarino, A. J. (2015). Caregivers' perception of the iPad's utility for

augmentative and alternative communication (AAC): A conflict between illusion and reality.

World Journal of Educational Research, *2*(1), 39. https://doi.org/10.22158/wjer.v2n1p39

American Speech-Language-Hearing Association. (2016a). *Code of ethics [Ethics]*.

https://www.asha.org/code-of-ethics/

American Speech-Language-Hearing Association. (2016b). *Scope of practice in speech-language*

pathology [Scope of practice]. www.asha.org/policy

American Speech-Language-Hearing Association. (2019). *2019 SLP health care survey: Survey summary*

report: Number and type of responses. https://www.asha.org/siteassets/surveys/2019-slp-hc-

survey-summary-report.pdf

American Speech-Language-Hearing Association. (2020). *2020 Schools survey: Survey summary report:*

Numbers and types of responses, SLPs. https://www.asha.org/siteassets/surveys/2020-schools-

slp-summary.pdf

Amundsen, S. (2014). *Augmentative-alternative communication access for individuals with*

communication disorders in medical settings [Master's thesis, University of Central Florida].

Electronic Theses and Dissertations, 2004-2019. https://stars.library.ucf.edu/etd/4582

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2014). Australian parents' experiences of speech

generating device (SGD) service delivery. *Developmental Neurorehabilitation*, *17*(2), 75–83.

https://doi.org/10.3109/17518423.2013.857735

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2015). Alternative service delivery models for families

with a new speech generating device: Perspectives of parents and therapists. *International*

Journal of Speech-Language Pathology, *17*(2), 185–195.

https://doi.org/10.3109/17549507.2014.979876

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2016). "It's got to be more than that". Parents and

speech-language pathologists discuss training content for families with a new speech generating

device. *Disability and Rehabilitation. Assistive Technology*, *11*(5), 375–384.

https://doi.org/10.3109/17483107.2014.967314

Arakkathara, J. G., & Bance, L. O. (2019). Promotion of Well-being, Resilience and Stress Management

(POWER): An intervention program for mothers of children with intellectual disability: A pilot

study. *Indian Journal of Positive Psychology*, *10*(4), 294–299.

Arora, N. (2017). Look at your blind spots. *The ASHA Leader*, *22*(11), 6–7.

https://doi.org/10.1044/leader.FMP.22112017.6

Assistive Technology Industry Association. (2017). *The critical need for knowledge and usage of AT and*

AAC among speech-language pathologists. https://www.atia.org/wp-

content/uploads/2018/12/ATIA-SLP-Survey-2011.pdf

Bailey, R. L., Parette, H. P., Stoner, J. B., Angell, M. E., & Carroll, K. (2006). Family members' perceptions

of augmentative and alternative communication device use. *Language, Speech, and Hearing*

Services in Schools, *37*(1), 50–60. https://doi.org/10.1044/0161-1461(2006/006)

Bailey, R. L., Stoner, J. B., Parette, H. P., & Angell, M. E. (2006). AAC team perceptions: Augmentative and alternative communication device use. *Education and Training in Developmental Disabilities*, *41*(2), 139–154.

Batorowicz, B., & Shepherd, T. A. (2011). Teamwork in AAC: Examining clinical perceptions. *Augmentative and Alternative Communication*, *27*(1), 16–25. https://doi.org/10.3109/07434618.2010.546809

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, *13*(4), 544–559. https://doi.org/10.46743/2160-3715/2008.1573

Baxter, S., Enderby, P., Evans, P., & Judge, S. (2012). Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: A systematic review and qualitative synthesis. *International Journal of Language & Communication Disorders*, *47*(2), 115–129. https://doi.org/10.1111/j.1460-6984.2011.00090.x

Beukelman, D. R., & Light, J. C. (2020). *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (5th ed.). Paul H. Brookes Publishing Co.

Beukelman, D. R., & Mirenda, P. (2013). *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (4th ed.). Paul H. Brookes Publishing Co.

Beukelman, D. R., & Mirenda, P. (1988). Communication options for persons who cannot speak: Assessment and evaluation. In C.A. Coston (Ed.), *Proceedings of the National Planners Conference on Assistive Device Service Delivery* (pp. 151–165). Association for the Advancement of Rehabilitation Technology.

Bevan, M. T. (2014). A method of phenomenological interviewing. *Qualitative Health Research*, *24*(1), 136–144. https://doi.org/10.1177/1049732313519710

Binger, C., Ball, L., Dietz, A., Kent-Walsh, J., Lasker, J., Lund, S., McKelvey, M., & Quach, W. (2012). Personnel roles in the AAC assessment process. *Augmentative and Alternative Communication*, *28*(4), 278–288. https://doi.org/10.3109/07434618.2012.716079

Binger, C. Kent-Walsh, J., Berens, J., Del Campo, S., & Rivera, D. (2008). Teaching Latino parents to support the multi-symbol message productions of their children who require AAC. *Augmentative and Alternative Communication*, *24*(4), 323–338. https://doi.org/10.1080/07434610802130978

Blackstone, S. (1999). Clinical news: Communication partners. *Augmentative Communication News*, *12*(1), 1–3.

Borg, S., Agius, M., & Agius, L. (2015). A user and their family's perspective of the use of a low-tech vs a high-tech AAC system. *Studies in Health Technology and Informatics*, *217*, 811–818.

Bowen, P., Rose, R., & Pilkington, A. (2017). Mixed-methods theory and practice. Sequential, explanatory approach. *International Journal of Quantitative and Qualitative Research Methods*, *5*(2), 10–27.

Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Paul, D., Romski, M. A., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, L., & Wilkinson, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities*, *121*(2), 121–138. https://doi.org/10.1352/1944-7558-121.2.121

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brinkmann, S., & Kvale, S. (2015). *InterViews: Learning the craft of qualitative research interviewing* (3rd ed.). SAGE Publications, Inc.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.

Butler, A., Hall, H., & Copnell, B. (2016). A guide to writing a qualitative systematic review protocol to enhance evidence-based practice in nursing and health care: The qualitative systematic review protocol. *Worldviews on Evidence-Based Nursing*, *13*(3), 241–249. https://doi.org/10.1111/wvn.12134

Campanelli, P. (2008). Testing survey questions. In de Leeuw, E.D., Hox, J.J., & Dillman, D.A. (Eds.), *International handbook of survey methodology* (pp. 176–200). Routledge.

Chung, Y.C., & Stoner, J. B. (2016). A meta-synthesis of team members' voices: What we need and what we do to support students who use AAC. *Augmentative and Alternative Communication*, *32*(3), 175–186. https://doi.org/10.1080/07434618.2016.1213766

Costigan, F. A., & Light, J.C. (2010). A review of preservice training in augmentative and alternative communication for speech-language pathologists, special education teachers, and occupational therapists. *Assistive Technology*, *22*(4), 200–212. https://doi.org/10.1080/10400435.2010.492774

Cox, M. J., & Paley, B. (1997). Families as systems. *Annual Review of Psychology*, *48*(1), 243–267. https://doi.org/10.1146/annurev.psych.48.1.243

Cox, M. J., & Paley, B. (2003). Understanding families as systems. *Current Directions in Psychological Science*, *12*(5), 193–196. https://doi.org/10.1111/1467-8721.01259

Cress, C. J. (2004). Augmentative and alternative communication and language: Understanding and responding to parents' perspectives. *Topics in Language Disorders*, *24*(1), 51–61. https://doi.org/10.1097/00011363-200401000-00006

Crisp, C., Draucker, C. B., & Ellett, M. L. C. (2014). Barriers and facilitators to children's use of speech-generating devices: A descriptive qualitative study of mothers' perspectives. *Journal for Specialists in Pediatric Nursing*, *19*(3), 229–237. https://doi.org/10.1111/jspn.12074

Critical Appraisal Skills Programme. (2018). *CASP qualitative checklist*. https://casp-uk.net/wp-

content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf

De Bortoli, T., Arthur-Kelly, M., Mathisen, B., & Balandin, S. (2014). Speech-language pathologists'

perceptions of implementing communication intervention with students with multiple and

severe disabilities. *Augmentative and Alternative Communication*, *30*(1), 55–70.

https://doi.org/10.3109/07434618.2014.881916

Delarosa, E., Horner, S., Eisenberg, C., Ball, L., Renzoni, A. M., & Ryan, S. E. (2012). Family Impact of

Assistive Technology Scale: Development of a measurement scale for parents of children with

complex communication needs. *Augmentative and Alternative Communication*, *28*(3), 171–180.

https://doi.org/10.3109/07434618.2012.704525

Dietz, A., Quach, W., Lund, S. K., & McKelvey, M. (2012). AAC assessment and clinical-decision making:

The impact of experience. *Augmentative and Alternative Communication*, *28*(3), 148–159.

https://doi.org/10.3109/07434618.2012.704521

Dillman, D., Smyth, J., & Christian, L. (2009). *Internet, mail, and mixed-mode surveys: The tailored design

method*. Wiley.

Donato, C., Shane, H. C., & Hemsley, B. (2014). Exploring the feasibility of the Visual Language in Autism

program for children in an early intervention group setting: Views of parents, educators, and

health professionals. *Developmental Neurorehabilitation*, *17*(2), 115–124.

https://doi.org/10.3109/17518423.2014.880526

Dunst, C. J. (2002). Family-centered practices: Birth through high school. *The Journal of Special

Education*, *36*(3), 141–149. https://doi.org/10.1177/00224669020360030401

Dunst, C. J., Trivette, C. M., & Jenkins, V. (1984). *Family Support Scale: Reliability and validity*.

Winterberry Press.

Dunst, C. J., & Trivette, C. M. (1988). Family Support Scale. In *Enabling and empowering families: Principles and guidelines for practice* (pp. 153–174). Brookline Books.

Erickson, K. A., & Koppenhaver, D. A. (2020). *Comprehensive literacy for all: Teaching students with significant disabilities to read and write.* Brookes Publishing Company.

Faul, F., Erdfelder, E., Lang, A.G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*(2), 175–191. https://doi.org/10.3758/BF03193146

Ferrer, H. B., Trotter, C., Hickman, M., & Audrey, S. (2014). Barriers and facilitators to HPV vaccination of young women in high-income countries: A qualitative systematic review and evidence synthesis. *BMC Public Health*, *14*(1), 700. https://doi.org/10.1186/1471-2458-14-700

Field, A. (2018). *Discovering statistics using IBM SPSS Statistics* (5th ed.). SAGE Publications, Inc.

Finlayson, K. W., & Dixon, A. (2008). Qualitative meta-synthesis: A guide for the novice. *Nurse Researcher*, *15*(2), 59–71. https://doi.org/10.7748/nr2008.01.15.2.59.c6330

Fowler, F. J., Jr., & Cosenza, C. (2008). Writing effective questions. In de Leeuw, E.D., Hox, J.J., & Dillman, D.A. (Eds.), *International handbook of survey methodology* (pp. 136–160). Routledge.

Fulcher-Rood, K., Castilla-Earls, A., & Higginbotham, J. (2020). What does evidence-based practice mean to you? A follow-up study examining school-based speech-language pathologists' perspectives on evidence-based practice. *American Journal of Speech-Language Pathology*, *29*(2), 688–704. https://doi.org/ 10.1044/2019_AJSLP-19-00171

Gewurtz, R., Stergiou-Kita, M., Shaw, L., Kirsh, B., & Rappolt, S. (2008). Qualitative meta-synthesis: Reflections on the utility and challenges in occupational therapy. *Canadian Journal of Occupational Therapy*, *75*(5), 301–308. https://doi.org/10.1177/000841740807500513

Glacken, M., Healy, D., Gilrane, U., Healy-Mc Gowan, S., Dolan, S., Walsh-Gallagher, D., Jennings, C., & James, N. (2019). Key word signing: Parents' experiences of an unaided form of augmentative

and alternative communication (Lámh). *Journal of Intellectual Disabilities*, *23*(3), 327–343.

https://doi.org/10.1177/1744629518790825

Goldbart, J., & Marshall, J. (2004). "Pushes and pulls" on the parents of children who use AAC.

Augmentative and Alternative Communication, *20*(4), 194–208.

https://doi.org/10.1080/07434610400010960

Gona, J. K., Newton, C. R., Hartley, S., & Bunning, K. (2014). A home-based intervention using

augmentative and alternative communication (AAC) techniques in rural Kenya: What are the

caregivers' experiences? *Child: Care, Health & Development*, *40*(1), 29–41. https://doi.org/

10.1111/cch.12031

Grant, M. J., & Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated

methodologies. *Health Information & Libraries Journal*, *26*(2), 91–108.

https://doi.org/10.1111/j.1471-1842.2009.00848.x

Hanley, B., Tassé, M. J., Aman, M. G., & Pace, P. (1998). Psychometric properties of the Family Support

Scale with Head Start families. *Journal of Child and Family Studies*, *7*(1), 69–77.

https://doi.org/10.1023/A:1022912130180

Harding, J. (2019). *Qualitative data analysis* (2nd ed.). SAGE Publications, Inc.

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual

disability: The effects of parental cognitions in relation to child characteristics and family

support. *Journal of Intellectual Disability Research*, *49*(6), 405–418.

https://doi.org/10.1111/j.1365-2788.2005.00673.x

Hays, D. G., & Singh, A. A. (2012). *Qualitative inquiry in clinical and educational settings*. The Guilford

Press.

Hettiarachchi, S., Kitnasamy, G., & Gopi, D. (2019). "Now I am a techie too"—Parental perceptions of

using mobile technology for communication by children with complex communication needs in

the Global South. *Disability and Rehabilitation. Assistive Technology, 15*(2), 183–194.

https://doi.org/10.1080/17483107.2018.1554713

Hocking, R. R. (1976). The analysis and selection of variables in linear regression. *Biometrics*, *32*(1), 1–49.

https://doi.org/10.2307/2529336

Høffding, S., & Martiny, K. (2016). Framing a phenomenological interview: What, why and how.

Phenomenology and the Cognitive Sciences, *15*(4), 539–564. https://doi.org/10.1007/s11097-

015-9433-z

Holly, L. E., Fenley, A. R., Kritikos, T. K., Merson, R. A., Abidin, R. R., & Langer, D. A. (2019). Evidence-base

update for parenting stress measures in clinical samples. *Journal of Clinical Child & Adolescent

Psychology*, *48*(5), 685–705. https://doi.org/10.1080/15374416.2019.1639515

Iacono, T., & Cameron, M. (2009). Australian speech-language pathologists' perceptions and experiences

of augmentative and alternative communication in early childhood intervention. *Augmentative

and Alternative Communication*, *25*(4), 236–249. https://doi.org/10.3109/07434610903322151

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004)

Jacob, S. A., & Furgerson, S. P. (2012). Writing interview protocols and conducting interviews: Tips for

students new to the field of qualitative research. *The Qualitative Report*, *17*(42).

https://doi.org/10.46743/2160-3715/2012.1718

Johnson, J. M., Inglebret, E., Jones, C., & Ray, J. (2006). Perspectives of speech language pathologists

regarding success versus abandonment of AAC. *Augmentative and Alternative Communication*,

22(2), 85–99. https://doi.org/10.1080/07434610500483588

Johnson, R. K., & Prebor, J. (2019). Update on preservice training in augmentative and alternative

communication for speech-language pathologists. *American Journal of Speech-Language

Pathology*, *28*(2), 536–549. https://doi.org/10.1044/2018_AJSLP-18-0004

Jones, S. D., Angelo, D. H., & Kokoska, S. M. (1999). Stressors and family supports: Families with children using augmentative & alternative communication technology. *Communication Disorders Quarterly*, *20*(2), 37–44. https://doi.org/10.1177/152574019902000205

Kent-Walsh, J., Binger, C., & Malani, M. D. (2010). Teaching partners to support the communication skills of young children who use AAC: Lessons from the ImPAACT program. *Early Childhood Services*, *4*(3), 155–170.

Kent-Walsh, J., & McNaughton, D. (2005). Communication partner instruction in AAC: Present practices and future directions. *Augmentative and Alternative Communication*, *21*(3), 195–204. https://doi.org/10.1080/07434610400006646

Kent-Walsh, J., Murza, K. A., Malani, M. D., & Binger, C. (2015). Effects of communication partner instruction on the communication of individuals using AAC: A meta-analysis. *Augmentative and Alternative Communication*, *31*(4), 271–284. https://doi.org/10.3109/07434618.2015.1052153

Kent-Walsh, J., Stark, C., & Binger, C. (2008). Tales from school trenches: AAC service-delivery and professional expertise. *Seminars in Speech and Language*, *29*(2), 146–154. https://doi.org/10.1055/s-2008-1079128

Kondrat, D., Swanke, J. R., Littlewood, K., & Strozier, A. (2015). Measuring social support among kinship caregivers: Confirming the factor structure of the Family Support Scale. *Child Welfare*, *93*(3), 19.

Light, J. C. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, *5*(2), 137–144. https://doi.org/10.1080/07434618912331275126

Light, J. C. (2003). Shattering the silence: Development of communicative competence by individuals who use AAC. In *Communicative competence for individuals who use AAC: From research to effective practice* (pp. 3–38). Paul H. Brookes Publishing Co.

Light, J. C., Collier, B., & Parnes, P. (1985a). Communicative interaction between young nonspeaking

physically disabled children and their primary caregivers: Part I - Discourse patterns.

Augmentative and Alternative Communication, *1*(2), 74–83.

https://doi.org/10.1080/07434618512331273561

Light, J. C., Collier, B., & Parnes, P. (1985b). Communicative interaction between young nonspeaking

physically disabled children and their primary caregivers: Part II - Communicative function.

Augmentative and Alternative Communication, *1*(3), 98–107.

https://doi.org/10.1080/07434618512331273591

Light, J. C., Collier, B., & Parnes, P. (1985c). Communication interaction between young nonspeaking

physically disabled children and their primary caregivers: Part III - Modes of communication.

Augmentative and Alternative Communication, *1*(4), 125–133.

https://doi.org/10.1080/07434618512331273621

Light, J. C., & Drager, K. (2007). AAC technologies for young children with complex communication

needs: State of the science and future research directions. *Augmentative and Alternative

Communication*, *23*(3), 204–216. https://doi.org/10.1080/07434610701553635

Light, J. C., & McNaughton, D. (2012a). *Literacy instruction for individuals with autism, cerebral palsy,

Down syndrome and other disabilities*. https://aacliteracy.psu.edu/

Light, J. C., & McNaughton, D. (2012b). Supporting the communication, language, and literacy

development of children with complex communication needs: State of the science and future

research priorities. *Assistive Technology*, *24*(1), 34–44.

https://doi.org/10.1080/10400435.2011.648717

Light, J. C., & McNaughton, D. (2014). Communicative competence for individuals who require

augmentative and alternative communication: A new definition for a new era of

communication? *Augmentative and Alternative Communication*, *30*(1), 1–18.

https://doi.org/10.3109/07434618.2014.885080

Light, J. C., & McNaughton, D. (2015). Designing AAC research and intervention to improve outcomes for

individuals with complex communication needs. *Augmentative and Alternative Communication*,

31(2), 85–96. https://doi.org/10.3109/07434618.2015.1036458

Light, J. C., McNaughton, D., Beukelman, D., Fager, S. K., Fried-Oken, M., Jakobs, T., & Jakobs, E. (2019).

Challenges and opportunities in augmentative and alternative communication: Research and

technology development to enhance communication and participation for individuals with

complex communication needs. *Augmentative and Alternative Communication*, *35*(1), 1–12.

https://doi.org/10.1080/07434618.2018.1556732

Lilienfeld, M., & Alant, E. (2005). The social interaction of an adolescent who uses AAC: The evaluation of

a peer-training program. *Augmentative and Alternative Communication*, *21*(4), 278–294.

https://doi.org/10.1080/07434610500103467

Littlewood, K., Swanke, J. R., Strozier, A., & Kondrat, D. (2012). Measuring social support among kinship

caregivers: Validity and reliability of the Family Support Scale. *Child Welfare*, *91*(6), 59–78.

Lohr, S. L. (2008). Coverage and sampling. In de Leeuw, E.D., Hox, J.J., & Dillman, D.A. (Eds.),

International handbook of survey methodology (pp. 97–112). Routledge.

Loncke, F. (2022). *Augmentative and alternative communication: Models and applications* (2nd ed.).

Plural Publishing Inc.

Mack, L. (2010). The philosophical underpinnings of educational research. *Polyglossia*, *19*, 7.

Mandak, K., O'Neill, T., Light, J.C., & Fosco, G. M. (2017). Bridging the gap from values to actions: A

family systems framework for family-centered AAC services. *Augmentative and Alternative

Communication*, *33*(1), 32–41. https://doi.org/10.1080/07434618.2016.1271453

Marra, L., & Micco, K. (2019). Communication partner training to increase interactive communication

using augmentative and alternative communication: A case study. *Perspectives of the ASHA Special Interest Groups*, *4*(4), 584–592. https://doi.org/10.1044/2019_PERS-SIG2-2018-0012

Marshall, J., & Goldbart, J. (2008). "Communication is everything I think." Parenting a child who needs

augmentative and alternative communication (AAC). *International Journal of Language & Communication Disorders*, *43*(1), 77–98. https://doi.org/10.1080/13682820701267444

Marvin, L. A., Montano, J. J., Fusco, L. M., & Gould, E. P. (2003). Speech-language pathologists'

perceptions of their training and experience in using alternative and augmentative

communication. *Contemporary Issues in Communication Science and Disorders*, *30*, 76–83.

https://doi.org/10.1044/cicsd_30_S_76

Matthews, R. (2001). A survey to identify therapists' high-tech AAC knowledge, application and training.

International Journal of Language & Communication Disorders, *36*(s1), 64–69.

https://doi.org/10.3109/13682820109177860

McNaughton, D. B., Light, J., & Groszyk, L. (2001). "Don't give up": Employment experiences of

individuals with amyotrophic lateral sclerosis who use augmentative and alternative

communication. *Augmentative and Alternative Communication*, 17, 179–195.

McNaughton, D., Rackensperger, T., Benedek-Wood, E., Krezman, C., Williams, M. B., & Light, J.C. (2008).

"A child needs to be given a chance to succeed": Parents of individuals who use AAC describe

the benefits and challenges of learning AAC technologies. *Augmentative and Alternative Communication*, *24*(1), 43–55. https://doi.org/10.1080/07434610701421007

Minuchin, P. (1985). Families and individual development: Provocations from the field of family therapy.

Child Development, *56*(2), 289–302. https://doi.org/10.2307/1129720

Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting stress in mothers of

children with autism without intellectual disability. Mediation of behavioral problems and

coping strategies. *Frontiers in Psychology*, *10*, 464. https://doi.org/10.3389/fpsyg.2019.00464

Mirenda, P. (2003). Toward functional augmentative and alternative communication for students with

autism: Manual signs, graphic symbols, and voice output communication aids. *Language, Speech

& Hearing Services in Schools*, *34*(3), 203–216. https://doi.org/10.1044/0161-1461(2003/017)

Moorcroft, A., Scarinci, N., & Meyer, C. (2019a). "I've had a love-hate, I mean mostly hate relationship

with these PODD books": Parent perceptions of how they and their child contributed to AAC

rejection and abandonment. *Disability and Rehabilitation: Assistive Technology*, 16(1), 72–82.

https://doi.org/10.1080/17483107.2019.1632944

Moorcroft, A., Scarinci, N., & Meyer, C. (2019b). "We were just kind of handed it and then it was smoke

bombed by everyone": How do external stakeholders contribute to parent rejection and the

abandonment of AAC systems? *International Journal of Language & Communication Disorders,

55(1)*. https://doi.org/10.1111/1460-6984.12502

Moustakas, C. E. (1994). *Phenomenological research methods*. SAGE Publications, Inc.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the

trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1), 160940691773384.

https://doi.org/10.1177/1609406917733847

Ogletree, B. T. (2012). Stakeholders as partners: Making AAC work better. *Perspectives on Augmentative

and Alternative Communication*, *21*(4), 151–158. https://doi.org/10.1044/aac21.4.151

O'Neill, T. (2019). *Perspectives of parents of children with cerebral palsy on the supports, challenges, and

realities of integrating AAC into everyday life* (Publication No. 13804033) (Doctoral dissertation,

The Pennsylvania State University). ProQuest Information & Learning.

O'Neill, T., & Wilkinson, K. M. (2020). Preliminary investigation of the perspectives of parents of children with cerebral palsy on the supports, challenges, and realities of integrating augmentative and alternative communication into everyday life. *American Journal of Speech-Language Pathology*, *29*(1), 238–254. https://doi.org/10.1044/2019_AJSLP-19-00103

Parette, H. P., Brotherson, M. J., & Huer, M. B. (2000). Giving families a voice in augmentative and alternative communication decision-making. *Education and Training in Mental Retardation and Developmental Disabilities*, *35*(2), 177–190.

Parette, H. P., Huer, M. B., & Brotherson, M. J. (2001). Related service personnel perceptions of team AAC decision-making across cultures. *Education & Training in Mental Retardation & Developmental Disabilities*, *36*(1), 69–82.

Pennington, L., & McConachie, H. (1999). Mother–child interaction revisited: Communication with non-speaking physically disabled children. *International Journal of Language & Communication Disorders*, *34*(4), 391–416. https://doi.org/10.1080/136828299247351

Pickl, G. (2011). Communication intervention in children with severe disabilities and multilingual backgrounds: Perceptions of pedagogues and parents. *Augmentative and Alternative Communication*, *27*(4), 229–244. https://doi.org/10.3109/07434618.2011.630021

Pino, O. (2000). The effect of context on mother's interaction style with Down's syndrome and typically developing children. *Research in Developmental Disabilities*, *21*(5), 329–346. https://doi.org/10.1016/S0891-4222(00)00046-9

Portney, L. G., & Watkins, M. P. (2015). *Foundation of clinical research: Applications to practice* (3rd ed.). F.A. Davis Company.

Ratcliff, A., & Beukelman, D. (1995). Preprofessional preparation in augmentative and alternative communication: State-of-the-art report. *Augmentative and Alternative Communication*, *11*(2), 61–73. https://doi.org/10.1080/07434619512331277149

Ratcliff, A., Koul, R., & Lloyd, L. L. (2008). Preparation in augmentative and alternative communication: An update for speech-language pathology training. *American Journal of Speech-Language Pathology*, *17*(1), 48–59. https://doi.org/10.1044/1058-0360(2008/005)

Romski, M., & Sevcik, R. A. (2005). Augmentative communication and early intervention: Myths and realities. *Infants & Young Children*, *18*(3), 174–185. https://doi.org/10.1097/00001163-200507000-00002

Rosenberg, S., & Beukelman, D. R. (1987). The participation model. In C.A. Coston (Ed.), *Proceedings of the National Planners Conference on Assistive Device Service Delivery* (pp. 159–161). Association for the Advancement of Rehabilitation Technology.

Saldana, J. (2009). *The coding manual for qualitative researchers*. SAGE Publications, Inc.

San, P. H., & Abdullah, A. C. (2013). The implementation of Picture Exchange Communication System: A mother's perspective of a young child with pervasive developmental disorder. *Pertnika Journal of Social Science and Humanities*, *21*(4), 1543–1553.

Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, *18*, 179–183. https://doi.org/10.1002/nur.4770180211

Senner, J. E., Post, K. A., Baud, M. R., Patterson, B., Bolin, B., Lopez, J., & Williams, E. (2019). Effects of parent instruction in partner-augmented input on parent and child speech generating device use. *Technology & Disability*, *31*(1–2), 27–38. https://doi.org/10.3233/TAD-190228

Serpentine, E. C., Tarnai, B., Drager, K. D. R., & Finke, E. H. (2011). Decision making of parents of children with autism spectrum disorder concerning augmentative and alternative communication in Hungary. *Communication Disorders Quarterly*, *32*(4), 221–231. https://doi.org/10.1177/1525740109353938

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63–75. https://doi.org/10.3233/EFI-2004-22201

Shire, S. Y., & Jones, N. (2015). Communication partners supporting children with complex

    communication needs who use AAC: A systematic review. *Communication Disorders Quarterly*,

    37(1), 3–15. https://doi.org/10.1177/1525740114558254

Silva, L. M. T., & Schalock, M. (2012). Autism Parenting Stress Index: Initial psychometric evidence.

    Journal of Autism and Developmental Disorders, *42*(4), 566–574.

    https://doi.org/10.1007/s10803-011-1274-1

Simpson, K., Beukelman, D., & Bird, A. (1999). Survey of school speech and language service provision to

    students with severe communication impairments in Nebraska. *Augmentative and Alternative*

    Communication, *14*(4), 212–221.

Singh, S. J., Hussein, N. H., Mustaffa Kamal, R., & Hassan, F. H. (2017). Reflections of Malaysian parents

    of children with developmental disabilities on their experiences with AAC. *Augmentative and*

    Alternative Communication, *33*(2), 110–120. https://doi.org/10.1080/07434618.2017.1309457

Smith, T. B., Oliver, M. N., & Innocenti, M. S. (2001). Parenting stress in families of children with

    disabilities. *American Journal of Orthopsychiatry*, *71*(2), 257–261. https://doi.org/10.1037/0002-

    9432.71.2.257

Soto, G., Mu Ller, E., Hunt, P., & Goetz, L. (2001). Professional skills for serving students who use AAC in

    general education classrooms: A team perspective. *Language, Speech, and Hearing Services in*

    Schools, *32*(1), 51–56. https://doi.org/10.1044/0161-1461(2001/005)

Stadskleiv, K. (2017). Experiences from a support group for families of preschool children in the

    expressive AAC user group. *Augmentative and Alternative Communication*, *33*(1), 3–13.

    https://doi.org/10.1080/07434618.2016.1276960

Starble, A., Hutchins, T., Favro, M. A., Prelock, P., & Bitner, B. (2005). Family-centered intervention and

    satisfaction with AAC device training. *Communication Disorders Quarterly*, *27*(1), 47–54.

    https://doi.org/10.1177/15257401050270010501

Strauss, A. L., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Sage Publications.

Sundler, A. J., Lindberg, E., Nilsson, C., & Palmér, L. (2019). Qualitative thematic analysis based on descriptive phenomenology. *Nursing Open*, *6*(3), 733–739. https://doi.org/10.1002/nop2.275

Sutherland, D. E., Gillon, G. G., & Yoder, D. E. (2005). AAC use and service provision: A survey of New Zealand speech-language therapists. *Augmentative and Alternative Communication*, *21*(4), 295–307. https://doi.org/10.1080/07434610500103483

Sutphin, S. T., McDonough, S., & Schrenkel, A. (2013). The role of formal theory in social work research: Formalizing family systems theory. *Advances in Social Work*, *14*(2), 501–517. https://doi.org/10.18060/7942

Taylor, M. J., Crowley, S. L., & White, K. R. (1993). *Measuring family support and resources: Psychometric investigations of the FSS and FRS.* Annual Meeting of the National Council on Measurement in Education, Atlanta, GA.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(45), 1471–2288. https://doi.org/10.1186/1471-2288-8-45

Thorne, S., Jensen, L., Kearney, M. H., Noblit, G., & Sandelowski, M. (2004). Qualitative metasynthesis: Reflections on methodological orientation and ideological agenda. *Qualitative Health Research*, *14*(10), 1342–1365. https://doi.org/10.1177/1049732304269888

Travis, J., & Geiger, M. (2010). The effectiveness of the Picture Exchange Communication System (PECS) for children with autism spectrum disorder (ASD): A South African pilot study. *Child Language Teaching & Therapy*, *26*(1), 39–59. https://doi.org/10.1177/0265659009349971

Tufford, L., & Newman, P. (2010). Bracketing in qualitative research. *Qualitative Social Work*, *11*(1), 80–96. https://doi.org/10.1177/1473325010368316

Wadnerkar, M. B., Pirinen, T., Haines-Bazrafshan, R., Rodgers, J., & James, D. (2012). A single case study

of a family-centred intervention with a young girl with cerebral palsy who is a multimodal

communicator. *Child: Care, Health and Development*, *38*(1), 87–97.

https://doi.org/10.1111/j.1365-2214.2011.01214.x

Wormnæs, S., & Abdel Malek, Y. (2004). Egyptian speech therapists want more knowledge about

augmentative and alternative communication. *Augmentative and Alternative Communication*,

20(1), 30–41. https://doi.org/10.1080/07434610310001629571

APPENDIX A

Block One:

1. **Perceived Barriers to Augmentative and Alternative Communication Service Delivery and Post-Professional Learning Preferences Among Speech-Language Pathologists**
   Participant Information
   This study aims to explore (1) current augmentative and alternative communication (AAC) services; (2) perceived barriers to AAC service delivery; and (3) learning preferences for post-professional instruction and training in AAC from the perspective of speech-language pathologists.
   To participate in this study, you must be a speech-language pathologist who:
   - Holds an American Speech-Language-Hearing Association (ASHA) Certificate of Clinical Competence
   - Has completed the Clinical Fellowship
   - Has at least one year of clinical experience post-graduation
   - Has written knowledge of English
   The survey will take approximately 10-15 minutes to complete.
   This study has ethical approval from Old Dominion University (Project #1487213-1). There are no expected risks to your participation in this study. Participant responses will be collected in a de-identifiable format and will be exported to a secure network drive maintained by Old Dominion University, which will only be accessed by the principal researchers.
   Participation in this study is entirely voluntary. Your decision of whether or not to participate will not prejudice your future relations with Old Dominion University. If you decide to complete this survey, you will be agreeing to your responses being used in the study. As you will be submitting your answers anonymously, you will not be able to withdraw your responses from the study once you have submitted your survey.
   - OK

2. **Perceived Barriers to Augmentative and Alternative Communication Service Delivery and Post-Professional Learning Preferences Among Speech-Language Pathologists**
   Research Consent:
   I have read the informed consent document and I understand what this research entails. I agree to be a part of this study. I understand that participation is voluntary. I do not have to take part in this study. I understand how much time participating in this study will involve. I understand that digital files will be stored on a secure computer server at Old Dominion University, which will only be accessed by the principal researchers. I understand that all data will be retained in accordance with Old Dominion University's policy for at least five years at the conclusion of the study. I understand that there are no expected risks to participation. I understand that this study may not benefit me directly. I understand that all information gained in this study will be treated in a confidential way and that my identify will not be revealed in any publications arising from this research. I understand that once I have completed the survey, I will be submitting my responses anonymously. I will not be able to withdraw from the study as my responses will not be identifiable. I understand that at the conclusion of the survey, I can indicate my interest in receiving a summary of the research findings. I understand that if I have any concerns or questions about the study, I can contact Dr. Rachel Johnson.
   Dr. Rachel Johnson
   Old Dominion University
   Norfolk, Virginia

r1johnson@odu.edu
757-683-6285
- OK

3. Do you consent to take part in the study titled: "Perceived Barriers to Augmentative and Alternative Communication Service Delivery and Post-Professional Learning Preferences Among Speech-Language Pathologists"?
    - Yes, I consent.
    - No, I do not consent. (Skip Logic: End of Survey)

Block Two:
4. The following questions relate to augmentative and alternative communication (AAC) service delivery and learning preferences. Sections will relate to your primary work setting, prior training, your use of AAC, barriers, training needs, and your perceptions of AAC.
The following terms and definitions will be used throughout the survey. All definitions have been retrieved from the (Anderson et al., 2014) (ASHA, n.d.).
 Augmentative and alternative communication (AAC): Uses a variety of techniques and tools... to help the individual express thoughts, wants and needs, feelings, and ideas
Unaided systems: Do not require an external tool, such as gestures, manual signs, facial expressions, vocalizations, verbalizations, and body language
Aided systems: Require some form of external support, such as pictures, objects, photographs, writing, communication boards/books, and speech-generating devices.
No-technology: Unaided systems
Low-technology: Non-electronic aided systems
High-technology: Electronic aided systems
AAC intervention: Developing and implementing plans that are culturally and linguistically appropriate to maximize effective communication between individuals who use AAC and their communication partners across the lifespan
AAC evaluation: Conducting a comprehensive, transdisciplinary, culturally, and linguistically appropriate assessment related to provision of AAC services and communication potential
American Speech-Language-Hearing Association (n.d.). Augmentative and Alternative Communication.
Retrieved from https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589942773&section=Key_Issues.
    - OK

5. What is your age?
    - 34 years and younger
    - 35 - 44 years
    - 45 -54 years
    - 55 - 64 years
    - 65 years and older

6. What is your primary work setting as defined by ASHA? Please select one.
    - General medical / Veterans Affairs (VA) / long-term acute care (LTAC) hospital
    - Home health
    - Outpatient clinic
    - Pediatric hospital
    - Rehabilitation hospital
    - Skilled nursing facility
    - School

- Early intervention
- University training clinic
- Private practice
- Other, please specify: _____

7. Which of the following are population(s) you currently serve? Select all that apply.
- Infant - toddler
- Preschooler
- School-age child
- Adult
- Older adult (65 years and older)

8. How many years have worked in your primary work setting?
- 0 - 5 years
- 6 - 10 years
- 11 - 15 years
- 16 - 20 years
- More than 20 years

9. What is your current employment status for your primary work setting position?
- Full time
- Part time
- PRN / Per diem
- Unemployed and seeking work
- Unemployed and not seeking work
- On leave of absence, please describe (for example: maternity leave, medical leave of absence): _____

10. How many speech-language pathologists are employed in your primary work setting?
- 1
- 2
- 3
- 4
- More than 5

11. What best describes your work situation? Please select one.
- **Multidisciplinary team**: Independent groups share results with a larger group (Choi and Pak, 2006)
- **Interdisciplinary team**: Decisions are made as a group, but practice remains in specific professional roles (Choi & Pak, 2006)
- **Transdisciplinary team**: Groups collaborate and boundaries between disciplines disappear (Thylefors, Persson, & Hellstrom, 2005)
- **None**, I do not work in a team.
- **None**, I am not currently working.

12. Which of the following best describes the community of your primary work setting?
- City / urban area
- Suburban area
- Rural area

13. In which state or territory do you clinically practice?
- Alabama
- Alaska

- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- US Territory
- Utah
- Vermont
- Virginia

- Washington
- West Virginia
- Wisconsin
- Wyoming

14. What is the average number of patients you serve each week?

_____

15. Of the patients served each week and indicated above, please indicate the response that best corresponds with the statement.
   What percentage of your patients CANNOT meet all of their communication needs using unaided or natural communication modalities alone?
   - 0%
   - 1-25%
   - 26-50
   - 51-75%
   - 76-99
   - 100%

   What percentage of your patients do you estimate use aided AAC?
   - 0%
   - 1-25%
   - 26-50
   - 51-75%
   - 76-99
   - 100%

   What percentage of your patients are you seeing for AAC intervention?
   - 0%
   - 1-25%
   - 26-50
   - 51-75%
   - 76-99
   - 100%

16. Please indicate the response that best corresponds with the statement.

   How many hours do you spend providing **direct** AAC services? *For example:* AAC evaluation activities, intervention and implementation activities
   - 0 hours
   - 0.1 – 1 hour
   - 1.1 – 2 hours
   - 2.1 – 3 hours
   - 3.1 – 4 hours
   - 4.1 – 5 hours
   - More than 5 hours

   How many hours do you spend providing **indirect** AAC services? *For example:* device programming, consulting families or caregivers, researching AAC options
   - 0 hours
   - 0.1 – 1 hour
   - 1.1 – 2 hours

- 2.1 – 3 hours
- 3.1 – 4 hours
- 4.1 – 5 hours
- More than 5 hours

17. Which of the following best describes your clinical role as defined by Binger et al., 2012 in reference to AAC in your primary work setting? Please select one.
    - **AAC finder**: Identify potential AAC beneficiaries and refer for AAC evaluation
    - **General practice speech-language pathologist**: Case management, speech-language evaluation, facilitate AAC decision-making, support funding documentation, AAC clinical implementation, and AAC troubleshooting
    - **AAC clinical specialist**: AAC evaluation, AAC device / strategy selection, complete funding reports, AAC technical support, AAC clinical implementation, and AAC troubleshooting
    - **AAC facilitator and/or communication partner**: Advocate for beneficiary, facilitate AAC evaluation and decision making, facilitate funding, service coordination, AAC support across transitions, Primary communication partner, AAC technical support and trouble shooting
    - **Collaborating professional**: OT/PT/vision/hearing evaluation, facilitate AAC decision-making, support funding documentation, AAC clinical/educational implementation, and AAC troubleshooting
    - **AAC research / policy specialist**: Develop evidence base to support AAC assessment and interventions
    - **AAC manufacturer / vendor**: Facilitate evaluation process, provide equipment loan, rentals for AAC evaluation trails, acquire funding from documentation provided, interact with funding agencies, and provide AAC equipment and accessories
    - **AAC funding agency / funding personnel**: Benefits qualification determination, provide benefits based on beneficiary individual policy, and provide benefits based on agency policy
    - **AAC technology training agency personnel**: Provide equipment loans for AAC evaluation and trials, facilitate AAC evaluations, support AAC evaluations, and provide AAC training and technical support
    - **Other**, please specify: _____

18. How many years have you been in the field of speech-language pathology?
    - Less than 1 year
    - 1 - 5 years
    - 6 - 10 years
    - 11 - 15 years
    - 16 - 20 years
    - 21 - 25 years
    - 26 - 30 years
    - More than 31 years

19. Which of the following are you prior work setting(s) as defined by ASHA? Select all that apply.
    - General medical / Veterans Affairs (VA) / long-term acute care (LTAC) hospital
    - Home health
    - Outpatient clinic
    - Pediatric hospital
    - Rehabilitation hospital

- Skilled nursing facility
- School
- Early intervention
- University training clinic
- Private practice
- Other, please specify: _____

Block 3

20. What is your highest earned degree?
    - Masters degree
    - Clinical doctoral degree
    - Research doctoral degree
21. Did you complete dedicated AAC coursework during undergraduate instruction?
    - No (Skip Logic: Question 24)
    - Yes (Skip Logic: Question 22)
22. Total number of courses during undergraduate instruction:
    - 1
    - 2
    - 3
    - Other, please specify: _____
23. Total number of credits during undergraduate instruction:
    - 1
    - 2
    - 3
    - Other, please specify: _____
24. Did you complete dedicated AAC coursework during graduate instruction?
    - No (Skip Logic: Question 27)
    - Yes (Skip Logic: Question 25)
25. Total number of courses during graduate instruction:
    - 1
    - 2
    - 3
    - Other, please specify: _____

26. Total number of credits during graduate instruction:
    - 1
    - 2
    - 3
    - Other, please specify: _____
27. Which of the following would describe your hands-on clinical training experience using aided AAC that counted toward clinical hours? Select all that apply.
    - None, I did not observe or have hands-on clinical training experiences. (Answer exclusive)
    - Observation training experience, characterized by AAC **intervention**
    - Observation training experience, characterized by AAC **evaluation**
    - Hands-on training experience, characterized by AAC **intervention**
    - Hands-on training experience, characterized by AAC **evaluation**

28. Do you hold any specialized certifications in AAC or assistive technology (AT)? Select all that apply.
    - None (Answer exclusive)
    - RESNA Assistive Technology Professional training
    - Assistive Technology certificate
    - Communication Sciences and Disorders program with Assistive Technology concentration
    - Education program with Assistive Technology concentration
    - Other, please specify: _____

Block 4

29. Indicate the importance of AAC related to the following clinical topics and diagnoses.
    Articulation
    - Strongly unimportant
    - Somewhat unimportant
    - Neutral
    - Somewhat important
    - Strongly important

    Fluency
    - Strongly unimportant
    - Somewhat unimportant
    - Neutral
    - Somewhat important
    - Strongly important

    Voice and resonance
    - Strongly unimportant
    - Somewhat unimportant
    - Neutral
    - Somewhat important
    - Strongly important

    Receptive and expressive language
    - Strongly unimportant
    - Somewhat unimportant
    - Neutral
    - Somewhat important
    - Strongly important

    Hearing
    - Strongly unimportant
    - Somewhat unimportant
    - Neutral
    - Somewhat important
    - Strongly important

    Swallowing
    - Strongly unimportant
    - Somewhat unimportant
    - Neutral
    - Somewhat important

- Strongly important

Cognitive aspects of communication
- Strongly unimportant
- Somewhat unimportant
- Neutral
- Somewhat important
- Strongly important

Social aspects of communication
- Strongly unimportant
- Somewhat unimportant
- Neutral
- Somewhat important
- Strongly important

AAC modalities
- Strongly unimportant
- Somewhat unimportant
- Neutral
- Somewhat important
- Strongly important

30. How often do you use AAC during clinical practice related to the following clinical topics and diagnoses?

Articulation
- Never
- Seldom
- Somethings
- Frequently
- Always
- Not applicable – I do not work with this population

Fluency
- Never
- Seldom
- Somethings
- Frequently
- Always
- Not applicable – I do not work with this population

Voice and resonance
- Never
- Seldom
- Somethings
- Frequently
- Always
- Not applicable – I do not work with this population

Receptive and expressive language
- Never
- Seldom
- Somethings

- Frequently
- Always
- Not applicable – I do not work with this population

Hearing
- Never
- Seldom
- Somethings
- Frequently
- Always
- Not applicable – I do not work with this population

Swallowing
- Never
- Seldom
- Somethings
- Frequently
- Always
- Not applicable – I do not work with this population

Cognitive aspects of communication
- Never
- Seldom
- Somethings
- Frequently
- Always
- Not applicable – I do not work with this population

Social aspects of communication
- Never
- Seldom
- Somethings
- Frequently
- Always
- Not applicable – I do not work with this population

AAC modalities
- Never
- Seldom
- Somethings
- Frequently
- Always
- Not applicable – I do not work with this population

31. What is your level of knowledge related to the following AAC areas?

AAC intervention
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

AAC intervention with focus on language

- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

AAC intervention with focus on literacy
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

AAC intervention with focus on aging
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

AAC intervention with focus on end stages of life
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

AAC evaluation
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

No-technology AAC
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

Low-technology AAC
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

High-technology AAC
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable

- Expert knowledge

Programming and maintenance of AAC
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

Collaboration with other professionals
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

Collaboration with families and caregivers
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

Collaboration with AAC vendors
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

Where to access AAC training and continuing education
- Not at all knowledgeable
- Somewhat knowledgeable
- Knowledgeable
- Very knowledgeable
- Expert knowledge

Block 5

32. When considering *work setting*, what is the most significant barrier to practice? Please select one.
    - Workplace (Skip Logic: Question 33)
    - Caseload (Skip Logic: Question 34)
    - Other, please specify: _____ (Skip Logic: Question 35)

33. What is the most significant workplace barrier to practice? Please select one.
    - Geographic location (Skip Logic: Question 35)
    - Work setting policies (Skip Logic: Question 35)
    - Other, please specify: _____ (Skip Logic: Question 35)

34. What is the most significant caseload barrier to practice? Please select one.
    - Frequently changing caseload (Skip Logic: Question 35)
    - Size of caseload (Skip Logic: Question 35)

- Productivity expectations (Skip Logic: Question 35)
- Patient medical condition (Skip Logic: Question 35)
- Other, please specify: _____ (Skip Logic: Question 35)

35. When considering *resources*, what is the most significant barrier to practice? Please select one.
- Time (Skip Logic: Question 36)
- Financial resources (Skip Logic: Question 37)
- Support (Skip Logic: Question 38)
- Other, please specify: _____ (Skip Logic: Question 39)

36. What is the most significant time barrier to practice? Please select one.
- Time for programming (Skip Logic: Question 39)
- Time for collaboration with other professionals (Skip Logic: Question 39)
- Time for collaboration with families/caregivers (Skip Logic: Question 39)
- Time for device funding process (Skip Logic: Question 39)
- Time for AAC training and continuing education (Skip Logic: Question 39)
- Time for AAC device troubleshooting (Skip Logic: Question 39)
- Other, please specify: _____ (Skip Logic: Question 39)

37. What is the most significant financial resource barrier to practice? Please select one.
- Financial resources and funding (Skip Logic: Question 39)
- Other, please specify: _____ (Skip Logic: Question 39)

38. What is the most significant support barrier to practice? Please select one.
- Patient/family support (Skip Logic: Question 39)
- Administrative support (Skip Logic: Question 39)
- Other, please specify: _____ (Skip Logic: Question 39)

39. When considering *AAC systems*, what is the most significant barrier to practice? Please select one.
- Availability (Skip Logic: Question 40)
- Knowledge (Skip Logic: Question 41)
- Other, please specify: _____ (Skip Logic: Question 42)

40. What is the most significant availability barrier to practice? Please select one.
- Availability of technical support (Skip Logic: Question 42)
- Availability of AAC systems (Skip Logic: Question 42)
- Availability of AAC training and continuing education (Skip Logic: Question 42)
- Other, please specify: _____ (Skip Logic: Question 42)

41. What is the most significant knowledge barrier to practice? Please select one.
- General knowledge about AAC systems
- Knowledge to implement the AAC system in therapy
- Knowledge to complete an AAC evaluation
- Knowledge to identify the most appropriate AAC system to meet the patient need
- Knowledge of voice output options

- Knowledge of the device funding process
- Knowledge of tailoring AAC to be culturally and linguistically responsive
- Technical and troubleshooting knowledge of AAC systems
- Technology changes
- Other, please specify: _____

Block 6

42. In your three-year certification period, approximately how many hours have you spent attending professional workshops, seminars, conference presentations, etc. dedicated to AAC?
    - 0 hours
    - 1 - 5 hours
    - 6 - 10 hours
    - 11 - 15 hours
    - 16 - 20 hours
    - 21 - 25 hours
    - 26 - 30 hours
    - At least 31 hours

43. What are your perceptions of AAC training and continuing education?
    I would benefit from training related to AAC.
    - Strongly disagree
    - Somewhat disagree
    - Neural
    - Somewhat agree
    - Strongly agree

    I plan to engage in training related to AAC.
    - Strongly disagree
    - Somewhat disagree
    - Neural
    - Somewhat agree
    - Strongly agree

44. Which of the following topics would best complete your continuing education needs? Select up to three responses.
    - AAC intervention
    - AAC intervention with focus on language
    - AAC intervention with focus on literacy
    - AAC intervention with focus on aging
    - AAC intervention with focus on end stages of life
    - AAC evaluation
    - No-technology AAC
    - Low-technology AAC
    - High-technology AAC
    - Programming and maintenance of AAC
    - Collaboration with other professionals
    - Collaboration with families and caregivers
    - Collaboration with AAC vendors
    - Other, please specify: _____

45. Which of the following training formats would best complete your continuing education needs? Select up to three responses.
- **In-service training**
- **Coaching**
- **Webinars**
- **Instructional videos**
- **Conferences**
- **Courses through a college / university**
- **Written information**: Such as publications, websites, and blogs
- **Communities of practice**: Groups focused on social interaction, knowledge-sharing, knowledge-creation, and identity-building (Li et al., 2009)
- **Other**, please specify: _____

46. Which of the following training dosing would best complete your continuing education needs? Select up to three responses.
- Single event training in one-day
- Single event training in one-day with follow-up
- Multiple training events in one week
- Multiple training events in one month
- Multiple training events in one year
- On-the-spot training for a specific need
- Interactive guide for troubleshooting
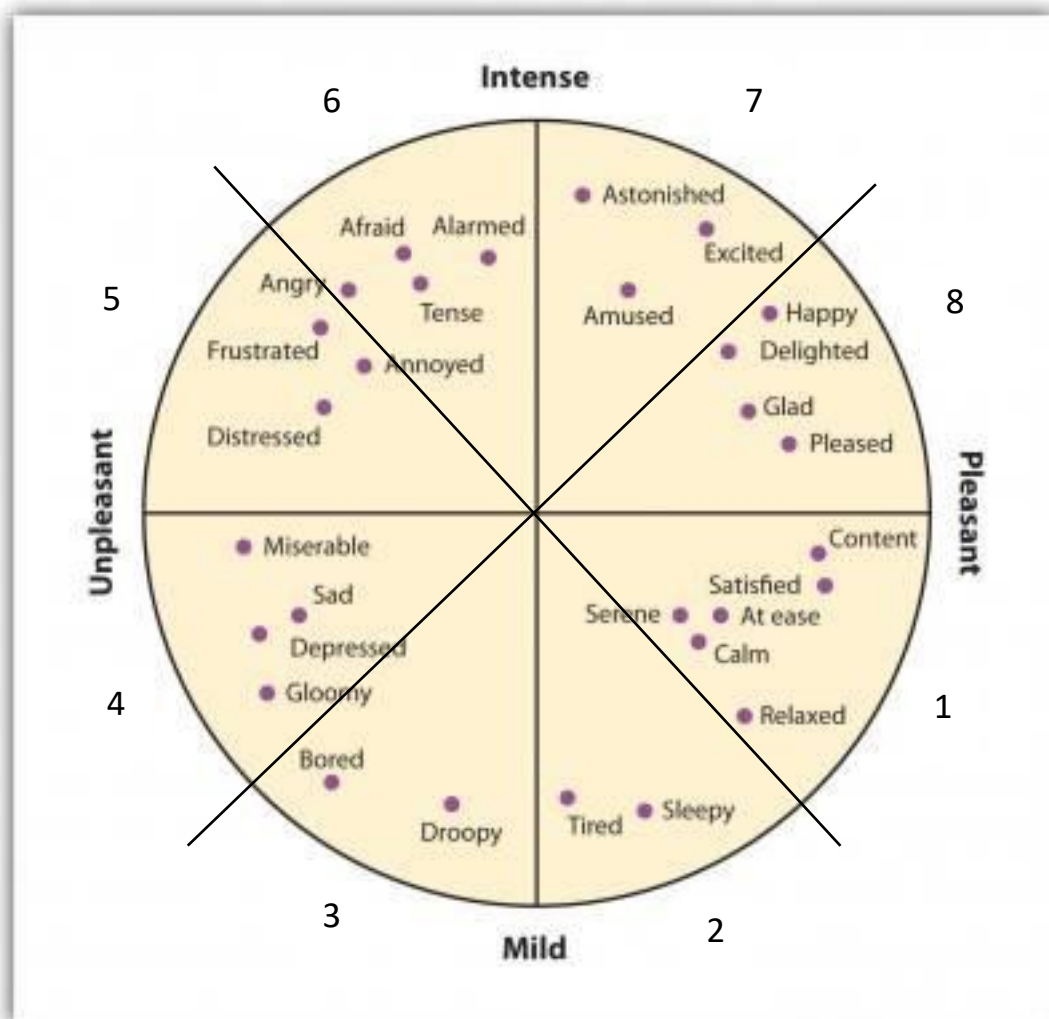- Other, please specify: _____

Block 7

47. **How do you generally feel about AAC when you think about the patient experience? Select one portion of the circle that corresponds to this feeling.**
Sources:
Open Educational Resources by Tompkins Cortland Community College. (n.d.). The Experience of Emotion. Retrieved from https://lumen.instructure.com/courses/170090/pages/the-experience-of-emotion?module_item_id=4055344.
Adapted from Russell, J. A. (1980). A circumplex model of affect. *Journal of Personality and Social Psychology, 39*, 1161–1178.

48. **How do you generally feel about AAC when you think about yourself as the clinician? Select one portion of the circle that corresponds to this feeling.**
Sources:
Open Educational Resources by Tompkins Cortland Community College. (n.d.). The Experience of Emotion. Retrieved from https://lumen.instructure.com/courses/170090/pages/the-experience-of-emotion?module_item_id=4055344.
Adapted from Russell, J. A. (1980). A circumplex model of affect. *Journal of Personality and Social Psychology, 39*, 1161–1178.
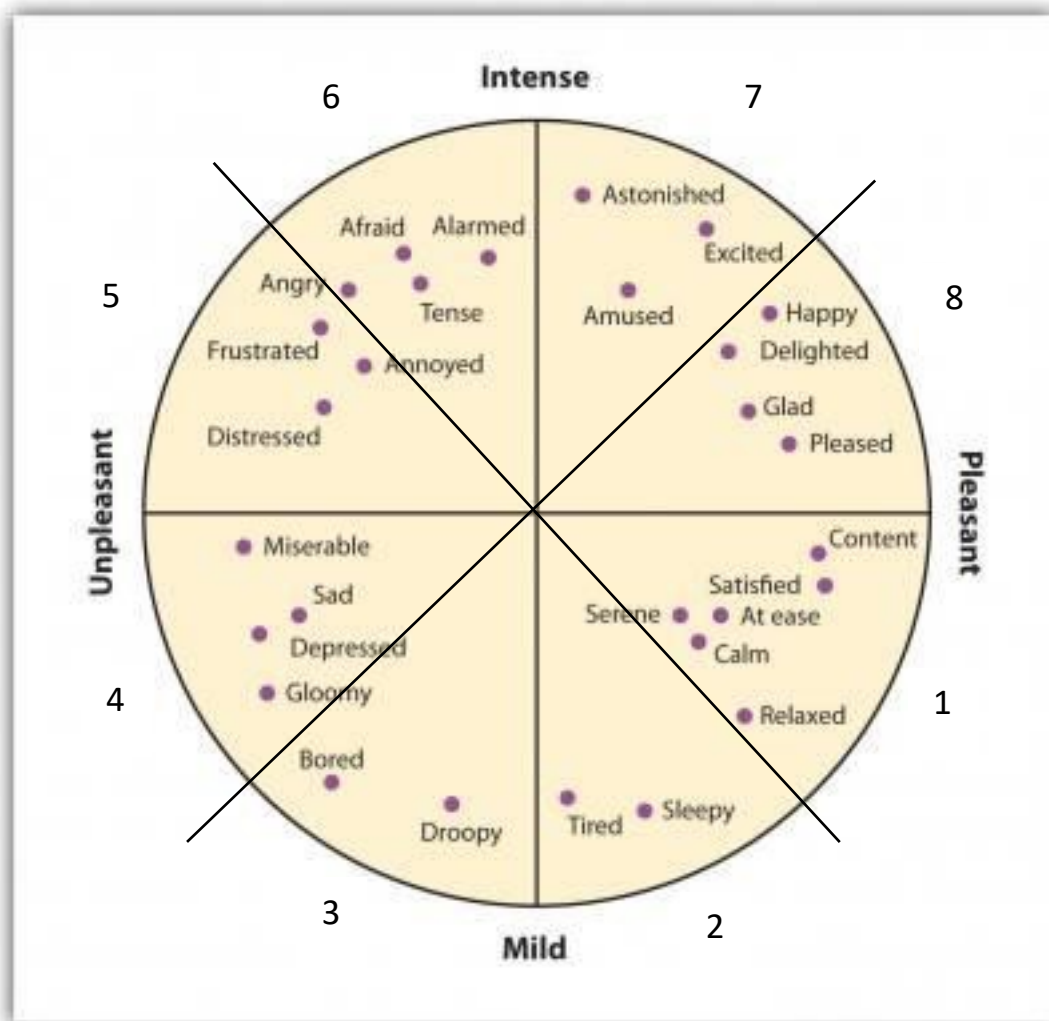
Block 8

    49. Thank you for your participation! Would you like to enter a raffle for the chance to win a $100 Amazon gift card or to receive a summary of the research findings?

- Yes
- No

APPENDIX B

SURVEY PART ONE

Introduction

1. Thank you for your interest in participating in this study! Please read the following information or watch the video about this research.

    Individuals who cannot use verbal speech alone to meet their daily communication needs can use augmentative and alternative communication (AAC) modalities. AAC modalities can include, but are not limited to: gestures, body language, sign language, facial expressions, sounds, words, pictures, objects, photographs, writing, communication boards/books, and speech generating devices. The caregivers of children with AAC needs for communication are tasked with many responsibilities. To improve collaboration, it is necessary to understand the experiences of parents, legal guardians, and caregivers of children with AAC needs for communication. Researchers at Old Dominion University are studying (1) predictors and (2) experiences of stress from the perspective of adult caregivers in a family system. Members of a family system interact with each other, as well as with various support systems and care providers.

    The study includes 3 parts.

    - Part 1 - This is Part 1, an online survey with questions about the family, the child with AAC needs for communication, and the contact information for the adult caregivers responsible for the care of the child. It will take approximately 15 minutes.

    - Part 2 - An online survey to be completed by each caregiver responsible for the care of the child. It will take approximately 25 minutes.

    - Part 3 - Some families will be invited to participate in a group interview, to be scheduled at a later date. It will take approximately 1 hour.

    To participate in this study, you must be an adult who:

    - Has no known speech, language, or hearing impairments

    - Is able to speak, understand, read, and write in English at a level of proficiency for participation in an interview without an interpreter present

    - Currently resides in the United States

    - Is a caregiver of a child who: (a) has AAC needs for communication and is unable to meet communication needs using verbal speech alone, (b) uses AAC modalities, (c) is between the ages of 3-9 years, (d) has a developmental, congenital, or acquired medical or educational diagnosis.

    - OK

Consent

2. This study has ethical approval from Old Dominion University (#1682195-2). Participation in this study is entirely voluntary. Your decision of whether or not to participate will not prejudice your future relations with Old Dominion University. If you decide to complete this survey, you will be agreeing to your responses being used in the study.

    Risks: If you decide to participate in this study, then you may face a risk of emotional response to items on the surveys or during the interview. The researchers have tried to reduce these risks by not requiring response to all questions during the interview and the participant may choose which questions they are comfortable with answering. There is potential risk of release of confidential information. To minimize the risk, identifiers will be removed from all private identifiable information collected. Subject numbers will be assigned to isolate participants'

identities from their experimental data. Deidentified research data, including surveys, interview recordings, and interview transcripts, will be stored on password-protected ODU network storage drives. All data will be retained for at least five years in accordance with Old Dominion University's policies. The key that links subject numbers to names will be stored separately from data in a password-protected file on ODU storage drives and within a locked filing cabinet. Neither audio or video recordings will be used in presentations. The results of this study may be used in reports, presentations, and publications, but the researcher will not identify you. Participant responses may be used as pilot data for future research studies with identifiers removed. Of course, your records may be subpoenaed by court order or inspected by government bodies with oversight authority. And, as with any research, there is some possibility that you may be subject to risks that have not yet been identified.

Benefits: There is no direct benefit to participation this study.

Research Consent: I have read the informed consent document and I understand what this research entails. I agree to be a part of this study. I understand that participation is voluntary. I do not have to take part in this study. I understand how much time participating in this study will involve. I understand that digital files will be stored on a secure computer server at Old Dominion University, which will only be accessed by the principal researchers. I understand that all data will be retained in accordance with Old Dominion University's policy for at least five years at the conclusion of the study. I understand that there are no expected risks to participation. I understand that this study may not benefit me directly. I understand that all information gained in this study will be treated in a confidential way and that my identity will not be revealed in any publications arising from this research. I understand that if I have any concerns or questions about the study, I can contact Meredith Gohsman or Dr. Rachel Johnson.

Meredith Gohsman
Old Dominion University
Norfolk, Virginia
mlave003@odu.edu

Dr. Rachel Johnson
Old Dominion University
Norfolk, Virginia
r1johnson@odu.edu

Do you consent to take part in the study titled: "Predictors and Experiences of Stress in Adult Caregivers of Children with Augmentative and Alternative Communication (AAC) Needs for Communication"?

- Yes, I consent.
- No, I do not consent. (Skip Logic: End of Survey)

3. Are you the parent, guardian, or caregiver of a child with a developmental, congenital, or acquired medical or educational diagnosis?

- Yes
- No (Skip Logic: End of Survey)

4. Does your child have AAC needs for communication and cannot meet their daily communication needs with verbal speech alone?

- Yes
- No (Skip Logic: End of Survey)

5. Does your child use augmentative and alternative communication (AAC) modalities? This can include, but is not limited to: gestures, body language, sign language, facial expressions, sounds,

words, pictures, objects, photographs, writing, communication boards/books, or speech generating devices.
- Yes
- No (Skip Logic: End of Survey)

6. Does your child use augmentative and alternative communication (AAC) modalities? This can include, but is not limited to: gestures, body language, sign language, facial expressions, sounds, words, pictures, objects, photographs, writing, communication boards/books, or speech generating devices.
- Yes
- No (Skip Logic: End of Survey)

Child Communication
7. How old is your child?
- 3
- 4
- 5
- 6
- 7
- 8
- 9

8. How many different words, signs, pictures, or other symbols does your child currently use to express him/herself?
- Less than 10
- 11 to 20
- 21 to 30
- 31 to 40
- 41 to 50
- More than 50

9. How many words, signs, pictures, or other symbols does your child currently understand? Select all that apply.
- Does not understand spoken words
- Understands single words
- Understands simple sentences
- Understands complex sentences
- Understands conversation
- Understands yes/no questions
- Understands complex questions

10. Unaided AAC modalities only involve use of the body and no external device. What unaided AAC modalities does your child use to communicate? Select all that apply.
- Gestures
- Pointing
- Body language
- Physically leading someone
- Sign language
- Facial expression
- Looking with eyes
- Sounds

- Words
- Other, list here: _____

11. How many years has your child been using unaided AAC modalities?
- Less than 1 year
- 1-2 years
- 2-3 years
- 3-4 years
- 4-5 years
- 5-6 years
- 6-7 years
- 7-8 years
- 8-9 years

12. Aided AAC modalities involve an external device. Aided AAC modalities include objects, photographs, pictures, communication boards and books, and speech-generating devices (i.e., tablet). What aided AAC modalities does your child use? Select all that apply.
- Low-technology AAC system: Pictures, objects, communication book, communication board, etc.
- Mid-technology and high-technology AAC systems: Communication systems that generate speech, such as switches, buttons, applications on an iPad or tablet, etc.
- No aided AAC modalities (Skip Logic: Question 14) (Answer exclusive)

13. How many years has your child been using aided AAC modalities?
- Less than 1 year
- 1-2 years
- 2-3 years
- 3-4 years
- 4-5 years
- 5-6 years
- 6-7 years
- 7-8 years
- 8-9 years

Child Information

14. What are your child's medical and educational diagnoses? Select all that apply.
- Angelman Syndrome
- Autism Spectrum Disorder
- Brain tumor
- Cerebral palsy
- Childhood Apraxia of Speech
- Deafness or hearing impairment
- Developmental delay
- Down syndrome
- Fragile X syndrome
- Genetic disorder
- Intellectual disability
- Learning disability
- Rett syndrome
- Traumatic brain injury

- Visual impairment, including blindness
- Other, list here: _____

15. What is your child's current grade?
    - Not in school
    - Preschool
    - Kindergarten
    - 1st grade
    - 2nd grade
    - 3rd grade
    - 4th grade
    - 5th grade

16. Which of the following describes your child's education before the COVID-19 pandemic?
    - Public
    - Private
    - Homeschool (Skip Logic: Question 19)

17. Which of the following describes your child's educational placement before the COVID-19 pandemic? Select all that apply.
    - Inclusion
    - Self-contained/Segregated
    - Homebound
    - Other, list here: _____

18. What is the current status of your child's education?
    - Virtual
    - Face-to-face
    - Hybrid (virtual and face-to-face)
    - Other, list here: _____

19. Which of the following describe your child's vision? Select all that apply.
    - No visual impairment (Answer exclusive)
    - Wears glasses to see far
    - Wears glasses to see near
    - Amblyopia (lazy eye)
    - Blindness
    - Cataracts
    - Cortical visual impairment
    - Optic nerve hypoplasia
    - Retinopathy of prematurity
    - Other visual impairment, list here:
      _____

20. Which of the following describe your child's hearing? Select all that apply.
    - No hearing impairment (Answer exclusive)
    - Wears hearing aids
    - Has cochlear implant
    - Deafness
    - Other hearing impairment, list here:
      _____

21. Which of the following describe your child's movement? Select all that apply.

- Walks unassisted
- Walks assisted (holds onto surfaces, walks with cane or walker, etc.)
- Uses stroller
- Uses wheelchair
- Other, list here: _____

22. Which of the following describe your child's feeding? Select all that apply.
- Participates in mealtime
- Eats a restricted range of foods
- Food allergies
- Requires extensive preparation of food choices
- Nutrition achieved with feeding by mouth
- Nutrition achieved with enteral feeding (i.e., g-tube)
- Other, list here: _____

Child Demographics

23. What is your child's sex?
- Male
- Female

24. What language(s) is your child exposed to in the home setting?
- English
- Other, list here: _____

25. Is your child of Hispanic, Latino, or Spanish origin?
- Yes
- No

26. What is your child's racial and ethnic identity? Select all that apply.
- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Unknown
- Other, list here: _____

Resources

27. What individuals are involved in the medical and educational care of your child? Select all that apply.
- Physician
- Nurse practitioner
- General education teacher
- Special education teacher
- Paraprofessional
- School administrators
- Speech-language pathologist
- Occupational therapist
- Physical therapist
- Behavior specialist
- Vision specialist
- Other, list here: _____

28. What settings are involved in the medical and educational care of your child? Select all that apply.
    - Inpatient hospital
    - Inpatient rehabilitation hospital
    - Speech and hearing clinic
    - School
    - Home health
    - Community center
    - Other, list here: _____

29. What are the funding sources used for the child's medical care? Select all that apply.
    - Private insurance
    - Public funding (Medicare, Medicaid)
    - Other, list here: _____

30. What is your annual household income?
    - < $20,000
    - $20,001-$40,000
    - $40,001-$60,000
    - $60,001-$80,000
    - $80,001-$100,000
    - >100,001

31. Please list the following information for the children in the home other than the child with complex communication addressed in earlier questions.

Child	Age?	Does the child have a medical or educational diagnosis?
Child 1		Yes No
Child 2		Yes No
Child 3		Yes No
Child 4		Yes No
Child 5		Yes No
Child 6		Yes No
Child 7		Yes No
Child 8		Yes No
Child 9		Yes No
Child 10		Yes No

Contact Information

32. How many adults live in the home?
    - 1
    - 2
    - 3
    - 4
    - 5
    - 6 or more

33. Members of a family system interact with each other, as well as with various support systems and care providers. Caregiver members of a family system are responsible for the care of the child and could include parents, guardians, step-parents, grandparents, aunts, uncles, family friends, adult siblings, and so on.

    What adults in your family system are responsible for the care of your child? Select all that apply.
    - Mother (Display Logic: Question 34)
    - Father (Display Logic: Question 35)
    - Adult sibling (Display Logic: Question 36)
    - Step-mother (Display Logic: Question 37)
    - Step-father (Display Logic: Question 38)
    - Foster mother (Display Logic: Question 39)
    - Foster father (Display Logic: Question 40)
    - Grandmother (Display Logic: Question 41)
    - Grandfather (Display Logic: Question 42)
    - Aunt (Display Logic: Question 43)
    - Uncle (Display Logic: Question 44)
    - Family friend (Display Logic: Question 45)
    - Other(s), list here: _____ (Display Logic: Question 46)

34. Please write the contact information for the child's mother. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

35. Please write the contact information for the child's father. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

36. Please write the contact information for the child's sibling. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

37. Please write the contact information for the child's step-mother. This information will be used to distribute Part 2 of the survey.

- Name _____
- Email Address _____
- Phone Number _____

38. Please write the contact information for the child's step-father. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

39. Please write the contact information for the child's foster mother. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

40. Please write the contact information for the child's foster father. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

41. Please write the contact information for the child's grandmother. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

42. Please write the contact information for the child's grandfather. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

43. Please write the contact information for the child's aunt. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

44. Please write the contact information for the child's uncle. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

45. Please write the contact information for the child's family friend. This information will be used to distribute Part 2 of the survey.
    - Name _____
    - Email Address _____
    - Phone Number _____

46. Please write the contact information for the child's other caregiver(s) in the family system. This information will be used to distribute Part 2 of the survey.
    - Name _____

- Email Address _____
- Phone Number _____

SURVEY PART TWO

Consent

1. Thank you for your interest in participating in this study! Please read the following information or watch the video about this research.

   Individuals who cannot use verbal speech alone to meet their daily communication needs can use augmentative and alternative communication (AAC) modalities. AAC modalities can include, but are not limited to: gestures, body language, sign language, facial expressions, sounds, words, pictures, objects, photographs, writing, communication boards/books, and speech generating devices. The caregivers of children with AAC needs for communication are tasked with many responsibilities. To improve collaboration, it is necessary to understand the experiences of parents, legal guardians, and caregivers of children with AAC needs for communication. Researchers at Old Dominion University are studying (1) predictors and (2) experiences of stress from the perspective of adult caregivers in a family system. Members of a family system interact with each other, as well as with various support systems and care providers.

   The study includes 3 parts.
   - Part 1 - Part 1 has already been completed.
   - Part 2 - This is Part 2, an online survey to be completed by each caregiver responsible for the care of the child. It will take approximately 25 minutes.
   - Part 3 - Some families will be invited to participate in a group interview, to be scheduled at a later date. It will take approximately 1 hour.

   To participate in this study, you must be an adult who:
   - Has no known speech, language, or hearing impairments
   - Is able to speak, understand, read, and write in English at a level of proficiency for participation in an interview without an interpreter present
   - Currently resides in the United States
   - Is a caregiver of a child who: (a) has AAC needs for communication and is unable to meet communication needs using verbal speech alone, (b) uses AAC modalities, (c) is between the ages of 3-9 years, (d) has a developmental, congenital, or acquired medical or educational diagnosis.

   - OK

Screening

2. Are you the parent, guardian, or caregiver who completed the previous survey (Part 1)?
   - Yes, I completed Part 1 of the survey. (Skip Logic: Question 8)
   - No, another caregiver in my family completed Part 1 of the survey.
3. This study has ethical approval from Old Dominion University (#1682195-2). Participation in this study is entirely voluntary. Your decision of whether or not to participate will not prejudice your future relations with Old Dominion University. If you decide to complete this survey, you will be agreeing to your responses being used in the study.

Risks: If you decide to participate in this study, then you may face a risk of emotional response to items on the surveys or during the interview. The researchers have tried to reduce these risks by not requiring response to all questions during the interview and the participant may choose which questions they are comfortable with answering. There is potential risk of release of confidential information. To minimize the risk, identifiers will be removed from all private identifiable information collected. Subject numbers will be assigned to isolate participants' identities from their experimental data. Deidentified research data, including surveys, interview recordings, and interview transcripts, will be stored on password-protected ODU network storage drives. All data will be retained for at least five years in accordance with Old Dominion University's policies. The key that links subject numbers to names will be stored separately from data in a password-protected file on ODU storage drives and within a locked filing cabinet. Neither audio or video recordings will be used in presentations. The results of this study may be used in reports, presentations, and publications, but the researcher will not identify you. Participant responses may be used as pilot data for future research studies with identifiers removed. Of course, your records may be subpoenaed by court order or inspected by government bodies with oversight authority. And, as with any research, there is some possibility that you may be subject to risks that have not yet been identified.

Benefits: There is no direct benefit to participation this study.

Research Consent: I have read the informed consent document and I understand what this research entails. I agree to be a part of this study. I understand that participation is voluntary. I do not have to take part in this study. I understand how much time participating in this study will involve. I understand that digital files will be stored on a secure computer server at Old Dominion University, which will only be accessed by the principal researchers. I understand that all data will be retained in accordance with Old Dominion University's policy for at least five years at the conclusion of the study. I understand that there are no expected risks to participation. I understand that this study may not benefit me directly. I understand that all information gained in this study will be treated in a confidential way and that my identity will not be revealed in any publications arising from this research. I understand that if I have any concerns or questions about the study, I can contact Meredith Gohsman or Dr. Rachel Johnson.

Meredith Gohsman
Old Dominion University
Norfolk, Virginia
mlave003@odu.edu

Dr. Rachel Johnson
Old Dominion University
Norfolk, Virginia
r1johnson@odu.edu

Do you consent to take part in the study titled: "Predictors and Experiences of Stress in Adult Caregivers of Children with Augmentative and Alternative Communication (AAC) Needs for Communication"?
- Yes, I consent.
- No, I do not consent. (Skip Logic: End of Survey)

4. Are you the parent, guardian, or caregiver of a child with a developmental, congenital, or acquired medical or educational diagnosis?
    - Yes
    - No (Skip Logic: End of Survey)
5. Does your child have AAC needs for communication and cannot meet their daily communication needs with verbal speech alone?
    - Yes
    - No (Skip Logic: End of Survey)
6. Does your child use augmentative and alternative communication (AAC) modalities? This can include, but is not limited to: gestures, body language, sign language, facial expressions, sounds, words, pictures, objects, photographs, writing, communication boards/books, or speech generating devices.
    - Yes
    - No (Skip Logic: End of Survey)
7. Is your child between 3 - 9 years old?
    - Yes
    - No (Skip Logic: End of Survey)

Child

8. Unaided AAC modalities only involve use of the body and no external device. Unaided AAC modalities include gestures, pointing, body language, physically leading someone, sign language, facial expression, looking with eyes, sounds, and spoken words.

    Aided AAC modalities involve an external device. Aided AAC modalities include pictures, photographs, objects, communication boards and books, and speech-generating devices (i.e., tablet).

    What percent of your child's daily communication with you occurs using unaided and aided AAC modalities?
    - Unaided AAC modalities: 0 – 100%
    - Aided AAC modalities: 0 – 100%

Caregiver

9. How old are you?
    - _____
10. What is your marital status?
    - Single
    - Separated or divorced
    - Married
    - Other, list here: _____
11. Which best describes your educational background?
    - Less than high school
    - High school graduate
    - Some college
    - 2 year degree
    - 4 year degree
    - Professional degree
    - Doctorate
    - Other, list here: _____

12. Which best describes your employment status?
    - Not employed outside of the home
    - Employed part time
    - Employed full time
    - Other, list here: _____

13. Are you of Hispanic, Latino, or Spanish origin?
    - Yes
    - No

14. What is your racial and ethnic identity? Select all that apply.
    - White
    - Black or African American
    - American Indian or Alaska Native
    - Asian
    - Native Hawaiian or Pacific Islander
    - Unknown
    - Other, list here: _____

15. What language(s) do you use in the home setting?
    - English
    - Other, list here: _____

16. In which state or territory do you live?
    - Alabama
    - Alaska
    - Arizona
    - Arkansas
    - California
    - Colorado
    - Connecticut
    - Delaware
    - District of Columbia
    - Florida
    - Georgia
    - Hawaii
    - Idaho
    - Illinois
    - Indiana
    - Iowa
    - Kansas
    - Kentucky
    - Louisiana
    - Maine
    - Maryland
    - Massachusetts
    - Michigan
    - Minnesota
    - Mississippi
    - Missouri

- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- US Territory
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming

PSI™-4-SF

17. Parenting Stress Index Fourth Edition Short Form
    Adapted and reproduced by special permission of the Publisher, Psychological Assessment Resources, Inc. (PAR), 16204 North Florida Avenue, Lutz, Florida 33549, from the Parenting Stress Index Fourth Edition Short Form by Richard R. Abidin, EdD, Copyright 1990, 1995, 2012 by PAR. Further reproduction is prohibited without permission of PAR.

    Read each statement carefully. For each statement, please focus on the child with AAC needs for communication and select the response that best represents your opinion. Answer all questions about the same child. While you may not find a response that exactly states your feelings, please select the response that comes closest to describing how you feel. Your first reaction to each question should be your answer.
    - OK
18. PSI™-4-SF
19. PSI™-4-SF
20. PSI™-4-SF
21. PSI™-4-SF
22. PSI™-4-SF
23. PSI™-4-SF
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46. PSI™-4-SF
47. PSI™-4-SF
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51. PSI™-4-SF
52. PSI™-4-SF
53. PSI™-4-SF

Beyond Microsystem

54. In the following questions, you will be asked to think about the collaboration and communication between members of your child's care team and you during the past 3-6 months.

    Collaboration is how the members of your child's care team have worked with you toward a consistent and shared goal.

    Rate your satisfaction with the quality of collaboration between you and the members of your child's care team in the past 3-6 months.
    - Strongly dissatisfied
    - Somewhat dissatisfied
    - Neutral
    - Somewhat satisfied
    - Strongly satisfied

55. Rate your satisfaction with the amount of collaboration between you and the members of your child's care team in the past 3-6 months.
- Strongly dissatisfied
- Somewhat dissatisfied
- Neutral
- Somewhat satisfied
- Strongly satisfied

56. Communication is the contact between the members of your child's care team and you.

Rate your satisfaction with the quality of communication between you and the members of your child's care team in the past 3-6 months.
- Strongly dissatisfied
- Somewhat dissatisfied
- Neutral
- Somewhat satisfied
- Strongly satisfied

57. Rate your satisfaction with the amount of communication between you and the members of your child's care team in the past 3-6 months.
- Strongly dissatisfied
- Somewhat dissatisfied
- Neutral
- Somewhat satisfied
- Strongly satisfied

Family Support Scale

58. Family Support Scale
    Dunst, Trivette, & Jenkins
    Winterberry Press

    Listed below are people and groups that often times are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to your family. Please select the response that best describes how helpful the people and groups have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, select the "Not Available" response.
- OK

59. FSS
- Not available
- Not at all helpful
- Sometimes helpful
- Generally helpful
- Very helpful
- Extremely helpful

60. FSS
61. FSS
62. FSS
63. FSS
64. FSS
65. FSS

66. FSS
67. FSS
68. FSS
69. FSS
70. FSS
71. FSS
72. FSS
73. FSS
74. FSS
75. FSS
76. FSS
77. FSS
78. FSS

APPENDIX C

Welcome and thank you for meeting me! My name is Meredith Gohsman. I'm a speech-language pathologist and now am completing my PhD at Old Dominion University. As part of that program, I am studying the experiences of parents, guardians, and caregivers of children using augmentative and alternative communication, or AAC. Before we get started, I'm going to go through some information about the study. This may be repetitive from the beginning of the survey that you completed.

AAC can refer to things like gestures, body language, sign language, facial expressions, sounds, words, pictures, objects, photographs, writing, communication boards/books, and speech generating devices. This is an interview in which we are going to talk about your experiences as a caregiver of a child who uses AAC. I have some questions to guide our conversation, which will take roughly an hour.

During the interview, you may face a risk of emotional response to questions. You are not required to respond to all of the questions during the interview and you may choose which questions you are comfortable with answering. There is potential risk of release of confidential information. To minimize this risk, identifiers will be removed from all private identifiable information collected. The results of this study may be used in reports, presentations, and publications, but I will not identify you. I'm going to record video and audio from this interview, but neither audio or video recordings will be used in presentations. The data from this study, including surveys, interview recordings, and interview transcripts, will be stored on password-protected ODU network storage drives. Your responses may be used as pilot data for future research studies with identifiers removed. And, as with any research, there is some possibility that you may be subject to risks that have not yet been identified. There is no direct benefit to participation this study.

Feel free to make any comments – negative or positive – about anything that comes up today. Do you have any questions?

Research Question	Participant Question	Follow-Up Topic
What are caregivers' microsystem contexts?	Tell me about yourself and family. Describe [Child]'s communication.	
How do caregivers' experiences of their child's communication interact with varying systems?	Tell me about your typical day caring for [Child]. How has [Child]'s communication with you changed over time?	• How did that experience affect **you**? • How did that experience affect **others in your life**?
What are the shared characteristics of caregivers' experiences of stress?	Tell me about a very stressful situation you have experienced as [Child]'s caregiver? Have you experienced a time when someone else didn't understand your role	• What **thoughts** stood out to you about this experience? • What **feelings** stood out to you about this experience? • How did you react? • How did that experience affect **you**?

	and responsibilities as a caregiver for a child who uses AAC? What happened?	
What are the shared characteristics of caregivers' experiences of support?	Describe a situation when you looked for support for caring for [Child].	• What feelings stood out about asking for support? • How did you decide where to seek support? • Did you get the support you were looking for? Why or why not?
	Tell me about a time that you felt really validated and confident as the expert in [Child]'s care.	• What **thoughts** stood out to you about this experience? • What **feelings** stood out to you about this experience?
What changes in stress occur for caregivers of children using AAC during times of transition?	Tell me about the very beginning stages of introducing [Child]'s aided AAC system.	• How did that experience affect **you**? • How did that experience affect **others in your life**? • How do you judge this experience today?
	Describe your experience of when [Child] was given a diagnosis.	• How did that experience affect **you**? • How did that experience affect **others in your life**? • What do you think about this experience today? How do you judge this experience?
	How has your experience caring for [Child] changed with the COVID-19 pandemic?	• What changes, if any, have you observed in your child? • How did that experience affect you?
	What is an "a-ha" moment that stands out to you related to being the caregiver of a child who uses AAC?	• What changes would I see if I were watching you navigate this moment? • What do you think about this experience today? How do you judge this experience?
How can support improve for caregivers of children using AAC?	Imagine you have all of the support you desire. How does that look to you? If your child's therapists or teachers could spend one whole day with you, what would you like them to learn about supporting your family? What advice would you give to a parent who is just beginning to navigate caring for a child using AAC? Describe how… would change if…	
	What else would you like to add that we have not talked about today?	

Thank you again for participating! Your experiences will be combined with the information from other interviews and the online surveys. Together, it will be used to make recommendations for improved collaboration between caregivers and the AAC team.

VITA

Meredith K. Gohsman

EDUCATION

2018 – 2021   Old Dominion University, Norfolk, VA
Doctor of Philosophy in Kinesiology and Rehabilitation

2012 – 2014   James Madison University, Harrisonburg, VA
Master of Science in Speech-Language Pathology

2009 – 2012   Old Dominion University, Norfolk, VA
Bachelor of Science in Speech-Language Pathology

PROFESSIONAL APPOINTMENTS

2021 – present Non-instructional part time faculty, Old Dominion University, Norfolk, VA
2019 – present Speech-Language Pathologist, Riverside Rehabilitation Hospital, Yorktown, VA
2018 – 2021   Graduate Assistant, Old Dominion University School of Rehabilitation Sciences, Norfolk, VA
2020   Lecturer, University of Virginia School of Education and Human Development, Charlottesville, VA
2014 – 2018   Speech-Language Pathologist, Children's Hospital of the King's Daughters, Hampton, VA

LICENSE AND CERTIFICATIONS

2015 – present American Speech-Language-Hearing Association, Number 14085711
2014 – present Virginia Board of Speech-Language and Audiology, Number 2202007394

SELECT PRESENTATIONS

Laverdure, M., Lawson, J., Melton, M., & Patton, H. (2021, February 3). *Go Boldly: Navigating Successful Post-Secondary Transitions in a Virtual World*. Paper to be presented at Assistive Technology Industry Association Conference, Orlando, FL.

Laverdure, M., Lawson, J., Melton, M., & Patton, H. (2020, January 30). *Building Communication Competence and Bridging Gaps Across Pediatric Settings*. Paper presented at Assistive Technology Industry Association Conference, Orlando, FL.

Laverdure, M., Lawson, J., & Melton, M. (2019, February 1). *Using Tactile Symbols to Facilitate Communication and Social Participation.* Paper presented at Assistive Technology Industry Association Conference, Orlando, FL.

Laverdure, M. & Lawson, J. (2019, January 31). *Minimizing Caregiver Stress and Burden Related to Augmentative-Alternative Communication*. Paper presented at Assistive Technology Industry Association Conference, Orlando, FL.

Laverdure, M. & Lawson, J. (2018, November 16). *The Talk Flock: AAC Group Intervention, Caregiver Stress, & Family Support*. Paper presented at American Speech-Language-Hearing Association Convention, Boston, MA.