Life Transitions of Children with Idiopathic Childhood Apraxia of Speech: A Qualitative

Descriptive Study

A Dissertation Presented By

Patricia J. Meza

Submitted to the Graduate School of Nursing

University of Massachusetts Medical School

in partial fulfilment of the requirements for the degree of

Doctor of Philosophy Nursing

April 2021

Approved as to style and content by:

_____

Nancy Morris

_____

Jesica Pagano-Therrien

_____

Donna Perry

April 30, 2021
Date

_____

Joan Vitello PhD, RN, NEA-BC, FAHA, FAAN
Dean & Professor
University of Massachusetts Worcester
Graduate School of Nursing

Table of Contents

Abstract

PURPOSE: The purpose of this qualitative descriptive study was to explore the experiences of emerging adults with idiopathic CAS, as they reflected on their transitions through childhood, adolescence, and young adulthood.

SPECIFIC AIMS:
1. Describe the experiences of emerging adults with idiopathic CAS as they reflect on developmental stages of childhood, adolescence, and young adulthood, including the situational experiences of transition occurring between elementary, middle, high school, and post-secondary education, training, or work.
2. Identify strategies and the effectiveness of the strategies utilized by emerging adults with idiopathic CAS to manage experiences during different developmental stages and situational experiences of transition occurring between elementary, middle, high school, and post-secondary education, training, or work.

FRAMEWORK: Meleis' Transitions Theory.

DESIGN: A qualitative descriptive design with purposive sampling was used. Data was analyzed using thematic analysis.

RESULTS: Findings support the use of Transitions Theory. Three major themes were identified: The Child's Environment, Implications of CAS, and Strategies. The school environment contributed to many implications for children. Older children were able to develop strategies to overcome challenges. In the school setting, children did not access nurses for concerns related to their CAS.

CONCLUSIONS: CAS creates many challenges for children. Emerging adults with CAS report that environments in which people are knowledgeable, patient, understanding, accepting, and supportive help them express themselves freely despite their speech impairment. The nurse's role in supporting children with CAS during grade school is untapped as they were largely invisible to the children as a potential resource for anything other than an injury or illness. To better facilitate supportive environments in which children with CAS can flourish, nursing assessment and interventions are needed.

KEYWORDS: CAS, childhood apraxia of speech, nursing, speech impairment, Transitions Theory

Proposal

Introduction

Childhood apraxia of speech (CAS) is a chronic condition of motor-speech sound disorder (Iuzzini-Seigel et al., 2017; Rusiewicz et al., 2018) whereby the child has difficulty producing precise and consistent sounds and syllables in order to speak words and sentences with clarity (Morgan et al., 2018). Childhood apraxia of speech affects approximately 0.1% - 0.2% or 1 – 2 children per one thousand (Morgan et al., 2018; Shriberg et al., 2019). Although this is a rare chronic condition, it is likely that the impact on a child's health and quality of life and challenges encountered during different stages of life aligns with research outcomes that have been identified for children with other chronic conditions such as diabetes, depression, and physical disability (Andrade & Alves, 2019; Deschenes et al., 2015; McCormack et al., 2012; National Institute on Deafness and Other Communication Disorders [NIDCD], 2019; Wang et al., 2019). Deficits in verbal communication create barriers to academic and social participation and may have long-term consequences for employment success (McCormack et al., 2009; McLaughlin, 2011). Evidence suggests an association between speech-sound disorder (SSD) and difficulties with learning and applying knowledge, lower academic expectations, interpersonal interactions, initiation and maintenance of peer relationships, and difficulties with sibling relationships (Hitchcock et al., 2015). Despite the large body of literature describing negative outcomes of children with other chronic conditions, research examining the impact of CAS during different stages of life and transitional times, strategies utilized to manage these experiences, and the perceived effectiveness of those strategies is minimal. Gaining insight from emerging adults with CAS will provide data needed to develop nursing interventions to improve support, facilitate the

child's transitions through different developmental stages and typical life transitions, and potentially manage and minimize the challenges encountered by these individuals.

The purpose of this qualitative descriptive study is to explore the experiences of emerging adults with idiopathic CAS, as they reflect on their transitions through childhood, adolescence, and young adulthood. To achieve this purpose, I will address the following specific aims.

Specific Aims

Specific Aim 1: Describe the experiences of emerging adults with idiopathic CAS as they reflect on developmental stages of childhood, adolescence, and young adulthood, including the situational experiences of transition occurring between elementary, middle, high school, and post-secondary education, training, or work.

Specific Aim 2: Identify strategies and the effectiveness of the strategies utilized by emerging adults with idiopathic CAS to manage experiences during different developmental stages and situational experiences of transition occurring between elementary, middle, high school, and post-secondary education, training, or work.

Childhood Apraxia of Speech

Childhood apraxia of speech literature and research is mainly focused on defining, diagnosing, and treating CAS. Despite the overall emphasis placed upon promoting biopsychosocial health and well-being of all children and families, qualitative research describing personal experiences of growing up with CAS is minimal. This qualitative descriptive study will present rich first-hand descriptions of experiences from individuals with CAS to provide insights about the impact of CAS during different developmental stages and situational experiences of transitions. Insight into successful and unsuccessful strategies

utilized by individuals with CAS will provide data necessary for the development of future studies regarding appropriate and effective nursing interventions to mitigate negative outcomes and foster improved support and outcomes for children with CAS.

Clinical Contexts of Childhood Apraxia of Speech

Childhood Apraxia of Speech is a chronic condition defined by the American Speech-Language-Hearing Association (2007a, pp. 3-4) as "a neurological childhood (pediatric) SSD resulting from primary deficits of motor planning and programming, in which the precision and consistency of movements underlying speech are impaired in the absence of neuromuscular deficits." Childhood apraxia of speech occurs in three clinical contexts. These include causal association with known neurological etiologies (intrauterine stroke, infections, or trauma); association with complex neurobehavioral disorders (autism, Down syndrome, attention deficit hyperactivity disorder); and idiopathic neurobehavioral SSD's that are not associated with any known neurological or complex neurobehavioral disorder (American Speech-Language-Hearing Association, 2007b). Idiopathic CAS accounts for the majority of reported cases (Murray et al., 2015). This research will focus on idiopathic CAS of unknown origin, of which difficulties with communication impairment occur independent of other diagnoses.

Speech / Language Differentiation

Differentiation between two synonymously used terms, *speech* and *language* is important when discussing idiopathic CAS. Essentially, language is the conceptual processing of communication, speech is a verbal production of language (McLaughlin, 2011). People express their ideas in meaningful ways through language (NIDCD, 2017). Language refers to the words that are used to express needs and share ideas (American

Speech-Language-Hearing Association, n.d.-a) and the comprehension or understanding of language is referred to as receptive language (Theakston & Adams, 2017). Language is considered an essential basic skill necessary for a child's social and emotional development and educational success (Conti-Ramsden et al., 2016; Visser-Bochane et al., 2019).

"Speech is how people say sounds and words" (American Speech-Language-Hearing Association, n.d.-a). Speech is the use of language to communicate thoughts or ideas and can be referred to as expressive language (NIDCD, 2017). Speech is inclusive of three components: articulation, voice, and fluency. Articulation refers to how speech sounds are made using the mouth, tongue, and lips. Voice is the sound produced by the vocal cords and breath, and fluency refers to the rhythm of speech (American Speech-Language-Hearing Association, n.d.-a). To produce the recognizable sounds that make up language, muscle actions of the jaw, lips, tongue, and vocal tract must be precisely coordinated (NIDCD, 2017). People with SSD's have difficulty with these coordinated movements and with producing speech sounds to share their thoughts. As idiopathic CAS is a result of an impairment related to the precision and consistency of movements underlying speech, and not that of the comprehension of language, this research is specifically about the experiences emerging adults had related to their speech.

Developmental Milestones of Speech Development

Though children vary slightly in their development of speech, they often follow a natural progression or timetable (Table 1) (NIDCD, 2017).

Table 1. Speech Milestones

Age	Milestones of Expressive Language
Birth – 4 months	Cooing, crying that changes with different needs.
4 – 8 months	Cooing, babbling speech sounds, giggling, laughing.
By 1 year	First word approximations (dada for daddy); Able to speak 1-2 words;

	Babbling evolving to long strings of sounds; Initiates vocalizations and sounds; Jargon (unintelligible speech) present; Imitation of different speech sounds.
18 months	Speaks 2-6 words; Jargon still present.
By 2 years	Repeats words overheard in conversation; Combines words; Use of simple phrases
By 3 years	Use of 3-5-word sentences; Use of pronouns (I, me, you, we); Ability to be understood by strangers.
4 – 5 years	Able to speak all speech sounds in words (some errors may be heard in sounds such as s, r, v, z, l, ch, sh, th) that are traditionally more difficult to say. Able to tell short stories, maintain conversations, and speak in different ways (louder in loud environment or outside, quieter or softer when inside, or with shorter sentences when speaking to babies or younger children.

*Adapted from (American Speech-Language-Hearing Association, n.d.-b; Let's Talk Apraxia.Org, 2016; American Speech-Language-Hearing Association, n.d.-c; McLaughlin, 2011).

Diagnostic markers for CAS have not been established however, three primary features are commonly reported. "Inconsistent errors on consonants and vowels in repeated productions of syllables or words" (ASHA, 2007, p. 7). For example, when saying the word car, the child may say dar, par, gar, or car. The same word is pronounced in different ways each time. "Lengthened and disrupted coarticulatory transitions between sounds and syllables" (ASHA, 2007, p. 7) can be explained as the inability to transition or combine consonants and vowels; as an example, when attempting to say the word puppy, the child will make the "p" sound which is followed by a pause or break, which will then be followed by the remainder of the word "uppy". "Inappropriate prosody, especially in the realization of lexical or phrasal stress" (ASHA, 2007, p. 7). Inappropriate prosody can be noted in a child with CAS when they begin speaking and there is little variation in the patterns of stress, loudness, and intonation or the rise and fall of the voice, making speech sound robotic.

Despite advances in the identification of these key characteristic features of CAS (Iuzzini-Seigel et al., 2017; Murray et al., 2015), expert clinical opinion remains the gold

standard for CAS diagnosis (Murray et al., 2015). What is clear is that children diagnosed with CAS do not follow the natural progression of speech development, and without speech intervention will not meet milestones for speech development (Let's Talk Apraxia.Org, 2016). Early identification and comprehensive developmental evaluation upon suspicion of speech disorder are essential (McLaughlin, 2011). Healthcare professionals as well as teachers and early childhood education (ECE) providers must be aware of subtle warning signs that may indicate need for further evaluation. These warning signs include limited vocalization and babbling throughout the first year of life; lack of verbal, vocal, or gestural reciprocity; restricted range of expressive communicative functions (requests, comments, greetings); nearly no multiword utterances by 2 years of age; poor intelligibility for family members and strangers by 3 years of age; and little or no conversational competence or vocabulary growth with inability to tell narratives by the age of 4 (Wankoff, 2011).

Treatment Interventions and Prognosis for Individuals With CAS.

Speech therapy is the primary treatment for CAS. Early referral and interventions targeting speech motor deficits in toddler and preschool age children should be made for any child suspected of speech or language delay (ASHA, 2007a). Children with CAS require extensive and frequent therapy sessions with speech-language pathologists, often for a long period of time (ASHA, 2007b). Early interventions may allow for decreased frequency of treatments over time (ASHA, 2007b) but mastery of all speech sounds, even after years of therapy, may not be possible (Lewis et al., 2004; Rusiewicz et al., 2018). Speech sound errors extending past eight to nine years of age, may be labeled as residual speech errors (RSE) (Shriberg et al., 1994), and can negatively impact a child's social and emotional well-being (Hitchcock et al., 2015).

Speech-language pathology is a covered service under the Medicaid program (American Speech-Language-Hearing Association, n.d.-d). Eligibility standards regarding type, amount, and duration of therapy, and payment rates for therapy are state controlled (American Speech-Language-Hearing Association, n.d.-d). Options for services for patients on Medicaid may be limited as not all speech therapy practices accept Medicaid (McLaughlin, 2011) however, speech therapy for children without health insurance is available through the Individuals with Disabilities Education Act (IDEA) which covers services from birth to 21 years of age (American Speech-Language-Hearing Association, n.d.-e; McLaughlin, 2011).

CAS: A Chronic Health Condition

Children with chronic health conditions experience developmental, psychosocial, and behavioral outcomes inclusive of anxiety, depression, difficulties with learning, communication, peer interactions and relationships, and difficulties with employment (Andrade & Alves, 2019; Bosma et al., 2020; Deschenes et al., 2015; Kostev et al., 2019; Lopez-Vargas et. al., 2019; Wang et al., 2019). Similar to children with other chronic conditions, children with CAS experience learning problems; difficulties with social communication, peer interactions and maintenance of peer relationships; anxiety and depression; and potentially difficulties later in life with employment such as harassment, hiring discrimination, and discharge (McCormack et al., 2012; McCormack et al., 2009; Miron, 2012; Rusiewicz, Maize, and Ptakowski, 2018; Teverovsky et al., 2009). Families and caregivers of children with CAS have also acknowledged difficulties with anxiety and depression, frustration, concerns related to their child's intelligibility and reliance on a parent to interpret for the child, and concerns related to their child's emotional responses such as

frustration, embarrassment, and stress (Farinelli Allen, & Babin, 2013; McCormack et al., 2009).

Many children with chronic health conditions adapt and can pursue and achieve their personal goals in spite of their chronic condition (Fisher & Palermo, 2016; Stommen et al., 2016). Research referencing first-hand accounts of an individual's experiences, ability to adapt to different experiences, and the pursuit and achievement of personal goals despite having CAS is minimal. In 2010, McCormack et al., utilized a phenomenological approach to understand the experience of speech impairment as described by 13 preschool children. In this study, although most children in preschool were happy with their speech abilities regardless of a speech impairment, children also noted frustrations associated with their inability to speak correctly and their strategies to address this problem, namely avoidance of talking with others or referring others to their parents for interpretation (McCormack et al., 2010).

McCormack et al., (2012) conducted a qualitative study revealing the emotional consequences of having a communication disorder. The study included two participants diagnosed with CAS, ages 17 and 23 years, who described childhood experiences, associated difficulties, and methods used to minimize the impact of CAS. Participants in this study indicated that their personal realization of communication difficulties occurred in later childhood during primary school years. McCormack et al., (2012) suggested this timing may be related to realization of self-concept which typically occurs with commencement of school when children begin comparing themselves to others. Difficulties with life activities such as learning and applying knowledge, communication, interpersonal interactions and

relationships, and community, social and civic life, as well as methods of management for speech impairment and difficulties were identified.

In 2013, McLeod et al., interviewed six children ages 5 – 9 years old with a SSD and presented experiences across varying contexts of everyday life. Researchers discussed the private (familial) and public worlds of these children. Results indicated that children felt safe and supported, and could be themselves and maintain a typical childhood within the context of the private world of family and close friends, however, in the public context, children struggled with difficulties related to unintelligibility, frustration, embarrassment, changes in relationships, and withdrawal (McLeod et al., 2013). Rusiewicz et al., (2018) reported experiences of CAS from the parent's perspective. Parents provided personal reflections highlighting the emotional impact of CAS on families and perceptions of the impact of CAS on their children, noting specifically perceived impact on peer relationships.

In 2015, Carrigg et al., reported the profound effects of living with a communication disorder. Recounted reflective experiences of a 22-year-old male identified feelings of being left out because of his inability to talk with other people, inability to talk with others regardless of knowing what he wanted to say, and of being "intentionally put in many distressing and upsetting situations" by his teachers (Carrigg et al., 2015, p. 46). By18 years of age, this individual had attempted suicide three times. Recent research continues to confirm that an individual's life experiences and interactions with others are significantly influenced by communication disorders.

McCormack et al., (2018) explored 17 first-person accounts from individuals with a history of communication disorder. Four themes emerged from this exploration. 1) The communication disorder did not define the individual but was only a part of who they were.

Although these individuals identified themselves as being intelligent, their communication disorder hid their abilities. Feelings of inadequacy, sadness, and frustration related to others inability to see their intelligence and realize their capabilities was noted; 2) The interactions with other people and the educational endeavors of individuals with communication disorders were significantly and profoundly affected; 3) More readily available services inclusive of consultations with health professionals, and programs for children with communication disorders and their families are needed and can improve outcomes. Individuals reported having more friends, increased participation in activities, and increased confidence with speaking as a result of effective and early interventions; 4) Early identification and intervention can change the life of an individual with a communication disorder for the better.
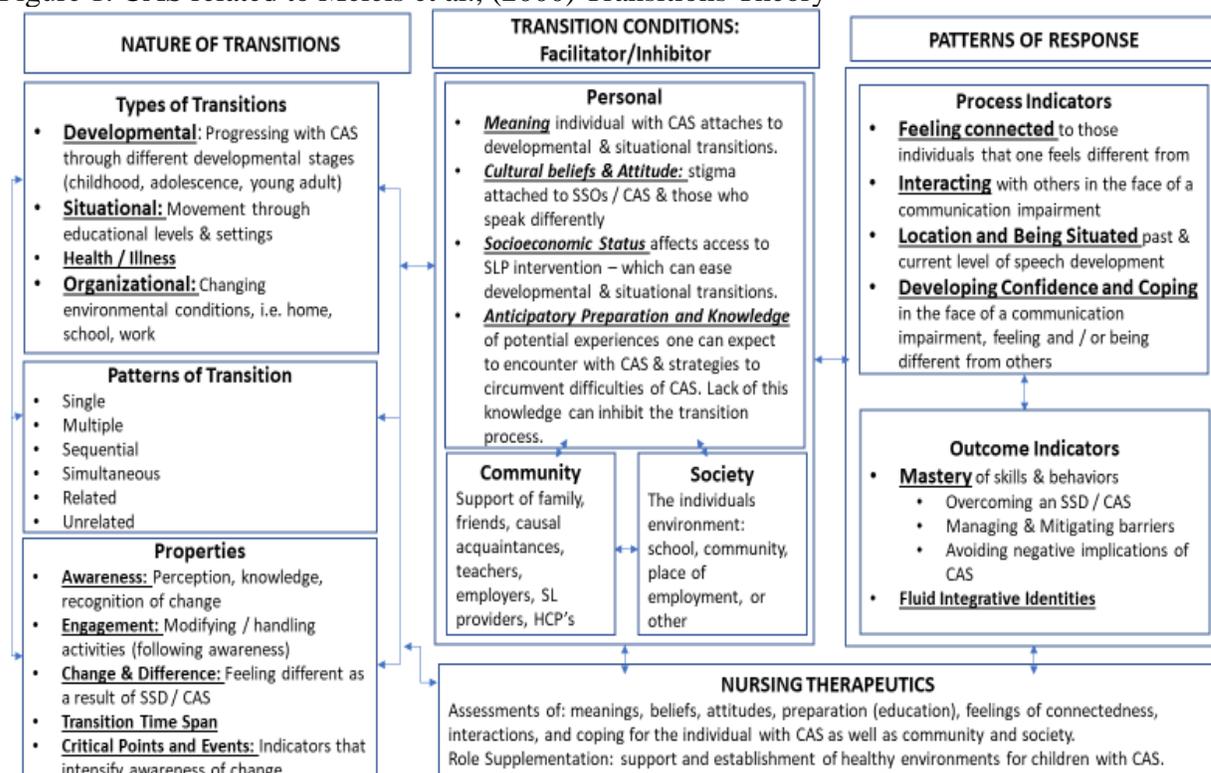
All of these studies, conducted by speech-language pathologists, recommend further research. While McLeod et al., (2013) suggested longitudinal studies, McCormack et al., (2010) recommended research with different age groups to determine how children's perceptions of living with a speech impairment changes over time. McCormack et al., (2012) and Rusiewicz et al., (2018) both called for studies with the same individuals at different stages and developmental levels, for the similar purpose of understanding how perceptions and experiences of individuals with CAS change over time. I will explore reflections of life experiences of emerging adults with idiopathic CAS at different developmental stages which will facilitate a comparative analysis across the age spectrum. I will also identify successful and perhaps unsuccessful strategies utilized by these individuals to manage life experiences. Through the lens of a nursing theory on life transitions, this study will provide a nursing

perspective which can inform future intervention studies to improve nursing support and outcomes for children with CAS.

Theoretical Framework

This study will be undergirded by Meleis' et al., (2000) Transitions Theory. Transitions Theory describes the process experienced by an individual occurring as a result of a change (Meleis et al., 2000; Schumacher & Meleis, 1994). Transition can be understood as a passage, or movement, from one life phase, condition, or status to another (Meleis et al., 2000). Transition requires the person to incorporate new knowledge, alter behavior, and therefore to change the definition of self in social context (Meleis, 2012). The process and experience of undergoing a transition can result in a changed perception of health, new meaning, and a sense of control (Meleis et al., 2000). While transitioning through childhood, adolescence, and young adulthood, individuals incorporate new knowledge, alter behaviors, and develop their definition of self in the social context. Speech-sound disorders and deficits in verbal communication that create barriers to academic and social participation (McCormack et al., 2009; McLaughlin, 2011) can influence an individual's definition of self, perception of health, and sense of control over a situation. Components of the Transitions Theory and their relationship to CAS are illustrated in Figure 1.

Figure 1. CAS related to Meleis et al., (2000) Transitions Theory

NATURE OF TRANSITIONS

Types of Transitions
- **Developmental**: Progressing with CAS through different developmental stages (childhood, adolescence, young adult)
- **Situational:** Movement through educational levels & settings
- **Health / Illness**
- **Organizational:** Changing environmental conditions, i.e. home, school, work

Patterns of Transition
- Single
- Multiple
- Sequential
- Simultaneous
- Related
- Unrelated

Properties
- **Awareness:** Perception, knowledge, recognition of change
- **Engagement:** Modifying / handling activities (following awareness)
- **Change & Difference:** Feeling different as a result of SSD / CAS
- **Transition Time Span**
- **Critical Points and Events:** Indicators that intensify awareness of change

TRANSITION CONDITIONS: Facilitator/Inhibitor

Personal
- *Meaning* individual with CAS attaches to developmental & situational transitions.
- *Cultural beliefs & Attitude:* stigma attached to SSOs / CAS & those who speak differently
- *Socioeconomic Status* affects access to SLP intervention – which can ease developmental & situational transitions.
- *Anticipatory Preparation and Knowledge* of potential experiences one can expect to encounter with CAS & strategies to circumvent difficulties of CAS. Lack of this knowledge can inhibit the transition process.

Community
Support of family, friends, causal acquaintances, teachers, employers, SL providers, HCP's

Society
The individuals environment: school, community, place of employment, or other

PATTERNS OF RESPONSE

Process Indicators
- **Feeling connected** to those individuals that one feels different from
- **Interacting** with others in the face of a communication impairment
- **Location and Being Situated** past & current level of speech development
- **Developing Confidence and Coping** in the face of a communication impairment, feeling and / or being different from others

Outcome Indicators
- **Mastery** of skills & behaviors
  - Overcoming an SSD / CAS
  - Managing & Mitigating barriers
  - Avoiding negative implications of CAS
- **Fluid Integrative Identities**

NURSING THERAPEUTICS
Assessments of: meanings, beliefs, attitudes, preparation (education), feelings of connectedness, interactions, and coping for the individual with CAS as well as community and society.
Role Supplementation: support and establishment of healthy environments for children with CAS.

Four key concepts central to this theory include the nature of transitions, transition conditions, patterns of response, and therapeutic interventions in nursing (Figure 1). The nature of transitions is broken down into three groups of type, pattern, and properties. Developmental, situational, health / illness, and organizational transitions are indicative of types of transitions (Meleis et al., 2000). This study will focus on developmental, situational, and organizational transitions. Developmental transitions refer to human development that continues through the life span, with each developmental stage presenting new challenges and opportunities. Situational transition can be viewed as a change in a person's life occurring as a result of a particular circumstance, for instance, movement through educational levels or settings. Organizational transitions occur with changing environmental

conditions (Schumacher, & Meleis, 1994). As with all individuals, those with CAS experience developmental, situational, and organizational transitions.

Patterns of transition are related to the sort of transition one is experiencing, ranging from a single transition to multiple, sequential, simultaneous, related, or unrelated transitions. For example, transitions can occur simultaneously with overlap as in a child entering the developmental stage of adolescence and at that same time moving from an elementary to a middle school setting, or the transition can be a single unrelated transition whereby the child moves to a different school unrelated to any other changes.

Properties outline specific attributes of transition and are defined by the framework to include awareness, engagement, change and difference, time span, and critical points and events (Meleis et al., 2000). Changing schools requires forming new relationships with peers. For a child with CAS, events that occur during this change can intensify the child's awareness of the change, potentially affecting their pattern of response as it relates to feelings of connectedness, ability to interact, develop confidence, cope, and ultimately avoid negative implications of CAS.

Transition conditions describe facilitators and inhibitors of transition. These facilitators and inhibitors are related to person, community, and society. (Meleis et al., 2000). Limited access to intervention for children with SSD's of families with low socioeconomic status (SES), stigmas attached to children with SSD's / CAS, and lack of familial, community, and societal support constitute inhibitors of transition, while opposite situations can facilitate ease of change.

The Transitions Theory will help guide interview questions for this study. Application of this middle-range nursing theory provides a much-needed nursing lens to CAS research,

which has traditionally been assumed by speech-language pathology, neurology, and psychology. Results of this study may have implications for nurses in pediatric and primary care practices, pediatric and family nurse practitioners, and school and camp nurses, all of whom have interactions with the pediatric population throughout childhood and adolescent transitions. These nurses may be the first to identify potential problems in speech, language, and communication (Enderby & Wren, 2016). Nursing research that promotes understanding of the nature of transitions, the strategies and the effectiveness of those strategies used by children with CAS through different experiences and changes in their lives, and the effects of transition conditions on patterns of response as they relate to children with CAS provides data that can inform nursing interventions and therapeutics, the fourth key concept of Meleis et al's., (2000) Transition Theory.

Methods

Design

The proposed study will use a qualitative descriptive (QD) design to describe experiences of emerging adults with idiopathic CAS, as they reflect on their transitions through developmental stages of childhood (5 – 12 years), adolescence (ages 13 – 17 years), and emerging adulthood (18 – 25 years), to identify strategies utilized by those individuals to manage these experiences, and to explore emerging adults perceived effectiveness of these strategies. Qualitative description is a naturalistic paradigm of inquiry (Lincoln & Guba, 1985) whereby the researcher stays close to the data and surface of the event using low inference interpretation and everyday language to present a rich description of the experience (Sandelowski, 2000, 2010; Sullivan-Bolyai et al., 2005). The everyday language used in QD research makes findings easily interpretable and readily understood by participants and non-

researchers (Sullivan-Bolyai et al., 2005). This is extremely important in this particular study as in addition to healthcare providers, results of this study will be shared with children diagnosed with CAS and their families, providers of ECE, and organizations that provide education and support for individuals with SSD's and other disorders involving speech and communication.

Sample

This study will use purposeful sampling in conjunction with snowball sampling. Homogeneous purposive sampling is a widely used strategy in qualitative research to identify and select information rich cases (Patton, 2002) while allowing for a more focused inquiry (Polit & Hungler, 1997). Use of homogenous sampling places greater emphasis on depth and similarities (Palinkas et al., 2015) of emerging adults (ages 18-25 years) who experienced childhood with CAS, providing unique and rich information of value to this study. Although dependent on the accuracy of recall, this age group will allow the exploration and comparison of each participant's reflective experiences during different developmental stages of childhood, adolescence, and young adulthood.

Additional participants will be recruited through a process of snowball sampling (Polit & Beck, 2008), whereby existing participants recruited through procedures discussed in the recruitment and retention section below share information about the study to attract future participants from among peers and acquaintances. This additional sampling method was chosen because of the rarity of CAS in the absence of neurobehavioral disorders or known neurological events. It should be noted however that with a snowball sampling technique, researchers cannot guarantee anonymity of participants with reference to outside conversations between participant friends. Sample size for a QD study may vary from 10 to

50 participants (Sandelowski, 1995). The target sample size for this QD study is 15 individuals. Should more participants be required to reach informational redundancy (Lincoln & Guba, 1985), the final sample size will be determined during the study as redundancy is achieved.

Recruitment and retention

Online recruitment will be used for this study. First, I will seek approval from Apraxia-kids.org (2019) to recruit participants through the Apraxia-Kids.org (2019) website research page. According to the Childhood Apraxia of Speech Association of North America [CASANA] 2018 annual report, there were 438,000 Apraxia-Kids.Org (2019) website visitors, 1,500.000 page views, 3,000 free webinars that were viewed, over 25,000 members in the national official support group with 2,834 new members added in 2018 (Childhood Apraxia of Speech Association of North America, 2018). For consideration of approval, researchers are required to submit an Institutional Review Board (IRB) approval letter and a fact sheet (Appendix B) providing a description of the study written in layman's terms. Fact sheet will include an email address and phone number for interested potential participants to contact the researcher.

I will also seek permission from Apraxia-Kids.org (2019) to recruit participants through the Apraxia-Kids Facebook page. Growing evidence suggests that Facebook is a useful recruitment tool that should be considered when conducting health research (Whitaker et al., 2017). Apraxia-Kids.org (2019) provides access to specialty Facebook groups such as: Apps for Apraxia Kids, Parents of Teens and Tweens with Apraxia, Resolved Apraxia: Beyond Speech Issues, Just for Dads of Kids with Apraxia, Apraxia Kids Grandparent Group, Apraxia Awareness, Severe/Profound Childhood Apraxia of Speech, and Apraxia

Kids Homeschoolers (Apraxia-Kids, 2019). A brief description of the study and a

promotional flyer will be posted with an email address and a phone number to contact the

researcher. During the initial contact, I will review the fact sheet (Appendix B), the study

details, inclusion / exclusion criteria, procedures, and the participants preferred method of

communication. If eligible and willing to participate, an interview will be scheduled. I may

also be available during the initial contact to conduct the interview at that time, adhering to

the data collection protocol discussed below, should this be requested by the eligible

participant. Retention issues are not anticipated for this QD study as only one interview per

participant is needed. Participants will receive a $25.00 Amazon gift card upon completion of

the approximate 60-minute interview. All participants completing the interview will also be

entered into a random drawing for a $100.00 Amazon gift card.

Inclusion Criteria

Inclusion criteria for this study include: able to communicate (verbally or in writing)

in English, able to provide informed consent, age 18 - 25 years old and diagnosed as a child

with idiopathic CAS, and self-report of comfort with speaking about experiences living with

CAS.

Exclusion Criteria

Exclusion criteria include: age <18 years old or >25 years old, diagnosed with CAS

associated with neurobehavioral disorders such as autism, epilepsy, or other syndromes, or

with known neurological events such as stroke, trauma, or infection.

Setting and Procedures

Video interviews will be conducted from a private location allowing for

confidentiality. Procedures for this study will consist of private open-ended one-on-one

Zoom interviews. Augmentative and alternative communication devices as well as chat features available through Zoom may be used for participants with speech difficulties. I will conduct all interviews. The interview guide (Appendix A) addresses and incorporates aspects noted in the Transition Theory developed by Meleis et al., (2000). Interviews will last for approximately 60 minutes and will be digitally recorded on two separate recording devices. Digital recordings will be maintained in the manner described in the data collection / management section below.

Data Collection / Management / Security

Institutional Review Board approval will be obtained. Each potential participant will receive a fact sheet (Appendix B). Contact information for the IRB will be provided to all participants in the event they prefer to speak with someone not associated with the study or have questions about rights as a research subject. Verbal consent will be obtained by all participants after review of the fact sheet and will also be indicated by participant's willingness to participate in the interview. Participants will be asked to complete a demographic information form (Appendix C). Demographic forms will be of electronic format using the RedCap platform. Demographic information will include: age, gender, race / ethnicity, approximate age of CAS diagnosis (if known), receipt of SLP treatment and ongoing treatment, marital status, level of education, occupation, and current employment status.

Interview questions will be open-ended. If clarification is needed, I will use additional prompting. Digitally recorded interviews will be reviewed in their entirety immediately after each session to assure audibility of interviews. I will transcribe recordings verbatim into word documents. Recording will be destroyed after transcription has been verified. To ensure

confidentiality, identifying features will be removed for analysis. Subject ID numbers will be

assigned to participants, and an equal (=) sign will be used before and after other names,

locations, or organizations used by the participant to easily identify sensitive information that

may require substitution. The link between participants and subject ID numbers will be

stored on a UMass secure password-protected research drive. Access to this drive will be

restricted to the researcher and the dissertation committee. Notes consisting of dated and

timed researcher observations, impressions, and reflections will be written during or

immediately upon completion of participant interviews to provide additional data for

analysis. When not in use, recordings will be locked in a secure location. Transcripts, notes,

and demographic data will be stored on the UMass secure password-protected research drive.

All transcripts, notes, and demographic data will be maintained for a minimum of three years

after the completion of research.

Thematic Analysis

Thematic analysis is a descriptive qualitative approach to data analysis (Vaismoradi

et al., 2013) used to identify, analyze, and report patterns within data, to provide a purely

qualitative, rich, detailed and complex account of the data (Braun & Clark, 2006). The six

phases of thematic analysis described by Braun and Clark (2006) and descriptions of data

analysis activities to be used in this study are presented in Table 2. The researcher will move

back and forth throughout these 6-phases in a non-linear iterative process, to produce a rich

insightful analysis (Braun and Clark, 2006).

Table 2. Thematic Analysis

	Phases	Description of Data Analysis Activities
1	Familiarizing myself with the data	• Data will be collected by the researcher to provide some knowledge of the data prior to analysis. • Reviews of audibility of recorded interviews completed after

		interviews and prior to transcription.
		• Repeated checking of the data to ensure trueness of data and accuracy has been maintained between recorded interviews and transcribed interviews.
		• Incorporation of field notes regarding researcher impressions, experiences and observations into each interview document. Informal notes / ideas will be written on transcripts in preparation for formal coding.
2	Generating initial codes	• Manual open coding approach working systematically through each data set, identifying, highlighting, and creating initial list of codes for all data related to reflections of life experiences of emerging adults with idiopathic CAS at different developmental stages. Codes will be collated with data extracts that demonstrate the code.
3	Searching for themes	• Analyze codes and consider how the codes may combine to form potential / candidate themes for each stage of development (childhood, adolescence, young adulthood), and throughout transitions between stages. • Thematic concept maps will be created and used to provide visual representations of candidate themes and sub-themes, and codes that fall under each theme. • Collation of data extracts within the identified candidate themes.
4	Reviewing themes	• Review collated extracts to determine fit between data extracts and themes. • Re-read data set. Consider validity of themes in relation to the data set, as well as accuracy of thematic map in reflecting the meanings evident in the data set. • Code inadvertently missed additional data from earlier coding stages and add into themes. • Review and refine coding until thematic maps are reflective of the overall story of the data set. • Create new themes if candidate themes do not fit the data extracts.
5	Defining and naming themes	• Continued analysis to refine specifics of each theme • Generate clear names for themes • Prepare a detailed analysis for each theme.
6	Producing the report	• Complete a final analysis and write up of the report. • Data extracts demonstrating prevalence of themes describing CAS as it relates to reflections of experiences and transitions during early childhood, adolescence, and young adulthood will be incorporated into the final report.

*Adapted from (Braun & Clark, 2006)

Reflexivity

A consciousness of biases, values, and experiences the researcher brings to a

qualitative study is referred to as reflexivity (Creswell, 2013). My research for this study has

been spurred by my granddaughter's diagnosis of CAS. At the time of this study, she is four years of age and has not yet been socialized to an educational environment. I currently have no definitive knowledge related to the overall childhood experience of CAS, and previous studies with this information are minimal. For this study, field notes inclusive of researcher experiences, observations, and personal reflections and feelings in relation to the study will be taken immediately after each interview. Review of reflexive journaling with members of the dissertation committee to identify over / underemphasized points, vague descriptions, errors in data, or biases or assumptions I may make will be conducted to help ensure my personal experiences or knowledge of CAS, or any other unexplored biases, will not affect the quality of the analysis (Creswell, 2013).

Trustworthiness

In qualitative research, trustworthiness of the findings includes credibility, confirmability, dependability, and transferability (Lincoln & Guba, 1985). To maintain the trustworthiness of this study, I will use various strategies within each qualitative construct. Credibility ensures the researcher has accurately identified and described the phenomenon (Lincoln & Guba, 1985). For this study, I will use member checking, rich detailed descriptions of the phenomenon, frequent debriefing, and peer scrutiny of the research project to establish credibility. According to Lincoln and Guba (1985), member checking is the most critical technique for establishing credibility. I will identify three participants who are willing to be contacted again to seek validation and provide feedback referencing the accuracy of my interpretations (Polit & Hungler, 1997). To help ensure honesty of participants, each will be given opportunities to refuse participation, thereby the researcher will collect data from those who are genuinely interested in the study. Frequent debriefing

sessions between myself and the research team, will be conducted to discuss alternative

approaches, developing ideas and interpretations, and potential development of researcher

bias (Shenton, 2004).

To properly evaluate the rigor of a qualitative study, evaluators must differentiate

between researchers' errors during data analysis (Sandelowski & Barroso, 2002). Lincoln

and Guba (1985) use dependability in preference to the quantitative construct of reliability as

a one of the constructs to establish trustworthiness (Creswell, 2013). For this study, I will

establish dependability with the use of an audit trail, code-recode strategy, frequent

debriefing sessions, and peer examination (Schwandt et al., 2007).

The audit trail is regarded as one of the principle techniques for establishing

confirmability in qualitative research (Lincoln & Guba, 1985). An audit trail will be used to

establish confirmability in this study and to provide observer insight into procedures and

decisions made throughout the study. The audit trail will consist of raw data, interview and

observation notes and will be maintained for cross-checking the inquiry process (Lincoln &

Guba, 1985).

To help ensure consistency in this study, interviews will be conducted until

informational redundancy (Lincoln & Guba, 1985) occurs, writing and rewriting of

interpretive notes and summaries will continue throughout all phases of the analysis, and

examination of the research plan and execution will be completed by a methodological

expert. To assess the extent to which findings of this study may be transferrable to people in

other settings, environments, or with other forms of SSD, further research studies using

identical methods will be needed. According to Lincoln and Guba (1985, p. 316), "It is, in

summary, not the naturalist's task to provide an index of transferability, it is his or her

responsibility to provide the data base that makes transferability judgements possible on the part of potential appliers."

Human Subjects Issues

Risk to participants of this study is considered minimal. Institutional Review Board approval will be obtained prior to the start of the study. This study will use a demographic form created by the researcher for the collection of demographic data, and interview procedures as discussed above in the data collection section. Participants will be informed prior to the interview, verbally and in writing via a fact sheet (Appendix B) of the following: 1) Purpose and specific aims of the research, 2) Contact information for the PI and the committee chair person, as well as IRB contact information for any questions or concerns regarding the research, 3) Information addressing the interview process and approximate length of interview, 4) Participant compensation upon completion of interview, 5) Participation is voluntary and participants can withdraw from the study at any time should they choose to do so, and 6) Risks of participation.

Rich descriptions about life experiences during different developmental stages and transitional times provided by those who have been diagnosed with idiopathic CAS present a risk of loss of confidentiality for participants. Participants will be informed that because of the rarity of the condition, anonymity cannot be promised; the researcher will however, deidentify all data within transcripts that include names of people, specific locations, places of employment, and places of SLP treatment, and follow procedures identified in the data collection / management / security discussion above. Participants will also be informed prior to interviews that risk of participating in this qualitative study may also include feelings of

discomfort answering some of the questions in the study and that they can choose to skip any questions they are uncomfortable answering.

I will attempt to provide rich descriptions of participant experiences to aid readers understanding of the childhood experiences of growing up with CAS. Reflective experiences of emerging adults with idiopathic CAS during each developmental stage of childhood, adolescence, and emerging adulthood, and strategies utilized by those adults to manage these experiences will be presented using themes developed for each stage. Limitations related to sample recruitment, size, and sampling technique have been considered during the planning stage of this study. I intend to continue recruitment as needed through the Apraxia-Kids.org website research page, the Apraxia-Kids Facebook page, and through continued use of snowball sampling until data analysis indicates that informational redundancy has been achieved. I also acknowledge the small sample size proposed for this study. This is due to the rarity of idiopathic CAS and the likelihood of reaching informational redundancy with 15 interviews. I will continue recruitment beyond the proposed sample size of 15 individuals if needed until reaching informational redundancy.

Recall bias is a potential limitation of this study. Participants will be asked to recall experiences that may have occurred 13 to 20 years prior. I recognize that recall of early events is likely to be incomplete. To address the purpose and specific aims of this study and facilitate a comparative analysis across the spectrum, it is necessary that participants have experienced each developmental level. Though participants older than 25 would meet this criterion, keeping the time period between the experience and the reflection to the least possible amount of time could possibly lessen the recall bias. In addition, as loss of recall is

less likely with salient events; interview questions for this study will focus on events that stand out as significant to participants.

Conclusion

Identification of successful coping strategies utilized by participants in this study should spur future studies focused on development of nursing interventions to support and facilitate transitions through different developmental stages, and potentially to manage and minimize the challenges encountered by children with CAS. A clearer understanding of the experiences, strategies, and effectiveness of strategies is pertinent for the promotion of optimal long-term biopsychosocial health and well-being of children affected by SSD's.

References

American Speech-Language-Hearing Association. (2007a). *Childhood apraxia of speech* [Position Statement]. Available from www.asha.org/policy.

American Speech-Language-Hearing Association. (2007b). *Childhood apraxia of speech* [Technical Report]. Available from http://www.asha.org/policy/TR2007-00278/.

American Speech-Language-Hearing Association. (n.d.-a). *What Is Speech? What Is Language?* https://www.asha.org/public/speech/development/language_speech/

American Speech-Language-Hearing Association. (n.d.-b). Birth to One Year. https://www.asha.org/public/speech/development/01/

American Speech-Language-Hearing Association. (n.d.-c). *Four to Five Years*. https://www.asha.org/public/speech/development/45.htm

American Speech-Language-Hearing Association. (n.d.-d). *Medicaid Coverage Policies*. https://www.asha.org/practice/reimbursement/medicaid/McaidCoverageSLP/

American Speech-Language-Hearing Association. (n.d.-e). Individuals with Disabilities Education Act. https://www.asha.org/public/coverage/IDEA.htm

Andrade, C., & Alves, C. A. D. (2019). Relationship between bullying and type 1 diabetes mellitus in children and adolescents: a systematic review. *Jornal de Pediatría, 95*(5), 509-518. doi:10.1016/j.jped.2018.10.003

Apraxia-kids.org. (2019). *Apraxia Kids*. https://www.apraxia-kids.org/

Bosma, A. R., Boot, C. R. L., Schaafsma, F. G., & Anema, J. R. (2020). Facilitators, barriers and support needs for staying at work with a chronic condition: a focus group study. *BMC Public Health, 20*(1), 201. doi:10.1186/s12889-020-8320-x

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research In Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Carrigg, B., Baker, E., Parry, L., & Ballard, K. (2015). Persistent Speech Sound Disorder in a 22-Year-Old Male: Communication, Educational, Socio-Emotional, and Vocational Outcomes. *Perspectives on School-Based Issues, 16*. https://doi.org/10.1044/sbi16.2.37

Childhood Apraxia of Speech Association of North America. (2018). *Apraxia Kids 2018 Annual Report: Bridging Communities*. file:///D:/2018-Apraxia-Kids-Annual-Report.pdf

Conti-Ramsden, G., Durkin, K., Mok, P. L., Toseeb, U., & Botting, N. (2016). Health, employment and relationships: Correlates of personal wellbeing in young adults with and without a history of childhood language impairment. *Social Science and Medicine, 160*, 20-28. doi:10.1016/j.socscimed.2016.05.014

Creswell, J. W. (2013). Qualitative Inquiry and Research Design. Thousand Oaks, California: Sage Publications. Inc.

Deschenes, S. S., Burns, R. J., & Schmitz, N. (2015). Associations between depression, chronic physical health conditions, and disability in a community sample: A focus on `the persistence of depression. *Journal of Affective Disorders, 179*, 6-13. doi:10.1016/j.jad.2015.03.020

Enderby, P., & Wren, Y. (2016, August 12). Speech, language and communication impairments – how the practice nurse can help. *Nursing in Practice*. Retrieved from https://www.nursinginpractice.com/speech-language-and-communication-impairments-–-how-practice-nurse-can-help

Farinelli Allen, L., & Babin, E. A. (2013). Associations between caregiving, social support, and well-being among parents of children with childhood apraxia of speech. *Health Commun, 28*(6), 568-576. doi:10.1080/10410236.2012.703120

Fisher, E., & Palermo, T. M. (2016). Goal Pursuit in Youth with Chronic Pain. *Children (Basel), 3*(4). doi:10.3390/children3040036

Hitchcock, E., Harel, D., & McAllister Byun, T. (2015). Social, Emotional, and Academic Impact of Residual Speech Errors in School-Aged Children: A Survey Study. *Seminars in Speech and Language, 36*, 283-294. doi:10.1055/s-0035-1562911

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Iuzzini-Seigel, J., Hogan, T. P., & Green, J. R. (2017). Speech Inconsistency in Children with Childhood Apraxia of Speech, Language Impairment, and Speech Delay: Depends on the Stimuli. *Journal of Speech, Language, and Hearing Research, 60*(5), 1194-1210. doi:10.1044/2016_jslhr-s-15-0184

Kostev, K., Teichgraber, F., Konrad, M., & Jacob, L. (2019). Association between chronic somatic conditions and depression in children and adolescents: A retrospective study of 13,326 patients. *Journal of Affective Disorders, 245*, 697-701. doi:10.1016/j.jad.2018.11.014

Let's Talk Apraxia.Org. (2016). *Milestones: Ages 1 to 4 years*. https://lets-talk-apraxia.org/ages- one-three-years-developmetal-milestones-late-talking/

Lewis, B. A., Freebairn, L. A., Hansen, A. J., Iyengar, S. K., & Taylor, H. G. (2004). School-Age follow-up of children with childhood apraxia of speech. *Lang Speech Hear Serv Sch, 35*(2), 122-140. doi:10.1044/0161-1461(2004/014)

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage.

Lopez-Vargas, P., Tong, A., Crowe, S., Alexander, S. I., Caldwell, P. H. Y., Campbell, D. E.,
. . . Craig, J. C. (2019). Research priorities for childhood chronic conditions: a
workshop report. *Archives of Disease in Childhood, 104*(3), 237-245.
doi:10.1136/archdischild-2018-315628

McCormack, J., McAllister, L., McLeod, S., & Harrison, L. (2012). Knowing, having, doing:
The battles of childhood speech impairment. *Child Language Teaching and Therapy,
28,* 141-157. doi: 10.1177/0265659011417313

McCormack, J., McLeod, S., McAllister, L., & Harrison, L. J. (2009). A systematic review of
The Association between childhood speech impairment and participation across the
lifespan. *International Journal of Speech-Language Pathology, 11*(2):155–170

McCormack, J., McLeod, S., McAllister, L., & Harrison, L. J. (2010). My speech problem,
your listening problem, and my frustration: the experience of living with childhood
speech impairment. *Lang Speech Hear Serv Sch, 41*(4), 379-392. doi:10.1044/0161-
1461(2009/08-0129)

McLaughlin, M. R. (2011). Speech and language delay in children. *American Family
Physician, 83*(10), 1183-1188.

McLeod, S., Daniel, G., & Barr, J. (2013). "When he's around his brothers ... he's not so
quiet": the private and public worlds of school-aged children with speech sound
disorder. *Journal of Communication Disorders, 46*(1), 70-83.
doi:10.1016/j.jcomdis.2012.08.006

Meleis, A. I. (2012). *Theoretical Nursing: Development and progress* (5th ed.). Philadelphia:
Wolters Kluwer Health/Lippencott Williams & Wilkins.

Meleis, A. I., Sawyer, L. M., Im, E. O., Hilfinger Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *ANS: Advances in Nursing Science, 23*(1), 12-28. https://doi.org/10.1097/00012272-200009000-00006

Miron, C. (2012). The parent experience: When a child a child is diagnosed with childhood apraxia of speech. *Communication Disorders Quarterly, 33,* 96-110. doi: 10.1177/1525740110384131

Morgan, A. T., Murray, E., & Liegeois, F. J. (2018). Interventions for childhood apraxia of speech. *Cochrane Database of Systematic Reviews, 5*, Cd006278. doi:10.1002/14651858.CD006278.pub3

Murray, E., McCabe, P., Heard, R., & Ballard, K. J. (2015). Differential diagnosis of children with suspected childhood apraxia of speech. *Journal of Speech, Language, and Hearing Research, 58*(1), 43-60. doi:10.1044/2014_jslhr-s-12-0358

National Institute on Deafness and Other Communication Disorders. (2019). *Voice, Speech, And Language Program.* https://www.nidcd.nih.gov/research/extramural/voice-speech-language-program

National Institute on Deafness and Other Communication Disorders. (2017). *Speech and Language Developmental Milestones*. https://www.nidcd.nih.gov/health/speech-and-language

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health, 42*(5), 533-544. doi:10.1007/s10488-013-0528-y

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks,

CA: Sage Publications.

Polit, D. F., & Beck, C. T. (2008). *Nursing research: Generating and assessing evidence for nursing practice* (8th ed.). New York, NY: Wolters Kluwer/Lippincott Williams & Wilkins.

Polit, D. F., & Hungler, B. P. (1997). *Nursing Research: Methods, Appraisal, and Utilization* (4th ed.). Philadelphia, NY: Lippincott-Raven Publishers.

Rusiewicz, H. L., Maize, K., & Ptakowski, T. (2018). Parental experiences and perceptions related to childhood apraxia of speech: Focus on functional implications. *International Journal of Speech-Language Pathology, 20*(5), 569-580. doi:10.1080/17549507.2017.1359333

Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health, 18,* 179-183.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing Health, 23, 334-340.*

Sandelowski, M. (2010). What's in a name: Qualitative description revisited. *Research in Nursing and Health, 33,* 77-84.

Sandelowski, M., & Barroso, J. (2002). Reading Qualitative Studies. *International Journal of Qualitative Methods, 1*(1), 74-108. https://doi.org/10.1177/160940690200100107

Schumacher, K. L., & Meleis, A. I. (1994). Transitions: a central concept in nursing. *Image – The Journal of Nursing Scholarship, 26*(2), 119-127. doi:10.1111/j.1547-5069.1994.tb00929.x

Schwandt, T. A., Lincoln, Y. S., & Guba, E. G. (2007). Judging interpretations: But is it rigorous? trustworthiness and authenticity in naturalistic evaluation. *New Directions*

for Evaluation, 2007(114), 11-25. https://doi.org/10.1002/ev.223

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research

      projects. *Education for Information, 22,* 63-75.

Shriberg, L. D., Kwiatkowski, J., & Mabie, H. L. (2019). Estimates of the prevalence of

      Motor speech disorders in children with idiopathic speech delay. *Clinical Linguistics*

      & Phonetics, 33(8), 679-706. doi:10.1080/02699206.2019.1595731

Shriberg, L. D., Gruber, F. A., & Kwiatkowski, J. (1994). Developmental phonological

      disorders. III: Long-term speech-sound normalization. *Journal of Speech and*

      Hearing Research, 37(5), 1151-1177. doi:10.1044/jshr.3705.1151

Stommen, N. C., Verbunt, J. A., & Goossens, M. E. (2016). Future goals of adolescents and

      young adults with chronic musculoskeletal pain. *European Journal of Pain (London,*

      England), 20(4), 564-572. doi:10.1002/ejp.762

Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in

      persons with health disparities: The use of qualitative description. *Nursing Outlook,*

      53, 127-133. doi: 10:1016/j.outlook2005.03.005

Teverovsky, E. G., Bickel, J. O., & Feldman, H. M. (2009). Functional characteristics of

      Children diagnosed with Childhood Apraxia of Speech. *Disability and Rehabilitation,*

      31(2), 94-102. doi:10.1080/09638280701795030

Theakston, A., & Adams, C. (2017, August 28). Speech and language development in

      children. *Nursing in Practice.* Retrieved from

      https://www.nursinginpractice.com/speech-and-language-development-children

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis:

Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences, 15*(3), 398-405. https://doi.org/10.1111/nhs.12048

Visser-Bochane, M. I., Reijneveld, S. A., Krijnen, W. P., van der Schans, C. P., & Luinge, M. R. (2019). Identifying Milestones in Language Development for Young Children Ages 1 to 6 Years. *Academic Pediatrics*. doi:10.1016/j.acap.2019.07.003

Wang, G. F., Han, A. Z., Zhang, G. B., Xu, N., Xie, G. D., Chen, L. R., & Su, P. Y. (2019). The association between childhood physical disability or long-term health problems and depression among adolescents in China: Mediating effect of childhood maltreatment. *Asian Journal of Psychiatry, 46*, 105-110. doi:10.1016/j.ajp.2019.10.010

Wankoff, L. S. (2011). Warning signs in the development of speech, language, and communication: when to refer to a speech-language pathologist. *Journal of Child and Adolescent Psychiatric Nursing, 24*(3), 175-184. doi:10.1111/j.1744-6171.2011.00292.x

Whitaker, C., Stevelink, S., & Fear, N. (2017). The Use of Facebook in Recruiting Participants for Health Research Purposes: A Systematic Review. *Journal of Medical Internet Research, 19*(8), e290. doi:10.2196/jmir.7071

Summary of Changes from Proposal

This study used a qualitative descriptive design to explore the experiences of emerging adults with idiopathic CAS, as they reflect on their transitions through childhood, adolescence, and young adulthood. The following change was made from the original proposal:

- Recruitment of participants was to be conducted through the Apraxia-Kids.org (2019) website research and Facebook pages. Due to minimal response, a modification to recruit through Twitter was requested and approved (11-18-2020).

Slide Presentation

Life Transitions of Children with Idiopathic Childhood Apraxia of Speech

_____

Dissertation Defense
Patricia J. Meza, MS, RN
April 30, 2021
University of Massachusetts, Worcester
Graduate School of Nursing

Idiopathic Childhood Apraxia of Speech (CAS)

• Chronic neurological condition of motor speech-sound disorder

• Difficulty producing precise and consistent sounds and syllables

(Iuzzini -Seigel et al., 2017; Rusiewicz et al., 2018)

• Words often unintelligible

Affects approximately 1-2 children per one thousand

(Morgan et al., 2018; Shriberg et al., 2019)

Clinical Contexts / Study Focus

1. Causal association with known neurological etiologies
   Intrauterine stroke, infection, trauma

2. Association with complex neurobehavioral disorders
   Autism, Down syndrome

3. Idiopathic CAS not associated with any known neurological or complex neurobehavioral disorder

   (American Speech-Language-Hearing Association, 2007)

Research Focus: Idiopathic CAS of unknown origin
- Difficulties with communication impairment occur independent of other diagnoses where communication impairment is inherent.

Common Primary Features

1. Inconsistent errors on consonants and vowels in repeated productions of the of syllables or words

2. Lengthened and disrupted coarticulatory transitions between sounds and syllables

3. Inappropriate prosody

(ASHA, 2007, p.7)

Background and Significance

- Evidence suggests association between speech-sound disorders and difficulties with:
    - Social communication
    - Anxiety
    - Peer interactions
    - Initiation & maintenance of peer relationships
    - Learning problems
    - Academic participation
            (Hitchcock et al., 2015)

- Aligns closely with outcomes for children with chronic conditions

(Andrade & Alves, 2019; Lewis et al., 2016; McCormack et al., 2012; McCormack et al., 2018; Miron, 2012; National Institute on Deafness and Other Communication Disorders, 2019;   Rusiewicz et al., 2018; Wang et al., 2019)

The Gap

- Large body of literature describing challenges faced by children with other chronic conditions

- Minimal qualitative research examining transitions, experiences, and challenges of children with CAS, strategies utilized to overcome difficulties, and effectiveness of strategies.

- Unable to ID CAS research completed primarily by nursing.

Purpose

To explore the experiences of emerging adults with idiopathic CAS as they reflected on their transitions through childhood, adolescence, and young adulthood.

Specific Aims

1. Describe the experiences of emerging adults with idiopathic CAS as they reflect on developmental stages of childhood, adolescence, and young adulthood, including the situational experiences of transition occurring between elementary, middle, high school, and post-secondary education, training, or work

2. Identify strategies and the effectiveness of the strategies utilized by emerging adults with idiopathic CAS to manage experiences during different developmental stages and situational experiences of transition occurring between elementary, middle, high school, and post-secondary education, training, or work.

Transitions Theory

Meleis et al., 2000
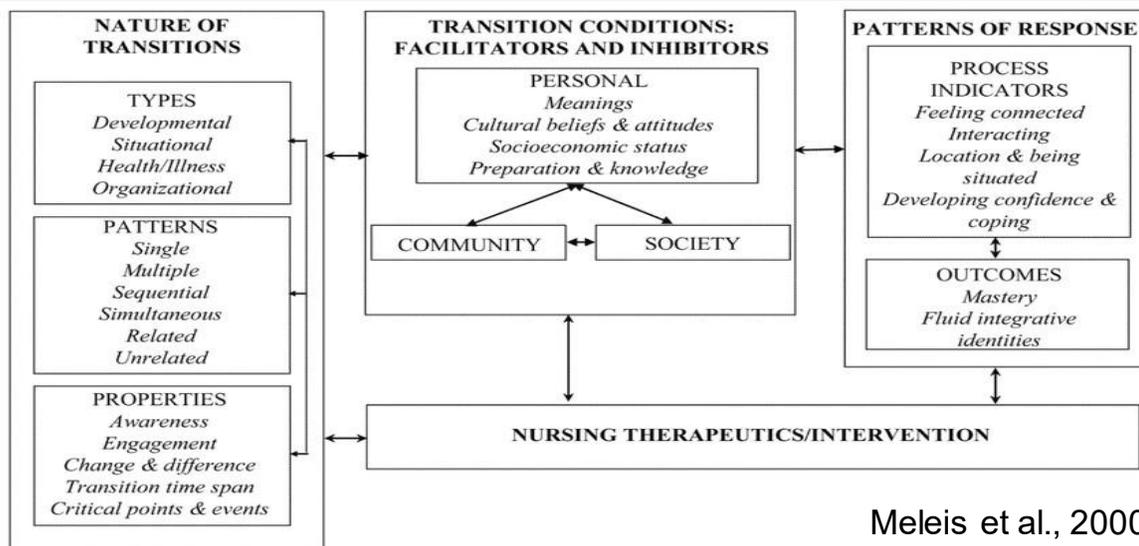
Methods

Design
- Qualitative description (Sandelowski, 2000, 2010)

    - Everyday language, easily interpretable, readily understood
                                    (Sullivan-Bolyai et al., 2005)

Recruitment
- Purposive sampling (Lincoln & Guba, 1985)
    - Emerging adults
- Online through Apraxia-Kids.org (2019) web and Facebook pages
- $25 Amazon e-gift card / Chance to win $100 Amazon e-gift card

Inclusion Criteria

- Age 18-25
- Diagnosis of idiopathic CAS during childhood
- Able to communicate (verbally or in writing) in English
- Able to provide informed consent
- Self-report of comfort with speaking about experiences living with CAS

Exclusion Criteria

- CAS associated with neurobehavioral disorders

- CAS associated with known neurological events

Setting and Sample

- Online interviews via Zoom
  - At participants convenience
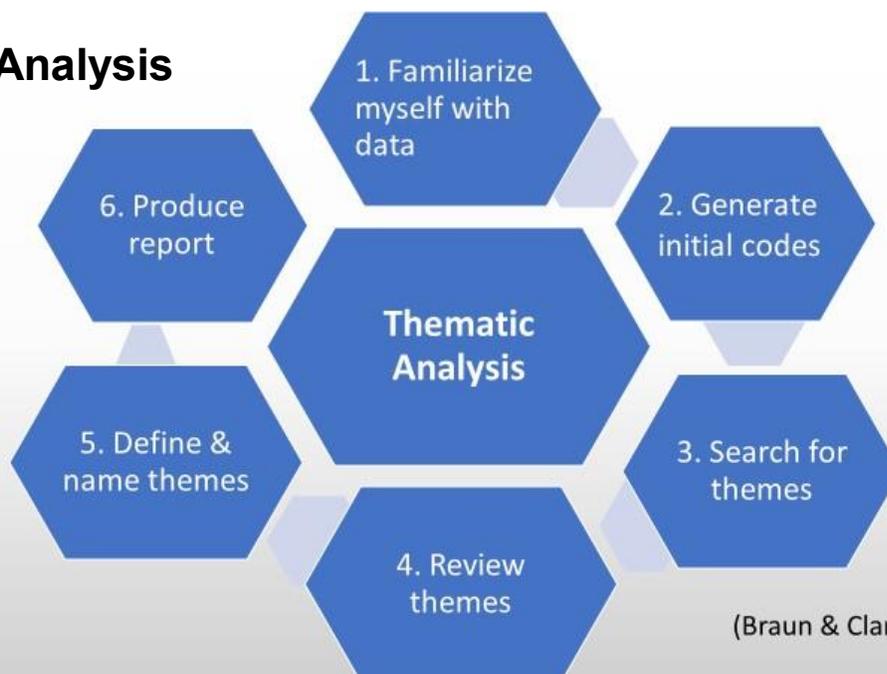 - In setting of choice
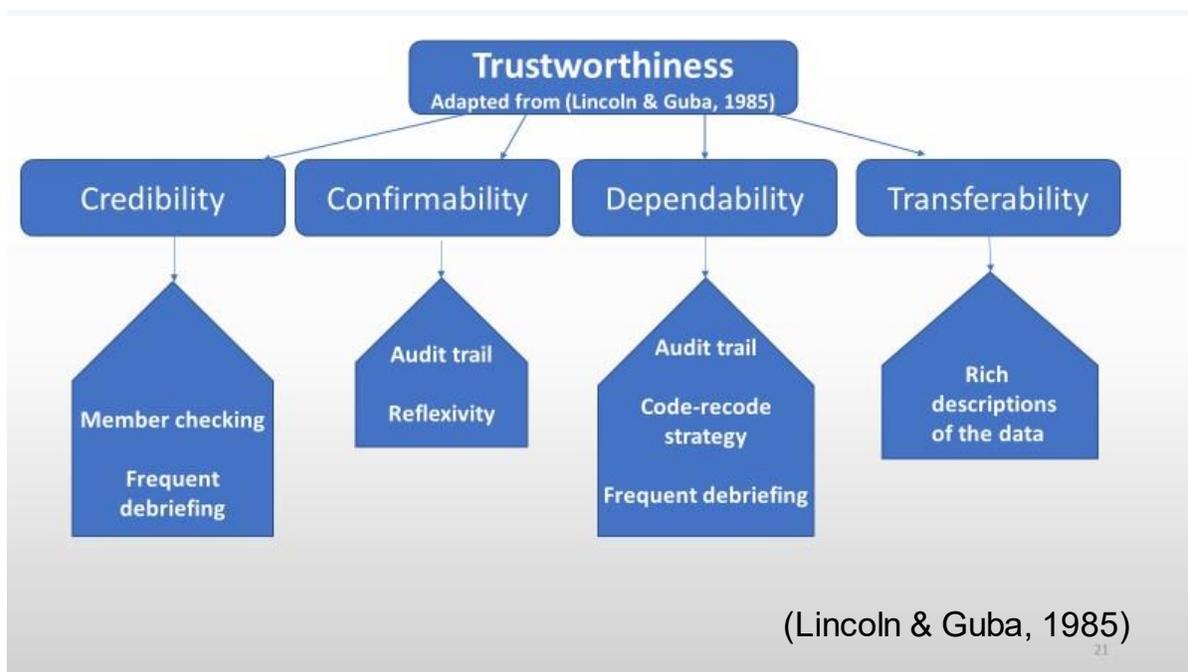
- 15 emerging adults

Procedures

- IRB approval granted from UMMS (H00021414)

- Recruitment/date collection period
  - 9/22/2020– 1/12/2021

- Informed consent
  - Fact sheet

Data Collection

- Demographics: REDCap
- Interviews
  - Private one-on-one (Zoom)
  - Chat features / Interpreter
  - Semi-structured interview guide
    - Open-ended questions
    - Undergirded by Meleis et al., (2000) Transition Theory
  - Range: 47 – 69 minutes
  - Digitally recorded
  - Field notes during and immediately after interviews
 - Transcribed by PI

Data Analysis

(Braun & Clark, 2006)

Trustworthiness
Adapted from (Lincoln & Guba, 1985)

Credibility | Confirmability | Dependability | Transferability

Member checking

Frequent debriefing

Audit trail

Reflexivity

Audit trail

Code-recode strategy

Frequent debriefing

Rich descriptions of the data

(Lincoln & Guba, 1985)

Participant Demographic Data

CATEGORY	NUMBER	PERCENTAGE	RANGE	MEAN
AGE	15		18-25 Years	20.9 Years
GENDER MALE	10	66.7		
FEMALE	5	33.3		
ETHNICITY CAUCASIAN	13	86.7		
AFRICAN AMERICAN	1	6.7		
MISSING	1	6.7		
MARITAL SINGLE	14	93.3		
STATUS UNMARRIED/PARTNERS	1	6.7		
EMPLOYMENT FULL -TIME	2	13.3		
STATUS PART -TIME	5	33.3		
STUDENT	6	40.0		
UNEMPLOYED	2	13.3		
LEVEL OF HIGH SCHOOL DIPLOMA	7	46.7		
EDUCATION SOME COLLEGE	2	13.3		
ASSOCIATE DEGREE	1	6.7		
BACHELORS DEGREE	3	20.0		
MASTERS DEGREE	2	13.3		

Participant Demographic Data

CATEGORY	NUMBER	PERCENTAGE	RANGE	MEAN
AGE of CAS DX (Years)			2-6 Years	3.25 Years
2	8	53.4		
3	2	13.3		
4 – 6	2	13.3		
Unknown	3	20.0		
PAST SLP YES	15	100		
TREATMENT NO	0	0		
CURRENT SLP YES	2	13.3		
TREATMENT NO	13	86.7		
AGE SLP TREATMENT ENDED (Years)	13		10-18 Years	14.8 Years
10 – 12	2	13.3		
13 – 14	5	33.3		
16 – 18	6	40.0		
YEARS OF SLP TREATMENT			6-22 Years	13.1 Years

Themes and Subthemes
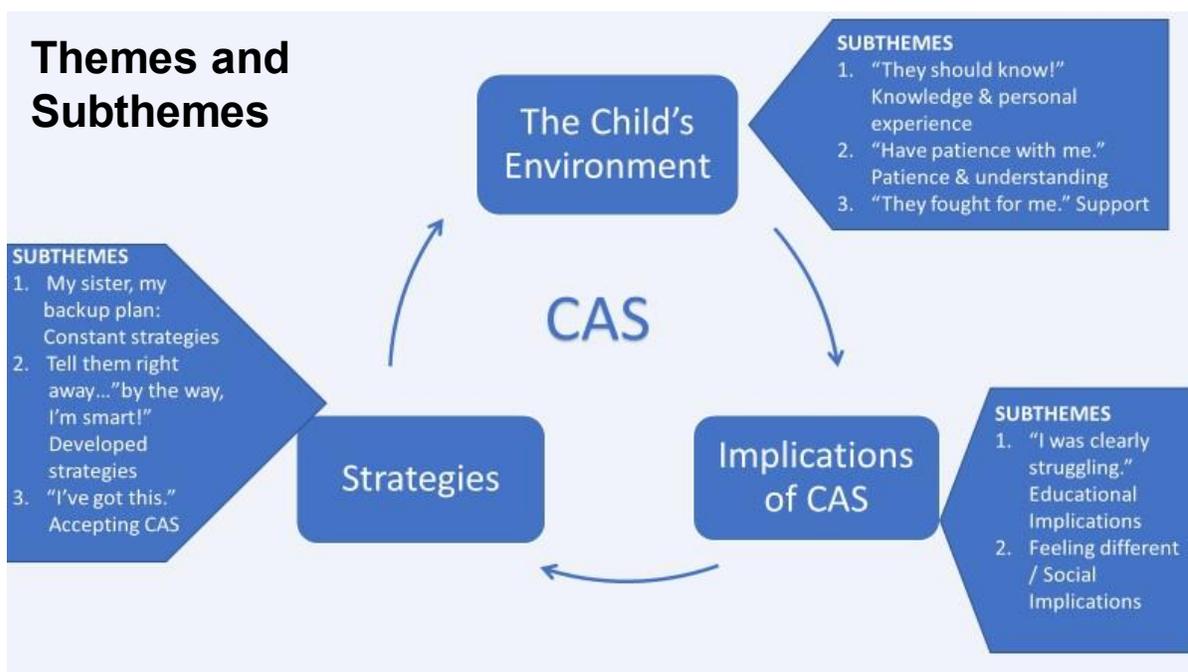
Theme 1: The Child's Environment

- Environmental impact
- Environment encompasses physical places where participants encounter other people
    - Home
    - School
    - Healthcare
- Attributes of people within the environment contribute to a "comfortable environment"
    - The child feels uninhibited and "free" and "open" to express themselves without fear of being judged, mocked, or laughed at.

Subtheme 1: "They should know!" Knowledge and Personal Experience

"To keep saying it [the word] over and over in the child's face is frustrating…I still might not be able to say it just because you say it ten times in front of my face."

"She [drama teacher] was one of the first outside of the family who really…allowed me to have a voice…and speak and be comfortable…this teacher had a very, very, severe stutter. She was very comforting; she knew how to interact with me. I never sounded right but I was comfortable speaking."

Subtheme 2: "Have patience with me." Patience and understanding

"It's like a image and you have no Wi-Fi. It's not gonna do anything until it gets Wi-Fi. That's what my brain was doing. It took a while for me to get the information correct."

Subtheme 3: "They fought for me." Support

"They [parents] wanted to make sure I was getting as much help as possible…they fought for me when the school system didn't really want to."

Theme 2: "Struggling all the time." Implications of CAS

- Educational / Social implications

- CAS as a chronic condition

"It [speech] will never be perfect. I am always gonna have apraxia."

Subtheme 1: "I was clearly struggling." Educational implications

"Some kids in class…took it as a sign of my intelligence…cuz I was clearly struggling like all the time. She [a girl in the class] could hear my speech impairment when I did talk. I think she interpreted that as instead of me being neurologically disabled, mentally disabled…and she kind of treated me a little differently, like my intellect wasn't as high as hers."

Subtheme 2: Feeling Different / Social Implications

• Bullying behaviors

• Feeling different from peers

• Anxiety

• Lack of confidence

> "I was actually valedictorian of my class…and to this day, I won't listen to that recording and I don't plan to ever listen. I can't listen to my own recordings. It frustrates me hearing how I sound."

• Frustration

> "I knew what I was saying but they just didn't quite understand. It comes out differently to other people than it does in my head."

Theme 3: Strategies

Strategies are action plans to mitigate educational and social implications of CAS.

• Constant Strategies

• Developed strategies

Subtheme 1:
My sister, my backup plan:
Constant strategies

"I always had a…back-up plan of just hanging out with her. I don't know what I would have done if I didn't have…my sister."

Subtheme 2: Tell them right away…"By the way, I'm smart!" Developed strategies

"I casually mentioned to like her friend that I got 600s on both my English writing exams. Six - hundreds are like the highest…like the perfect score…so, I hope she got the message. I hope it was delivered on. That was the only time I ever kind of was just like…by the way…I'm smart!"

Subtheme 3: "I've got this."
Accepting Apraxia

"That's when [high school] I became very social and interacting with people." "I made good friends…it was a really good transition for me."

"I'll always have it. As I've gotten older, I've gotten more patient and I've gotten more understanding of…okay, I have this going on and I just need to take a moment. I know not everyone's going to understand the first time, or the second time…or the third time. But I think it's less about patience and more about perseverance now."
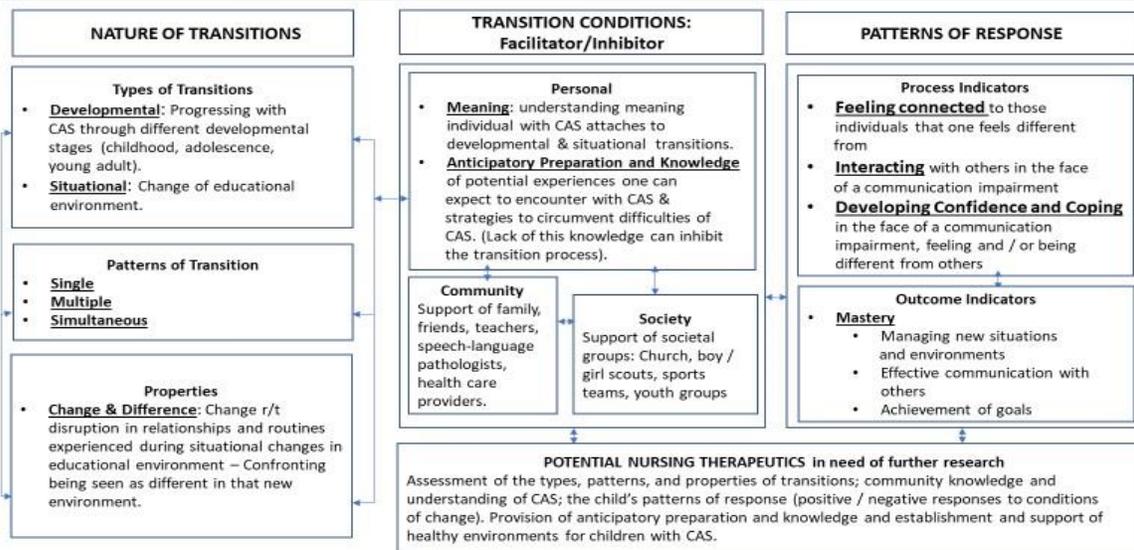
What about nursing?

"They [the nurses] never really like asked or checked up on me. My guidance counselor…she would be the one in charge of like…am I doing ok…academically and emotionally…it's not really nurses helping out there."

How can nurses help?

• Learn about CAS

• Educate teachers and other children

• Be patient, understanding, available, and encouraging!

Application of Study Findings to Transitions Theory

NATURE OF TRANSITIONS	TRANSITION CONDITIONS: Facilitator/Inhibitor	PATTERNS OF RESPONSE

Types of Transitions
- **Developmental**: Progressing with CAS through different developmental stages (childhood, adolescence, young adult).
- **Situational**: Change of educational environment.

Patterns of Transition
- **Single**
- **Multiple**
- **Simultaneous**

Properties
- **Change & Difference**: Change r/t disruption in relationships and routines experienced during situational changes in educational environment – Confronting being seen as different in that new environment.

Personal
- **Meaning**: understanding meaning individual with CAS attaches to developmental & situational transitions.
- **Anticipatory Preparation and Knowledge** of potential experiences one can expect to encounter with CAS & strategies to circumvent difficulties of CAS. (Lack of this knowledge can inhibit the transition process).

Community
Support of family, friends, teachers, speech-language pathologists, health care providers.

Society
Support of societal groups: Church, boy / girl scouts, sports teams, youth groups

Process Indicators
- **Feeling connected** to those individuals that one feels different from
- **Interacting** with others in the face of a communication impairment
- **Developing Confidence and Coping** in the face of a communication impairment, feeling and / or being different from others

Outcome Indicators
- Mastery
  - Managing new situations and environments
  - Effective communication with others
  - Achievement of goals

POTENTIAL NURSING THERAPEUTICS in need of further research
Assessment of the types, patterns, and properties of transitions; community knowledge and understanding of CAS; the child's patterns of response (positive / negative responses to conditions of change). Provision of anticipatory preparation and knowledge and establishment and support of healthy environments for children with CAS.

Meleis Transition Theory (Meleis et al., (2000), applied to CAS study findings with permission

Nursing Implications

- Help ID challenges related to communication and peer interactions.

- Educate self, teachers, staff, all others in child's environment

- Influence school environments to create a comfortable setting for children with CAS to socialize and learn comfortably with peers and teachers.

Limitations

- Lack of diversity

- Recall bias
  - All participants able to recall salient events from each developmental stage
  - Exact recollection of age of diagnosis and specific number of years in speech therapy

Conclusion

- CAS is a chronic condition
- Many consequences / implications exist
- Comfortable environments with people who are knowledgeable, patient, understanding, supportive and accepting are needed.
- Nurses are an untapped resource.
- Assessment of school nurse's knowledge of CAS / creation and testing of interventions to facilitate comfortable environments needed.

Acknowledgements

References

Andrade, C., & Alves, C. A. D. (2019). Relationship between bullying and type 1 diabetes mellitus in children and adolescents: a systematic review. *Jornal de Pediatria, 95*(5), 509-518. doi:10.1016/j.jped.2018.10.003

American Speech-Language-Hearing Association. (2007). *Childhood apraxia of speech* [Technical Report]. Available from http://www.asha.org/policy/TR2007-00278/.

Apraxia-kids.org. (2019). *Apraxia Kids* https://www.apraxia-kids.org/

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Hitchcock, E., Harel, D., & McAllister Byun, T. (2015). Social, Emotional, and Academic Impact of Residual Speech Errors in School-aged Children: A Survey Study. *Seminars in Speech and Language, 36*, 283-294. doi:10.1055/s-0035-1562911

Iuzzini-Seigel, J., Hogan, T. P., & Green, J. R. (2017). Speech Inconsistency in Children with Childhood Apraxia of Speech, Language Impairment, and Speech Delay: Depends on the Stimuli. *Journal of Speech, Language, and Hearing Research, 60*(5), 1194-1210. doi:10.1044/2016_jslhr-s-15-0184

Lewis, B. A., Patton, E., Freebairn, L., Tag, J., Iyengar, S. K., Stein, C. M., & Taylor, H. G. (2016). Psychosocial comorbidities in adolescents and adults with histories of communication disorders. *Journal of communication disorders, 61*, 60-70. https://doi-org.umassmed.idm.oclc.org/10.1016/j.jcomdis.2016.03.004

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage.

McCormack, J., Baker, E., & Crowe, K. (2018). The human right to communicate and our need to listen: Learning from people with a history of childhood communication disorder. *International journal of speech-language pathology, 20*(1), 142-151. https://doi-org.umassmed.idm.oclc.org/10.1080/17549507.2018.1397747

McCormack, J., McAllister, L., McLeod, S., & Harrison, L. (2012). Knowing, having, doing: The battles of childhood speech impairment. *Child Language Teaching and Therapy, 28*, 141-157. doi: 10.1177/0265659011417313

References

Meleis, A. I., Sawyer, L. M., Im, E. O., Hilfinger Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *ANS: Advances in Nursing Science, 23*(1), 12-28. https://doi.org/10.1097/00012272-200009000-00006

Miron, C. (2012). The parent experience: When a child a child is diagnosed with childhood apraxia of speech. *Communication Disorders Quarterly, 33*, 96-110. doi:10.1177/1525740110384131

Morgan, A. T., Murray, E., & Liegeois, F. J. (2018). Interventions for childhood apraxia of speech. *Cochrane Database of Systematic Reviews, 5*, Cd006278. doi:10.1002/14651858.CD006278.pub3

National Institute on Deafness and Other Communication Disorders. (2019). *Voice, Speech, and Language Program*. https://www.nidcd.nih.gov/research/extramural/voice-speech-language-program

Rusiewicz, H. L., Maize, K., & Ptakowski, T. (2018). Parental experiences and perceptions related to childhood apraxia of speech: Focus on functional implications. *International Journal of Speech-Language Pathology, 20*(6), 569-580. doi:10.1080/17549507.2017.1359333

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing Health, 23*, 334-340.

Sandelowski, M. (2010). What's in a name: Qualitative description revisited. *Research in Nursing and Health, 33*, 77-84.

Shriberg, L. D., Kwiatkowski, J., & Mabie, H. L. (2019). Estimates of the prevalence of motor speech disorders in children with idiopathic speech delay. *Clinical Linguistics & Phonetics, 33*(8), 679-706. doi:10.1080/02699206.2019.1595731

Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of qualitative description. *Nursing Outlook, 53*, 127-133. doi: 10.1016/j.outlook.2005.03.005

Wang, G. F., Han, A. Z., Zhang, G. B., Xu, N., Xie, G. D., Chen, L. R., & Su, P. Y. (2019). The association between childhood physical disability or long-term health problems and depression among adolescents in China: Mediating effect of childhood maltreatment. *Asian Journal of Psychiatry, 46*, 105-110. doi:10.1016/j.ajp.2019.10.010

Dissemination Plan

The primary description of this dissertation work was submitted as a manuscript on June 24, 2021 to The Journal of School Nursing for review and consideration for publication.

Appendices

Appendix A

Interview Guide

Childhood (Ages 5-12 years old) -Grade school		
Conceptual Area	**Main Question**	**Probes**

• Nature of Transitions
   ➤ Properties
       ○ Awareness
	1. Tell me what it was like for you when you first realized you spoke differently from others around you?	1. Did anyone specifically point this out or help you understand this?
		2. Do you remember where you were (home, school, another place)?
		3. How did you feel when this realization / awareness happened?
		4. How did you feel when others did not understand you?

• Nature of Transitions • Transition Conditions • Patterns of Response	2. Can you tell me about experiences that occurred during childhood that are related to your CAS and your ability to communication that stand out in your mind?	1. How did this experience make you feel? 2. How did you handle the experience? 3. Who were your sources of support during this experience? 4. Is there anything you would change about the way you handled the experience?

Conceptual Area	Main Question	Probes

• Nature of Transitions
  ➤ Properties
    o Engagement
• Transition Conditions
• Patterns of Response
  ➤ Process Indicators
    o Feeling connected, Interacting, Developing confidence & coping
	3. How did your speech affect your participation in social or community activities?	1. How did you handle the experience?
		2. Is there anything you would change about the way you handled the experience?

• Transition Conditions
  ➤ Community
  ➤ Society
• Nursing Therapeutics
	4. Can you tell me about any interactions with nurses in school or in a doctor's office related to your CAS?	Interaction – Was the nurse helpful? Were you comfortable communicating your health care needs? Is there anything the nurse could have done that might have been more helpful?
		
		No interaction - Can you tell me why you may not have thought to talk with the nurse?

Adolescence (Ages 13-17 years) **-Middle school & High school**		
Conceptual Area	**Main Question**	**Probes**

• Nature of Transitions
  ➤ Properties of Transitions
    o Awareness
	1. How was your speech during your adolescence (middle and high school years)?	1. How did you feel when others may have had difficulty understanding you?

• Refer to Childhood Main Question 2.	2. Tell me about experiences that occurred during adolescence that are related to your CAS and your ability to communication that stand out in your mind?	1. How did this experience make you feel? 2. How did you handle the experience? 3. Who were your sources of support during this experience? 4. Is there anything you would change about

		the way you handled the experience?
• Nature of Transitions ➢ Types of Transitions ▪ Situational ▪ Organizational • Transition Conditions • Patterns of Response ➢ Process Indicators o Feeling connected, Interacting, developing confidence & coping	3. How did your speech affect your changing schools (from grade school to middle school - from middle school to high school)?	1. What was it like for you being in a new school environment? 2. What was it like for you to meet new people and make new friends?
• Refer to Childhood Main Question 3.	4. How did your speech affect your participation in social or community activities?	1. How did you handle the experience? 2. Is there anything you would change about the way you handled the experience?
• Refer to Childhood Main Question 4.	5. Tell me about any interactions with nurses in school or in a doctor's office related to your CAS?	<u>Interaction</u> – Was the nurse helpful? Were you comfortable communicating your health care needs? Is there anything the nurse could have done that might have been more helpful? <u>No interaction</u> - Can you tell me why you may not have thought to talk with the nurse?
Young / Emerging Adulthood (Ages 18-25 years) -College and / or Work		
Conceptual Area	**Main Question**	**Probes**
• Nature of Transitions ➢ Properties of Transitions o Awareness	1. How does CAS affect your life today?	1. If affected- How do you feel when others may have difficulty understanding you? 2. When you enter a new social situation

		(job / school), are you aware of your speech and what strategies do you use to ease into that new situation?
• Refer to Childhood Main Question 2.	2. Tell me about experiences that have occurred since you turned 18 as they relate to CAS?	1. How did this experience make you feel? 2. How did you handle the experience? 3. Who were your sources of support during this experience? 4. Is there anything you would change about the way you handled the experience?
• Refer to Adolescence Main Question 3.	3. How did your speech affect the change from high school to college / work?	1. What was/is it like for you being in a new school / work environment? 2. What was/is it like for you to meet new people and make new friends?
• Refer to Childhood Main Question 3.	4. How does your speech affect your participation in social or community activities?	1. How did you handle the experience? 2. Is there anything you would change about the way you handled the experience?
• Refer to Childhood Main Question 4.	5. Can you tell me about any interactions with nurses in school, in your employment setting, or in a doctor's office related to your CAS?	Interaction – Was the nurse helpful? Did you feel comfortable communication your health care needs? Is there anything the nurse could have done that might have been more helpful? No interaction - Can you

		tell me why you may not have thought to talk with the nurse?

• Patterns of Response
   ➤ Outcome Indicators
      ○ Mastery
	6. Reflecting back, what do you see as key things that helped you successfully manage your CAS?	

Appendix B

Fact Sheet
UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS IN RESEARCH

FACT SHEET

A. You are invited to participate in a research study called *Life Transitions of Children with Childhood Apraxia of Speech: A Qualitative Study*

B. The primary investigator for this research is Patricia Meza M.S., R.N.

C. The purpose of this study is to explore the experiences 18 – 25-year-old individuals with idiopathic childhood apraxia of speech (CAS) had during their childhood, adolescence, and young adulthood.

D. If you agree to take part in this study, we will have a one-time Zoom interview expected to last approximately one hour. All interviews will be private.

E. As part of this study, you will be asked to talk about how, if at all, having CAS impacted your experiences during childhood, adolescence, and young adulthood. You may experience feelings of discomfort answering some of the questions in the study. You can choose to skip any questions you want to.

   All interviews will be digitally-recorded. There is a risk that someone could get access to the information about you and misuse it. To help protect your personal information, I will code all your information with a special ID number, that will not be connected to your name. All the recordings will be transcribed into a file kept on a secure computer network. The recordings will be destroyed after I verify the transcription. These computer networks have many levels of protection. All the information I collect will be destroyed after 3 years.

   I will not report any information that directly identifies that you were in the study but because not many people have idiopathic CAS, there is a risk of loss of confidentiality if someone recognizes your experiences, and also if you decide to share information about the study with others who may be eligible to participate in the study. I will not include the names of people you might mention, where you work or went to school, or where you got speech therapy or health care, nor will your specific information be discussed with any other participants.

F. At this time, we do not think that the information you share will lead to commercial profit. If it does, there are no plans to share any financial gains with you.

G. As a thank you for your participation, you will receive a $25.00 Amazon gift card after we finish the interview. All participants completing the interview will be entered into a random drawing for a $100.00 Amazon gift card.

H. Taking part in this research is voluntary and completely up to you. You are free to say no or to leave the research at any time.

I. Researcher's will not share your information and will limit exposure of your personal information to only people who need to review the information. We cannot promise complete privacy. The University of Massachusetts Medical School, including the Institutional Review Board (IRB), the researcher's dissertation committee, and other representatives of UMMS may see your information. and research, billing, and compliance offices, may see your information.

J. It is possible that we might use the research data for future research. We will not share your name or other information that identifies you directly, and we will not come back to you to ask you for your consent.

K. This study has been approved by the UMMS Institutional Review Board. If you have any questions or concerns, you can contact the Chair of the researcher's dissertation committee, Nancy Morris, PhD, University of Massachusetts Worcester Graduate School of Nursing at Nancy.Morris@umassmed.edu or at 508-856-3661. If you prefer to speak with someone not associated with the study or have questions about rights as a research subject, you can contact the UMMS Institutional Review Board at (508) 856-4261 or irb@umassmed.edu

L. The University of Massachusetts Medical School does not provide funds for the treatment of research-related injury. It is highly unlikely, but if you are injured as a result of your participation in this study, treatment will be provided. You or your insurance carrier will be expected to pay the costs of this treatment. No additional financial compensation for injury of lost wages is available. You do not give up any of your legal rights by participating in this research.

If you or anyone you know are interested in participating in this study, please contact Patricia Meza, M.S., R.N. at Patricia.Meza@umassmed.edu or at 978-855-5427.

Appendix C

Participant Demographic Form

Date: _____ Participant ID # _____

Age: _____

Gender: _____ Male _____ Female _____Other

Race/Ethnicity:

_____Caucasian _____African American _____Hispanic or Latino

_____Asian _____Native American _____Other

Approximate age of CAS diagnosis (if known): _____

Did receive any treatment for CAS from a speech-language pathologist? _____ Yes _____ No

If yes, are you still receiving treatment from a speech-language pathologist _____Yes ____ No

If no, at approximately what age did you stop / end your treatments with the SLP? _____

Marital Status:

_____Single _____Married _____Unmarried partners

_____Separated _____Divorced _____Widowed

Level of Education:

_____Some High School _____High School Diploma or GED

_____Some college _____ Associates degree _____ Bachelor's degree

_____Master's degree _____PhD

Employment Status:

_____ Full time _____Part time _____Unemployed _____ Student

If working, what type of work you are doing: _____