

Medical communication and advocacy through eye-tracking AAC: Implications for applied linguistics

USREE BHATTACHARYA
University of Georgia

WISNU A. PRADANA
University of Georgia

XING WEI
University of Georgia

DANIEL TARQUINIO
Center for Rare Neurological
Diseases

OLIVIA DATTA
University of Georgia

KALEIGH ANDERSON
University of Georgia

NICOLE CRUZ-DÍAZ
University of Georgia

Received 19 November 2021; accepted after revisions 28 February 2022

ABSTRACT

EN Historically, individuals with Rett syndrome, a rare neurodevelopmental disorder, have been cast as “silent angels,” “nonverbal,” and “speechless.” As a consequence, they have not been consulted in their medical care. Recently, however, augmentative and alternative communication (AAC) devices that use eye-tracking technology have facilitated communication for individuals with Rett syndrome. Yet, no prior research has investigated how such communication occurs within medical settings. Through an applied linguistics lens that centers the analysis of language use, we construct a case report capturing how Kalika, a child with Rett syndrome, offers medical information. Kalika’s device-mediated language use suggests multiple implications for applied linguistics scholars and language educators, including: broadening notions of speaking, increasing consideration of AAC, exploring more device-mediated language use, extending multimodal considerations, nuancing notions of communicative competence, presuming competence, and, last but not least, more deliberately espousing principles of linguistic justice in our field.

Key words: RETT SYNDROME, EYE TRACKING, AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC), DISABILITY, MEDICAL COMMUNICATION

ES Históricamente, los individuos con síndrome de Rett, un trastorno raro del desarrollo neurológico, han sido presentados como “ángeles silenciosos”, “no verbales” y “mudos”. Como consecuencia, estos individuos no han sido atendidos en consulta médica. Recientemente, los dispositivos de comunicación aumentativos y alternativos (AAC) que utilizan tecnología de seguimiento ocular han facilitado la comunicación de individuos con síndrome de Rett. Sin embargo, ningún estudio ha investigado cómo se produce dicha comunicación en entornos médicos. Desde la perspectiva de la lingüística aplicada que analiza el uso del lenguaje, construimos un caso clínico que captura cómo Kalika, una niña con síndrome de Rett, proporciona información médica. El lenguaje mediado por dispositivos de Kalika sugiere implicaciones para académicos de lingüística aplicada y educadores del lenguaje, que incluyen: ampliar las nociones del discurso y la consideración de AAC, explorar más el uso del lenguaje mediado por dispositivos, ampliar las consideraciones multimodales, matizar las nociones de la competencia comunicativa, suponer competencia y apoyar deliberadamente los principios de justicia lingüística.

Palabras clave: SÍNDROME DE RETT, SEGUIMIENTO OCULAR, COMUNICACIÓN AUMENTATIVA Y ALTERNATIVA, DISCAPACIDAD, COMUNICACIÓN MÉDICA

IT Storicamente le persone con la sindrome di Rett, un raro disturbo del neurosviluppo, sono state considerate “angeli silenziosi”, “non verbali” e “senza parole”; questo ha comportato che non venissero consultati per le loro cure mediche. Di recente, però, i dispositivi di comunicazione aumentativa e alternativa (CAA) con tecnologia eye-tracking hanno facilitato la comunicazione di queste persone. Nessuna ricerca ha però indagato come tale comunicazione avvenga in contesti medici. Utilizzando una prospettiva di linguistica applicata che analizza l’uso del linguaggio, presentiamo un caso che illustra come Kalika, una bambina con la sindrome di Rett, offra informazioni mediche. Il linguaggio di Kalika, mediato da dispositivi, suggerisce, tanto agli studiosi di linguistica applicata quanto docenti ed educatori in ambito linguistico, molteplici implicazioni per ampliare le nozioni di parlato e la considerazione della CAA, approfondire l’uso del linguaggio mediato da dispositivi, estendere le considerazioni multimodali, dettagliare le nozioni di competenza comunicativa, presumere la competenza, e sostenere in modo deliberato i principi di giustizia linguistica nel nostro campo.

Parole chiave: SINDROME DI RETT, EYE TRACKING, COMUNICAZIONE AUMENTATIVA E ALTERNATIVA CAA, DISABILITÀ, COMUNICAZIONE MEDICA

✉ **Usree Bhattacharya**, University of Georgia
ubhattacharya@uga.edu

1. Introduction

As Demjén (2020) has noted, “most aspects of illness and healthcare are mediated by language” (p. 1). Applied linguistics as a field, in particular, has deep ties to communication in medical settings and provides a powerful lens for elucidating the intricacies of high-stakes communication exchanges within them (Udvardi, 2019). However, applied linguistics approaches remain limited in the study of medical settings, and are mostly absent in significant disability and rare disease contexts (Demjén, 2020; Pickering, 2020; Roberts & Satangi, 2003). Our study intervenes within this neglected area, taking on Brumfit’s (1995) call that a key charge of applied linguistics is to analyze “real-world problems in which language is a central issue” (in Demjén, 2020, p. 2; see also Patricia, 2019). We harness an applied linguistics perspective to frame a medical case report of a 5-year-old child, Kalika, with Rett syndrome (a rare neurological disorder), who is medically classified as “nonverbal”, but powerfully uses an Augmentative and Alternative Communication (AAC) device to navigate medical settings. In the process of elucidating her purposeful languaging of medical and health-related information as well as advocacy of her own care using the device, we highlight important implications for applied linguistics scholars and educators. These include a call for: broadening notions of speaking; increasing consideration of AAC; exploring more device-mediated language use; extending multimodal considerations; continuing complication of notions about communicative competence; presuming competence; and, last but not least, more deliberately espousing principles of linguistic justice.

Historically, individuals with Rett syndrome have been characterized as “silent angels” (e.g., Dziwota et al., 2016, p. 285), “nonverbal” (e.g., Djukic et al., 2016, p. 52), and “speechless” (e.g., Oldfors et al., 1990, p. 310). Resulting from mutations on the X-linked MECP2 gene, Rett syndrome occurs mostly in females, with a prevalence of about 1 in 10,000 to 23,000 girls worldwide (Armstrong, 2005). Children with Rett syndrome develop somewhat “typically” until regression sets in, between one to two years of age (Bartolotta, Zipp, Simpkins, & Glazewski, 2011). *Regression* marks the onset of a variety of symptoms, such as near total loss of verbal speech, poor fine and gross motor skills, development of hand stereotypies, breathing dysfunction, gastrointestinal difficulties, sleep disruption, and seizures, among others. Due to the combination of the first three symptoms in particular, individuals with Rett syndrome experience complex communication challenges. These challenges impact every aspect of daily life, but the stakes are particularly high from a medical perspective. Given that the disease entails management of a wide variety of symptoms, individuals with Rett syndrome frequently encounter medical settings and professionals across a range of disciplines (Lotan, 2006). However, the communication challenges mean that their input is rarely and/or inadequately considered in their care. This has significantly impacted treatment of symptoms, restricted research into Rett syndrome, and limited the development of robust outcome measures for clinical trials (which benefit from patient input), among other issues (see Hou, Bhattacharya, Pradana, & Tarquinio, 2020). Fortunately, cutting-edge AAC devices using eye-tracking technology have recently begun reshaping patients’ communicative possibilities. AAC technology is powered by intentional eye gaze, which is largely preserved in Rett syndrome. While such devices are prescribed out of medical necessity in Rett syndrome, no previous study has explored how they are used in practice for providing medical information or for medical advocacy. Situated within this gap in research, this study aspires to contribute to cross-disciplinary knowledge about the languaging of medical advocacy in a significant disability setting, with implications for applied linguistics scholars and educators more broadly.

2. Complex communication

AAC refers to all the ways we share our thoughts that do not involve spoken language. There are two main types of AAC: 1) *unaided AAC*, i.e., ways of non-spoken communication without the use of external aid, e.g., facial expressions, gestures, eye-contact, and posture; and 2) *aided AAC*, i.e., communication that involves external aids, e.g., writing a note, picture communication board, and speech generating devices. Researchers across disciplines have noted the critical role of AAC in improving the quality of life of individuals with complex communication repertoires, i.e., in assisting with daily needs, facilitating family and community engagement, and developing language and literacy skills (Campbell, Milbourne, Dugan, & Wilcox, 2006; Floyd, Smith Canter, Jeffs, & Judge, 2008; Kemp, 1999; Kling, Campbell, & Wilcox, 2010; Schall, Targett, & Wehman, 2006). Importantly, Pickering (2020) has argued that the field of applied linguistics can answer Pullin, Treviranus, Patel, and Higginbotham’s (2017) call for “new research tools as apparatus for engaging, accessible, and contextual participatory research” (p. 146). This study hopes to help craft a path forward in this area.

Broadly conceived language-focused investigations into the speech of individuals with complex communication challenges is useful in this regard; they do communicate in powerful, multimodal ways, even if

it is not always recognized (Beukelman & Mirenda, 2005; Pickering, 2020; Townend, Bartolotta, Urbanowicz, Wandin, & Curfs, 2020). There has been limited research on this in Rett syndrome. Some researchers have explored the various ways that AAC is used in dyadic communication among families with individuals with Rett syndrome. For example, Skotko, Koppenhaver, and Erickson (2004), studied a variety of strategies in parent-implemented story reading activities to enhance the communication and literacy skills in children with Rett syndrome. One important finding was the effectiveness of multimodal engagement during reading mediated by various AAC tools. Additionally, Koppenhaver et al. (2001) examined the supportive effects of resting hand splints, use of low tech AAC systems, and parent training on labeling and symbolic communication of children with Rett syndrome in story reading activities. There is also emerging interest in newer AAC devices that track eye gaze to trigger speech (Vessoyan et al., 2018). Townend et al. (2016), for instance, investigated family perception on the use of eye tracking AAC devices to promote communication of individuals with Rett syndrome. The findings indicated that the device provided substantial benefits to mediate communication within families. Further, Wandin, Lindberg, and Sonnander (2021) examined the efficacy of communication intervention in individuals with Rett syndrome and suggested that aided language modeling, responsive partner strategies, and the use of gaze-controlled devices could effectively increase expressive communication in individuals with Rett syndrome. While these studies have illuminated the complex, rich, and multimodal communication possibilities that exist within a significant disability context like Rett syndrome, deficit perspectives regarding communication challenges endure.

3. Eye-tracking AAC

The idea of eye-tracking has garnered scholarly interest since the 1800s, but it was not until much later, in 2005, when the first eye-tracker was used as assistive technology to help individuals with communication disorders. An eye-tracking AAC device allows a user to control a computer with one's eye movements to generate speech (see Vessoyan et al., 2018). Many thousands of individuals now use eye-tracking AAC devices to communicate. For individuals with complex communication challenges who have limited functional hand use, such as those with Rett syndrome, eye-tracking AAC devices hold revolutionary and life-changing communicative potential.

Currently, there is nascent research on the use of eye-tracking AAC devices for elicitation of medical/health information specifically. Limited studies have involved individuals using AAC devices across a variety of diseases, such as spinal muscular atrophy type II and Ewing Sarcoma (Costello, Patak, & Pritchard, 2010), neck cancer (Rodriguez et al., 2012; Happ, Roesch, & Kagan, 2005), head cancer (Rodriguez et al., 2012), and pneumonia and lung cancer (Happ, Tuite, Dobbin, DiVirgilio-Thomas, & Kitutu, 2004). These studies examined individuals' use of eye-tracking to communicate with medical personnel and families using various types of AAC devices, such as DynaMyte (Happ et al., 2004, 2005; Costello, 2000), and software, such as BoardMaker (Costello, 2000). Various themes were noted regarding the topic of communication. These include medical attention (Costello et al., 2010; Happ et al., 2005), personal care and comfort (e.g., Happ et al., 2005; Costello, 2000), psychosocial aspects (e.g., Costello et al., 2010; Costello, 2000), pain (e.g., Costello, et al., 2010), feelings (e.g., Happ et al., 2004; Etchels et al., 2003), greetings (e.g., Happ et al., 2005), and establishing relationships with others/general chit-chat (e.g., Etchels et al., 2003). As noted earlier, information regarding how individuals with Rett syndrome navigate medical information specifically is non-existent (in applied linguistics and beyond); in this manner, our study hopes to contribute new knowledge in this area. As we take the field into a new technological frontier, we hope that scholarly interest continues to grow in the affordances of AAC devices for facilitating medical communication.

4. Methods

4.1. Participant

At the time we began to collect the caregiver reports, Kalika, the focal participant, was five years old. She was diagnosed with Rett syndrome in 2018, at two and a half years of age. She met most developmental milestones until about a year and a half of age, after which she began to experience regression. Prior to regression, she had a vocabulary of more than 80 words in Bengali and English. In the ensuing years, she experienced a variety of symptoms, including anxiety, limited mobility, hand stereotypies and poor functional hand use, vision difficulties (accommodative esotropia, myopia, and astigmatism), seizures, sleep disruptions, cataplexy, kyphosis, swallowing difficulty, teeth grinding, and dystonia, among others. During the period of this study, she had a limited range of verbal production by mouth, a total of 5-6 words across both Bengali and

English. Kalika was prescribed an eye-tracking AAC device in October 2018 and, after receiving it on her third birthday in December of 2018, used it daily. Starting with a relatively restrictive speech software, which focused on basic needs, she transitioned to higher-level speech software, speaking hundreds of words a day. Speech therapy services from speech and hearing clinic at a local university provided support in developing her language skills. She navigated the software both in English and Bengali (the latter language section created by her mother on the device). Though she began with just a few words, Kalika made extensive progress in communicating using the AAC device over time, and she used it daily at home, in school, and in other contexts. She also used the AAC device for a variety of activities beyond communicating, including playing online games and painting using eye gaze software.

4.2. Study design

Case reports are used in medical literature to offer a window into extraordinary and unanticipated issues and events (Guidelines To Writing A Clinical Case Report, 2017). Such reports also provide new perspectives on patients' experiences (Woolston & Connelly, 2017), and have the potential to shed light on "important scientific observations that are missed or undetected in clinical trials" (Rison, 2013, p. 3). The chief goal of this type of report is the development of a singular, particular, multi-layered portrayal of a single case (Hyett, Kenny, & Dickinson-Swift, 2014). Importing this format within applied linguistics research, this study focuses on unusual observations related to medical and health communication (Guidelines To Writing A Clinical Case Report, 2017), centering the use of language within the descriptions. We employed methods from qualitative case study design as well; we drew on specific data sources (anecdotes), aimed for triangulation, and conducted the coding process through qualitative means. This allowed us to treat the case report as we would have a qualitative study framed within the boundaries of applied linguistics research.

For this report, our main goal was to arrive at a comprehensive, context-bound understanding of how Kalika engaged in medical/health discourse using her eye-tracking AAC device. We used a purposive sampling of one person with Rett syndrome. Given that Rett syndrome is a rare neurological disorder, and that eye-tracking AAC communication had never previously been reported for medical and health information, a case report was particularly well suited to capturing its complexity. This combined approach is relatively novel within the literature on Rett syndrome, allowing us to bridge applied linguistics and medicine through this unique structure. The study protocol was submitted for ethics review and the IRB deemed that approval was not required given the nature and goals of the study.

4.3. Data sources

We used a variety of data sources to achieve triangulation, which entails "the observation of the research issue from (at least) two different points" (Flick, 2004, p. 179). This allowed us to offer depth and detail on Kalika's language use. We considered data from two sources in this study, both involving Kalika's speech software TD Snap. The first involved eye-tracking language usage reports gathered from mytobiidynavox.com, an online tool supported by Tobii to provide users with service and assistance in setting and managing their AAC devices and getting feedback. The usage reports were connected to a concussion Kalika had on April 29, 2020. They tracked the top 20 words and phrases that she said on her AAC device from April 15, 2020 to May 15, 2020. Secondly, we collected 50 written caregiver observational reports about Kalika's use of the AAC device over a 14-month period. We coded the observational reports to focus on medical/health related information using the same approach that we employed for coding the usage reports. The research team reviewed the full data corpus to get a broader sense of how Kalika used language related to health, then dove into it a second time, isolating and then coding data related to medical discourse more narrowly (see Saldaña, 2021). The research team then examined salient patterns and used those to develop themes (e.g., "asking for assistance"). The themes organize the discussion section, leading us to new ideas and perspectives in understanding how medical and health-related language use is mediated through innovative AAC devices.

4.4. The speech software: TD snap

Kalika's speech software, TD Snap, was loaded within her AAC device with words and phrases stored in different cells that she could speak (i.e., "trigger") with her eyes. A critical issue was the dwell time, which was set to a specific time. Kalika learned within the first hour of using the AAC device that any cell containing speech would be triggered only after she stared at a cell for that set dwell time. Here is an example of this in practice. Kalika was taken to her "Occupations" category page in her software, and asked: "Who is Joe Biden?"

Kalika scanned the page quickly, and then paused for 0.4 seconds (the dwell time set for her) on the word she did wish to trigger: the occupation “president,” the last cell in the second row. This cell was one of 13 options for occupations (alongside six other options that were linked to other pages). She selected the correct response out of multiple possibilities; this provides clear evidence of her intentionality.



Figure 1. Kalika communicating using her AAC device

TD Snap is described as “a comprehensive, evidence-based solution that makes communication, literacy and independence possible” (Hagen, 2020, para. 2). It is organized around “core vocabulary, a small number of words that make up 70-90% of what we all use in many daily situations” (Hagen, 2020, para. 3). Core words are a popular organizing principle for such types of software because they “(a) are generic to many communication situations; and (b) allow for the generation of unique novel sentences” (Mothapo, Tönsing, & Morwane, 2021, p. 296). The structural organization for the English (U.S.) version is that the main (Core¹) page has the words/phrases “I,” “you,” “it,” “is,” “want,” “like,” “do,” “go,” “help,” among others. From this page, one link takes the user to Action Verbs, and another link to different Word Forms (where, for example, can be turned into “be,” “was”). There is also a link to Quickfires, which offers messages that can be used in various contexts, such as “don’t,” “Mom,” “wait,” and “thank you.” Additionally, there is a Topics page, where individuals can find language concentrated around a specific topic. For example, Kalika’s “Arguing” page had phrases such as “you are mean.” Another link takes users to Little Words which has words like “if” and “but.” There is also an All Word Lists page, which contains categories of different units, such as a Descriptions page with adjectives. Additional pages are embedded within these pages, such as Positions within Descriptions, with adjectives that only relate to location. In order to say one sentence with a subject, verb, and an object, Kalika thus needed to navigate across multiple pages, and paused a mandatory 0.4 seconds to trigger (speak) any word or phrase. The per minute count of word production with such AAC devices, thus, was low overall.

Importantly, Kalika conveyed health-related information daily using a variety of pages on TD Snap. There were several different areas of her software which she routinely navigated for this purpose. Under her All Word Lists category, for example, there was a Feelings page. This page allowed her to express a range of feelings related to health and medical conditions, for example, “thirsty,” “hungry,” “sleepy,” and “sick.” Another section of her software dealt with health-related feelings, this was the Feelings page under the Quickfires category. This section included items such as “Can I tell you how I feel?” among others. Under her Personal Needs section in Quickfires, she could say things like “I don’t feel well” or “I am uncomfortable” or “Something

¹ Underline indicates specific pages within the software.

is hurting me.” Kalika also had access to pages specifically dedicated to health and medical issues. Among these, there was an External Body Parts page with items such as “head,” “stomach,” and “nose”; Internal Body Parts with items such as “Nervous system,” “heart,” and “bowels”; Health problems page with items such as “headache,” “fever,” and “tired”; Medical Items such as “shot,” “stethoscope,” and “bandage.” In addition, Kalika also had certain Topics pages that contained phrases useful in medical contexts. For example, her Appointment page had “I want an earlier time,” “Sorry that I am late,” and “I need an appointment.” In this manner, Kalika had access to a wide range of vocabulary to express herself in medical (and other) contexts.

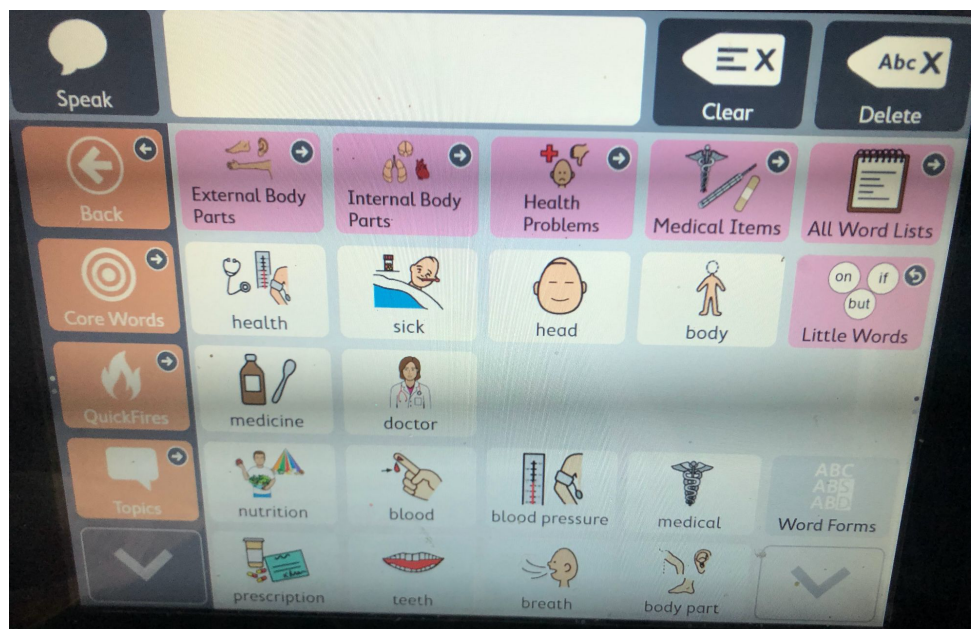


Figure 2. Kalika's pages specifically dedicated to health/medical issues

4.5. Reflexivity

Given the qualitative grounding of this study, the authors engaged in reflexivity individually and as a team. The team involved the mother of the focal participant, her neurologist, the mother's PhD advisees, and graduate and undergraduate students who collaborated as part of an interdisciplinary Rett Communication Lab. The reflexivity was modeled on previous work in this area (Barry, Britten, Barber, Bradley, & Stevenson, 1999), which constructed it as “awareness of the researcher's own presence in the research process” (Barry et al., 1999, p. 30). This prior research showed that “[t]hrough sharing common ground, enabling multiple voices to emerge, and developing a productive dialectic, we have improved our conceptual thinking, capitalized on our multiple disciplines, and improved the rigor and quality of our research” (Barry et al., 1999, p. 40). Inspired by this work, the authors of this present study reflected on issues such as: How their backgrounds positioned them within the project; their perspectives on qualitative inquiry; the theories that framed their thinking; and their intellectual (and other) investments in the research.

5. Findings

The findings section highlights different ways in which Kalika offered health and medical information using the eye-tracking AAC device: the first section examines usage reports, and the second section entails anecdotes from medical visits.

5.1. Behind the scenes: Usage reports before and after a medical event

The authors closely examined Kalika's language use with the eye-tracking AAC device as revealed by usage reports generated online. The mytobiidynavox.com site stored such reports, capturing the top 20-most triggered lexical items (words, phrases, and expressions) in TD Snap in a day for each subscriber. The data discussed here relates to a major medical event, in this case, a concussion Kalika experienced after lunging and falling from a toilet the day after moving into a new home on April 29, 2020. The reports collected included her

language use in the 14 days preceding and succeeding the event. The data was reviewed and coded, with the team isolating terms that related specifically to her health and medical condition. Figure 3 outlines 13 select lexical items (words and phrases) that were determined to be related to conveying medical/health information out of the full corpus.

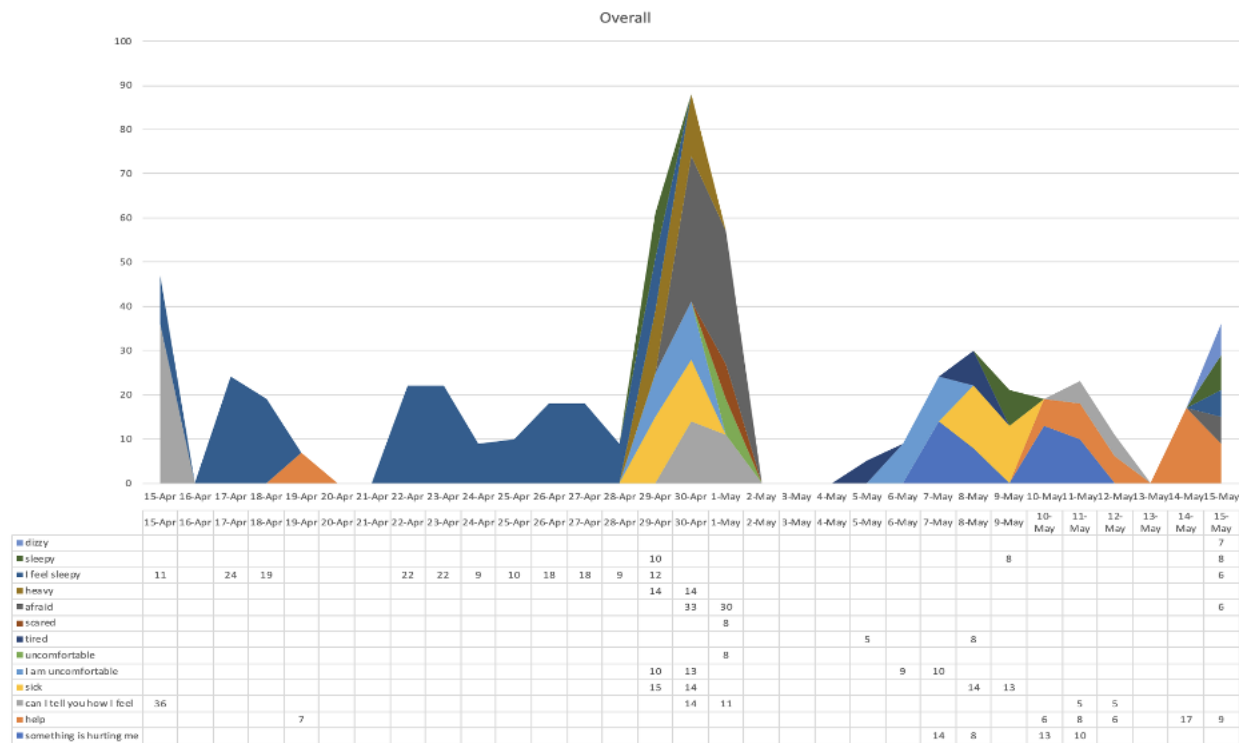


Figure 3. Lexical items related to medical/health communication

We found that in the two weeks prior to the concussion, the mean of her word counts was 238.7, with a minimum of 108 words to a maximum of 361 words per day. On the day of the incident and the day after, she spoke a total of 427 lexical items and 479 lexical items respectively.

Figure 3 lists all of the words and phrases that Kalika used to describe her medical/health state. The figure maps out the lexical items used to describe her medical/health state before, during, and after the concussion. Before the concussion occurred, the health-related words used by her were limited to items such as “I feel sleepy” and “can I tell you how I feel.” When the concussion happened, the total number of health-related words uttered increased significantly. Further, the range of words related to health/medical vocabulary expanded considerably. For example, in addition to the previously used health related words, she also used terms such as “uncomfortable,” “heavy,” “afraid,” “scared,” “sick,” and “something is hurting me.”

5.2. Observational reports

5.2.1. Observational report 1: Participating in medical exams

Kalika used her AAC device during eye appointments to assist her doctor in assessing her vision. Kalika’s vision issues primarily revolved around the development of strabismus, which became noticeable a few days after her second birthday in late December of 2017. Nine months later, her pediatric ophthalmologist conducted surgery to correct the turns in both of Kalika’s eyes. In order to continue monitoring the health of her eyes, her ophthalmologist recommended that she attend eye appointments every four months.

During one visit in January 2020, Kalika sat on her father’s lap in the large patient chair. Her mother helped her navigate between the AAC device (set up on a chair in front of her) and an illuminated eye chart on a facing wall approximately 20 feet away. After a quick exchange of greetings, the ophthalmologist asked gently, “Is it ok if I look at your eyes?” Kalika turned quickly to her AAC device and said: “Yes.” After a physical examination of the eyes, the ophthalmologist started a shape matching exam: Kalika was asked to match shapes

on her AAC device with those on the eye chart. Some of the shapes on the eye chart, it was discovered, were not available on her AAC device (e.g., a shape that outlined a house). Her mother quickly added the missing shapes to Kalika's Shapes page, and the exam continued. Kalika was then again directed to look at the eye chart and match the shapes there with what she was seeing on her AAC device. Next, the ophthalmologist flashed letters on the eye chart, which Kalika had to match with letters on the Alphabets page on her AAC device. Kalika matched two of the three shapes and letters correctly, which was consistent, according to the ophthalmologist, with measurements assessed by the physical examination of the eyes.

Kalika's next eye appointment occurred in March 2021, delayed as a result of the pandemic. In order to prepare for the visit, Kalika's father called the office a few days prior to the appointment and was informed about the shapes and HOTV visual acuity charts that Kalika would be tested with during the upcoming visit. Kalika was then familiarized with an updated Shapes page and an HOTV page (with just the letters H, O, T, V) over a two-day period. During the appointment, after Kalika and the ophthalmologist shared brief greetings, Kalika was told by the ophthalmologist that she was going to have to match the letter and shapes on the distant eye chart to the letters and shapes on her AAC device. The first procedure was called "HOTV single letter matching" and was conducted with both eyes open. The ophthalmologist stood close to the eye chart to draw Kalika's attention to it. It was noticed by her mother that Kalika was giving the correct response, but in a delayed manner, by which time the doctor had moved on to the next letter. After discussing this delayed response with the ophthalmologist (likely a result of attention issues in Rett syndrome [see Rosa et al., 2016]), the process was slowed down, and Kalika then gave four right answers of the six letters and shapes presented, which matched the results obtained through the physical eye examination. Thus, using the AAC device, Kalika was able to successfully participate in eye exams over different visits.

5.2.2. Observational report 2: Describing symptoms

Kalika also routinely used her AAC device to describe and discuss the impact of her symptoms. For example, in summer 2021 she developed what were characterized as head drops, diagnosed as either atonic seizures or a result of cataplexy (investigations were ongoing). When these drops first started, she appeared confused. One day in June, she asked "can what's going on" right after a head drop, and then described her feelings: "worried, awful, weird, stressed." Later that day, she said "try doing stop" right before the head drops started, stating that she felt "confused, terrible, weird" afterward. This happened often: she described the aftereffect as making her feel "funny, dizzy, worried, worried" (July 1), "bad, afraid, hot, dizzy, awful" (July 6), and "afraid, afraid, sleepy, weird, weird, awful, awful, weird, weird, weird, weird, dizzy" (July 15), as some examples. She consistently used these words to describe her feelings, navigating between two pages of her Feelings page, scrolling down to the second page herself to say "weird" and "dizzy" in particular.

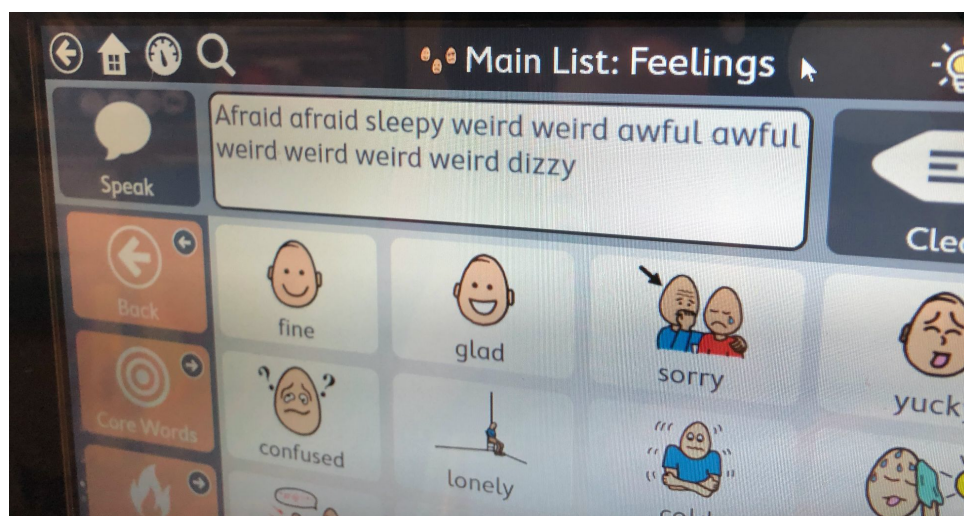


Figure 4. Kalika described her feelings related to symptoms using her AAC device

After a serious seizure at school on Aug 12, she returned home and upon being asked by her parents how she felt, she said: "bad, bad, bad, bad." Perhaps most poignantly, on August 10, after two severe head drop

sequences, Kalika's mother took her to her [Health Problems](#) page. The mother started trying to model saying "head drops," but Kalika said, "sick of pain." She had to navigate across two sets of pages, with "sick" and "pain" on the same page and "of" on another in order to express this sentiment.

5.2.3. *Observational report 3: Asking for assistance*

In July of 2021, about three weeks into the development of head drops, Kalika began to appeal for help in stopping these before they occurred. She would alert caregivers to the head drops prior to their starting. On July 21st, for example, she told her parents: "your happen have and helped ask a stop more have" right before she started head drops. At speech therapy summer camp, the next day, she told her attending therapist: "help like stopping do" immediately prior to having head drops. The therapist reported this to the mother by text; after hearing Kalika's words, the therapist immediately stopped the activity they were engaged in and worked to calm her and support her. A few days later, on July 29, Kalika told her father, who briefly stepped away from the breakfast table where they were eating: "stop having gone help help help your your your help ask ask do ask try stop happening" and then immediately started head drops. These were the only words she uttered in a ten-minute span and entailed navigation across three pages (2 [Core](#) pages and [Action Words](#)).

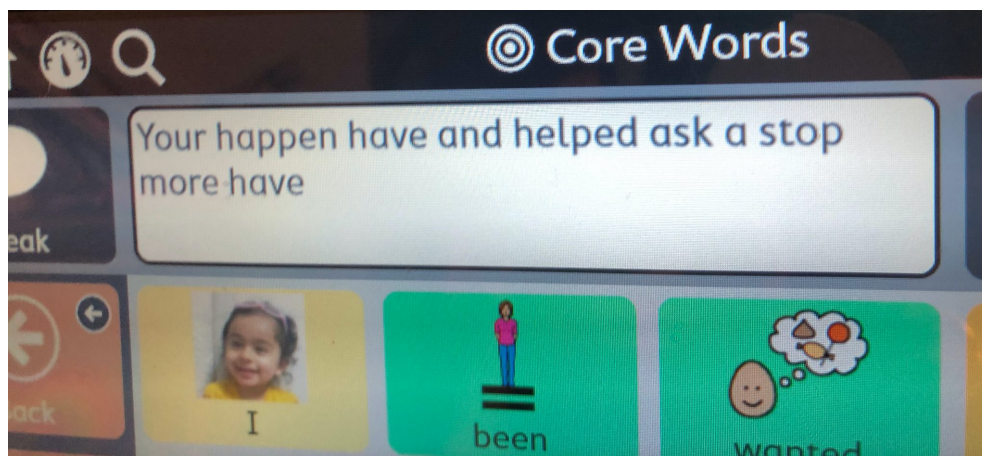


Figure 5. Kalika used the main page of her TD snap to ask for help for seizures

On August 11, as another example, in the middle of her physical therapy session at school, she informed her therapist: "I don't feel very well" followed by "I am scared." The therapist, alerted to the fact that she typically expressed these sentiments prior to the start of head drops, paused and made sure Kalika was in a safe and comfortable position, just as the head drops commenced. The therapist outlined this incident in an email to the parents. A similar event occurred the next day when Kalika was at school. She had a three-minute-long seizure which led to administration of Diastat² for seizure cessation as well as a call to her parents and emergency medical services. One of her teachers later messaged the parents to inform them that Kalika went to her medical [Appointments](#) page and said to her teacher: "I need an appointment please." Becoming alarmed, they prepared for a seizure, which started immediately after.

While pleas for help were most consistently tied to head drops, they had previously occurred in other contexts as well. In December of 2020, for example, Kalika had a virtual appointment with her Rett specialist/neurologist. Her parents wanted to discuss the worsening of two common Rett syndrome symptoms that Kalika was experiencing: hyperventilation and gastrointestinal issues. A day prior to the appointment, Kalika was told by her parents that her specialist would be able to help her with those issues. As soon as the visit started, Kalika greeted him and repeated "Do help" several times. During a different visit, she listened intently to a discussion of her symptoms between her parents and her specialist. As her parents brought up bouts of severe forced breathing and hyperventilation, she interjected by saying, "out of breath stop," navigating across three pages to do so.

² Diastat is a medication that treats increased seizures in individuals who are already on medications to control seizures.

5.2.4. Observational report 4: Reporting injuries

Kalika also used the AAC device to provide information about injuries during multiple incidents. On the evening of September 8, 2020, Kalika lunged off a living room sofa while watching a TV show, landing face-first on the hardwood floor. Blood poured out of her mouth at first, subsiding only after a few minutes. Later, she expressed discomfort using her AAC device: "I am uncomfortable," but managed to eat reasonably well and go to sleep at her usual time. Her father then checked her mouth again and noticed a gaping wound on her gums that continued to bleed. He rushed Kalika to the emergency department at a hospital nearby, where they spent some three hours waiting before being seen by the attending physician. The physician examined her mouth and said that Kalika only needed over the counter pain medications and would recover quickly. They returned home around midnight, with Kalika barely stirring. The next morning, Kalika's mother asked her father whether the doctor had checked Kalika all over for injuries or if he had only focused on her mouth. Kalika's father responded that it was the latter. Realizing that she might have been injured elsewhere as well, Kalika's mother took her to the External Body Parts page and asked: "Does anything else hurt apart from your mouth?" Kalika said: "elbow, elbow." It was not a word she had spontaneously uttered before. Kalika's father repeated: "Elbow?" He rolled up Kalika's sleeves and checked her elbows, one of which showed large purple bruising that had been missed.

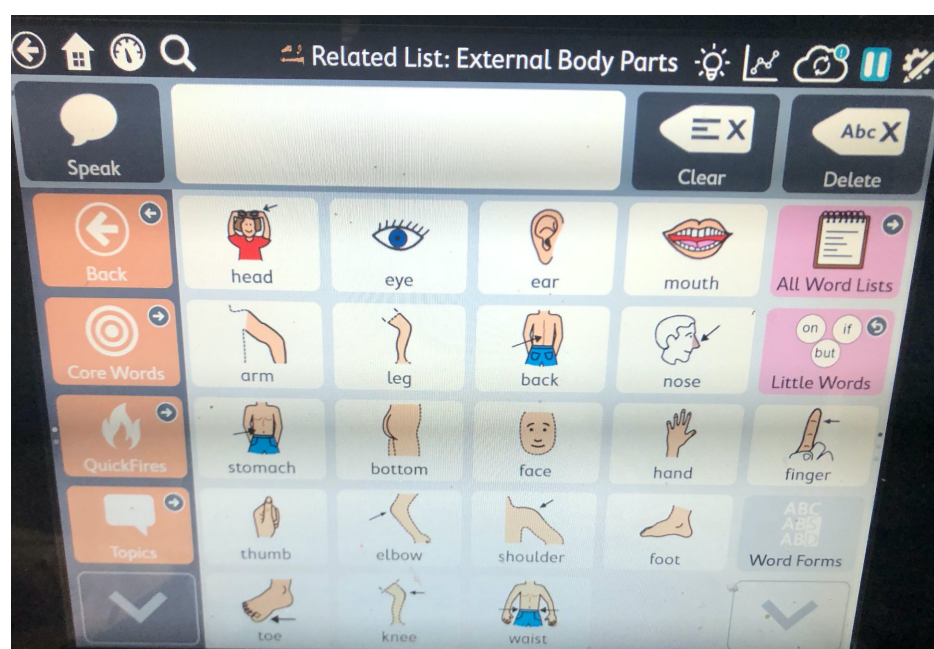


Figure 6. Kalika selected the word "elbow" from different options on this External Body Parts page

A similar incident occurred a few months later, on March 16, 2021. That evening, Kalika appeared to be feeling unwell. She used her AAC device to say that her "head hurt." When asked if she was hurt anywhere else, Kalika said "nose." Given no outward indications of injury to the nose, her parents figured that she had misspoken. The next morning, however, a small bruise appeared on the bridge of Kalika's nose. The parents were informed that she had taken a tumble in the backyard while in the care of another caregiver. She had fallen on her face, and the lenses had been knocked out of her glasses. The description of her head hurting and the injury to the nose then made sense. The bruise on her nose, likely the result of that fall, only became visible overnight. As a result of both of these incidents, Kalika's parents were able to note and attend to the injuries.

5.2.5. Observational report 5: Advocating during medical visits

Kalika also advocated for herself in a variety of ways during medical appointments. In January of 2021, for example, Kalika and her parents had a meeting with her nutritionist. When the session started, Kalika went to her Topics page, then selected her Advocacy page. When the nutritionist asked how Kalika had been doing since they had last met, Kalika said "Let's review that." Then, as the nutritionist and her parents began discussing what the nutritional goals needed to be for the coming three weeks, Kalika said "Let's develop a

plan.” Further, while discussing melatonin gummy drops as an option for sleep disruption, the parents expressed concern about her ability to consume them. However, Kalika said: “I can do it myself.” This made sense, the parents reported, since Kalika had recently started practicing eating gummy worms during feeding therapy. Next, when Kalika’s father inquired about valerian root, an unfamiliar supplement, Kalika said: “I want to discuss.” A discussion ensued. Finally, when her mother brought up some of Kalika’s gastrointestinal issues, Kalika went to her [Topics/Arguing](#) page and said: “I can’t believe you said that!” She then protested by commenting “How embarrassing!” several times. The parents reported that this was one of the first appointments during which Kalika followed along and participated throughout.

Furthermore, the parents reported that Kalika used the eye-tracker extensively during interactions with her pediatric neurologist/Rett specialist. Previously we noted Kalika’s description and discussion of symptoms and asking for help. Once during discussions with her doctor about the use of a novel device to treat her hyperventilation, Kalika repeatedly asked him, “Please explain.” During the setup of a cylinder for this purpose, further, she repeatedly said, “I am totally lost,” and asked him to “Slow down a little.” In this manner, Kalika asked questions, made comments, and advocated for herself in the context of medical appointments.

6. Discussion

The data presented above elucidates the powerful and empowering ways in which Kalika, who is medically classified as a “nonverbal” individual, offered valuable medical information using an eye-tracking AAC device and compellingly self-advocated for her own care in medical contexts.

The usage reports offered a powerful account of the change in Kalika’s language, both quantitatively and qualitatively before, during, and after a medical event. As we saw in Figure 3, the number of lexical items decreased to 231 words on the day her parents took her to the hospital, where she was diagnosed with a concussion. The change in the number of words suggests a desire to communicate more as a result of the concussion, in order to describe her condition and to get attention and help. Further, there was a qualitative change in the language Kalika used after her concussion, demonstrating a greater preoccupation with health-related issues. We assess this from the fact that the range of medical/health-related vocabulary was noticeably more varied on the day of the concussion and thereafter. Among the 20 frequently uttered lexical items during those two critical days, five of them suggested Kalika’s feeling of discomfort and a need to convey her feelings, for example, “afraid,” “sick,” “can I tell you how I feel?,” “heavy,” and “I am uncomfortable.” Figure 3 lays out how Kalika’s use of health/medical-related language not only increased significantly after her concussion, but also drew on a wider range of language. The peak in terms of use of this kind of language, as well as in numbers of occurrences, also happened around the time of the concussion. The data from the usage reports thus offered us a useful glimpse of how an AAC device was purposefully and meaningfully used by Kalika to convey health and medical information.

The observational reports offer supportive evidence as well. In the first observational report, for example, we saw how Kalika gave consent for an eye exam. Alderson, Sutcliffe, and Curtis (2006) have pointed out that regrettably, children are rarely asked for consent in medical contexts. This is tied to the fact that in general, children with disabilities are considered even less in discussions around consent, even though multiple studies have shown that “they have far higher levels of knowledge and competence relating to their condition” (Alderson et al., 2006, p. 26). In obtaining consent from individuals with disabilities for whom communication is a profound challenge, AAC can be a useful medium to elicit this (Curran & Hollins, 1994). The fact that Kalika was able to explicitly consent to having her eyes examined was thus an important step. Furthermore, she was able to offer valuable information about the state of her vision, by matching shapes and letters using her AAC device. The ophthalmologist was, because of this, able to triangulate the findings from the physical exam with what Kalika said. In this way, Kalika was able to assist in the assessment of her own health.

Meanwhile, the second observational report highlighted how Kalika used the AAC device to describe how she felt as a result of the experience of her symptoms. Her descriptions of how the seizures felt were not atypical. For example, she often described them as “weird,” which is not an uncommon description of a seizure. For example, Lord Tennyson used the word “weird” to describe seizures in the 1851 edition of *The Princess* (see Wright, 1987). Linguistic analyses have suggested that descriptions of seizures may be clinically meaningful (see Plug, Sharrack, & Reuber, 2010, 2011; Schwabe, Reuber, Schondienst, & Gulich, 2008). It is hoped that as Kalika’s descriptions get more complex with age and language proficiency, she will be able to offer clinically meaningful descriptions of seizures if and when they occur. It is also powerful that Kalika was

able to express a range of complex emotions related to her state of feeling, such as “sick of pain,” as a result of symptoms.

The third observational report highlighted how Kalika consistently asked for help and assistance to prevent or arrest a medical issue. As a result of her doing so, her parents, therapists, and teachers were able to offer assistance in three different settings (at home, at camp, and at school). They were able to anticipate the onset of head drops, ensure timely removal of hazards, and get her into a safe and comfortable position.

The fourth observational report elucidated how Kalika offered information about injuries, pain, or symptoms that may not be easily visible or noticeable. This is not an insignificant problem in Rett syndrome. Symons, Byiers, Tervo, and Beisang (2013), for example, conducted a preliminary study and found that obstacles in communication led to “an increased risk that the problem of pain may be overlooked or discounted in this vulnerable population” (Symons et al., 2013, p. 746). In their study, while a fourth of caregivers noted that their children (who all had Rett syndrome) experienced “over a week of pain per month...Of concern was that almost none of the respondents indicated that their daughters used words to communicate about pain” (Symons et al., 2013, p. 746). Kalika bringing attention to her elbow and nose in different falls offered important information to her parents, who then ensured that these injuries received appropriate medical care. Because most individuals with Rett syndrome have complex communication challenges and lack access to AAC, they “are at risk for living with pain but not having it readily recognized” (Symons et al., 2013, p. 746). Fortunately, Kalika’s proficient use of the AAC device offered her a way to bring attention to issues that caused pain.

The final observational report shows how Kalika advocated for herself in a variety of ways in medical contexts. The interaction with her nutritionist, for example, revealed how closely she followed the discussions and participated in the exchange. The interaction highlighted that she understood the necessity of reviewing the developments since the previous appointment. She also realized the importance of planning future goals. Further, she was able to offer her opinion of being able to swallow gummies (contradicting her parents’ assessment of her chewing abilities) and to ask for further clarity on issues that she did not understand. This is something she also did with her neurologist. In this manner, she was able to advocate for herself and contribute to her treatment in a number of ways.

It is remarkable of course, that Kalika, notwithstanding her medical classification as “nonverbal,” was able to participate actively and meaningfully in high-stakes medical encounters. Previous research has never captured this type of complex communication. We want to be clear, however, that shedding light on this previously unexamined area is not the sole purpose of this paper. This communicative portrait of Kalika also offers valuable lessons for applied linguists and language educators, which we outline below. Our suggestions are as follows:

- 1) *Broadening notions of speaking*: Part of what this study elucidates is the complexity of speech. Spoken language continues to be in focus within the field of applied linguistics in largely *normative* ways (Cruz-Ferreira, 2018; Phuong, 2019). Kalika’s speech production, melding gaze, technology, and synthetic voice, demonstrates how this could be a generative area for deeper inquiry (see also Chung & Douglas, 2014). Importantly, this study supports the expansion of the notion of “speaker,” since Kalika’s speech goes beyond the typical research realms of mouth words. Kusters, Spotti, Swanwick, and Tapio (2017) have previously outlined the importance of the concept of *repertoires* instead, which encompasses “all the ‘means of speaking’ that users of a language know, know how to use, and use with a specific reasoning in mind, while they are engaged in a communicative encounter” (p. 222). Kalika’s communication is better captured within this idea, since her speech includes (many times simultaneously) diverse resources such as verbalizations, vocalizations, gaze, gaze-triggered speech, and body movements, among others. Further, this investigation revealed that, not only did Kalika offer medical information in important ways through the device, but also that caregivers and medical professionals *legitimized* her speech. It was fortunate that Kalika’s words were not dismissed *because* they were mediated by a device. In the same way, we hope applied linguists and educators recognize and legitimize different forms of speech, whatever the means or modalities of expression.
- 2) *Increasing consideration of AAC*: As Chung and Douglas (2014) put it, “AAC is essential in enabling expressions of needs and emotions, establishing relationships, and promoting full participation for many students with significant disabilities” (p. 56). Despite being central to modes of self-expression for many individuals with disabilities, AAC remains largely marginalized in applied linguistics research. In fact, much of the scholarship in this area falls within communication disorders sciences.

This is not a small area of neglect. Beukelman and Light (2020) state that some 5 million individuals use AAC in the US context alone. As Kalika's speech showed in this study, AAC language use has important real-world applications and should be considered a meaningful area of study for applied linguistics scholars. Among other aspects, AAC also offers a path to more inclusive research involving individuals with disabilities, which has traditionally been excluded in research (see Feldman, Battin, Shaw, & Luckasson, 2013; Coons & Watson, 2013). Language educators would also benefit from learning about AACs given their growing popularity in use (especially in educational contexts).

- 3) *Exploring device-mediated language use*: Similarly, there remains a dearth of applied linguistics research examining device-mediated interactions (Higginbotham & Engelke, 2013). Without AAC and without her device, Kalika would not have been able to navigate medical (or any other) encounters in such extraordinary ways. The AAC device made language possible for her far beyond the few words she could speak by mouth. While digital language spaces have been generative and popular areas of study for applied linguists, technologically mediated language, as used by those with disabilities, remains sidelined. There are fascinating aspects to uncover, such as the fact that grammatical structures of language enabled by such devices are not exactly aligned with common speech practices (as can be seen with Kalika's language use here). Given the growing population of AAC device users (Beukelman & Light, 2020), this again needs to receive more attention within our field.
- 4) *Extending multimodal considerations*: Multimodality is not just a critical area for research in our field because of how it *adds* to our understanding of what is languaged, but in significant disability contexts, it can stand for the most powerful expressions of language itself (see, e.g., Al Zidjaly, 2012; Al Zidjaly, 2016; Jewitt, Bezemer, & O'Halloran, 2016; Kusters et al., 2017). This study shows us how multimodal expression—the eye activating speech—can be far more complex than is typically constructed within applied linguistics. Continuing the expansion of our understanding of what multimodality means is a necessary and critical part of our move toward more inclusive and richer analysis within applied linguistics (Kusters et al., 2017).
- 5) *Further complicating notions about communicative competence*: There is some emerging research examining communicative competence within AAC use in education and communication disorders (DeThorne, Hengst, Fisher, & King, 2014; Light & McNaughton, 2014; Radici, Heboyan, Mantovani, & De Leo, 2020), but there is relative silence within applied linguistics. Communicative competence is complex; it “invokes authenticity, plurality, and mobility, and links people's ability to communicate with others with their moral valuation, rights to citizenship and belonging, and position in the hierarchies and structure of inequality, both local and non-local” (Kataoka, Ikeda, & Besnier, 2013, p. 349). Individuals with disabilities are often mired in structures of inequality and have to wrestle with constraints on access when it relates to these aspects. How multimodal, device-mediated language is used to navigate medical encounters across disciplines, within the interplay of potent (and often oppressive) social, cultural, and historical forces, is a powerful question to explore using the lens of communicative competence. There needs to be more focused analysis within high-stakes encounters, such as those Kalika navigates, where using language appropriately could be a matter of life or death. In Kalika's case, communicative competence necessitates physical assistance; for example, within some of the contexts, Kalika needed to be taken to a specific page so that she could offer important medical information (e.g., the HOTV test). Context-specific language is found in different pages, which she located by herself and was also often guided to by her caregivers. One possible question for us to consider as applied linguists, then, is how communicative competence is interactionally achieved when there is disability.
- 6) *Presuming cognitive competence*: Kalika's use of language pushes against still prevailing attitudes regarding Rett syndrome, that individuals are unable to communicate and have severe cognitive deficits (see Fabio, Castelli, Marchetti, & Antonietti, 2013). In this study, she offers a glimpse of communicative and cognitive life in Rett syndrome that has mostly remained hidden until now. This paper offers evidence that such perspectives may be misleading and inaccurate; not only in Rett syndrome but within other significant disability contexts as well, possibly, where communication functions as a major barrier in assessment. In Rett syndrome, deficit perspectives have derived from

inappropriate assessment measures centering on speech and hand use that invariably fail when applied to individuals with the disorder. In the field of applied linguistics, it is accepted that *appropriate* assessment measures are key to the analysis of a learner's language level. This study shows how critical it is to keep this in mind within the significant disability context as well, particularly because of how language use is used to frame and assess individuals' cognitive abilities.

- 7) *Espousing linguistic justice*: As Henner and Robinson (2021) pointed out, neglect of “disabled ways of languaging” (p. 2) is a process by which the larger field of “[l]inguistics reproduces and refracts structures of power” (p. 2). The authors assert that for linguistic justice, *all* inquiry within the entire field of linguistics must engage with disability. Similarly, Kusters et al. (2017) noted: “it [is] extremely important to pay attention to...asymmetries: people have differential access to languages, literacies, objects and other resources, and different uses of the senses” (p. 227). Attending to these issues is an *imperative*, rather than a peripheral charge for applied linguists, if we are to aspire for linguistic justice in our field.

Ultimately, we call for applied linguists and language educators to broaden and *humanize* their understanding of how language circulates in the real world. It is our hope that this study can help offer a gentle but compelling nudge in that direction.

7. Conclusion

There are some caveats to keep in mind within this study. Given that this study focused on a medical case report of a single participant, it is not possible to make claims about generalizability across the entire population of individuals with Rett syndrome. The intent of this study is to show how one child with Rett syndrome used an AAC device purposefully for medical communication and advocacy, and to draw out lessons for the field of applied linguistics. Individuals with Rett syndrome are a heterogeneous group; for that reason, broad generalizations may be inappropriate. What we have, instead, is a picture of a new world of possibilities in terms of how individuals with significant communication challenges can language their world. We hope that future research will involve a more diverse population, extending the limited knowledge in this area.

Another important note to attend to is that Kalika's communication was facilitated but also limited by her device. The device imposed constraints in terms of how the language was pre-designed and structured; while the parents had made interventions and changes, those were minor overall. Kalika's talk and advocacy had to occur within mostly a pre-configured set of software cells, and therefore, communicative possibilities. As noted earlier, her first language was unavailable on TD Snap, and the small Bengali section her mother devised was rudimentary. Despite these constraints, the data reveals intriguing language use that merits further study.

Ultimately, this study offers a tantalizing glimpse of future possibilities where individuals with serious communication challenges can provide medical information in ways that were previously unimaginable. This is no small matter in a complex disease like Rett syndrome, where accurate pain assessment is especially crucial (Solodiuk & Curley, 2003); the consequences of neglecting or misunderstanding medical issues can severely impact quality of life. Understanding the patient experience is also critical for suitable drug development (Morel & Cano, 2017). At the cusp of gene therapy trials and other ground-breaking treatments being developed for Rett syndrome (Neul & Chang, 2020), it is hoped that this exciting possibility is recognized and valued as a result of this study within the broader medical community. Language will be central to these advancements; and there is room for applied linguists to break new ground in this high-stakes space.

References

- Alderson, Priscilla, Sutcliffe, Katy, & Curtis, Katherine (2006). Children as partners with adults in their medical care. *Archives of Disease in Childhood*, 91(4), 300–303. <https://doi.org/10.1136/ad.2005.079442>
- Al Zidjaly, Najma (2016). *Disability, discourse and technology: Agency and inclusion in (inter)action*. Springer.
- Al Zidjaly, Najma (2012). Multimodality and disability. In Carol A. Chapelle (Ed.), *The encyclopedia of applied linguistics*. Wiley-Blackwell.

- Armstrong, Dawna D. (2005). Neuropathology of Rett syndrome. *Journal of Child Neurology*, 20(9), 747–753. <https://doi.org/10.1177/08830738050200090901>
- Barry, Christine A., Britten, Nicky, Barber, Nick, Bradley, Colin, & Stevenson, Fiona (1999). Using reflexivity to optimize teamwork in qualitative research. *Qualitative Health Research*, 9(1), 26–44. <https://doi.org/10.1177%2F104973299129121677>
- Bartolotta, Theresa E., Zipp, Genevieve P., Simpkins, Susan D., & Glazewski, Barbara (2011). Communication skills in girls with Rett syndrome. *Focus on Autism and Other Developmental Disabilities*, 26(1), 15–24. <https://doi.org/10.1177%2F1088357610380042>
- Beukelman, David R., & Mirenda, Pat (2005). *Augmentative and alternative communication: management of severe communication disorders in children and adults* (3rd ed.). Paul H. Brookes.
- Beukelman, David R., & Light, Janice C. (2020). *Augmentative & alternative communication: supporting children and adults with complex communication needs*. Paul H. Brookes.
- Brumfit, Christopher J. (1995). Teacher professionalism and research. In Guy Cook & Barbara Seidlhofer (Eds.), *Principle and practice in applied linguistics*. Oxford University Press.
- Campbell, Philippa H., Milbourne, Suzanne, Dugan, Lauren M., & Wilcox, M. Jeanne (2006). A review of evidence on practices for teaching young children to use assistive technology devices. *Topics in Early Childhood Special Education*, 26(1), 3–13. <https://doi.org/10.1177%2F02711214060260010101>
- Chung, Yun-Ching, & Douglas, Karen H. (2014). Communicative competence inventory for students who use augmentative and alternative communication: A team approach. *Teaching Exceptional Children*, 47(1), 56–68. <https://doi.org/10.1177%2F0040059914534620>
- Coons, Kelly D., & Watson, Shelley L. (2013). Conducting research with individuals who have intellectual disabilities: Ethical and practical implications for qualitative research. *Journal on Developmental Disabilities*, 19(2), 14.
- Costello, John (2000). AAC intervention in the intensive care unit: The children's hospital Boston model. *Augmentative and Alternative Communication*, 16(3), 137–153. <https://doi.org/10.1080/07434610012331279004>
- Costello, John M., Patak, Lance, & Pritchard, Jennifer (2010). Communication vulnerable patients in the pediatric ICU: Enhancing care through augmentative and alternative communication. *Journal of Pediatric Rehabilitation Medicine*, 3(4), 289–301. <https://doi.org/10.3233/prm-2010-0140>
- Cruz-Ferreira, Madalena (2018). Assessment of communication abilities in multilingual children: Language rights or human rights?. *International Journal of Speech-Language Pathology*, 20(1), 166–169. <http://dx.doi.org/10.1080/17549507.2018.1392607>
- Curran, Jenny, & Hollins, Sheila (1994). Consent to medical treatment and people with learning disability. *Psychiatric Bulletin*, 18(11), 691–693. <http://dx.doi.org/10.1192/pb.18.11.691>
- Demjén, Zsófia (Ed.). (2020). *Applying linguistics in illness and healthcare contexts*. Bloomsbury Publishing.
- DeThorne, Laura S., Hengst, Julie, Fisher, Kim, & King, Amie (2014). Keep your eye on the prize: Implementing AAC within the broader context of communicative competence. *Young Exceptional Children*, 17(1), 39–50. <https://doi.org/10.1177%2F1096250613485453>
- Djukic, Aleksandra, Holtzer, Roe, Shinnar, Shlomo, Muzumdar, Hiren, Rose, Susan A., Mowrey, Wenzhu, Galanopoulou, Aristeia S., Shinnar, Ruth, Jankowski, Jeffrey J., Feldman, Judith F., Pillai, Sophia, & Moshé, Solomon L. (2016). Pharmacologic treatment of Rett syndrome with glatiramer acetate. *Pediatric Neurology*, 61, 51–57. <https://doi.org/10.1016/j.pediatrneurol.2016.05.010>
- Dziwota, Ewelina, Fałkowska, Urszula, Adamczyk, Katarzyna, Adamczyk, Dorota, Stefańska, Alena, Pawęzka, Justyna, & Olajosy, Marcin (2016). Silent angels the genetic and clinical aspects of Rett syndrome. *Current Problems of Psychiatry*, 17(4), 282–296. <https://doi.org/10.1515/cpp-2016-0028>
- Etchels, Maria C., MacAulay, Fiona, Judson, Andrew, Ashraf, Saqib, Ricketts, Ian W., Waller, Annalu, Alm, Norman, Warden, Audrey, Gordon, Brian, Brodie, Jan & Shearer, Alfred J. (2003). ICU-Talk: the development of a computerised communication aid for patients in ICU. *Care of the Critically Ill*, 19(1), 4–9.
- Fabio, Rosa A., Castelli, Ilaria, Marchetti, Antonella, & Antonietti, Alessandro (2013). Training communication abilities in Rett Syndrome through reading and writing. *Frontiers in Psychology*, 4, 911. <https://doi.org/10.3389/fpsyg.2013.00911>

- Feldman, Maurice A., Battin, Susan M., Shaw, Olivia A., & Luckasson, Ruth (2013). Inclusion of children with disabilities in mainstream child development research. *Disability & Society*, 28(7), 997–1011. <https://doi.org/10.1080/09687599.2012.748647>
- Floyd, Kimberly K., Smith Canter, Lora Lee, Jeffs, Tara, & Judge, Sharon A. (2008). Assistive technology and emergent literacy for preschoolers: A literature review. *Assistive Technology Outcomes and Benefits*, 5(1), 92–102.
- Friedrich, Patricia (2019). *Applied linguistics in the real world*. Routledge.
- Guidelines To Writing A Clinical Case Report. (2017). *Heart Views: The Official Journal of the Gulf Heart Association*, 18(3), 104–105. <https://doi.org/10.4103/1995-705X.217857>
- Hagen, Marc (2020, October 14). *Snap core first for Windows-A symbol based communication app custom built for aac*. <https://www.closingthegap.com/snap-core-first-for-windows-a-symbol-based-communication-app-custom-built-for-aac/>
- Happ, Mary B., Roesch, Tricia K., & Kagan, Sarah H. (2005, November). Patient communication following head and neck cancer surgery: a pilot study using electronic speech-generating devices. *Oncology Nursing Forum*, 32(6), 1179–1187. <https://doi.org/10.1188/05.onf.1179-1187>
- Happ, Mary B., Tuite, Patricia, Dobbin, Kathy, DiVirgilio-Thomas, Dana, & Kitutu, Julius (2004). Communication ability, method, and content among nonspeaking nonsurviving patients treated with mechanical ventilation in the intensive care unit. *American Journal of Critical Care*, 13(3), 210–218.
- Henner, Jon, & Robinson, Octavian (2021, July 8). Unsettling Languages, Unruly Bodyminds: Imaging a Crip Linguistics. <https://doi.org/10.31234/osf.io/7bzaw>
- Higginbotham, David J., & Engelke, Christopher R. (2013). A primer for doing talk-in-interaction research in augmentative and alternative communication. *Augmentative and Alternative Communication*, 29(1), 3–19. <https://doi.org/10.3109/07434618.2013.767556>
- Hou, Wei, Bhattacharya, Usree, Pradana, Wisnu A., & Tarquinio, Daniel C. (2020). Assessment of a clinical trial metric for Rett syndrome: critical analysis of the Rett syndrome behavioural questionnaire. *Pediatric Neurology*, 107, 48–56. <https://doi.org/10.1016/j.pediatrneurol.2020.01.009>
- Hyett, Nerida, Kenny, Amanda, & Dickson-Swift, Virginia (2014). Methodology or method? A critical review of qualitative case study reports. *International Journal of Qualitative Studies on Health and Well-being*, 9(1), 1–13. <https://doi.org/10.3402/qhw.v9.23606>
- Jewitt, Carey, Bezemer, Jeff, & O'Halloran, Kay (2016). *Introducing multimodality*. Routledge.
- Kataoka, Kuniyoshi, Ikeda, Keiko, & Besnier, Niko (2013). Decentering and recentering communicative competence. *Language & Communication*, 33(4), 345–350. <https://doi.org/10.1016/j.langcom.2013.03.009>
- Kemp, Bryan J. (1999). Quality of life while aging with a disability. *Assistive Technology*, 11(2), 158–163. <https://doi.org/10.1080/10400435.1999.10131999>
- Kling, Adria, Campbell, Philippa H., & Wilcox, Jeanne (2010). Young children with physical disabilities: Caregiver perspectives about assistive technology. *Infants & Young Children*, 23(3), 169–183. <http://dx.doi.org/10.1097/IYC.0b013e3181e1a873>
- Koppenhaver, David A., Erickson, Karen A., Harris, Beverly, McLellan, Janet, Skotko, Brian G., Newton, Robbin A. (2001). Storybook-based communication intervention for girls with Rett syndrome and their mothers. *Disability and Rehabilitation*, 23(3-4), 149–159. <https://doi.org/10.1080/09638280150504225>
- Kusters, Annelies, Spotti, Massimiliano, Swanwick, Ruth, & Tapio Elina (2017). Beyond languages, beyond modalities: transforming the study of semiotic repertoires, *International Journal of Multilingualism*, 14(3), 219–232. <https://doi.org/10.1080/14790718.2017.1321651>
- Light, Janice, & McNaughton, David (2014). Communicative competence for individuals who require augmentative and alternative communication: A new definition for a new era of communication?. *Augmentative and Alternative Communication*, 30(1), 1–18. <https://doi.org/10.3109/07434618.2014.885080>
- Lotan, Meir (2006). Rett syndrome. Guidelines for individual intervention. *The Scientific World Journal*, 6, 1504–1516. <https://dx.doi.org/10.1100%2Ftsw.2006.252>

- Morel, Thomas, & Cano, Stefan J. (2017). Measuring what matters to rare disease patients—reflections on the work by the IRDiRC taskforce on patient-centered outcome measures. *Orphanet Journal of Rare Diseases*, 12(1), 1–13. <https://doi.org/10.1186/s13023-017-0718-x>
- Mothapo, Ngwanamashiane R., Tönsing, Kerstin M., & Morwane, Refilwe E. (2021). Determining the core vocabulary used by Sepedi-speaking children during regular preschool activities. *International Journal of Speech-Language Pathology*, 23(3), 1–10. <https://doi.org/10.1080/17549507.2020.1821774>
- Neul, Jeffrey L., & Chang, Qiang (2020). Rett syndrome and MECP2-related disorders. *Neurodevelopmental Disorders*, 269–284. <http://dx.doi.org/10.1016/B978-0-12-814409-1.00011-2>
- Oldfors, Anders, Sourander, Patrick, Armstrong, Dawna L., Percy, Alan K., Witt-Engerström, Ingegerd, & Hagberg, Bengt A. (1990). Rett syndrome: cerebellar pathology. *Pediatric Neurology*, 6(5), 310–314. [https://doi.org/10.1016/0887-8994\(90\)90022-s](https://doi.org/10.1016/0887-8994(90)90022-s)
- Phuong, Jennifer (2019). What is normal in educational linguistics? [Note from the field]. *Working Papers in Educational Linguistics*, 34, 1–6.
- Pickering, Lucy (2020). Applications of applied linguistics to augmentative and alternative communication device users in the workplace. In Susan Conrad, Alissa Hartig, & Lynn Santelmann (Eds.), *The Cambridge Introduction to Applied Linguistics* (187–203). Cambridge University Press.
- Plug, Leendert, Sharrack, Basil, & Reuber, Markus (2010). Seizure, fit or attack? The use of diagnostic labels by patients with epileptic or non-epileptic seizures. *Applied Linguistics*, 31(1), 94–114. <http://dx.doi.org/10.1093/applin/amp012>
- Plug, Leendert, Sharrack, Basil, & Reuber, Markus (2011). Metaphors in the description of seizure experiences: Common expressions and differential diagnosis. *Language and Cognition*, 3(2), 209–233. <http://dx.doi.org/10.1515/LANGCOG.2011.008>
- Pullin, Graham, Treviranus, Jutta, Patel, Rupal, & Higginbotham, Jeff (2017). Designing interaction, voice, and inclusion in AAC research. *Augmentative and Alternative Communication*, 33(3), 139–148. <https://doi.org/10.1080/07434618.2017.1342690>
- Radici, Elena, Heboyan, Vahe, Mantovani, Fabrizia, & De Leo, Gianluca (2020). Attitudes and perceived communicative competence: The impact of different AAC means of communication among Italian teenagers. *International Journal of Disability, Development and Education*, 2020, 1–11. <http://dx.doi.org/10.1080/1034912X.2020.1740185>
- Rison, Richard A. (2013). A guide to writing case reports for the Journal of Medical Case Reports and BioMed Central Research Notes. *Journal of Medical Case Reports*, 7(239), 1–9. <https://doi.org/10.1186/1752-1947-7-239>
- Roberts, Celia, & Sarangi, Srikant (2003). Uptake of discourse research in interprofessional settings: Reporting from medical consultancy. *Applied Linguistics*, 24(3), 338–359. <https://doi.org/10.1093/applin/24.3.338>
- Rodriguez, Cristina P., Adelstein, David J., Rybicki, Lisa A., Saxton, Jerrold P., Lorenz, Robert R., Wood, Benjamin G., Scharpf, Joseph, & Ives, Denise I. (2012). Single-arm phase II study of multiagent concurrent chemoradiotherapy and gefitinib in locoregionally advanced squamous cell carcinoma of the head and neck. *Head & Neck*, 34(11), 1517–1523. <https://doi.org/10.1002/hed.21971>
- Saldaña, Johnny (2021). *The coding manual for qualitative researchers*. SAGE.
- Schall, Carol, Targett, Pamela, & Wehman, Paul (2006). Applications for youth with autism spectrum disorders. In Paul Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (pp. 447–472). Brookes Publishing.
- Schwabe, Meike, Reuber, Markus, Schondienst, Martin, & Gulich, Elisabeth (2008). Listening to people with seizures: how can linguistic analysis help in the differential diagnosis of seizure disorders?. *Communication & Medicine*, 5(1), 59–72. <https://doi.org/10.1558/cam.v5i1.59>
- Skotko, Brian G., Koppenhaver, Dave A., & Erickson, Karen A. (2004). Parent reading behaviors and communication outcomes in girls with Rett syndrome. *Exceptional Children*, 70(2), 145–166. <https://doi.org/10.1177%2F001440290407000202>
- Solodiuk, Jean, & Curley, Martha A. (2003). Pain assessment in nonverbal children with severe cognitive impairments: the Individualized Numeric Rating Scale (INRS). *Journal of Pediatric Nursing*, 18(4), 295–299. [https://doi.org/10.1016/s0882-5963\(03\)00090-3](https://doi.org/10.1016/s0882-5963(03)00090-3)

- Symons, Frank J., Byiers, Breanne, Tervo, Raymond, & Beisang, Arthur (2013). Parent reported pain in Rett syndrome. *The Clinical Journal of Pain*, 29(8), 744–746. <https://dx.doi.org/10.1097%2FAJP.0b013e318274b6bd>
- Tobii Dynavox [Internet]. Danderyd, Sweden: Tobii Dynavox; [cited 2021 Aug 13]. Available from: <https://www.mytobiidynavox.com/store/Snap>
- Tobii [Internet]. Danderyd, Sweden: Tobii; [cited 2021 Aug 13]. Available from: <https://www.tobii.com/group/contacts/>
- Townend, Gillian S., Bartolotta, Theresa E., Urbanowicz, Anna, Wandin, Helena, & Curfs, Leopold M. (2020). Development of consensus-based guidelines for managing communication of individuals with Rett syndrome. *Augmentative and Alternative Communication*, 36(2), 71–81. <https://doi.org/10.1080/07434618.2020.1785009>
- Townend, Gillian S., Marschik, Peter B., Smeets, Eric, van de Berg, Raymond, van den Berg, Marielle, & Curfs, Leopold M. (2016). Eye gaze technology as a form of augmentative and alternative communication for individuals with Rett syndrome: experiences of families in the Netherlands. *Journal of Developmental and Physical Disabilities*, 28(1), 101–112. <https://doi.org/10.1007/s10882-015-9455-z>
- Udvardi, Anna (2019). The role of linguistics in improving the evidence base of healthcare communication. *Patient Education and Counseling*, 102(2), 388–393. <https://doi.org/10.1016/j.pec.2018.09.012>
- Vessoyan, Kelli, Steckle, Gill, Easton, Barb, Nichols, Megan, Mok Siu, Victoria, & McDougall, Janette (2018). Using eye-tracking technology for communication in Rett syndrome: perceptions of impact. *Augmentative and Alternative Communication*, 34(3), 230–241. <https://doi.org/10.1080/07434618.2018.1462848>
- Wandin, Helena, Lindberg, Per, & Sonnander, K. (2021). Aided language modelling, responsive communication and eye-gaze technology as communication intervention for adults with Rett syndrome: three experimental single case studies. *Disability and Rehabilitation: Assistive Technology*, 1–15. <https://doi.org/10.1080/17483107.2021.1967469>
- Woolston, Wendy, & Connelly, Lynne M. (2017). Felty's syndrome: a qualitative case study. *Medsurg Nursing*, 26(2), 105–118.
- Wright, Barbara H. (1987). Tennyson, the weird seizures in The Princess, and epilepsy. *Literature and Medicine*, 6(1), 61–76. <https://doi.org/10.1353/lm.2011.0022>

Usree Bhattacharya, University of Georgia
 ubhattacharya@uga.edu

- EN** | **Usree Bhattacharya** is an Associate Professor in the Department of Language and Literacy Education within the Mary Frances Early College of Education at the University of Georgia. Her research is inspired by questions of diversity, equity, and inclusion in multilingual educational settings. Motivated by her daughter's diagnosis of Rett syndrome in 2018, her research currently explores language and literacy socialization within this rare disease context.
- ES** | **Usree Bhattacharya** es profesora asociada en el Department of Language and Literacy Education del Mary Frances Early College of Education dell' University of Georgia. Su investigación se inspira en cuestiones de diversidad, equidad e inclusión en entornos educativos multilingües. Motivada por el diagnóstico de síndrome de Rett de su hija en 2018, su investigación explora en la actualidad la socialización a través del lenguaje y la alfabetización en este contexto de enfermedades raras.
- IT** | **Usree Bhattacharya** è professoressa associata presso il Department of Language and Literacy Education del Mary Frances Early College of Education dell'University of Georgia. La sua ricerca è ispirata da questioni di diversità, equità e inclusione in contesti educativi multilingue. Motivata dalla diagnosi di sindrome di Rett di sua figlia nel 2018, la sua ricerca esplora attualmente la socializzazione del linguaggio e dell'alfabetizzazione in questo contesto di malattia rara.

Wisnu A. Pradana, University of Georgia
wisnu.pradana@uga.edu

- EN** **Wisnu A. Pradana** is a Ph.D. student in the Department of Language and Literacy Education, Mary Frances Early College of Education, at the University of Georgia. His research interests include Rett syndrome and social justice issues surrounding persons with disability and their families.
- ES** **Wisnu A. Pradana** es estudiante de doctorado en el Department of Language and Literacy Education del Mary Frances Early College of Education dell' University of Georgia. Sus intereses en investigación incluyen el síndrome de Rett y temas de justicia social que rodean a las personas con discapacidad y sus familiares.
- IT** **Wisnu A. Pradana** è uno studente di dottorato presso il Department of Language and Literacy Education, Mary Frances Early College of Education, all'University of Georgia. I suoi interessi di ricerca includono la sindrome di Rett e le questioni di giustizia sociale che riguardano le persone con disabilità e le loro famiglie.

Xing Wei, University of Georgia
xing.wei@uga.edu

- EN** **Xing Wei** is a Ph.D. candidate in the Department of Language and Literacy Education, Mary Frances Early College of Education, at the University of Georgia. Her research focuses on language modeling using aided augmentative and alternative communication (AAC) devices for individuals with disabilities.
- ES** **Xing Wei** es 89icercar89 a doctorado en el Department of Language and Literacy Education del Mary Frances Early College of Education dell' University of Georgia. Su investigación se centra en el modelado del lenguaje utilizando dispositivos de comunicación alternativa y aumentativa (AAC) para personas con discapacidades.
- IT** **Xing Wei** è dottoranda di 89icercar presso il Department of Language and Literacy Education, Mary Frances Early College of Education, alla University of Georgia. La sua ricerca si concentra sulla modellizzazione del linguaggio utilizzando dispositivi di comunicazione aumentativa e alternativa (AAC) per gli individui con disabilità.

Daniel Tarquinio, Center for Rare Neurological Diseases
daniel@rareneuro.com

- EN** **Daniel Tarquinio** is a pediatric neurologist and epileptologist. He is the managing director of the Center for Rare Neurological Diseases. His research interests include the treatment of epilepsy in Rett syndrome, validation and refinement of outcome measures for clinical research, and identification of neurophysiological predictors of outcome.
- ES** **Daniel Tarquinio** es neurólogo pediátrico y epileptólogo. Es el director general del Center for Rare Neurological Diseases. Sus intereses de investigación incluyen el tratamiento de la epilepsia en el síndrome de Rett, la validación y el ajuste de medidas de resultados para la investigación clínica, y la identificación de indicadores de resultado neurofisiológicos.
- IT** **Daniel Tarquinio** è neurologo ed epilettologo pediatrico. È direttore del Center for Rare Neurological Diseases. I suoi interessi di ricerca includono il trattamento dell'epilessia nella sindrome di Rett, la convalida e il perfezionamento delle misure di esito per la ricerca clinica, e l'identificazione di predittori neurofisiologici di risultati.

Olivia Datta, University of Georgia
olivia.datta@uga.edu

- EN** | **Olivia Datta** is an undergraduate student at Franklin College of Arts and Science at the University of Georgia. She is majoring in biology and completing a certificate in disabilities studies. Olivia is in the process of pursuing becoming a physician.
- ES** | **Olivia Datta** es estudiante de licenciatura en la Franklin College of Arts and Science at the University of Georgia. Ella se especializa en biología y está finalizando un diploma de estudios en discapacidad. Olivia se encuentra en el proceso de formación para ser médico.
- IT** | **Olivia Datta** è una studentessa universitaria al Franklin College of Arts and Science dell'University of Georgia. Si sta specializzando in biologia e sta completando un diploma in studi sulle disabilità. Olivia ha intrapreso il percorso di formazione per diventare un medico.

Kaleigh Anderson, University of Georgia
kaleigh.anderson@uga.edu

- EN** | **Kaleigh Anderson** is a graduate student in the Department of Communication Science and Disorders in the Mary Frances Early College of Education at the University of Georgia. Her research interests include social communication, neurodevelopmental disorders, and emerging AAC technology.
- ES** | **Kaleigh Anderson** es estudiante de posgrado en el Department of Communication Science and Disorders in the Mary Frances Early College of Education at the University of Georgia. Sus intereses de investigación incluyen la comunicación social, los trastornos del neurodesarrollo y la tecnología emergente de AAC.
- IT** | **Kaleigh Anderson** è una studentessa laureata presso il Department of Communication Science and Disorders del Mary Frances Early College of Education dell'University of Georgia. I suoi interessi di ricerca includono la comunicazione sociale, i disturbi del neurosviluppo e la tecnologia AAC emergente.

Nicole Cruz-Díaz, University of Georgia
nicole.cruz1@uga.edu

- EN** | **Nicole Cruz-Díaz** is a graduate student in the Department of Communication Science and Disorders in the Mary Frances Early College of Education at the University of Georgia. She is speech-language pathologist certified (Chile, 2014) with a Graduate Diploma in Neuropsychology and Neuropsychiatry in Adults. Her research includes Rett Syndrome in Latin-American contexts and bilingualism.
- ES** | **Nicole Cruz-Díaz** es estudiante de posgrado en el Department of Communication Science and Disorders in the Mary Frances Early College of Education at the University of Georgia. Es patóloga del habla y el lenguaje (Chile, 2014) con un título de postgrado en Neuropsicología y Neuropsiquiatría en Adultos. Su investigación incluye el síndrome de Rett en contextos latinoamericanos y bilingüismo.
- IT** | **Nicole Cruz-Díaz** è iscritta al programma post lauream presso il Dipartimento di Scienze della Comunicazione e Disturbi nel Mary Frances Early College of Education dell'University of Georgia. È certificata come logopedista (Cile, 2014) con un diploma di laurea in neuropsicologia e neuropsichiatria degli adulti. La sua ricerca comprende la sindrome di Rett in contesti latino-americani e il bilinguismo.