

Rationale

- Hospitals are mandated to provide services that meet the unique communication needs of all patients, regardless of age or disability (The Joint Commission, 2010).
- Many young children with severe communication disabilities rely on alternative and augmentative communication (AAC) strategies to communicate with hospital staff.
- Unfortunately, these children are at increased risk for experiencing preventable adverse events (e.g., medication errors) and communication challenges with staff (Blackstone, Beukelman, & Yorkston, 2015) which can contribute to poor health outcomes.
- To design and implement effective services to support children with severe communication disabilities, hospitals must understand the complex contextual factors influencing hospital interactions.
- A paucity of evidence is available to describe the critical features of the inpatient communication experiences of children with severe communication disabilities, their families, and providers (Hemsley & Balandin, 2014)
- No direct observation techniques have been used to describe such interactions.

Research Questions

- During day shift hours on an inpatient rehabilitation unit,
- how many unique communication partners does a young child with a severe communication disability interact with during medical encounters?
 - what activities occur during medical encounters?
 - where do medical encounters occur?
 - what communication modes does the child use during these interactions?

Methods



- An observational study was conducted to describe the communication interactions among a young child with a severe communication disability, her parents, and medical personnel on an inpatient rehabilitation unit.

Participants and Setting

Child Participant: Mae (pseudonym)

- 28-month-old girl with a history of prematurity (born 28 weeks gestation), developmental delays, and diagnosis of failure to thrive
- Admitted to a rehabilitation hospital to participate in an intensive inpatient feeding program (daily speech therapy and occupational therapy sessions)
- Communicated primarily using manual signs, conventional gestures, speech approximations, graphic symbols, and challenging behaviors.

Adult Participants: Mae's adult communication partners

- Mae's mother and father
- 10 medical professionals: (a) 5 nurses, (b) 4 nursing assistants, and (c) 1 physician.
 - Mean age = 33.5 years (range = 23-54)

Setting:

- A 20-bed inpatient pediatric unit in the Northeast region of the United States

Materials

A handheld Sony Handycam® CX440 was used to record all medical encounters and to minimize researcher interference in the communication interactions.

Procedures



- Following informed consent, naturalistic video-recordings were collected during 10 days of a five-week period.
- Video-recordings occurred (a) between the hours of 7:00AM and 7:00PM, (b) during medical encounters (e.g., medication administration), and (c) involved a nurse, certified nursing assistant, and/or physician
- Recording started upon the medical provider's entrance into the same room as the child participant and was discontinued if (a) an unconsented individual entered the shared space, (b) the provider exited the room, or (c) client privacy was required (e.g., a diaper change).

Results



27 video samples were collected (duration = 122.08 minutes)
Communication Partners: Parents were present for 100% of encounters (Mae's mother = 71%, Mae's father = 29%)

- 71% time spent with nurses, 14.5% with nursing assistants, 2.4% with physician, and 11.9% with multiple providers
- Activities:** administering medication ($n = 12$), completing rounding tasks ($n = 6$), taking vital signs ($n = 5$), measuring the child's weight ($n = 3$), and inserting a nasogastric tube ($n = 1$).
Locations (whole or part): Mae's room ($n = 23$), dining room ($n = 3$), hallway ($n = 1$), and procedure room ($n = 11$).

Communication Modes: Mae used multimodal communication in all sessions

- Significant variability in the providers' interpretations of Mae's use of non-symbolic and unaided AAC methods
- No attempts were made by an adult partner to use low- or high-tech AAC strategies.

Discussion & Implications

- Mae encountered a myriad of medical staff when hospitalized. Although interactions lasted only a few minutes, Mae used multimodal communication during each interaction. To effectively interact during medical encounters with Mae, hospital staff were required to use AAC strategies to support communication.
- Future research should consider the substantial number of communication partners, limited time, and the unique settings and activities within the hospital when designing AAC tools and trainings.
- A detailed analysis of the sequence and content of child-parent-provider interactions is warranted to better understand and support communicative effectiveness in the hospital.

Acknowledgements

The contents of this presentation were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number #90RE5017) to the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (RERC on AAC). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government

Additionally, the first author received funding from the U.S. Department of Education grant #H325D110008 during her doctoral training at Pennsylvania State University, and the fifth author received funding from the U.S. Department of Education grant #H325K080333 during her graduate training at Pennsylvania State University.