

Child-parent-provider interactions during medical encounters on an inpatient unit: A preliminary investigation

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INTRODUCTION

Background and rationale

Many young children with severe communication disabilities rely on alternative and augmentative communication (AAC) strategies (i.e., any method of communication other than oral speech) to communicate with hospital staff (e.g., physicians, nurses) during inpatient stays. Past research demonstrates that individuals with severe communication disabilities are at increased risks for experiencing preventable adverse events (e.g., medication errors) and often experience communication challenges with hospital staff which can, ultimately, contribute to poor health outcomes [1]. These are alarming findings as inpatient hospitals are mandated to provide services that meet the unique communication of all patients, including young children who experience severe communication disabilities [2]. For hospitals to achieve such a mandate, staff must be prepared to deliver family-centered services, equipped with the knowledge and tools to identify the patient's communication needs, and equipped to use techniques that best suit these unique needs regardless of age or disability [2].

To design and implement effective interventions for individuals with severe communication disabilities, hospitals must understand the complex contextual factors influencing patients and their families. Contextual factors that affect each individual include the dynamic interplay of personal relationships (e.g., child-provider), the interactions among multiple relationships (e.g., between a child's family and providers), social policies governing relational networks (e.g., staffing requirements), and socio-cultural beliefs [3].

However, there is a paucity of evidence available to describe the critical features of the complex relational network affecting children with severe communication disabilities, their families, and medical providers [4]. To date, only three qualitative studies have investigated the experiences of these key stakeholders within the hospital setting [5, 6, 7]. In such studies, limited time, limited staff AAC knowledge and experience, limited access to appropriate communication tools, and the propensity for children with severe communication disabilities to assume passive roles during communication exchanges were cited as barriers [5, 6, 7]. However, no empirical evidence is available to objectively describe the communication patterns among health care professionals, children with severe communication disabilities, and their families in hospitals. Systematic observation of communication during medical encounters (e.g., medication administration by nursing staff, physician rounding) can objectively document critical components of child-family-provider communication patterns which, in turn, can inform future intervention and AAC system design in the hospital setting.

Purpose statement

The purpose of this study was to describe child-parent-provider interaction patterns of a young child with a severe communication disability in an inpatient rehabilitation hospital during medical encounters.

METHODS

Design

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

Participants

Prior to initiation of recruitment procedures, approval was obtained from both university Institutional Review Board and hospital Institutional Review Board to ensure the protection of human subjects.

Child participant

Purposive sampling techniques were used to recruit children at an inpatient rehabilitation unit in Eastern Pennsylvania that (a) were between the ages of twelve months and eighteen years, (b) demonstrated a significant communication impairment such that speech was not functional to meet their daily needs, and (c) was reported by

parents to have no known hearing or vision impairments. The child's parent provided informed consent for participation.

A 28-month-old girl named May (pseudonym) participated in this study. May had a history of prematurity (born at 28 weeks gestation), developmental delays, and diagnosis of failure to thrive. The primary reason for her inpatient stay was to participate in an intensive inpatient feeding program to address feeding challenges. She participated in daily sessions with a speech-language pathologist and occupational therapist to address these challenges as she was unable to meet nutrition and hydration needs by mouth. At the initiation of study procedures, May communicated through use of signs, conventional gestures, speech approximations, facial expressions, and challenging behaviors (e.g., hitting to protest participation in a non-preferred activity such as placement of her nasogastric tube). She was able to follow one-step commands and could identify body parts consistently. May was ambulatory yet demonstrated mild delays in gross motor and fine motor skills for which she received physical therapy three to five times weekly on the unit.

Adult participants

The adult participants in this study consisted of May's parents and medical providers who worked on the inpatient rehabilitation unit. Medical providers were included in this study if they met the following criteria: (a) were older than 18 years of age, (b) provided direct clinical services to May on the inpatient rehabilitation unit during day shift hours (i.e., 7:00 am through 7:00 pm), and (c) completed informed consent procedures.

A total of twelve adults participated in this study. Specifically, (a) May's mother, (b) May's father, (c) five registered nurses, (d) four certified nursing assistants, and (e) one physician participated in the study. All adult participants were female with the exception of May's father, one registered nurse, and the physician.

Materials

A hand-held Sony Handycam® CX440 was used to record all medical encounters used in this study. This camera was selected due to its size for portability, fold-out screen to allow the researcher to simultaneously view the camera screen and event, and zoom feature to minimize researcher interference in the communication interactions [8].

Procedures

Following informed consent, naturalistic video-recordings were collected during 10 days of a five-week period. The first author collected all video-recordings within the same room as participants, used a hand-held camcorder to collect all recordings, and moved freely in the room to minimize intrusion of the interaction. The researcher and video camera were visible to all participants at all times. All video-recordings (a) occurred between the hours of 7:00 am and 7:00 pm, (b) occurred during medical encounters, and (c) involved a nurse, nursing assistant, and/or physician with goal to complete a medical procedure (e.g., medication administration) or discuss information about the child's health, plan of care, schedule, and/or safety. The researcher started recording upon the medical provider's entrance into the same room as the child participant. Recording was discontinued if (a) the participants entered a shared space with an unconsented individual (e.g., another child patient), (b) the provider left the room that the child was in, or (c) client privacy was required (e.g., during a diaper change).

Analysis

Each medical encounter was video-recorded and uploaded to StudioCode, a software program used to capture, view, manage, and store video files [9]. A research assistant viewed all video-recordings of medical encounters and coded the following variables: (a) total number of the child's unique communication partners, (b) total duration and percentage of interactions across medical provider roles (i.e., registered nurse, nursing assistant, physician, multiple providers), (d) total duration and percentage of interactions that parents were present (i.e., mother, father), (e) total number of activities completed in each encounter (e.g., taking vital signs, administering medications), and (f) the setting that the encounter was completed in (e.g., hospital room, dining room).

RESULTS

Video samples of 27 medical encounters were obtained over ten nonconsecutive days of a five-week period. May interacted with 12 unique communication partners (i.e., mother, father, and 10 medical providers) during the observation period for a total duration of 122.08 minutes. Specifically, May interacted with five different nurses for a total of 87.03 minutes (71.2%), four different nursing assistants for a total of 17.75 minutes (14.5%), and one physician for 2.87 minutes (2.4%). There were also medical encounters that occurred with multiple staff present which amounted to 14.43 minutes (11.8%). At least one parent was present for all 122.08 minutes of medical encounters with May's mother present for 87.02 minutes (71%) and May's father present for the remaining 35.05 minutes (29%).

Participants engaged in a variety of activities during medical encounters including administering medications and/or formula ($n = 12$), completing rounding tasks ($n = 6$), taking vitals ($n = 5$), measuring the child's weight ($n = 3$), and placing a nasogastric tube ($n = 2$).

The majority of medical encounters occurred in May's room ($n = 23$); however, whole or partial encounters also occurred in the hospital dining room ($n = 3$), hallway ($n = 1$), and procedure room ($n = 1$).

May used multiple modes of communication (i.e., signs, speech approximations, conventional gestures, challenging behaviors, vocalizations) to interact with adult communication partners during encounters with mixed success across communication partners. No attempts were made by any adult partner to trial low- or high-tech AAC strategies (e.g., picture communication boards, a communication app on a tablet) even though May was capable of using such modes.

DISCUSSION

Children with severe communication disabilities may encounter a myriad of medical personnel throughout an inpatient hospital stay. In 27 medical encounters, May interacted with 12 unique providers that consented for the study. However, given that four additional physicians declined to participate in the present study and that night staff were not included, these numbers are an underrepresentation of the amount of medical personnel with whom May interacted in the study period. It is also important to consider that many non-medical staff (e.g., therapists, dining staff) frequently interact with children with severe communication disabilities during a hospital stay which further elevates the number of unique communication partners. Although a medical provider may only interact with a child and family for a few minutes, each provider must possess the knowledge and skills to effectively support a child's unique communication needs [2].

It is also important to recognize the limitations of this study. Since this study included only one child participant, generalizability to other children and populations is limited. This study was also completed over five weeks with day shift staff which may not represent other important communication partners or communication activities. Furthermore, results of this study represent variables associated with policies governing relational networks in the hospital. Preliminary analyses suggest that medical staff demonstrated highly variable responses to May's communication attempts; a detailed analysis of communicative functions and modes is warranted to understand the nature and quality of communication among May, her parents, and medical staff during medical encounters.

CONCLUSIONS

Development of AAC systems and communication partner training should consider the broad context in which communication occurs [10]. This study is the first of its kind to objectively describe communication variables among a child with a severe communication disability, her family members, and medical providers in an inpatient setting. This information can be used by technology developers, clinicians, and researchers to inform future AAC design and practice to maximize the communicative competence of children with severe communication disabilities, their families, and medical providers. Specifically, these individuals may need to consider the substantial number of communication partners that the child may encounter during an inpatient stay, the potentially limited duration of time that the provider can spend interacting with the child and family within this setting, as well as the varying communication settings and activities that occur within the hospital setting.

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