WHY STUDY CHILD-PARENT-PROVIDER COMMUNICATION?

"Communication is the most common 'procedure' in medicine." (Levetown & the Committee on Bioethics, 2008, p. e1444)

WHAT ARE UNDERLYING FACTORS AFFECTING A CHILD WITH COMPLEX COMMUNICATION NEEDS?

(Levetown & the Committee on Bioethics, 2008, p. e1444)

CHILDREN WITH COMPLEX COMMUNICATION NEEDS IN THE HOSPITAL:

- Rely on AAC strategies to communicate
- Experience multiple challenges communicating with staff (Shilling et al., 2013)
- Children with complex communication needs have been reported to:
  - Play passive roles during interactions (Hemsley et al., 2013)
  - Express a desire to more actively participate in interactions (Hemsley et al., 2013)

PARENTS OF CHILDREN WITH DISABILITIES:

- Report higher perceived levels of stress and lower satisfaction with hospital services relative parents of children without disabilities (Phua et al., 2009)
- Parents of children with complex communication needs report:
  - Feelings of reluctance or stress when leaving their child in the hospital for fear of communication breakdowns (Hemsley et al., 2013)
  - Feelings of comfort when staff talk directly to child, use the child’s AAC system, assign professionals that are familiar with the child (Hemsley et al., 2013; Sharkey et al., 2016)

DISCLOSURES

- This research was supported in part through:
  - A grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant #90RE5017) to the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (The RERC on AAC).
  - Penn State AAC Doctoral Leadership grant from the U.S. Department of Education (grant #H155D120224).
HOSPITAL PROVIDERS WHO SERVE CHILDREN WITH DISABILITIES REPORT:

- Time constraints as a critical barrier to effective communication (e.g., Gormley & Light, 2018; Hemsley & Balandin, 2014)
- Limited training to effectively communicate with individuals with complex communication needs (e.g., Finke et al., 2008)
- Supporting the child’s communication in hospitals is not part of their roles on the interdisciplinary team (Sharkey et al., 2016)
- Prioritizing other aspects of care (e.g., feeding) above communication (Hemsley et al., 2014)

PURPOSE

To describe the child-parent-provider communication patterns of a young child with complex medical and communication needs in an inpatient rehabilitation unit during day shift hours

RESEARCH QUESTIONS

Mesosystem
- How many unique communication partners does the child interact with during day shift hours?
- Where, when, and during what activities do child-parent-provider interactions occur?
- What percentage of conversational turns is taken by each partner? Who are these turns directed to?

Microsystem
- What communicative purposes are directed to the child by adults?
- What communication modes are used by the child during interactions?

METHODS

RESEARCH DESIGN

- A descriptive, exploratory case study was selected for this investigation.
- Allows for rich, in-depth exploration of a topic using direct observation to provide a detailed description of a phenomenon (Gillham, 2000)
- Can be useful to build theory, generate research hypotheses, and inform future intervention targets (McEwen & Karlan, 1990)

PROCEDURES

- Purposeful sampling
- Informed consent and demographics obtained
- Data collected in rehab hospital
- Research assistants trained
- Transcription, coding, and reliability completed for interactions
ADULT PARTICIPANTS

Parents = 2
- Mae’s mother
- Mae’s father

Total Providers = 26
- 5 registered nurses
- 4 certified nursing assistants
- 3 physicians
- 4 physical therapists
- 4 occupational therapists
- 6 speech-language pathologists
- 2 recreational therapists

DATA SAMPLING AND ANALYSIS

Total Observation Period:
10 days (49 interactions, 745 minutes)

Weekend:
- 6 interactions, 108 minutes;
- Weekday: 8 interactions, 149 minutes

Conversational Turn, Microsystems:
20 minute maximum samples from the 2 days (14 interactions, weekend: 48 minutes; weekday: 71 minutes)

RESULTS

INTERACTION TYPES

VIDEO 1 – MEDICAL ENCOUNTER

VIDEO 2 – FEEDING
MINUTES OF INTERACTION TYPES ACROSS CONTEXTS

- Medical encounters: 115, 16%
- Therapy sessions: 248, 33%
- Feeding sessions: 380, 52%

MINUTES OF INTERACTION ACROSS PROFESSION

- OT: 14%
- SLP: 19%
- TR: 7%
- MD: 0%
- PT: 20%
- RN: 5%
- CNA: 3%
- Co-treat: 32%

ACTIVITIES OCCURRING DURING INTERACTIONS

<table>
<thead>
<tr>
<th>Activity</th>
<th>% of sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervising mobility</td>
<td>67%</td>
</tr>
<tr>
<td>Rounding/parent education</td>
<td>41%</td>
</tr>
<tr>
<td>Feeding sessions</td>
<td>31%</td>
</tr>
<tr>
<td>Medication or formula</td>
<td>25%</td>
</tr>
<tr>
<td>administration</td>
<td></td>
</tr>
<tr>
<td>Physical therapy sessions</td>
<td>16%</td>
</tr>
<tr>
<td>Taking vitals</td>
<td>12%</td>
</tr>
<tr>
<td>Speech-language sessions</td>
<td>6%</td>
</tr>
<tr>
<td>Inserting or removing a feeding tube</td>
<td>4%</td>
</tr>
<tr>
<td>Recreational therapy</td>
<td>4%</td>
</tr>
<tr>
<td>Occupational therapy (non-feeding)</td>
<td>3%</td>
</tr>
</tbody>
</table>

LOCATION OF INTERACTIONS

<table>
<thead>
<tr>
<th>Activity</th>
<th>% of sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mae's room</td>
<td>63%</td>
</tr>
<tr>
<td>Feeding room</td>
<td>18%</td>
</tr>
<tr>
<td>Gym</td>
<td>14%</td>
</tr>
<tr>
<td>Play room</td>
<td>12%</td>
</tr>
<tr>
<td>Cafeteria</td>
<td>8%</td>
</tr>
<tr>
<td>Hallway</td>
<td>6%</td>
</tr>
<tr>
<td>Outside the unit</td>
<td>6%</td>
</tr>
<tr>
<td>Procedure room</td>
<td>2%</td>
</tr>
</tbody>
</table>

PERCENTAGE OF TURNS TAKEN BY EACH PARTNER

- Mae: 34%
- Providers: 54%
- Mae's mother: 12%

DIRECTIONALITY OF TURNS TAKEN BY ADULTS

- Mae: 82%
- Parent: < 24%
- Provider: 46%
**ADULT COMMUNICATION CONTENT**

<table>
<thead>
<tr>
<th>Communication Purpose</th>
<th>% Total Parent Speech Acts</th>
<th>% Total Provider Speech Acts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statements*</td>
<td>60% (n=32)</td>
<td>45% (n=572)</td>
</tr>
<tr>
<td>Praise*</td>
<td>2% (n=1)</td>
<td>5% (n=58)</td>
</tr>
<tr>
<td>Questions*</td>
<td>11% (n=6)</td>
<td>30% (n=347)</td>
</tr>
<tr>
<td>Commands</td>
<td>25% (n=13)</td>
<td>15% (n=173)</td>
</tr>
<tr>
<td>Negative Talk</td>
<td>2% (n=1)</td>
<td>1% (n=7)</td>
</tr>
<tr>
<td>Multiple Categories</td>
<td>7% (n=3)</td>
<td>12% (n=168)</td>
</tr>
</tbody>
</table>

**MAE'S COMMUNICATION MODE USE**

<table>
<thead>
<tr>
<th>Communication Mode</th>
<th>% Total of Mae's Conversational Turns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral</td>
<td>59% (n=534)</td>
</tr>
<tr>
<td>Manual</td>
<td>38% (n=346)</td>
</tr>
<tr>
<td>Aided AAC</td>
<td>0% (n=0)</td>
</tr>
<tr>
<td>Challenging Behavior</td>
<td>3% (n=29)</td>
</tr>
</tbody>
</table>

27% of Mae’s turns contained multiple modes (n = 203)

**DISCUSSION**

**MESOSYSTEM**

- During 49 interactions with providers over 10 days, Mae interacted with 28 unique communication partners.
- Low representation of total number of providers who interacted with her.
- Variability was observed in Mae's routine (duration of each interaction, activity location, staff member) which could present challenges establishing consistency and support Mae’s anticipation of interaction goals and content.
- The focus of interactions was completion of a structured, goal-oriented activity dictated by a provider.

**MICROSYSTEM**

- Health care providers tended to dominate the interactions by taking the most turns.
- Mae was observed to actively participate in each interaction; however, there were instances where she (a) did not interact frequently and (b) adults did not direct many turns towards her.
- Mae’s mother was observed to act as an interpreter of Mae’s communication attempts.
- No aided AAC mode was used in any interaction despite materials being available and Mae possessing the skills to use this mode.

**MACROSYSTEM AND EXOSYSTEM**

- Approximately 20% of Mae’s life was spent in a hospital.
- Mae’s mother often described the challenges living within a hospital and her fear and hesitance of leaving Mae with staff due to communication and behavior challenges.
- Only 6% of sessions in the total observation period were dedicated to directly supporting Mae’s speech and language skills.
- Although attitudes and beliefs were not directly measured, it is suggested that use of aided AAC tools when interacting with Mae may not be highly valued.
CLINICAL IMPLICATIONS

- Consider efficient and effective methods to train a large number of communication partners, across a variety of settings and locations, for potentially short durations of time.
- Establish parent-provider partnerships to ensure active involvement of the child, the child and providers during each communication interaction.
- Train health care providers and parents to be responsive to child communication attempts with diverse linguistic input.
- Train health care providers to comprehend and model use of aided and unaided AAC strategies to support the child’s communication within the hospital.

FUTURE DIRECTIONS

- Development and evaluation of specialized trainings to support AAC use in hospitals.
- Use direct observational techniques to rate aspects of family-centeredness between parents of children with complex communication needs and inpatient providers.
- Investigations related to environmental factors and participant characteristics on the family-centeredness and communication effectiveness of reliant interactions with this group.

REFERENCES


FUTURE DIRECTIONS

THANK YOU!!!

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REFERENCES


