Tedious versus Taxing: Needs Assessment in a Pediatric Feeding Disorder Clinic

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ABSTRACT

Children with feeding disorders can be dependent on feeding tubes until they obtain access to treatment. Evidence-based behavioral therapy is very effective, but there are not enough professionals in this specialization to meet demand. This work aims to characterize how information systems could help with scaling available resources to more children. We conducted a qualitative needs assessment study consisting of in-depth semi-structured interviews and naturalistic observations at a Midwestern pediatric feeding disorder clinic. We found that behavior technicians play a central role in managing the flow of information, through several kinds of explicit and invisible work. Further, real-time data collection is more taxing but less tedious than offline data entry; the innocuous-seeming analog timer is a key perceptual cue for children; and both therapy and data collection vary by child and over time. Hence, we recommend that interactive systems designed to support the feeding clinic aim to eliminate offline data entry, retain key perceptual cues, and remain flexible to procedural changes. We intend to deepen our field engagement to design and deploy real-world systems that complement and extend access to clinical care.

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Definitions of common terms used in behavioral treatment of pediatric feeding disorders [3]

Oral Aversion: children with feeding disorders exhibit avoidance or fear of eating, drinking, or accepting sensation in or around the mouth.

Desensitization: pairing conditioned aversive stimulus with positive reinforcement or absence of aversive events. For example, using brushes to desensitize particular areas in the child's mouth before beginning the feeding session. This helps separate food-related anxiety from that of the presence of an object near the face.

Negative Reinforcement: removing aversive stimulus as reward for good behavior by, for example, teaching children that they get to end the meal based on cooperation and not resistance.

Escape Extinction: preventing escape behavior by, for example, holding the spoon close to child's mouth until they accept the bite instead of moving away in case the child refuses the bite.

BACKGROUND

Feeding disorders occur in up to 10% of children without medical or developmental issues, 70-90% of children born prematurely and/or with chronic medical issues, and up to 90% of children with autism. Children with feeding disorders have a traumatic relationship to food and exhibit oral aversion, food selectivity, trouble chewing or swallowing food which may cause gag reflexes and regurgitation due to underdeveloped oral-motor skills. Untreated feeding disorders are known to persist in 70-76% of cases and have negative long-term impacts on mental health and social development, and in extreme cases, a failure to thrive.

In over 80% of cases, feeding disorders are behavioral in origin. That is, children learn to associate eating with pain or danger due to a complex interaction of medical, developmental, and environmental factors [4, 6, 8, 9]. Behavioral intervention based on applied behavior analysis (ABA) is the only evidence-based therapy proven to effectively treat feeding disorders, but the demand far exceeds the capacities of the few existing trained professionals. Consequently, children currently wait over 20 months to be seen by treatment programs, and clinics have wait-lists of over 300 patients [8].

Figure 1: Feeding program professionals use a variety of spoons to develop the correct oral-motor skills in children.

Figure 2: Food is meticulously prepared into portions (called bolus sizes), to train children to swallow larger bite sizes.

The aim of this work is investigating to what extent information systems could help scale existing evidence-based practice, improving access to treatment while maintaining efficacy and quality of care. We conducted a qualitative needs assessment study across one clinic's staff, to understand the tightly-knit and paper-based nature of their work. The contribution of this paper is a detailed characterization of the work practices of behavior technicians including preliminary implications for system design.

Human-computer interaction research has long explored how clinical care is coordinated through workplace studies focusing on medical doctors, nurses, and the patient health record [1]. The limited literature on pediatric feeding employs gamification to improve self-feeding and mitigate poor eating in children (e.g., [2, 5]). We follow recent work extending the literature into behavioral contexts (e.g., [7]) by studying existing work practices of healthcare professionals in the intensive feeding program to understand how interactive systems can support staff in the provision of care.

METHODS

We conducted interviews (n=4) and in-situ observations (8.5 hours) with staff of a pediatric feeding disorder clinic housed in a large Midwestern teaching hospital. We focused on the healthcare professionals' everyday work practices with a particular emphasis on meal sessions. We conducted four in-depth semi-structured interviews lasting an average of 45 minutes each with: the psychologist & director in charge of the feeding program, one dietician, and two behavior technicians (techs). Interviews were audio-recorded and transcribed for analysis. In parallel, we performed naturalistic observation during two types of activities, over a total of nine sessions lasting an average of 60 minutes each. During seven meal sessions, we observed technicians carry out the feeding process for three children aged 1 to 12 years. Over two end-of-the-day sessions, we observed technicians carry out data management duties such as transferring meal session data to internal spreadsheets and patients' electronic health records. Two members of the research team were present at and wrote fieldnotes after each observation. We conducted data sessions involving the entire research team to triangulate findings at the per-professional and per-child level by comparing observations across data collection sessions.

CLINIC CONTEXT

The inpatient behavioral feeding program is staffed by seven full-time healthcare professionals: a behavioral psychologist, a dietician, a speech-language pathologist, and four behavior technicians. Upon intake into the intensive program, children and caregivers meet with the psychologist and dietician to formulate goals and a treatment protocol in consultation with the speech-language pathologist. The eight-week long intensive program requires children and caregivers to attend treatment five days per week, where the child is individually fed 3-4 meals per day by a behavior technician (tech) to model

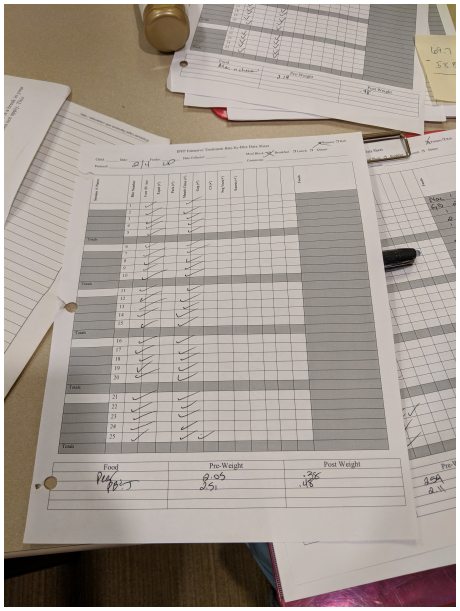

Figure 3: Paper-based data sheets are used to track per-bite behavioral data for each meal session. For each bite, the sheet tracks positive behavior (5-second acceptance and mouth clean) and problem behavior (expel, packing, gag, , negative vocalization, emesis), and provides additional columns for child-specific behaviors and notes. The sheet also summarizes the weight of food before and after the meal to track the amount of food consumed during the session.

and develop the correct oral-motor skills for eating. Feeding sessions are conducted in one of four treatment rooms, each containing one chair (or high-chair, if age-appropriate) for the child, one chair for the tech, and additional chairs for caregivers. Each room has a desk with a weighing scale, two kinds of timers (one digital break timer and one analog clock-faced meal timer), and a walkie-talkie. During feeding sessions, the desk also holds the meal tray, paper (hard copy) data collection sheets, pens, and toys. A two-way mirror next to the desk allows the psychologist and speech-language pathologist to observe feeding sessions from an adjacent observation room.

FINDINGS

In the feeding clinic ecosystem, behavior technicians (techs) are key to both day-to-day provision of care to individual children and to the overall functioning of the feeding program. We present a close description of their work practices followed by implications for interactive system design.

Behavior Technicians' Work Practices

Behavior techs perform a combination of explicit and invisible work that can be grouped as: preparation, outside-meal caregiver & staff interaction, feeding, and data upkeep.

Preparation. Techs perform several kinds of preparation work: at the beginning of each day, techs sterilize meal utensils and trays to ensure their ready availability during meals. Before each meal, techs look up the child's treatment protocol to determine the feeding techniques to be used. Further, techs prepare a meal tray according to the treatment protocol three times a day or before each meal, which includes defrosting, heating, and dividing the food into precise portions (see Figure 2 for examples). Next, techs print empty data sheets to record data during feeding. After each meal, techs sanitize the treatment room and refrigerate or freeze leftover food in accordance with food safety guidelines for the next meal.

Outside-meal caregiver & staff interaction. Techs greet the child and caregiver in the clinic lobby and escort them to the treatment room. They also escort them out to the lobby after the meal, answering caregiver questions about the next meal or the overall treatment. After each meal, techs also provide the psychologist with a short verbal update about the meal and the child's behavior during the meal. Changes to the treatment protocol are often made during this exchange, which the tech is then responsible for remembering and recording.

Feeding. At the beginning of every feeding session, the tech installs the child in the chair, sets the analog clock-faced meal timer to 45 minutes, and places it on the desk where the child can easily see. The tech then typically spends 10 minutes desensitizing specific areas inside the child's mouth using a specialized 'Nuk' brush, with regular rest periods that are timed using a preset electronic break

timer. Desensitizing areas and time intervals vary by child. After desensitization, the tech feeds the child pre-sized food bite-by-bite using a protocol-specified spoon and carefully observes for feeding behaviors. After each bite, the tech provides feedback by saying, e.g., *"that was a super good bite!"* or *"keep your tongue still, please,"* or cheering and clapping, and resets the break timer to 30 seconds (unless otherwise specified) to reward the child with a break from eating. During this break, the tech records behavioral data by ticking several boxes on a paper data collection sheet (see Figure 3): did the child swallow this bite within five seconds resulting in a clean mouth (a successful bite); or alternatively, did the child exhibit one or more problem behaviors (expelling or retaining food in the mouth, gagging, negative vocalization, vomiting, or other child-specific oral-motor or behavioral problems). With every beep of the break timer, the tech moves on to the next bite. If the child eats well for 80% or more of five consecutive bites, the tech is required to increase the bite size ('bolus fading' – see Figure 2), i.e., the quantity of food eaten per bite. If the child is eating more than one kind of the food, the tech must also alternate between foods every few bites. Finally, the tech also monitors for tracheal-tube problems and newly-acquired problem oral-motor behaviors.

The tech's cyclic *present food–check mouth–provide feedback–set break timer–monitor behavior–record data–prepare next bite* routine carries on until the analog meal timer goes off or the child shows signs of fatigue, because *"when [children are] fatigued, they're just practising the wrong oral-motor skills and we don't want them to do that.'* If the child is fatigued, therefore, the tech manually turns the hands of the clock to indicate the end of the meal session. The resultant beep acts as additional feedback for the child, indicating the end of meal time. *Importantly, throughout the meal and in parallel with these other tasks, the tech is responsible for keeping the child entertained* through playing with toys, chatting about the child's interests, playing competitive games on handheld electronic devices, or in rare cases, playing a YouTube video.

Data upkeep. Ideally after each meal or during the last working hour of the day, techs manually type in the data recorded for each meal into a Microsoft Excel spreadsheet maintained per child in the clinic's desktop computer. The spreadsheet consists of three tabs or pages, that track three different kinds of data. The first tab tracks behavior data, which records the tick marks from each column of the paper data collection sheets averaged per five bite 'trial'. Handwritten notes are also entered into this tab. The second tab records pre- and post-meal food weight in ounces, and the third tab contains an automatically-calculated daily summary (based on data entered in the previous two tabs). The goal is to generate graphs of the child's trajectory through the treatment program, but currently remains unfulfilled because *"it takes forever and a day"* to generate graphs. Finally, techs type up daily notes in the electronic health record system, including contextual descriptions of the day's therapy and the results from the daily summary.

Preliminary Design Implications

We present early implications for designing systems to support techs in feeding sessions.

Real-time data collection is more taxing but less tedious than data entry. Techs are required to perform multiple tasks in a specific sequence: *present food–check mouth–provide feedback–set break timer–monitor behavior–record data–prepare next bite*, in addition to entertaining the child. Despite being demanding, techs enjoy real-time data collection and find the retroactive task of manually entering data into the spreadsheet (roughly 20 minutes per meal) and generating graphs much more tedious.

The innocuous-seeming analog timer is a key perceptual cue for children. The analog clock-faced timer plays a critical role in feeding: techs use it to remind children of the amount of meal time left. Even if the session ends early, techs manually set the visual timer to 0 to make it ring. The ring serves as an auditory reminder for patients of all age to recognize the end of each session.

Therapy and data collection vary by child and over time. Although treatment protocols share an overall structure, treatment specifics vary significantly based on the child's dietary requirements, co-morbid health conditions, progress in the intensive feeding program, and child-specific problem behavior; making it difficult to standardize data collection into a single rubric. Additionally, data collection itself can vary according to the child: for instance, we observed an experienced tech use post-it notes to record data instead of the regular data sheets to avoid disturbing a particularly sensitive child.

CONCLUSION

We conducted a qualitative needs assessment study at a Midwestern pediatric feeding disorder clinic to investigate the role interactive systems could play in scaling treatment for improved access. One of our most interesting findings was that for behavior technicians, real-time data collection is more taxing but less tedious than retroactive data entry. Design efforts should balance the tension between addressing the taxing (data collection during meals) versus the tedious (manually entering data into spreadsheets). Although addressing the taxing improves within-routine efficiency, addressing the tedious improves overall morale. In our specific case, the two happily coincide: streamlining in-meal data collection could address both the taxing and tedious by removing the need for manual data entry at the expense of minor adjustments to in-meal routines. Second, designers tend to overlook the importance of innocuous and low-tech artifacts such as the analog clock-faced timer, when in fact by signaling the end of much-dreaded mealtime, it serves as a key perceptual cue for children. We recommend that designers remain attentive to the routine and unremarkable aspects of specific contexts [10]. Finally, we saw how treatment trajectories vary regularly and dramatically across children, so we suggest making systems adaptable to procedural changes. Through continued fieldwork, we will further explore these considerations through the design and deployment of novel systems.

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