Assessment and Treatment of a Pediatric Patient in Chronic Care: Ethnographic Methods Applied to Occupational Therapy Practice

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Ethnographic methods were used to examine how an experienced occupational therapist assesses and treats a pediatric patient within a relatively long-term clinical relationship. Treatment goals for this preverbal child with Hirschsprung disease, who began occupational therapy at 22 months of age, included (a) introduction of oral feeding to reduce dependence on total parenteral nutrition through intravenous feeding and (b) facilitation of exploratory play, which had been developmentally delayed during extensive periods of immobilization during medical care. This article shows how the meaning of therapeutic activities changes for the patient over time, as the occupational therapist builds trust through affect attunement, validates his or her empathic interpretations, and develops common understandings with the patient's family and others within the social and cultural contexts of chronic care.

Clinical practice in occupational therapy with patients with chronic illnesses makes use of activities, often in the context of relatively long-term relationships, to assess incapacity and develop skills needed for functional independence in age-appropriate roles. Initially, the meaning of therapeutic activities may differ for the occupational therapist and the patient because professional and popular understandings of illnesses and their remedies differ (Eisenberg, 1977; Mishler, 1984; Toombs, 1987). Because the philosophical foundations of occupational therapy involve engagement of the patient in activities that are purposeful and meaningful (Engelhardt, 1983; Meyer, 1922) and not just the elicitation of compliance, the establishment of common meanings and ways to negotiate differences is desirable. In this paper, we consider how an occupational therapist in the course of treatment comes to understand the needs, concerns, and responses of a pediatric patient and his family. We also examine the effects of such understandings on the course of treatment. To this end, we have applied ethnographic methods in an exploratory manner to help specify the distinctiveness and uniqueness of practice in occupational therapy as a health profession (e.g., Mosey, 1981; Rogers, 1983; Yerxa, 1967).

Ethnography, the discovery procedure of anthropology, is the systematic description of a people and their way of life, including all manner of customary actions and their meanings (Beattie, 1964; Edgerton & Langness, 1974 [see also McCuaig & Frank, 1991]). In contemporary medical anthropology, ethnographic methods are used to understand how illness is defined and treated in various sectors of our own complex postindustrial society. The social transformation of American medicine in the present century has resulted in a form of hospital-based practice that emphasizes specialization and technical expertise (Rosenberg, 1987; Starr, 1982). A well-documented crisis in health care has developed concerning such factors as the cost of high technology, overuse of costly

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tests to avoid malpractice liability, restrictions on medical practice by third-party payers, and unaffordability of insurance premiums for large segments of the population (Califano, 1989; Miller et al., 1989). This inflationary crisis exaggerates the trend, established in the 19th century, in which the patient's reported symptoms and experience of illness are considered by physicians to be less important for treatment than laboratory tests and clinical signs (Gordon, 1987; Konner, 1987; Reiser, 1978). Critics within the health professions argue that care means more than technical proficiency plus bedside manner (Benner & Wrubel, 1989). Rather, it involves attentiveness to the uniqueness of the patient and his or her possibilities for meaningful change (cf. Deveraux, 1984; Gilfoyle, 1980; Peloquin, 1989; Yerxa, 1980). More fully attuned relationships with patients occur despite the system, not because of it, and address human suffering in ways that technological intervention alone cannot (e.g., Sacks, 1985). Kleinman (1988), a medical anthropologist and psychiatrist, recommended that clinicians prepare a mini-ethnography of the patient's illness experiences so that the meanings of illness for the patient and family, in their particular sociocultural contexts, can contribute to informed interventions.

Patients with chronic illnesses treated by occupational therapists pose a fascinating ethnographic challenge: How does one understand the experience of a person whose incapacity involves developmental, physical, or psychiatric disabilities that may make conventional communication difficult, even impossible? (Estroff, 1981; Langness & Levine, 1986; Zola, 1982). Yet this challenge already exists for occupational therapists because of their ethical responsibility for providing meaningful therapeutic activities. In the present paper, an occupational therapist experienced in pediatric practice (the second author) describes the process by which she established and successively revised her understanding of a patient with physical and developmental disabilities related to the condition of Hirschsprung disease, whom the occupational therapist began treating with activities to introduce the oral intake of food at 22 months of age. Although clinically the child displayed some developmental motor delays, he showed no cognitive or emotional abnormalities, yet was still largely preverbal. The occupational therapist began to understand his illness experience by translating the meaning of therapeutic activities to the patient's mother and, with the mother's help, establishing a common language with the patient through the activities she used.

Understanding the Preverbal Patient in Occupational Therapy Pediatric Practice

In all professions, skilled performance involves not only the procedures described in textbooks, but also a rich body of practices that are routinely used but taken for granted (Benner, 1984; Dreyfus, 1972; Schön, 1983; Sudnow, 1978). Such practices are learned in training and on the job but are often unarticulated; they may be thought idiosyncratic to particular practitioners or settings and considered illegitimate even if common and essential to carrying out professional activities. How things are actually done in practice, until identified and analyzed, remains a tacit or intuitive dimension of skilled performance (Polanyi, 1958).

An often-used textbook on case method in occupational therapy (Lucci, 1980), for example, shows no evidence of such practices, despite a detailed narrative approach that does consider the patient's family and social contexts. It describes therapeutic changes in occupational therapy more as a series of outcomes than as a process. Distinctive relationships with particular occupational therapists are kept in the background rather than examined for the part they might play in the way activities are provided and assessed. In actual practice, however, changes in a patient are understood because of contrasts between the patient's past and current situations (Benner, 1984). Thus, important areas of practice include the making of graded qualitative distinctions and the establishment of shared expectations with other practitioners and family members about how to act in certain situations.

Occupational therapists, including those in pediatric practice, attempt to elicit their patients' highest level of adaptive response (King, 1978) in appropriate activities. Play is recognized in occupational therapy as the fundamental occupation of the child, through which skills needed for adult competency are developed and shaped (Reilly, 1974). In the treatment of sensory integrative dysfunction, for example, the therapist's skill in adapting and innovating play activities, as the immediate situation requires, depends on "watching the child as he performs, seeing his mood, his emotional state, and his motor action" (Ayres, 1972, pp. 258–259). With very young children or when verbal expression of complex feelings and thoughts has been developmentally delayed, the analysis of play activities is essential to practice.

Occupational therapists' skilled use of play activities with preverbal patients develops mutuality and trust. A process of attunement occurs in which the occupational therapist and child establish a shared language of actions focused on the quality of the child's experience. The phenomenon of affect attunement (Stern, 1985) has been observed in research on mothers' interactions with their infants and has been recorded in the mother–child dyad as early as 9 months of age. This phenomenon is characterized by a matching of the child's overt behavior with the mother's response, not strictly imitatively, but cross-modally. In the following example, recorded on videotape, a child vocalizes a sense of joy at getting a toy, while the mother responds in another mode by moving her body, but in a way that matches the child's response in
intensity and duration, thereby producing shared joy and excitement:

A nine-month-old girl becomes very excited about a toy and reaches for it. As she grabs it, she lets out an exuberant “aaahh!” and looks at her mother. Her mother looks back, scrunches up her shoulders, and performs a terrific shimmy with her upper body, like a go-go dancer. The shimmy lasts only about as long as her daughter’s “aaahh!” but is equally excited, joyful, and intense. (Stern, 1985, p. 148)

The mothers who were interviewed while being shown videotapes of these interactions with their infants indicated that they were usually unconscious of their behaviors; they retrospectively attributed their actions to a desire “to be with their infant” or “to share,” “to participate in,” or “to join in” the infant’s experience (Stern, 1985, p. 148). Stern stressed that the importance of these interactions is not in the mother’s behavior, but rather, in the mother’s communicating that she recognizes and shares precisely the quality of the child’s experience of pleasure. Skilled occupational therapists in pediatric practice similarly attune to their preverbal patients, thereby providing a relationship of trust and sharing through which the child’s quality of experience in therapeutic activities can be felt and assessed.

In addition to the process of affect attunement, a more cognitive perspective takes place of interpreting the child’s experience empathically (Frank, 1984; see also, Eisenberg & Strayer, 1987; Goldstein & Michaels, 1985; Kohut, 1977; Rogers, 1980). Because the child is unable to describe his or her experience, the occupational therapist makes sense of the child’s expressions of pleasure or displeasure in terms of the immediate circumstances as he or she understands them. The better the occupational therapist’s understanding of the patient’s life history and family situation (i.e., the better the mini-ethnography), the more likely these interpretations of the child’s viewpoint will be valid. The process of making such interpretations and revising them as the situation changes is assisted by the presence of the family and of other professional team members who may share or challenge them. The skilled occupational therapist treats the patient guided by these interpretations, seeking in the patient’s behavior a confirming response, such as a positive shift in the patient’s engagement in the therapeutic activities at hand.

Using Ethnographic Methods to Describe the Course of Treatment in an Occupational Therapy Clinical Setting

The theoretical objectives for the collection of ethnographic data vary within the founding discipline of anthropology. We emphasize here the definition of ethnography as an interpretive method in search of meaning rather than laws (Geertz, 1973; Rabinow & Sullivan, 1979). In classical ethnographic research, the anthropologist lives with and observes the people studied for an extended period of time, a year or more, in a village or other well-bounded unit of social organization. Participant observation, the principal method for data collection in ethnography, is conducted as naturalistically as possible. Events are followed as they occur, discussed with informants, and recorded in field notes. Field notes, like an occupational therapist’s chart notes, present the distilled pieces of information that we call facts (e.g., lists of kinship terms, steps in performing a curing ritual). Unlike chart notes, however, field notes also consist of richly detailed narratives that document events as they unfold, along with various informants’ perspectives on them. The ethnographer’s personal impressions, puzzles, and emotional reactions may also be carefully noted. Such reactions can be an important resource when the data are analyzed, because an ethnographer’s understanding of events changes with greater experience in a field situation. He or she draws on relevant local contexts to make formerly strange events meaningful.

Although classic ethnographic methods were established in the study of relatively simple, preindustrial societies (i.e., “primitive cultures”), they are now commonly applied to groups and issues within complex societies. Anthropologists study subcultures, families, self-help groups, and other kinds of social institutions in which persons experience disabilities, problems adapting to aging, and other conditions of professional interest to occupational therapists (e.g., Ablon, 1984, 1988; Becker, 1980; Myerhoff, 1978). Ethnography is also conducted in the study of health care provision in clinical and community settings (e.g., Chrisman & Maretzki, 1982; Gaines & Hahn, 1982; Plough, 1986). It is no longer expected that the ethnographer come from a different society or culture than the one being studied (Messerschmidt, 1981). In fact, the native ethnographer may have an advantage. As a member of the social setting being studied, he or she may begin with a more naturalistic research situation, greater rapport with informants, and better access to certain data than an ethnographer coming from outside. The critical thing in such a situation is that the ethnographer maintain the role of participant-observer (Junker, 1960; Lofland & Lofland, 1984; Schatzman & Strauss, 1973). This involves continually stepping back while engaging in usual activities to examine their pattern and participants’ underlying assumptions. Finally, contemporary ethnography may deviate from the classic model by including materials that once were kept carefully out of frame. Experimental field techniques and writing devices have been introduced increasingly in recent years, such as the inclusion in the text of dialogues between ethnographers and informants in which they negotiate differing perspectives on the same events. The purpose of such innovative writing is to document how meaning emerges through human experiences and is not simply a matter of reporting outcomes or facts (Clifford & Marcus, 1986).

Ethnography concerns cultural meanings and an attempt to understand events “from the native’s point of
view." The extended case method, for example, has been used to interpret personal distress (e.g., illness, dysfunctional role performance) as an expression of social disorder, examining the person’s precise relationships and interactions within family contexts and social networks (Turner, 1974). Extensive interviews with key informants are heavily relied on. These may culminate in the recording of life histories (Kluckhohn, 1945; Langness, 1965). The life history method reconstructs a person’s life experiences developmentally, presenting events in terms of the person’s situation in the social order. Recent life history studies, reflecting the interpretive approach to ethnography, emphasize the idea that meaning is not fixed but negotiated to some degree between the informant and life historian (Angrosino, 1989; Langness & Frank, 1981; Watson & Watson-Franke, 1985).

In the present paper, an occupational therapist (the second author) acted as an ethnographer and key informant to answer the research question, “How does my understanding of patients with chronic conditions emerge within the relatively long-term relationships of occupational therapy clinical practice?” Her narrative is structured and analyzed through turnings in the course of treatment. In life history studies, the term turning refers to an event or series of events in which a person takes on a new role that changes his or her identity and provides the basis for meaningful action for a stable period until the next turning (Frank, 1984; Mandelbaum, 1973). In applying this concept to occupational therapy treatments, events qualified as turnings according to two criteria. First, there was an experience of personal engagement by the occupational therapist that prompted a revised or deepened understanding of her patient; second, a shift in the treatment pattern followed for an extended period. We selected this case purposely, not randomly, to study an occupational therapist who indeed had experienced feelings that were powerful enough to provoke particularly meaningful shifts in treatment. The following case study was written by Esther Huecker (the second author) and discussed through numerous drafts in a graduate seminar in the Department of Occupational Therapy at the University of Southern California, Los Angeles, in the spring of 1989, which we all attended. This seminar, which addressed social and cultural aspects of adaptation to disabilities, was led by the first author.

The narrative account combines both retrospective and contemporaneous reporting, with the advantage that the occupational therapist was able to document ongoing experiences in treatment in the light of her developing understandings.

Case Study: A Kiss of Approval
Establishing a Relationship
When I met Timmy Bauer (a pseudonym) for the first time in September 1987, I was reminded of my own son as an infant. They both had a chubby build, straight blond hair, and blue eyes. But the similarity was more than just physical. Like my son, Timmy had an enticing, engaging smile that commanded attention. This smile yielded pudgy cheeks and flirtatious eyes, whose expression could quickly turn to dubious caution if one came too close, signaling an invasion of personal space.

At 22 months of age, Timmy had had ample experience dealing with strangers. Since birth, he had been hospitalized eight times, usually for extended periods, and had had extensive surgeries. At 2 weeks of age, he had been diagnosed with Hirschsprung disease. This is a disease that affects the parasympathetic innervation of the bowel, and in Timmy’s case it was considered severe, involving his entire colon and all but 8 inches of his small bowel. He was also diagnosed as having a factor C deficiency, a condition associated with excessive blood clotting. He therefore receives an anticoagulant daily, increasing his risk of hemorrhage if he should fall. Timmy receives total parenteral nutrition (TPN), which involves intravenous feedings for 12 hours each night through a catheter placed in his inferior vena cava. Due to the long-term use of TPN, he has developed osteopenia and fractured his leg 2 months earlier.

Now that Timmy was home and considered medically stable, the gastroenterologist planned to begin some feeding through a jejunostomy in the abdomen and oral feedings to see if the TPN could be reduced. The plan had been complicated, however, by Timmy’s frequent vomiting and gagging and by his refusal to take anything by mouth except water. He was referred for occupational therapy at an outpatient rehabilitation facility at which I was employed, to increase his oral intake of food and fluids. As Timmy and I began to play on that first day, it became obvious that like many children who are hospitalized for extended periods of time, Timmy’s developmental skills were below his chronological age. He crept on the floor like a 10-month-old. He held a few toys in his hands, but very cautiously, without exploring the possibilities they offered for play. His eyes were alert and absorbed everything happening in the room, but his hands investigated little in his surroundings. He appeared to understand appropriately for his age, but he spoke only a few words. Facial expressions and body postures communicated his wishes and needs. Shrugging his shoulders and raising his eyebrows, he indicated, “I don’t know,” to my question, “What would you like to play?” He held a cup and drank the water with no difficulty but refused to put anything else in his mouth. In fact, his parents could not remember a time when he placed toys in his mouth. He gradually allowed me to hold him and play a game using the firm pressure of my finger to touch him as I sang. If he smiled, I continued to move up his arm toward his face. If he wrinkled his forehead into a frown, I stopped and went to a new spot. We had begun our first step toward understanding each other.
Tom and Barbara Bauer were articulate about their son’s history and were aware that hospitalization had affected his development. As strong advocates for Timmy, they had requested that the hospital teach them how to administer the TPN and medication, so that Timmy could be at home rather than in the hospital. Timmy, through his parents’ creative efforts, was included in every family activity, even mealtime. The Bauers appeared to accept my assessment that, although Timmy had potential to learn to eat orally, it would be a slow process and probably not totally functional as his only means of nutrition, especially because there was some question as to how much could be absorbed in his short bowel. Another major concern I shared was the difficulty encountered in encouraging eating in a child who has never felt hunger.

On the positive side, however, I explained that feeding can be used to facilitate the movements required for speech. Tom and Barbara believed that reducing the TPN even a small amount, in addition to possibly benefiting Timmy’s speech, was worth the commitment of time that would be needed.

After this initial evaluation, I did not see Timmy again for over 5 months. He was readmitted to the hospital for several surgeries, including placement of a gastrostomy tube. After returning home, he was authorized by his insurance provider to begin treatment in March 1988, but for no more than 60 calendar days from the date he had started. Originally, I had planned to incorporate various play experiences into the program rather than just focus on oral skills, but the plans were changed. Since our first meeting, Timmy had become even more reticent with strangers and less willing to allow physical contact. It would take time to build a strong trusting relationship with Timmy so that he would feel comfortable with my facilitating oral motor control. Therefore, I decided, with his parents’ agreement, to combine my expertise in oral motor treatment with Barbara’s strong relationship with her son to encourage Timmy to enrich his oral sensory experiences. I would limit my physical contact with Timmy and concentrate on verbally guiding his mother. This was a change from my usual method of establishing a relationship with the child so that I could explore various intervention techniques and then develop a model that appeared successful.

For 1 hour a day, 5 days a week, Timmy and his mother would come to the clinic. I remember therapy during this time as being very inconsistent, with many ups and downs. On one day, Timmy would be very playful and would attempt most activities. On another day, he would cry and refuse to move from his mother’s lap, hiding his face in her clothes. Arlene, another occupational therapist on the staff, began to observe our treatment sessions in anticipation of her eventual involvement in Timmy’s treatment. (I had planned to begin working on a part-time basis in order to begin graduate school.) Arlene and I exchanged impressions of what happened each day and found ourselves labeling the day in Barbara’s terms of a “good day” or a “bad day.” A “good day” might go as follows:

As I blew soap bubbles, Timmy would pop them with his finger. He liked to watch the bubbles pop but did not like the soap on his finger. He would reach his hand out to his mother, who would wipe it dry. We would look for “dirty places” on his feet, legs, and arms for Mom to wipe with a cloth, gradually working up to his face and lips. He would turn his head when he wanted to stop. Next we might take turns putting a drop of water on our tongues with a straw or tasting red wine licorice dipped in water, with Timmy pointing to whose turn was next. If water dripped on his hand, he would want to stop. Generally, we were relaxed and enjoyed the time. As he left, Timmy would smile and wave goodbye and Barbara would comment, “He had a good day today.”

The next day, I might plan some additional activities to build on the accomplishments of the day before. If I ignored or was unable to read Timmy’s more subtle cues telling me that he did not return to the clinic in necessarily the same state that he left the day before, and if I continued to push Barbara to try new challenges, we would have a “bad day”:

As Timmy popped bubbles, his mother was to encourage him to hold the cloth and wipe his hands. He refused with a strong “Uh uh,” tucking his hands under the table. As his mother wiped the “dirty spots,” I suggested she let go of the Terry cloth so that Timmy could remove it from his hand. He shook his hand away from the cloth and wanted to be held. We set a glass of apple juice, which we coaxed him to taste after smelling. He liked the first taste but refused a second. I suggested he take “one more taste” before going home. When the drop of juice was placed on his tongue with a straw he began to gag and cry. Timmy would leave with his head on his mother’s shoulder, refusing to look at me, and Barbara would reply, “He’s just having a bad day.”

After a day like this, I would slow down the pace and Timmy would become more cooperative. Barbara later told me, “It seemed that I always knew before you when he was not going to like something by how he looked.” At first, I did not know that look, because I did not know his more subtle nonverbal cues. They were so obvious and second nature to his mother that she did not think she needed to explain them to me. She thought I understood. Even when she knew I was not understanding Timmy’s signals, it was difficult for her to explain them to me. Moreover, she assumed that my pushing Timmy beyond his expressed limits must have been an intentional part of the treatment.

During the second week of therapy, Timmy began to complain of a pain in his side. I began to analyze his inconsistent behavior as well as my own. I talked to my supervisor concerning my commitment to trying to accomplish certain goals with Timmy as well as the pressure I felt (and was obviously passing on to Timmy and his mother) to do so before his insurance coverage was to be terminated. My initial 2 weeks with Timmy confirmed that the goals I had set for him were realistic for a 1-year but not a 2-month period. Although my supervisor was seeking alternative funding sources, none were confirmed, and I needed to know that I could have the additional time. My remaining option was to drastically reduce...
Timmy's goals to a level that would not give him the independence that he needed. My supervisor was supportive about my dilemma and stated that I could plan to keep Timmy in therapy for as long as needed to accomplish his feeding goals, regardless of funding decisions.

Barbara and I then met the next day to talk about what was happening with Timmy. We both noted that Timmy did his best when the focus was not directly on oral motor skills but embedded in play or other activities in which he could make choices; he became more motivated, for example, when he could choose which toy to play with, the order of the activities, or whose turn (i.e., his, his mother's, or mine) should be next. Barbara agreed that Timmy and I needed to establish our own relationship so that trust and understanding could develop between us. I needed to learn his subtle cues in order to more accurately understand his responses and better anticipate the next step. In our session that day, for example, Timmy appeared to be feeling pain in his abdomen. Were his pains a response to a medical problem or a behavior created in therapy? Barbara contacted his physician that morning. The next day, Timmy was readmitted to the hospital for emergency surgery due to a bowel blockage.

Because our relationship would continue after his release and I wanted to continue to cultivate our fragile relationship, on my day off I would place toys in a backpack that I had made for my son and visit Timmy about once a week during his 5-week stay in the hospital. He appeared to be content in the hospital, even if his parents were gone for a period of time, and seemed completely accepting of the invasive procedures critical to his survival. The same child who could not tolerate drops of water on his hand never complained, holding out his arm to get a blood test. Seeing him in the hospital made me face the reality of the restrictions that had been placed on his life. Why was I unaware of this before? I had not pictured the medical support that was necessary to keep him alive. It was no wonder he explored so little with his hands when they were covered, allowing only a little finger movement, so that the intravenous tubes would not be pulled loose.

Five weeks later, when Timmy returned home, I decided to shift the emphasis of his therapy program to allow him to experience a variety of sensory play, to reduce the tactile defensiveness, and to encourage him to make choices. He continued to teach me to know when he liked something and when he did not. Identifying a variety of emotions through his facial and body gestures, I would help him to put a name to what he was experiencing so that I could anticipate and help him to choose his next response. As he sat on a suspended swing, I gave him a gentle push and he smiled. "I think you enjoyed that—should I do it again?" "Yeah," he responded with a laugh. After a faster push, his eyes opened wide and his forehead began to wrinkle. I asked, "Do you want me to go slow or stop?" "Top," he replied. Although activities were carefully selected so as to entice Timmy into new play experiences, he was beginning to explore the room, to spontaneously scoop up dry beans with his hands and roll them around between his fingers, to rub shaving cream on the mirror, or to ask for a whistle to take home.

Snack time was incorporated toward the end of each therapy session. First, Timmy would get ready by brushing his teeth, selecting from a variety of musical, electrical, or colorful brushes in his box. He would then help to make his snack by opening containers, smelling and sometimes tasting the ingredients he selected to put into the blender. Initially, he spent 20 minutes making his shake and choosing the eight color of straw, only to take one or two sips. He gradually began to want to have his snack after just a short time of play. Within a month, he wanted to begin the treatment session with snack time, choosing to eat before playing. He seldom gagged and I now easily recognized when he felt uncomfortable with a particular food. He seemed to understand that I could help him to control what was in his mouth. This was our first major turning in the course of our treatment.

Everything did not always go smoothly during this period. At one point, Timmy expected a reward for each bite he took and a circus atmosphere developed until emphasis was shifted back to more internal motivators. The other occupational therapist, Arlene, had become involved in Timmy's treatment 1 day a week, which allowed for more problem solving between staff and a chance to encourage Timmy to generalize his skills. For a while, however, Timmy began to want only to drink with Arlene and only to eat crackers with me. Although Timmy's mother was involved in the feeding program at the clinic and followed through with opportunities in the home, carryover had been at a slower rate. Generally, however, these 10 months were a time of progress. Timmy, now 3 years old, could speak in sentences. He was becoming to taste small amounts of mixed as well as pureed food and to drink up to 4 oz at a time of lactose-reduced milk with a caloric additive. His TPN had been reduced to 10 hours a night. He had begun to look like other 3-year-olds as he played and explored his environment.

On February 21, 1989, after Timmy had been out of the hospital for 10 months, Barbara called to say that he was being readmitted. His doctors were going to try to dissolve a blood clot at the end of the catheter in his inferior vena cava. This had been the longest period of time that Timmy had spent out of the hospital in his life. We knew how fortunate we had been to gain so much momentum in his occupational therapy without interruption during that time.

My Reactions to Timmy's Hospitalization

I put toys into the backpack and went to visit Timmy the next day, but he had just fallen asleep. As his mother and I
talked, she told me that Timmy did not want to stay at the hospital and would not let her out of his sight. A few days later, I arrived at his room just as he was returning from having X rays taken. The blood clot showed no sign of dissolving, and surgery appeared imminent. The nurse began to connect new medication through Timmy’s intravenous tube and to take a blood test. Timmy began to cry, and Barbara held him so that the procedures could be done. I had not heard Timmy cry for several months, and I felt anxious that he was so unhappy. I handed him a toy I had brought. After a few minutes, he took his Ernie doll and began pushing the toy to the floor. Was he angry? I could feel an anger growing inside me because of what was happening to him, because he had no choice in what was being done to his body, and because I was helpless to help him understand. Barbara seemed so calm. Why could not I be more accepting of what was happening?

Barbara asked a nurse for some pudding so that we could have a snack time. Barbara then enthusiastically put up, as she explained, “this cute little tray that fits on your bed, Timmy.” She found a plate, spoon, and washcloth. She appeared to be trying to redirect Timmy and me to the more playful mood that we usually experienced in the clinic. I could only think, What if the clot does not dissolve? What if it begins to move? Medical personnel moved in and out of the room every few minutes, reminding me of the frailness of Timmy’s life.

Timmy refused to taste the pudding. I halfheartedly tried to get him to lick his fingers. I do not think I fooled Timmy. He reached over and began to smear pudding on my hands. Barbara seemed disappointed. I tried to appear calm, but I had no control in this setting and I wanted to scream or cry. Leaving as Timmy whimpered in his mother’s arms and a nurse attempted to change the location of the intravenous tube, I felt glad to escape. For the next 2 days, I drove to the parking garage at the hospital but could not make myself go in. I climbed back into my car and went to a phone. I called Barbara, telling her I did not have time to stop by. A week later, I went to Timmy’s room but was relieved to see him and his father asleep.

As I sat in my graduate seminar, which had been meeting weekly during this time, my thoughts kept wandering to Timmy. The class readings included a study on the life history of a woman with severe congenital limb deficiencies (Frank, 1984). I was struck by the author’s method of paying attention to strong feelings as she did her research and then stepping back from them to arrive at a new understanding of her life history subject (Frank, 1985). She had used her empathy as a starting point for examining her assumptions about the other person’s experience. I reflected on how my empathy had helped me to develop a better understanding of Timmy but now led to a deep pain and sadness that I could not understand or explain.

I had been practicing as a clinician for 20 years, yet I was embarrassed to share my concerns with my colleagues. After all, I knew that I was to keep all feelings at a professional level. Another student raised the question that I had been reluctant to ask, “How do you handle your feelings and remain objective as you become so involved in a person’s life?” Using the model of our instructor’s research, we decided each to write a paper describing the development of a single case and to identify critical incidents, or turnings, that resulted in a deeper understanding of the patient and a change in the course of treatment.

Immediately, I knew I would write about Timmy. A sense of relief replaced the tension I was feeling. Now I could begin to analyze what was happening and, more importantly, to work toward a solution. The relief I experienced after leaving class encouraged me to talk to Arlene. Listening to my confession about my behavior over the past week, Arlene responded with moist eyes, “I know just how you feel!” Explaining that she, too, had been unable to visit Timmy, she reminded me that just 2 months earlier a young girl that we had been seeing in therapy had died suddenly at the same hospital after our visit. Arlene said that the memory of this child was still fresh and painful. Although I did not believe that this entirely accounted for my behavior (Why did I not get upset the first day I visited?), it was comforting to know that my feelings were shared. Talking to someone helped me to feel more in control.

During the next 3 weeks, I began to reconstruct the development of my relationship with Timmy. The process involved discussions with my co-workers, my classmates, Timmy’s family, and my instructor. I began to see how important our attunement was to the progress we had made. The more I recognized and acknowledged my feelings of sadness about Timmy’s situation as my own, the more I could monitor and adjust my actions. With a new perspective, I entered Timmy’s room at the hospital. The obtrusiveness of the environment seemed to fade into the background as I was able to concentrate on Timmy and what he was doing. His mother had saved his food tray so that we could have dinner together. We began our usual rituals. He brushed his teeth, washed his face, opened all of the containers, and began to smell and name what was on his plate. Timmy picked up a green bean and dipped it into the gravy to lick. I talked about putting gravy on his potatoes, but there was no hole to keep it from spilling. He gingerly poked a hole with his finger and licked the potatoes. He helped to mince some chicken in a grinder and then took small tastes from a spoon. The meal felt like a well-choreographed dance. I could anticipate his needs and prepare him for his risk-taking actions. His success generated more risk taking. After exploring and tasting everything on his tray several times, Timmy announced he was “all done.” Picking him up from the high chair, I felt exhilarated that the experience had been so satisfying. Timmy put his arms around my neck and gave me a kiss, something that had never
occurred in a spontaneous moment. I had been given a kiss of approval and a memory to cherish.

Assessment and Treatment of a Pediatric Patient: Discussion of the Turnings

In the above case study, two turnings occurred in which the occupational therapist (the second author) came to a deeper, more affectively powerful understanding of her patient and his situation. Each turning involved an important shift in treatment within a flow of interactions with the patient, Timmy Bauer, his family, fellow therapists, and interested others outside the clinical setting. These interactions offered the occupational therapist opportunities to assess and reassess her treatment approach. From the beginning, she worked at establishing a sense of rapport with her patient and his parents, finding in Timmy’s alternating playfulness and reserve a familiar and manageable pattern of behavior, as this interactive style was characteristic of her own son at the same age. In conversations with her fellow students and instructor, Timmy’s occupational therapist elaborated on her narrative, translating Timmy’s body language to say, “Don’t get too close; don’t invade my space.” She told herself, “I need to take it slow and easy with this child.” She believed that if Timmy’s style of flirting and retreating were like those of her son’s, then she should “hold back and let him make the moves.” She let Timmy’s family know that she also had a son, although he was nondysfunctional, and through further actions expressed her ability to be an empathic party to their concerns as parents of a chronically ill child. On her own time, she brought toys to Timmy during his first hospital admission, which relates to treatment goals, because it permits the therapist to nurture the beginning of progress in occupational therapy. It also showed her to be a caring professional capable of engagement in the family’s experience of human suffering, not a disengaged technician.

The narrative and, thus far, the discussion, reflect our interest in bringing out skilled aspects of occupational therapy practice that remain tacit in descriptions of treatment in the professional literature. To develop a fuller ethnographic understanding of this case, however, we must point out that the bonds of trust established by the therapist with the patient and his family were not solely the result of her personal, intuitive, caring approach. The social organization of health care, in which the treatment took place, had already set up expectations for parents entering the clinical setting. As highly motivated advocates for their child’s independence in extensive encounters with the medical profession, Timmy’s parents had come to learn that occupational therapy was appropriate for remedying their child’s need for oral feeding skills. Thus, rapport in treatment is facilitated by their finding in the occupational therapist, as well as in the particular treatment facility recommended to them, nothing that appears to have disappointed their anticipation of competent professional treatment. An experienced practitioner in pediatrics, the occupational therapist used her experience to assess her patient’s strengths and limitations. She had a well-developed set of expectations about what she could accomplish with such a child and how long it should take. After 2 weeks of therapy, she was able to confirm her initial assessment that the treatment goals could be accomplished in 1 year, but not in the 60 days that the insurer would provide.

The therapist’s first turning involved frustration in the course of treatment. Having a well-established treatment approach, she knew she would not have time, as was otherwise customary for her, to build a trusting relationship with her patient that would permit oral motor exploration. She thus adapted her procedures to maximize the time for effective therapeutic intervention by enlisting her patient’s mother to perform the treatment, which she observed, assessed, and guided. Although attuned to Timmy’s pacing in activities, the occupational therapist overrode her intuitive sense of the rhythm needed to elicit his optimal response. Pushing too hard toward her treatment goals, she got an inconsistent response. At this point, despite critically limited reimbursement policies for health care services, the occupational therapist was able to make a difference for her patient and his family. She discussed the case with her supervisor, with whom she had built a strong reputation as a therapist and had developed good relations over time, and gained a commitment from the facility to cover any unreimbursed expense in meeting Timmy’s extensive treatment goals.

Released from the constraints and pressures of the 60-day reimbursement limit, the occupational therapist renegotiated her treatment approach with Timmy’s mother. Until this time, she had been relying on the mother’s rapport with her son to perform treatment activities. It is important to note that, despite the close cooperation between the occupational therapist and the mother, important differences in their interpretation of Timmy’s responses to activities in the clinical setting had not yet been discussed. The mother had known precisely when the therapist had failed to pick up Timmy’s subtle cues, but assumed that, as an expert, the occupational therapist had a reason for pushing her son beyond his limits. At this point, the therapist expressed her desire to establish her own relationship with Timmy and gained support for this plan from the child’s mother. This collaboration between them was essential to treatment progress, as mother and occupational therapist established together a common language to describe the ups and downs of Timmy’s treatment. “Good days” and “bad days” were marked by postures, gestures, and actions that expressed to Timmy’s mother and the occupational therapist his feelings about the activity in which he was engaged and his willingness to continue. Thus, a shared
Timmy’s hospitalization followed the therapist’s uncertain interpretation of his reaction to treatment. The thought that his abdominal pains may express a negative response to his occupational therapy program was invalidated by the medical diagnosis of a bowel obstruction. Visiting Timmy in the hospital, the occupational therapist gained a fuller realization of the graveness of his medical condition and its effect on his development. Seeing the restraint with which he accepted his numerous intravenous hookups, the occupational therapist comprehended Timmy’s initial passivity in the clinic and his disinclination toward movement. On Timmy’s return to occupational therapy 5 weeks later, the therapist’s treatment incorporated a deeper understanding of her patient and a more direct relationship with him than she had been developing. Her approach became more child-directed. Until this time, oral feeding activities had been difficult for this child and the connotations negative. When Timmy expressed a desire to prepare and eat his snack at the start of his treatment sessions, his occupational therapist was confident that this activity had become more positive and meaningful to him. With this important shift, the occupational therapist’s treatment goals for Timmy were closer to being met, not just incrementally but qualitatively. It was a meaningful turning.

Several months of progress followed in a relatively stable pattern, although not without problems to be negotiated. Timmy’s success in playing off his occupational therapist and his mother in rewarding him for each activity, for example, created an atmosphere of a “circus performance” that temporarily escaped the occupational therapist’s control. Yet the goals of treatment were to develop Timmy’s skills to make choices for himself in feeding, oral hygiene, and exploratory play. Against these areas of deficit, his successes in occupational therapy were deeply moving. An especially deep joy came later in the narrative in the shared playfulness with which Timmy and his occupational therapist poked holes with their fingers in mashed potatoes for the gravy that he then poured and ate.

The second turning in this narrative again involved the occupational therapist’s frustration. Specifically, it concerned her distress at witnessing Timmy’s immobilization and submission during his next hospitalization. Following his marked gains in occupational therapy, Timmy displayed a new uncooperativeness and anger in the hospital, which the therapist assessed to be an appropriate sign of his growing independence. Although she had no professional responsibility to Timmy in the hospital, she wished to visit him but found herself unable to go back. The narrative suggests that the therapist’s pain overwhelmed her because she could find no proper context, as a professional, in which to express it. Thus, she was blocked from more fully examining and making use of its meaning to her. She compared her demeanor with that of Timmy’s mother, envying the mother’s calm acceptance, and tried to hide her own grief. Similarly, the therapist felt uncomfortable admitting her feelings to Arlene, the occupational therapist who shared responsibility for Timmy’s treatment. After 20 years of experience, she knew that a professional is not supposed to feel this way.

The seminar experience in which the therapist read about her instructor’s method of clarifying intuitions about another’s experience was very helpful to her at this point. She made use of the published material to bring her feelings back into a context in which their meaning could be shared, reinterpreted, and used to guide further interactions with her patient. The discussions of her own case with her seminar instructor and fellow students widened to include her co-worker and, eventually, Timmy’s mother. The process of recontextualizing and revising the meaning of her painful feelings was freeing for her. She was able to visit Timmy at last and to see the possibility of movement and change once again in his situation. This resulted in a “well-choreographed dance” of activity with Timmy as he ate his meal. Timmy’s spontaneous “kiss of approval,” with which the narrative ends, was cherished as a validation of the therapist’s revised approach to the situation. This is the second turning in a long-term clinical relationship that continued beyond the frame of the present account.

Conclusion

In this article, ethnographic methods were used to examine how an occupational therapist’s understanding of a pediatric patient emerged within a relatively long-term clinical relationship. The narrative was organized by means of critical experiences, or turnings, in which the occupational therapist’s engagement in revising her understanding of the patient was followed by a meaningful shift in treatment. Although ethnographic cases are never strictly generalizable, they do reveal meanings of shared activities that can be usefully applied to understanding of other situations in similar social settings. The present case brings out important tacit features of skilled clinical practice in occupational therapy that contribute, along with technical proficiency, to effective care.

In providing care, occupational therapists strive to engage patients in the meaning of activities used to achieve treatment goals. In the present case, the occupational therapist’s task was to transform eating into a meaningful activity for a child who had never felt hunger, who had adversive reactions to the smells and textures of food, and who lacked oral motor control when anything was placed in his mouth. This case study indicates that the meaning of activities for the patient is not given once and for all, but rather, changes over time and can be
effectively monitored from moment to moment according to the patient's affect. Affective cues (e.g., turning toward or away from an activity or smiling or grimacing) can be understood because of their basis in the behavioral repertoire of the human species (Ekman, Friesen, & Ellsworth, 1972). A process of affect attunement can take place in skilled practice by which the occupational therapist establishes a common language with the child through pacing, intensity, and other dynamics in the performance of activities. Trust is built as the occupational therapist begins to appreciate and share the child's basic preferences in the organization of activities. This becomes the starting point for the introduction of graded challenges in therapeutic activities through which treatment goals can be met.

Grasping the meaning of certain gestures over time for the particular patient and recognizing subtle distinctions denoting change require interpretation. It is a cultural activity. As with an anthropologist who strives to understand things "from the native's point of view," the occupational therapist in this case attempted to develop a child-directed approach to treatment. Cultures vary in their expressive styles; it has been documented, for example, that infants in the United States and Japan, by the age of 4 months, become distinctly American or Japanese ability may further shape the way a child's affect is displayed. Thus, to assess a patient empathically, one must place interpretations in appropriate contexts and subject them to a process of validation and invalidation. Although we expect that this is true in treating any patient, the point is brought out compellingly with the preverbal child in chronic care.

The context of the patient's illness involves situations already richly imbued with meaning. In the case of Timmy Bauer, the sociocultural context included, for example, the tension between expectations that this child with serious impairments should become as independent as possible against the realities of third-party reimbursement that initially restricted his occupational therapist's ability to provide needed treatment. The family context included a well-developed relationship of attunement between the patient and his mother, with whom the occupational therapist learned to share a common language that made therapeutic activities with her patient more effective. The clinical context involved the skilled occupational therapist's background of experiences in working with patients with similar conditions and her well-established pattern of relations with her supervisor and co-workers, which facilitated treatment. The developing treatment relationship between the occupational therapist and the patient itself became a source of contextual understanding. Finally, the occupational therapist was able to make use of a wider set of relations and resources as a scholar so as to make an impact on her practice.

Together, the case study narrative and discussion present a mini-ethnography of clinical practice in a pediatric case in occupational therapy by building contexts for validating or invalidating interpretations or assessments. The making of meaning is ongoing and open-ended, but it is not a random or fruitless exercise. Rather, for the occupational therapist, it centers on puzzles and difficulties that arise in treatment. In clinical practice, context for the mini-ethnography is sought as relevant to the advancement of treatment goals. Confirmation of interpretations occurs in terms of a shift in treatment, in which a more positive response to therapeutic activities by the patient is found. In the case study presented in this paper, the notion of turnings provides an alternative and useful way of discussing salient shifts in the course of occupational therapy, as opposed to discussing it in terms of session-to-session or week-to-week progress, discharge goals, or other conventionally organized units within the bureaucratic structure of health care today. Thus, the application of ethnographic methods to occupational therapy can support aspects of clinical practice attuned to the uniqueness of the patient and to the pursuit of meaningful gains in the contexts of social and cultural life.

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References


Toombs, S. R. (1987). The meaning of illness: A phenomenon-


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