The Depersonalization of Patients: A Profile Gleaned from Narratives

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Occupational therapists who would better understand and advocate against depersonalization in health care can find specific references in narratives to the attitudes and behaviors that seem problematic. Patients argue that helpers fail to recognize that illness and disability are events charged with personal meaning. Instead of communicating with patients, helpers establish a distance that diminishes them. They withhold information in a manner that precludes hope, they use brusque manners, and they misuse their powers. Each of these behaviors seems unreasonable and impersonal, and each discourages patients. Together these narratives might inspire therapists to value interactive reasoning as central to practice, to recommit to their consideration of persons, and to enact a climate of caring.

Patients say that their experiences with health care practitioners are difficult, describing their grasp of the problem with the words dehumanizing or depersonalizing. The abstractions have become the shorthand expression for a dismay that persons who seek health care are often treated carelessly. But what do depersonalizing behaviors look like? Woven throughout a large number of narratives is a profile of impersonal attitudes and behaviors that patients say discourage them when they most need courage. Such a profile can be a powerful resource for therapists who aim to truly care for patients.

More than a decade ago, several therapists addressed the concept of caring at the 60th Annual Conference of the American Occupational Therapy Association in Denver, Colorado (Baum, 1980; Gilfoyle, 1980; King, 1980; Yerxa, 1980). Their collective message encouraged practitioners to recommit to caring, continue the profession’s tradition of arguing the dignity of persons, and shape the social climates within which they practice. Yerxa (1980) further argued that occupational therapists can become powerful advocates for a climate of caring because of their unique perspectives.

This article summarizes one step in a larger inquiry into the climate of caring. Conducted between January 1990 and September 1991, the inquiry researched the following as they relate to the encounters that patients have with caregivers: (a) personal narratives that describe impersonal treatment; (b) the historical events and societal constructs that have shaped the patient-helper relationship; (c) empathy and the manner in which helpers learn to be empathic; (d) the nature, practice, and experience of art; and (e) the proposition that empathy might be cultivated through the use of art. Each step of the inquiry required an extensive literature review in each of the areas specified: phenomenological narratives, the social sciences, history, philosophy, and the arts. From each review a number of major themes emerged, and these were subjected to reflection, analysis, and synthesis.

The literature that describes unhelpful encounters between patients and their helpers is the subject of this article. This literature review includes stories about the experience of illness and disability because encounters with caregivers often appear in these. Articles from behavioral science and health professional journals published within the last 10 years also served as resources when their titles suggested some consideration of the patient-helper relationship. Of more than 100 vignettes found, those included in this article most clearly delineate the unhelpful behaviors and attitudes of helpers and clarify the meaning of depersonalization in a compelling manner.

Sarason (1985), a clinician who is troubled by the carelessness of helpers, identified one reason for any caregiver to listen to a number of stories:

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In a vague, inchoate way, people feel and know that the clinical endeavor has become problematic, that those who are in helping roles are both cause and victim, that something is wrong somewhere, and that, far from getting better, it seems to be getting worse. (pp. 203–204)

The personal hurts described in narratives may hone a vague feeling that something is wrong into a keener understanding.

Other reasons for occupational therapists to consider such stories can be found in the literature that emerged during the same time period as this investigation. Within the context of clinical reasoning, Fleming (1991) asked therapists to consider face-to-face interactions with patients as the “interactive” or “underground” practice that often goes unreported (p. 1011). Her observations of the clinicians who participated in the clinical reasoning study suggest that therapists do not always articulate the interactional aspects of their behaviors as central to practice:

It seems that although the therapists did not initially recognize interaction and interactive reasoning as central to their practice, they used it at least as an adjunct to practice on many occasions for various reasons. (p. 1010)

But this underground practice was important to patients, and the narratives included in this discussion affirm its importance. When patients’ encounters with helpers fail to communicate the attempt to understand that is the hallmark of interactive reasoning, treatment will not be felt as therapy (Fleming, 1991). Armed with the clarity and specificity of complaint that the narratives in this selection depict, occupational therapists might more clearly perceive and openly affirm interactive reasoning as a central part of their treatments.

The concept of caring for and interacting with patients as persons is not new to the profession. Arguments that the patient–therapist relationship matters have been variously articulated within discussions of moral treatment (Bing, 1981; Peloquin, 1989a), the therapeutic use of self (Frank, 1958; Peloquin, 1990), and the art of practice (Devereaux, 1984; Mosey, 1981; Peloquin, 1989b). But there is much merit to arguing that these concepts are central to the reasoning process. Embedding the patient–therapist relationship within clinical reasoning might allow therapists to reconceptualize caring as a reasonable activity as opposed to a merely expressive adjunct. Providing occupational therapists with compelling stories that illustrate the effects of uncaring attitudes and behaviors might inspire them to care. Together, the reconceptualization and the inspiration might empower therapists to create a day-to-day climate of caring.

The Narratives

Within the body of literature on clinical reasoning, Mattingly (1991) suggested that “perhaps occupational therapy as a profession needs to take its phenomenological tasks more seriously” because the phenomenological perspective is “neglected as an articulating and legitimizing framework for practice” (p. 986). Phenomenological narratives that speak to the nature and consequences of impersonal treatments need to be taken seriously. Patients say that practitioners act in a way that belies any claim to understanding. Patients say that because of new and special connection that illness spins, practitioners become significant others but do not seem to recognize their heightened significance.

Patients say that helpers depersonalize health care practice by failing to see the personal consequences of illness and disability. They deny the feelings of those whom they treat; they ignore patients and dismiss their concerns. They fail to show, even in small ways, that they are persons who feel, who participate in their patients’ pain. Instead they engage in distancing behaviors and harmful withholdings; they are silent, aloof, and brusque. They misuse their power. Patients say that these behaviors discourage them when they are in much need of encouragement. Stories such as these can serve as a legitimizing framework for promoting the kinds of actions that encourage.

Eric Hodgins, a former editor of Fortune magazine, spoke to those assembled at a meeting of the American Association for the Advancement of Science in 1964. His address later graced the Annals of the New York Academy of Sciences as a well-crafted essay about his medical treatment after a stroke. Because Hodgins’s experience happened at mid-century and is the earliest story included in this discussion, his comments lead each wave of patient complaints about the various actions that depersonalize.

Failure to See the Personal Consequences of Illness or Disability

Hodgins (1964) has regretted that practitioners fail to recognize illness as an experience of personal problems.

If the patient’s personality, his trade or job, and the residual disabilities with which his stroke has left him—if these factors line up adversely enough, then a depressed and perhaps despairing human being has now supplanted, in February, someone who, in January, was earning his living, supporting his family, and planning the events of his own future. In my own case, I found it both depressing and infuriating that I encountered no physician with the willingness or capacity to say, “Yes, I agree you are in a jam—indeed several jams.” (p. 899)

Hodgins wanted his caregivers to understand that his cerebrovascular accident had damaged far more than his brain. His stroke meant much more. For example, Hodgins had lost considerable dexterity, and, because he could no longer button his shirt, he imagined that he could no longer appear in public, let alone return to work. Although he squeezed a manual gauge with a growing strength that pleased his physician, he had lost the fine
capacity to compose at his typewriter — the essence of his passion, his livelihood, and his connection with others. Hodgins's treatment neglected these "jams" of his illness; no one supposed his grief, sense of incompetence, or loneliness. He wanted solutions to his physical problems, but more than these, he sought someone who grasped their deeper meaning in his life. He needed to hear a practitioner say "I understand what this must mean to you, and I am so sorry about your losses." Instead, surrounded by practitioners who attended to his bodily functions, Hodgins faced the meaning of his stroke alone.

Benziger (1969) struggled with the emotional jams of her chronic depression: "I must accept the fact that my illness may recur ... I must accept the fact that fear does and will jump out at me at the most unexpected moments, and haunt me for no apparent reason" (p. 166). She grieved most when her fear careened between herself and others, but she believed that illness prompted her heightened sensitivity: "An abrupt word, or a harsh one, can bring resentment, anger, and a desire to retaliate" (p. 166). Beisser (1989) agreed that illness is an emotional prod:

Overwhelming feelings greatly sensitized me to those who cared for me. I scrutinized the countenance of my attendants for every mood and whim. Everything that affected them affected me. If I was cared for willingly and without reluctance, I felt good and the world was sunny. If my care was given grudgingly or irritably, in a callous way, powerful feelings of degradation swept over me. (p. 33)

In this manner, anger joins fear, and their companionship in illness is not surprising. Murphy (1987) felt the anger, often stifling his "hoarse and futile cry of rage against fortune" (p. 106) against an ill-fated force that made a fortune "against an ill-fated force that made a fortune" (p. 106) against an ill-fated force that made a fortune.

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Harmful Withholdings

Hodgins (1964) suggested that when helpers’ dismissals consist of silences, patients feel these as withholdings: “I am thinking of the enigmatic smile after the blood pressure readings and the utter silence after examining retinal blood vessels... I am thinking of the nurse’s stolid mask after removal of the thermometer from wherever it was” (p. 841).

Hodgins was bright and curious, but he did not believe that he was singular in wanting to learn the reason for or the results of a procedure done in his presence. He felt that knowing his condition would allow him to better understand and take part in his treatment. Utter silence angered him. His anger seems legitimate; when patients seek information, helpers’ withholdings create new problems for them. Caregivers withheld much from Leete (1987):

I resent the fact that I was not given information about my illness and the methods used to treat it, some of which I feel were harmful. For example, alternating electroshock with insulin coma therapy in 1966 only served to virtually eradicate my memories while probably adversely affecting my ability to learn new information. Doing so without my awareness was criminal. (p. 486)

Most patients argue that they have a reasonable stake in the outcome of their treatments. When practitioners give silent treatments that both dismiss and deprive them, patients wonder why any helper might so readily discount a patient’s interest in care. Lear repeatedly asked about his condition because he wanted to know what to expect (1980). His persistent inquiries led many of his practitioners to tag him a “bad patient”; he was often denied information. After he found the severity of his problems through a solitary investigation of his records, his anger erupted: “None of you understood; the truth would have been easier!” (p. 267). Only with some clarity about what he might expect did Lear feel that he could muster the courage to face his illness.

Discouraging Words

Often when practitioners break silence to share more than an enigmatic smile, they fail to fathom that it may be comfort or hope that patients seek. They furnish discouraging words rather than helpful information. Hodgins (1964) explained whose courage such words seem to muster:

It seems to this patient that many persons in medicine today continue to foster and cherish mystery for mystery’s sake. I am thinking of the prescriptions still written illegibly in pig Latin... I am thinking of what H. W. Fowler called love-of-the-long-word... All such conventions exist for the convenience and protection of doctors; their effect and perhaps their intent is to diminish the patient. (p. 841)

Even when helpers use technical terms not so much to diminish their patients but to hand them the truth, Lee (1987) wrote that they forget the ferocity found in their words:

A hematologist examined me. He had a closet of pet lions, and his recommendations unleashed several for my contemplation. Their mouths were open, “Although she is still clinically, [sic] in Stage III, the severity of the symptoms makes more widespread involvement a possibility. Because of this, chemotherapy (MOP) is in order...” These lions stayed in my room. At times they were very big, and I would tremble. Sometimes they were small, but they were always present, with teeth. (p. 110)
Many practitioners are blind to the fears that they unleash. Because medical language is so familiar to them, they choose their words without care. It then sometimes surprises them that even simple words hold different meanings for their patients. A medical student explained, "Last week someone quoted the example of a woman who was told she had a tumor and she responded with, 'Oh well, I'm glad I haven't got cancer.'" (Moore, 1978, p. 165). Too often, patients say that the concerns and words of practitioners differ from their own. Patients want to know how they might face their illness, but helpers think in other terms.

Practitioners, according to Coles (1989), are taught to think in abstractions, such as "a phobic, a depressive, an acting-out disorder" (p. 17). These terms work against their understanding the meaning of these illnesses to their patients; the labels remove helpers from the reality that the patient's experience is one of fear, sadness, or anger. Coles remembered how William Carlos Williams fretted about the pervasive use of abstractions in health care:

I can say, "The patient is phobic"—not a callous or coldhearted or impersonal attitude, but a brief, pointed piece of information shared with another busy professional. Yes, but Dr. Williams had this amplification: "Who's against shorthand? No one I know. Who wants to be shorthanded? No one I know." (p. 29)

Helpers often shortchange patients. Instead of speaking everyday language that might let patients share their sense of the illness or let helpers tell their own concern, they choose words that camouflage meaning. They hold conversations impersonally, lest they catch their patients' pain. Instead of saying "I know that you are frightened" and risking a portion of that fear, they announce "You have a phobia" and remain unaffected. Helpers cherish words that discourage patients.

**Brusque Behaviors**

Sometimes it is not so much meaningless or dispassionate long words that discourage patients as it is ill-considered remarks. Hodgins (1964) regretted the brusqueness, the negligence of good manners, the disregard for the bedside manner:

Its connotations used to be straight; now they are crooked. To say that a physician had a good bedside manner was once to say that he brought hope and comfort to his recumbent or expiring patient; now the phrase is more likely to be a sneering jibe. (p. 843)

Courtesy and social graces are increasingly uncommon in health care practice. Benziger (1969) remembered, "A rather cross-looking old woman came into my room and locked my clothes closet, my bureau, and my bathroom. 'But I have to use the bathroom during the night,' I protested. 'That's your problem,' she said" (p. 34). Brice (1987) recalled an equally upsetting event. After surgery for an ileostomy, she suffered an excruciating pain that she thought signified a bowel obstruction. She sent her husband out to beg the nurses to help, because, up until that point, she had failed to convince them that she had pain. She remembers that a charge nurse soon "barreled" into the room, saying "I want you to quit moaning and quit manipulating" (p. 31). When the nurse returned a few minutes later to see on the floor the 1000 ccs of vomitus that confirmed the obstruction and the pain, she said "Oh shit!" but nothing else.

Even worse is this story. Jacques (1983), a patient representative, soothed a patient who had naively asked the doctor if her neck brace might have caused her problems. She told Jacques,

"He flew into a rage and called me a 'smart ass'!" When she tried to explain, the doctor told her that he didn't like his patients telling him what to do, told her that she could get another doctor, and then discharged her. (p. 106)

When practitioners behave so brusquely, patients cannot possibly sense that their enlarged sensitivity or fragile courage is understood.

There is also this piece that appeared in a medical journal (Nicky, 1982). An older woman emerged from a taxi in the winter of 1981, "cold, feeble, and wobbly on her feet." She was confused by the crowds and by the din of the clinic where she met brusqueness head-on:

Behind a "cage" a few feet away she saw a young and pretty clerk. As the elderly lady, full of hope, approached the counter, a sharp voice stopped her: "Stay in line." Which line? she pondered. She felt incapable of either arguing or waiting. First nausea, headache, blurry vision, fever, unsteady gait. Now this! She broke into tears. Why did she venture to get help? She went home to die... . A neighbor found her in extremis and called an ambulance. She was dead on arrival at the hospital. (p. 1906)

The consequence of keeping this woman at bay was fatal. Although an illustration, perhaps, of ill-considered remarks in the extreme, the story underscores the power of practitioners: People may die if helpers do not care. This story also differs from that of Hodgins, Murphy, or Sacks because it is told by another, one who is not a patient. Many patients like this woman, who never take pen in hand to protest, are often those who feel dismissal in the form of prejudice. An old woman with yellowed hair and failed hearing may not get an explanation because she is judged incomprehending. A black man wearing tattered clothes may wait for hours because his time is judged less valuable. An unkempt teenager who reeks of liquor might face rough handling because her life is judged loathsome. Patients like these hear sharp demands to "stay in line" because they are seen as having stepped beyond some value-laden boundaries set up by their practitioners. Although genuinely ill, these patients attract labels like difficult or noncompliant that rationalize the hidden bias of their helpers while mitigating their care. Prejudice moves the story of this man, judged both ignorant and hostile:

The gunshot victim is brought into the trauma unit of the hospital with very unstable vital signs. The doctors and nurses immediately set about stabilizing the patient. One of the nurses starts an IV in

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**Note:** The last part of the text seems to be missing or incomplete.
his left arm, while an intern calls for a Foley catheter tray so he can insert the catheter... While the intern inserts the catheter, a resident decides to do a rectal examination. Naturally, the patient reacts to the probing finger.

Doctor: Dammit, RELAX!

Patient: Hey man, be cool. Just ask nice. You don't have to cuss me out, just ask nice and you don't have to jab your finger up my ass.

Doctor: Shut up. And relax. We know what we're doing. The patient seems to be stabilizing because the vital signs are improving... It is at this point that the senior surgical resident decides to put down an NG tube.

Doctor: Hey man, just cool it. Relax, this isn't going to hurt.

Patient: Doc, look, I've had one of those things before and it wouldn't go in my nose. They had to put it into my mouth. The doctor struggles to insert the tube.

Doctor: Dammit, stay still, I'm trying to save your life!

Patient: Hey doc, I appreciate that, but man, I'm scared and I know you can't put that tube in my nose. Other doctors have tried and they couldn't. They had to put it in my mouth.

Doctor: Look, tie him down so I can get this tube in. I'm not going to fool around all night with this guy. (Holderby & McNulty, 1982, pp. 91-92)

The doctor did not fool around much longer. The patient had a cardiac arrest while trying to get loose. Two nurses who later protested were reported as unprofessional.

Many health care narratives show helpers grappling with their powers. There is, of course, the awesome power that holds over the balance of a life—whether and how it might be lived. But life-changing power also dwells in treatments. Patients seek some position from which they might control these powers and their fears. Hodgins, for example, yearned to hear a practitioner say, “You will encounter some difficulties no one can foresee, but for most of these you will find your own individualistic solutions. It will take time, but it will happen” (p. 840). With these words, he might have taken heart. But instead of hearing words that might turn him toward his own resources, Hodgins felt locked out of his care and powerless.

The Misuse of Power

The next wave of patient complaints protests a mismanagement of power:

Almost everyone who has been in a hospital has seen examples—perhaps not in his own case—where neglect of this truism that the patient is part of his treatment has brought the relationships between patient and health personnel to the point of being adversarial proceedings. (Hodgins, 1984, p. 842)

Hodgins believed that it is reasonable for an ill person to fret over what might happen next. Given the despair that often stalks illness, a patient’s wrestling control of steps along the course of treatment is understandable. Equally understandable is another patient’s frantic abandonment of choice to someone thought in a better place to fix the problem. When ill with cancer, Harris (Harris & Stripling, 1980) shared what must be every patient’s unspoken fear over whether to take or yield control:

When am I going to be able to control my life and be able to make my own decisions? I realize the doctors know what is best for me medically, but do they know what is best for me mentally as well? Doctors need to realize that I’m not just a patient number, a tumor, or a disease, but that I am a human who needs a sense of security, a feeling of responsibility, a feeling of control over what is happening in my life and what I think should be done about it. (p. 20

But in battles for command over what will happen, the patient depends on the practitioner and often withers in conflicts over choosing. Brice (1987) remembered the one-downmanship:

When, with the naiveté of a layman, my husband asked him why I wasn’t getting better, my surgeon twice-protested that he was sure it wasn’t his fault. Thinking he might take offense, my husband and I were frightened of being forthright in requesting a second opinion. At that point my care was too critical. My life hung too precariously in his hands. (p. 31)

If helpers could imagine how frightened and troubled patients are, they might expect them to seek other opinions and curse mistakes. But all too often practitioners interpret patient challenges as personal assaults rather than reasonable expressions of distress. When practitioners admit that much outstrips their knowledge or control, patients can be quite forgiving. Martha Lear (1980) remembered a medical student who tried to draw blood from her husband. The young man explained that he was nervous. He apologized profusely after his third failure to angle the needle correctly. Hal Lear appraised the student favorably: "That kid was nervous, but he wasn’t a snot... He was concerned. You can learn to give an injection, but you can’t learn concern. He’ll be okay" (p. 218). Lear’s pessimism about whether concern can be learned is sad. But stories in which practitioners elbow into or out of patient rooms, conversations, and lives justify such pessimism.

Conclusion

The voices within these narratives send out a steady plea. The central complaint is that when practitioners de-personalize, they are not inclined to care, and their behaviors sap a patient’s courage. Helpers rarely listen when patients ask them to attend; patients then reason that practitioners lack the required sensitivity. They despair of being understood.

When helpers neglect their patients’ heightened sensitivity, they intensify the pain of illness. At a time in their lives when patients need someone to be there, helpers hold them at bay. They press patients, who experience little control and much anxiety, to be good. They ask for compliance even as they become evasive, curt, or arrogant. They then seem startled to stir a patient’s anger; they are baffled when a struggle ensues.

Practitioners withhold important information as part of taking charge. They fail to talk about the experience of illness, about possibilities, about the future. They rarely broach feelings. They have a hard time saying that they
are sorry—for the illness, for the pain, for their mistakes. They have a harder time showing, even in small ways, that they are persons who see, who reflect, and who participate in their patients' pain. They dread that pain.

Helpers sometimes argue that patients long for a magical cure, for the impossible. And at these times they sound like this young physician (Kleinman, 1988):

There is only so much you can tolerate—all the problems, the calls, the other patients and families. . . They want so much, every one of them. If this keeps up, I'll either burn out in another year or two or become a danger to my patients and myself (p. 214).

Because of this threat, many rehearse their distance as students. Helpers might recall, with Coles (1989), this lesson: “I learned it was best for me to be ‘cautious, polite, meticulous’; best for me to set aside therapeutic zeal; best for me not to get ‘too involved’” (p. 9). And all too often, practitioners set themselves aside; practice becomes impersonal. Helpers feel torn between contradictory pleas that they be sensitive on the one hand and competent on the other. Many don the professional mask only to discover it is of small use when “after midnight, the professional protection is gone. You feel very alone, vulnerable” (Kleinman, 1988, p. 216). Masked, they stay unseen, unknown, guarding against their pain. But, over time, persistence in wearing the mask will stifle them. Slaby (1986), a physician, explained:

You are not sharing human experiences. . . . The sharing that I have done with my families has sustained me. The sharing relationship with my patients leads to feelings of growing both in wisdom and emotionally as a human being. It actually prevents burnout. (Slaby & Glickman, p. 162)

Although most distancing behaviors aim to safeguard helpers against pain, the distance often thwarts their being unified selves. Practitioners must see that they can step into their patients' worlds with compassion. Any small part of the pain that helpers share makes room in which patients can then turn to their own courage. When practitioners doubt the capacities of persons to encourage one another, they diminish themselves and their patients, forgetting that personal presence is the fundament of care.

Occupational therapists who seek in patients' stories a profile of unhelpful attitudes and behaviors can find them. Anyone who is tempted to see such stories as unlike occupational therapy practice and thus irrelevant might remember the stories told by Parham (1987) or Peloquin (1990) about patient-therapist encounters that were not helpful, such as this one:

June Kailes, a leader in the Independent Living Movement and Director of the Westside Independent Living Center in Santa Monica, California, is a talented and intelligent woman who happens to have cerebral palsy. Her recollection of therapy is that she was asked repeatedly to drill on tasks like putting beads in jars, presumably for coordination: “Anybody could see that wasn't going to be my thing!” Why had no one attempted to help her channel her considerable intellectual abilities toward more satisfying goals? (Parham, 1987, p. 556)

Those who do not see such practices within their occupational therapy clinics might recall the plea for patient advocacy articulated more than a decade ago by leaders in the profession (Baum et al., 1980). Occupational therapists are part of the larger health care system, and they often work in close proximity to manifestations of the disregard, distance, and impersonality that preclude a climate of caring. Historically, therapists have acted in response to societal trends. Clinicians and educators alike have prepared for the trend to see practice as an accountable business by improving documentation and assuring quality care. They prepare now to meet the needs of tomorrow's large population of elderly patients. It seems at least equally important to carefully consider and advocate against any trend that darkens the countenance of caring.

At the very least, occupational therapists can take from these stories a renewed conviction that the exchanges that patients have with their helpers matter very much. Stories such as these suggest that the time has come to openly support the practice of striving to understand patients as unique persons. One group of therapists speaks to the aptness of doing so:

"With the emphasis we have always placed on the person, we have much we can share with others as we try to incorporate a holistic perspective on achieving and maintaining wellness, particularly in the face of adversity" (Hamlin, Loukas, Froehlich, & MacRae, 1992, p. 969). ▲

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References


JUNE KAILES, a leader in the Independent Living Movement and Director of the Westside Independent Living Center in Santa Monica, California, is a talented and intelligent woman who happens to have cerebral palsy. Her recollection of therapy is that she was asked repeatedly to drill on tasks like putting beads in jars, presumably for coordination: "Anybody could see that wasn't going to be my thing!" Why had no one attempted to help her channel her considerable intellectual abilities toward more satisfying goals? (Parham, 1987, p. 556).


