Alma: Coping With Culture, Poverty, and Disability

Erna Imperatore Blanche

Key Words: culture (anthropology) • family • socioeconomic factors

In many parts of the United States, the rapid increase of Spanish-speaking families among occupational therapy clients creates a need for exploration of more relevant interaction methods with this group (Dillard et al., 1992; Evans, 1992; Hinojosa & Kramer, 1992; Koss-Chioino & Vargas, 1992; Mauras-Neslen, 1990). Many researchers emphasize that to establish relevant interaction methods and provide meaningful services, practitioners must perceive and respect the unique cultural values and interpretations of different ethnic groups (Christensen, 1992; Litterst, 1985; Wells, 1991), which is particularly important when including parents in making decisions about therapeutic services (Salisbury, 1992).

Literature Review

Culture

The field of anthropology has many definitions of culture, each representing a different theoretical orientation (Litterst, 1985). In occupational therapy, culture has been defined as a “system of shared meanings or ideas” used “as a label for ethnic identification and categorization” (Litterst, 1985, p. 603). Although clinicians attempt to identify each client’s ethnic or racial characteristics, these cultural characteristics tend to take precedence and are often treated as “static stereotypes rather than genuine understanding of the diversity of social groups” (Litterst, 1985, p. 603). This article subscribes to the view that culture is the person’s “most important instrument of adaptation—that is, an extension of their physiology and an artificial instrument for maintaining a viable relationship with the human habitat” (Cohen, 1980, p. 45). Each culture represents a special system of adaptation strategies or “unique designs for extracting energy from the habitat” (Cohen, 1980, p. 46). Each of these strategies in turn requires appropriate organization of social relations (Cohen, 1980). Culture, therefore, emerges as an organization of social relationships, activities, and thought processes that evolved from the group’s adaptation process.
within the physical habitat (Cohen, 1980).

According to Cohen (1980), the adaptation process of each culture is tied to its level of sociotechnological development. For example, cultures "whose food consumption depends on the cycles of nature...follow the rhythm of nature in their way of thinking about the world" (Cohen, 1980, p. 49); that is, they have a greater mastery over natural processes to meet basic needs for food and shelter and tend to be more casual and incidental in their social relations. This group may tend to assume attitudes of "God provides"; "Whatever will be, will be"; or "Nothing can be done about it anyway." Cultures with a higher level of technological advancement tend to plan ahead and may actively pursue strategies to manage a given situation. These different styles of interaction may affect interactions with health care providers as well.

Economic and Educational Factors of Poverty

Cohen's (1980) view of culture was also influenced by economic and educational factors, which are either not taken into account or submerged in analysis of culture. Nevertheless, within a culture, persons with low income often have less access to the technological advances than do affluent persons. Lewis (1961, 1966/1994) distinguishes between poverty and what he has called "the culture of poverty" (Lewis, 1961, p. xxiv). This culture of poverty exists when a "dominant class asserts a set of values that prizes thrift and the accumulation of wealth and property, stresses the possibility of upward mobility, and explains low economic status as the result of individual personal inadequacy and inferiority" (Lewis, 1966/1994, p. 165). Poverty differs from the culture of poverty in that persons who are poor because of low technology or low resources, such as in primitive societies, often have high degrees of social organization and a relatively satisfying and self-fulfilling culture. The culture of poverty is based on deprivation or the absence of something, but it also affects the person's interactions with the physical world, creating a mind-set and system of social relations with a set of values, attitudes, and modes of behavior and lifestyles (subculture) that are different from that used by the economically more advantaged group (dominant culture) (Abercrombie, Hill, & Turner, 1984). In such subcultures, persons may have a template of strategies that transcends national boundaries to cope with feelings of inferiority, hopelessness, and despair that arise from living in marginal societies (Lewis, 1966/1994).

Poverty status depends on total family income, age of children, number of family members, and age of the householder (Barrett, 1994). It is also strongly related to ethnicity and race and education (Harrington, 1984; Hilfiker, 1994). Children living in poverty are at greater risk of experiencing family stress and inadequate social support (Kaplan-Sanoff, Parker, & Zuckerman, 1991). This stress may increase when children have a disability and are members of a non-English-speaking family because being able to speak English and knowing what services are available are highly important when deciding on the most appropriate services offered by the U.S. medical and social systems. This increased stress affects the child's well-being and, thus, needs to be recognized by health care providers.

The purpose of this article is to explore the effect of cultural differences, including ethnicity and language, education, and economic factors, on the delivery of health care services. The article is based on the life story of Alma, a Central American woman; her child, Vanessa; and their interactions with health care providers. The impact of educational, economic, ethnic and racial, and linguistic differences on delivery of health care services is emphasized. The effects of cultural differences will be identified from three perspectives of coping and adaptation: (a) Alma's adaptation style; (b) health care providers' adaptation mechanism to poor, non-English-speaking clients; and (c) my increased awareness of my roles as clinician and researcher.

Method

Because ethnographic studies are particularly useful when studying a natural setting, they also can be useful in studying clinical interactions. One of the characteristics of ethnography relevant to this study is the context of cooperative story making, which rejects the ideology of "observed versus observer" and sees both the interviewer and the informer as building the story together (Tyler, 1986). The ethnographer then reflects on his or her own writings, positioning himself or herself inside the story (Linden, 1993). The ethnographic methods used were life history, case study, and reflective ethnography.

Life History

"A life history is the account of a life, completed or ongoing" and emphasizes "the experiences and requirements of the individual—how the person copes with society" (Mandelbaum, 1973, p. 177). Life histories include the dimension of time, provide information about a person's reality, and provide information about cultural norms and priorities (Langness & Frank, 1981, Seidman, 1991; Tesch, 1990).

Case Study

The case study is the study of a phenomenon "occurring
in a bounded context” in which the focus of attention is the “more or less vaguely defined temporal, social, and/or physical boundary involved (e.g., a bypass surgery patient, before, during, and six months after surgery, in the family and hospital context)” (Huberman & Miles, 1994, p. 440). Life histories, case studies, and biographies are used by different disciplines, each with different purposes (Langness & Frank, 1981). Case studies and life histories are differentiated here to increase awareness of the importance of including life history methodology in the longitudinal study of clients’ adaptation style within their cultural context. In this case, Alma’s present interactions with the health care delivery system were explored with a traditional case study approach. However, her distinct coping style was explored with a life history approach. Analysis of experiences within her cultural context provides an increased understanding of her present interactions with the health care delivery system.

Reflective Ethnography

In reflective ethnography, the researcher and data construct affect each other, exposing the ethnographer’s values and beliefs (Linden, 1993). Linden described how this dialogue with one’s self during reflection affects one’s own actions:

All too often, the dialectical relationship between an ethnographer’s life and the research she conducts remains implicit and unarticulated—worse yet—actively suppressed. Thus, we also need to consider how our lives, prior to and apart from our research, continuously shape our epistemological positions, the problems we explore and do not explore, the sites in which we chose to work and so on. (p. 7)

As clinicians, we reflect on our observations of a case (Schon, 1983). Clinical reasoning skills require continuous reflection of our ongoing responses to the client’s behaviors. This reasoning relates primarily to clients’ strengths and weaknesses and to the clinical skills used to meet their needs. Reflection on social and cultural positions is encountered less often in the occupational therapy literature. Through reflective ethnography, the researcher’s or clinician’s implicit cultural belief system is exposed along with its possible effects on the delivery of services. My own thoughts, feelings, and reactions to interactions with Alma were recorded in addition to my field notes.

My biggest ethical dilemma concerned doubts about whether I should affect the outcome by getting involved as an advocate or maintain my position as an observer. This question is central in clinical occupational therapy research because it poses an ethical dilemma of withdrawing necessary intervention, which in this case, was the form of communication. This dilemma will be explored later in the article.

Data Collection

The data were collected over an 18-month period from interviews, participant observation, and review of available records. Interviews with the health care providers, such as the physical therapist and case manager, served to establish credibility because they yielded information about their interactions with Alma and Vanessa and the veracity of Alma’s reports and my observations. Interviews and communications with Alma were in Spanish, Alma’s and my first language, because she did not speak or understand conversational English. Alma narrated her life story in response to my questions.

The interview sessions were taped and transcribed in Spanish. Interviews with the other informants were transcribed in English. Credibility was established by my having prolonged exposure to the case, persistent observations, and triangulation of specific data and by having the conclusions examined by other members of the professional and research community (Guba, 1981).

Alma’s Life Story

Alma, the Salvadoran mother of a young child referred to occupational therapy, was 29 years old when first interviewed. She had moved to the United States 6 years before our first contact and was living in a major city with her husband, Jorge, and three young children. She did not work outside the home and spent most of her time taking care of the children and the home. Part of taking care of her children included taking her youngest daughter, Vanessa, to therapy and other appointments. When I met Alma, Vanessa had been coming to occupational therapy for 1 week.

Alma did not remember her mother who had abandoned her when she was 1 year old. At that time, she was taken to live with her father’s wife and a stepsister and remained there until her father died when she was 12 years old. Between the ages of 12 and 16, Alma lived with an aunt and uncle in another city in El Salvador. She finished 5th grade in El Salvador and moved to Guatemala when she was 16 to live with another aunt. In Guatemala, Alma met Jorge, but he moved to the United States. She married her first husband, Pedro, and lived with him a short time before becoming pregnant with her oldest son. Soon after, Pedro was diagnosed with bone cancer. Because of his illness, Pedro’s family took him to their home, leaving Alma to live with her aunt. She saw Pedro again when their son was 20 days old; soon after, Pedro died.

When Jorge returned to Guatemala to visit his fami-
...was given two spinal taps, with a third (and possible fourth) the following week in a different hospital. (The number of reported spinal taps [both by the mother and by the case manager] varies between three and four. The records from the two hospitals were not available.) At age 8 months, Vanessa was admitted to a hospital again because of high fever and a urinary tract infection. At that time, the pediatrician found Vanessa to be developmentally delayed and referred Alma to a social service funding agency.

Vanessa was initially evaluated by the funding agency for early intervention services when she was 9 months old. She was reported to have a global developmental delay, with her gross motor skills primarily affected. She was referred for home therapy, preferably physical therapy. Ten months passed from the time of that referral until she was referred to our agency for physical and occupational therapy. Early intervention had been provided at home for the previous 2 months by a “developmental specialist.” It was unclear what the role and professional affiliation of the specialist was and the reasons for the lengthy delay from the time Alma first approached the funding agency to the time she was referred to our agency. The records indicated that the family had moved; however, Alma reported that she contacted the funding agency shortly after the move.

When members of the assessment team at our clinic first consulted on Vanessa, they realized that the diagnosis for her might have been incorrect. Evaluation revealed that Vanessa exhibited decreased sensation in the lower extremities, major weakness in the lower trunk and lower extremities, frequent urinary infections, and an unusual sporadic increase in muscle tone. Vanessa’s scores on the Bayley Scales of Infant Development (Bayley, 1969) at age 21 months showed that she was functioning at the following levels: cognitive development, 22 months; language development, 12 months; social development, 11 months; fine motor development, 13 months; and gross motor development, 8 months. These findings, in combination with clinical observations, were more indicative of a neuromotor dysfunction than of a global developmental delay.

Vanessa’s records indicated that she had not been evaluated by a pediatrician or neurologist at the funding agency, which was routine for all children funded by that agency. I contacted the case manager and reported my concerns about the diagnosis. After several misunderstandings, during which the counselor confused Vanessa’s case with that of another child, she realized that my concerns were valid and immediately arranged for a pediatric evaluation.

Vanessa was seen by an English-speaking pediatrician, and the counselor translated for Alma and the physician. Our agency received the evaluation report only after we made two phone calls requesting it, and it took 1 month to arrive at our office. The report read: “Muscle bulk and strength perhaps mildly decreased in her lower extremities” and “...she is able to sit well but doesn’t crawl. Instead, she will drag her trunk and legs pulling with her arms.” The pediatrician concluded: “diagnosis of spastic diplegic cerebral palsy. In addition her overall development appears to be significantly delayed. The etiology of her developmental problems is unknown.” Additionally, the pediatrician’s report included the inaccuracy that all three children in the family were fathered by Alma’s present husband. When I asked Alma to state her perceptions of the pediatrician’s impressions, she reported that she was told that a part of Vanessa’s brain did not send signals and that “the child would walk when she decided to walk.” As a matter of fact, Alma said, “Vanessa was doing a lot of standing.”

Vanessa continued to receive physical and occupational therapy at our center. At age 36 months, 18 months after the original evaluation, Vanessa was able to stand and ambulate with ankle-foot orthoses and a walker. Muscle tone in the upper trunk and upper extremities remained low; muscle tone in the lower trunk and lower extremities was spastic. Vanessa was referred to a public school program and discharged from our center because therapeutic services were part of the educational program. Up to the time that she was discharged from the center, the clinicians treating Vanessa never agreed on the diagnosis of cerebral palsy or developmental delay because neither adequately portrayed the complexity of her clinical signs.

The Therapist—Researcher Identity

I am an immigrant occupational therapist from Chile and have lived in the United States for the past 20 years. My pediatric experience covers a cross-cultural sector of the population, including many Spanish-speaking clients. One of my responsibilities as coordinator of services at the clinic is to make the initial contact with the clients, even if I may not directly treat them. In this case, I chose at first to remain disengaged from the clinician’s role so that I could maintain a researcher’s role. However, as I...
shall explain later, I felt compelled to respond to this mother's needs by modifying my role.

During my initial interaction with Alma, I became aware of my assumptions about her and how these assumptions can, in general, shape the interaction between the therapist and client. First, I believed that I understood the Hispanic culture and that Alma and I shared a somewhat common experience because I was able to communicate with her more effectively than a non-Spanish-speaking professional. Although I was aware that non-English-speaking clients often belong to a disadvantaged socioeconomic group, I assumed, based on the existing literature, that racial and ethnic aspects of diversity were the primary cultural factors influencing provider-client interaction. As Alma's story unfolded, I became keenly aware that even though we shared the same language, we did not share the same experiences. I then realized that culture goes beyond race and ethnicity because education and economic power played a key role in the services delivered to Alma and Vanessa.

This new awareness led me to question my belief system. Until I met Alma, I had not seriously questioned the tenet that the U.S. health care system provides appropriate services for all clients. However, I soon realized the system's shortcomings of not being equipped to deal efficiently or appropriately with poor persons. As Hilfiker (1994) wrote, the health care delivery system has "a way of not working when dealing with the poor" (p. 236) because there is a gap between what is supposed to be available to poor persons and what they can actually access.

My second assumption was that I believed Alma was aware of the language barrier and of the cultural differences between life in the United States and life in her country. According to my experience, I believed that moving to another country required adaptation to a different system of social interactions. Hence, I assumed that non-English-speaking parents of children with disabilities adapted both to their children and to the language and cultural differences in U.S. society. However, I came to understand after reflection and discussions with peers and mentors that Alma was either minimally aware of the cultural differences, or she denied these differences and hence continued to operate in a casual mode that did not always prove to be effective in her interactions with the health care system in this country.

Third, I assumed that I could maintain an unattached role of researcher, but as a clinician, I felt confused about Alma's story, my role, and my clinical style. Until I met Alma, I believed that transferring decision-making power to family members invited and facilitated their participation so that they could question, choose, and modify services. However, I learned that Alma did not have the tools to make some decisions. Even after modeling strategies for her, she continued to accept whatever was said, did not ask questions, and seldom expressed her desires. Did she feel disempowered and hence did not take charge of the intervention issues, and was this the reason Vanessa did not receive appropriate services?

As Alma's story unfolded, I became aware that as the only Spanish-speaking professional in our center, I had learned details that were lost to the rest of the staff members, and that, in fact, these communications with Alma were vital for the clinician's understanding of the case. I then had to make an ethical decision to either advocate for Vanessa or stay unattached. I chose to act as an advocate for this child because I saw myself as being more effective in Vanessa's life if I served as a vehicle of understanding between Alma and the professionals in the clinic and if I searched for the most appropriate services to meet her needs. Additionally, deciding to take the advocate role required that I accept the patient's right to be less actively involved in seeking adequate services. As a researcher, I needed to review my role because I was no longer an unattached observer. This is a dilemma that often faces practitioners doing research in the field. I resolved this dilemma by becoming both, resulting in a reflective practitioner (Schon, 1983) who takes into consideration not only the clinical but also the cultural aspects of the interactions with the client and a research instrument who carefully collects data and attends to my own position and the role I play in shaping the context (Hammersley & Atkinson, 1983). In my opinion, this is ultimately the role that clinicians need to adopt for all cases. In this dual role of clinician and researcher, I identified with the service providers who felt frustrated and impatient with delayed answers, untimely reports, and Alma's acceptance of these services.

On the basis of my interactions with Alma, I concluded that reflective clinicians need to be aware of their implied culture, including ethnicity and race, sexual orientation, and economic and educational position. I realized that in my case, although I was often aware of ethnic and racial differences, I was not always aware of other cultural dimensions. Because my ethnic background places me within a minority group and my educational and economic positions are part of the dominant culture, I was less aware of their effect when I interacted with others. The clinician's implied culture may often include the group they represent rather than the group they believe they belong to. For example, I believed that I belonged to the Hispanic group, which meant Alma and I had similar experiences; however, I was also part of the health care
Analysis: Coping Strategies

From a middle-class viewpoint, Alma's interactions with the health care delivery system indicate that she appeared to engage in behaviors that were inefficient and even detrimental to Vanessa's well-being. Although some of these interactions are encountered in daily clinical practice with middle-class clients, they occurred more frequently and intensely in Alma's story. These interactions appeared to be shaped by Alma's coping style and by the health care providers' coping methods.

Alma's Coping Style

A person's unique cultural history and present circumstances shape his or her adaptation style (Cohen, 1980). According to White (1974), "coping refers to adaptation under relatively difficult conditions" (p. 49). Alma often did not express initial awareness of difficulties and hence allowed situations to run a natural or externally controlled course until they became more difficult to manage. This passive interaction style may have been a successful adaptation strategy when dealing with her own life events and when interacting with other health care delivery systems in Central America. However, this style was unsuccessful and led to more difficulties when used in the United States. Hence, her interaction style is described in this article as coping, because it became adaptive in more difficult conditions.

A review of Alma's interaction with the health care delivery system suggests at least four coping mechanisms: (a) minimizing cultural and language differences or denial, (b) acceptance or no questioning during interactions with medical personnel, (c) subtle questioning to trusted persons, and (d) passive resistance often referred to as "noncompliance" by the medical system. These coping mechanisms overlap and cannot be easily separated.

Minimizing cultural and language differences. Throughout Alma's story there are incidents during which I wondered whether she was denying the importance of cultural and language differences, was not aware of them, or was somewhat aware but minimized their importance in an attempt to avoid conflict or please others. The following set of answers to my (interviewer) questions illustrates this point. To the first question, "Do you feel your life is very different in the USA from Guatemala?" Alma answered:

Alma: Well, I think it is the same.
Interviewer: The same? [I wonder.]
Alma: I think that as I do not work, well, I think it is the same.

Did Alma not report any differences between life in Guatemala and the United States because she perceived the number and types of resources available to her in both countries to be the same?

However, when asked if not speaking English has an effect on the services provided for her daughter, Alma's responses became more hesitant. She reported on what occurs when she goes to a health care provider who does not speak Spanish:

Alma: ...they look for someone else who speaks.
Interviewer: Who translates?
Alma: Yes.
Interviewer: Have you ever had a problem with the translation?
Alma: No, I don't think so.
Interviewer: Would you like to know what they are really saying?
Alma: Well, they tell me...what is wrong with the child, what I need to give her, buy the medicine, and they give [me] the prescription in Spanish. They look for forms that are in Spanish, so I can read them.

It was difficult for me to differentiate among minimal awareness, denial, or a desire to please me. Was she unaware that speaking English would increase her understanding, or was she telling me what she thought I wanted to hear? The following answers prompted me to believe that she was somewhat aware that speaking English made a difference but that she chose to minimize its importance. When asked whether, in reality, not knowing English had affected her interactions with the health care providers, she said:

Alma: Approximately a month ago, I took [Vanessa] to emergency. She had a high fever and an ear infection, and, well, there are problems because sometimes the doctors do not speak Spanish, and I have to wait for someone to come and translate, and if not, some-
...times a nurse that may talk a little half explains it.

Interviewer: Half explains it?
Alma: Like...the doctor, she speaks Spanish, but what she said the other day that the child has desdelamiento, what is that? Something like that, desdelamiento, that's what she said.

Interviewer: Desdelamiento? [I do not understand.]
Alma: Yes, that her movements are late she says?

Interviewer: Desdelamiento? Are you sure she used that word?
Alma: Something like that.

Interviewer: What was the word in English?
Alma: That's what she said, desdelamiento, something like that she said.

Interviewer: Developmental?
Alma: Something like that. I did not well understand.

These answers suggest that even when Alma appeared to understand most of the interaction, and the pediatrician believed that she understood, a vital piece of information was missed—the diagnosis. It is also evident that the pediatrician did not identify the mother's lack of understanding, probably because Alma did not raise any questions. Communication between parents and medical personnel may be inadequate, even when both speak the same language. However, not speaking the same language and having a different style of interaction can make these existing communication difficulties even more obvious. Although these answers show evidence of Alma’s little awareness of the importance of speaking English, they also show evidence of a feeling that she had missed some important information in the communication with the physician.

Apparent acceptance or little or no questioning: Closely related to minimal awareness or minimizing the importance of cultural and language differences was a tendency not to ask about a procedure, and, if she did, to go along with the answer, even if she did not understand it. Alma appeared to accept life events as being unchangeable. Hence, she tended to allow medical personnel to make decisions about procedures, even when she did not understand why they were being performed. Accepting others’ authority to make everyday decisions is seen throughout Alma’s life story and during her interactions with Vanessa’s health care providers. The following passage on how Alma felt about her first husband’s parents taking him back to their home when he was ill illustrates this point:

Interviewer: It must have been difficult.
Alma: Well, on one hand...[the in-laws] helped me a lot, you see? In not letting me be with him...instead of making it bad for me, they made it better.

This passage suggests that Alma believed that accepting her in-laws’ decision was a successful strategy because in the end, she benefited from it. Questioning authority is not an acceptable rule of social interaction in male-dominant cultures, and, hence, it is not a successful adaptation strategy. However, when dealing with the health care delivery system in the United States, the client needs to become an active participant in the decision-making process, and manifesting concerns is part of that process. Alma’s apparent acceptance of medical procedures, even when she was dissatisfied, is evident in the following incident:

Alma: I took her [to the neighborhood clinic] so they would give me a cream, and, well, that day, I took her, and they gave her an injection and gave her a cream.

Interviewer: And what was the injection for?
Alma: Well, I don’t know. They just gave it to her.

Interviewer: You don’t know?
Alma: No.

Interviewer: And did you ask?
Alma: Well...they wanted to do a blood test and the lead test, I believe he said, and I say what is what for?...he says the government is asking for it, the lead test, to see if she has [mental] retardation...But they did not take it. I said that it is hard with the girl because she is a little fat. It is hard to find the vein, and they only stick her because they can’t find the vein, and he said I should come another day, and I said that they already took blood at the hospital...and he said...“Did they do the lead test?...well, the truth is I don’t know, but I did see that they took blood.

At another time Alma relates:

Because almost every time I took Vanessa there sick with a fever they put an injection, something like antibiotics, I think.

Interviewer: Oh! Did they explain...did you ask them?
Alma: I forgot.

This initial apparent acceptance was often accompanied by later subtle questioning to other chosen, trusted persons (e.g., other health care providers; i.e., myself). Even when she accepted the situation, she appeared to intuitively know that something was not right and sought validation through subtle questioning of other persons. However, in spite of this, she did not question the authority of the health care providers.

Subtle questioning to chosen, trusted persons: In conjunction with apparent acceptance, Alma exhibited a basic feeling that there was something wrong with some medical procedures, which prompted her to subtly find information through different sources, such as neighbors, friends, and therapists (or other health care providers), sometimes after she allowed for a procedure to take place. For example, during the initial interview with me, Alma...
often raised questions about the validity of medical procedures that had been performed on Vanessa:

One day...[the developmental specialist] said that maybe she was going to have polio, could it be true...that is the reason that they took liquid from her back and what else!

...That is the reason they admitted her, and then they took liquid from her back. They say that taking liquid from the back is dangerous? The doctor says no, that it is not bad?

This subtle questioning can be misinterpreted by health care professionals. For example, during the initial interview with me, Alma explained:

...after [Vanessa] was 1 year old, she started to turn so she could sleep alone. Today, she turns and everything, she is trying to stand, but because she doesn't have much strength in her legs...because sometimes she is sitting...and she wants to lift her leg and she grasps it like this [showing] she lifts it [lifting thighs with her hands].

This dialogue should have alerted me that the diagnosis of developmental delay was not appropriate because picking up the thighs with the hands is associated with weakness in the lower extremities. However, rather than take the mother's accounts as true, I discounted them as her own explanation of the child's difficulties. Later, when I saw Vanessa and consulted with the therapist, I understood that Alma was probably trying to alert me to an unusual pattern—a pattern that coincides more with a spinal cord problem or neuromotor dysfunction than with a global developmental delay. I reacted to Alma's questions by providing explanations that supported the need for the procedure. I saw myself as educating Alma. However, I later questioned whether she was really trying to communicate her concerns, and my response had been inappropriate.

 Passive resistance (referred to as "noncompliance" by the medical system). Vanessa often missed appointments. Sometimes Alma informed us beforehand; other times, she just did not show up. The appointments were missed because of economic reasons (i.e., no money for the bus) conflicting appointments, illnesses, and other unexplained reasons. In most cases, the absence indicated that there were more pressing matters that took priority over the treatment program. However, lack of attendance also appeared to be a way of passively protesting the services being provided. For example, Alma reported to have stopped going to the neighborhood clinic after the following incident:

Alma: It is strange how they are in that clinic, that is the reason I don't go there any more...
Interviewer: Why is it strange?
Alma: Because the doctor only half examines, and he soon goes out and says what is wrong and what to do.

So-called noncompliance needs to be understood in the context of the client's life. In Alma's case, noncompliance could be seen as either dissatisfaction and passive resistance to inadequate care or the presence of more pressing issues such as economic difficulties, sickness, or conflicting appointments.

 Health Care Providers' Coping Strategies

The interactions between Alma and health care providers lacked clarity because services provided were often inappropriate, diagnoses were inaccurate, or communication between health care providers was delayed and confusing. This lack of clarity was probably partly because of Alma's coping strategies and partly because of the health care providers' coping mechanisms. The health care system strategies that affected this case included valuing language qualifications over professional expertise, lacking trained translators, and having misguided professional assumptions.

 Language qualifications over professional expertise. Health care agencies tend to hire Spanish-speaking professionals to treat clients who speak that language, often at the expense of the practitioner's level of competence. In other words, the qualification of "Spanish speaking" is weighted more heavily than that of "professional expertise." Clients feel more comfortable when staff members speak the same language (Dillard et al., 1992); however, being professionally competent requires clinical skills in addition to the ability to communicate. In Alma's case, Vanessa received early intervention services by a Spanish-speaking developmental specialist whose professional qualifications were unclear, which was revealed through a conversation with the physical therapist. According to the physical therapist, on one occasion she called the case manager about where to reach the developmental specialist after he had provided an exercise program that contradicted her recommendations. The case manager reported not to know who had hired the services of the specialist, even when it was later clarified that the case manager herself had done the hiring. Furthermore, the physical therapist added that hiring the services of the developmental specialist was inappropriate because the diagnosis of cerebral palsy should have warranted the services of a professional who would have recognized the need for a diagnostic workup.

The conversations with the case manager illustrate...
again the confusion around this case. The use of nonprofessionals may reduce the cost of services; however, Vanessa's condition of cerebral palsy should have warranted the services of specialized personnel before considering the provider's ability to speak Vanessa's language. In this case, the case manager did not know the diagnosis until after she had hired the services of the developmental specialist; therefore, he was hired on the basis of his ability to speak Spanish, not on the child's needs. This situation also exemplifies how Alma did not believe that she had choices or did not have the skills to challenge the choice of service provider and ended up with a nonprofessional, regardless of her child's needs.

Untrained translators. Often, the system indiscriminately uses persons who do not speak the second language well. These translators may not consistently communicate all the information or use their own style of social interactions. Wells (1991) recommended that professionals dealing with translators should meet with them regularly to discuss the information to be given to the client and to understand the translator's own style in his or her approach to the client. These meetings may eliminate interpreter-related problems such as changes in messages due to paraphrasing, omission, or a combination of separated and unrelated issues (Wells, 1991). Alma's story indicates that information was not communicated appropriately on several occasions. For example, when Vanessa visited the pediatrician, Alma seldom understood the information and reported that translators "half explained" the procedures. It is important to notice that communication difficulties often exist between medical personnel and clients, and, in this case, they existed even when we both spoke Spanish. However, being able to speak her language helped me realize what Alma did not understand and how to attempt to correct it.

Misguided professional assumptions. Professionals make assumptions about the client's needs on the basis of their own experiences. The present movement of family-centered care addresses the importance of recognizing the client's family, beliefs, desires, and resources (Hanft, 1988). Emphasis is placed on working as an interactive system by incorporating the family's input in the intervention process (Hanft, 1988). In Vanessa's case, both English-speaking and Spanish-speaking professionals often assumed Alma understood everything that was being said, and they decided what was in the best interests of the child. This style of interaction is evidenced during Alma's interaction with the pediatricians, the case manager at the funding agency, and even with me. According to the physical therapist's interview with the case manager, the case manager decided to have the developmental specialist see Vanessa in the home instead of offering Alma and Vanessa the opportunity to attend a comprehensive early intervention program where occupational, physical, and speech therapy were offered. The case manager made this decision even though the usual pattern of service delivery encourages the referral of children to a center-based program when they turn 18 months.

After this interview, I asked Alma whether she had been given a choice about where the services were to be provided, and she replied that she had not. The physical therapists and I assumed that the case manager might have given her the choice because it was difficult for Alma to get to the center, given transportation issues. However, that was not the case. There were two assumptions in this incident: (a) our assumption that Alma had chosen home-based treatment and, hence, we did not pursue this issue, and (b) the case manager's assumption that the mother preferred home-based treatment regardless of who provided the services.

Discussion

Alma's story is fragmented and contains inconsistencies. It appears to be determined by external circumstances beyond Alma's manifest control. From a middle-class perspective, it appears chaotic. This apparent lack of manifest control is also evident in her interactions with health care providers, yet it is probably a result of Alma's coping strategies, the health care practitioners' adaptation mechanisms, and a lack of a shared set of assumptions among them. Alma's coping mechanisms are probably rooted in the society she comes from—one that is less technologically advanced and has more casual styles of social interactions (Cohen, 1980) than the United States—and in her personal life history. Her apparent lack of control over life's events as a coping mechanism is probably also shaped by her present disadvantaged economic situation (poverty). Poverty is often accompanied by fatalism (Lewis, 1961) and acceptance of life's events as being unchangeable (Hilfiker, 1994). Alma's interaction style is often characterized by selectivity and a lack of consistency. Professional assumptions and choices are often demonstrated during Alma's contacts with professionals. For example, when Alma first missed several appointments in 1 month, we wondered about her interest in the services. However, she once came to therapy without having the money for the bus fare back home, and we then realized that she was much more committed than we had previously thought. Moreover, in the unfolding of the story, Alma appears to leave something unsaid, and the health care practitioners appear to leave something unanswered. For example, questions such as these remain unanswered: Why did Vanessa
receive three spinal taps in 2 weeks? Or was it four? Why was she referred to the funding agency but did not receive services for almost 1 year? Why was she not seen by the pediatrician or neurologist at the funding agency as part of the intake process? Why did she not have a comprehensive diagnostic workup?

**Recommendations to Improve Practice**

Pediatric occupational therapy services need to be implemented in the context of the child’s family. Parents are considered essential members of the treatment team and need to be encouraged to actively participate in the decision making (Rainforth et al., 1992). Delivering meaningful services requires taking into account the client’s background, one’s own background, and the interaction between the client and the clinician. All these aspects require consideration of cultural factors. In reference to the client’s background, to be an effective consumer of services in the United States and to build what could be constructed by the practitioner and the client together. Services are needed for the child, and (c) the ability to advocate to obtain those services. Consumers need to be able to question the practitioner about the services being provided and thus share control over the decisions made about those services (Rainforth et al., 1992). However, Alma’s style of interaction was not one of taking control, and she lacked the tools to interact with the system to her daughter’s best advantage. Alma accepted most decisions made by service providers and did not actively seek other avenues.

The method health care providers use in caring for underprivileged clients may further contribute to the clients’ feelings of powerlessness and confusion. Hilfiker (1994) postulated that medical treatment of poor persons “takes place in the absence of shared assumptions, which only increases the disorder and uncertainty” (p. 224) already present in poverty. If poverty is compounded by a language barrier, the set of standards and shared assumptions is absent, and our assumptions might be wrong. Thus, providing adequate services to poor persons requires a different set of standards (Hilfiker, 1994), may differ from client to client, and may need to be constructed by the practitioner and the client together.

Applying the same standards across different groups results in frustration and chaos. There is frustration because previously applied principles of intervention do not generate the expected results, and there is chaos because a basic lack of understanding of the other group’s expectations exists. This frustration and chaos prompt the practitioner to withdraw and sometimes avoid entering into the client’s life story (Hilfiker, 1994) because it can become overpowering. However, entering into the client’s life story can ultimately shed light onto the context of the interaction and, thus, decrease chaos.

In reference to the therapist’s background, a culturally competent health care provider has clinical expertise; is able to communicate; and is aware of his or her own and the client’s cultural background, including racial, ethnic, educational, and economic differences. First, with regard to clinical competency, Hilfiker (1994) proposed that professionals usually lack clear guidance when dealing with poor persons and, hence, practice becomes more complicated. Therefore, increased clinical expertise becomes even more important when addressing a different cultural group because appropriate information is often not available, and dealing with diverse cultures requires flexibility to tailor one’s clinical expertise to the client’s needs. In this case, expertise was required when professionals assumed the role of advocate for Vanessa or the role of teacher for Alma. Flexibility and creativity are often the product of experience and characterize the highest levels of mastery in the occupational therapy clinic (Slater & Cohn, 1991). Health care providers need to go beyond direct treatment and tailor previous experiences to provide the best services for their clients. The occupational therapist needs to differentiate among conditions and services (e.g., global intervention program, physical therapy). The occupational therapist also needs to be aware that when administering a developmental evaluation, incorporating speech and language scores obtained from a test administered in English could lead to clouded findings and confuse the diagnosis.

Second, providing appropriate services to any client requires communication. When the client belongs to a different cultural group, communication becomes central in the interaction. If a clinician does not speak the client’s language fluently, it is important to ensure that translations are accurate. Ensuring accuracy can be done by having the client repeat the information given them, even when it is assumed that the communication was clear, or by setting time aside to meet with the translator to understand his or her style and to discuss the information needed to be transmitted (Wells, 1991).

Third, clinicians need to acknowledge the client’s and their own culture as well as the perceptions, expectations, values, and beliefs that are inherent in each (Christensen, 1992). Each client’s background has to be considered separately regardless of his or her culture. When identifying culture, we need to consider subtle aspects, including communication style, decision-making style, and coping
methods. Stereotyping persons and treating them as homogeneous ethnic or racial groups saves time but is not effective. Listening to a client's life story may give us the information we need to place our services within the complexity of his or her life. Health care providers also need to be aware of their own culture. Providers who belong to the white middle class represent the American majority. Because the majority's "culture is assumed rather than observed" (Christensen, 1992, p. 55), members of the health delivery system may not recognize their practice beliefs as a culture per se. Health care providers, regardless of their cultural background, are viewed by clients as powerful and may represent the dominant powerful culture, even if they do not necessarily label themselves as such.

Summary

The purpose of this article was to raise questions about the nature of our services. It does not attempt to provide ready-made answers that can be easily applied to a culturally diverse population. This article emphasizes that the complexity of each person's life experiences cannot be penetrated by applying homogeneous formulas of cultural diversity to our persistent middle-class standards of practice. The life story provides a means to begin to explore the complexity of each person's diverse experience, regardless of their culture. Understanding the client's story will help develop a shared set of assumptions that will guide effective and meaningful therapeutic interactions.

Acknowledgments

This article is based on research conducted in partial fulfillment of the requirements for the degree of doctor of philosophy in occupational science at the University of Southern California, Los Angeles California. I thank Ruth Linden, Ph.D. for her support during the first drafts of this article and the therapists working with Vanessa and Alma. I presented an earlier version of this article at the 1995 AOTA Annual Conference and Exposition.

References


---

**AJOT UPDATE**

**Coming in May:**

- Metaphor and Meaning in Clinical Interview
- Perceptions and Experiences of Occupational Therapists in Rural Schools
- Minimal Forces to Move Patients

Turn to *AJOT* for the latest information on occupational therapy treatment modalities, aids and equipment, legal and social issues, education, and research.