The Story of Maricela and Miguel: A Narrative Analysis of Dimensions of Adaptation

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Objectives. A mother–child life history was analyzed to examine the multiple dimensions of adaptation in a family grouping, including temporality, maternal values, and life contexts.

Method. In-depth interviews, participant observation, and documents (e.g., therapy notes, medical records) produced the data for this study. A multiple step narrative analysis included narrative shaping, analysis of major life turnings, and macrostructural analysis of the progress toward life goals.

Results. This mother–child life history portrays the challenging life events of a Mexican-origin mother, Maricela, seeking care and assistance to further the development of her son with disabilities, Miguel. Major turnings in her life had both costs and benefits for her in the present and future. Analysis of her multiple roles of mother, professional, daughter, lover–wife, and spiritual devotee revealed that Maricela’s life choices, driven by maternal values, diminished the achievement of her personal goals, except those related to her maternal and spiritual roles. Maricela chose actions to realign current and future happenings with her desired life trajectory for her son, which instead of enhancing life conditions for the family often involved short-term and long-term costs.

Conclusion. This mother–child life history demonstrates that a series of moral, relational, and circumstantial factors influence a mother’s projected life course for herself and her child. Adaptation appears to be a dynamic process of realigning life paths to desired life courses, with success evaluated not in a microcosm of time, but from a larger view as these actions contribute to the achievement of desired life goals within a constellation of the person’s life goals.
Historically, these aims have not always been achieved in parent-professional relationships. The following quotes from three different parents (Dickman & Gordon, 1985) demonstrate past failures of health care providers to achieve Dunst’s collaborative aims:

I’m sure there are many good doctors, therapists, and counselors, but there are also many rude, inconsiderate know-it-alls who think parents are stupid and don’t know anything. These “experts” expect us to follow their suggestions just because we are parents, and they think we don’t know any better. When I found out about my son’s problem, I read every book, article and magazine about cerebral palsy. So when I go to doctors, I ask questions. If they cannot spare five minutes to help me understand, I don’t go back. (p. 102)

The professionals would say, “As you can tell, I have no children, but you should do this, this and this.” I always felt when they said things like that they needed personal experience before handing out advice. (p. 314)

No offense to any professional who may hear this, but I resent most professionals I’ve run into treating parents as nonprofessionals and incompetent idiots. I think professionals should realize that parents are intelligent human beings too. (p. 314)

Collaboration, as defined by The New Merriam-Webster Dictionary (1989) embraces both the optimal collaborative circumstance and a less desirable one. Collaboration is defined first as “to work jointly with others” and secondly, “to cooperate with an enemy force occupying one’s country” (p. 157). Burke (1994) pointed out that families seek pediatric occupational therapy services to remedy the child’s deficit condition, with the motivation being the alleviation of a negative condition rather than the optimization of a positive circumstance. In working with the family, the occupational therapist may suggest changes in methods of child rearing or child care, additional developmentally appropriate activities for the family to engage in, or changes in the family’s daily routines to facilitate the child’s development. Typically, most parents engage in parenting without needing assistance from a health professional. Most parents who have children with disabilities may feel that their role of parent has been intruded on.

The health professional may have a narrower or different viewpoint of parenting tasks that has been shaped by their own area of expertise and background. In many cases, this viewpoint may differ from the mother’s viewpoint, which is broader given the wider range of activities she engages in and is responsible for in caring for her child. Ruddick (1989) claimed that there are three demands of maternal work: preservation of physically fragile or vulnerable children in dependent stages (including scrutinizing the environment for potential dangers); nurturing of the child’s emotional, intellectual, and physical growth; and training the child for social membership to make the child acceptable to society as a whole.

From the health professional’s perspective, families often make parenting choices that appear maladaptive, such as not accepting or following professional advice, not being realistic about the child’s potential and abilities, and persisting in practices of questionable benefit to the child. Munro (1985) listed a number of maladaptive behaviors expressed by families of children with disabilities, including program sabotage, extreme overprotectiveness, and symbiotic relationships with the child. Pollner and McDonald-Wilder (1985) described as maladaptive one family’s behaviors concerning a daughter with severe mental retardation, which, though not based in reality, were perpetuated over time. This family gave explanations of the child’s behavior that appeared to suggest intention and cognition well beyond her capabilities (from the researcher’s point of view), framed interactions so as to make any response from the child seem meaningful, and gave credit to the child for any verbal responses by putting words in her mouth. Murphy (1981) gave an example of a mother’s time-consuming behavior of questionable purposefulness:

My wife would not accept the fact of Susan’s deafness. Our school had a policy of having the kids wear their hearing aids on top of their clothing. But Phyllis found every excuse to hide Susan’s aid. She even got to the point of making a heart-shaped, lace-trimmed harness for the aid, then a different harness for every outfit. It got ridiculous. (p. 3)

In addition, research demonstrates that families may engage in care routines of high cost to other members of the family. Mothers of children with disabilities may make choices that, although adaptive in creating a high functioning family, may be achieved at the expense of their own well-being (Shapiro & Tittle, 1990). Tew, Payne, and Laurence (1974) found that some parents subordinated all parental activities to the needs of the child.

Adaptation
The concept of adaptation has a strong theoretical foundation in occupational therapy. The premises by which occupational therapy defines adaptation lead practitioners to view the families with whom they collaborate through a particular lens, guided by a specific set of professional values and beliefs. Some definitions characterize adaptation as an active, individual change process that leads to positive outcomes. For example, adaptation is defined as:

- “adjustments made by the individual that primarily enhance personal...survival and...contribute to actualization of personal potential” (King, 1978, p. 431)
- “a change in functional state of the person as a result of movement toward relative mastery over occupa-
tional challenges" (Schkade & Schultz, 1992, p. 831)
• "a change in function that promotes survival and self-
actualization" (AOTA, 1993, p. 1119)
• "a process of selecting and organizing activities to
improve life opportunities and enhance quality of life
according to the experience of individuals or groups.
(Frank, in press).

Occupational therapy practitioners who are guided
by these definitions may make implicit assumptions and
claims that adaptation results in a positive, successful, or
good outcome; occurs at an individual level; and is a
result of a process-adjustment, or change. Current de-
definitions do not explain adaptation among family group-
ings or related persons (except Frank [in press] who
included the person and groups in her definition) or the
influence of relationships on adaptation. These defini-
tions generate further questions: Which and whose val-
ues, beliefs, and perspectives determine whether the out-
come is in fact positive, enhancing, or actualizing to the
person? Which set of criteria is used to judge the good-


ness of outcomes— independence, physical skill and pro-
duction, efficiency of daily routines, emotional satisfac-
tion, or spiritual peace? How does adaptation unfold
over time, and at what point in the process is the out-
come judged?

In the previous examples of families parenting chil-
dren with disabilities, practitioners who are guided by
these definitions of adaptation—mainly that of a resul-
tant improved quality of life or good outcomes—may
view some of the parents’ behaviors as maladaptive.
From Ruddick's (1989) perspective, these same descrip-
tions of maladaptive parental behaviors could be viewed
as satisfying one of the three aims of maternal work.
Those families accused of program sabotage or overpro-
tection may view themselves as the only guardians of
a fragile child whose well-being is their charge to pre-
serv.e. Those mothers subordinating their own activities
to the child's needs may be funneling their resources to
promote the child's emotional, intellectual, and physical
growth. The family doing “reality work,” and the moth-
er making heart-shaped harnesses may both be attempt-
ing to promote the social acceptance of the child.

Given the disparate viewpoints of parenting and
adaptation that parents and health professionals bring to
therapy, it is easy to see how instead of working with
health professionals, parents may believe that they are
cooperating with an “enemy force occupying one's terri-
tory.” Judgments of family’s management of the child's
disability, beliefs of the purviews of parenting or therapy,
priorities in fostering the child's development, and mean-
ing and value of family activities may differ between the
parents and the occupational therapist. The purpose of
this study was to investigate the concept of adaptation in
a family grouping over time from the perspective and val-
ues of a mother of a child with disabilities to more closely
examine the multiple contextual factors guiding the
mother's choices in relation to the resultant outcomes.

Method
Selection of Informant
This study was part of a larger project of multiple in-
depth case studies of Mexican-origin mothers that focus
on the mother's well-being as affected by parenting a child
with disabilities. Informants were selected from a group of
volunteers solicited by letter through a local agency that
provides occupational therapy services. Criteria for inclu-
sion were parenting a "high burden" child who required
physical care beyond infancy and being of Mexican eth-
nicity. The current mother-child life history was selected
for closer analysis because of its paradoxical nature; that is,
many of the informant's well-intended choices arguably
lead to disappointing conclusions rather than positive cir-
cumstances.

Data Collection
Data for the informant included 130 pages of interview
transcripts and field notes and 41 pages of medical rec-
ords, including therapy notes, parent contact logs, and
medical reports. In the first interview, the question “How
have your days changed since you had Miguel?” elicited
the mother-child life history. Her initial response was,
“Oh....More than 360 degrees, I believe two revolutions.”

Procedure
Interviews were conducted as three-way conversations,
with the interpreter asking my questions in Spanish and
then translating the informant’s responses in English,
allowing for follow-up and probing questions. The inter-
preter was a second generation Mexican-American who
was proficient in both English and Spanish and worked
with children in exceptional education. The informant
spoke fluent Spanish and had limited English conversa-
tional skills.

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1 This presentation of occupational therapy conceptualizations of
adaptation is somewhat simplistic in taking the quoted definitions at
face value while knowing that there is an implicit or explicit assump-
tion in these definitions that the person's interaction with the envi-
ronment and occupation are essential components in adaptation.
Occupational therapists' tacit practice knowledge about adaptation,
like clinical reasoning (Mattingly, 1991), is probably much more
sophisticated, intricate, and as yet unarticulated.
To decrease the likelihood of misunderstandings or error in interpretation, the interviews were transcribed verbatim in both English and Spanish, with a second written translation of the original spoken Spanish. In addition, the transcriptions were reviewed for accuracy of translation by two additional persons literate in both English and Spanish. Pseudonyms were used to protect the identities of the informant and her child. Findings were reviewed and critiqued by another professional familiar with the informant, her son, and her story.

**Data Analysis**

The transcribed interviews were analyzed in a multiple step process beginning with narrative shaping (a procedure where data are organized into a coherent developmental account [Polkinghorne, 1995]) followed by an analysis of turnings (life junctures where a person “takes on a new set of roles, enters fresh relations with people, and acquires a new self-conception” [Mandelbaum, 1973, p. 181]) and a macrostructural analysis of plot (i.e., progress toward achieving desired goals).

The informant’s mother-child life story was initially shaped by ordering it chronologically and by selecting pertinent data elements and excluding data that did not contribute to the plot. The informant’s major life turnings were examined to see which junctures elicited change and, therefore, adaptations (Frank, 1984). The macrostructural analysis examined the informant’s progress over time in achieving her desired life goals.

**Results and Discussion**

This section contains the shaped narrative, analysis of turnings, and macrostructural analysis and draws the findings into a theoretical framework extending the concept of adaptation. The informant’s narrative not only serves as study data but also has an important function for the informant, who retold this mother-child life story to new teachers, assistants, or therapists working with her son so that those professionals understood the path they had traveled to the present. The analysis of turnings focuses on the informant’s choices, values, and outcomes in relation to the current definitions of adaptation. (As suggested earlier, adaptation may be defined as a process or change resulting in a positive, successful, or good outcome occurring at an individual level.) Turnings and the resultant changes in roles, outcomes, and life revisions are used to reflect on this definition of adaptation. The macrostructural analysis draws on the analysis of turnings and examines the multiple threads of the informant’s life in relation to the achievement of personal goals, including maternal goals. This analysis leads to a discussion of the informant’s attempts to revise and redirect her son’s life trajectory back to the desired path. Finally, on the basis of this study’s findings, a definition of adaptation that combines temporal dimensions, maternal values, family relationships, and life contexts is presented.

**Narrative**

The story begins in an urban city in Mexico with Maricela, a 29-year-old obstetrician. She was the eldest daughter of a well-established professional family and the first professional of the six children, who all trained for professional careers. Her father, a lawyer, and her mother, a full-time homemaker, raised their children Catholic. Maricela’s unwed pregnancy shocked, angered, and shamed her family. Maricela was delighted with being pregnant: “...in spite of my parents telling me to leave the house...I felt happy with my pregnancy, in other words, it did not hurt me that they rejected me.” Maricela’s shunning included abandonment by all her family members, especially her father, and led her to leave the city to live and work in a rural area, a move that had serious consequences shortly thereafter for her and her baby.

Maricela gave herself her own prenatal program of diet, exercise, and stimulation:

Before he was born, I started following programs, since I was a doctor...prenatal programs that I...prescribed to myself [laughs]...And above all, I started talking to him from the first month...telling him that he was growing, that he was forming...I would talk to him about the outside world, “When I have you in my hands, we are going to see this, you are going to see the grass, the flowers.”

I think that his happy face he now has...despite the accident he had...is because before he was [born he was very happy because he and I talked a lot.”

Maricela carefully recounted the ultrasound; planned cesarean section; the perinatal developmental exam findings; and her son’s psychomotor development at birth, including holding up his head and batting at toys: “he was very active the first few days, like everything was perfect.”

As a baby, Miguel accompanied his mother to the clinic where she worked. A caregiver watched the child while Maricela performed surgery and delivered babies. When Miguel was 3 months old, Maricela clearly remembered finishing a cesarean section, taking a shower, and then visiting her son. Despite warm weather, Miguel was swaddled: “[the caregiver] tells me that the child is shivering, cold.” The third time she found the baby swaddled, Maricela realized that the shaking was really a seizure and that this particular one was a grand mal in which Miguel’s hands postured and his eyes rolled back. As she told the story, Maricela commented, “Every time
I remember that... I feel bad like it's happening all over again.... And the aggressive convulsion he under went, it was too much... I am a doctor. I know what a convulsion leads to.” She injected him with valium and left for the city to find a neurologist, the nearest hospital being 2 hours away.

Even after a neurologist was found, Miguel continued to seizure for 3 to 4 days. No medical intervention proved effective, and he slipped into a coma:

And during all that time while he was in a coma; he did not con­vulse, he was totally in a coma. Some said it was better... since they knew me...to take everything off and take him home because he would be finished in a matter of hours, why suffer? Others would tell me to keep on ahead; they did not agree with the diagnosis. Since he was a healthy boy... he did not have... [a] precedent, [the physicians] could not find the cause.

The medical tests proved inconclusive, suggesting Miguel’s seizures to be an idiopathic condition perhaps caused by a virus. Although Maricela detailed the medical problems—electrolyte imbalance, brain embolisms, minor hemorrhages, cortical atrophy—no cause was discovered. She described giving him nasogasotic feedings 8 to 12 times per day and injecting drugs to calm him after he was released from the hospital 1 month later.

To accommodate Miguel’s continuing seizures and high need for skilled care, Maricela left her home and moved into the clinic. She became severely depressed, crying for days and trying to sift through what went wrong. She ruminated over the magnitude of changes in her life when everything was so fine. Now feeling alone and distraught, she willingly accepted her parents asking her to leave and took responsibility for her pregnancy, but Miguel’s illness “was too much.” Maricela said that her family’s position, supported by religious and cultural belief of actions and consequences, was that “Miguel... is the proof of my sin.”

Invisible in this story is the biological father, her first love, but his actions would affect Maricela’s future relationships. Although present when Miguel was born and in the first few months of his life, the father was unable to accept the changed Miguel:

When the child had the embolism he told me, “I am sorry, this is a son I cannot present before anyone. It is a big package. It is yours. We can continue the same... maybe we get married, but we are going to send the child to an institution in Mexico,” a hospital like that, detainted.

Maricela then said pointedly, “So, no I’m sorry... I have always thought, as a woman one can find a man on any corner, good or bad, but one can find someone... become accustomed to anyone whatsoever... It is not worth it, that is why I was alone with my son.”

In the midst of this pain, Maricela became confused, “I did not understand, I would say, nothing had to happen because everything was planned to be... I have learned that I cannot plan my life. It is not up to me to plan my life.” She continued working and living at the clinic:

All that time, I worked 24 hours... I started to leave my job little by little in order to care for my son... After 2 years, it was more difficult for someone to care for him, and that is when I began to work less.

Then Maricela decided to return to school to earn a master’s degree in education to better meet her son’s future educational needs. Armed with a scholarship that provided full financial support and her salary, she found a home near the school and a caregiver for Miguel. On breaks, she would check on Miguel. Her outlook improved slightly, and she had strategies for lifting her spirits:

I experienced a great crisis of depression because it was only him and I at home. When I would fix something to eat, I would tell him, “Is it not good?” and I would answer myself, “Yes mami, mami, I want more.” I did things like when it was [my saint’s day], I would go out to the store and I would get a flower arrangement. I would put nice things, and I would sign... Miguel. I would go to the telegraph company and would send myself a telegram. I would send it to my house, or I would send it where I was studying. The worst of it all is that when I received it, I would scream like if it was really a surprise... I would feel more normal

Choosing to be alone with Miguel and estranged from her family, Maricela was under a cloud of depression:

Sometimes I would take his hands, and I would put them here [touching her heart] and I would tell him, “Please caress me.” It is hard being alone, no family, no husband and having a child that one knows he is a son, that I know he is my son but having, like having a letter, a chair.

Even when she reached out to her family for help, they told her, “Being a mother is not feeling good for a little while, being a mother is your problem. You wanted to be a mother, face it.” There was no one with whom to talk about her concerns and problems. Her sisters married and had normally developing children; when they asked about Miguel, all she could say was that he was the same.

Prefacing the next part of the story with “I’m not apologizing,” Maricela recounted how she planned a second child when Miguel was about 4 years old; “I needed mischief, I needed to see the red roses, a stained thing.”

Maricela’s daughter Alicia was born prematurely, weighing only 2 pounds. Alicia’s birth was a secret; Maricela believed that this child was “a gift from God.” She mislead her family by implying that she was adopting the child:

They thought, since I used those terms, delivering and a gift from
This time her family came to the hospital to see the baby. Her life appeared to take an upward trajectory; she finished school and bought a house. Economically she was pleased to be self-sufficient: "freedom is achieved with economic freedom." Maricela’s sisters came to visit the new baby at Christmas, bringing gifts for her but not for Miguel. Alicia was advanced in all areas of development. Despite previous family differences, Maricela’s family accepted and loved Alicia and her precociousness. She also brought joy to Maricela: “She would attract attention…this little girl came to fill my life with happiness…because Miguel causes me pain…she gives me happiness.”

Although Maricela and her daughter were accepted into the family by her sisters, Miguel remained an outcast who was uninvited to family gatherings. Additionally, he was an outcast in the larger social picture, for example, taxi drivers would not stop to help them after seeing Miguel in his wheelchair:

[Miguel’s being an outcast made] everything…harder,…I was not resigned to have my son’s life in a room in the house, even though his room was full of little things for him; I could not be at peace with that being his only world.

Maricela decided to try to seek treatment for Miguel in the United States. The first time she attempted to enter the United States, she readied her papers and honestly answered the immigration officials’ inquiries into the purpose of her visit. “I got my passport, went to the embassy to request a visa…I only came seeking a different medical opinion, probably a different therapy [to get help for my son].” This honesty she said was clearly a mistake; her replies led to denial of a visa. Other methods for legal immigration such as a sponsor or a job offer were not possible because she knew no one in the United States. Impelled by many things, Maricela decided to enter the United States illegally with her son, paying a smuggler to take her across the border and later paying a family to take Miguel across the border with another child’s birth certificate. Although risking the consequences for herself and Miguel, Maricela decided it was unreasonable for her daughter to take the same risks and left Alicia with her grandmother.

For the sake of Miguel, Maricela ventured into a foreign country, leaving her beloved daughter behind. Maricela was not expecting what was to come after her immigration. Finding no employment, she ran out of money and was reduced to living on the streets:

I understood [the consequences of being undocumented and unemployed] when we had nothing to eat, when we had nowhere to live, and I had to knock on a door and say, “Miss, do you not have something for me to sew?” and she said “I do not need you, what for?” “Well let me wash your bathroom, the kitchen, your clothes, but give me some milk for my son.”

Having previously been refused by her family, Maricela promised herself that she would not go back to them and ask for help. Not knowing the laws regarding immigration and employment was a fatal flaw in Maricela’s plan: “I [would] tell them at the hospital…I am a doctor, I want you to give me a job…” We believe you, but here [a Mexican physician’s license] is nothing.’ It is like you were nothing.” Because she was born and raised in an upper-middle-class family and was financially independent as an adult, this turn of events surprised Maricela. Believing that a physician could find work anywhere, she found instead that she was caught in a web of political red tape.

Maricela met up with an old acquaintance from Mexico who offered to share his trailer and who later became her husband. According to Maricela, her relationship with her husband was initially based on need, not attraction. Maricela’s marriage pleased her family. Her husband Luis, unlike the previous two men, had gone to great lengths to build a relationship with Maricela and had proven capable of accepting and loving both her children.

From the beginning of this relationship, Maricela made it clear that Miguel was her first priority: “…before me, I as a woman could be happy; I would stop being it if [Miguel] was not…He is always to be first.” She related how Luis had “accepted [Miguel] quite fully” and was even able to understand Miguel’s likes and dislikes by reading his facial expressions.

While the family was living in the trailer, Luis lost his job. They managed, however, with Maricela doing odd jobs for neighbors and caring for other children. Maricela then heard about a center that coordinated services for persons with disabilities and went there in an attempt to enroll Miguel in school. Around this same time, she accidentally bumped into a woman on the street while pushing Miguel in his wheelchair. This stranger inquired about where she lived and told her about shelters for the homeless, emphasizing that she did not have to live in such a small trailer. The pressure to find better housing also was exacerbated by the center official:

She told me, “If we take the child as a client, he cannot live here, we are going to take the baby to a special residence.” I told her, “You know, if the child is taken away, I might as well take him back to Mexico. In Mexico, he has a decent house…to live in… I did not come here to leave my son, if I did not want to care for him, I would have just come here abandoning him… It is not that.” And

The American Journal of Occupational Therapy

291
the fear of him being taken away was great...[The official] said, "If within 15 days, which is when your appointment date is, he is not living in a clean place, I will draw up the order for him to be picked up." I went to the shelter the lady told me about...and there I almost knelt down before the social worker. I explained to her that my child was going to be taken away. She told me, "They cannot do that if you do not sign." I tell her..."I am afraid...what should I do? I only want a place where he can live, please." She told me, "We do not have room, we have a room here, but it is for a person whom we authorized already."

Her only hope was that reserved room, which had not been claimed. Fortunately, the family was given the room, and soon after, Maricela found a job in a restaurant, and Miguel went to school:

The social worker learned that what we really wanted was an opportunity to work...she was able to get to know us, then she said, "Look...I am going to help you because it hurts me to see professionals in your situation and that you really are doing this for the child."

The social worker gave the family an application for section 8 public housing. During the first year in the shelter, they had a small room at the top of 25 stairs that they had to drag the wheelchair up and down every day. During the 6 months they waited for an apartment, both Maricela and Luis worked, saved, and put furniture on layaway to be ready for their new home. Their new apartment was in a secure modern public housing complex that was fully wheelchair accessible.

At the time of the study, 10-year-old Miguel was in school and receiving occupational therapy services at a hospital. Maricela used public transportation to take him to therapy in his wheelchair. After school, he attended a recreational program for children with disabilities. Maricela's anxieties now revolved around Miguel's inability to communicate, his physical safety when he was out of her care, and how he would be cared for in the future:

His body is different, and it causes me a lot of anguish for someone to harm him in any way...and he does not talk; in other words, my anguish is that he will not be able to tell me what happens.

Knowing that he is vulnerable and unable to defend himself, she remarked,

...that is permanent anguish...It worries me to die soon—before him and leave him. I never want to die....Yes, because I have asked God that the day I am going to die, that my son die, at least a day before, because I do not want to leave him.

Maricela also missed her daughter greatly. Saying goodbye to her on the phone was one of the things that distressed her. When asked what the hard things were, she said:

The most difficult things that [Miguel] has taught me is that life is hard, that life is always a struggle, to struggle and to continue ahead. He has taught me to cry a lot, but he has taught me to cry for love not desperation. There is something I believe is very important, that I am not resigned to my son's situation, right? Because if I were resigned, I would be in Mexico at my job, and my son put away...surrounded by comforts...but I am not resigned at this moment, and if I knew that there is something on the moon to change my son's [condition] and I had to go nose first from here to the moon, I would take Miguel, and nose first, I would go.

Maricela is committed to a hopeful future for Miguel.

Currently, Luis works in a factory. Maricela said that she chooses not to be employed full-time outside the home, but she "works all the time." She contributes to the family income by working on weekends as a cashier at a swap meet, doing child day care, and making food and clothing in the home to sell. Her acceptance of this menial labor, which is well beneath her educational level, is driven by a valuing of family:

Is it not more important for us to be together rather than doing what each one of us wants? Or me bringing home a lot money to satisfy tastes? That will not buy all the caring and the attention. Values are learned at home...not outside.

This story is of a life with ups and downs, but the protagonist does not see herself as a victim or an unsung hero. Maricela's current ambition is to become a physical therapy assistant, yet her role of mother is still preeminent:

I am studying, and God permitting, when I finish, I want to be a physical therapist assistant. I would like to study only the time my son is in school....If my daughter is here...only the time when the two of them are in school...what is important is that I could be my children's full-time mother.

To this end, she has enrolled in English classes. She still dreams of returning to performing surgery again.

This brief description of her family history describes a mother heavily invested in providing her child with optimal experiences for growth and development. She admits that

[it] has been many years that I do not do what I like to do. I liked to swim a lot, have friends...and talk about books I read of privileged subjects. Like for instance, what do you think about those who want to live 200 years? Or about parapsychology....My son began to absorb my time. I stopped swimming, going to the gymnasium....I stopped doing all this because it was not compatible with my duties with him. Yes, everything changes. For instance, I did not go see a movie at the [theater]....He does not tolerate a program about violence where there are wars, shootings. He has Walt Disney movies. These are things that he likes, so then I had to change my taste...I changed my whole rhythm...everything changes. All. Totally! But, besides, it is very important to take note that the change is voluntary; that is why I do not feel sad, that is why I am content. It makes me happy to care for my son. It keeps me tranquil, it gives me com-
fort, it is no problem. I do not lament it or see it as a disgrace.

Analysis of Turnings

Drawn from the narrative presented, and other data gathered, Table 1 lists a series of turnings in Maricela's life (selected on the basis of Mandelbaum's (1973) definition); the changes evoked by those turnings in her life roles, relationships, or self-concept; outcomes; and resultant shifts or revisions of her life path. Closer examination of just a few of these turnings illuminates the complexity of Maricela's life decisions and the broad, sometimes differing, effects on various aspects of her life. These turnings may not be the same as Maricela herself would highlight; they are my interpretation of the major events in her life.

The first turning in this story is her pregnancy. Shunned by her family, Maricela moved, took up a residence in a distant place, and prepared for her child, losing and winning family members in this event. Did this move improve her quality of life, and if so, was this adaptive? She desired to have a child and did not regret having to leave her family to do so. It would be hard for anyone but Maricela to judge the adaptiveness of this response, if adaptation is defined as a positive outcome. Simply applied, the current definitions of adaptation do not expose the subtleties of this action. Life's decisions are based on complex factors that may rely more on the person's interpretations of outcomes and future expectations rather than on an outsider's objective analysis.

Miguel's birth was another important turning. In her role as mother, Maricela gloved about the perfection of her new son. She altered her time use and behavior, preparing for her role as mother. After Miguel's seizures, another major turning, Maricela embraced maternal values above all others. Her commitment to Miguel's survival and growth was all consuming. Maricela had chosen to have him while unwed, and when he became ill, her investment in mothering intensified. The result was that the mother-child relationship was the only close relationship that remained. Was it in her best interests to choose Miguel over her family and her lover; was this adaptive? Or was her construction of motherhood such a powerful, internalized social force that she saw her commitment to her child as the only possible choice, even at the expense of her support network? An objective analysis that is removed from the powerful emotional situation is unsatisfactory; Maricela's choices might appear on the surface to be at her expense because she lost her support network, but no one except Maricela could address how she weighed and balanced these multiple factors to make her choices.

Through her narrative, Maricela reshapes and redefines her story of herself by looking backward from her current perspective. Often, from the present perspective, clients and therapists evaluate the adaptiveness of past and present responses. Herein lies the difficulty of evaluating adaptation from a single point in time because people's actions are based on the available information in a given moment, and they are never fully aware of all the possible future consequences (R. Linden, personal communication, February 1993). Adaptiveness must have a time configuration component; in the present, it is possible to look back and view something as a mistake, such as, in Maricela's case, honesty to the immigration officials, or as a good choice, such as having a baby. This perspective can shift on the basis of consequent events; for example, the move away from the city protected both Maricela and her family from shame but increased the time Miguel was in physical crisis without treatment after his seizures. This closer examination of Maricela's story in some ways clouds the issues of adaptation. Initially, this life history appears to be the valiant tale of a loving mother, but when examined with current definitions of adaptation that suggest positive outcomes, many of Maricela's choices, at the point in time when they occurred, do not seem to have resulted in only positive outcomes.

Macrostructural Analysis

Although an analysis of turnings permits examination of the immediate or near-future outcomes, it does not completely address the implications of these important events or the importance of relationships with regard to adaptation. Analysis of plot, or the protagonist's success or failure at achieving his or her ultimate goal, can further extend this examination of adaptation in this narrative. Robinson (1990), drawing on Gergen and Gergen's work, suggested using a narrative macrostructural analysis where "all elements in the narrative relate to the valued goal state (coherence), and the time frame in moving towards or away from the goal state (directionality)" (p. 1176). The progress toward or away from the valued goals leads to a regressive narrative (away from goals), a stable narrative (status quo), or a progressive narrative (toward goals) (Robinson, 1990). Because people have multiple life goals in which they engage simultaneously, multiple patterns of narrative could be drawn from the same story. In Maricela's case, mothering Miguel seems to be the foregrounded story, but in the background and intertwined with these events is the family relationship story, intimate relationship story, professional story, and spiritual story.
# Table 1

## Analysis of Turnings

<table>
<thead>
<tr>
<th>Turning</th>
<th>Changes in Roles, Relationships, Self-Concept</th>
<th>Outcomes</th>
<th>Shifts or Revisions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-Shunning during pregnancy</td>
<td>breaks off family relationships</td>
<td>loss of family support, social outcast, no hurt because of joy at being pregnant</td>
<td>shift in defining family from extended to nuclear, move to distant community to protect parents from disgrace</td>
</tr>
<tr>
<td>2-Birth of Miguel</td>
<td>becomes mother</td>
<td>happiness at healthy birth</td>
<td>alter lifestyle to be mother, arrange child care at work</td>
</tr>
<tr>
<td>3-Seizure--medical intervention</td>
<td>moves from parenting a healthy child to parenting a sick child</td>
<td>severe medical problems, uncontrolled seizures, coma; left to decide whether to continue treatment or let child die</td>
<td>change in daily life, all effort and time focused on child’s care, uncertain future, change in expectations for Miguel’s development</td>
</tr>
<tr>
<td>4-Miguel’s father rejects him</td>
<td>loss of father for son</td>
<td>ends relationship in response to rejections of son, loss of significant other</td>
<td>shift from nuclear family to single motherhood</td>
</tr>
<tr>
<td>5-Single motherhood</td>
<td>loss of all significant others</td>
<td>lack of social support network, loneliness, severe depression</td>
<td>shift in belief about control over life, yields to acceptance of other forces affecting planned outcomes</td>
</tr>
<tr>
<td>6-Change in work hours</td>
<td>decreases emphasis on professional role, increases emphasis on mother-caregiver role</td>
<td>loss of wages, change of residence to clinic (loss of home)</td>
<td>shift in emphasis from physician to mother</td>
</tr>
<tr>
<td>7-Return to school for master’s degree in education</td>
<td>changes from professional to student</td>
<td>increased leisure hours, improved outlook although still depressed, continued financial stability (from scholarship)</td>
<td>uses strategies to lift spirits</td>
</tr>
<tr>
<td>8-Reaching out to family</td>
<td>repeat of rejection by family</td>
<td>decision not to ask for further help and make it on her own</td>
<td>acceptance that Miguel, disabled or well, is her responsibility as a mother; her family’s responsibility is past</td>
</tr>
<tr>
<td>9-Planning second pregnancy</td>
<td>normal motherhood</td>
<td>rejection by second man of Miguel, continued single motherhood</td>
<td>desire for normal motherhood</td>
</tr>
<tr>
<td>10-Alicia’s prematurity</td>
<td>potentially becoming a parent of a second child with severe disabilities</td>
<td>child survives and thrives, exceptional development; family comes to visit daughter, reestablishment of relationships with sisters and mother</td>
<td>mother of both a child with and a child without a disability</td>
</tr>
<tr>
<td>11-Finishing school, establishing a home</td>
<td>financial independence and self-sufficiency in single motherhood</td>
<td>established for her and her children financial security, able to provide for children’s needs, some difficulty managing child care as Miguel is no longer an infant, and caregivers are hard to find</td>
<td>comfortable lifestyle with her children</td>
</tr>
<tr>
<td>12-Shunning of Miguel</td>
<td>advocate for her son</td>
<td>distress over family’s ignoring of her son, distract that Miguel is confined to one room rather than being accepted in and able to access society</td>
<td>decision to seek other medical treatments in the United States</td>
</tr>
<tr>
<td>13-Entry into United States</td>
<td>immigrant</td>
<td>without contacts or resources in another country, separation from her beloved daughter, entry into society more accommodating to disabled</td>
<td>loss of status, loss of resources, changed social environment (country)</td>
</tr>
<tr>
<td>14-Attempts to find employment</td>
<td>physician credentials not acceptable, “It is like you were nothing”</td>
<td>loss of professional status and employment, homelessness, poverty</td>
<td>not accepted as a professional (devalued in the United States), accepts menial work as means to an end, still informs others that she is professionally trained</td>
</tr>
<tr>
<td>15-Meets current husband, Luis</td>
<td>enters into interdependent relationship</td>
<td>shared trailer, off streets, rebuilds relationships with family because of legitimizing Alicia, fear of exploitation, not alone any more</td>
<td>legitimizing Alicia, revising marital status, giving notice up front that Miguel is first in the relationship, avoidance of past difficulties</td>
</tr>
<tr>
<td>16-Luis loses job</td>
<td>accepts any work she can find</td>
<td>continued financial insecurity, concern over getting sufficient food for Miguel</td>
<td>achieved goal of getting services for Miguel, including school, therapy, and after school program</td>
</tr>
<tr>
<td>17-Enrolling Miguel in school, threatened loss of Miguel, moving into shelter</td>
<td>threatened loss of motherhood</td>
<td>threatened loss of Miguel, improvement in residence, services for Miguel</td>
<td>achieved goal of getting services for Miguel, including school, therapy, and after school program</td>
</tr>
<tr>
<td>18-Getting an apartment</td>
<td>establishing family</td>
<td>establishing a real home</td>
<td>guarded commitment to relationship with Luis</td>
</tr>
<tr>
<td>19-Employment</td>
<td>part-time worker</td>
<td>increased family income, available for caregiving</td>
<td>valuing family above income</td>
</tr>
<tr>
<td>20-Studying English</td>
<td>increase participation in and access to American society</td>
<td>access to higher paying employment, greater access to American society</td>
<td>future goal of improved professional status</td>
</tr>
</tbody>
</table>
From a macrostructural analysis of the narrative, one could argue that in the family relationship story, Maricela's pregnancy with Miguel initially elicits a regressive narrative where family relationships were strained and deteriorating. After her daughter's birth, the family relationships improved, although still limited, to take on a stable to progressive trajectory, with gradual improvement over time. Likewise, in her intimate relationship story, the advent of Miguel's seizures evoked a sudden and dramatic regression in her personal relationships, which only began a slow progressive upward trend when she met Luis and began to build a relationship with him.

Maricela's professional story can be examined in the same vein. After Miguel's birth, she continued on the same track with her career goals. His seizure evoked major changes in her work hours and eventually bolstered her choice to pursue an education degree so that she could better parent her son. Throughout this time, her financial status remained stable because of the scholarship, as did her professional trajectory. After immigration to the United States, her professional aspirations and goals were dashed. She was unable to secure employment as a physician and became homeless and jobless. Now, as she learns English, she aspires and plans to return to the health profession, although at a much less prestigious and well-paying position, reasserting a slowly ascending progressive trend in her professional narrative.

Analysis of Maricela's spiritual story is very different from the preceding ones. A deeply faithful woman in her teenage years, Maricela considered the religious life. Throughout her story, she seemed to describe revisions of life events on the basis of spiritual themes—accepting after the seizures and while in a midst of a great depression that a larger force governed her life; viewing Alicia as a gift from God; describing Miguel as the "road God sent me to walk so that I would not be lost" as a way of life requiring trust in God; describing God as a force in her life to assist her in completing her education; and describing Miguel as the giver of a new perspective of the beautiful things in life. Maricela's story appears to suggest that the spiritual strand of the narrative has a progressive trajectory that increases in strength because of her son's disability. Without the life challenges, beginning with the advent of Miguel's disability, she seems to suggest that she would not have developed her character:

What I feel good about having Miguel is that as limited as he is...he has filled my life with happiness. He has given me a very different perspective about my life, of living, of love, of patience....in other words, the beautiful things I learned with him.

The many decisions, chance circumstances, and events that have led to the alteration of these multiple trajectories seem to be deciphered by exploring the maternal or mother-child strand of the narrative. Maricela's choices were not driven solely in terms of her own adaptation but were highly influenced by maternal thinking (Ruddick, 1989). She struck a balance, often heavily weighted toward her child, in making decisions and taking action. She attempted to get Miguel the needed care that would enhance his health and development by moving to the clinic and going back to school. Maricela's high expectations for Miguel's quality of life led her to continue to pursue other options for Miguel, even after her daughter was born and her life temporarily resumed a smooth upward trend.

Maricela described, vaguely, an accumulation of factors that led her to decide to come to the United States. This decision, made with the best information available at the time, had catastrophic effects for both Miguel and Maricela. Homeless and alone; separated from her daughter; stripped of her resources, including her social class and professional identities; and devoid of a support network, Maricela's situation was more desperate than ever. Finding Luis and a place to live did not stem the downward trend that continued when authorities threatened to take Miguel from her. The decision to leave Mexico and find other resources in the United States was reasonable within the range of her experience as a physician and her knowledge at the time. It was adaptive in the sense that it would or might improve Miguel's condition. But from a longer view, this decision was catastrophic and further compounded by her refusal to turn to her parents for assistance, even in this desperate moment. In the end, however, Miguel got the care his mother sought.

In coping with new conditions, Maricela survived, finding food and living on the streets until she met her husband. Joining their lives and pooling their resources was adaptive in that it continued her existence. All her actions and turnings after her marriage involved moves that improved the family's quality of life (i.e., moving to the homeless shelter, getting a job, saving money and laying away furniture, moving into their own apartment in public housing). These life changes were all improvements compared with living on the street but not compared with Maricela's past lifestyle when she was financially independent and had the benefits of comfortable living.

**Maternal Thinking**

Maricela's life story is entwined with Miguel's. As a mother, her story cannot be separated from her child's. Who and what she is, what she has done, reflects many aspects
of her character as well as her being a mother. Ruddick's (1989) ideas of maternal work—preservation of life, fostering of growth, and training in socially acceptable behaviors—can clearly be seen throughout this story. For example, Maricela's moving to the clinic to accommodate Miguel's need for medical care, providing the intensive nursing care after he left the hospital, preparing special foods, hand feeding him until he learned to eat from a spoon, and being concerned about his physical safety when away from her are instances of preservation work. Her nurturing work includes carefully planning a prenatal program, returning to school for an education degree, providing stimulating toys and activities, seeking appropriate educational and school programs, enrolling Miguel in after school programs, and speaking with his teacher and therapists about his progress. Maricela's concerns over the social environment in Mexico for a child with a disability, in her own family and society in general, led her to immigrate to the United States to increase her son's opportunities rather than limit his world to just one room. She also made special efforts to allow him to attend a recreational program where he could be with other children.

With whose values and by what standards can adaptation in this case be judged? Is Maricela's persistence, despite the heavy costs, an adaptive trait, or is her independent streak, forced by her family's disinheritance, a maladaptive trait? I believe that each day Maricela lived her life and made her choices, she did the best she could to create continuity and to strive toward helping Miguel achieve the best possible. Even now, she struggles between contentment and discontentment, sadness and happiness, hopefulness and lost faith:

I am not happy because...I believe that it is most difficult to have a child with a problem that you know you cannot ever solve. But I am at peace. I am content with my son because with the limitations he has. I have learned to know him, to love him, to understand the way of living...Instead of practicing my career and having a good social and economic status...Ah, my life has changed to that degree. It has not mattered to me what usually matters to a professional person. He is first.

Maricela chose to make the maternal narrative dominant in her life story and in her life goals, reorganizing her other life goals around it. Yet, major changes in any of the narrative strands resulted in a reorganization, demonstrating the interactive effects among multiple life trajectories.

Theorizing About Adaptation

Maricela's story pushes our profession to redefine adaptation, forcing the examination of how value systems and beliefs affect our life choices and how the goodness of choices can be examined. Evaluating individual psychological, social, economic, and physiological outcomes does not appear to be sufficient to describe success in adaptation. A trajectory projection (Corbin & Strauss, 1988), or probable life course, is developed by each person on the basis of his or her own values and expectations as influenced by culturally constructed ideals. "Violations" of the projected life trajectory lead to the need for active responses from the person to mobilize resources on a number of levels—emotional, rational, physical, and spiritual. These responses are attempts to promote a return to the expected ideal life course, unless the person instead chooses to make a simple or radical revision in the direction or goal of the life trajectory in response to events, chance circumstances, or relationships.

A violation of Maricela's life trajectory was Miguel's seizures. As Maricela related, "Since he was a healthy boy...he did not have...[a] precedent, they could not find the cause." Maricela had laid out her plans expecting a happy healthy baby: "When the child was born, I already had a house prepared...I had a room for my son with toys, with clothes, with furniture. He did not need anything but to be there, grow, and use everything." People have a tendency to believe that children with disabilities, like traffic accidents, happen to other people. Miguel's illness and subsequent disability led Maricela to believe that she could not plan her life and that it was not up to her to plan her life. Miguel's birth and severe disability changed the direction of her expected life trajectory, as she had expressed in geometric terms, by 720 degrees. Maricela's immigration to the United States was another jolt to her life trajectory: "I thought it was easy to come and look for a job. And I brought money...that would last for a few months...And I understood it when we had nothing to eat, when we had no place to live."

Expectations for life trajectories appear to be personally defined within a cultural context, culturally bound within societal norms, and intertwining between persons, especially family members. In addition to having her own projected life trajectory, Maricela's family had expectations for her life course that she violated by becoming a single mother. Maricela had a projected life trajectory for Miguel that was violated by his acquiring a disability.

A key facet of the concept of adaptation is the interaction of current events, chance circumstances, and relationships with the projected trajectory of one's life. Circumstances and relationships that cause deviations from the trajectory may also cause the person to react and act in ways to reset the course back toward the expected path. In Maricela's case, she had chosen a trajectory that included being a mother. Her expectations were for a healthy
child who would develop and grow; her actions throughout the story were to find the resources and assistance that would enhance Miguel's development and put it closer to the expected trajectory, altering other life goals to redirect this one trajectory strand. In an attempt to respond proactively to the major life events and daily stresses, Maricela chose responses aimed at enhancing Miguel's development in the present, near, and distant future.

Adaptations, in this case, are actions and responses whose function is to readjust the current circumstances or direct future happenings to more closely align with the desired life trajectory. Responses are made to past, current, and future circumstances and reflect a balancing toward the desired trajectory; however, there may be a cost in these actions. This definition illuminates how adaptation, instead of enhancing life conditions, may lead to outcomes that have short-term or long-term negative effects or costs for all persons involved.

The story of Maricela and Miguel demonstrates how a single life has a projected life trajectory that weaves and intertwines with other lives. For Maricela, the role of mother is prominent in her life, superseding her role as daughter, lover-wife, and physician. As the parent of a child with a severe disability, she acts to adjust and maintain not only the course of her own projected life course, but his as well.

Maricela's story illustrates how the self as a story (Polkinghorne, 1991) can be extended to a conception of the self in motion, moving along a trajectory with a temporal horizon that integrates the past, present, and future. Deviations from the trajectory evoke responses aimed at realigning current circumstances back to the desired path and possible revisions in the final trajectory. These trajectories are multidimensional and intertwined within roles and within sociocultural contexts. How the person forms his or her conceptions of a desired trajectory is heavily influenced by social relationships and internalized cultural constructions within the environmental context. Adaptation, therefore, depending on the vantage point, may not appear to improve life opportunities immediately or enhance the quality of life, if Maricela's life is an example of this process. Adaptation may restore and remold circumstances to a set of expectations and belief systems that compose the projected life trajectory. In the strong desire to make sense of the world, people are sometimes intolerant of violations of their own expectations. For good or bad, people attempt to construct the pieces of their lives into a meaningful whole that matches a projected life course. Adaptation appears to be a dynamic process through which people shift and align the oscillating paths of their lives to attempt to achieve their many life goals as embedded in multiple, culturally constructed life roles when thwarted or buoyed by events, chance circumstances, and relationships.

Conclusion

Not all mothers may embrace maternal values above all else as did Maricela. Yet, her story and the understanding of the temporal, relational, and circumstantial factors on the balancing and shifting of a projected mother–child life trajectory add to our understanding of the multiple dimensions of adaptation. This adaptive process may or may not lead to self-actualization, mastery, or enhanced life quality in the immediate or short term but instead may have costs for one or several family members to redirect the life trajectory of the child with a disability to a hopeful, acceptable one. Adaptation cannot, therefore, be judged only according to the objective outcome but rather on how the action contributes to the achievement of desired life goals within a temporal stream, inherently affecting multiple sets of other life goals with possible costs and benefits.

To comprehend the reasons behind a caregiver's actions requires a threefold understanding of the rational claim based on objective criteria; a normative-evaluative judgement of what is good, right, and proper; and the person's subjective experience (Carspecken & Corderio, 1995). In revising our professional view of adaptation, both the objective criteria for viewing parent's responses and normative-evaluative judgments may need modification in light of this study's findings. Because these first two claims about the reasonableness of actions reside in shared world claims, both the clinician and therapist need to arrive at negotiated, or shared, meanings about adaptation and the values surrounding it because collaboration requires a mutual acknowledgment of the other's position. The therapist can offer, on the basis of his or her knowledge, perspective, and experience with families, possible avenues to explore and possible ramifications of choices, helping to broaden the paths families may consider. Family members, or the mother in this case, need to share their vision for their child as well as pressing priorities. By better understanding the parents' view, the misunderstandings and differences of opinions that are barriers to collaboration and the therapeutic process can be minimized. Extracting narrative can assist health professionals to look past existing interpretations that may suggest noncompliant or difficult clients to examine the contexts in which families' actions or adaptations make sense (Ventres, 1994). Therapists need to examine their own stance regarding adaptation and how they question.
to elicit the families' subjective experience because the professional's values shape the questions he or she asks and hence the information given (Brock, 1995).

Palmer (1987) described the relationship of professional knowledge and practice:

"Every epistemology tends to become an ethic, and that every way of knowing tends to become a way of living...every mode of knowing contains its own moral trajectory, its own ethical directions and outcomes. (p. 22)

Knowing this relationship, we must contemplate the implications of how our professional beliefs about adaptation affect our practice and directly influence our collaboration with parents.

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