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Educational/Support Group for Latino Families of Children With Down Syndrome

Johanna Shapiro and Denise Simonsen

Abstract: Experiences and observations based on an ongoing parent education-support group for Mexican-origin Latino parents of children with Down syndrome were described. Culturally mediated concepts were discussed in terms of their relevance to specific aspects of group functioning, including group structure, membership, and leadership. Problems of particular concern to this population that might adversely affect maintenance and growth of the group were also examined. Finally, the potential value of such support groups for this parent population were considered as were guidelines for enhancing the group experience.

It has long been recognized that support groups serve an important function for individuals experiencing stressful situations, whether the stress is acute or chronic (Dunst, Trivette, & Deal, 1988; Gottlieb, 1981). A large research literature suggests that informal social support buffers stress and promotes health (Felton & Berry, 1992; Cohen, 1988). This finding has also been substantiated for parents of children with mental retardation (Flynt, Wood, & Scott, 1992). Even for individuals with strong familial and interpersonal networks, support groups have been shown to fill an important informational and psychological gap (Rosenberg, 1984); the need for such groups is even more critical for individuals without strong personal support networks. In medical settings, patient support groups for a wide variety of medical conditions, from cancer to Alzheimer disease, have been successfully introduced. Support groups for parents of children who are chronically ill or have developmental disabilities are also widespread. Such groups generally focus on issues of grieving, anger, guilt, financial difficulties, parenting, and coping skills (Gurfein, 1989). Rosenberg (1984) hypothesized that support groups serve an affiliative function and address the sense of marginality that inevitably triggers membership in a support group. Parent support is often one of the services provided by early intervention programs targeting children with developmental delays (Black & Weiss, 1989).

Despite the popularity of support and self-help groups, however, there have been several problems in attempting to apply the concept to ethnic populations. Language differences for Spanish-speaking clients are often cited as one of the most difficult obstacles (Marcus & Marcus, 1988; Putsch, 1985). Yet, as the numbers of Latinos continues to grow in the United States (Davis, Haub, & Willette, 1988), it becomes increasingly important to include this segment of the population in all forms of support services. The more recently arrived immigrant Latino population is at particular risk for mental and physical dysfunction resulting from the stressors of acculturation and immigration (Guendelman, 1983; Sanchez, 1987) and has also been identified as a severely undeserved population in terms of health care needs (Humm-Delgado & Delgado, 1983; Padilla, Ruiz, & Alvarez, 1983). Cross-cultural tensions can be exacerbated when parents participate in the health care system on behalf of a child who is sick or medically compromised (Porter & Villaruel, 1991; Siantz de Leon, 1990). Others have noted that Latino parents often have very little psychosocial support available to them in dealing with such pressures (Saltoun & Gracia, 1991).

Yet efforts to involve Latinos in group support activities are often unsuccessful. In addition to language barriers, commonly reported problems are a lack of attendance at groups with primarily majority culture membership, significant discomfort of individuals from ethnically diverse backgrounds with the group discussion format, and a clash of world views and values between middle-class leaders and members of ethnic minorities (Henderson & Gutierrez-Mayka, 1992). In light of these problems, professionals must consider whether support groups make sense for Latinos and whether they can be an appropriate and culturally sensitive form of intervention.

Several authors have suggested that a support group is an alien, American concept, inappropriate for Asians or Latinos (Atkinson, Morten, & Sue, 1983). This viewpoint holds that self-disclosure is not a strong value in the Latino culture, especially among individuals with whom one has not established a close personal relationship (Rogler, Malgady, Constantino, & Blumenthal, 1987; Taylor-Gibbs, 1989). A Latina professional counselor expressed the view that for Latinos, one-on-one therapy is preferable to group approaches and that men will generally be reluctant to participate in any kind of therapy or support group because of values of machismo (Henderson, personal communication, 1993). A related issue is that Latinos may tend to seek out a religious leader in preference to a medical professional for problems they perceive to be emotional/spiritual in nature (Padilla et al., 1983). This general viewpoint also includes the concerns that Latinos may avoid counseling out of shame and stigma as well as fear of the unknown. Others have expressed the opinion that Latinas do not make good candidates for traditional psychotherapy, often complaining about their situation but unwilling to make changes (Texidor del Portillo, 1987).

Still others have pointed out that by imposing the norms of group process on a population unfamiliar with these rules, such groups are engaging in a kind of cultural imperialism, inflicting culturally inappropriate expectations and standards of behavior.

These arguments criticize counseling approaches to minorities and ethnic populations for expecting them to adapt to mainstream services and applying middle-class treatment norms that may not be relevant to lower-class patients (Canino & Canino, 1980; Lum, 1987). They also accuse nonminority counselors of cultural biases, such as perceiving lower class patients as hostile, suspicious, and expecting purely symptomatic relief (Padilla et al., 1983), and of not empathizing with their patients because of different life experiences (Borkan & Neher, 1991). These commentators have also observed that long-standing oppression and discrimination in the American culture make minorities wary of any services offered through formal social institutions (Keefe, 1982; Miranda, 1986).

On the opposite side of the coin is the argument that groups for Latinos or other ethnic minorities are really no different in their structure and process from mainstream groups, thus minimizing the importance of class and culture (Green & Leigh, 1989).

This point of view contends that all groups are plagued by generic problems of erratic attendance, changing membership, leadership vacuum, and discomfort at expressing personal feelings. They also deal with the same universal emotions of grief, guilt, and anger. All share the common goals of strengthening coping mechanisms and providing support. What then, proponents of this perspective might ask, is different about a support group for Latinos?

As one author has sensibly commented, many parental experiences and reactions are transcultural (Vassiliou & Vassiliou, 1974), that is, broadly speaking, certain emotions and behaviors are common to all human beings, regardless of race or ethnicity. Thus, one would not expect dramatic difference among ethnic groups on these large dimensions. Rather, it is the cumulative effect of cultural differences and perceptions, matters of degree and intensity, that create subtle, but significant, variations in experience between mainstream and ethnic support groups (Henderson & Gutierrez-Mayka, 1992).

Despite these concerns, many professionals and paraprofessionals have persisted in efforts to make group experiences relevant to Latino individuals. In fact, Latinos have an impressive indigenous history of several different types of self-help groups (Rivera, 1987). More recently, many successful group experiences have been documented for Latinos, from health care (Schaefer, 1983) to education (Ada, 1988). Much of the relevant literature regarding Latinos deals with group therapy, a treatment modality only marginally comparable to parental support groups. In one study of a group of Latino psychiatric patients, McKinley (1987) reported problems relating to time frame orientation, erratic attendance, and somatization but also found benefits to patients in terms of self-reliance and self-assertion. Delgado and Humm-Delgado concluded in their review of the literature that group therapy can provide good results for group members when used in a culturally sensitive way (Delgado, 1979;Delgado & Humm-Delgado, 1984). Group therapy approaches utilizing behavioral and experiential methods (Acosta & Yamamoto, 1984), including the use of relevant activities (Delgado, 1983) appear to meet with considerable success in Latino patient populations.

Padilla et al. (1983) have identified three generic approaches to enhance relevance of mental health activities for Latino individuals: (a) *professional adaptation*, in which conscious efforts are made to involve individuals of appropriate ethnic backgrounds in professional roles and to overtly educate non-Latino professionals regarding the culture and values of traditional Latinos; (b) *family adaptation*, where attempts are made to pattern group therapy after traditional Latino family roles, and (c) *the barrio (Spanish-speaking quarter or neighborhood) center experience*, where issues of community involvement, language, outreach, and location are dealt with in ways sympathetic to the targeted patient population. Padilla criticized the argument that Latinos are generally not in need of mental health services because they have large, informal family networks and identified them as one of the most seriously underserved mental health populations.

Investigators looking specifically at training groups for Latino parents of children with disabilities have noted significant positive changes in mother's teaching ability, child's self-help skills, child's behavior problems, and family home-teaching (Prieto-Bayard & Baker, 1986). In a study of a population of parents of children with severe cerebral palsy, Pilon and Smith (1985) showed similar findings resulting from group intervention.

In an excellent study Henderson, Gutierrez-Mayka, Garcia, and Boyd (1993) identified specific approaches to ensuring participation and relevance in support groups for African–American and Latino caregivers of patients with Alzheimer disease, including (a) development of *ethnic competence* in group facilitators, a term implying some familiarity with Latino ethnic history and culture; (b) involvement of community leaders and extensive community preparation; (c) outreach using ethnic media; (d) repeated personal contact; (e) activation of multiple feedback loops to make the group culturally relevant; and (f) identification of a neutral and/or culturally significant location. Finally, in another article on self-help support groups for Latino mothers, Leon, Manzur, Montalvo, and Rodrieguez (1984) commented on the successful development of a mutual aid system and progressively increasing signs of leadership within the group.

Method

The methodology employed was basically anecdotal and descriptive. The basis for this article was a journal kept by the second author in which she recorded impressions and observations after each group meeting. In addition, the two group members who attended most regularly were interviewed by phone regarding their perceptions of the interaction of group process and cultural factors. Finally, 4 parent leader/participants of PROUD, an information and support group for English-speaking parents of children with Down syndrome; 2 professionals who have worked primarily with Anglo support groups; and 5 professionals who have worked with both Latinos and Anglos were interviewed to assess their perceptions of the role of cultural factors in various aspects of group structure and process. The group described in this paper was in existence for approximately 3 years.

Group Formation

Previous authors have emphasized several dimensions that must be addressed in order to increase the likelihood of success in an ethnically oriented support group (Henderson et al., 1993). One key point is advance preparation. In part because of the cultural lack of familiarity with the concept of group support, group leaders must put forth extra effort to promote the concept within the community, to make explicit ways in which potential members might benefit from involvement, and to elicit input from the community in terms of how the group might be structured to enhance comfort and

participation. These guidelines were followed for this group in the following ways.

The second author and a Latina caseworker from the Developmental Disabilities Center identified a need for a Latino parent support group for families of children with Down syndrome. They felt that these parents required more support than was provided within existing institutional frameworks. Although the local chapter of PROUD did not exclude Latinos, all their meetings and informational mailings were in English. There were no monolingual Latino members, very few bilingual members, and none who consistently attended meetings. Thus, there seemed to be a need for a support group targeted specifically at Latino parents. At the time, the objectives for such a group were seen to be very similar to those of other support groups, including (a) dissemination of educational information about their children's diagnosis and prognosis; (b) discussion of reactions, fears, anxieties, and other feelings, both positive and negative; and (c) development of supportive networks with other parents facing similarly stressful situations (Hartman, Radin, & McConnell, 1992).

Prior to starting the group, the second author and the Latina social worker contacted the founder and facilitator of the Los Angeles Down Syndrome Parent Group for Latinos. They also met four times with a Latino family of a child with Down syndrome to brainstorm about group goals, structure, and format. In addition, the second author attended a conference sponsored by the Los Angeles group to gain additional information about the Latino culture. Other preliminary steps included sending a letter in Spanish to hospital patients and clients of the Developmental Disabilities Center who might have had a need for the support group as well as placing a notice in Spanish in two newsletters for families of children with disabilities. Flyers in Spanish were distributed to hospitals and professionals in the community. All these efforts were designed to inform the community as to who might potentially benefit from services as well as to solicit their input and suggestions.

Cultural Considerations and Observations

Group structure. Using the information gained from the process just described, group leaders decided to meet on a monthly basis on Sunday evenings for about 3 hours, create a leisurely atmosphere, be more accessible to working parents, and encourage the whole family to participate. The format consisted of a presentation in Spanish by a speaker with expertise in some aspect of the care and treatment of children with Down syndrome, followed by group discussion and information exchange. Representative topics included genetic aspects of Down syndrome, occupational and physical therapy for the child with Down syndrome, overview of services provided by the Developmental Disabilities Center (Regional Center), nutrition for the child with Down syndrome, and general pediatric care and special needs of the Down syndrome child. These topics tended to be educational in nature and emphasized knowledge and skill acquisition rather than expression of emotion. However, the group discussions regularly touched on the emotional aspects of the child's condition, and new members were always encouraged to share their emotional responses to their child's diagnosis. In addition, informal discussions at the start of the group, as well as one-to-one interactions with the speaker, frequently triggered group member emotions.

Location of meetings. Meeting sites for groups can be a salient issue because locations that are perceived as intimidating or uncomfortable may discourage participation. Meetings of this group were held in a conference room of the local Developmental Disabilities Center (Regional Center). This location was chosen partly for pragmatic reasons: The space was available and Center administrators were willing to assume liability as well as provide occasional staff support. From the families' perspective, this location was a good choice because (a) it was familiar to families because most of the children were clients at the Center, (b) it was easily accessible by bus, (c) free parking was provided, (d) it was centrally located geographically, and (e) it was a reasonably comfortable, informal setting.

Group membership. Given the fact that members of the same ethnic group may be at different points along the acculturation continuum (Valle, 1989), we decided to target a very specific subset of families in the Latino community, specifically, Mexican-origin Latinos who had been in this country 5 years or less. The perceptions of the originators of the group were that this was the largest group of underserved Latino families in the community and the one in greatest need of additional support. Because of the strong family-oriented nature of traditional Mexican culture (Harry, 1992), a special effort was made to make the group meetings a "family" event.

The initial mailing list included approximately 70 families. At any given meeting, however, the total number of families attending was about 3 to 8. Usually 1 or 2 new families attended the group each month. The total number of individuals attending, including friends, extended family members, and siblings of the target child, was about 20. Membership fluctuated, with the most long-standing member having been in the group 2 years. The average length of participation in the group was approximately 3 to 4 meetings over an 8-month period. Few families participated longer than one year, although members sometimes stopped attending and then later resumed attending.

Although the traditional Latino family usually is characterized by large, supportive extended family networks (Sobogal, Marin, Otero-Sobogal, Van Oss Marin, & Perez-Sable, 1987), often this support system is fragmented because of the fact that many family members remain in Mexico. Although there were large extended families that participated in the support group, there were also many families who involved friends rather than relatives, as well as single mothers who had virtually no outside support. Further, even in two-parent families, the mother was as likely to work as the father.

Both mothers and fathers were invited to participate, and approximately one-half of the fathers did so on a regular basis. Siblings were also welcome, and almost all the participating families had at least one other child. The age of the target child was usually under 2 years, although they ranged in age from newborn to 5 years. The group participants were primarily Spanish-speaking, although many knew some English. This group was very similar to other support groups in terms of the number of participants and the frequency of meetings (Crandles, Syssman, Berthaud, & Sunderland, 1992; Gurfein, 1989; Henderson et al., 1993). It differed somewhat in its inclusiveness of other family members and friends and because it was held on a weekend evening. The reasons for these and other variations are discussed later.

Personalismo. A crucial component of the group was a sensitivity to the concept of personalismo, a construct deeply rooted in traditional Latino culture. In brief, *personalismo* refers to a pervasive attitude that combines the primacy of interpersonal relationships based on trust with a dislike of formal, impersonal institutions (Fitzpatrick, 1987; Padilla et al., 1983). Several authors have noted contrasts between the more distant, "object-oriented" culture of the United States and the warmer more personal process cultures of Latin America (Falicov, 1982; McGowan, 1988). One of the implications of personalismo is that groups for Latinos need to be personalized and individualized, differentiated from the impersonal health care system with which many Latinos have had previous problematic encounters.

There were several ways in which efforts were made to make this particular group a friendly, intimate experience. The meeting time of Sunday evening separated the sessions from the normal work week. The presence of refreshments also created a more social atmosphere. Insofar as was possible (given an absence of telephones in many of the family houses), group members were personally contacted before each meeting and invited to attend. A Christmas party, held annually, was a festive occasion that drew large numbers of participants (in 1992, over 200 people attended).

Other ways of promoting informality included circular seating, and nonlecture presentation styles encouraged for guest speakers. One way, recommended by Myerson (1990), to increase the operation of personalismo in a group format is for the facilitating professional to talk to participants about his or her own family. Fortunately, during the second year of the group, the second author was expecting her first child. Sharing this increasingly obvious fact with a roomful of parents, all more experienced and familiar with the ins-and-outs of child-rearing, served to reduce professional distance and create shared bonds. The facilitator also increased intimacy by asking parents to address her on a first-name basis and by using their first names after the first few meetings, an approach frequently preferred by Latinos when they are not functioning in the formal setting of a medical or professional appointment (Ruiz & Padilla, 1983).

Another implication of personalismo is that Latino families are more accustomed to a slower paced, generalized style of interaction. The instant intimacy, quick-fix approach of many support groups might appear to some Latinos to be

uncomfortably hasty and insincere. Thus, although sensitive topics were discussed routinely in the group, they were introduced in a more casual indirect fashion and were allowed to unfold at a leisurely pace.

Familism. Familism refers to the primacy of the family rather than the individual in traditional Latino culture and the importance of honoring duties toward the family before external obligations (Harry, 1992; Hoppe & Heller, 1975). This value manifests itself in health care because decision-making about medical care is rooted in the family (Meyerson, 1990). It also plays a role in the sense that any stigma perceived to be attached to a disability such as Down syndrome is perceived to extend to the entire family (Henderson & Gutierrez-Mayka, 1992).

Thus, a family-oriented "treatment" seemed most appropriate. For this reason, the boundaries of the group were extended to include not only the mother as primary caretaker, but father, siblings, other relatives, and family friends. Although at times this enlargement diffused the intimacy and focus of the group, it created a clear sense that the group was concerned with the viewpoints and feelings of all those affected, an approach very compatible with the traditional Latino understanding of illness.

Further, it was apparent early on that if other children had to remain at home, the complexities of child-care arrangements discouraged parents from attending. This family-oriented approach included regular focusing on the needs of family members other than the target child. For example, between 17 and 35 families routinely attended the annual Christmas meeting, when food, toys, and clothes were distributed.

Concept of a "support group." The concept of a support group was foreign to nearly all of the Mexican-origin Latino families who participated in the program. They were usually unfamiliar with group dynamics (e.g., personal introductions, group discussion, sharing emotions or problems with strangers). However, they appeared to have little difficulty in familiarizing themselves with this situation. When asked about the idea of a support group, one participant replied, "I think it's a lot more positive in a group. One-on-one Latinos are more likely to hide their feelings. Latinos like to hide their feelings or hurt, and when they're in a group, it's easier." Another mother said, "It's very hard in the beginning, because we're not familiar with it. Once you start, it's great."

The role of self-disclosure. Traditional Latinos are often considered to be uncomfortable discussing personal issues outside the family context (Henderson, 1989). Sharing personal information is usually reserved for a close friend. Professionals interviewed shared this view, stating that "Hispanics tend to be less expressive [than Anglos] in a group." On the other hand, few individuals are initially comfortable with self-disclosure, regardless of their cultural background. Another parent–professional who works exclusively with Anglo groups has noted, "Emotional expression is a big problem for almost everyone, especially for newcomers and men."

In the Latino culture, this reluctance to express feelings among strangers is closely related both to personalismo, and the notion of *confianza*, or trust. As one group member expressed it, "Trust is Number One!" Some authorities believe it may take years to establish the level of trust required for significant self-disclosure (Velez, 1982). However, the experience of this group seemed to follow patterns similar to other support groups, in which group members also tend to exhibit initial hesitancy and caution about expressing feelings, later giving way to openness and spontaneity (Gurfein, 1989). In our experience, helping these Latino parents overcome initial barriers again related to the personalismo of the group facilitator. One group member commented that "It's the way [the group facilitator] talks to us that makes us comfortable. . . . these things makes us feel mucho confianza." Another participant said simply, regarding confianza, "If you attend the group, you will get it."

Further, meeting other families facing similar problems appeared to reduce the sense of isolation and alienation experienced by new families. This has been referred to by other authors describing Latino self-help groups as *desahogo*, or "emotional release achieved through ventilation of problems" (Leon et al., 1984). Older members who had attended previous meetings assisted in normalizing the sharing of personal feelings for new members.

Simpatia As a Potential Barrier to Group Process. Simpatia is a global term used to define a cluster of culturally mediated behavioral tendencies that characterize many Mexican-origin Latinos (Triandis, Hui, et al., 1984). These tendencies include an emphasis on politeness and respect, a desire to avoid conflict, and the promotion of harmony (Diaz, 1987; Triandis, Marin, Lisansky, & Betancourt, 1984). In the group context, the presence of simpatia sometimes made it difficult to tell whether the group was succeeding in its objectives because members stressed agreement and minimization of differences. One group member stated that sympatia for other group members might cause a suppression of comments that might result in distress to others: "It might happen because we are not all the same, our children have different disabilities, some are smarter than others. I think they would speak up but it may take time."

The operation of simpatia may also have made it less likely that group members would take initiative in the group, as this might have appeared to challenge the facilitator's authority. Respect for the authority of professionals, especially medically related professionals, is also taught early within the family unit (Duran, 1988). Most of the parents appeared hesitant to ask speakers questions following their presentation. One group member observed that "They may be afraid that they won't respond in the right way or that they are not intelligent enough." By encouraging speakers to linger after their presentation and talking with parents informally, one-on-one, the facilitator made the interactions more mutual, and parents became noticeably more vocal. Thus, the familiar format of presentation followed by group discussion was modified to include time for one-on-one interaction.

In general, the presence of simpatia and the desire to demonstrate respect for authority figures may have altered the interaction of the group somewhat. However, in our opinion, these inhibitions were less significant in a support group than they might have been in a psychotherapy group, where confrontation about interpersonal relations in the group is a critical therapeutic factor. In a support group that stressed caring and compassion, the presence of simpatia on the whole was a positive construct, cultivating a sensitivity among group members to the needs of others.

The role of machismo. Much has been written about the concept of machismo in Latino cultures. *Machismo* stresses the dominant role of the male but recognizes leadership of the woman in the sphere of home and children (Comas-Diaz, 1989; Taylor-Gibbs, 1989). Often, machismo is incorrectly interpreted to mean noninvolvement or lack of interest on the part of the man in child-rearing and child development. Although negatively viewed by the American culture, machismo in the Mexican-origin Latino is basically a positive construct and encompasses virtues of courage and fearlessness as well as a responsibility to care for and make important decisions regarding the family (Padilla et al., 1983; Schaeffer, 1983). One implication of machismo is that fathers should be included whenever possible in discussions regarding their child's condition and treatment. Although Latino professionals in our informal survey regarded paternal group attendance as more of a problem among Latino than Anglo families, in this group, it was often the fathers who were first to participate in discussion and, even more surprisingly, express their emotions. At the first group meeting, the fathers tended to speak first and by its conclusion, most had become teary-eyed.

Fathers who attended the group appeared to be very involved, supportive, and accepting of their children with Down syndrome, a reaction partly attributable to the machismo ethic. One group member said, "Because of machismo, they [the dads] care for them [children with Down syndrome] almost more because they need help."

Some of the men did appear to feel that having a child with Down syndrome was a negative reflection on themselves and represented a type of failure. In the words of one respondent, "It is related to machismo because they make illusions of what the child can do with them when they grow up and when the child has a disability the child can't do these things." This type of response may have been in part a reflection of a machismo ethic but may also be related to the stigma of familism discussed previously and, in fact, is a commonly observed reaction in Anglo fathers as well (Shapiro, 1988). Some women whose husbands did not attend the group reported that the fathers did not participate because it was difficult for them to face their child's condition. This observation has some support in the research literature, which documents an unusually high level of denial among Latino fathers as reported by their wives (Mary, 1990). Wives who came to group meetings without their husbands often reported that their husbands evinced particularly strong denial and seemed to avoid dealing with the child's diagnosis.

Religious belief and fatalismo in context. Some authors have reported that the traditional world view of many Latinos implies a certain fatalism about destiny (Leon et al., 1984; Meyerson, 1990; Williams & Williams, 1979). This religious/cultural distinction emphasizing God's will superseding human will does not necessarily lead to resignation so much as acceptance (Betancourt, Hardin, & Manzi, 1992; Mardiros, 1989), even of outcomes that are antithetical to the individual's desires. It is important to note, however, that *fatalismo* is a controversial topic, and many contend that little documentation is available in support of its existence (Duran, 1988; Ruiz & Padilla, 1983).

Most group members were Catholic and expressed the belief that they had a child with Down syndrome because "that is what God wanted." One woman described her son as a "hidden angel." Many of the parents stated that they have accepted what God has given them. However, although most of the group members were churchgoers, religion appeared to be a fairly private arena and was rarely discussed specifically in group.

Although the belief that difficult events are an expression of God's will provides a context for families to understand what has befallen them, blaming of self and others occasionally occurred, a phenomenon found in both traditional Mexican culture (Shapiro & Tittle, 1986) and among middle-class Anglo parents. In the group, when one parent was held accountable in some fashion for the child's condition, it was often the mother who took the brunt of this guilt. However, at times mothers blamed their child's condition on father's drinking or physical abuse during pregnancy.

Group attendance. There is a perception that lower-class Latino patients are less prompt and less reliable than middle-class Anglos in keeping medical appointments, although there is little documentation for this belief, and professionals familiar with Latino patients anecdotally reported them to be on-time. To the extent that this perception accurately reflects a certain reality, the primary explanation is probably to be found in issues of poor access and lack of transportation. Attendance problems did plague this particular group, although this is a common complaint among many support groups (Crandles et al., 1992). When funding for a taxi voucher system was obtained, which provided transportation for needy members, participation improved markedly, with anywhere from 3 to 15 families using the service per meeting. A related factor may be the day-to-day survival mentality noted in many families in low socioeconomic (SES) circumstances, regardless of ethnicity. A family living in poverty, as were most of the families in this group, may prioritize differently than does a more affluent family. Thus, cashing a check to pay the rent or buying food when money is available may take precedence over a support group meeting.

Finally, time orientation may play a role in prompt start-up times for meetings, although this too is a subject of much debate (Duran, 1988; Ruiz & Padilla, 1983). Some authors argue that the concept of time has a somewhat different meaning in the Latino than in the Anglo culture (Dana, 1993). For example, the Mexican patient may consider it acceptable to be late for a medical appointment but would not expect to be kept waiting by the physician (Henderson, 1989). Similarly, in traditional Latino culture, the focus on relationship rather than task (Kluckhohn & Strodtbeck, 1961) may mean it can be more important to continue a conversation with a friend than to be on time for an appointment. All these considerations led to the expectation of a slow start-up time for group meetings and scheduling of speakers later in the evening in response to the gradual commencement of the group session. This solution seemed to reduce pressure on parents and facilitators alike and proved to be an agreeable accommodation.

A related issue was the difficulty in obtaining long-term commitments from many of the group members. This again is a common problem reported by support groups and is probably a function more of SES than culture. The undocumented status of many families in this group, coupled with, for example, lack of jobs, money, food, education, transportation, housing, and phone, may have contributed to the feeling of many group participants that they were so absorbed surviving in the present that they did not have the luxury to think far into the future. It is also true that the group had targeted a highly transient population, whose movements were in large part determined by available jobs and housing. In any case, few families made long-term commitments to the group, and many came to only two or three meetings.

Interviews with professionals and parent–professionals in general tended toward the conclusion that ethnicity in general was not an important factor in either attendance or long-term commitment. Those who did feel this was more of a problem for Latinos attributed difficulties to transportation and child-care problems and the absence of a "critical mass" of Latinos in mainstream groups.

Group leadership. One persistent difficulty was in getting group members to take a more active leadership role in the group. Although leadership issues are a pervasive problem in many support groups, our informal survey indicated that professionals who worked with both Latino and Anglo groups felt that lack of parental leadership was more of a problem in Latino groups. In this group, although members occasionally suggested topics for speakers or brought refreshments, they generally were hesitant to take more major responsibility for group functioning (e.g., planning the next meeting, facilitating meetings). Their nonverbal cues often expressed that they preferred to be observers rather than active participants. The use of a questionnaire in Spanish to elicit topics for discussion was unproductive, with every option eliciting a "fine" response, possibly in part because it was an approach that violated expectations of personalismo. Despite their disinterest in taking a leadership role, many families were repeatedly generous and altruistic toward other group members, willing to go to great lengths to provide help and support, including transportation and child care.

Toward the end of the 3-year period reported here, the leadership situation began to change. Many articles regarding successful ethnically based support groups emphasize the importance of actively involving indigenous community people (Henderson et al., 1993; Padilla et al., 1983). To the great frustration of the group's facilitator, this had been difficult to accomplish, despite many attempts to involve parents at a higher level of responsibility. At about the same time that the facilitator decided to play a more low-key role in the group for personal reasons, a Latino, who was the parent of a Down syndrome child and was well-known to some in the community for her enthusiasm and activism, agreed to assume responsibility for facilitating the group; graduate students retained responsibility for organizational and administrative issues, such as mailing announcements and arranging for speakers. This represented a significant shift in the emphasis of the group, sparking an enhanced sense of ownership and involvement among group members.

The role of a non-Latino group facilitator. One of the most controversial issues in counseling in general or counseling individuals of a particular ethnic group is whether, and to what extent, an individual from a dissimilar cultural and ethnic background can adequately serve in a counseling role. There is some evidence that low-income patients engage in significantly more self-exploration in treatment if matched with their therapist on race or social class (Padilla et al., 1983). Many of the critics of mainstream counseling who were cited at the beginning of this paper lay the blame squarely on counselor limitations and biases resulting from lack of familiarity with the ethnic background of clients. Some frankly recommended that the facilitator share the ethnic background of group members as a way of ensuring group acceptance (Guendelman, 1983).

In this case, although a Latina caseworker was involved in the initial formation of the group, the ongoing facilitation fell to the second author, a non-Latina genetics counselor, who spoke some Spanish but did use an interpreter during group sessions in order not to misconstrue parent statements or inadvertently miscommunicate. The experience of this group suggested that, although a lack of shared cultural background may create certain difficulties, these can be overcome in large part by an emphasis on *personalismo* and a willingness to accept group input and guidance. When asked about this issue, group members expressed a variety of opinions: "Maybe if her Spanish was better, it would be easier." "If _____ [facilitator] was a Latina, it would depend on the person, it could be worse." "By _____ [facilitator] not being Latina, we got the American thinking of the subject. With our own thinking, your way of thinking helped us to see it [Down syndrome] as not so negative." In fact, this perspective of a cross-cultural presence in counseling opening up new understandings and new ways of interacting reflects a point of view also reflected in the professional literature (Padilla et al., 1983). The fact that the facilitator recognized language and cultural limits; employed an informal, personal approach; and treated group members with respect and dignity (Canino &

Canino, 1980) appeared to outweigh cultural differences.

Here again the type of group may have been a significant variable. In a self-help group, leadership is dependent on members who share a similar background and common stressful experiences (Madara & Meese, 1990). A support group, however, recognizes that authority for leadership comes from expertise and training, and this seemed to harmonize well with the traditional Latino respect for authority (Duran, 1988).

Discussion

Potentially Helpful Aspects of a Support Group

Despite chronic problems with attendance and participation, a support group such as the one described in this paper can make real contributions to Latino parents and families. Some of the most important ways this support group was helpful to participants were the following:

Normalizing of the family's experience. Often families of a child with Down syndrome become socially isolated (Seligman & Darling, 1989; Shapiro, 1988). Understanding their personal experience in light of others' accounts provides both information and understanding.

Improving families' interface with the outside world. The group provided the opportunity for structured interaction with a variety of professionals. In this sense, it offered members a kind of behavioral rehearsal, a successive approximation of strategies and approaches that they could then use successfully in other real life contexts.

Enlarging options. Through education and communication of information, one of the functions of the support group was to give parents the skills to be social change agents within the larger society.

Caregiving from the facilitator. Many Mexican-origin Latino families have a fragmented social support system, with many family members remaining in Mexico. Consequently, they often have limited social resources to turn to for nurturance and support. The group facilitator played an important role in expressing caring and concern for group members.

Modeling of appropriate behaviors, both with their child and with the larger society, including professionals. Modeling occurred from three sources: (a) the group facilitator, (b) speakers, and (c) other parents. Through this process, parents developed new skills for how to behave with and think about their child and how to interact with the larger society.

Facilitating one-on-one networking among parents (Velez, 1982). Although many participants initially experienced the group format as somewhat alien, it provided a convenient forum for individual mothers and fathers to become acquainted, develop friendships, and serve as an informal supportive infrastructure for each other.

Developing skills in using a problem-solving model. For these parents, addressing the needs of their children was complicated by the need to function within a strange culture. The group environment allowed for problem-solving approaches to be explored regarding their child's interface with such organizations as the Developmental Disabilities Center, the school system, and the health care system. Group members became adept at short-term planning and received help in learning how to articulate their needs to health care professionals.

Facilitating grief resolution. The support group helped with grief resolution in that it gave permission for the expression of sorrowful or angry feelings and removed some of the social stigma attached to these emotions.

Enhancing empowerment and responsibility. Finally, as the group process moved from reliance on professional to more leadership from paraprofessionals and group members, it became an exercise in empowerment and responsibility.

In conclusion, the concept of an educational support group, although culturally strange, can offer benefits to Latino families of children with Down syndrome. Facilitators must exercise special sensitivity in discovering how traditional cultural values and modes of being may impact group participation and interactions.

They must also be aware of personal biases and assumptions and strive to achieve "cultural competence." For continuing success, the group must have an evolving sensitivity and flexibility to address culturally mediated issues as they arise and to recognize that culture is not a static entity, but itself a process in constant flux. When the structure and process of the group are flexible enough to accommodate cultural differences, parents learn valuable skills of problem-solving and emotional expression. Over time, they may also acquire important understandings about how to create informal structures that enable them to better care for their children, their families, and others within their community.

References

Acosta, F. X., & Yamamoto, S. (1984). The utility of group work practice for Hispanic Americans. *Social Work with Groups, 7,* 63–73.

Ada, A. F. (1988). The Pajaro Valley experience. In T. Skutnabb-Kangas & J. Cummins (Eds.), *Minority education: From shame to struggle* (pp. 223–238). Clevedon, England: Multicultural Matters.

Atkinson, D. R., Morten, G., & Sue, D. W. (1983). *Counseling American minorities: A cross-cultural perspective* (pp. 0–31). Dubuque, IA: Brown.

Betancourt, H., Hardin, C., & Manzi, J. (1992). Beliefs, value orientation, and culture in attribution processes and helping behavior. *Journal of Cross-Cultural Psychology, 23,* 179–195.

Black, R. B., & Weiss, J. O. (1989). Genetic support groups in the delivery of comprehensive genetic services. *American Journal of Human Genetics, 45,* 647–654.

Borkan, J. M., & Neher, J. O. (1991). A developmental model of ethnosensitivity in family practice training. *Family Medicine, 23,* 212–217.

Canino, I. A,. & Canino, G. (1980). Impact of stress on the Puerto Rican family: Treatment considerations. *American Journal of Orthopsychiatry, 50,* 535–541.

Cohen, S. (1988). Psychosocial models of the role of social support in the etiology of physical disease. *Health Psychology, 7,* 269–297.

Comas-Diaz, L. (1989). Culturally relevant issues and treatment implications for Hispanics. In D. R. Koslow & E. P. Salett (Eds.), *Crossing cultures in mental health* (pp. 31–48). Washington, DC: SIETAR International.

Crandles, S., Syssman, A., Berthaud, M., & Sunderland, A. (1992). Development of a weekly support group for caregivers of children with HIV disease. *AIDS Care, 4,* 339–351.

Dana, R. H. (1993). *Multicultural assessment perspectives for professional psychology* (pp. 65–78). Boston: Allyn & Bacon.

Davis, C., Haub, C., & Willette, J. L. (1988). U.S. Hispanics: Changing the face of America. In E. Acosta-Belen & B. R. Sjostrom, (Eds.), *The Hispanic experience in the United States: Contemporary issues and perspectives* (pp. 3–55). New York: Praeger.

Delgado, M. (1979). Therapy Latino style: Implications for psychiatric care. *Perspectives in Psychiatric Care, 17,* 107–113.

Delgado, M., & Humm-Delgado, D. (1984). Hispanics and group work: A review of the literature. *Social Work with Groups, 8,* 85–96.

Diaz, V. (1987). Caribbean Hispanics. In B. Biesecker, P. Magyari, & N. W. Paul (Eds.), *Strategies in genetic counseling. II: Religious, cultural and ethnic influences on the counseling process* (pp. 174–176). (March of Dimes Birth Defects Foundation. Birth Defects: Original Article Series, 23)

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). *Enabling and empowering families* (pp. 0–32). Cambridge: Brookline Books.

Duran, E. (1988). *Teaching the moderately and severely handicapped student and autistic adolescent.* Springfield, IL: Thomas.

Falicov, C. J. (1982). Mexican families. In M. McGoldrick, J. K. Pearce, & J. Giordano (Eds.), *Ethnicity and family therapy* (pp. 134–163). New York: Guilford Press.

Felton, B. J., & Berry, C. (1992). Groups as social network members: Overlooked sources of social support. *American Journal of Community Psychology, 20,* 253–260.

Fitzpatrick, J. P. (1987). *Puerto Rican Americans: The meaning of migration to the mainland.* Englewood Cliffs, NJ: Prentice-Hall.

Flynt, S. N., Wood, T. A., & Scott, R. L. (1992). Social support of mothers of children with mental retardation. *Mental Retardation, 30,* 233–236.

Gottlieb, B. H. (1981). Preventive interventions involving social networks and social support. In B. H. Gottlieb (Ed.) *Social networks and social support.* Beverly Hills: Sage Publications.

Green, J. W., & Leigh, J. W. (1989). Teaching ethnographic methods to social service workers. *Practicing Anthropology, 11,* 8–10.

Guendelman, S. (1983). Developing responsiveness to the health needs of Hispanic children and families. *Social Work in Health Care, 8,* 1–15.

Gurfein, H. N. (1989). Group therapy with the parents of children with chronic illness. In D. A. Halperin (Ed.) ,*Group psychodynamics: New paradigms and new perspectives* (pp. 189–208). Chicago: Year Book Medical Publishers.

Harry, B. (1992). *Cultural diversity, families and the special education system: Communication and empowerment.* New York: Teachers College Press.

Hartman, A. E., Radin, M. B., & McConnell, B. (1992). Parent-to-parent support: A critical component of health care services for families. *Issues in Comprehensive Pediatric Nursing, 15,* 55–67.

Henderson, G. (1989). *A practitioner's guide to understanding indigenous and foreign cultures.* Springfield, IL: Thomas.

Henderson, J. N., & Gutierrez-Mayka, M. (1992). Ethnocultural themes in caregiving to Alzheimer's disease patients in Hispanic families. *Clinical Gerontologist, 11,* 59–74.

Henderson, J. N., Gutierrez-Mayka, M., Garcia, J., & Boyd, S. (1993). A model for Alzheimer's disease support group development in African-American and Hispanic populations. *The Gerontologist, 33,* 409–414.

Hoppe, S., & Heller, P. (1975). Alienation, familism, and the utilization of health services by Mexican Americans. *Job Health and Social Behavior, 16,* 304–314.

Humm-Delgado, D., & Delgado, M. (1983). Assessing Hispanic mental health needs: Issues and recommendations. *Journal of Community Psychology, 11,* 363–375.

Keefe, S. E. (1982). Help-seeking behavior among foreign-born and native-born Mexican Americans. *Social Science & Medicine, 16*, 1467–1472.
Kluckhohn, F. R., & Strodtbeck, F. C. (1961). *Variations in value orientations*. Homewood, IL: Dorsey.
Leon, A. M., Manzur, R., Montalvo, E., & Rodriguez, M. (1984). Self-help support groups for Hispanic mothers. *Child Welfare, 63*, 261–268.
Lum, R. G. (1987). The patient-counselor relationship in a cross-cultural context. In B. Biesecker, P. A. Magyari, & N. W. Paul (Eds.), *Strategies in genetic counseling, II: Religious, cultural, and ethnic differences in the counseling process* (pp. 133–143). (March of Dimes Birth Defects Foundation, Original Articles Series 23)
Madara, E. F,. & Meese, A. (Eds.) (1990). *The self-help sourcebook*. Nutley, NJ: Hoffman La Roche.
Marcus, L., & Marcus, A. (1988). From psyche to soma: The crucial connection. Part I. *Family Medicine, 20*, 368–373.
Mardiros, M. (1989). Conceptions of childhood disability among Mexican-American parents. *Medical Anthropology, 12*, 55–68.
Mary, N. L. (1990). Reactions of black, Hispanic, and white mothers to having a child with handicaps. *Mental Retardation, 28*, 1–5.
McGowan, B. G. (1988). Helping Puerto Rican families at risk: Responsive use of time, space, and relationships. In C. Jacobs & D. D. Bowles (Eds.), *Ethnicity and race: Critical concepts in social work* (pp. 48–70). Silver Spring, MD: National Association of Social Workers.
McKinley, V. (1987). Group therapy as a treatment modality of special value for Hispanic patients. *International Journal of Group Psychotherapy, 37*, 255–268.
Meyerson, M. D. (1990). Cultural considerations in the treatment of Latinos with craniofacial malformations. *Cleft Palate Journal, 27*, 279–287.
Miranda, M. R. (Ed.). (1986). *Psychotherapy with the Spanish-speaking: Issues in research and services delivery* (Monograph No. 3). Los Angeles: University of California, Spanish-Speaking Mental Health Research Center.
Padilla, A. M., Ruiz, R. A., & Alvarez, R. (1983). Community mental health services for the Spanish-speaking surnamed population. In D. R. Atkinson, G. Morten, & D. W. Sue (Eds.), *Counseling American minorities: A cross-cultural perspective* (pp. 181–203). Dubuque, IA: Brown.
Pilon, B., & Smith, K. A. (1985). A parent group for Hispanic parents of children with severe cerebral palsy. *Children's Health Care, 14*, 96–102.
Porter, C. I,. & Villaruel, A. M. (1991). Socialization and caring for hospitalized African and Mexican American children. *Issues in Comprehensive Pediatric Nursing, 14*, 1–10.
Prieto-Bayard, M., & Baker, B. L. (1986). Parent training for Spanish-speaking families with a retarded child. *Journal of Community Psychology, 14*, 134–143.
Putsch, R. W. (1985). Cross-cultural communication: The special case of interpreters in health care. *Journal of the American Medical Association, 254*, 3344–3348.
Rivera, J. A. (1987). Self-help as mutual protection: The development of Hispanic fraternal benefit societies. *The Journal of Applied Behavioral Science, 23*, 387–396.
Rogler, L. H., Malgady, R. G., Constantino, G., & Blumenthal, R. (1987). What do culturally sensitive mental health services mean? *American Psychologist, 42*, 565–570.
Rosenberg, P. P. (1984). Support groups: A special therapeutic entity. *Small Group Behavior, 15*, 173–186.
Ruiz, R. A., & Padilla, A. M. (1983). Counseling Latinos. In D. R. Atkinson, G. Morten, & D. W. Sue (Eds.), *Counseling American minorities: A cross-cultural perspective* (pp. 213–234). Dubuque, IA: Brown.
Saltoun, M., & Gracia, D. (1991). Helping Latino parents cope. Conference Proceedings, CHLA. *Journal of Pediatric Oncology Nursing, 2*, 79–80.
Sanchez, G. A. (1987). Hispanic Americans. In B. Biesecker, P. A. Magyari, & N. W. Paul (Eds.), *Strategies in genetic counseling: II Religious, cultural and ethnic influences on the counseling process* (pp. 171–173. (March of Dimes Birth Defects Foundation. Birth Defects: Original Article Series, 23).
Schaefer, D. S. (1983). Issues related to psychosocial intervention with Hispanic families in a pediatric cancer setting. *Journal of Psychosocial Oncology, 14*, 39–46.
Seligman, M., & Darling, R. B. (1989). *Ordinary families, special children*. New York: Guilford Press.
Shapiro, J. (1988). Stresses in the lives of parents of children with disabilities: Providing effective caregiving. *Stress Medicine, 4*, 77–93.
Shapiro, J., & Tittle, K. (1986). Psychosocial adjustment of poor Mexican mothers of disabled and non-disabled children. *American Journal of Orthopsychiatry, 56*, 289–302.
Siantz de Leon, M. L. (1990). Maternal acceptance/rejection of Mexican migrant mothers. *Psychology of Women Quarterly, 14*, 245–254.
Sobogal, F., Marin, G., Otero-Sobogal, R., Van Oss Marin, B., & Perez-Sable, E. J. (1987). Hispanic familism and acculturation: What changes and what doesn't? *Hispanic Journal of Behavioral Science, 9*, 397–402.
Taylor-Gibbs, J. (1989). *Children of color: Psychological interventions with minority youth*. San Francisco: Jossey-Bass.
Texidor del Portillo, C. (1987). Poverty, self-concept & health: Experience of Latinas. *Women & Health, 12*, 229–242.
Triandis, H. C., Hui, C. H., Albert, R. D., Leung, S., Lisansky, J., Diaz-Loving, R., Plascencia, L., Marin, G., Betancourt, H., & Loyola-Cintron, L. (1984). Individual models of social behavior. *Journal of Personality and Social Psychology, 46*, 1389–1404.

Triandis, H. C., Marin, G., Lisansky, J., & Betancourt, H. (1984). Simpatia as a cultural script of Hispanics. *Journal of Personality and Social Psychology, 47*, 1363–1375.
Valle, R. (1989). Cultural and ethnic issues in Alzheimer's disease research. In E. Light & B. D. Leibowitz (Eds.), *Alzheimer's disease treatment and family stress: Directions for research* (pp. 122–154). Rockville, MD: National Institute of Mental Health.
Vassiliou, V. G., & Vassiliou, G. (1974). Variations of the group process across cultures. *International Journal of Group Psychotherapy, 24*, 55–56.
Velez, C. G. (1982). Mexican/Hispano support systems and confianza: Theoretical issues of cultural adaptation. In R. Valle & W. Vega, (Eds.), *Hispanic natural support systems: Mental health promotion perspectives* (pp. 45–54). Sacramento: State of California Department of Mental Health.
Williams, H. B., & Williams, E. (1979). Some aspects of childrearing practices in three minority subcultures in the United States. *Journal of Negro Education, 49*, 1136–1145.

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Editor-in-Charge: Steven Taylor

Authors: JOHANNA SHAPIRO, PhD, Department of Family Medicine, and DENISE SIMONSEN, MS, Department of Pediatrics, Division of Genetics, University of California Irvine Medical Center, PO Box 14091, Orange, CA 92613-1491.