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**By Caring for Myself I Can Care Better for my Family:
A Pilot Health Education Intervention**

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Background

Research on Latina mothers of children with intellectual and developmental disabilities (IDD) has found that these mothers are in poor physical health and have high rates of depressive symptoms (Blacher, Lopez, Shapiro, & Fusco, 1997; Magaña, 1999; Magaña, Schwartz, Rubert, & Szapocznik, 2006; Magaña & Smith, 2006a). Furthermore, Latina mothers are more likely than non-Latina white mothers to co-reside with and care for their child with IDD throughout the lifespan of the child (Kraemer, & Blacher, 2008; Magaña & Smith, 2006b). While this pattern may contribute to reduced public costs for residential care of some adults with IDD, the burden on maternal caregiver health is rarely taken into account. Supportive services are primarily aimed at the child with IDD and often do not include any services for the caregiver. Furthermore, mothers of children with IDD often focus on the needs of their children at the expense of their own needs, which is particularly true for Latina mothers who often identify their caregiving role as their primary responsibility (Magaña, & Smith, 2006b; Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005). Therefore, interventions that focus on the health and well-being of Latina mothers who provide lifelong care to their child with IDD will support these caregivers in their efforts to provide in-home care, while maintaining cost savings in the residential care budget.

Health education research has found that high levels of self-efficacy contribute to psychological well-being and better health outcomes (Lorig, Ritter, & Gonzalez, 2003); and that the use of community health educators is an effective way to implement a health education program for underserved communities (Rhodes, Foley, Zometa, & Bloom, 2007). Therefore, we have developed an intervention called, "*By Caring for Myself, I Can Care Better for My Family,*" which incorporates both of these concepts. The purpose of this paper is to examine outcomes from the pilot study using this intervention to determine if it has the potential to improve self-

efficacy and health behaviors and influence depressive symptoms in Latina mothers of children with developmental disabilities.

Supportive Services for Latina Mothers of Children with IDD

In the National Health Care Disparities Report (AHRQ, 2010), Latinos were found to have lower access to care and poorer quality of care compared to non-Latino Whites. Very few studies have been conducted on the health and health care access of Latino family caregivers of children with special health care needs. Magaña and Smith (2008) found that older Latina mothers of a child with IDD were less likely to see a doctor than their non-caregiving counterparts, and midlife Latina mothers of children with IDD were more likely to smoke than same aged mothers who did not have a child with IDD. Latina mothers of children with IDD were also found to have more chronic health conditions and higher levels of depressive symptoms than those not caring for a child with IDD (Blacher et al., 1997; Magaña & Smith, 2006a).

Factors that contribute to poorer health outcomes and lower quality of and access to care for Latinos include language barriers, immigration status, poverty, discrimination, lack of transportation and lack of knowledge about services (Acevedo, 2007; Barrio et al., 2008). The stress of caring for a child with IDD may compound the stress imposed by these factors, contributing to poor health outcomes. Other determinants of health that may be at play for these mothers are limited use of positive health behaviors and lack of social supports. Parental caregivers of children with IDD are often socially isolated and have little time for taking care of themselves. Heller and Caldwell (2006) demonstrated the effectiveness of a peer support intervention to support aging caregivers and adults with developmental disabilities in planning for the future. Families of children with IDD are in need of supportive programs; however, their needs are usually not met (Heller and Factor, 1991). Clearly, given the growth in the Latino population and the disparities in health care related to children with IDD, it is important to develop health interventions that are culturally relevant for Latino family caregivers of children with IDD. Latino family caregivers (who are predominantly mothers) may benefit from a culturally sensitive program that takes into account their particular social conditions and encourages them to seek mental and physical health services, helps them reduce levels of stress, and helps them pay attention to their overall health.

Research on Health Education Programs using Self-Efficacy Theory

Self-efficacy theory has been used in health education research as a way to understand the mechanisms by which health education programs may lead to positive health behaviors and ultimately better health outcomes. Studies have shown that those who demonstrate higher levels of self-efficacy -- the belief that they are able to engage confidently in behaviors and activities that promote better health -- demonstrate improved health outcomes (Bandura, 1977; Lorig & Gonzalez, 1992). Bandura (2007) emphasizes the difference between the ability to execute a healthy behavior such as exercising, relaxing, and eating healthy and the belief that one can undertake such activity regularly even under dissuading conditions such as busy schedules, stress, lack of resources, etc. Self-efficacy is an ability that must be developed and reinforced first before expecting to see sustained behavioral change.

Individual self-efficacy expectations are developed from four main sources: performance accomplishment, vicarious experience, verbal persuasion, and emotional states (Bandura, 1977,

Pajares, 2002). The most influential source is the performance or mastery experience which implies participants actually engage in activities. When the outcome of an activity is interpreted as successful, the positive impact raises self-efficacy and is generalized to other situations. Vicarious experience is accomplished by observing others perform activities that may seem impossible or threatening. Verbal persuasion is used to encourage participants to believe they can take control of the situations that may overwhelm them. Emotional states can affect perceived self-efficacy in coping with difficult situations; high arousal often debilitates performance (Bandura, 1977). Lorig and colleagues (2003) found that a chronic disease self-management intervention based on the theory of self-efficacy, and that used peer leaders, was effective in increasing confidence among a Latino population in taking care of their health and improving health behaviors. This suggests that a peer leader model may contribute to self-efficacy and better health behaviors (Lorig et al., 2003).

Promotora de Salud Model

A model that is consistent with self-efficacy theory, uses peer leaders and has been used successfully with Latino populations to provide education and encourage positive health behaviors is the *Promotores de Salud Model* or community health educator model (Balcázar, Alvarado, Hollen, Gonzalez-Cruz, Pedregón, 2005; Elder, et al., 2005; Reinschmidt, Hunter, Fernández, Lacy-Martínez, Guernsey de Zapien, & Meister, 2006). A *promotor/a* is a lay health educator, or peer leader, who is indigenous to the community in question and receives training to provide health education and to encourage behavioral change (Elder et al., 2005). *Promotores* are usually natural helpers who are insiders in their communities and can help motivate other community members around a specific topic or problem (Reinschmidt et al., 2006). This taps into the modeling and social persuasion aspects of self-efficacy models. Equipped with training on aspects of health care specific to the project they are working on, *promotores* provide education to groups and individuals in their communities. The *promotores de salud* model has been used for a variety of health related projects including increasing chronic disease screening (Hansen et al., 2005; Reinschmidt et al., 2006), education about nutrition and dietary practices (Elder et al., 2005), improving heart healthy behaviors (Balcázar et al., 2005) and learning about environmental health (Ramos, May, & Ramos, 2001). All of these projects found significant changes in behaviors between pre and post-tests, and two of the studies showed positive results using a randomized controlled study design (Elder et al. 2005; Reinschmidt et al., 2006).

Research Objectives

Pilot Study of health education intervention

Taking into account the challenges that Latina mothers of children with IDD face, self-efficacy theory, and the promotora de salud model, we developed an eight-week health education intervention designed to help Latina mothers of children with IDD engage in activities that may improve their healthy behavior habits and reduce stress. A unique aspect about our use of promotoras is that they were not just women leaders from the Latino community; they were also mothers of children with IDD. The content of the 8 weeks included the following topics: taking care of yourself, health care for you, well-being activities, nutrition, exercise, reducing stress and depression, including others, and personal growth. Each unit lasted about 1 hour and was delivered weekly by a promotora at the participant's home during a time that fit both the

promotora’s and the participant’s schedules. The home visit model was used to overcome barriers to participation such as transportation, child care and scheduling conflicts.

This intervention draws on all four sources of self-efficacy as outlined by Pajares (2002). The promotora guides each activity providing modeling and *performance accomplishment*. She also provides *vicarious experience* as a parent of a child with IDD who has similar experiences as the participants and can demonstrate or discuss how she accomplishes the activities. She uses *verbal persuasion* by setting goals through homework assignments with the participants and encouraging them to accomplish them. Lastly, the promotora helps participants to reduce stress by practicing breathing and relaxing techniques and having someone to talk to about their challenges thereby taking some control of their own *emotional states*.

The purpose of this paper is to report on the results of this pilot health education intervention in which we used a one-group pre and post-test design. Our research questions are: 1) Did participants increase their self-efficacy between pre and post tests? 2) Are higher levels of self-efficacy related to more healthy behaviors at post-test? 3) Did participants improve their health behaviors (exercise, nutrition, and self-care) between pre and post-test? And 4) Did participants reduce their level of psychological distress as measured by depressive symptoms between pre and post-test?

Methods

Participant

Table 1. Demographic Characteristics

Maternal Characteristics	Participants N=27	Promotoras N=10
Mean age (SD)	40.2 (9.7)	38.0 (6.8)
Level of education		
Less than High School	64.0	40.0
High School	20.0	30.0
More than High school	16.0	30.0
Income		
0 to \$19,999	64.0	57.1
\$20,000 to 39,999	32.0	28.6
\$40,000 and up	4.0	6.3
Percent employed	36.0	70.0
Percent married or living together	74.1	70.0
Percent foreign born	100.0	100.0
Ethnicity		
Mexican descent	96.2	80.0
Other Latino		
Percent good/excellent health	33.3	40.0
Child Characteristics		
Mean age (SD)	12.5 (8.2)	10.3 (4.3)
Percent male	51.9	70.0
Diagnosis		
Autism	21.7	57.1
Down Syndrome	21.7	0.0
Cerebral Palsy	17.4	14.3
Intellectual disability	13.0	14.3
Other	26.0	14.3

Twenty-seven mothers participated in the intervention program and received a pre and post-test. Participants were recruited through local support groups of Latino families who have children with developmental services and through agencies that serve these families. Promotoras also recruited mothers they knew to participate in the intervention study. Because our focus was on midlife and older mothers, criteria for participation were that the mother was either at least 40 years old, or their child with a developmental disability was 8 years old or older. We required that mothers be of Latin American descent because our intent was to design and test a culturally relevant intervention for Latina mothers. Thirty mothers agreed to participate and completed the informed consents and a pre-test. Out of the

30 mothers that began the study, 27 remained in the study and completed a post-test which indicates a 90% completion rate. With respect to the three mothers who were not able to complete the intervention: one of them dropped out because she had a newborn baby during the course of the intervention, another returned to Puerto Rico, and the third one did not respond to multiple attempts to contact her. We report pre and post-test results of the 27 completed cases. In addition to the 27 participants, we trained 10 promotoras who attended 12 to 15 hours of training in a group format over 3 weeks. In Table 1, we report demographic characteristics of the promotoras as a reference point for the participants. In general, mothers in the study had low levels of education, the majority of whom did not have a high school degree. The majority of promotoras had a high school degree or higher, however this was not statistically significant. Another area in which participants and promotoras appear to differ was in employment status. The promotoras were more likely to be employed at least part time compared to the participants. The majority of mothers had household incomes that were less than \$20,000 a year, and were either married or living with a partner. All of the mothers were born in a Latin American country and most were from Mexico.

Training Procedures

Promotoras were selected using three main criteria: 1) Latina mothers caring for a child of any age with a developmental disability who were 2) Spanish speakers and who 3) possessed some leadership skills and/or were recognized as emerging community leaders. We contacted local community organizations that served Latino families of children with IDD and asked the respective coordinators to identify potential candidates. The community organization staff contacted mothers of children with IDD who met the criteria and asked if they were interested in finding out more about the project. Those who expressed interest were invited to an informational meeting in which questions about the program were answered, and the actual training meetings were scheduled with those who wanted to participate as promotoras.

The promotora training was conducted in a group format during three well-defined and structured half day training sessions. The training sessions were conducted in Spanish and the promotoras were given a stipend for their time at the trainings and breakfast and lunch were provided at all trainings. During the training sessions, promotoras took the role of the participant by completing a pre-test evaluation identical to those administered to program participants and by listening to the trainers as they delivered the manual. Through this process, they reviewed the program manual in detail; learned tools and techniques to guide program sessions; and asked questions about the implementation of the sessions that were discussed. Promotoras were given one or 2 cases to complete and they were asked to report back to the training coordinator after each completed session. The training coordinator was available to answer questions and problem solve with the promotora if needed. After each promotora completed their first case, a meeting was scheduled to review how the implementation went for them, and to provide further support. Promotoras received a stipend for each case they completed, the amount covered the 8 session plus some traveling time. Participants received a program manual and a folder containing information about local resources in addition to the home visits.

Study Instruments

The pre-test included a demographic questionnaire with questions about the mother's date of birth, education, employment status, income, ethnicity, language preferences, marital status and physical health status. Also included are date of birth, gender, and primary disability of the child. The pre and post-test included measures of health related self-efficacy, depressive symptoms, and positive health behaviors described below:

Health Related Self-Efficacy was measured by an adaptation of the Self-Efficacy Scales for Health-related Diet and Exercise Behaviors (Pinski, Grossman, Patterson, & Nader, 1988). There are 10 items that ask respondent how confident she is in doing specific activities that were discussed during the program, with response categories ranging from (1) not at all confident to (10) totally confident. This measure was introduced after the pilot study was underway; therefore, we only have data on this measure from 13 of the participants and 7 of the promotoras. Chronbach's alpha for present sample was .80.

Depressive symptoms were measured by the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) which has been established as a valid and reliable measure of depressive symptoms in different ethnic groups including Latinos (Cho et al., 1993; Guarnaccia, Angel, & Worebey, 1989). The CES-D consists of 20 items that rate the frequency of depressive symptoms over the last week with response categories range from (1) rarely to (4) most of the time. Chronbach's alpha was .81 for the present sample.

Positive health behaviors were measured by an adaptation of the Family Habits Scale which was developed for the Health for your Heart Promotora Intervention (Balcazar et al., 2005). There are 36 items that ask, "How often do you do the following?" followed by items on self-care (8 items), nutrition (18 items) and exercise habits (10 items). We created subscales for each of these 3 categories. Response categories range from (1) never, to (4) always. Content validity and reliability were established by Balcazar et al. (2005; Chronbach alpha $>.60$). For the present sample, Chronbach's alphas were: Overall scale .90; Self-care habits .67; nutrition habits .86; and exercise habits .79.

Findings of Pilot Study

We report results of our pilot study in Wisconsin which is complete. For research question 1, we asked whether self-efficacy changed between pre and post-tests for the participants. Using paired-sample t-tests, the 13 participants who completed this scale significantly improved in health related self-efficacy between the two time points (see **Table 2**).

For research question 2 we asked whether self-efficacy at post-test was related to healthy behaviors at the post-test. Using Pearson product moment correlations, we found that higher levels of self-efficacy was significantly related to better nutrition habits ($r = .68$; $p = .01$) and better exercise habits ($r = .64$; $p = .02$); however, the correlation between self-care habits was not significant ($r = .50$; $p = .08$) for the 13 participants who completed the self-efficacy measure. Combining the three habit measures, there was a significant relationship between overall healthy habits and self-efficacy at ($r = .69$; $p = .01$).

Table 2. Pre and Post-test differences among participants (n=27)

Participants	Pre-test	Post-test	Paired t
Self-Efficacy (N=13)	70.9 (14.4)	87.2 (9.7)	-5.9***
Exercise habits	7.3 (4.9)	12.0 (5.7)	-5.8***
Self-care habits	8.0 (3.7)	13.6 (4.2)	-8.0***
Nutrition habits	27.1 (9.1)	35.2 (7.8)	-4.2***
Overall habits	44.4 (14.7)	62.5 (15.1)	-7.4***
Depressive symptoms	18.9 (9.0)	12.3 (8.2)	4.1***

* p < .05; ** p < .01; *** p < .001

To answer Research Question 3, whether participants improved their health behaviors between pre and post-test, we again used paired-sample t-tests. Table 2 shows that the 27 participants significantly increased their positive exercise, nutrition and self-care behaviors, and their healthy behaviors overall.

In Research Question 4 we asked whether participants reduced their depressive symptoms between pre and post-test. It is important to note that the depressive symptoms (CES-D) mean at pre-test was 18.8 which is relatively high (See Table 2). A cut-off score of 16 is conventionally used as an indication that the person is at risk for major depression (Radloff, 1977). At post-test, the CES-D mean was reduced to 12.3 which is below the cut-off.

Discussion, Conclusion and Next Steps

Discussion

In this paper, we have presented findings from a pilot study of a health education intervention developed for Latina mothers of children with IDD. This intervention took into account research on health outcomes and healthcare access and utilization among Latina caregivers of children with IDD, and incorporated self-efficacy theory and the promotores de salud health education model. In this intervention, we included promotoras who were Spanish speaking Latina mothers of children with IDD themselves and were identified as emerging leaders in their community. The promotoras served as role models, guided performance accomplishment, used verbal persuasion and provided participants with strategies to reduce stress while delivering the content of a manual that covered 8 health care topics.

We found that participants reported higher levels of self-efficacy at post-test than they did at pre-test; and that self-efficacy at post-test was related to higher levels of positive health behaviors at post-test. We also found that participants reported more positive health behaviors overall and for each of the specific subscales of exercise habits, nutrition habits, and self-care habits between the pre and post-test. These findings are consistent with self-efficacy theory by suggesting that the intervention may increase self-efficacy, which leads to more positive health behaviors (Lorig Ritter, & Gonzalez, 2003).

Another important finding was that participants reported significantly fewer depressive symptoms at post-test than they did at pre-test. In fact, the mothers in our study reported very high rates of depressive symptoms at pre-test which was consistent with the rates reported in studies on emotional well-being of Latina caregivers of children with IDD (Blacher et al., 1997;

Magaña, et al., 2006). Our post-test results suggest that this intervention may be a promising way to counter emotional distress among Latina mothers of children with IDD.

Limitations and Lessons Learned

Limitations of this study included: 1) sample size, we need a larger sample to adequately test the mediation model of self-efficacy theory in a multivariate analysis. The fact that we began using the self-efficacy measure after the study was underway further undercut the sample size for testing this theory; and 2) our study lacked a comparison group. In order to address threats to validity and determine whether changes between pre and post-test can be contributed to our intervention, it is important to conduct a randomized trial including an intervention group and a non-intervention group. One of the lessons we learned in implementing the pilot study is the importance of having a solid community-based collaborator and the importance of compensating the collaborative organization for their effort. We had a couple of community organizations that helped us with recruitment and space, but they were not as committed to the project as we would have liked. We felt that being able to compensate them with a budget and asking them to help administrate the project would have helped. Another lesson we learned is that while participants remained in the project at high levels, we had a drop in promotora participation. Out of 10 original promotoras, four remained throughout the project. One of the issues was that while we compensated them for their time, several of them need to work a steady job and had to put our project on the back burner. Adding to this, the University reimbursement process took too long for the promotoras who needed the income more quickly. Overall, despite the small sample and the difficulties retaining promotoras, the findings between pre and post-test were quite robust, suggesting that the intervention is promising and a randomized trial using a larger sample is warranted.

Next Steps

The next stage of the project is to conduct a randomized trial in which participants are assigned to an intervention group and a wait list group. This stage is now underway. The goal is to recruit a total of 100 participants, 50 to the intervention group and 50 to the wait list group. Those on the waiting list complete the pre-test, wait for a period of three month, complete the post-test and then receive the intervention. As of today we have recruited 40 mothers (20 in each group) and have trained five promotoras. To take into account lessons learned, we are collaborating with an organization in the Pilsen Neighborhood of Chicago, El Valor. This is an established nonprofit organization that has service the Latino community of people and families with developmental disabilities for many years. We have developed a financial agreement with them and they pay for a person from El Valor who coordinates the day-to-day aspects of the study, and they compensate the promotoras directly. The collaboration and work of the agency has been excellent so far.

In addition, we are pilot-testing a group model of the intervention in which participants attend five sessions. We are conducting this pilot with a different community agency in the Cicero area of Chicago, Community Support Services. We came to agreement with the agency on reimbursing them for their efforts. The agency has also contributed in-kind donations to the project including supervision. Three promotoras were trained from this agency. Two groups have been completed with promising results with respect to interest and regular attendance of participants. We look forward to examining the pre and post-tests from these groups. In March

2011, we help a meeting and luncheon with all of the promotoras from both El Valor and Community Support Services to learn about their experiences with the project, and to honor their participant.

In conclusion, it is important to develop culturally sensitive health interventions for Latina mothers of children with developmental disabilities given their health challenges, and the increase in the Latino population. This pilot study tested a health education intervention that showed promising results relating to better health behaviors and lower depressive symptoms among Latina mothers of children with IDD. Further research is needed to test the efficacy of the intervention using a randomized control trial, which is currently underway.

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