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## Latina Mothers Caring for a Son or Daughter with Autism or Schizophrenia: Similarities, Differences and the Relationship Between Co-Residency and Maternal Well-Being

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### Abstract

In this cross-sectional study, we examined similarities and differences in depressive symptoms and psychological well-being between Latina maternal caregivers of persons with autism (N=29) and schizophrenia (N=33). We also explored predictors of maternal outcomes and the relationship of co-residence to them. Regression analysis found that mothers of adults with schizophrenia had lower levels of psychological well-being than mothers of youth or adults with autism. For the overall sample of mothers, co-residing with their son or daughter was significantly related to lower levels of depressive symptoms. Qualitative analysis of the nine mothers who lived apart from their son or daughter revealed that extreme behavior problems of the son or daughter and poor maternal health contributed to living apart. Despite overcoming these challenges, mothers expressed a profound sense of sadness about their son or daughters' living arrangements.

### Keywords

caregiving; Latinos; schizophrenia; autism; depression; psychological well-being

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It is important to examine the experiences of Latino caregivers across disability contexts to determine whether and how these experiences may differ depending on the diagnosis of the child. Latinos have become the largest minority group in the United States (Cohn, 2003), and are very likely to be intimately involved with caring for family members with disabilities across the lifespan. While there is a moderate amount of research on Latino caregivers of older adults with dementia and other disabilities (Magaña, 2006), this paper will focus on Latina mothers who care for their own youth or adult children with one of two neurological disorders, autism and schizophrenia. This is a topic that has not received much attention in the literature. We explore whether maternal depressive symptoms and psychological well-being differ between the two groups of mothers, what the overall predictors are, and the relationship between co-residency and maternal well-being.

### Caregiving in Autism and Mental Illness

There are many aspects that are different about caring for a son or daughter with autism and caring for a son or daughter with schizophrenia that are important to consider. Age of diagnosis is one distinct difference; autism is typically diagnosed between the ages of 2 and 5 years old and schizophrenia is diagnosed in adolescence and young adulthood. Thus the timing of diagnosis occurs in different stages of the parents' life-course, early adulthood for

parents of children with autism and midlife for parents of children with schizophrenia (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). Not only is the life stage of the parents different between the two, but also the life stage of the child is different which may affect the parent's perspective and acceptance of the child. A diagnosis such as autism or schizophrenia may be difficult to accept at first for any parent. Receiving the diagnosis when the child is young as is the case with autism, may influence maternal perception and acceptance of that child differently than if the child had grown up normally and then changed in behavior and character, as is frequently the case with schizophrenia. For both autism and schizophrenia, behavior problems of the son or daughter may challenge parental caregivers. Behavior problems and symptoms for children with autism can be severe, but tend to decrease into adulthood (Shattuck, Seltzer, Greenberg, Orsmond, Bolt, Kring, Lounds & Lord 2007). In contrast, behavior problems in schizophrenia can be less predictable and often occur in cycles (American Psychiatric Association (APA), 2000).

With respect to behavior problems, it is important to differentiate behaviors from symptoms and understand how they relate to each diagnostic group. For autism, core symptoms involve impaired development in reciprocal social interaction and communication, and restricted and repetitive behaviors (APA, 2000). Behavior problems may develop from the interaction of these core symptoms with family and societal expectations. For example, the child may become frustrated by the inability to communicate well, or may be averse to social and other stimulation thus reacting in a negative way. People with schizophrenia may manifest positive or negative symptoms (APA). Positive symptoms are those that are seen as overtly psychotic such as experiencing hallucinations or delusions. As a result of these symptoms, the person may exhibit what are seen as strange behaviors that can be offensive to others or embarrassing to caregivers. Negative symptoms include inability to initiate or sustain goal directed activities, poverty of speech and flat affect (APA). These symptoms can be seen as problematic for caregivers who would like their son or daughter to be more active in becoming independent in their own life goals. The behavior problems that result from symptoms interacting with the social environment may be very similar across both groups. For example both groups may exhibit behaviors such as hurting oneself or others, embarrassing caregivers in public, or being uncooperative or offensive in public.

Some of the similarities between the two groups allow for comparison because variables that are difficult to measure are more likely to remain constant between the two groups. For example, both of these groups experience hardships in the diagnostic process because diagnosis is based on a behavioral assessment as opposed to a genetic or biological test, and may experience stress as a result of their "diagnostic odyssey" (Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004). In addition, there is some evidence among both groups of caregivers that there is an elevated genetic risk for psychiatric problems such as depression; therefore, comparisons between these two groups may control for these potential genetic predispositions (Seltzer et al., 2004).

Other similarities between caregivers of persons with autism and schizophrenia include the quality of relationships between parent and child and that this relationship is significant in predicting parental well-being (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). Because of social impairments in both groups, the quality of relationship between the son or daughter and their parental caregivers may be affected. A study that compared mothers of adults with autism to mothers of adults with schizophrenia found no differences in either quality of relationship or level of caregiver optimism (Greenberg et al.). These researchers also found that better quality relationships was related to higher levels of optimism and better well-being outcomes for both groups. Additionally, they found that there were no differences in depressive symptoms or psychological well-being between the two groups of caregivers (Greenberg et al.). Research has been mixed on whether there are differences in well-being

outcomes among caregivers of adults with intellectual disabilities (ID) and caregivers of adults with mental illness (Greenberg, Seltzer, & Greenley, 1993; Seltzer, Greenberg, Floyd, & Hong, 2004); however, so far, researchers who have examined differences between caregivers of adults with autism and schizophrenia have found more similarities than differences in caregiver outcomes. While these studies demonstrate emerging data on how these two groups may be similar; there has been no research examining these two groups of caregivers together among Latino families; and little research of Latino caregivers of persons with mental illness or autism at all.

## **Research on Latina Mothers of Children/Adults With Intellectual Disabilities (ID) and Mental Illness**

Latina mothers of children with disabilities, similar to mothers in other minority groups, may be faced with challenges associated with low socio-economic status such as poor housing, poor health, and limited access to health insurance and resources. Recent research has found that Latina and African American mothers who care for adult children with schizophrenia and children or adults with ID are more likely to suffer from poorer health and higher rates of psychological distress than their non caregiving peers (Blacher, Lopez, Shapiro, & Fusco, 1997; Magaña, Greenberg, & Seltzer, 2004; Magaña & Smith, 2006a). Differences in health and psychological distress between non-Latino caregivers of adult children with ID and parents that do not have children with disabilities have not been found (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001); however, these differences have been found between non-Latina mothers of adults with mental illness and mothers who do not have children with mental illness (Seltzer, Greenberg, Floyd, & Hong, 2004). These findings suggest a cumulative affect of caregiving on health that may have a greater impact on some mothers as they age.

While there are different countries of origin for Latinos, with distinct political histories, practices, and customs, there is some evidence that cultural values and practices related to the family may provide a common experience for many Latino caregivers (Aranda & Knight, 1997). For example, within group studies have found that Latino caregivers of persons with mental illness or ID tend to rely on family members for advice and support (Blacher, et al., 1997; Guarnaccia & Parra, 1996; Magaña, 1999). Informal social support networks of caregivers of adults with an ID tend to consist primarily of family members and size of and satisfaction with social support networks have been found to be significantly related to caregiver well-being (Magaña).

Latino youth and adults with an ID or mental illness are more likely to live with their parents than non-Latino white persons with these disabilities (Heller, Markwardt, Rowitz, & Farber, 1994; Magaña & Smith, 2006b; Milstein, Guarnaccia, & Midlarsky, 1995). Studies find that around seventy five percent of Latino caregivers co-reside with their son or daughter with autism or mental illness compared to thirty three to forty five percent among non-Latino white families (Greenberg et al., 2004; Heller et al., 1994; Magaña, Garcia, Hernandez, & Cortez, 2007; Milstein et al., 1995). While Heller et al. found that differences in co-residence between Latinos and non-Latinos were no longer significant when controlling for SES and child age, other studies found that Latino caregivers are more likely to prefer these arrangements (Kraemer & Blacher, 2008; Magaña & Smith, 2006b; Milstein, et al., 1995; Rueda, Monzo, Shapiro, Gomez, Blacher, 2005). In a qualitative study, Rueda et al. found that the predominant theme among Latina mothers of children with ID was the belief that no one could care better for their child than themselves. In a study comparing non-Latina white mothers to Latina mothers who were co-residing with their youth and adults with autism, researchers found that Latina mothers were more satisfied with the living arrangement than

the white mothers, which was related to lower levels of psychological distress and higher levels of psychological well-being among the Latina mothers (Magaña & Smith, 2006b).

## Research on Out of Home Placement of Persons With ID and Mental Illness

Factors that may precipitate placing a son or daughter with ID or mental illness outside the family home include high levels of maladaptive behaviors, severe physical impairments of the son or daughter, caregiver stress and declining physical capacity of the caregiver (Heller & Factor, 1994; Seltzer, Greenberg, Krauss, & Hong, 1997). Seltzer et al found differential factors predicting out of home placement for adults with intellectual disabilities (ID) vs. severe mental illness mental illness. Predictors for mothers caring for an adult with ID were older mothers' age and poorer health, and whether their child was on a waiting list for placement. On the other hand, gender of the person with mental illness, increased venting of emotions by the caregiver, and psychiatric crisis were predictors of out of home placement for caregivers of adults with mental illness. Another risk factor predicting out of home placement of children with ID include reaching adolescence (Blacher & Hanneman, 1993). As physical maturation of the child increases, so do their daily needs (Blacher, & Bromley, 1990). It is possible that similar factors may influence Latino family caregivers; however, due to a strong cultural commitment to live with the son or daughter they may have higher thresholds for these factors.

A few studies have explored the relationship between out-of-home placement and caregiver well-being for parents who have a son or a daughter with developmental disabilities or severe mental illnesses like schizophrenia. The majority of the studies focused on people with ID and found that parents who lived apart from their child reported more positive well-being outcomes compared to when they were living with their child (Baker & Blacher, 2002; Gallagher & Mechanic, 1996; Seltzer et al. 1997; Werner Edwards & Baum, 2009). For example, Baker and Blacher found that caregivers experienced reduced stress, increased peace of mind, and increased opportunities to pursue a career or personal interest. Gallagher & Mechanic found that caregivers reported better health and fewer physical limitations; and Warner et al. reported improved emotional well-being, social life and marital satisfaction, and overall quality of life. Investigating the role of end-of-co-residence on burden and depression among maternal caregivers of persons with ID and mental illness, Seltzer and colleagues found that end of co-residence predicted lower levels of subjective burden for both mothers of adults with mental retardation as well as mental illness; however, there was no difference in depressive symptoms. Only one study found no differences in any of the well-being outcomes they examined between older caregivers of adults with ID who co-reside with their son or daughter and those who do not (McDermott, Valentine, Anderson, Gallup & Thompson, 1997).

Interestingly, the gains or advantages identified by families following placement are also accompanied by ambivalent feelings of loss or guilt for having placed the child. The most common feeling is that of being unable to fulfill one's role as a parent (Baker & Blacher, 2002; Werner et al., 2009). However, much of this guilt and worry varies by the age of child being placed. As noted by Hayden & Heller (1997) and Baker & Blacher (2002), guilt and worry was characteristic of parents of young children. When compared to parents of adults with ID, parents of children with ID experienced high levels of burden, irrespective of their place of residence (Hayden & Heller). Similarly, families of children with ID when compared to others (families of adolescents, young adults or adults) report the lower levels of marital satisfaction and the higher levels of burden and stress. Thus, parents of young children with ID maybe more vulnerable to psychological distress when placing their child outside of the home (Baker & Blacher).

Overall, most research on placement and caregiver well-being provides evidence of better outcomes experienced by caregivers when their son or daughter with ID lives outside the home, particularly when their children are adults. However, this body of research has focused primarily on European American caregiver samples. Thus more needs to be known about how Latina/o caregivers adapt to out-of-home placement.

## Current Study Variables and Research Questions

In order to determine what variables were important to include in our analyses, we took guidance from a paper that discussed methodological challenges of research comparing families of children with autism with families of children with other disabilities (Seltzer et al., 2004). The authors list several variables for which adjustments are important. These variables include child or parent age, parent marital status, number of children in the family, child gender, time since diagnosis, and behavior problems as well as contextual variables such as parental education and ethnicity (Seltzer et al., 2004). Research on mothers of children with developmental disabilities find maternal health is important to take into account as well (Magaña, Seltzer, & Krauss, 2004). For Latinos, some form of acculturation is important to measure. A study of Cuban American mothers of adults with mental retardation found that greater levels of acculturation was related to lower levels of psychological distress (Magaña, Schwartz, Rubert, & Szapocznik, 2006).

Our research questions are exploratory as there is no clear evidence to suggest hypothesized relationships. Previous research summarized thus far suggests that while experiences may be different, well-being outcomes between mothers of children with autism and mothers of children schizophrenia may be very similar. Additionally, research that has focused on Latino caregiving has reported similar findings with respect to culture and family in individual studies despite different disability contexts. Our research questions are:

1. Do depressive symptoms and psychological well-being differ between Latina mothers of persons with autism and Latina mothers of persons with schizophrenia?
2. What are the most important predictors of depressive symptoms and psychological well-being for both groups of Latina caregiving mothers?
3. What is the relationship between mothers co-residing with their child and maternal outcomes; and are these relationships similar for both groups of mothers?

## Method

### Study Sample and Data Collection

Participants in the present analysis included Latina mothers from two separate but related studies designed to explore the experiences of caregiving families who have a son or a daughter with autism (N=29) or schizophrenia (N=33).

Latina mothers of children with autism were part of the first wave of a larger longitudinal study of aging mothers of adults or adolescents with a diagnosis of Autism spectrum disorder in Wisconsin and Massachusetts. The respondents for this study were recruited through agencies, diagnostic clinics and the media between 1998 and 2002. A special effort was made to recruit Latino families for the study, particularly in Massachusetts where more Latinos were connected to the service systems. The families in the Latino sample had three criteria that needed to be met for sample selection. These were, (1) to have a son or a daughter 8 years old or older (2) with a diagnosis of an Autism Spectrum Disorder (ASD) from a medical, psychological or educational professional, as reported by parents and (3) a careful review of multiple sources of diagnostic information confirming the diagnosis for an ASD. The Autism Diagnostic Interview-Revised (ADI-R), the Autism Behavior Checklist

(ABC), and parental report were the primary sources of data used to ascertain diagnosis. There were 32 original mother and child dyads in the sample. However, because of missing data on the outcome variables we removed 3 cases. Therefore, the final sample size of mothers of children with autism was 29 in the present analyses. All interviews were conducted in the home of the participant.

Mothers of adults with schizophrenia were part of the first wave of a larger longitudinal study of aging families of adults with schizophrenia in Wisconsin. Criteria for inclusion in the study were that the respondent was the primary family caregiver of the person with schizophrenia, and the relative being cared for had a diagnosis of schizophrenia or schizoaffective disorder. In order to expand the number of Latino participants, recruitment was also conducted in Los Angeles, CA. There were 42 Latino caregivers in the study, however, 33 of them were the mothers of the person with schizophrenia (others were spouses, fathers, siblings, and other relatives), and only mothers were included in our present analyses (25 mothers from Los Angeles and 8 mothers from Wisconsin). The participants were recruited primarily through county mental health agencies, community support groups and the media between 2000 and 2003. Caregivers were interviewed in their home or at the mental health agency, according to their preferences.

For both studies, interviews were conducted in the language of preference (Spanish or English) by bilingual and bicultural interviewers. All the instruments not already available in Spanish were translated using the translation/back translation method (Kurtines & Szapocznik, 1995).

## Measures

**Dependent variables**—Maternal psychological distress and well-being were the two dependent variables in the study. Psychological distress was measured by Radloff's (1977) Center for Epidemiological Studies Depression Scale (CES-D) and psychological well-being was measured by the sum of three subscales from Ryff's (1989) measure of psychological well-being. The CES-D is a valid and reliable measure of depressive symptoms in the general population and its validity and reliability is also evident across cultural groups, including Latino population (Cho, Mocicki, Narrow, Rae, Locke, Regier 1993; Guarnaccia, Angel, & Worobey, 1989; Stroup-Benham, Lawrence & Trevino, 1992). The CES-D consists of 20 items in which respondents report the frequency of depressive symptoms exhibited in the last week. For example, respondents are asked to indicate how often they felt unhappy, lonely, experienced crying spells, and had thoughts that life has been a failure etc, in the last one week. The measure uses a 4-point scale ranging from *rarely*= 0 (less than 1 day) to *most of the time*, =3 (5–7 days). Items were summed to obtain the total score. Possible scores range from 0 to 60, with higher scores indicating higher levels of depressive symptoms. The Chronbach's alpha for the present sample was .90.

A modified version of Ryff's (1989) psychological well-being measure was used to assess positive psychological well-being. Five items from each of three subscales (Personal Growth, Self Acceptance, and Purpose in Life) were used in both samples for a total of 15 items. Respondents rated their level of agreement for each item on a 6-point scale (1 = *strongly disagree* to 6 = *strongly agree*). Total score was calculated by summing their responses. Possible scores range from 15 to 90, with higher scores indicating positive psychological well-being. Respondents indicate the extent to which they are interested in activities that expand their horizon, feel positive with how life turned out to be and that they have a sense of purpose and direction in life. Ryff's psychological well-being measure has been used successfully with Latino populations (Gloria, Castellanos & Orozco, 2005; Ryff, Keyes & Hughes, 2004). Chronbach's Alpha for the present sample was .82.

**Maternal characteristics**—Maternal characteristics were gathered in the demographic portion of the questionnaire and included age (in years), number of children in the family, marital status (1 = *married*, 0 = *not married*) level of education (1 = *less than high school*, 2 = *high school*, 3 = *some college*, 4 = *bachelor's degree or higher*) and total family income was calculated using a categorical variable where '1' indicated an annual income of \$0-\$4,999, '2' \$5,000 - \$9,999, and so on, to '13', \$70,000 and above. While an acculturation scale was used in both studies, not all of the respondents received this part of the questionnaire. Therefore, in order to assess some level of acculturation, language of interview (0 = *English*, 1 = *Spanish*) was used as a proxy. Respondents were asked about their Latino ethnicity or country of origin. The two largest groups identified were Mexican/Mexican American and Puerto Rican. Other respondents were from the Caribbean (Dominican Republic and Cuba), Central and South America but the numbers in each group were too small to statistically analyze. Therefore, we categorized Latino ethnicity as (1 = Mexican, 2 = Puerto Rican, and 3 = Other Latino).

Maternal health status was measured by a single item in which the mother rated her health on a 4 point scale (1 = *poor* to 4 = *excellent*), with higher score indicating better perceived health (Stewart, Hays, & Ware, 1988).

**Youth/adult characteristics**—Maladaptive behaviors were assessed through the Inventory for Client and Agency Planning (Bruinicks, Hill, Weatherman, & Woodcock, 1986). The measure was adapted and validated for a Spanish-speaking population (Montero, 1993). The ICAP is a measure of 8 items that assesses the presence and severity of behavior problems across three domains: internalizing behaviors (behaviors being hurtful to one self), externalizing behaviors (behaviors hurtful to others) and asocial behaviors (socially uncooperative and offensive behavior). The respondents were asked to confirm the presence of a behavior problem and then report on the severity. The scale for maladaptive behavior problems was constructed by taking a count of the 8 behavior problems reported as present. Possible scale values range from 0 to 8.

Other youth/adult characteristics included age (in years), place of residence (1 = *home*, 0 = *outside residence*), gender (0 = *son*, 1 = *daughter*), time since diagnosis (computed by subtracting year of diagnosis from year of interview), and health status based on mothers' report of son or daughters' health on a 4-point scale ranging from poor excellent. The key youth/adult characteristic related to research question 1 is diagnosis (0 = schizophrenia, 1 = ASD).

**Open-ended questions**—We analyzed two open-ended questions that were asked of participants who were no long co-residing with their son or daughter: 1) Could you describe for me why your (son or daughter) moved out of the home? 2) How do you feel about your (son or daughter) living outside the home?

### Quantitative Data Analysis

In preliminary analyses, we examined differences between the two diagnostic groups on maternal and youth/adult characteristics using chi square and t-test analyses. We also examined differences between the three Latino ethnicity groups on the dependent variables. After conducting a t-test on dependent variables between the two diagnostic groups, Ordinary Least Squares Regression (OLS) was used to test our first research question. Hierarchical Linear Regression was used to test our second and third research questions. Regarding missing data, one mother (in the schizophrenia sample) did not fill out the Ryff Psychological Well-being measure, so was excluded from analyses involving this measure.

Subsequently the N for the regressions using Ryff as a dependent measure was 61, while the N for the regressions using the CES-D was 62.

We conducted content analysis of two open-ended questions in order to further explore how mothers experienced living apart from their son or daughter. The procedure used in this analysis is outlined by Skinner, Rodriguez, and Bailey (1999) and included the following: First, the lead author and a graduate student reviewed the open-ended responses to the two questions on the 9 cases in which mothers lived apart from their son or daughter in order to develop a tentative list of key themes. We then met to discuss and agree upon the themes that would be used for categorizing individual responses. We then reread the responses and categorized them into the themes that were developed. We met again to determine agreement with the decisions made.

## Results

### Preliminary Analysis

Table 1 shows differences between the two diagnostic groups on maternal and youth/adult characteristics. Mothers of adults with schizophrenia were significantly older than mothers of youth/adults with autism. Mothers in the autism study were less likely to be married than mothers in the schizophrenia study. While 14 (42.4%) mothers of adults with schizophrenia were of Mexican American descent, none of the mothers in the autism study were. About 12 (41.4%) mothers in the autism study were Puerto Rican while 4 (12.1%) the Schizophrenia study mothers were. Health status, education, household income and language of interviews did not differ between the two groups of mothers.

As expected, age of the person with a disability differed between the two groups, which was a function of recruitment criteria, the autism study recruited youth and adults from 8 years and up while the schizophrenia study focused on adults. Other youth/adult characteristics that differed between the two diagnostic groups included behavior problems, those with autism had significantly higher levels; and physical health status, and persons with schizophrenia were in worse physical health. Gender, time since diagnosis and residential status did not significantly differ between the two groups. More than 80% of both offspring with autism (N=24) and schizophrenia (N=29) lived at home with their mothers.

An important preliminary question was to determine whether there were differences between mothers of Mexican, Puerto Rican or other Latino descent in our dependent variables. We found that Mexican descent mothers ( $M = 60.6$ ;  $SD = 12.9$ ) had significantly lower levels of psychological well-being than both Puerto Rican mothers ( $M = 72.6$ ;  $SD = 12.9$ ) and other Latina mothers ( $M = 71.3$ ;  $SD = 10.3$ ,  $F(2, 58) = 5.0$ ,  $p = .01$ ). Mothers of Puerto Rican and other Latino descent were not significantly different from each other on these two dependent variables. Because there are no mothers of Mexican descent in the autism sample, we also examined these differences within the schizophrenia sample to ensure the ethnicity differences we found were not a function of difference in diagnosis. We found that the means of the three ethnic groups within the schizophrenia group were very similar to those in our overall sample. Therefore, we created a dummy variable (0 = other Latino, 1 = Mexican descent) and used it in our subsequent analyses.

### Research Question 1

In our first research question, we asked whether depressive symptoms and psychological well-being differed between mothers of youth and adults with autism and mothers of adults with schizophrenia. Bivariate comparisons indicated that there are no differences between the two groups on depressive symptoms; however, the mothers of the youth/adults with autism reported higher levels of psychological well-being (see Table 2). In our regression



analyses shown on Tables 3 and 4, these findings remain consistent even while adjusting for other variables in the model; caring for a child with schizophrenia predicts lower levels of psychological well-being but is not related to depressive symptoms.

## Research Question 2

In our second research question we asked what the most important predictors were of depressive symptoms and psychological well-being for mothers of youth/adults with autism and schizophrenia. To answer this question, we conducted ordinary least squares regression. Because of our limited sample size, we needed to reduce the number of variables used in the regression models in order to maximize the degrees of freedom. First, we decided to use maternal age rather than son or daughter age because these variables are highly correlated with each other and because the focus of our analysis is on maternal outcomes. We then examined correlations of all independent variables (maternal and child characteristics) with the dependent variables; however, only one independent variable was statistically significant in bivariate correlations, level of education. Greater levels of education was related to greater levels of psychological well-being ( $r = .31; p = .02$ ) and lower levels of depressive symptoms ( $r = -.27; p = .04$ ). We then tested all of the maternal and child characteristics in regression models to determine their relationship to the dependent variables while adjusting for the others, and to determine multicollinearity effects with other variables in the model. Variables that did not contribute to the regression models were marital status, number of children, maternal education, income, son or daughters' health and gender; therefore they were removed in the final models. We will report regression analyses separately for the two dependent variables, depressive symptoms and psychological well-being.

Table 3, Model 1 shows that more behavior problems, a longer time since diagnosis, and younger maternal age were related to higher levels of depressive symptoms. This model explained 21% of the variance in maternal depression.

In addition to the relationship between caring for a child with schizophrenia and lower levels of psychological well-being; shorter time since diagnosis, older maternal age, not being of Mexican descent and interviews conducted in English were related to higher levels of psychological well-being (see Table 4). Overall, the model explained 29% of the variance in maternal psychological well-being. Findings that were common across the two maternal outcomes were that mothers being younger and mothers experiencing a longer time since diagnosis predicted worse outcomes.

## Research Question 3

We asked whether there was a relationship between co-residing with a child with autism or schizophrenia and the maternal outcomes in our study. Table 3 Model 2 shows that mothers who lived apart from their son or daughter had significantly higher levels of depressive symptoms. Furthermore, two of the variables that were not related in Model 1 became statistically significant: poorer maternal health and interview conducted in Spanish were related to higher depressive symptoms after taking into account whether the son or daughter was living at home. The explained variance in Model 2 for depressive symptoms was 28 percent.

Having a son or daughter who lived at home was not significantly related to greater levels of psychological well-being (see Table 4, Model 2); However, the  $p$  value was barely above the cut-off for statistical significance ( $p = .052$ ). Consistent with Model 1, having a son or daughter with autism, shorter time since diagnosis, older maternal age, other Latino descent, and interview conducted in English were significantly related to greater levels of psychological well-being. Findings explained 37% of the variance in Model 2.

## Open-Ended Analysis

In this analysis, we wished to explore open-ended data in our study to better understand why having the son or daughter living outside the home might be contributing to higher levels of depressive symptoms among these mothers. There were a total of nine such cases in our sample, four from the schizophrenia study and five from the autism study.

Reasons for their son or daughter moving out of the home that emerged from this analysis were severe behavior problems, educational opportunities for the son or daughter, deteriorating caregiver health, and the decision of the son or daughter. Themes that emerged regarding how mothers felt about their son or daughter living apart included feeling like mothers could live a normal life, and feelings of deep sadness and guilt. These sentiments were often experienced simultaneously.

For all of the cases in the autism study (3 males and 2 females aged between 10 and 27 years old), mothers reported severe behavior problems such as biting or hurting self and others, destroying property, and staying up all night as the reason for placement in a residential facility. Parents generally felt they were unable to manage behaviors and needed help. Two mothers also indicated that the placement was better for their son or daughter and would provide important education that they needed. Mothers reported some of the positive aspects of living apart from their son or daughter such as “living a normal life,” spending more time with their other children, and attending church. However, great sadness was conveyed as well by all of the mothers. For example, one mother said, “but my greatest wish is to be able to have her live with us. I miss her a lot. I wish to take care of her and give her a lot of a mother’s love and that she lives with her family and tries to live a normal life. And I would like to give her everything she wants. Without my daughter I feel empty.” Another said, “It is very difficult but I love my son and I always pray to God that I live a long life to take care of my son. I love him with all of my heart. If there is anything to change the way he is I would give my life for that.” A third mother put it succinctly by stating, “Me hace mucha falta” or “I miss him very much.”

Mothers of adults with schizophrenia had less choice in the matter of whether their son or daughter lived with them. All four of the cases were sons, and for three of them mothers indicated that their son chose to live on his own or elsewhere. In two cases, mothers cited extreme psychiatric conditions, or being up all night as reasons contributing to him living away from home. In another case, the son had moved from place to place due to behavioral issues such as getting into fights with other residents or co-workers, and was in jail at the time of the interview. This mother had been through a lifetime of traumas and what she referred to as a dysfunctional family. She reported that another son had committed suicide many years before, and her other children were addicted to drugs or not functioning well. She felt that she was unable to help her children and stated that she was in a lot of emotional pain due to being at her limit, disoriented and impotent to help. Another mother indicated that her heart problems coupled with her son’s behavioral issues prompted her to seek outside placement. This mother said, “I have chosen to detach myself from his daily care because of the tremendous impact it has had on my health and my depression as a result of his problems.” One mother who was a widow wanted her son to come home but psychiatrists did not recommend it. She felt guilty, sad and stressed about his living situation.

## Discussion

Our study focused on two unique caregiving experiences among Latina mothers, that of caring for a youth or adult with autism and that of caring for an adult with schizophrenia. One of the main differences between the two groups of care recipients besides age was that

the son or daughter with autism had higher levels of behavior problems than the son or daughter with schizophrenia. Also, the adults with schizophrenia, who were on average older, were in worse physical health than the persons with autism. Mothers of the adults with schizophrenia were older and more to be married than mothers of youth or adults with autism.

Our analyses showed that mothers of youth or adults with autism had higher levels of psychological well-being than mothers of adults with schizophrenia. This finding is unique as previous research that has used the same psychological well-being measure found no differences between European American mothers of adults with autism and schizophrenia (Greenberg et al., 2004). The mean levels of psychological well-being of the Latina mothers caring for a child with autism were similar to the levels reported in the Greenberg et al. study while the mean levels for Latina mothers in our schizophrenia sample were much lower. While there was no significant difference in the years since diagnosis for both groups of mothers in our study, the experiences of adapting to the diagnosis and feeling positive about it may differ. Our measure of psychological well-being consisted of three subscales, Personal Growth, Self-Acceptance, and Purpose in Live (Ryff, 1989). Because parents learn about autism early in the child's life, they may be more accepting of the child as someone special in their lives that can contribute to their purpose in live, accepting of themselves and feeling like they have grown personally. In contrast, parents learn about schizophrenia later in their child's life when things may have been going well from the parents' perspective but are suddenly interrupted by their young adult child exhibiting strange behaviors and activities. For Latino parents of adults with schizophrenia who are more likely than European American parents to live with their child and see them suffer on a daily basis, their personal outlook on their own life may be less positive.

We did not find significant differences between the two groups of mothers in levels of depressive symptoms. As reported in other studies, we found that higher levels of care recipient behavior problems, and poorer maternal health (when controlling for child's place of residence) were related to higher levels of maternal depressive symptoms across disability groups (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004; Pruchno & Patrick, 1999; Magaña, Seltzer, & Krauss, 2004). Similar findings in other studies have been robust across disability and ethnic groups. For this reason, services and treatments that work to reduce behavioral problems among persons with autism and mental illness would benefit parental caregivers in addition to the person with the disability. Some of these may include psycho-educational models that show parents how to respond to maladaptive behaviors or psychiatric symptoms (Cohen, Glynn, Murray-Swank, Barrio, Fischer et al, 2008; McIntyre, 2008). These services are mostly used for caregivers of persons with serious mental illness, but may be emerging in the autism field. Services of psychologists or behaviorists who can provide consultations to parents and treatment for the person with the disability and that are culturally and linguistically appropriate may serve to reduce maladaptive behaviors and subsequently depressive symptoms in Latina mothers.

At the same time it is important to note that the relationship of maladaptive behaviors and maternal depressive symptoms can have bidirectional effects in which behaviors predict more depressive symptoms overtime, but depressive symptoms can also predict higher levels of maladaptive behaviors overtime (Orsmond, Seltzer, Krauss, & Hong, 2003). Because some research has found that mothers of offspring with schizophrenia and autism are more likely to have psychological problems (Daniels, Forssen, Hultman, Cnatingius, Savitz, Feychting, & Sparen, 2008; Faridi, Pawliuk, King, Jooper, & Malla; 2009), attention and resources should be given to the treatment of psychological distress in mothers as much in treating behavior problems in the son or daughter.

An interesting finding for both maternal outcomes in our study was that older maternal age was related to better outcomes, a finding that is consistent with research on Latina mothers of adults with schizophrenia and ID (Magaña et al., 2007; Magaña & Smith 2006a). While maternal age significantly correlates with time since diagnosis as would be expected, time since diagnosis is related to higher levels of depressive symptoms and lower levels of psychological well-being when adjusting for maternal age and other factors; thus demonstrating the independent contribution of each of these variables. This finding that suggests that the accumulation of time caring for a person with either disorder may take its toll on Latina mothers. At the same time older mothers may have learned effective coping strategies over the course of their child's illness.

Other interesting relationships we found in our study were that mothers of Mexican descent had lower levels of psychological well-being than other Latina mothers and mothers who were primarily Spanish speaking had higher levels of depressive symptoms and lower levels of psychological well-being in our final models. Because all of the Mexican descent mothers were mothers of adults with schizophrenia, it is difficult to tease out whether the former relationship is due to the schizophrenia caregiving or a cultural factor related to being of Mexican descent. Using language of interview as a rough proxy for acculturation, the latter finding suggests that more acculturated mothers may have better well-being outcomes than less acculturated mothers. This finding is consistent with previous research of Latino parents of adults with developmental disabilities and may be due in part to stressors mothers face in navigating the service and treatment systems for their son or daughter which are primarily English based (Magaña et al., 2006).

Our finding related to our last research question was that mothers whose son or daughter was living outside the home had higher levels of depressive symptoms. More than eighty percent of the mothers in both studies lived with their son or daughter which is quite remarkable in itself. There were nine mothers who did not live with their son or daughter, and we explored their experiences more in-depth. What emerged in the open-ended data was that for mothers of children with autism, a placement decision was typically made because of extreme behavioral issues that parents were unable to handle. While mothers in these cases were able to talk about things that were better in their lives, they expressed a profound sadness about not being able to provide their child with the family and caring experiences they thought he or she deserved. Baker and Blacher (2002) found similar results for non-Latina mothers of young children with ID; however, they found that mothers of adults with ID had better outcomes. The children in our sample were not young children; however, two of the children with autism that lived outside the home were under 18 (ages 10 and 13), and the other three were adults. Mothers of adults with schizophrenia had less say about whether their sons moved out (all of the cases were male). However, they also cited behavioral concerns as well as their own health as factors that contributed to their son moving out. Consistent with other research on out of home placement, mothers from both groups described feelings of guilt for having to live apart from their son or daughter, and in some cases these feelings were experienced simultaneously with the positive feelings (Baker & Blacher). What is unique about our findings is that Latino caregivers of adults and older children with disabilities had worse outcomes if their child lived outside the home; whereas most research on non-Latino caregivers of adults has found the opposite (Baker & Blacher, 2002; Gallagher & Mechanic, 1996; Seltzer et al. 1997; Werner et al. 2009).

There are a few limitations to our study. We used a convenient sample with a small number of Latino families which limits generalizability of the findings to all Latino families caring for a son or a daughter with autism or schizophrenia, and limits the detection of significant relationships. Another limitation is that there were no Latinos of Mexican descent in our autism sample, which made it difficult to determine differences between Latino ethnicities.

Participants in the study volunteered to participate which increased the likelihood that our sample includes only those who were most willing to share information and had time to participate in a research study. The participants were primarily recruited through service agencies and it is difficult to say whether families who are not in the system face more or fewer challenges. It is not known how recruitment from different sampling sites may have influenced the findings in our study. Differences in services vary for autism and schizophrenia from one state to the other and it is not known whether services have an impact on the well-being of caregiving Latinas. Lastly, the cross-sectional nature of the study limited our ability to detect the direction of relationship between variables.

Implications for future research suggest that a larger longitudinal study of caregivers of both adults with autism and schizophrenia would be able to confirm or negate findings and explore trends found in this study. In order to control for the limitations from the present study, the larger study could be multi-site, but would need to include both persons with autism and schizophrenia from the same cities, and ensure that major Latino ethnicities are represented in both disability groups. Future research should also examine similar well-being outcomes among Latino adults with schizophrenia and autism to determine how they experience living at home versus in an out of home setting.

Despite the small sample size, our study found a number of significant relationships which have implications for practice. The study sensitizes us to the unique cultural context within which Latina mothers of children with autism and schizophrenia provide care. The predominant goal of services for individuals with autism or schizophrenia is focused on independent living, which may not be appropriate for all ethnic communities. Caring for the person with autism or schizophrenia in the home well into adulthood may be culturally appropriate for Latino families. Therefore service systems need to address the special needs of parents who would like to care for their children at home, as well as modify goals and objectives of treatment to adapt to the cultural context of caregivers.

On the other hand, our study suggests that there are circumstances, such as extreme and difficult behaviors as well as declining health of the parental caregiver, in which Latino families must resort to having their child live outside the home. Due to cultural pressures, mothers may feel guilty resorting to this decision and may need help and validation within the context of their cultural values to accept this decision. For example, helping the mother to consider the well-being of the whole family and how the family may benefit from increased attention to their needs, helping the mother to continue to provide care to their son or daughter by visiting and making phone calls if they desire, and involving other family members in overseeing the son or daughter's care in the outside residence may help maternal caregivers accept their decision as a good one.

Another important issue for practice with Latino family caregivers is the finding that Spanish speaking Latina mothers had poorer well-being compared to the English speaking counterparts. This finding suggests that language barriers may make it difficult to navigate service delivery systems. Therefore, agencies need to have bilingual and bicultural service coordinators that can communicate with and adequately assess the needs of Spanish-speaking families.

Service agencies must try to address the needs of caregivers over time, because our study found a relationship between higher depressive symptoms, lower levels of psychological well-being and time since diagnosis. This may arise due to parents having lower expectations for recovery for a child with a disability, as well as increasing concern over the future of the child. There may be different needs that caregivers have at different stages of the life-course of caring for their son or daughter.

Finally, as discussed earlier, the strong relationship of behavior problems to depressive symptoms found in our study indicates the need to address both treatment of the behavior problems of the son or daughter, and treatment of psychological distress among mothers in a culturally and linguistically relevant manner utilizing a two-pronged approach.

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Table 1

## Maternal and Youth/Adult Characteristics

|                                   | Schizophrenia<br>N=33 | Autism<br>N=29 | Test Value<br>(t or $\chi^2$ ) |
|-----------------------------------|-----------------------|----------------|--------------------------------|
| Maternal Characteristics          |                       |                |                                |
| Age (M±SD)                        | 59.8 (10.2)           | 44.1 (8.3)     | 6.5**                          |
| range                             | 35–89                 | 33–62          |                                |
| # of children (M±SD)              | 2.4 (2.1)             | 1.7 (1.3)      | 1.8                            |
| Marital Status (percent)          |                       |                |                                |
| Married                           | 51.5                  | 27.6           | 3.7*                           |
| Annual Income (percent)           |                       |                |                                |
| \$0 to 19,999                     | 57.0                  | 65.5           | 2.4                            |
| \$20,000 to 39,999                | 18.2                  | 20.7           |                                |
| \$40,000 to 59,999                | 15.2                  | 3.4            |                                |
| \$60,000 +                        | 9.1                   | 10.3           |                                |
| Education (percent)               |                       |                |                                |
| Less than high school             | 54.5                  | 34.5           | 6.5                            |
| High School                       | 15.2                  | 31.0           |                                |
| Some College                      | 24.2                  | 13.8           |                                |
| Bachelors and higher              | 6.1                   | 20.7           |                                |
| Health Status (percent)           |                       |                |                                |
| Excellent/Good                    | 48.5                  | 51.7           | .06                            |
| Language of interview (percent)   |                       |                |                                |
| Spanish                           | 81.8                  | 65.5           | 2.1                            |
| Ethnicity (percent)               |                       |                |                                |
| Mexican Origin                    | 42.4                  | 0              | 17.9***                        |
| Puerto Rican                      | 12.1                  | 41.4           |                                |
| Other Latino                      | 45.5                  | 58.6           |                                |
| Youth/Adult Characteristics       |                       |                |                                |
| Age (M±SD)                        | 36.3 (10.1)           | 16.7(8.1)      | 8.5                            |
| range                             | 19–65                 | 8–40           |                                |
| # of Maladaptive Behaviors (M±SD) | 1.8 (1.8)             | 3.6 (2.2)      | −3.6***                        |
| Time since diagnosis              | 16.4 (9.5)            | 12.8 (8.0)     | 1.6                            |
| Residential Status (percent)      |                       |                |                                |
| Co-Residing                       | 87.9                  | 82.8           | 0.3                            |
| Placed                            | 12.1                  | 17.2           |                                |
| Gender (percent)                  |                       |                |                                |
| Male                              | 81.8                  | 69.0           | 1.4                            |
| Health Status (percent)           |                       |                |                                |

|                | Schizophrenia<br>N=33 | Autism<br>N=29 | Test Value<br>(t or $\chi^2$ ) |
|----------------|-----------------------|----------------|--------------------------------|
| Good/Excellent | 42.4                  | 79.3           | 8.7**                          |

\*\*\*  
p < .001,

\*\*  
p < .01,

\*  
p < .05

**Table 2**  
Mean-Level Differences of Depressive Symptoms and Psychological Well-Being

|                          | Schizophrenia<br>N=33 <sup>f</sup> |      | Autism<br>N=29 |      | t statistic |
|--------------------------|------------------------------------|------|----------------|------|-------------|
|                          | M                                  | SD   | M              | SD   |             |
| Depressive Symptoms      | 15.0                               | 11.7 | 13.2           | 11.6 | .6          |
| Psychological Well-Being | 65.9                               | 12.5 | 72.8           | 11.3 | -2.3*       |

\* P < .05

<sup>f</sup> 32 mothers of adults with schizophrenia completed the psychological well-being measure

Table 3

*Regression of Depressive Symptoms (N=62)*

| Predictors                 | Model 1 |      | Model 2 |       |
|----------------------------|---------|------|---------|-------|
|                            | B       | SE   | B       | SE    |
| Diagnosis                  | -6.25   | 4.19 | -2.27   | -7.88 |
| Behavior Problems          | 1.55    | .72  | .29*    | 1.51  |
| Time since Diagnosis       | .06     | .21  | .47**   | .59   |
| Age of Mother              | -.46    | 1.49 | -.48*   | -.54  |
| Mothers Health             | -2.93   | 3.68 | -.24    | -3.41 |
| Ethnicity                  | 4.21    | 3.22 | .15     | 3.71  |
| Language of Interview      | 5.68    | .22  | 6.54    | 3.09  |
| Child's Place of residence | 9.42    | 3.74 | .29*    |       |
| Adjusted R <sup>2</sup>    |         |      | .21     | .28   |

\*\*\* p &lt; .001,

\*\* p &lt; .01,

\* p &lt; .05

Diagnosis (0= schizophrenia, 1 = autism); Ethnicity (0= others, 1 = Mexican descent); Language of interview (0= English, 1 = Spanish); Residence (0= co-residing, 1= placed)

Table 4

Regression of Psychological Well-being (N=61)

| Predictors                 | Model 1 |      |         | Model 2 |      |         |
|----------------------------|---------|------|---------|---------|------|---------|
|                            | B       | SE   | $\beta$ | B       | SE   | $\beta$ |
| Diagnosis                  | 11.34   | 4.22 | .46*    | 12.55   | 4.15 | .51***  |
| Behavior Problems          | -1.38   | .72  | -.24    | -1.35   | .70  | .23     |
| Time since Diagnosis       | -.63    | .21  | -.42**  | -.63    | .20  | -.42**  |
| Age of Mother              | .58     | .20  | .53***  | .62     | .20  | .57***  |
| Mothers Health             | .57     | 1.52 | .04     | .85     | 1.48 | .06     |
| Ethnicity                  | -8.11   | 3.72 | -.28*   | -7.45   | 3.64 | -.26*   |
| Language of Interview      | -7.03   | 3.26 | -.25*   | -7.98   | 3.21 | -.29*   |
| Child's Place of residence |         |      |         | -7.91   | 3.98 | -.22    |
| Adjusted R <sup>2</sup>    |         |      | .29***  |         |      | .37***  |

\*\*\*  
p < .001,\*\*  
p < .01,\*  
p < .05

Diagnosis (0= schizophrenia, 1= autism); Ethnicity (0= others, 1= Mexican descent); Language of interview (0= English, 1= Spanish); Residence (0= co-residing, 1= placed)