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The role of caregivers' depressive symptoms and asthma beliefs on asthma outcomes among low-income Puerto Rican children ¹

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Abstract

OBJECTIVE—To examine the relationship between depressive symptoms and asthma beliefs (self efficacy and empowerment), child asthma outcomes, and caregiver's quality of life among Puerto Rican caregivers of children with asthma.

METHODS—The caregivers of 221 children with persistent bronchial asthma were stratified into those with no/low or high levels of depressive symptoms. Differences between the groups in caregiver self-efficacy, family empowerment, child asthma outcomes and quality of life were examined.

RESULTS—Caregivers with more depressive symptoms reported lower self-efficacy, less empowerment, less symptom free days and nights for their children and a lower quality of life compared to caregivers with no or fewer depressive symptoms.

CONCLUSIONS—Depressive symptoms among Puerto Rican caregivers were associated with asthma beliefs, children's asthma symptoms and caregiver quality of life. Our findings reinforce the importance of physician screening skills in recognizing caregiver depression in parents of asthma patients.

Keywords

caregiver depression; pediatric asthma; asthma outcomes

Introduction

Island Puerto Rican children have lifetime rates of asthma over 30%, higher than mainland children of any other ethnic group (1–5). In addition, compared to other children, both mainland and island Puerto Rican children have the highest rates of asthma morbidity and service utilization (6–8). Asthma related-disparities could be even greater among low-income island Puerto Rican children (9).

This observed disparity in asthma prevalence and morbidity among Puerto Rican children is likely attributable to multiple interacting factors operating at the individual, family, health care system, and environmental level (10). In this paper, we examine individual and family level factors and focus on the inter-relationships between caregiver characteristics, including

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depressive symptoms, self-efficacy and empowerment, and both child and caregiver asthma-related outcomes.

Caregiver depressive symptoms have been highlighted in multiple family-level asthma studies as an important contributing factor in asthma morbidity. Depressive symptoms in caregivers of children with asthma have been associated with worse asthma outcomes in their children and with reductions in their quality of life (11–16). Furthermore, asthmatic children of mothers with depressive symptoms have an increased rate of emergency service use and hospitalizations as compared to mothers without depressive symptoms (13,15,17–18). Managing asthma requires a complex set of behaviors, including assessment and monitoring of asthma symptoms, prevention strategies, such as taking preventive medications and avoiding precipitants, attack management behaviors, and social and communication skills necessary to communicate with providers (19). Depressed caregivers as compared to non-depressed ones may feel less able to cope with these challenges, and as a consequence may be more likely to misinterpret their child's symptoms, underestimate their ability to deal with their child's asthma and feel overwhelmed by the demands of a sick child (13,15). Depression in Puerto Rican caregivers is an important area of study since rates of depressive symptoms among low-income Puerto Rican women have been reported to be as high as 28.6%, which is two times greater than those reported for mainland women or women of higher income (20). No previous studies have examined the link between depressive symptoms and asthma morbidity in low-income island Puerto Rican families of children with asthma.

Depressive symptoms have also been associated with worse caregiver quality of life. This finding is not surprising since depressive disorders are classified as one of the diseases having the most impact on quality of life (21–22). At the same time, the severity of the child's asthma has also been related to decreased caregiver quality of life (12,16,23). A limited number of studies have examined caregiver depression and the child's asthma as individual factors contributing to the caregiver's quality of life; however, this association in Latino families has not been examined (13,15).

In order to further understand the role of Puerto Rican caregiver depressive symptoms on both child and caregiver asthma outcomes, we evaluated the relationship of depressive symptoms with caregiver asthma beliefs, including self-efficacy and empowerment. Self-efficacy (i.e. a person's belief that he or she has the knowledge and ability to perform asthma-related behaviors) and empowerment (i.e. the process in which people gain mastery over issues of concern to them) have been associated with asthma management practices (13,16,24–26). There is also evidence that an increase in depressive symptoms is associated with decreased confidence in caregivers' ability to manage their child's chronic condition (i.e. self-efficacy) (27–30). However, the association of self-efficacy and empowerment with caregiver depressive symptoms and asthma morbidity among low-income, Latino families has not been studied.

The present study is the first to investigate the relationship between caregiver's depression, self-efficacy, empowerment and asthma outcomes such as caregiver quality of life and child asthma measures in a sample of low-income Puerto Rican children with persistent asthma. The study is timely given the high rates of depressive symptoms previously found in an island-wide study of low-income Puerto Rican women of childbearing age (20) and the high rates of asthma morbidity found in Puerto Rican children (3,31–32).

Methods

Study Sample and Participants

In this paper we present baseline results from a prospective study designed to test the effectiveness of a culturally adapted family-based intervention for the reduction of asthma morbidity in poor Puerto Rican children (CALMA). Study methods and outcomes have been described elsewhere (33). Using claims data from two health regions of the Medicaid funded *Reforma* health care plan⁵ of Puerto Rico, 341 families with children 5 to 12 years old who met HEDIS criteria⁶ for persistent asthma were contacted. A total of 332 (97.4%) caregivers consented to be screened by telephone. Caregivers, defined as the biological parent or adult legally responsible for the child, were eligible to participate if they reported that their child had: (1) used asthma medication, (2) experienced wheezing, tightness of chest, problems coughing, waking up at night because of asthma, or (3) been hospitalized, visited the emergency department or a doctor for urgent care in the previous year. From all eligible families, 221 (86%) agreed to participate and completed baseline information.

Procedures

The Institutional Review Board (IRB) of the Medical Science Campus at the University of Puerto Rico approved all questionnaires and procedures. Enrollment and baseline interviews took place between April and June of 2006. Informed consent was obtained at enrollment and reviewed before each interview. A trained lay interviewer visited caregivers who met eligibility criteria in their homes and conducted a face-to-face, pen and pencil, one-hour baseline interview. Interviews were conducted in Spanish and recorded for quality control.

Measures

The comprehensive interview included several measures cross-culturally adapted for use among Spanish-speaking populations (34–35). For this paper, we organized measures in four groups: socio-demographics, caregiver characteristics (depressive symptoms, self-efficacy and empowerment), caregiver's asthma outcome (parental quality of life) and child asthma outcomes (symptom-free days, symptom-free nights, hospitalizations and emergency room visits).

Socio-demographics—Caregivers were asked about their educational attainment, marital status, employment, and child's age and gender. Income was measured according to annual income, perception of poverty, household composition and governmental/social assistance.

Caregiver characteristics

Center for Epidemiological Study-Depression (CES-D): The CES-D is a widely used screening instrument that measures current levels of depressive symptomatology (36–39). The overall score is calculated by summing the scores for each item ranging from 0 to 60. Previous research studies conducted in Puerto Rico recommend a cut-off score of 21 to determine the presence of significant depressive symptoms in Puerto Rican populations (20). The psychometric properties of the CES-D have been previously investigated and generally accepted as a standard and reliable measure for depressive symptoms in primary care settings

⁵To be able to enroll in the government health plan (*Reforma*) the family must be at the 200% Federal Poverty level.

⁶The modified HEDIS criteria requires that the patient be diagnosed with asthma or reactive airway disease (diagnostic code 493.xx) and in a one year period presents one or more of the following related to their asthma condition: had been hospitalized, had at least 2 Emergency Department (ED) visits, had 3 or more ambulatory visits, or utilized asthma medication from at least 2 therapeutic categories: anticholinergics, cromolyn, sympathomimetics, steroid Inhalants, xanthenes, leukotrine Inhibitors, or corticosteroids. The usual HEDIS criteria require 1 ED visit and the use of 4 asthma medications.

(40–41), including its use with Latino populations (42–44). Internal consistency reliability has been in 0.8 to 0.9 ranges. In this study, CES-D the standardized alpha reached 0.87.

Parent Asthma Self-Efficacy Scale: Asthma-related self-efficacy was measured with the Asthma Self-Efficacy Scale (25), consisting of 13 items and two sub-scales: asthma prevention ($\alpha = 0.77$) and management ($\alpha = 0.82$) (25). Higher scores on the scale and on the sub-scales represent better self-efficacy, reflecting respondents' increased confidence that they have the knowledge and ability to perform asthma-related behaviors. In our study, the internal consistency score were 0.81 and 0.75, respectively for the sub-scales and 0.84 overall.

Family empowerment, service system subscale (FES): The Family Empowerment Scale (FES) has a three-dimensional design to measure the family's feeling of empowerment in relationship to the health care system (45). The entire test consists of 34 Likert-like questions, with a subscale of 12 items designed to assess the health service system. In this study, only the Service system sub-scale (12 item, $\alpha = 0.87$) of the FES was administered. The items measure the caregiver's beliefs and confidence regarding the services the child needs, their initiative in obtaining these services and making sure that the professionals understand and respect their opinions regarding what the child needs, their knowledge and understanding of services and their positive attitudes about their ability to obtain and claim the services the child needs. The items are scored in the same direction and higher scores indicate relatively more empowerment in a specific area. Our internal consistency at baseline was the same as that published in previous studies ($\alpha = 0.87$).

Caregiver's asthma outcome

Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ): The PACQLQ, Spanish version, is a 13-item scale that measures the impact of asthma on the daily activities of parents of children with asthma and their fears and preoccupations about their asthmatic children (46). It includes two sub-scale scores: activities (4 items) and emotional functions (9 items) items rated from low (1) to high (7) impairment. The emotional items refer to the caregiver's feelings of helplessness, upset, or anger when their child has asthma symptoms, and feelings of frustration, impatience or irritability due to their child's asthma. The activities items refer to whether the caregiver had to change plans because of the child's asthma, interfered with the caregiver's job, or was awakened during the night. The internal consistency of the PACQLQ in normal samples is adequate ($\alpha = 0.84$). In this sample it was 0.75.

Child asthma variables

Asthma severity: Severity of asthma was measured with the Asthma Assessment Form developed to assess the child's asthma symptoms and physiological severity, as well as the overall level of functional limitation and burden of illness that has occurred over the last four weeks and the past 12 months including days missed from school. The scale was adapted from the Rosier Scale (47). The severity scale measures frequency and intensity of episodes, frequency of symptoms (morning wheeze and wake at nights), and intensity of impairment (home and sport activities). An asthma impairment severity score is computed by summing scores between 1 and 22. In this study children were classified into the following severity categories with the following point distribution: low to mild (0–8), moderate (9–14), and severe (15–22).

Symptom-free days/nights: This is an index of asthma morbidity recommended by the NAEPP (48) and strongly associated with the Juniper Asthma-Related Quality of Life measure and the St. George's Respiratory Questionnaire (49). A symptom-free day measure is estimated by subtracting the numbers of caregiver reported days and/or nights with asthma symptoms (i.e., cough, wheeze, chest tightness, loss of sleep, shortness of breath) from the total days in

the past month or in the past two weeks. Previous asthma educational intervention studies have shown that improvements of two to three symptom-free days are clinically meaningful (50).

Health service use: Emergency Department (ED) visits and number of hospitalizations were measured with items previously used (51) that assessed the number of emergency room visits or hospitalizations during lifetime, last 30 days and last 6 months.

Statistical Analysis

Descriptive statistics were used to determine the distribution of the socio-demographics variables under study. Depressive symptoms were measured as a continuous variable and then used to dichotomously classify caregivers (high or low/no depressive symptoms). A cut-off score of 21 was used to determine the presence of significant depressive symptoms (20). Baseline differences in sociodemographic characteristics between the stratified groups of caregivers with high or with low or no depressive symptoms were tested for statistical significance by means of an independent group *t*-test for continuous variables and a Chi-square test (χ^2) for the dichotomous variables.

Student *t*-test analyses were performed to evaluate differences between the caregivers with and without depressive symptoms and caregiver asthma beliefs (self-efficacy, family empowerment), caregiver outcomes (quality of life) and child outcomes (asthma morbidity). The results are expressed with mean scores for each sub-scale as well as for overall scales. SAS statistical package was used to complete the statistical procedures.

Results

Caregiver and Child characteristics (Table 1)

Of the sample of 221 caregivers of children with asthma, 88.69% (n=196) were biological mothers. These caregivers were mostly unemployed (70%), with yearly incomes of less than \$6,999 (72%) and receiving social assistance benefits (75%). Most of them had an education level of high school (31%) or less than high school (33%) and perceived their economical status as poor (20%) or living from check to check (41%). There were no statistically significant differences between the caregivers with high and with low or no depressive symptoms in terms of sociodemographic characteristics (Table 1). Although all participants qualified for the Puerto Rico health plan by being at 200% or lower of the federal poverty level, a tendency was observed for mothers with high levels of depressive symptoms to have higher reports of receiving social assistance (81% vs. 71%, $p=0.10$) and of perceiving economic difficulties (27% vs. 42%, $p=0.10$) as compared to mothers with low or no depressive symptoms. Children's mean age was 7.35 years and most children were male (60%). There were no statistically significant differences in the Rosier severity index of the children's asthma between the two groups of caregivers. For this reason, further analysis did not control for severity.

Caregiver Depressive Symptoms

One third (33%) of the island Puerto Rican caregivers of children with asthma enrolled in this study presented with high levels of depressive symptoms (n=73). This rate of depressive symptoms is similar to previous studies of depressive symptoms among women in low socioeconomic areas in Puerto Rico (20).

Caregiver Depressive Symptoms and Self-Efficacy, Family Empowerment and Quality of Life (Table 2)

Caregivers with high depressive symptoms were significantly more likely to report that they had the knowledge or ability to perform asthma related behaviors with their children, (38.6 vs. 41.19 self-efficacy scale scores, $p < 0.01$), and to feel less empowered to deal effectively with their child's condition (41.45 vs. 44.18 family empowerment scale scores, $p < 0.05$) (Table 2). Depressed mothers were significantly less likely to feel confident in using preventive strategies and to manage their child's asthma effectively (self efficacy prevention sub-scale and management sub-scales respectively).

Caregivers with high symptoms of depression were significantly more likely to report lower quality of life scores as compared to caregivers without high symptoms of depression (52.36 vs. 58.24, $p < 0.01$; Table 2). Depressed caregivers were significantly more likely to feel frustrated, helpless, upset, anger and worried about their child's asthma symptoms (QOL emotional sub-scale) and to feel that their child's asthma interfered with activities in their daily living such as their job, family relations and sleep. (QOL activity sub-scale).

Caregiver Depressive Symptoms And Child Asthma Morbidity (Table 3)

Children of caregivers with high depressive symptoms reported significant fewer symptom free days and nights over the past six months ($p < .01$) There was no statistically significant difference in hospitalization and emergency room use between the two caregiver groups. There was an increased rate of intensive health service use in both groups with children having a mean of 4 visits to the emergency room and a mean of 1.25 hospitalizations in the last 6 months (Table 3).

Discussion

This study presents several important findings that further elucidate the role of caregiver depression in pediatric asthma outcomes. Caregivers with high depressive symptoms reported significantly less self-efficacy and empowerment in dealing with their children's asthma as well as more asthma symptoms in their children. In addition, depressed caregivers were more likely to report a poor quality of life as compared to non-depressed caregivers. However, unlike prior studies with non-Latino samples (13,15,17–18), our study failed to find an association between caregiver depressive symptoms and service use possibly because our sample was composed mostly of very poor mothers.

The caregivers participating in this study were at least 200% below the federal poverty level. Poverty has been associated with high rates of emergency room use and hospitalizations (Rand et al, 2000; Miller, 2000; Stingone & Claudio, 2006; Liu et al, 2000). The high rates of elevated symptoms of depression found in this sample (31%) could also be related to the high poverty level of the same. Low socioeconomic status has been associated with depression in mothers (20,52,53). In this study, we cannot explore the role of poverty further since there were no statistically significant differences between the groups in socioeconomic status, but it would be important to evaluate if the same findings could be replicated with caregivers of asthmatic children of Puerto Ricans in other socioeconomic strata.

The results of this study demonstrate the importance of taking into consideration the caregiver's burden when dealing with high-risk populations, such as low-income Puerto Rican mothers. The associations observed between high level of caregivers' depressive symptoms and caregiver's low self efficacy in managing their child's asthma as well as lack of empowerment in dealing effectively with the health system, may be contributing factors in the increased morbidity observed among Puerto Rican children with asthma. Furthermore, these

caregivers had a significantly lower quality of life as compared with non-depressed mothers. However, because several items in the quality of life emotional sub-scale also assess common symptoms of depression, (i.e. frustration, feeling upset and angry) this association should be interpreted with caution. Future studies evaluating asthma-related health disparities should consider the role depressive symptoms might have on caregivers' self-efficacy, empowerment and quality of life related to asthma management and outcomes.

Although our study had a number of methodological strengths, such as the use of mixed-block randomization scheme and high participation rates, there are several limitations related to measurement and generalizability of these results. All measures were based on caregiver's self-report without confirmation. Caregivers with depressive symptoms may have underestimated their ability of effectively dealing with their child's asthma given that depressive symptoms are associated with negative and pessimistic perceptions of reality. Furthermore, this study was designed to evaluate a family-based intervention for asthma management and was not developed to evaluate for depressive symptoms in the caregivers nor the particular relationships between depressive symptoms and caregiver self efficacy, empowerment and quality of life. It is also important to emphasize that no direct causality can be attributed regarding the relationship between depressive symptoms and any of the outcomes assessed. This study presents cross-sectional data and the cause and effect relationship between caregivers' depressive symptoms and their self efficacy, empowerment, quality of life as well as with their children's asthma morbidity can not be elucidated. In order to further understand these relationships and validate the findings from our study, future longitudinal studies should be designed to evaluate these associations in other samples of caregivers of asthmatic children.

Finally, the study has important implications for pediatric asthma prevention and health promotion. Parental empowerment and self-efficacy are important caregiver characteristics that can improve the caregiver's participation in problem formulation, decision-making, and action towards healthy choices (54–55). Several programs that focus on improving chronic pediatric conditions by increasing caregiver empowerment and self-efficacy have demonstrated the beneficial effect of targeting these characteristics as part of the treatment process (16,24,26). At the same time, an intervention that can improve the management of the child's asthma will likely have a positive impact on the caregiver's quality of life. For example, we have previously demonstrated that CALMA intervention improved both the management of the child's asthma as well as the caregiver's quality of life (33). Similarly, given the added burden of illness observed in depressed caregivers, the identification of depressive symptoms in this population as well as the development of specialized interventions geared toward appropriate referral and care, are sorely needed. Several cost-efficient screening measures for depressive symptoms are available that can be used in the clinical settings where children with persistent asthma are being evaluated and treated (56–58). At the same time, several low cost and evidence-based treatments such as cognitive behavior therapy are available for the treatment of depressive symptoms and the disorders associated with these symptoms (59–61) so that these caregivers could be motivated and referred to receive these interventions. The current strength of evidence for the importance of maternal depressive symptoms in pediatric asthma management and outcomes argues strongly for the importance of developing clinical strategies to address maternal depression in the context of pediatric care.

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Table 1
Comparison of caregiver and children characteristics by depressive symptom status

Variables	Depressed (73)	Non-depressed (148)	Total (221)	t/χ^2
	n (%) X	n (%) X	n (%) X	
Children characteristics				
Mean age	73 7.56	148 7.24	221 7.35	0.99
Male	47 (64.38)	84 (56.76)	131 (59.28)	1.18
<i>Rosier's Functional Limitation</i>				4.58
Mild	8 (10.96)	34(22.97)	42(19.00)	
Moderate	43 (58.90)	75(50.68)	118(53.39)	
Severe	22 (30.14)	39(26.35)	61 (27.60)	
Family characteristics				
Married/Living as a couple	40 (58.82)	98 (68.06)	138 (65.09)	1.73
Father educational level				0.36
Less than high school	26 (40.00)	52 (38.24)	78 (38.81)	
High school	24 (36.92)	56 (41.18)	80 (39.80)	
Some college or college degree	15 (23.08)	28 (20.59)	43 (21.39)	
Mother educational level				1.85
Less than high school	26 (37.68)	46 (31.51)	72 (33.49)	
High school	23 (33.33)	44 (30.14)	67 (31.16)	
Some college or college degree	20 (28.99)	56 (38.36)	76 (35.35)	
Father employed	41 (60.29)	88 (64.23)	129 (62.93)	0.30
Mother employed	18 (25.71)	46 (31.29)	64 (29.49)	0.71
Annual Income				3.75
None	22 (30.99)	39 (28.47)	61 (29.33)	
50 to 6,999	35 (49.30)	54 (39.42)	89 (42.79)	
7,000 or more	14 (19.72)	44 (32.12)	58 (27.88)	
Receives social assistance	59 (81.94)	106 (71.62)	165 (75.00)	2.75*
Household composition	73 4.05	147 4.20	220 4.15	0.81
Perception of poverty				4.66*
Live well	22 (30.14)	63 (42.57)	85 (38.46)	
Check to check	31 (42.47)	60 (40.54)	91 (41.18)	
Poor	20 (27.40)	25 (16.89)	45 (20.36)	

* p. <0.10 (tendency) χ^2 for categorical variables t for continuous variables

Depressed=High Depression Symptom; CESD \geq 21 Non-depressed= Low depression symptoms; CESD <21

Table 2

Comparison of caregiver characteristics

Variables	Depressed (73)	Non-depressed (148)	Total (221)	t
	n (%) X	n (%) X	n (%) X	
Family empowerment scale	73 41.45	148 44.18	221 43.28	2.07*
Self-efficacy	70 38.66	138 41.49	208 40.04	3.06**
Self-efficacy, prevention	70 19.60	138 21.00	208 20.53	3.53**
Self-efficacy, management	70 19.04	138 20.48	208 19.99	2.17*
QOL	73 46.03	148 52.36	221 50.27	3.56**
QOL, emotional	73 30.64	148 35.31	221 33.77	3.99**
QOL, activity	73 15.38	148 17.04	221 16.50	2.2*

* p<0.05

** p<0.01

Depressed=High Depression Symptom; CESD ≥ 21 Non Depressed=Low depressive symptoms; CESD <21

Table 3 Child asthma variables by caregiver depressive symptom status

Child asthma variables	Depressed (73)		Non-depressed (148)		Total (221)		t
	n	Mean	n	Mean	n	Mean	
Symptoms Free Days (30d)	72	20.72	147	24.36	219	23.16	3.26***
Symptoms Free Nights (30d)	72	22.39	145	26.09	217	24.86	3.28***
Emergency Room (6mo)	70	4.5	147	3.76	217	4.00	0.79
Hospitalizations (6mo)	72	1.58	144	1.09	216	1.25	1.19

p<0.01