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Ethnic Differences in Caregiver Quality of Life in Pediatric Asthma

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Abstract

Objective—The aim of this study was to determine ethnic and site differences in quality of life (QOL) in a sample of Latino (Puerto Rican and Dominican) and non-Latino White (NLW) caregivers of children with asthma in mainland US and Island PR. We also investigated ethnic and site differences in associations between caregiver QOL and indicators of asthma morbidity.

Method—Seven-hundred and eighty-seven children with asthma (7–16 years of age) and their primary caregivers participated. Primary caregivers completed a measure of QOL, child asthma control, and emergency department utilization, among other measures.

Results—Ethnic and site differences were found on total QOL scores ($\Delta F(1, 783) = 29.46, p < .001$). Island PR caregivers reported worse QOL scores than RI Latino and NLW caregivers; RI Latino caregivers reported significantly worse QOL scores than NLW caregivers. In RI Latino and Island PR children, worse caregiver QOL was associated with asthma that was not in control and with 1 or more ED visits.

Conclusion—Latino caregivers may be experiencing a greater level of burden related to their child's asthma than NLW caregivers. Caregiver QOL in pediatric asthma may be a reflection of broader, contextual stress that some Latino caregivers experience on a daily basis (e.g., cultural beliefs, acculturation). Future research should continue to investigate mechanisms that explain the burden associated with pediatric asthma in Latino families, as well as whether QOL assessments should consider the impact of everyday stressors on caregiver QOL in pediatric asthma.

Key terms

pediatric asthma; quality of life; caregivers; disparities; ethnicity

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Ethnic minority children are at greater risk for asthma morbidity and more severe asthma than non-Latino White (NLW) children.¹ The increase in asthma morbidity is a significant

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public health concern for Latino groups. Puerto Rican (PR) children residing in mainland US and Island PR experience greater morbidity as indicated by more clinic visits, missed school days, and emergency department (ED) visits, compared to other Latino ethnic subgroups, African American, and NLW children.^{2, 3} Research on health disparities suggests that poor asthma outcomes are multi-determined, and stem from factors related to the underlying pathophysiology of asthma (e.g., severity), characteristics of the health care system, provider beliefs, patient beliefs and expectations, and the environment or context within which the child lives.^{4, 5}

As pediatric asthma is managed within the family context, caregivers are required to identify symptoms, minimize triggers within the home, and ensure that children adhere to daily medication regimens.⁶ The burden of managing asthma can affect caregiver quality of life (QOL), particularly for ethnic minority families who may face additional stressors related to urban poverty and cultural background.^{7, 8} In pediatric asthma, caregiver QOL is defined as a subjective measure of how well a caregiver is adapting to having a child with asthma both emotionally and socially. A caregiver with lower levels of QOL may experience greater anxiety about their child's asthma, worry that the child may die from an asthma attack, miss more days of work, or suffer from sleepless nights. There is a well-established body of literature suggesting that caregiver functioning (psychological and physical) influences child functioning.⁹ In pediatric asthma, maternal depressive symptoms have been associated with increased ED utilization and high hospitalization rates.^{10, 11} Thus, caregivers with lower levels of QOL may be at risk for mismanaging their child's asthma, putting their child at risk for poor asthma outcomes.

Clinical utility of caregiver QOL

Assessments of caregiver QOL provide a critical piece of knowledge to health care providers regarding the burden that childhood asthma and treatment present on the family's daily life and barriers to effective asthma control.¹² Caregiver QOL assessments, such as the commonly used Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ),¹³ may be predictive of caregiver behaviors to manage the child's illness, including use of the ED or other specific day-to-day treatment decisions. Thus, the impact of lower levels of caregiver QOL extends beyond the daily functioning of families; it affects asthma morbidity, with implications for child health and academic performance.¹⁴ In fact, a recent NHLBI workshop identified QOL as an important asthma outcome for assessments in clinical research.¹⁵ Although QOL is often considered an outcome measure, it is important to note that the association between QOL and asthma morbidity is likely bidirectional,¹⁶ in that QOL may also impact asthma morbidity.

Existing caregiver QOL research in pediatric asthma

Despite the clinical importance of caregiver QOL, it is unclear how well QOL measures, such as the PACQLQ, are able to assess reports of caregiver QOL among different cultural groups. Most caregiver QOL research in pediatric asthma to date has considered specific predictors associated with variations in QOL in predominantly NLW samples. Across studies, caregiver negative affect, family burden, asthma control, and lower levels of child QOL are associated with lower levels of caregiver QOL.¹⁷⁻¹⁹ The interaction of family level risk factors (e.g., family stress, child QOL, socioeconomic status, asthma severity) was also found to predict caregiver QOL using a cumulative risk model.²⁰ A growing body of research is beginning to investigate differences in caregiver QOL within Latino families. For example, in a sample of Island PR caregivers, more depressive symptoms were associated with lower levels of caregiver QOL.²¹ In a small sample of Latino caregivers in the US, asthma severity and child QOL were associated with caregiver QOL.²²

Only one study has specifically considered differences in caregiver QOL between NLW and Latino caregivers. In a sample of children that was 59% African American, 12% NLW, 29% “other racial background”, and 32% Hispanic ethnicity, Halterman and colleagues²³ found that Hispanic ethnicity predicted worse caregiver QOL scores. Our study adds to the existing literature by investigating whether the experience of caregiver QOL in pediatric asthma differs by ethnic group. We investigated ethnic differences in caregiver QOL across a large sample of NLW and Latino caregivers. Further, as children with asthma from Island PR have the highest asthma morbidity rates,²⁴ we also investigated site differences in QOL among Latino caregivers both in mainland US and Island PR. Finally, we considered ethnic differences in associations between caregiver QOL and indicators of asthma morbidity, including asthma control and ED use.

Health disparities research in pediatric asthma

As only one study has considered ethnicity as a predictor of caregiver QOL,²³ health disparities research may provide guidance as to how caregiver QOL may differ across ethnic groups. For instance, research has found support for ethnic differences in beliefs about asthma etiology,^{25, 26} medication effectiveness,²⁷ the use of alternative medications,^{8, 28} symptom perception,²⁹ and fear of mortality.³ For example, Latino caregivers have been found to underestimate their ability to control their child’s asthma and utilize emergent care out of fear that their child will die from asthma symptoms.^{3, 30} Latino families have also been found to report more barriers related to the health care system than NLW families (e.g., insurance status, language differences, inconsistent asthma health care providers).³¹ Further, McQuaid and colleagues³² found that Island PR caregivers reported more barriers to filling prescriptions (e.g., medication costs) for their children than NLW and PR caregivers from the mainland US and that these barriers were associated with less controller medication use in children. Cultural beliefs may guide how caregivers experience their child’s asthma, which in turn, may influence day-to-day decisions that caregivers make about their child’s asthma treatment. If children are less adherent to their controller medication, children may experience greater asthma morbidity, which can increase the burden that caregivers face in managing child asthma.

Study hypotheses

The present study had three main goals. First, we aimed to determine ethnic and site differences in caregiver QOL in a sample of Latino (Puerto Rican and Dominican) and NLW caregivers of children with asthma in Rhode Island (RI) and Island PR. For purposes of this study, we chose to combine caregivers of Caribbean descent into one category, RI Latino caregivers, based on the high asthma prevalence and asthma morbidity in both groups.^{2, 3} We hypothesized that Latino caregivers would experience worse caregiver QOL than NLW caregivers and further, that Latino caregivers in Island PR would have the lowest levels of QOL relative to their counterparts in mainland US. Consistent with the focus of health disparities research which aims to delineate mechanisms underlying health outcomes (e.g., individual, environment) through a careful methodological approach,⁴ we chose to control for poverty in our study and consider the unique contribution of ethnic background to caregiver QOL.

Our second goal was to determine ethnic and site differences in associations between caregiver QOL and well-established indicators of poor control in children with asthma (e.g., ED use, asthma control).³³ For this study, asthma control was defined as “in control” or “not in control” based on asthma symptoms and prealbuterol FEV₁. Based on our previous research,³² we hypothesized that we would find more robust associations between caregiver QOL and morbidity indicators among Latino families, and especially those from Island PR. Latino children and particularly those in Island PR often have higher rates of ED utilization

and poor asthma control,³⁴ which may impact the QOL of caregivers in these families more so than in NLW families.

Finally, we hypothesized that we would find differences by ethnicity and site, in two specific areas on the PACQLQ: we expected Latino caregivers to endorse more fear related to child asthma symptoms and more concern related to medication usage than NLW caregivers. We also expected Island PR caregivers to report more fear and medication concerns than Latino caregivers in RI. These hypotheses were based on previous research suggesting that Latino caregivers may underestimate their ability to control their child's asthma and fear that their child may die from their asthma symptoms.^{3, 30} Furthermore, Latino families, especially in Island PR, often report more concerns related to medication side effects than their NLW counterparts.³²

METHODS

Participants

Data were collected as part of a larger study in pediatric asthma assessing contributing factors to pediatric asthma disparities among NLW children and Latino children in both mainland US and Island PR.^{4, 5} Nine-hundred seventy-two children with asthma between the ages of 7 and 16 years and their primary caregivers were initially enrolled in the larger study. Subjects were recruited from convenience samples. In RI, participants were recruited from ambulatory pediatric hospital clinics, community primary care clinics, a hospital-based asthma educational program, health fairs and other community events, schools, and grassroots sources (e.g., word of mouth, flyers). In Island PR, participants were recruited from independent provider organizations, ambulatory pediatric hospital clinics, and private practice pediatric offices.

Given the central question for the current study related to caregiver QOL, participants included the 787 children with asthma whose caregivers completed the QOL measure (81% of original sample). Families that were retained for this study differed from those families not included with respect to poverty threshold ($X^2 = 5.02, p < .05$). Sixty-three percent of families who were not retained for these analyses were below poverty threshold, as compared to 54% of families that were retained for this study.

Child and caregiver demographic characteristics by ethnicity and site for this sample are shown in Table 1. Fifty-one percent of participants (403 children) were Island PR, 30% were RI Latino (235 children), and 19% were RI NLW (149 children). Of the RI Latino families, 13% self-identified as PR (102 children) and 17% self-identified as Dominican (133 children). Inclusion criteria included physician-diagnosed asthma (e.g., a doctor told the parent that the child has asthma) or breathing problems in the past 12 months. Other inclusion criteria included Puerto Rican, Dominican or NLW ethnicity and child age between 7 and 16 years. Exclusion criteria included a child cognitive impairment that would make it difficult for the child to complete questionnaires.

Procedures

This study was approved by relevant Institutional Review Boards at RI Hospital and University of PR. The study occurred across four separate research sessions during a four-month period, with approximately 4 weeks between sessions (methods of the larger study can also be found elsewhere).⁴ Families were recruited through standard procedures with families completing a "Consent-to-Contact" form, which gave study staff permission to contact families to determine eligibility. During screening, caregivers were asked if their child had had breathing problems in the last year, or if the child had been diagnosed with asthma by a physician. Once a family was deemed eligible to participate in the study, an

initial session was scheduled. Consent forms and questionnaires were translated and back-translated prior to use with Spanish speaking families and administered by a bilingual research assistant.

Informed consent and child assent were obtained at the initial visit, prior to the administration of questionnaires. Questionnaire data were collected in face-to-face interviews with children and their primary caregivers. Demographic information (e.g., child age, child gender, parental education) and parent report of ethnicity were obtained at the initial visit. At a second visit, child medical history, physical exam, and a pulmonary function test occurred. Caregivers also completed questionnaires related to asthma control and ED use at this session. Caregivers completed the QOL measure at the third visit.

Measures

Poverty threshold—An income-to-needs ratio was calculated for each family by dividing yearly income by the poverty threshold for a family of that size.³⁵ Families with a ratio that was 1.0 or less were considered at or below poverty threshold. Poverty is often preferred as an indicator of socioeconomic status (SES) as it more sensitively captures family resources based on the number of people in the home.³⁶

Asthma severity—Using a structured checklist, asthma diagnosis was verified by study clinicians to determine eligibility for families to continue with study participation. Clinicians then classified asthma severity by applying a visual grid adapted from the Global Initiative for Asthma (GINA).³⁷ This grid used reported symptom frequency, prescribed controller medications, and prealbuterol FEV₁ from a Koko Spirometer⁵ to determine asthma severity. Asthma severity was classified as “mild intermittent”, “mild persistent”, “moderate persistent”, or “severe persistent”. In-person meetings and teleconferences involving study clinicians at both sites were utilized to ensure consistency across sites.

Caregiver QOL—Caregivers completed the 13-item, Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ).¹³ The PACQLQ assesses the impact of child asthma on caregiver daily activities (4 items) and emotional functioning (9 items) over the last week. Responses range from “all of the time” to “none of the time” or “very, very worried/concerned” to “not worried/concerned” on a 7-point scale. Higher scores reflect a better QOL. Item-level differences were assessed on two specific PACQLQ items: 1) “How often did you feel helpless or frightened when your child experienced cough, wheeze, or breathlessness?” and 2) “How worried or concerned were you about your child’s asthma medications and side effects?” For caregivers in Island PR, Cronbach’s α of .91, .86, and .87 were calculated for the full scale, emotional functioning, and activity limitation subscales, respectively. For Latino caregivers in RI, Cronbach’s α of .91, .87, and .87 were calculated for the full scale, emotional functioning, and activity limitation subscales, respectively. Finally, for NLW caregivers, Cronbach’s α of .90, .85, and .85 were calculated for the full scale, emotional functioning, and activity limitation subscales, respectively.

Asthma morbidity—Morbidity indicators included ED visits due to asthma and asthma control. ED use was coded dichotomously as 0 visits or 1 or more visits in the past 12 years. Asthma control was coded dichotomously as “in control” or “not in control” based on a computer algorithm constructed for this study based on asthma symptoms and prealbuterol FEV₁.⁵ We developed this algorithm after GINA updated its guidelines in 2006 (which was toward the end of our study) and emphasized the importance of asthma control.³⁸ For the algorithm, asthma symptoms were derived from caregiver report on the Asthma Functional Severity Scale (AFSS).³⁹

Data Analysis Plan

All analyses were performed using SPSS version 13.0 software (Statistical Product and Service Solutions 13.0; SPSS Inc., Chicago, IL). Chi-square analyses were used to generate the descriptive breakdown of poverty threshold and asthma severity by ethnicity and site. Consistent with asthma disparities research, poverty threshold, asthma severity, caregiver education (in years completed), child gender, and child age were tested for their associations with caregiver QOL; a significant association between one of these potential covariates and caregiver QOL then informed whether we would account for these covariates in subsequent analyses. Correlational analyses were used to assess for associations between caregiver QOL, child age, and caregiver educational level. Simple *t*-tests were used to examine whether caregiver QOL differed by child gender or poverty threshold. Finally, an analysis of variance (ANOVA) was used to assess for differences in caregiver QOL by asthma severity.

Regression analyses were used to examine the association between ethnic group/site and caregiver QOL, adjusting for covariates that emerged as significantly associated with caregiver QOL. Post hoc comparisons using Tukey's Honestly Significant Difference (HSD) test were used to evaluate QOL differences between ethnic groups and site. Logistic regressions were used to analyze associations between caregiver QOL and asthma control and between caregiver QOL and ED visits within each group (e.g., RI NLW, RI Latino, Island PR). Item level analyses were conducted on two specific items of interest: one item focused on medication concerns and one item focus on fear related to child breathing symptoms. Similar to analyses for caregiver QOL scores, regression analyses adjusting for appropriate covariates and post hoc comparisons using Tukey's HSD were utilized to examine differences in these two items by ethnic group and site.

RESULTS

The proportion of families below the poverty threshold differed across the three groups ($X^2 = 116.24, p < .001$). Sixty-six percent of Island PR and 58% of RI Latino caregivers qualified as being below the poverty threshold as opposed to 15% of NLW caregivers. Asthma severity also significantly differed by ethnicity ($X^2 = 67.04, p < .001$). More severe persistent asthma levels were found in RI (both in NLW and Latino children) than in Island PR based in part on healthcare system differences (e.g., barriers to medication use).⁵

Caregiver QOL did not differ by child age or child gender. Higher levels of QOL on the total scale were found among those caregivers whose children were classified as having less severe asthma ($F(3, 786) = 5.63, p < .05$). Similarly, caregivers whose children were classified as having less severe asthma reported better QOL on the emotional functioning ($F(3, 786) = 5.04, p < .05$) and activity limitation subscales ($F(3, 786) = 7.07, p < .05$). Better caregiver QOL on the total scale was found among those caregivers that qualified as being above poverty threshold ($t(785) = -9.86, p < .001$). Caregivers who qualified as being above the poverty threshold line also reported better scores on the emotional functioning ($t(785) = -8.14, p < .001$) and activity limitation subscales ($t(785) = -9.78, p < .001$). Higher educational level was also associated with better overall QOL scores ($r = .23, p < .001$), and better scores on the emotional functioning ($r = .24, p < .001$) and activity limitation subscales ($r = .17, p < .001$). Because educational level and poverty were significantly associated ($t(778) = 14.12, p < .001$), we chose to only control for poverty threshold as it has been shown to accurately captures family resources based on the number of people in the home³⁶ and has been shown to be robust indicator of asthma morbidity.⁴⁰ Therefore, asthma severity and poverty threshold were controlled for in all subsequent analyses.

Mean differences in caregiver QOL

Total PACQLQ scores differed significantly by ethnic group and site with poverty and asthma severity in the model ($\Delta F(1, 783) = 29.46, p < .001$; see Table 2). Emotional functioning and activity limitation subscale scores also differed by ethnic group and site ($\Delta F(1, 783) = 33.66, p < .001$; $\Delta F(1, 783) = 12.54, p < .001$; respectively). Post-hoc analyses indicated significant differences between all groups such that Island PR caregivers reported worse QOL scores than RI Latino and NLW caregivers; RI Latino caregivers reported significantly worse QOL scores than NLW caregivers.

Caregiver QOL and asthma morbidity

Sixty-four percent of Island PR children, 59% of NLW children, and 70% of RI Latino children were classified as having asthma not in control. Asthma control was associated with total QOL and both subscales in RI Latino and Island PR caregivers (see Table 3). Better caregiver QOL was associated with asthma that was in control.

Sixty-three percent of Island PR children, 26% of NLW children, and 37% of RI Latino children had one or more ED visits in the last year according to parent report. Number of ED visits in the last year was significantly associated with total QOL and both subscales in RI Latino caregivers. Lower levels of caregiver QOL was reported in those caregivers whose children had visited the ED one or more times. In Island PR caregivers, ED visits were significantly associated with total QOL, and associated at a trend level ($p = .06$) with both subscales.

Item-level differences in the PACQLQ

With asthma severity and poverty threshold in the model, the PACQLQ item inquiring about fear/helplessness differed significantly by ethnic group ($\Delta F(1, 777) = 9.06, p < .01$; see Table 4). Island PR and RI Latino caregivers reported more fear and helplessness as compared to NLW caregivers. Post-hoc analyses indicated significant differences between NLW caregivers and all other groups. Scores on the PACQLQ item asking about medication concerns differed by ethnic group and site ($\Delta F(1, 777) = 22.94, p < .01$). Island PR caregivers reported the highest levels of worry/concern as compared to RI Latino and NLW caregivers. Post-hoc analyses indicated significant differences between all groups.

DISCUSSION

Differences in caregiver QOL by ethnicity and site

Consistent with our hypothesis, Latino caregivers in our sample from both Island PR and mainland US had worse caregiver QOL than NLW caregivers. As Latino children with asthma often experience more severe asthma than NLW children,^{5, 24} it may be that Latino caregivers in this sample felt overwhelmed or burdened in caring for a child they perceived to have severe asthma. Other studies have shown that Latino caregivers often express concerns related to medication side effects and usage,³² and often prefer alternative treatments in treating their child's asthma.²⁵ These beliefs can lead to underutilization of controller medications,⁴¹ which may contribute to the increased burden experienced by Latino caregivers. Other factors may contribute to increased burden, including acculturative stress,⁴² neighborhood stress,⁷ and factors related to the health care system (e.g., health insurance coverage, access to a consistent health care provider).³¹

We also found significant differences in caregiver QOL by site in that Island PR caregivers were more likely to experience lower levels of QOL as compared to Latino caregivers in RI. This finding suggests that Latino caregivers in Island PR vs. mainland US might experience differences in aspects of burden related to caring for a child with asthma, including health

care system differences. For instance, Rhode Island's Medicaid managed care program ensures that almost all children in RI are covered by insurance. On the other hand, in Island PR, medication costs for prescribing medications are often contained within capitation given to providers, suggesting that financial barriers may prevent the prescription of asthma medications.⁵ In fact, caregivers in Island PR have reported more barriers to accessing and using asthma medications for their children than both Latino caregivers in RI and NLW caregivers.⁵

It is important to note that these differences in health care systems and barriers to medication use may contribute to the fact that we found greater asthma severity among Latino children in mainland US as compared to Island PR. For instance, as previously reported,⁵ the state of the art asthma severity assessment included in our study relies on self-report of medication which can lead to a "severity rating conundrum". As providers in Island PR may be less likely to prescribe controller medications, asthma severity ratings that depend on medication level for classification may be biased, reflecting lower levels of asthma severity among children in Island PR.

Associations between caregiver QOL and asthma morbidity

We found significant associations between caregiver QOL and asthma morbidity (e.g., asthma control, ED use) in RI Latino and Island PR families. This is the first study to document associations between caregiver QOL and child asthma morbidity in Latino and NLW caregivers, and between Latino caregivers in mainland US and Island PR. Lower levels of caregiver QOL was associated with child asthma that was not in control and with one or more ED visits in the last year. Consistent with our hypothesis, associations between caregiver QOL and asthma morbidity were more prevalent in Latino families. No significant associations emerged between caregiver QOL and child asthma morbidity among NLWs.

There are several plausible pathways to account for the association between caregiver QOL and asthma morbidity in Latino families in this sample. First, caregiver functioning may be compromised; caregivers may feel more overwhelmed by their child's asthma symptoms or feel less confident in their ability to manage their child's illness. This is consistent with research suggesting that caregiver functioning is associated with greater asthma morbidity in children with asthma.^{10, 11} Second, families may experience more burden related to a lack of preventative care and limited knowledge of effective strategies to control symptoms. Thus, some Latino caregivers may experience more stress related to their child having more severe asthma. Third, problems related to the health care system (e.g., insurance coverage, language barriers) may make it less likely for Latino families to access a consistent provider and receive regular asthma care. Future research should continue to investigate mechanisms that may explain the burden associated with pediatric asthma in Latino families, as it is likely associated with child asthma morbidity.

Fear/helplessness and medication beliefs

With respect to our exploratory analyses, we found that Latino caregivers in both Island PR and RI in this sample described feeling more helpless or frightened as a result of child breathing problems than NLW caregivers. Ethnic differences in symptom perception have been found such that Latino families may have an increased sensitivity to physical symptoms and may magnify their child's asthma symptoms.²⁹ As Latino children often have more severe asthma, Latino caregivers may be more fearful that their child could die from their asthma symptoms and may be more inclined to utilize emergent care earlier and even in the presence of milder symptoms.³⁰ Contrary to our hypothesis, we did not find site differences on this item between Island PR and RI Latino caregivers, suggesting that fear

related to child asthma symptoms is important and meaningful for Latino caregivers regardless of place of residence.

Consistent with our hypothesis, we found that Latino caregivers in RI and Island PR reported more worry/concern related to asthma medications and side effects than NLW caregivers. This finding is consistent with the study by McQuaid and colleagues,³² in that for some Latino caregivers, medication concerns outweighed beliefs in the necessity of asthma medications, leading to lower rates of medication usage. Discrepancies in controller use by ethnicity have been well-documented such that the rate of controller use among Latino children is often lower than that of NLW children.⁴³ Site differences in this item may reflect the fact that Island PR caregivers often report more barriers related to filling prescriptions, including both medication cost and a preference for alternative medications.³²

Limitations

There are several limitations to our study. First, our study used a sample of convenience from both RI and Island PR and as such, our findings may not demonstrate broad generalizability. Second, as our study utilized a cross-sectional approach, it is not possible for us to determine casual associations between our variables. In addition, we are unable to determine directionality in the association between caregiver QOL and asthma morbidity. Future research should consider utilizing longitudinal studies to determine whether improvements in caregiver QOL account for changes in asthma morbidity. It is also important to note that findings in this study were largely based on self-report measures from the child's primary caregiver. It is possible that both informant and method bias were introduced into the study. Future studies should improve upon this methodology by incorporating assessments of family burden from other informants and objective measures of asthma morbidity.

We also acknowledge that although we chose to combine DR and PR caregivers in mainland US into one group, there are immigration-related factors (e.g., acculturative stress levels, foreign-born status),⁴² and beliefs about alternative medications²⁵ that have been found to differ between groups. For instance, our previous work suggests that PR caregivers living in RI may experience more acculturative stress than Dominican caregivers in RI, which is related to more ED use in children born to PR born caregivers.⁴² It has also been shown that Dominican caregivers may use more alternative medications than Puerto Rican caregivers.²⁵ As Dominican families are an understudied group, our findings speak to the importance of continuing to investigate pediatric asthma in Dominican and PR families, as well as between Caribbean and non-Caribbean Latino families.

Finally, it is important to note that families that were not retained were more likely to be below poverty threshold. It is important to recognize that our findings may not generalize to families experiencing more burden and stress related to poverty. Future research should continue to work to include those families that are most at risk for lower levels of caregiver QOL in pediatric asthma research.

Caregiver QOL in pediatric asthma: Where do we go from here?

Despite these limitations, our findings have important implications for caregiver QOL assessments among Latino and NLW caregivers with a child with asthma. Results from this study suggest that Latino caregivers may be experiencing a greater level of burden related to their child's asthma than NLW caregivers. Information captured by the PACQLQ may be a reflection of broader, contextual stress that some Latino caregivers experience on a daily basis (e.g., related to acculturation) that may influence the management of their children's asthma. It is also possible that specific beliefs focused on fear related to child asthma

symptoms or concerns related to asthma medications may drive some of these differences in caregiver QOL by ethnic group. Future research should, therefore, take into consideration both scores on individual PACQLQ items that might be culture-specific, as well as overall QOL scores.

Our findings have important implications for healthcare providers and clinicians caring for children with asthma. QOL measures should be incorporated into clinical practice when feasible, as such measures may provide an indication of which families are doing poorly with respect to their child's asthma. We recognize, however, that in many busy practices, providers do not have time to administer a measure of QOL. It may be helpful to refer the family to a psychologist or another provider who can administer these measures. Findings from our study highlight the importance of focusing on caregiver QOL in ethnic minority families, as it is possible that these caregivers may require more support around their children's asthma management. More specific education may be required to ensure that caregivers feel confident in managing their child's asthma at home versus utilizing the emergency room when their child is having breathing problems.

It is important to note that our study is a first step in documenting differences in caregiver QOL in pediatric asthma by cultural background. Next steps for inquiry include examining specific predictors of caregiver QOL in pediatric asthma that may vary by ethnic group to inform interventions focused on improving caregiver QOL. Our results suggest that Latino caregivers' beliefs around fear of child dying from asthma symptoms and concerns about medication usage might be important areas for further exploration as predictors of caregiver QOL in pediatric asthma. Future research should also consider whether acculturative stress might serve to worsen a caregiver's QOL with respect to child asthma.

Finally, researchers should investigate the relationship between asthma severity and caregiver QOL and whether it is a linear or curvilinear association. For instance, it may be that there is a threshold of asthma severity and that caregivers with a child with asthma above that threshold begin to experience a dramatic worsening of QOL. It may also be that this threshold differs within and between ethnic groups. It is crucial that researchers continue to better understand caregiver QOL among different cultural groups as it has important implications for child asthma outcomes.

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Table 1

Child and Caregiver Demographic Characteristics By Ethnic Group and Site

	Island PR n = 403	RI NLW n = 149	RI Latino n = 235
Child			
Age, mean year (SD)	10.68 (2.52)	10.50 (2.56)	10.63 (2.44)
Gender, female, n (%)	177 (44%)	53 (36%)	113 (48%)
FEV ₁ , mean (SD)	87.29 (12.92)	91.95 (14.04)	84.5 (12.68)
Asthma severity, n (%)			
Mild intermittent	131 (33%)	29 (20%)	36 (15%)
Mild persistent	128 (32%)	38 (26%)	54 (23%)
Moderate persistent	107 (27%)	50 (33%)	73 (31%)
Severe	37 (9%)	32 (21%)	72 (31%)
Caregiver			
Biological mother, n (%)	391 (97%)	140 (94%)	215 (91%)
Education (highest year completed), mean (SD)	13.11 (2.94)	14.60 (2.27)	11.90 (2.66)
Marital status, n (%)			
Married	180 (44%)	108 (73%)	96 (41%)
Separated	38 (9%)	1 (10%)	36 (15%)
Divorced	82 (20%)	20 (13%)	44 (19%)
Widowed	11 (3%)	0 (0%)	6 (3%)
Never married	92 (23%)	20 (13%)	53 (23%)
Below poverty threshold, n (%)	265 (66%)	22 (15%)	137 (58%)

Table 2

PACQLQ Means By Ethnic Group and Site (Mainland US vs Island PR)

	Island PR	RI Latino	RI NLW
Total QOL, mean (SD)	5.09 (1.35) ^a	5.50 (1.22) ^a	6.49 (.69) ^a
Emotional functioning	4.81 (1.37) ^a	5.27 (1.29) ^a	6.42 (.72) ^a
Activity limitation	5.71 (1.57) ^a	6.00 (1.34) ^a	6.65 (.80) ^a

^aCorresponding letters designate significant differences between groups at p [lt] .05.

Table 3

Associations Between PACQLQ Scores and Asthma Morbidity

	Asthma Control	ED Use
Island PR		
Total QOL	$b = -0.34$, Wald $\chi^2 = 5.75$, OR = 0.71 *	$b = -0.16$, Wald $\chi^2 = 3.88$, OR = 0.85 **
Emotional functioning	$b = -0.30$, Wald $\chi^2 = 12.34$, OR = 0.74 *	$b = -0.15$, Wald $\chi^2 = 3.39$, OR = 0.86
Activity limitation	$b = -0.30$, Wald $\chi^2 = 14.34$, OR = 0.74 *	$b = -0.14$, Wald $\chi^2 = 3.48$, OR = 0.87
RI Latino		
Total QOL	$b = -0.48$, Wald $\chi^2 = 9.58$, OR = 0.62 *	$b = -0.35$, Wald $\chi^2 = 8.45$, OR = 0.71 *
Emotional functioning	$b = -0.45$, Wald $\chi^2 = 10.83$, OR = 0.64 *	$b = -0.32$, Wald $\chi^2 = 8.22$, OR = 0.72 *
Activity limitation	$b = -0.29$, Wald $\chi^2 = 3.92$, OR = 0.75 **	$b = -0.26$, Wald $\chi^2 = 5.74$, OR = 0.77 **
RI NLW		
Total QOL	$b = 0.03$, Wald $\chi^2 = 0.01$, OR = 1.03	$b = -0.19$, Wald $\chi^2 = 0.47$, OR = 0.83
Emotional functioning	$b = -0.01$, Wald $\chi^2 = 0.01$, OR = 0.99	$b = -0.21$, Wald $\chi^2 = 0.60$, OR = 0.81
Activity limitation	$b = 0.08$, Wald $\chi^2 = 0.09$, OR = 1.09	$b = -0.08$, Wald $\chi^2 = 0.12$, OR = 0.92

OR, odds ratio.

* p [It] .01,** p [It] .05.

Table 4

PACQLQ Items by Ethnic Group and Site (Mainland US vs Island PR)

	Island PR	RI Latino	NLW
“How often did you feel helpless or frightened when your child experienced cough, wheeze, or breathlessness?”	5.38 (1.93) ^a	5.69 (1.63) ^b	6.60 (.90) ^{a,b}
“How worried or concerned were you about your child’s asthma medications and side effects?”	3.86 (2.36) ^a	4.49 (2.28) ^a	6.40 (1.09) ^a

^{a,b}Corresponding letters designate significant differences between groups at p [lt] .05.