Caregiver stress among inner-city school children with asthma

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Clinical Implications

• Our novel method of defining high stress among caregivers of asthmatic children considers 4-item perceived stress scale scores in relation to normative data, allowing for comparison across study populations. When applied to inner-city caregivers, stress was associated with worsened asthma morbidity among children.

TO THE EDITOR:

Psychosocial stress among asthmatic children and/or their caregivers is an important variable affecting childhood asthma morbidity,¹ but few studies have examined stress among caregivers of inner-city asthmatic children. The 4-item perceived stress scale (PSS-4) is a validated measure of the degree to which situations in a person's life are perceived as stressful.² It is scored from 0 to 16, with higher scores indicating higher degrees of stress. To our knowledge, there is no well-established cutoff in the PSS-4 score to define high stress among caregivers of asthmatic children, making it challenging to compare stress across study populations. We sought to assess PSS-4 scores among caregivers of inner-city children with asthma by considering scores in relation to published normative data. In addition, we aimed to determine whether caregiver stress was related to asthma morbidity.

The School Inner City Asthma Study (SICAS) was conducted between 2008 and 2013. We recruited school-aged students with physician-diagnosed asthma from schools in a northeastern US city and followed through an academic year. Detailed methods have been described elsewhere.³ At the baseline visit, caregiver stress was assessed using the PSS-4. To define stress levels, we used the mean PSS-4 score of 4.49 and a standard deviation (SD) of 2.96 from a publication that validated the PSS-4 in a large population-based sample of the United States.² We defined "normal," "high," and "very high" stress in our cohort as less than 1 SD, more than 1 SD, and more than 2 SD above this mean, respectively. Asthma morbidity was measured as 2-week symptom recall at baseline followed by quarterly telephone survey at 3, 6, 9, and 12 months. The primary morbidity outcome, maximum symptom days over the last 2 weeks, was defined as the largest value among (1) number of days the participant experienced wheeze, cough, or chest tightness, or (2) number of nights the participant awoke due to asthma, or (3) number of days the participant slowed down or discontinued activities because of asthma. Secondary outcomes included individual measures of poor asthma control, based on symptoms in the last 4 weeks. Categories included dyspnea, nighttime symptoms, decreased daytime activity, and rescue medication use. For each category, caregiver responses were categorized as "well controlled" or "not well controlled" asthma, based on the National Asthma Education and Prevention Program guidelines.⁴ Supplement E1 (available in this article's Online Repository at www.jaci-inpractice.org) contains variable definitions and statistical methods.

There were 247 caregivers (70.4%) in the "normal stress" group (PSS-4 score \leq 7), 88 (25.1%) in the "high stress" group (PSS-4 score 8-10), and 16 (4.6%) in the "very high stress" group (PSS-4 score \geq 11). These findings demonstrate that 29.6% of caregivers in our study had stress levels greater than 1 SD above the population mean, compared with an estimated 15.9% in the general US population² (P < .001) (see Figure 1). PSS-4 scores in SICAS are also higher (mean [SD]: 5.6 [3.1]) than those reported by Islam et al⁵ (mean [SD]: 3.9 [2.8]), which may be due to inherent differences in the populations studied.

There is no single, broadly accepted definition of high stress among caregivers of asthmatic children using the PSS-4. Islam et al⁵ defined "high stress" as above the median PSS-4 score within their sample, which was 4. In contrast, using our method, our cohort's "high stress" group had a PSS-4 score of \geq 8. Wright et al¹ examined PSS-4 scores in tertiles in their study of caregivers of infants at risk for asthma. In that cohort, the means (SD) PSS-4 scores in the "low," "intermediate," and "high" stress groups were 1.1 (0.8), 4.1 (0.8), and 7.4 (1.7), respectively, compared with our "normal," "high," and "very high" stress groups in which means (SD) are 4.1 (2.1), 8.5 (0.7), and 12.6 (1.9), respectively. The examples above demonstrate that the definition of high stress varies between studies, making comparison difficult. Therefore, rather than confining the gauge of stress to the distribution contained within our own study population, we defined stress groups using population-based normative data,² which allows for both characterization of the overall stress level in our own cohort and ability to compare stress levels across studies.

Consistent with the validation cohort,² we found that higher degrees of stress were more likely to come from lower income households, and those with higher rates of household unemployment (Table E1, available in this article's Online Repository at www.jaci-inpractice.org).

Participants whose caregivers had very high stress had more than 2-fold odds of having a symptom day (odds ratio [OR] = 2.21, 95% confidence interval [CI] = [1.27, 3.85], P = .005, Figure 2). They had 5.0 symptom days per 2-week period compared with 2.9 symptom days for participants whose caregivers had normal stress. Similarly, very high stress was associated with greater dyspnea (OR 5.08, CI = [2.64-9.78], P < .001) and high stress was associated with greater activity limitation (OR 1.68, CI = [1.02-2.78], P = .04) compared with normal stress. These findings are consistent with previous studies that examined populations with different sociodemographics from the SICAS population (such as age and socioeconomic status [SES])¹ or which used tools other than the PSS-4 to measure stress,⁶ or which reported on different outcomes⁶ from the SICAS.



FIGURE 1. Distribution of PSS-4 scores among the SICAS cohort compared with expected PSS-4 scores from a published validation sample.² The bars represent the distribution of stress scores in the SICAS cohort. The line represents the normal population distribution of PSS scores.² *PSS-4*, 4-Item perceived stress scale; *SD*, standard deviation; *SICAS*, School Inner City Asthma Study.



FIGURE 2. Asthma morbidity outcomes in the high stress group and very high stress group, compared with the normal stress group. The dotted vertical line represents the normal stress (reference) group.

It has been speculated that caregiver stress may lead to asthma morbidity by intermediaries such as tobacco smoking,⁷ child anxiety, disorganized home conditions, or may affect the child's perception of control and self-efficacy, asthma management skills, or the family's problem-solving abilities,⁸ which may in turn affect medication adherence. However, we found no associations between caregiver stress and any of these factors (Table E1, available in this article's Online Repository at www. jaci-inpractice.org).

We acknowledge that subjects' symptoms were reported by caregivers. However, we have previously demonstrated good caregiver-subject agreement on screening surveys in this cohort.⁹ Prior studies have also used caregiver responses to predict childhood outcomes.^{1,5}. In addition, measuring the PSS-4 at

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