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Depression among Caregivers of Children with Asthma and its Impact on Communication with Health Care Providers

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Abstract

Background—Caregiver depression is common, can negatively influence one's ability to communicate with healthcare providers, and may hinder appropriate care for children with asthma.

Objective—To evaluate the impact of caregiver depression on communication and self-efficacy in interactions about asthma with their child's physician.

Study Design—Cross sectional analysis using data from the Prompting Asthma Intervention in Rochester—Uniting Parents and Providers study.

Methods—We enrolled caregivers of children (2–12 yrs) with persistent asthma prior to their healthcare visit. Caregivers were interviewed via telephone after the visit to assess depression, self-efficacy, and provider communication at the visit. Caregiver depression was measured using the Kessler Psychological Distress scale. We assessed caregiver self-efficacy using items from the Perceived Efficacy in Patient Physician Interactions scale; caregivers rated their confidence for each item (range 0–10). We also inquired about how well the provider communicated regarding the child's asthma care. Bivariate and multivariate analyses were used.

Results—We interviewed 195 caregivers (response rate 78%; 41% Black, 37% Hispanic), and 30% had depressive symptoms. Caregiver rating of provider communication did not differ by depression. Most caregivers reported high self-efficacy in their interactions with providers; however depressed caregivers had lower scores (8.7 vs. 9.4, $p=.001$) than non-depressed caregivers. Further, depressed caregivers were less likely to be satisfied with the visit (66% vs. 83%, $p=.014$), and to feel all of their needs were met (66% vs. 85%, $p=.007$). In multivariate analyses, depressed caregivers were $>2\times$ more likely to be unsatisfied with the visit and to have unmet needs compared to non-depressed caregivers.

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Ethical approval: The University of Rochester and Rochester General Health System's Institutional Review Boards approved the study protocol.

Conclusions—Depressed caregivers of children with asthma report lower confidence in interactions with providers about asthma and are less likely to feel that their needs are met at a visit. Further study is needed to determine the best methods to communicate with and meet the needs of these caregivers.

Keywords

asthma; caregiver depression; health care provider; communication

BACKGROUND

An estimated 6 million children in the United States are living with asthma, making it one of the most common chronic diseases of childhood.¹ The effects of poorly controlled pediatric asthma are widespread and include missed school and work days, rising health care utilization costs, emergency department visits, hospitalizations, and avoidable deaths.^{2–5} As a result, the health care community has paid significant attention to the prevention of asthma morbidity and mortality. Despite these efforts, inadequate asthma management has remained prevalent, especially in urban and minority populations.^{2,6} The National Heart, Lung and Blood Institute (NHLBI) has established asthma guidelines that provide specific recommendations for asthma management to reduce morbidity. In these recommendations, the guidelines emphasize the importance of ongoing asthma education and effective communication with caregivers to develop a partnership with providers, elicit specific symptom information and concerns, and establish shared treatment goals.⁷

Effective patient-provider communication can improve patient satisfaction and health outcomes.⁸ Studies have demonstrated a correlation between effective communication and improved physiologic status, functional outcomes, mental health and symptom resolution.⁹ However, little is known about caregiver-provider communication for children with asthma. In a prior study, we found that poor communication can be a significant barrier to appropriate preventive asthma care for urban children, leading to underestimation of symptom severity and missed opportunities to provide guideline-based treatments.^{10,11}

Additionally, depression is common among caregivers of children with asthma, and is associated with poor adherence to preventive asthma care and increased health care utilization.^{12–14} Caregiver depression may compromise the family's ability to comply with an asthma treatment plan and may inhibit active participation in the child's care.¹⁵ Studies have also indicated that in caregivers, especially mothers, life stressors and depression are associated with worse pediatric asthma symptom severity and overall morbidity.^{15,16} Further, Weil et al found that children of caregivers with mental health problems were almost twice as likely to require hospitalization for their asthma.¹³ Depression also can impact one's ability to comprehend information and communicate effectively.^{14,17} Thus, depression in caregivers of children with asthma may impact the way in which caregivers communicate with health care providers as well as their understanding and perceptions of the health care visit.

The purpose of this study is to evaluate the impact of caregiver depression on caregiver-provider communication, as well as caregiver self-efficacy in interactions about asthma and satisfaction with the care they received. We hypothesize that depressed caregivers will report worse communication and have lower self-efficacy in interacting with their child's physician and lower satisfaction with care compared to non-depressed caregivers.

METHODS

SETTING AND PARTICIPANTS

This study uses data from the *Prompting Asthma Intervention in Rochester – Uniting Parents and Providers (PAIR-UP)* trial in Rochester, NY. Potential participants included caregivers of children 2 to 12 years old with documentation of asthma in their medical record who were visiting a health care provider at one of 12 participating urban practices in Rochester, NY. We approached families in the waiting room prior to their visit to assess eligibility for the study based on current asthma severity or level of control. Children who had persistent or poorly controlled asthma symptoms based on NHLBI guidelines were eligible for enrollment (participation rate: 78%). We obtained written informed consent from the primary caregiver and assent from children 7 years or older. The University of Rochester and Rochester General Health System's Institutional Review Boards approved the study protocol.

For the PAIR-UP intervention study, each participating practice was randomly assigned as either a treatment or usual care site. Families enrolled at the intervention sites received a paper prompt at the time of the visit to give to the provider that was designed to assist the provider in assessing severity and delivering guideline-based asthma care. We used data from the initial baseline survey and a follow-up telephone survey from this larger study, and controlled for treatment effect in this analysis.

We collected data in-person in the waiting room prior to the child's visit, as well as by telephone following the visit to inquire about actions related to the visit. While all eligible children had persistent asthma or poor control, not all were being seen for an asthma-related visit. Eligible health care visits included well child exams, asthma-related visits, and any other visit in which the child was seen by a physician or nurse practitioner. Caregivers were asked to think about their child's recent health care visit when answering questions about provider communication, caregiver's self-efficacy in interactions with the provider, and satisfaction with care. Caregiver depression also was assessed. Between October 2009 and October 2010, we collected data for 195 families.

Assessment of Caregiver Depression—We assessed caregiver depression using the validated 10-item Kessler Psychological Distress scale, which measures symptoms of anxiety and depression.¹⁸ Caregivers were asked to indicate how often they had certain feelings (i.e. nervous, fidgety, tired for no good reason, etc.) over the past 4 weeks on a scale of *None of the Time* to *All of the Time* (range 10–50). Scores ≥20 indicate measurable psychological distress consistent with depressive symptoms.¹⁹ Caregivers with scores above this cut-off were considered “Depressed” and caregivers with scores <20 were considered “Not Depressed” in our analyses based on prior use of this scale.¹⁹

Assessment of Provider Communication—We evaluated provider communication using 5 statements previously used by Clark et al regarding caregiver views of their pediatrician's performance regarding asthma care.²⁰ Caregivers were asked to indicate their level of agreement (1=Strongly Disagree, 5=Strongly Agree) regarding interactions related to asthma at the enrollment visit (e.g. My child's doctor looked into how my family manages asthma day to day; My child's doctor gave my family information to relieve specific worries). We evaluated mean scores and also dichotomized responses into positive (Strongly Agree and Agree) and negative or neutral communication (No Opinion, Disagree and Strongly Disagree).

Assessment of Caregiver Self-Efficacy—Primary caregivers' self-efficacy in interactions with their child's physician about asthma was determined using a 5-item

modified and validated version of the Perceived Efficacy in Patient-Physician Interactions (PEPPI) scale.²¹ Caregivers were asked to rate their confidence level for 5 asthma-related interactions with their child's doctor on a scale of 0 (not confident) to 10 (extremely confident). Mean self-efficacy scores for each individual interaction and a combined interaction score (total self-efficacy mean score) were analyzed separately. Examples of questions include "your ability to know what questions to ask your child's doctor" and "your ability to get your child's doctor to answer all of your questions about your child's asthma." Perceived caregiver self-efficacy is indicated by the combined interaction score.

Assessment of Satisfaction with Care—We asked caregivers questions about their satisfaction with the care received at their child's health care visit. Caregivers were asked if the physician discussed their family's concerns regarding the child's asthma (yes/no) at the visit. We also asked caregivers if all of their needs were met at the visit (All vs. Some/None), and whether they were satisfied with their visit overall (Completely Satisfied vs. Somewhat Satisfied/Somewhat Unsatisfied/Completely Unsatisfied).

Assessment of Covariates—We inquired about family demographics, including child's age, race (White, Black or Other), ethnicity (Hispanic or not Hispanic), Medicaid insurance coverage (yes/no), overall health status (Excellent/Very Good or Good/Fair/Poor), caregiver age (<30 or ≥30 years), caregiver education (<high school or ≥high school), caregiver marital status (married/domestic partner or single), caregiver language preference (English or Spanish), and whether the primary caregiver smokes (yes/no). We also included treatment group assignment (treatment/usual care) as an independent variable. Asthma severity was assessed based on the national guideline criteria;⁷ children were categorized as having either mild persistent or moderate/severe persistent asthma.

ANALYSIS

We performed analyses using SPSS version 17 software (Statistical Product and Service Solutions 17.0; SPSS Inc, Chicago, IL). We used bivariate statistics to compare caregiver depression with demographic variables and dichotomized provider communication items. We used the non-parametric Mann-Whitney test to explore provider communication mean scores and individual mean self-efficacy scores with caregiver depression. The Student's t-test was used to compare the total mean self-efficacy score and depression. To assess the independent effects of caregiver depression, we conducted multiple linear regression analyses in models predicting self efficacy scores, and we performed multiple logistic regression analyses for each dichotomized communication item. For all regression analyses we controlled for treatment group, standard demographic variables (child's race, ethnicity, Medicaid insurance, caregiver age), and variables that were significantly different between groups at baseline (marital status, caregiver education, caregiver's smoking status, child's overall health status). A 2-sided alpha <.05 was considered statistically significant.

RESULTS

Of the 195 caregivers included in this analysis, 59 (30%) indicated symptoms consistent with depression. As shown in Table 1, 51% of the children were male, 41% Black, 37% Hispanic, and 54% had Medicaid insurance. Many children had moderate to severe asthma symptoms (55%), and most caregivers described their child's overall health as excellent or very good (60%). Twenty-four percent of visits to the doctor were related to the child's asthma, and 32% were for well-child exams. The majority of caregivers were female (90%) and single (61%). The mean caregiver age was 34.9 years (SD 9.4), 38% of caregivers did not complete a high school education, and 33% smoked cigarettes.

Depressed caregivers were significantly more likely to be single (75% vs. 55%, $p=.011$), have less than a high school education (53% vs. 31%, $p=.003$), and to smoke cigarettes (52% vs. 25%, $p<.001$) compared to non-depressed caregivers (Table 1). Depressed caregivers were also less likely to report that their child's overall health was excellent/very good (48% vs. 65%, $p=.027$). There were no differences in child demographics between depressed and non-depressed caregivers, nor were there differences in asthma severity, reason for visit, insurance, caregiver gender, caregiver age, language, or treatment assignment between the two groups.

Table 2 shows the mean communication scores and the percentage of caregivers who agreed or strongly agreed with each of the provider communication items. Many of the caregivers had positive perceptions of their child's doctor's communication about asthma, and 91% of caregivers felt that the physician was reassuring and encouraging during their visit. Depressed caregivers had lower mean communication scores compared to the non-depressed caregivers on all items, and this difference was statistically significant for the item, "My child's doctor was reassuring and encouraging," (4.18 vs. 3.94, $p=.032$).

Results of the mean self-efficacy scores for each item as well as the total self-efficacy score are shown in Table 3. The scores ranged from 0 (not confident) to 10 (extremely confident). Overall, caregivers reported relatively high scores on each of the items; however, depressed caregivers had significantly lower scores than non-depressed caregivers on four of the items as well as the total mean self-efficacy score (all $p<.05$). For example, depressed caregivers reported less confidence in their ability to get the child's doctor to answer all of their questions about asthma (mean score 8.47 vs. 9.40, $p=.006$), and to get the child's doctor to take their chief health complaint seriously (8.78 vs. 9.53, $p=.02$). There was also a trend for depressed caregivers to have lower scores on the item "to make the most of your visits with your doctor," ($p=.053$). These results remained significant in a linear regression controlling for child's race, ethnicity, insurance, overall health status, caregiver's age, marital status, education, smoking status, and treatment group assignment (Table 4).

Table 5 shows the caregivers' satisfaction with care at their child's appointment. Approximately half of the caregivers reported that their concerns were discussed at their visit, with no difference noted by depression. However caregivers with depressive symptoms were significantly less likely to report that all of their needs were met at the visit (66% vs. 85%, $p=.007$) and were less likely to feel completely satisfied with their visit (66% vs. 83%, $p=.014$). In a logistic regression analysis, we found that the odds of depressed caregivers reporting they had unmet needs and felt unsatisfied with their visit was twice as high as non-depressed caregivers (results not shown).

DISCUSSION

We explored the influence of caregiver depressive symptoms on caregiver-provider communication at a recent health care visit. Our sample included caregivers of children with persistent asthma symptoms visiting a pediatrician, family medicine physician or nurse practitioner in a low-income, urban community. Overall, we found that one third of caregivers in this sample had significant depressive symptoms. Although depression did not influence the caregiver's report of their provider's communication, depressed caregivers reported lower self-efficacy in their interactions with providers about asthma, and were less likely to be satisfied and feel that their needs were met at the health care visit.

Our finding that 30% of caregivers reported significant depressive symptoms is consistent with prior reports of depressive symptoms among urban mothers of children with asthma,²²⁻²⁶ and is well above the 9% prevalence reported in the general population.²⁷ This

high rate of depressive symptoms is alarming, yet is not surprising due to the stress incurred by caregivers of chronically ill children that is often unavoidable and may affect caregiver mental health status.^{26,28} Furthermore, many of these caregivers are exposed to the daily stresses associated with living in the inner-city and having young children.^{13,24,26}

Depressed caregivers rated their provider's communication somewhat worse than non-depressed caregivers on all communication items. Importantly, only 63% to 70% of caregivers overall reported positive (agree or strongly agree) communication from their provider on four of the five communication items included in our survey. These results suggest that from the caregiver's perspective, provider communication with families about asthma could be improved. This is particularly pertinent since all children included in the study had persistent asthma that warranted enhanced care according to national guidelines. While the children were not necessarily being seen for an asthma visit, these findings suggest missed opportunities for discussions regarding preventive asthma care.

While caregivers in this study in general reported high self-efficacy scores in their interactions with health care providers, caregivers with depressive symptoms reported lower self-efficacy on each of the items compared to caregivers without depression, and these findings persisted after controlling for pertinent covariates. Similarly, prior research has shown that depressive symptoms are associated with decreased confidence in and understanding of asthma medications and their use,^{12,23,25,29,30} resulting in poor disease management for children. Low self-efficacy in interactions may hinder establishing an effective caregiver-provider partnership, and this relationship is important to developing and adhering to an asthma management plan for children.

In addition, it is important to note that only half of all caregivers reported that their concerns were discussed at the health care visit, again representing missed opportunities to provide care. Depressed caregivers were less likely to be satisfied with the visit compared with non-depressed caregivers, and only 66% reported that their needs were fully met. These findings are comparable to prior results that indicated that more than half of depressed mothers of children with asthma were dissatisfied with their child's provider.¹² While this could be related either to the interactions at the visit, or to the caregiver's perception of what occurred at the visit, it strongly suggests a need for more comprehensive care for this population, with specific attention towards eliciting and addressing caregiver's concerns and needs. Other studies have reported an association between maternal depression and childhood asthma morbidity, including increased visits to the emergency department and decreased adherence to asthma medications.^{13,22,23,30} Our data indicate no difference in asthma severity between depressed and non-depressed caregivers, however, eligibility for this study required all children to be experiencing persistent asthma symptoms at the time of the assessment, thus our ability to detect differences in severity may have been limited.

Previous studies have explored the effect of mental health on perceived communication, as well as the relationship between caregiver depression and child asthma outcomes. However, to our knowledge this is the first study to specifically assess the relationship between depressive symptoms in caregivers of children with persistent asthma and communication with their children's providers. Our study also reports on a recent health care visit aimed to reduce recall bias by referring to a specific interaction. Importantly, we targeted a population at high risk for caregiver depression due to multiple psychosocial risk factors including living in the inner-city, low socioeconomic status, exposure to neighborhood violence and having a child with a chronic illness.

There are some potential limitations to our study. Our data are solely based on caregiver report, and due to the high rate of depression in this population, reporting bias is

possible.^{29,30} Moreover, only one assessment of caregiver depression was used. Lastly, due to the demographics of our sample, our results cannot be generalized to all populations.

Delivery of optimal preventive asthma care for children is complex, and many aspects depend on effective caregiver-provider communication in order to be successful. Our study highlights the importance of assessing the needs of both the child and the caregiver in each pediatric clinical encounter. In addition to improving asthma care and reducing morbidity, addressing caregiver mental health may also lead to reduced health care costs.³¹ Our findings that depressed caregivers of asthmatic children feel less confident in and satisfied with their interactions with health care providers demonstrate the importance of depression screening within this population. Looking forward, clinicians could consider pediatric office visits as an opportunity to screen for caregiver depression, refer caregivers to assistance where appropriate and enlist help from other family members in the treatment of the child's asthma. Further efforts at enhanced communication to elicit and address concerns are needed. For example, written handouts, teach-back methods, and other communication aids should be considered. More frequent follow-up visits might also be helpful for this vulnerable population. Attending to the caregiver's needs and concerns during a pediatric clinical encounter may improve caregivers' self-efficacy, decision-making skills, communication with providers, and overall satisfaction with care.

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Table 1

Demographics by Caregiver Depression

Demographics	Total N=195	Not Depressed N=136	Depressed N=59	P-value
Child's Gender: Male	99 (51%)	65 (48%)	34 (58%)	.134
Child's Age, mean (SD)	6.70 (2.9)	6.65 (2.7)	6.8 (3.2)	.753
Child's Race: White Black Other	36 (18%) 80 (41%) 79 (40%)	30 (22%) 54 (40%) 52 (27%)	6 (10%) 26 (44%) 27 (46%)	.141
Child's Ethnicity: Hispanic	72 (37%)	45 (33%)	27 (46%)	.107
Asthma Severity Level: Mild persistent Moderate/Severe persistent	83 (45%) 103 (55%)	64 (49%) 68 (52%)	19 (35%) 35 (65%)	.107
Child's Health Status: Excellent/Very good	116 (60%)	88 (65%)	28 (48%)	.027
Child's Health Insurance: Medicaid	106 (54%)	68 (50%)	38 (64%)	.085
Type of Visit: Well child exam Asthma-related visit Other visit	62 (32%) 47 (24%) 86 (44%)	43 (32%) 33 (24%) 60 (44%)	19 (32%) 14 (24%) 26 (44%)	.995
Primary Language: Spanish	52 (27%)	33 (24%)	19 (32%)	.291
Caregiver Age, mean (SD)	34.9 (9.4)	34.9 (9.8)	34.8 (8.4)	.949
Caregiver Marital Status: Single	119 (61%)	75 (55%)	44 (75%)	.011
Caregiver Education: < High school	72 (38%)	41 (31%)	31 (53%)	.003
Caregiver Smoking Status: Yes, smoker	65 (33%)	34 (25%)	31 (52%)	<.001
Group Assignment: Treatment	100 (51%)	70 (52%)	30 (51%)	1.00

Table 2

Caregiver Depression and Provider Communication Items

My child's doctor...	Total N=195	Not Depressed N=136	Depressed N=59	P-value
Was reassuring and encouraging mean (SD) <i>Agree, N (%)</i>	4.11 (.87) 177 (91%)	4.18 (.86) 127 (93%)	3.95 (.86) 50 (85%)	.032 .064
Looked into how my family manages asthma day to day mean (SD) <i>Agree, N (%)</i>	3.62 (1.1) 137 (70%)	3.66 (1.1) 98 (72%)	3.51 (1.1) 39 (66%)	.420 .400
Described at least 1 of these goals: child sleep through night, child have no symptoms when active, child be fully active mean (SD) <i>Agree, N (%)</i>	3.44 (1.2) 122 (63%)	3.49 (1.2) 88 (65%)	3.32 (1.1) 34 (58%)	.287 .421
Gave family information to relieve specific worries mean (SD) <i>Agree, N (%)</i>	3.59 (1.1) 133 (68%)	3.65 (1.1) 95 (70%)	3.46 (1.2) 38 (64%)	.319 .504
Enabled family to know how to make asthma management decisions mean (SD) <i>Agree, N (%)</i>	3.51 (1.2) 128 (66%)	3.53 (1.2) 89 (66%)	3.46 (1.1) 39 (66%)	.648 1.00

Table 3

Caregiver Depression and Self-Efficacy Scores

How confident are you in your ability to...	Total N=195	Not Depressed N=136	Depressed N=59	P-value
To know what questions to ask your child's doctor ^a	9.06 (1.6)	9.28 (1.3)	8.54 (2.0)	.029
To get your child's doctor to answer all of your questions about your child's asthma ^a	9.12 (1.6)	9.40 (1.1)	8.47 (2.2)	.006
To make the most of your visits with your child's doctor ^a	9.40 (1.2)	9.51 (1.1)	9.13 (1.4)	.053
To get your child's doctor to take your chief health complaint seriously ^a	9.30 (1.6)	9.53 (1.3)	8.78 (2.1)	.020
To get your child's doctor to do something about your chief health concerns ^a	9.30 (1.5)	9.52 (1.0)	8.78 (2.1)	.043
Total Self-Efficacy Mean Score ^b	9.2 (1.3)	9.45 (0.9)	8.74 (1.7)	<.001

^a Mann-Whitney Non-Parametric test

^b Student's T-test

Table 4Linear Regression: Caregiver Depression and Mean Self-Efficacy Scores ^a

How confident are you in your ability to...	Unstandardized Beta	T	P-value
To know what questions to ask your child's doctor	-.819	-3.079	.002
To get your child's doctor to answer all of your questions (about your child's asthma)	-.988	-3.997	<.001
To make the most of your visits with your child's doctor	-.447	-2.206	.029
To get your child's doctor to take your chief health complaint seriously	-.699	-2.636	.009
To get your child's doctor to do something about your chief health concerns	-.653	-2.697	.008
Total Self Efficacy Mean Score	-.721	-3.469	.001

^aControlling for Race, Ethnicity, Medicaid, Caregiver Age, Marital Status, Education, Smoking Status, Child's Health Status, and Treatment Group

Table 5

Caregiver Depression and Satisfaction with Care

	Total N=195	Not Depressed N=136	Depressed N=59	P-value
Discussed Concerns At Visit	104 (53%)	70 (52%)	34 (58%)	.440
All of My Needs Were Met	154 (79%)	115 (85%)	39 (66%)	.007
Completely Satisfied with Visit	152 (78%)	113 (83%)	39 (66%)	.014