Developing a Mobile Health Intervention for Low-Income, Urban Caregivers of Children with Asthma: A Pilot Study

Robin S. Everhart, PhD,¹ Kristin E. Heron, PhD,^{2,3} Gillian G. Leibach, PhD,¹ and Samantha A. Miadich, PhD¹

Objective: This pilot study explored the initial feasibility and efficacy of providing feedback to low-income, urban caregivers of children with persistent asthma about their daily experiences reported via ecological momentary assessment (EMA) on caregiver emotional health (quality of life, perceived stress, and positive affect).

Methods: Data were collected from 28 caregivers and their children (7–12 years). Caregivers completed a baseline session, 14 days of EMA surveys via smartphone, and were randomized to intervention or control groups. The intervention group received individualized EMA feedback regarding areas of daily life that may be making it harder to manage child asthma. The control group received information on general child health. Caregivers completed assessments 4 weeks and 4 months postintervention.

Results: In the EMA group, caregivers experienced an increase in perceived stress from baseline to postintervention, but a decrease in perceived stress from postintervention to follow-up. There were no significant changes in outcome measures for the control group.

Conclusion: Preliminary findings suggest that providing caregivers with feedback from daily assessments may reduce stress, which could be targeted in future mobile health interventions for low-income, urban families of children with asthma.

Keywords: asthma, caregivers, EMA, stress, mHealth, urban

Introduction

ASTHMA PREVALENCE, MORBIDITY, and mortality rates continue to increase in children from low-income families, especially those living in urban environments.¹ Caregivers living in urban settings may be exposed to stressors (eg, violence and poverty) that make it challenging to manage child asthma. Caregiver stress and psychological difficulties can have negative implications for daily treatment decisions, such as greater reliance on emergency care.² Interventions for caregivers, however, have been primarily education-focused, without considering daily stressors that may hinder the sustainability of such interventions.

There is a growing body of literature on mobile health (mHealth) initiatives aimed at enhancing data collection and communication to improve chronic disease management through mobile technology.^{3,4} Preliminary studies are needed to establish feasibility and identify variables to target in real-time mHealth interventions. In the current study, we

used ecological momentary assessment (EMA) delivered via smartphone to capture information about caregivers' daily experiences. EMA is a methodology that allows participants to provide repeated reports on their experiences in real-time, thus reducing retrospective recall bias.⁵ In this study, EMA data were then used to develop tailored strategies to fit caregivers' needs. The goal of this small, randomized control trial was to explore the initial feasibility and efficacy of providing EMA feedback to urban caregivers of children with asthma on their quality of life (QOL), stress, and positive affect.

Materials and Methods

Participants

Data were collected from 28 caregivers (89% African American; 89% female; mean age = 39.96, SD = 7.93) and their children with asthma (7–12 years; mean = 9.67, SD = 1.50; 68% male) from low-income, urban families. A monthly

¹Department of Psychology, Virginia Commonwealth University, Richmond, Virginia.

²Department of Psychology, Old Dominion University, Norfolk, Virginia.

³Virginia Consortium Program in Clinical Psychology, Norfolk, Virginia.

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household income <\$1,999 was reported by 65% of caregivers, and most had never been married (68%); 64% of children were prescribed a controller medication, and 64% had at least one asthma-related emergency department (ED) visit in the last year.

Potentially eligible families were identified through electronic health records of a major hospital system serving the urban area. Study inclusion criteria were as follows: physician diagnosed child asthma as reported by the caregiver; child with persistent asthma (prescribed an asthma controller medication *or* met asthma symptom/frequency consistent with published guidelines)⁶; and urban address verified by zip code. Families were excluded if there was additional child pulmonary disease or significant developmental delay.

Procedures

Institutional Review Board approvals and consent/assent were obtained. Eligible families attended a baseline research session in their homes or the research office, depending on preference. Questionnaires were administered separately to caregivers and children by trained research assistants (RAs). Caregivers were taught to use study-provided smartphones and completed surveys in an app twice daily for 14 days. Smartphones were retrieved and caregivers were assigned to the EMA feedback (eg, intervention) or control group through block randomization.

Two weeks after smartphones were retrieved, caregivers participated in an individual, 60-minute problem-solving session. For each caregiver in the EMA feedback group, a spreadsheet of daily responses to survey items across the 14-day period was generated; caregivers received feedback regarding areas of their daily lives that may be making it harder to manage their child's asthma. RAs went over the EMA spreadsheet with caregivers, described what each response meant (eg, reported poor sleep quality on 10 days), and asked caregivers to pick two areas to improve. Together, RAs and caregivers problem-solved and generated strategies caregivers could use to address areas identified via EMA. Caregivers in the control group did not receive feedback on their EMA data, but did meet with RAs and picked two general lifestyle areas (eg, physical activity) to target to improve their children's overall health. All caregivers completed follow-up questionnaires ~4 weeks and 4 months after the intervention session. Families were compensated \$25 at each follow-up session for their participation.

Measures

Background information. Primary caregivers provided demographic information, as well as information regarding child asthma medications and asthma-related ED visits in the last year.

FIG. 1. CONSORT flow diagram outlining caregiver participation in intervention trial. EMA, ecological momentary assessment.

Asthma control. At baseline, children 7–11 years completed the well-validated, seven-item Childhood Asthma Control Test (cACT),⁷ which assesses frequency of daytime and nighttime asthma symptoms, activity limitation, and perception of disease control. Children completed four items and caregivers completed three items. Twelve-year old children completed the well-validated, five-item ACT.⁸ Scores ≤ 19 were classified as asthma that was not well controlled. Mean asthma control for our sample was 18.27 (SD = 5.65).

Caregiver QOL. Caregivers completed the 13-item Pediatric Asthma Caregiver Quality-of-Life Questionnaire, which assesses QOL related to child asthma,⁹ at all assessment times. Responses were on a 7-point scale from 1 “all of the time” to 7 “none of the time.”

Perceived stress. Caregivers completed the 14-item Perceived Stress Scale (PSS)¹⁰ at all assessment times. The PSS assesses perceived stress experienced over the last month. Caregivers responded to questions on a 0 “never” to 4 “very often” scale.

Positive affect. At each assessment, caregivers rated how they felt in the past week from 1 “not at all” to 5 “extremely” for 10 positive mood items (eg, happy and proud) taken from the Positive and Negative Affect Schedule.¹¹ A positive affect score was calculated from the sum of all scores.

EMA survey items. Caregivers reported on their child’s and their own sleep using items adapted from the Pittsburgh Sleep Quality Index.¹² Items related to mood, social support, and family cohesion were adapted from the Behavior and Symptom Identification Scale (BASIS-32),¹³ the Social Support Questionnaire,¹⁴ and the Family Assessment Device.¹⁵ Stress and neighborhood safety items were adapted from the PSS⁹ and the Stress Index: Neighborhood Stress Scale.¹⁶ Items about child asthma were adapted from the Asthma Assessment Form.¹⁷ EMA compliance was assessed by calculating the number of days of completed EMA surveys for each caregiver.

Results

Analyses were performed using SPSS version 21.0. Sixty-one families were initially screened eligible and enrolled in the study. Of these 61 families, 54% were lost to follow-up after enrollment, resulting in 28 families in the current study. Sixty-one percent of the 28 caregivers completed intervention and follow-up sessions (see CONSORT flow diagram, Fig. 1). Groups were compared on caregiver and child characteristics at baseline using Chi-square analyses and *t*-tests; randomization was successful (P ’s > 0.05). Caregivers completed an average of 71% of EMA surveys across the 2-week period.

Table 1 presents the means of caregiver outcome measures at baseline, 4 weeks after the intervention, and 4 months after the intervention. A two-group repeated measures analysis of variance (ANOVA) was used to assess differences in caregiver QOL, perceived stress, and positive affect across the three time points. There were no significant group*time interactions across assessments.

We followed up the omnibus repeated measure ANOVAs with a priori paired sample *t*-tests by treatment group to evaluate for changes in outcomes from baseline (T_0) to postintervention (4 weeks follow-up; T_1) to identify short-term treatment effects, and from postintervention (T_1) to 4 months follow-up (T_2) to examine long-term effects (Table 1). In the

TABLE 1. MEAN (STANDARD DEVIATION) OF CAREGIVER OUTCOME MEASURES AT BASELINE, POSTINTERVENTION (4 WEEKS), AND 4 MONTHS FOLLOW-UP BY TREATMENT GROUP

	EMA group					Control group				
	Baseline T_0 , n = 15	Postintervention T_1 , n = 11		Follow-up T_2 , n = 10		Baseline T_0 , n = 13	Postintervention T_1 , n = 10		Follow-up T_2 , n = 9	
			T_0-T_1	T_1-T_2				T_0-T_1	T_1-T_2	
			P-value, Cohen’s d	P-value, Cohen’s d				P-value, Cohen’s d	P-value, Cohen’s d	
QOL	5.40 (1.59)	5.33 (1.57)	0.25 –0.37	0.82 0.08	5.49 (1.39)	4.87 (1.48)	5.41 (1.58)	0.14 0.52	0.15 0.57	
Stress	23.73 (2.92)	25.63 (3.11)	0.04* 0.72	0.02* –1.02	22.7 (2.58)	24.46 (1.90)	24.70 (3.47)	0.95 0.02	0.93 0.03	
PA	34.73 (7.65)	32.91 (9.43)	0.76 –0.09	0.53 0.22	36.6 (6.64)	33.00 (7.86)	38.8 (8.00)	0.17 0.46	0.36 –0.35	

Results of paired *t*-tests comparing baseline to postintervention and postintervention to 4 months follow-up.

* $P < 0.05$.

EMA, ecological momentary assessment; QOL, overall quality of life from the Pediatric Asthma Caregiver Quality-of-Life Questionnaire; PA = positive affect total score from the Positive and Negative Affect Schedule; Stress, total stress score from the Perceived Stress Scale.

EMA group, caregivers experienced an increase in perceived stress from baseline to postintervention, but a decrease in perceived stress from postintervention to follow-up. There were no significant changes in outcome measures for the control group.

Discussion

The goal of this pilot study was to explore the initial efficacy of providing caregivers with individualized feedback from information gathered via EMA and evaluate the impact of this intervention on caregiver emotional health. Findings from this study are important in the development of mHealth interventions that can be delivered in real-time and meet the needs of urban caregivers managing children's asthma. Although this was a small pilot study, we found changes in caregiver stress following the EMA feedback intervention. Interestingly, caregivers in the intervention group experienced an increase in stress from baseline to 4 weeks after the intervention, but reported a significant decrease in stress from postintervention to follow-up (4 months after the intervention). One explanation may be that, although self-monitoring increased perceived stress, across a longer period of time, caregivers were able to reconcile areas of cognitive dissonance (eg, conflict between attitudes and behavior) and experience less stress. Interventions aimed at reducing caregiver stress among children with asthma remains an understudied area and, in fact, existing studies have found it challenging to address the daily stressors experienced by low-income, urban families.^{18,19}

Our preliminary findings suggest that providing caregivers with feedback from daily assessments and developing strategies to minimize daily challenges may be one strategy for reducing caregiver stress. This was a pilot study, with a small number of families participating, and replication is needed. The focus of the present study was on developing an intervention to target caregiver emotional functioning, which has been linked to daily asthma care behaviors.²⁰ Future studies should consider targets of interventions to improve child outcomes as well, including medication adherence and asthma control. Moreover, our EMA items were completed by caregivers with caregivers reporting on behalf of the child, which may limit the validity of some of our data. We also recognize attrition in our sample from baseline to follow-up. Retention of urban families is often challenging due to additional priorities and stressors that families may be experiencing. In fact, a large percentage of eligible families were lost to follow-up after enrollment, which is a limitation of our study. An mHealth platform that delivers intervention components via smartphones may be one-way to deliver interventions to families that are often the hardest to reach, but most in need.

Conclusion

Findings from our pilot study support the initial feasibility of implementing interventions based on EMA with urban caregivers and suggest that an intervention related to daily caregiver experiences may decrease caregiver stress. Future studies should test the efficacy of this pilot intervention in a larger sample of families as well as incorporate child-specific outcomes. Our findings suggest that urban caregivers may benefit from future mHealth initiatives

that are able to reach caregivers in their daily lives as they experience challenges in the management of childhood asthma.

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Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:

Robin S. Everhart, Ph.D.

Department of Psychology

Virginia Commonwealth University

P.O. Box 842018

Richmond, VA 23284

E-mail: reverhart@vcu.edu

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