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Recruitment and Retention of the Hardest to Reach Families in Community-Based Asthma Interventions

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Abstract

Background/Aims: Engaging underserved populations in research requires substantial effort for recruitment and retention. The objective of this study is to describe the effort needed to recruit and retain urban participants in pediatric asthma studies and to characterize the hardest-to-reach group by demographics and asthma severity.

Methods: We included 311 children (3-10 years) with persistent asthma enrolled in 2 school-based asthma interventions in Rochester, NY. Contact logs were collected at 4 time points (baseline, 2-month, 4-month, 6-month). We defined ‘Hardest-to-Reach’ (vs. ‘Easier-to-Reach’) as being unable to reach a family by telephone at any given contact attempt due to disconnected or wrong numbers. Chi-Square and Mann-Whitney tests were used to compare groups.

Results: Overall, we enrolled 311 children (60% Black, 29% Hispanic, 70% Medicaid, response rate 70%). On average, 3.1 contact attempts were required for recruitment (range 1-15), and 35% required rescheduling at least once for the enrollment visit. All but 12 participants completed each follow-up (retention rate=96%). Completion of follow-ups required an average of 7.6 attempts; we considered 38% of caregivers ‘Hardest-to-Reach’. Caregivers in the Hardest-to-Reach group were slightly younger (33 vs 36 yrs, $p=.007$) with more depressive symptoms (41% vs 29%, $p=.035$) and smokers in the home (59% vs 48%, $p=.048$). Further, more of the Hardest-to-Reach children had moderate-severe vs. mild persistent asthma (64% vs 52%, $p=.045$). Importantly, even the Easier-to-Reach families required many contact attempts, with 52% having >5 attempts for at least one follow-up.

Conclusions: In conclusion, we found that among an already vulnerable population, the Hardest-to-Reach families demonstrated higher risk and had children with significantly worse asthma. This study highlights the importance of persistence in reaching those in greatest need.

Keywords

Recruitment and retention; hard-to-reach; implementation research; underserved; asthma; pediatrics

Background

Despite having well-established, effective asthma care guidelines in the United States,¹ children living in poverty and from minority ethnic and racial backgrounds continue to suffer disproportionately from asthma morbidity.²⁻⁵ While many programs have been designed to improve care for these children by promoting adherence to preventive asthma guidelines,⁶⁻¹⁰ rigorous evaluation of programs in traditionally underserved populations can be difficult. Combating disparities in asthma management must begin with accurately representing, engaging, and retaining underserved populations in research to optimally evaluate the effectiveness of programs.

Historically, ethnic and racial minority groups have been underrepresented in clinical research.¹¹⁻¹³ The National Institutes of Health (NIH) Revitalization Act cites several barriers to research participation including high mobility of the participants, inconsistent phone service, and competing demands on a participant's time.¹⁴ Other commonly cited barriers include psychosocial distress and mental health concerns, cumbersome protocols, and mistrust of research.^{15,16} While those participants that are hardest to reach for research trials are likely among the highest risk for poor outcomes, there is limited information on recruitment and retention strategies for underserved pediatric populations and the success of those efforts. The inclusion of the more difficult to reach subjects may be crucial for ensuring the integrity, generalizability and sustainability of randomized control trials.^{17,18}

Over the past several years, our research team has designed and implemented community-based trials for high-risk, urban children with asthma and their caregivers.^{10,19} Each trial successfully recruited hundreds of children and their caregivers, and maintained long-term follow-up with the majority of participants.^{9,20} Therefore, we have the opportunity to consider characteristics of the participants related to the effort required to recruit and retain them in the clinical studies. The objectives of this study were to: 1) Describe the effort needed to recruit and retain urban participants in 2 similar clinical pediatric asthma studies; 2) Characterize the 'Hardest-to-Reach' group and compare to an 'Easier-to-Reach' group, by demographic factors and asthma severity; and 3) Highlight successful strategies to overcome commonly cited barriers to working with an underserved pediatric community.

Methods

Overview of the 2 intervention studies: The School-Based Preventive Asthma Care Technology (SB-PACT) trial & School-Based Telemedicine Enhanced Asthma Management (SB-TEAM)

For these analyses, we used data from 2 school-based asthma studies; the *School-Based Preventive Asthma Care Technology (SB-PACT)* trial^{8,20} and the *School-Based Telemedicine Enhanced Asthma Management (SB-TEAM)*^{9,10} program based in Rochester, New York. Through a unique partnership with the Rochester City School District, the SB-PACT (2010-2011) and SB-TEAM (2012-2016) programs aimed to improve adherence to national asthma guidelines for urban children through directly observed administration of preventive asthma medication in school. Both the SB-PACT and SB-TEAM programs build from our previous school-based asthma programs^{19,21} using directly observed therapy of

preventive asthma medications in school, and incorporate technology to link children to primary care for asthma assessments and follow-up and to support sustainability of the programs. The University of Rochester Institutional Review Board approved both study protocols.

Setting & participants

Both programs recruited participants between the ages of 3-10 years who were students in the Rochester City School District, had physician-diagnosed asthma, and were experiencing persistent asthma symptoms or poor control based on the National Heart, Lung and Blood Institute guidelines.¹ Children were excluded if the caregiver could not speak and understand English, reported they did not have access to a telephone for follow-up calls, or if the child had another chronic illness which could interfere with the assessment of asthma.

We initially identified children with asthma or breathing problems from school health records and conducted a telephone survey with the child's caregiver to assess eligibility. After eligibility screening, a home visit was scheduled to obtain written consent and assent from children 7 years old, and to conduct baseline measures and randomization. After randomization, participants were contacted during the study period by an independent group, blinded to treatment allocation, for telephone interview follow-up assessments.

Recruitment and retention protocol

At the point of the first telephone contact for eligibility screening, all available phone numbers were collected from caregivers, including emergency contact information. We specifically asked caregivers to provide contact information for an individual who is 'always able to reach you, in case we lose contact'. Contact information was continually confirmed and updated at every follow-up time point thereafter. We asked caregivers for their preferred time for calls, and repeated call attempts at various times, with emphasis on evening hours and weekends. Participants were given grocery store gift cards (ranging from \$20.00-\$50.00) for each survey time point that was completed. If we were unable to contact the family by telephone, we mailed letters to the home requesting them to call us back and also conducted unscheduled home visits to reach families.

Data collection for this study

Recruitment and retention data were collected at the 4 time points that were consistent across the 2 studies; baseline, 2-month, 4-month and 6-month follow-ups. All contact attempts (telephone calls, home visits and mailings) were tracked in an electronic database for all participants at each time point. Only participant records with 'contact attempt logs' from all 4 time points were used for these analyses.

Definition of Hardest-to-Reach and Easier-to-Reach

We defined the 'Hardest-to-Reach' group by the inability to contact the primary caregiver by telephone due to a disconnected or wrong telephone number (for all available contact numbers) at any given contact attempt. All other participants were defined as 'Easier-to-Reach'.

Baseline measures

We assessed standard demographic variables based on caregiver report at baseline, including child's gender, age, race, ethnicity, and insurance coverage (public vs. private). We also collected information about caregiver characteristics, including age, race, ethnicity, marital status, and education. Caregivers were asked about depressive symptoms using either the 10 item Kessler Psychological Distress Scale (SB-PACT study) or the 20-item Center for Epidemiological Studies Depression Scale (SB-TEAM study). Caregivers with scores >20 on the K10 and scores >16 on the CESD-R were considered to have depressive symptomology.^{22,23} We assessed exposure to secondhand smoke by caregiver survey.²⁴ Caregivers reported smokers living in the child's home, as well as whether a home smoking ban was in place.²⁵

Assessment of health outcomes

During the baseline assessment, we used a structured survey tool based on national guidelines¹ to assess the child's asthma severity. Caregivers reported how often their children experienced symptom-free days over the prior two weeks, defined as a 24-hour period with no symptoms of asthma. Caregivers also reported the frequency of days and nights the child had asthma symptoms over the prior 2 weeks, activity limitation due to asthma, rescue and preventative medication use, and visits to the emergency department due to asthma over the past year. We categorized asthma severity into two groups: "mild persistent" and "moderate/severe persistent" asthma. We also assessed the caregivers' asthma related quality of life using Juniper's Asthma Related Caregiver Quality of Life Scale.²⁶ Mean scores range from 1-7, with higher scores indicating better quality of life.

Caregiver satisfaction

At the end of the school year, research assistants who were blinded to the intervention group asked for feedback about the program. We used two questions to assess caregivers' overall satisfaction: 1) Did you find this program to be helpful for yourself and your child? 2) Would you be willing to participate in a similar program if it were offered to you again?

Data analysis

We performed analyses using SPSS software, version 22. Students' t-tests were used to compare the number of contact attempts between the 2 groups. We also used Chi-Square and Mann-Whitney tests to determine the associations between demographic variables and asthma outcomes between the Hardest-to-Reach and Easier-to-Reach groups. Multivariable regression analyses were conducted to determine the independent associations of Hardest-to-Reach status and asthma severity factors, while controlling for potential confounders including, caregiver age, depressive symptoms, and smoke exposure. A two-sided alpha of <0.05 was considered statistically significant.

Results

Response rate

Data from 330 study participant call logs and surveys were analyzed (100 from SB-PACT and 230 from SB-TEAM), with an overall study participation rate of 70% and a retention rate of 96%. Only one subject was excluded because the caregiver reported no access to a telephone for follow-up calls. We excluded 19 subject records because they did not have all 4 call logs present despite completing the surveys, leaving us with 311 participants for this analysis. Excluded participants were not more likely to be lost to follow-up than included participants, with only 1 of the 19 subjects missing a single follow-up.

Recruitment

On average, we found that participants required 3.1 contact attempts (range 1-15 attempts) before enrolling into the studies. Appointments were rescheduled if they were cancelled when the research team called to confirm the appointment, or if the family was not home when the interviewer arrived for a scheduled visit. More than 1/3 of recruited families (35%) required at least 1 rescheduled baseline home visit before completing enrollment.

Demographics

Table 1 shows the demographic characteristics of the caregivers and children enrolled in the sample. Overall, caregivers were primarily female (94%), African American (60%), and not married (72%). Child participants had a mean age of 7.6 years, 41% were female, and over half were African American (60%) and on public health insurance (70%).

Retention

In considering the effort required to retain participants in the study, we found that the average follow-up required 7.6 contacts before completion. Approximately one-third of participants (38%; $n=118$) were defined as 'Hardest-to-Reach' by having a disconnected or wrong telephone number during the course of the study. The Hardest-to-Reach caregivers were consistently more difficult to retain at each assessment time point, with an average of around 10 contacts required to complete each follow-up (range 8.51-13.18 contacts; Figure 1). We also found that the Easier-to-Reach caregivers required several contact attempts with, on average, >5 contacts needed to complete each follow-up survey. There was no difference in retention rates between the Hardest-to-Reach and Easier-to-Reach groups ($p=.771$).

Comparisons of Hardest-to-Reach versus Easier-to-Reach

Family characteristics.—We found that the Hardest-to-Reach caregivers were slightly younger, with a mean age of 32.9 years, compared to the Easier-to-Reach caregivers with a mean age of 35.6 years ($p=.007$). The Hardest-to-Reach caregivers also reported experiencing more depressive symptoms compared to the Easier-to-Reach caregivers (41% vs. 29%, $p=.035$), and children of the Hardest-to-Reach caregivers were more likely to live in a home with a smoker (59% vs. 48%; $p=.048$). There were no significant differences in gender, race, caregiver marital status, and child's age, insurance coverage or treatment group assignment between Hardest-to-Reach and Easier-to-Reach families (Table 1).

Asthma severity.—More children with Hardest-to-Reach caregivers had moderate to severe persistent asthma at baseline (64% vs 52%, $p=.045$), compared to children with Easier-to-Reach caregivers. The Hardest-to-Reach caregivers reported their children had fewer symptom free days (6.4 vs. 7.9, $p=.007$) and more days with symptoms (5.0 vs 4.3, $p=.049$) over 2 weeks compared to the Easier-to-Reach caregivers (Table 2). There were no statistically significant differences between groups for nighttime symptoms, medication use, acute healthcare visits, or asthma-related quality of life. After adjusting for potentially confounding demographic variables, the association with symptom free days remained statistically significant between groups.

Program satisfaction.—Nearly all of the families reported high satisfaction with the program, with the majority of both Easier-to-Reach and Hardest-to-Reach caregivers stating they found the programs helpful (93% vs. 94%) and that they would be willing to participate in a similar program again (97% vs. 96%). There were no significant differences in program satisfaction on any measure between the Hardest-to-Reach and Easier-to-Reach groups.

Discussion

Underserved children suffer disproportionately from asthma,²⁷⁻³⁰ and novel programs are needed in order to improve the delivery of effective preventive care to these populations.³¹⁻³⁵ When testing new programs, it is important to ensure that the participants appropriately represent the population of interest. We found that a significant amount of effort was required to recruit and retain participants in our school-based asthma programs, and these efforts were successful in engaging a diverse group throughout the study period, with a retention rate of 96%. We considered more than 1/3 of the group ‘Hardest-to-Reach’ based on disconnected or incorrect telephone numbers at assessment time-points.

We found that the Hardest-to-Reach participants were higher risk than the Easier-to-Reach participants based on several factors, including caregiver depression, exposure to smoke, and more severe asthma symptoms. Thus, they were arguably at greatest need for the program. Importantly, exclusion of these participants would likely impact the integrity of the studies, either biasing results if unequally distributed between intervention arms, or making findings more difficult to interpret due to selection bias and the omission of this highest risk group. However, in light of known barriers to research participation that have been described including transient living situations,¹⁴ distrust of research,^{15,16,36} and inconsistent contact information,³⁷⁻³⁹ researchers may struggle with low participation and high attrition rates, and potentially lose these Hardest-to-Reach subjects.^{40,41}

Consistent with other programs successfully reaching similar populations,^{14,42-44} we used a multicomponent approach to ensure engagement of the participants in the trial. Strategies included having a fully staffed research team to perform calls and visits, highlighting our engagement with community partners to enhance trust, providing appropriate participant incentives, and using multiple methods to track families based on an understanding of the mobility of many individuals in underserved communities. We provided to the team extensive education about our own urban community, and included cultural humility training led by a colleague in the School of Nursing. For all families, we collected multiple phone

numbers with at least 2 ‘additional’ contact numbers when possible, and continually updated contact information at every follow-up survey. We called caregivers at various times, including evenings and weekends. We have found that for many families their telephones fluctuate between having working service or not. Thus we kept all contact information and continued call attempts even if there was a disconnected number. We reached out for additional contact information from our community partners when needed (schools, primary care providers), and sent letters to the home asking the family to call us back. We also established protocols for when and how to attempt unscheduled home visits when our attempts at calling were unsuccessful.

Importantly, high program satisfaction (>90%) demonstrated that, while research efforts were labor-intensive, they were well received by caregivers. While there may be concern about ‘badgering’ with repeated contact efforts, we found that once we connected with families they were consistently highly engaged and agreeable. Multiple call attempts and unscheduled home visits were acceptable to the majority of our study participants, and few caregivers requested that we not do unscheduled home visits. Respecting our participants’ preferences, we alternatively offered a neutral place to meet to complete the follow-up surveys in person. Schools, physician waiting rooms, public libraries and our offices have all been used as neutral locations.

A systematic review of the clinical trials registration database highlights the limited information on recruitment and retention available for many studies, and particularly those involving minority or low income children.⁴⁵ The multicomponent strategies outlined above require resources to adequately staff and mobilize the research team, which may not be practical for all studies. However, a summary of guidelines developed from a workshop hosted by the National Heart, Lung, and Blood Institute outlined critical steps that are required to ensure adequate participation in trials, and the need to budget appropriately to meet recruitment or retention goals, particularly when underserved subjects are involved.⁴⁶ We strongly suggest considering the effort necessary for successful and representative recruitment and retention before study initiation. It is important to note that even the ‘Easier-to-Reach’ in this population of study subjects required a significant commitment of effort from the research team. Further, when considering those families who were not represented in this study and would potentially be considered the *most* difficult to reach (i.e.; non-English speaking families or families whom are not accessible by telephone), even more resources would be required for successful engagement. These factors should be considered upfront in the research planning process.

In the future, it would be helpful to explore novel, inexpensive methods to assist in retaining the hardest to reach populations. These could include open discussions with caregivers about keeping in contact to tailor tracking plans individually, implementing standardized protocols to address overdue assessments, and considering new platforms such as social media to connect with families and collect data. Engagement with caregivers who have depressive symptoms may be the most difficult, and offering support services and referrals should be considered. When working with limited resources, it is important to think creatively and pragmatically to establish parameters that are achievable. Even when underserved populations aren’t the specific target of an intervention, representativeness is critical to

enhance the generalizability of study findings and to ensure equal representation in clinical research, and ultimately equal access to health services.

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Figure 1.
Retention Effort.

Table 1:

Demographics

N (%)	Overall (n=311)	Hardest To Reach (n=118)	Easier To Reach (n=193)	P-Value
CAREGIVER				
Gender (Female)	293 (94%)	111 (94%)	182 (94%)	1.000
Average Age (Years) ^a	34.6 (9.0)	32.9 (8.1)	35.6 (9.4)	0.007
Race (African American)	183 (58%)	70 (59%)	113 (58%)	0.487
Ethnicity (Hispanic)	73 (24%)	22 (19%)	51 (26%)	0.130
Marital Status (Single)	223 (72%)	79 (67%)	144 (75%)	0.152
Depressive Symptoms (Yes)	104 (34%)	48 (41%)	56 (29%)	0.035
Education (Less than High School Graduate)	125 (40%)	50 (42%)	92 (48%)	0.553
CHILD				
Gender (Female)	126 (41%)	48 (41%)	78 (40%)	1.000
Age (Years) ^a	7.6 (1.7)	7.7 (1.7)	7.6 (1.8)	0.533
Race (African American)	186 (60%)	69 (58%)	117 (61%)	0.762
Ethnicity (Hispanic)	89 (29%)	31 (26%)	58 (30%)	0.519
Public Insurance (Yes)	216 (70%)	85 (72%)	131 (68%)	0.450
Assigned to Intervention Treatment Group (Yes)	152 (49%)	58 (49%)	94 (49%)	1.00
ENVIRONMENTAL				
Home Smoking Ban	181 (58%)	65 (55%)	116 (60%)	0.408
Smokers in the Home	162 (52%)	70 (59%)	92(48%)	0.048

^aMean (SD)

Table 2:

Asthma Severity

	Overall (n=311)	Hardest To Reach (n=118)	Easier To Reach (n=193)	P-Value	Adj. P-Value ^c
Severity Level (Moderate to Severe) ^a	177 (57%)	76 (64%)	101 (52%)	0.045	0.086
Preventive Medication Prescription ^a	197 (63%)	68 (58%)	129 (67%)	0.115	0.251
Acute ED Visits for Asthma ^a	89 (29%)	41 (35%)	48 (25%)	0.071	0.093
Symptom-free Days (0-14 days) ^b	7.4 (5.0)	6.4 (4.8)	7.9 (5)	0.007	0.024
Days with Daytime Symptoms (0-14 days) ^b	4.6 (4.4)	5.0 (4.3)	4.3 (4.5)	0.049	0.342
Nights with Nighttime Symptoms (0-14 nights) ^b	3.4 (4.2)	3.7 (4.2)	3.2 (4.1)	0.087	0.437
Days Needing Rescue Medication (0-14 days) ^b	4.1 (4.6)	4.4 (4.7)	3.9 (4.5)	0.187	0.354
Quality of Life (range 1-7) ^b	5.8 (1.1)	5.7 (1.1)	5.9 (1.2)	0.088	0.618

^aN (%)^bMean (SD)^cRegression analysis including caregivers' age, depressive symptoms, and smokers in the home.