

Retention strategies and predictors of attrition in an urban pediatric asthma study

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Background The Urban Environment and Childhood Asthma (URECA) study is a multicenter prospective birth cohort study designed to examine factors related to the development of childhood asthma and allergies in an inner-city population. The retention of these participants has been challenging due to high mobility, inconsistent phone service, custody issues, and stressful life situations.

Purpose In this article, we describe the specific retention challenges we encountered during the first 2 years of follow-up in URECA and the strategies we utilized to address them. We also examine how selected maternal characteristics and other factors are related to retention and missed study visits.

Methods Strategies implemented to engage participants included: collecting updated and alternative contact information, after-hours phone calls to participants, culturally competent staff, flexible study event scheduling, clinic visit transportation, quarterly newsletters, retention events, drop-in home visits, and cell phone reimbursements. An internally developed web-based data management system enabled close monitoring by site teams and the coordinating center. The rate of deactivations was calculated using survival analysis. Characteristics of active and deactivated participants were compared using the chi-squared test with a Cochran–Mantel – Haenszel adjustment for study site. The proportion of missed visits of the total expected in the first 2 years was calculated and compared by family characteristics using an ANOVA model or a trend test controlling for study site. All analyses were performed using SAS version 9.1 (Cary, NC).

Results The 2-year retention rate was 89%. Participation in the first study event predicted subsequent engagement in study activities. Mothers who did not complete the first visit were more likely to miss future events (46.1% vs. 8.9%, $p < 0.0001$) and to be deactivated (38.5% vs. 4.5%, $p < 0.0001$). Mothers under 18 years of age were more likely to leave the study compared to older mothers (22.7% vs. 10.1%, $p = 0.02$). Also, mothers who were married missed fewer events than those not married (8.8% vs. 15.6%, $p = 0.01$). In addition, deactivations were more common when the child had entered daycare by 3 months of age (10.9% vs. 3.6%, $p = 0.05$).

Limitations The URECA population is predominantly minority, thus our findings might not be generalizable to other populations. Furthermore, we may not be able to observe the effects that might exist in a more diverse population. For example, 86% of the mothers are unmarried, making it difficult to reliably examine the effect of marital status.

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Conclusion In research, successfully engaging and retaining participants is essential for achieving the study objectives. Identifying factors related to missed visits and deactivations are the initial step in recognizing the potential at-risk participants and can enable the design of targeted strategies to retain participants. *Clinical Trials* 2010; 7: 400–410. <http://ctj.sagepub.com>

Background

In a longitudinal study, participant retention is challenging, requiring extensive effort and time from the research site staff. Residential addresses and phone numbers change, and participant employment schedules restrict the times that can be used for study events. Inner-city urban environments can intensify the challenges: transportation costs for study visits can be high, and participant use of healthcare facilities may be irregular. Inner-city populations tend to be more mobile than suburban residents and residents in nonmetropolitan areas, with 50.6% of people in central cities having changed addresses from 1995–2000 [1]. When contact information becomes inaccurate, current addresses and phone numbers are hard to locate. Also, friends or family members may be reluctant to release new addresses to unknown callers. The resulting loss of study participants negatively affects statistical power and could lead to selection bias when study dropout is related to the exposures or outcomes of interest.

For any longitudinal study, the motivation of the participants to continue their commitment to the study activities may decline over time. In many developmental studies, participant loss ranges from 10% to 15% per year [2]. For example, in a pediatric respiratory distress syndrome study, a 37% dropout rate occurred over 3 years [2]. In an observational study, when no treatments or medications are given to the participants, fewer perceived benefits from participation may exist, requiring even greater effort to maintain consistent and continued participant engagement.

Retention activities, if not effective, can add to the time and effort that the participant is asked to invest, so it is especially important to evaluate their usefulness. The National Cooperative Inner-City Asthma Study (NCICAS) found that staff flexibility, computer tracking, and face-to-face recruitment were essential for good followup [3]. In the Inner-City Asthma Study (ICAS), frequent contact quickly identified participants who had become disengaged, and methods were implemented immediately to reinitiate contact. Staff found that no single strategy could be relied upon, but persistence with a variety of methods (phone, mail, and 'in-person' attempts) proved successful [4].

This report describes our experience with retention during the first 2 years of each child's study participation in the Urban Environment and Childhood Asthma (URECA) study. We describe specific retention challenges we encountered and illustrate strategies utilized to address these challenges. We also examine the relationship of participant characteristics to missed events and deactivation from the study.

Methods

Study description

The URECA study is a longitudinal birth cohort study exploring the immunologic and environmental factors leading to the development of asthma by age 7 [5]. After the study was approved by Institutional Review Boards at the participating institutions, the URECA site staff enrolled 606 pregnant women at four sites (Baltimore, Boston, New York, and St. Louis) from February 2005 to March 2007. Generally, two staff members recruited for at least 20 h weekly at each study site with basically the same strategies. Interested pregnant women were interviewed to determine if they met the initial inclusion criteria (self-reported history of asthma, allergic rhinitis, or hay fever in either parent and residence in an urban census tract where at least 20% of the household incomes were below the federal poverty level defined in 2000 US census data). If the pregnant women were eligible and consented for participation, then cord blood was collected after the delivery. Among these delivered children, those who met the remaining entry criteria (delivery at ≥ 34 weeks with no other exclusionary health conditions) were enrolled into the study ($N = 609$; three sets of twins). The staff visited the participant's home when the child was 3 months old for interviewing, dust collection for exposure to selected allergens, and air sample collection for specific household exposures. Home visits for dust collection continue to occur yearly. Telephone interviews occur every 3 months, and the mother and child visit the study clinic yearly for the following assessments of the child: blood collection, physical examination, height, weight, BIA measurements, and nasal sample collection. The mother is also interviewed at these yearly visits.

A blood sample is collected once from the mother at a yearly clinic visit. (The scheduling window for the quarterly calls is 2 weeks before and 6 weeks after the target call date; for clinic visits, 4 weeks before and 12 weeks after.)

Monitoring study progress

The web-based data management system used by URECA (which was internally developed) enables close monitoring by the site teams. Examples of helpful reports include:

- An Upcoming Events Report that lists upcoming events by the date they should be scheduled and each event's deadline.
- A Missed Visits Report that shows the events that are past the end of the scheduling window and have not occurred.
- A Participant Retention Report that shows participants who have missed the last two study events or greater than 25% of the events overall, in order to identify families who are not fully engaged in the study.

Participant tracking

A major challenge for any longitudinal study is maintaining contact with the participants. In three URECA sites, an average of 55% of the 487 study mothers had moved at least once by the time their child had reached 2 years of age. However, at the remaining site, New York, only 27% of the 119 mothers had moved.

To help locate the participants who move or change phone numbers, the mothers were asked, at the initial study visit, to provide the names, telephone numbers, and addresses of up to three family members, neighbors, or friends who would be willing to help the staff communicate with the mother. At every event, updated contact information is requested, which is entered into the URECA data management system.

Study management

Table 1 lists the strategies that have been employed by the URECA staff to maintain or improve recruitment and retention. The effectiveness of these strategies was monitored and discussed during weekly coordinators conference calls. Some of these strategies were utilized in previous studies that the investigators had led and some were new

strategies not used by the URECA investigators before. The categorization of the strategies is based on the opinions and experience of the site coordinators and staff.

Staff structure

In URECA, having full-time staff has been more effective than part-time staff for establishing and maintaining rapport with the participating mothers. The URECA study had rolling recruitment, so work volume depends on the number of mothers enrolled within a specific time frame with overlapping study events.

Management strategies are designed for each study phase to increase staff efficiency and to accommodate the mothers' schedules. For example, for mothers whose employment has minimal scheduling flexibility, staff administers some clinic forms via telephone before the clinic visit so that the clinic visit time can be shortened. At one site, weekend clinic visits are scheduled to accommodate working mothers' schedules.

Telephone communication

Early in the URECA study, fewer phone calls were needed to reach the participants since the mothers were home with the infants. As mothers returned to work, or addresses and/or phone numbers changed, the number of needed call attempts increased. For some mothers, 8–10 phone calls are needed to complete a single event. Approximately 20% of the Baltimore families, 25% of the Boston families, 25% of the New York families, and 5% of the St. Louis families prefer evening or weekend phone calls. It appears that the mothers in St. Louis could more easily be contacted during work lunch breaks or school breaks than the mothers at other sites.

If the mothers indicate time preferences for study communication (daytime, evening, weekends, or a specific day), documentation of the requests is made to increase efficiency and avoid imposition. The mothers can also indicate if they prefer contact via e-mail, cell phone, or home visits. When a mother's phone is disconnected, a letter is sent requesting that the mother call the site; alternate contacts are also called to obtain the updated telephone information. All attempts to reach the mother are documented.

Two paid Internet search engines have been used to find the updated phone numbers and addresses. Generally, the staff has independently acquired more current contact information via the methods

described in the previous paragraph than the search engines.

Reimbursements

Research institutions typically reimburse study participants with checks. Many URECA mothers do not have checking accounts and some do not have government-issued identification; thus they are unable to cash checks. Alternative strategies for reimbursement were developed, including vouchers that can be redeemed for cash at the hospital cashier's office, postal money orders, and gift cards.

Additionally, many mothers use their cell phones exclusively and were reluctant to use their minutes on potentially lengthy study interviews. To address this problem, a reimbursement for cell phone use was added.

Study reminders

Reminder calls (the week before, day before, and/or the day of the appointment) are standard for all sites. All sites provide transportation to clinic visits via cabs. Quarterly newsletters are sent to mothers that include childhood development and basic

Table 1 Recruitment and retention strategies by category

Essential	<p>Recruitment:</p> <ul style="list-style-type: none"> • Efficiency with recruitment: Use site hospital-affiliated outpatient clinic waiting areas, quieter, and smaller clinics to meet potential mothers. Use private clinic space for completing eligibility form. • Assign at least two staff members to recruit for a minimum of 20 h weekly. • Establish relationships with clinic personnel at recruitment sites to increase study awareness. <p>Retention:</p> <ul style="list-style-type: none"> • Site coordinator should continuously monitor staff assignments and the effectiveness of the assignment delegation. • Establish minimum number of required call attempts for completion of study calls/visits. • Collect name/contact information for alternate contacts at the initial interview. • Update alternate contact information during subsequent study events. • Allow for after-hours staffing to complete calls. • Organize calls by order of priority and document date/time of each call made. • Purchase site cell phones to use for calling participants who are difficult to reach and who may not answer a hospital number. • Hire culturally competent and culturally sensitive staff with strong interpersonal skills. • Use tracking/monitoring reports to chart the study progress and identify problem areas. • Mail appointment letters. • Provide transportation and/or cover the cost of parking charges for visits made to the study site. • Provide sufficient and timely reimbursements. • Offer more than one method of reimbursement.
Helpful	<p>Recruitment:</p> <ul style="list-style-type: none"> • Post study flyers describing eligibility criteria and URECA contact information. • Present information about URECA study at child health community programs and in clinic areas. • Conduct consenting procedure at the initial screening interview. • Identify a clinic in the correct catchment area. • Involve the study nurse or coordinator during the consenting process to accentuate the importance of complying to study guidelines. <p>Retention:</p> <ul style="list-style-type: none"> • Mailings: Send (1) follow-up letters to participants who are difficult to reach, (2) monthly postcards as reminders of study events or check-in requests, and (3) greeting cards, e.g., Mother's or Father's Day, holiday cards, and thank you notes. • Make event reminder calls: (1) 1 week before visit, (2) day before/of visit, and (3) home visit in place of call for 'difficult to reach' participants. • Use incentive gifts.
Effectiveness Unknown	<p>Recruitment:</p> <ul style="list-style-type: none"> • Use child health pamphlets. • Use novelty advertisements (URECA buttons). • Initiate informal discussions of asthma and other child health issues. <p>Retention:</p> <ul style="list-style-type: none"> • Reimburse for cell phone use. • Use Internet search engine to find updated phone numbers and addresses. • Have retention parties/events.

health information and a brief summary of the study findings. For occasions such as birthdays, Mother's Day, and holidays, cards are mailed. Some sites have incorporated 'thank you' notes for completion of scheduled events, which are included with reimbursement mailings.

Retention events

Each URECA site has held retention activities beginning in 2007. These events included activities such as a city zoo trip and a magic show. In 2007, event attendance was low (12% of enrolled mothers) and attending mothers and children were already engaged with study activities (5.5% missed events vs. 22.6% in nonattending mothers). However, attendees requested future events and attendance improved in 2008 (17% of enrolled mothers). Pictures of those who attended were included in the quarterly newsletters (with the mother's consent).

Staff selection and interpersonal skills

Two URECA sites include non-English speaking Latino participants, so these sites hired full-time bilingual staff who are also culturally competent (Latino descent). They are assigned to routine calls, clinic, and home visits for the Latino participants. Study questionnaires, informed consent forms, brochures, thank you notes, and quarterly newsletters are also prepared in Spanish.

Staff were trained in interviewing skills that emphasized respect for the participating mothers in an effort to encourage honesty and more accurate data collection. For example, rodents and infestations are commonplace in urban environments; any indication that staff disapproves of the mother's home may lessen enthusiasm for the study. The staff were also fully trained with respect to study procedures and potential adverse events and were prepared to openly discuss them during the consenting process before enrollment or anytime questions are asked during the study events.

Statistical analysis

All analyses were performed using SAS version 9.1 (Cary, NC). The rate of deactivation from age 0 to 24 months was calculated using survival analysis. Characteristics of active and deactivated participants were compared using the chi-squared test with a Cochran-Mantel-Haenszel adjustment for the study site. The proportion of missed visits of the

total expected in the first 2 years was calculated and compared by family characteristics using an ANOVA model (two-level variables) or a trend test (three-level variables) controlling for study site.

Results

Recruitment and maternal characteristics

The characteristics of the mothers of children enrolled in the URECA cohort were reported by the mother at the prenatal interview (Table 2). The majority of mothers are African American and unmarried, and 40.9% do not have a high school degree. Although 67.6% of the households include someone with a regular job, 68.5% have a household income of \$15,000 or less.

Table 2 Characteristics of mothers at enrollment

	N	%
Total number of mothers	606	
Age of mother at the birth of child (years)		
13–17	44	7.3
18–19	95	15.7
20–29	350	57.8
30–42	117	19.3
Race/ethnicity of mother		
Hispanic	116	19.4
Non-Hispanic black	429	71.6
Non-Hispanic white	22	3.7
More than one race	21	3.5
All others	11	1.8
Missing	7	
Education of mother		
Less than high school	245	40.9
High school or GED	206	34.4
More than high school	148	24.7
Missing	7	
Married	80	13.4
Adult in household with regular job	404	67.6
Household income ≤ \$15,000	387	68.5
Number of other children in household under age 5		
0	307	50.7
1	200	33.0
2	65	10.7
3 or more	34	5.6
Missing	7	
Number of years lived at current address		
Less than 1	205	34.2
1–2	157	26.2
3–4	78	13.0
5–9	72	12.0
10 or more	87	14.5
Missing	7	

Rates of retention and reasons for discontinuation

A total of 40 children (6.6%) were deactivated within their first year of observation and 27 were deactivated in the second year, for a cumulative loss of 11% through 2 years of follow-up (Table 3). Table 4 shows the reasons for deactivation. The most common reason for deactivation was out-of-date contact information and inability to locate the mother (39%). The second most frequent deactivation reason (25%) was the mother's request to stop study participation. Other reasons included custody issues, incarceration of the mother, medical issues that would compromise study data, or family relocation that prohibited study participation.

Staff retention and stability were possibly related to sustaining participant retention. In the URECA study, the site team with the highest retention rate (95% active at 2 years) had only two replacement staff during the period covered by this article. The personnel of this site were the same race and gender of most of the participants, as well as natives of the site city, so they had a deep understanding of the city's culture and knew many people in the inner-city community. The retention rates for the other sites were 91%, 86%, and 85%. These sites have replaced at least five staff members each, and, in two sites, the majority of the staff moved to the site city from elsewhere. However, each site team used slightly different strategies which were successful to strengthen the staff's relationships with their participants.

Maternal characteristics associated with missed study events

The rate of missed visits for each type of event is shown in Table 5. The home evaluation in year one had the highest missed rate (26.1%), which reflects the difficulty of accessing some mothers at home. Many 15-month calls (21.8%) were missed because the 12-month clinic visit was scheduled late enough to be in this event time frame, and staff were instructed to skip this call.

Completion of the first home visit (which was the initial study event after the child's birth) was

associated with increased engagement in study activities through the first 2 years of observation (Table 6). Among those who completed the first home visit, only 8.9% of the future events were missed. If the first home visit was missed, 46.1% of subsequent visits were missed ($p < 0.0001$). Furthermore, of the mothers who missed the first home visit, 38.5% were later deactivated. Among those who completed the first home visit, only 4.5% were deactivated from age 0 to 24 months ($p < 0.0001$). Those who completed the 12-month clinic visit were also more likely to complete subsequent visits than those who missed this clinic visit.

The mother's age at enrollment was related to study continuation but not missed visits; 22.7% of

Table 4 Reasons for deactivations in the first 2 years

Reason	Number	Percentage of deactivations
Lost contact with family	26	39
Consent withdrawn	17	25
Other (custody issues, incarcerations)	12	18
Family moved from area	8	12
Medical reasons	4	6
Total	67	100

Table 5 Percent of missed events by type of event in the first 2 years of study

Event	Events completed	Events missed	Percent missed (%)
12-month clinic visit	466	90	16.2
24-month clinic visit	460	81	15.0
First home visit (at 3 months)	491	106	17.8
Home evaluation-year one	340	120	26.1
6-month call	502	81	13.9
9-month call	488	85	14.8
15-month call	433	121	21.8
18-month call	474	74	13.5
21-month call	482	62	11.4

Table 3 Deactivation rate through two years of study

Age (months)	Number active at the beginning of interval ^a	Number deactivated in the interval	Percentage deactivated in the interval	Cumulative deactivation rate (%)
0-12	609	40	6.6	6.6
13-24	569	27	4.4	11.0

^aChildren are censored if they have not reached the end of the interval and are still active.

Table 6 Deactivations and missed visits in the first 2 years of study by maternal characteristics

Maternal characteristic	N ^a	Percent deactivated (%)	Chi-squared <i>p</i> -value ^b	Percent of quarterly events missed (%)	ANOVA <i>p</i> -value ^b
First home visit completed	489	4.5	<0.0001	8.9	<0.0001
First home visit missed	117	38.5		46.1	
12-month clinic visit completed	466			10.0 ^c	<0.0001
12-month clinic visit missed	90			51.7 ^c	
Before cell phone reimbursements ^d	1825			16.2	0.65
After cell phone reimbursements	977			17.1	
Mother under 18 years of age	44	22.7	0.02	16.7	0.63
Mother 18 years and over	562	10.1		14.9	
Less than high school education	245	11.8	0.36	16.6	0.11
High school or GED	206	8.7		13.7	
More than high school	148	10.1		12.8	
No previous children	237	11.0	0.92	14.9	0.83
One previous child	166	11.4		14.8	
Two or more previous children	203	10.8		15.4	
Married	80	6.2	0.16	8.8	0.01
Unmarried	519	11.0		15.6	
Household income ≤ \$15,000/year	388	9.3	0.29	13.5	0.99
Household income > \$15,000/year	178	6.2		13.4	
Child in daycare at 3 months	64	10.9	0.05	9.5	0.79
Child not in daycare at 3 months	419	3.6		9.0	
EPDS (depression) score ≥ 12	163	8.0	0.46	14.3	0.81
EPDS (depression) score < 12	435	11.0		14.8	
Low perceived stress (0–4)	250	10.0	0.95	16.1	0.10
Medium perceived stress (5–8)	231	10.0		14.4	
High perceived stress (9–16)	117	11.1		12.0	
Low stressful events (0–2)	216	10.6	0.29	12.6	0.52
Medium stressful events (3–5)	218	12.4		17.1	
High stressful events (6+)	157	7.0		14.1	

EPDS, Edinburgh Postnatal Depression Scale.

^aN does not always add to 606 because of sporadic missing data.

^bTest for trend for all three-level variables. All analyses control for study center.

^cOf visits beyond 1 year.

^dN represents number of events rather than mothers.

mothers under 18 were deactivated, compared to only 10.1% of mothers over 18 years of age ($p=0.02$). However, young mothers who continued with the study did not miss more visits than older mothers. Deactivations were also more common when the child had entered daycare by 3 months of age compared with children who were not in daycare by 3 months of age (10.9% vs. 3.6%; $p=0.05$). Women who were married missed fewer events than those not married (8.8% vs. 15.6%; $p=0.01$).

Mothers with high perceived stress missed somewhat fewer visits than those with lower reported stress (12.0% vs. 16.1%; $p=0.10$). Significant depression as measured by the Edinburgh Postnatal Depression Scale [6], external stressful life events, education, income, and parity were not related to missed events or deactivations.

In a multivariate analysis of covariance including all of the variables from Table 6, study site

($F=2.98$, $p<0.03$), completing the first home visit ($F=210.0$, $p<0.0001$), and marital status ($F=5.85$, $p=0.02$) remained the significant predictors of study visit completion.

Discussion

Recruitment of birth cohort studies is challenging, especially in urban locations where connections with medical systems are not well established. Once recruitment is finished, retention is critical for the success of the study. This study evaluated factors that affected or predicted subject retention in urban environments.

One of the primary challenges with retention in URECA emerged from the high mobility of the mother. As discussed earlier, over half of the mothers in three of the sites had moved.

In New York, since only 27% of the mothers had moved, it is possible that the rent control laws contributed to the lower percentage.

Even when the participants do not move, they frequently have their phone service disconnected or change cell phone numbers, and thus become difficult to contact. For recruitment in a diabetes research study, 34% of the 53 individuals who were referred could not be contacted by telephone; several could not be contacted because of disconnected or inaccurate numbers [7]. Cell phones are now commonly used, but their use presents new challenges for research studies. Participants may be reluctant to use their cell phones for study interviews if they do not have a plan with unlimited minutes. In a longitudinal study involving adolescent mothers and their babies, frequent cell phone usage by the mothers presented additional challenges. Many mothers changed carriers frequently, and cell phone numbers could not be searched on the Internet or obtained from directory assistance. Also, mothers frequently did not answer when they did not recognize the incoming phone number [8]. The URECA study attempted to address these challenges by collecting multiple phone numbers and names of alternate contacts. Senturia et al. [3] showed that the participation in study activities was positively correlated with the number of contacts that were provided. Researchers for an HIV/STD Prevention Trial in Peru reported that successful retention is thought to involve, above all else, the collection of as much locator information as possible [9].

The data management system and reports used in the URECA study have been extremely useful to facilitate tracking efforts. Event windows are tracked with the Upcoming Events Report, so that the increased attempts to schedule participants can occur, as needed, before windows end. The Missed Events Report helps site teams keep track of 'difficult to schedule' events, as well as participants who are not keeping their appointments. The Participant Retention Report shows the mothers who require extra encouragement for participation and the events they have missed.

In the URECA study, the mother's early study performance was the best predictor of future involvement. When a study is explained to the potential participant and before the consent is signed, the study staff could emphasize the necessity of consistently completing study events throughout the study. As part of the informed consent process at the site with the highest retention rate, a staff member reviewed the consent with the mother, after which the site coordinator summarized the study components and emphasized the importance of long-term commitment to the study. This site has had very few deactivations, perhaps

because the participants fully understood what was expected of them. In a longitudinal sickle cell research study report, the researchers discussed the need for full disclosure about all aspects of the study, including participant burden [10].

In addition, since early participation is a strong predictor of continuation, site coordinators could carefully evaluate study subjects who miss the initial study events. If, after several attempts, a participant does not complete the initial events, staff could discuss with the participant his/her intent to continue the study. If recruitment is occurring over time, staff could consider over-recruiting to compensate for potential deactivations. Communicating clear expectations to the participants and early recognition of sporadic participation are critical from the onset. Frank et al. [11] in a literature review regarding adherence, found that a participant's initial response to questionnaires indicated whether or not he/she will become a 'participant-adherer.'

At any given time, each URECA site has 10–20 mothers that are challenging to contact; however, these mothers change throughout the course of the study, depending more on life events and personal circumstances than on general sociodemographic characteristics. Sensitivity and flexibility of staff members facilitate continued participation of these mothers. A normal work week entails numerous phone calls to the mothers to schedule events and reschedule the cancelled or 'no-show' clinic visits. Gilliss et al. [12] also reported the need for staff flexibility because of forgotten appointments or rescheduling requirements, as well as staff continuity with participants, in their longitudinal study with healthy minority women. Differences in the retention rates among URECA sites occurred; we can look at the number and type of site staff, but intangible measures were present. The staff must have time for contacting and maintaining relationships with the participants.

Many URECA mothers are living under adverse conditions, and there are a number of stressors related to household economics, housing, family neighborhood violence, and/or other sources. (As shown in Table 2, only 13.4% are married, 68.5% have a household income less than \$15,000, and 60.4% have lived at their current address for 2 years or less.) In URECA, the deactivation of mothers less than 18 years of age is significant; these young mothers may have fewer organizational skills for dealing with the challenges of parenthood. Skilled staff members have been crucial for engaging the remaining younger mothers in study activities. Notably, women with higher perceived stress more reliably attended study events than women who perceived less stress. Perhaps the URECA staff served as a support mechanism for these women

in need. An analysis based on data collected as part of the Pediatric AIDS Clinical Trials Group (PACTG 219C) cohort study found that the occurrence of stressful events was associated with improved retention, especially when a death of a family member occurred or the family experienced financial instability. However, when the child started school or the mother began working, decreased retention resulted [13]. A participant's published statement in a sickle cell research study stated that: 'Things seemed to get better with continued support and the availability of [research staff] at the drop of the hat. That availability gave me the urge to continue and work with everyone' [10]. In addition, researchers for two diabetic studies learned that culturally competent approaches and caring, trusting relationships were important for the retention of their African-American participants [7].

It is important, however, for the site staff of observational studies to monitor their involvement with study participants so that outcomes are not affected. The staff must be aware of the difference between providing direct patient care and performing research data collection. Study staff need to have the ability to facilitate comfortable communication with the participants. Questionnaires may ask for personal information; staff must be sensitive, appropriately responsive, and comfortable probing for information. The Study of Children's Activity and Nutrition (SCAN) researchers think that successful retention of their cohort was partially due to direct attention to the uniqueness of each family [11]. Researchers for a sickle cell longitudinal study also found that the relationships over time, consisting of regular communication and caring concern, built strong connections between the staff and the participants [10].

Retention events provided opportunities for all staff members, including the site investigators, to interact with the mothers in a relaxed atmosphere. Continued monitoring of involvement and subsequent effects on overall study participation will occur. In a 5-year multicenter study of pediatric complications of vertically transmitted HIV, holiday parties helped foster staff and family relationships in a nonmedical context and were considered worthwhile retention strategies [14].

Studies have shown that cooperation rates regarding sensitive issues are enhanced when the interviewer and participant are of the same race and gender. Moorman [15] reports that, in a long-term breast cancer study, cooperation rates were higher when the interviewer and participant were concordant for race. Communication regarding substance use among the homeless was also reported to be least inhibited between respondents and

interviewers when they were of the same race and gender [16].

If an interviewer can speak the individual's language, but is not familiar with his/her culture, the questions or answers may not be fully understood. For example, in URECA, when Hispanic staff are administering questionnaires to Hispanic mothers, the staff can more effectively clarify when questions are misunderstood by the mothers, as well as understand the differences in vocabulary from various Hispanic areas. Also, the participants may report information differently or discontinue study activities if they feel that they may be judged by the interviewer. The ability to understand and honor cultural differences of participants is crucial for successful retention [10]. To address these concerns, whenever possible, the URECA sites have hired study staff from the community in which the research participants live. In a community-based research study with African Americans [7], the researchers found that the group using the culturally competent diabetic intervention had 78% retention, while the usual-care group had 56% retention; the researchers reemphasized the importance of cultural competence for recruitment and retention. In a community-based environmental randomized trial, the researchers found that, because the field staff lived in or had previous work experience in the community, neighbors were willing to provide information about their missing participants [17].

Research participants should be compensated punctually for study activities. Timely payment of promised reimbursements was shown to improve retention in a nutrition/physical activity trial in 2005 [18]. If reimbursements are delayed, participants may become disinterested in study continuation. A study by Stevens-Simon et al. [19] showed that 58% of participants who were offered a monetary incentive joined, while only 9% participated who were not offered the incentive. Research institutions typically reimburse study participants with checks. However, in the URECA population, many mothers do not have a checking account or a drivers license, which makes cashing a check either costly or, in some cases, not possible. Flexibility regarding the mode of reimbursement is important in this study population and perhaps contributed to study subject retention.

Strengths of this study include the longitudinal study design which enables the staff to have repeated contact with mothers, funding for separate retention activities, activities in the mothers' homes as well as the study center, and an emphasis on cultural sensitivity. URECA study activities are closely monitored to ensure that events are not overlooked and to identify problems early. Reports are generated weekly by the web-based data

management system so the sponsoring agency, site teams, administrative center, and coordinating center can track recruitment information (including reasons for ineligibility), enrollment status (with the deactivation reasons), and completion status of all study events in a timely manner.

One limitation of the study is that the URECA population is predominantly minority, thus we may not be able to observe the effects that might exist in a more diverse population. For example, 519 of the 606 mothers are unmarried, which could accentuate some factors while minimizing others.

Conclusions

The URECA study had a solid retention rate (89%) through the first 2 years of study participation, despite working with a challenging population. This is partly a result of the monitoring systems that have been developed, but we feel it is mostly due to the efforts of the site research staff in establishing positive relationships with the study participants. Notably, we were surprised to find that highly stressed women were somewhat more likely to remain in the study, and this suggests that study staff can form mutually beneficial relationships with the mothers.

When preparing a longitudinal observational study, it is important to recognize that no single strategy will result in continuous participant involvement. A variety of methods relevant to the specific phase of the study and tailored to the participant's circumstances should be utilized. Each participant's engagement in initial study events should be carefully evaluated since it may predict future participation. Timely and appropriate reimbursements, positive rapport between the staff and the participants, and convenient scheduling and administration of study events are also necessary to engage and retain families.

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