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Reconnecting with urban youth enrolled in a randomized controlled trial and overdue for a 12-month follow-up survey

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Abstract

Background—Retention of study participants in randomized controlled trials (RCTs) is crucial to study validity.

Purpose—We analyzed the result of four retention strategies used to reconnect with urban teens enrolled in a school-based randomized controlled trial (RCT) and overdue for a 12-month follow-up survey.

Methods—Traditional retention strategies used to reconnect with teens categorized as “unable to contact” were weekly re-dials of non-working telephone numbers and mailings to the student’s home. Non-traditional retention strategies were obtaining assistance from school administration and communication through Facebook.

Results—Of the 422 students enrolled, 125 (29.5%) were overdue for a 12-month follow-up survey, but had no working telephone number (unable to contact). We made 196 attempts to contact these 125 students, of which 82 attempts (41.8%) were successful in “reconnecting,” defined as (1) a student contacting research staff as a result of a mailed notice; (2) a research staff member leaving a voicemail at a previously disconnected telephone number; (3) a student responding to Facebook outreach; or (4) research staff obtaining a new telephone number and talking to a person at the new telephone number. We used “mailed reminder letters” as the referent category, in our analysis. Odds ratios (95% confidence intervals) for the association between the strategy used and success (“reconnecting”) for telephone number re-dials, Facebook, and school administration assistance were 4.60 (1.8–11.8), 1.94 (1.01–3.73), and 2.91 (0.58–14.50), respectively.

Limitations—Retention strategies were not applied hierarchically or systematically across students, and we were unable to ascertain student preference for a particular strategy. In addition, our findings may be applicable only to study populations with characteristics similar to those of students included in this study.

Conclusion—Overall, of the 422 students who enrolled in the study, 380 (90%), ultimately completed the 12-month follow-up survey. A mix of traditional retention strategies, such as telephone number re-dials, and more contemporary methods, such as use of Facebook, were effective in reconnecting with urban teenagers enrolled in a school-based RCT, and controlling attrition during the 12-month follow-up survey period.

Keywords

Retention; adherence; attrition; urban teens; students; asthma management; intervention; randomized controlled trial; Facebook; social networking

INTRODUCTION

Retention of study participants in randomized controlled trials (RCTs) is crucial to preserving study validity.¹ Investigators seeking to follow study participants over time to monitor response to an intervention must rely on continuing participation and retention throughout all phases of the RCT, including follow-up data collection, to achieve the statistical power needed to estimate treatment effects.² Historically, racial and ethnic minorities such as African Americans and Hispanics have shown lower rates of participation and retention in longitudinal research studies than their Caucasian counterparts.^{2–4} Hypothesized reasons for the lower levels of engagement of racial and ethnic minorities and other disenfranchised or “at risk” groups in longitudinal research studies include mistrust of research, concerns about privacy or confidentiality of health information, and other reasons potentially related to socioeconomic status, such as competing everyday priorities and residential mobility.^{3–6}

Several reports in the literature can inform the choice of retention strategies, such as mailed reminders or retrying disconnected telephone numbers. Mailed reminder letters, for example, are reportedly less successful in reaching low-income households compared to higher income households, perhaps due to greater housing transience and multiple address changes in the former group.^{7, 8} Furthermore, intermittent telephone service has been documented in low-income populations.^{8, 9}

Less traditional retention strategies described in the literature include locating and contacting study participants using outreach on the social networking site Facebook, which has been explored for recruitment or retention purposes by several investigators.^{10–12} Recent estimates from the Pew Research Center indicate that usage of some mainstream social networking sites among non-Hispanic Black youth and Hispanic youth and individuals with lower household incomes may be higher than it is among non-Hispanic White youth and individuals with higher household incomes.^{13,14} Many of the most popular social networking sites, such as Facebook, Twitter and Instagram, are accessible both via Internet-connected computers as well as on many less costly mobile phones,¹³ expanding the means by which users can be engaged for research purposes. In one recent study, research staff were able to locate and contact 78 of 175 participants (44.6%) by using Facebook as an outreach tool.¹⁰

Our purpose is to report on attempts to reconnect with urban adolescents participating in an RCT to evaluate an online asthma management program. To date, few researchers have reported on retention strategies used to retain or contact urban youth enrolled in RCTs. Reconnecting with a participant may or may not result in completion of follow-up surveys or other assessments; however, without reconnecting, the probability of completion is markedly reduced. We compared four strategies applied to study participants found to have non-working telephone numbers at the time they were overdue for their 12-month follow-up survey. We also examined the characteristics of study participants who actually completed the 12-month follow up-survey.

METHODS

Overview of Puff City Trial

Puff City¹⁵ is a web-based program developed by researchers at the Henry Ford Health System (HFHS), in conjunction with the Center for Health Communications Research (CHCR) at the University of Michigan, and the Georgia Health Sciences University. The goal of the collaboration was to create an online educational tool that combined health education theories with motivational interviewing techniques in the form of tailored responses to help urban teens better understand and manage their asthma. The research study and protocol were approved by the participating school districts' Office of Research, Evaluation, and Assessment and the institutional review boards of HFHS, the University of Michigan, and the Georgia Health Sciences University.

Students eligible for the randomized trial were identified using a case-identification process described elsewhere.^{15, 16} Briefly, letters announcing a lung health questionnaire to be administered during English class were mailed to the homes of students in grades 9 through 12 attending one of six participating Detroit public high schools. Parents could opt-out of having their child complete the questionnaire by returning the letter or notifying the school. Students whose parents did not refuse participation were prompted to complete the questionnaire during a scheduled English class. The questionnaire asked about asthma diagnoses and respiratory symptoms. To be eligible for the RCT, participants had to report current symptoms of asthma, with or without a physician's diagnosis.¹⁶ Informational packets containing consent forms were mailed to the homes of eligible students. To participate in the RCT, written parental consent and written student assent were required.

The Puff City program software, as evaluated in the RCT, comprised a tailored component, a generic component, and an online data collection component (6- and 12-month survey). The objective of the RCT was to compare asthma outcomes of students exposed to tailored asthma management versus those exposed to generic asthma management. After completing a baseline survey, students randomized to the treatment group received the tailored, web-based asthma management component. Students randomized to the control group were provided with existing generic, web-based asthma management websites and resources. All students (treatment and control) received four online computer sessions at least one week apart, a 6-month follow-up survey, and a 12-month follow-up survey. Students were allowed to access the Puff City website and program using school computers.

Retention Efforts

Students were compensated incrementally for participation in the RCT, with the possibility of receiving a total of \$80 for completion of all program modules and surveys (\$20 for the baseline survey; \$10 upon completion of program module #2; \$20 upon completion of program module #4; \$10 for the 6-month follow-up survey; and \$20 for the 12-month follow-up survey). Students also could receive small gift cards by participating in contests.¹⁷ Students were not required to have an Internet-connected computer at home to participate in the study (since they were allowed to access the program modules using school computers). During Summer months and days when school was not in session, students who required transportation to access an Internet-connected computer at a library or relative's home were offered public transportation passes to cover round-trip travel expenses to and from the student's home.^{17, 18}

Students could withdraw from the study at any time. To withdraw from the study, students or their caregivers needed only to express a desire to discontinue participation and/or request that calls from research staff be discontinued. All participant withdrawals from the study were documented in a tracking database, along with the date of withdrawal; these students subsequently were excluded from any further retention activities.

All data for consenting/assenting students were entered into a tracking database which generated retention reports. Our analysis focuses on those students who were found to have non-working telephone numbers (i.e., telephone services that were disconnected or no longer in service) at the time they were overdue for their 12-month follow-up survey. Our analysis focuses on participants categorized as "unable to contact" or whom we could not locate because the telephone number on file was not working.

Reconnection Strategies

We used one or more of four different strategies to connect with these students. The first two retention strategies (mailed reminders and retrying a non-working telephone number) were selected because they are used traditionally in research studies¹⁹ and represent the methods by which teenagers commonly communicate with each other and with adults.^{20, 21} The third and fourth retention strategies (social media and school staff assistance) were selected based on the current mode of communication known to be widely used among urban youth today²⁰ and on our relationship with the schools. Research staff was encouraged to try each of the four retention strategies and to record the date and time of each attempted contact. No minimum or maximum number of attempts was established to ensure that study staff would be more active and creative in their engagement efforts. One or more strategies, each used one or more times, may have been employed to attempt contact with a student. Some strategies may not have been attempted for some students.

The four retention strategies applied to students categorized as "unable to contact" are described below:

1. *Mailing a reminder letter to the home:* A colorful reminder letter addressed to the student was mailed to the student's home address indicating that Puff City study

staff were trying to make contact. The letter provided the participant with research staff contact information.

2. *Re-dialing the non-working telephone number:* Non-working telephone numbers were re-dialed on a weekly basis.
3. *Performing outreach on Facebook:* Research staff created a study-specific Puff City page on the Facebook website (<http://www.facebook.com>) and used the network's user directory to search for the student by first and last name. Once name matches were found, other data from existing study files for the student were referenced to ensure that the correct participant had been located. Whenever identities were confirmed, staff initiated a "Friend Request" with the student and, upon the student's acceptance, reminded the student about the overdue 12-month follow-up survey.
4. *Obtaining assistance from school administration:* Each participating school identified a school staff person to act as liaison between the study and the school. Liaisons were counselors, administrative staff, or nurses. Liaisons assisted research staff in contacting consenting participants with whom we had lost touch or who had left the school. In the latter situation, the staff person contacted the student and asked that the student contact Puff City staff.

Utilization of the four retention strategies began in December 2008.

Data Analysis

Results of each of the above strategies were coded as either a "success" or "failure." A success was defined as "reconnecting" with the student, and included 1) a student contacting research staff as a result of a mailed notice; (2) a research staff member leaving a voice-mail at a previously disconnected telephone number; (3) a student responding to Facebook outreach; or (4) research staff obtaining a new telephone number from updated school records or alternate contact person provided on consent forms and talking to a person at the new telephone number. A "failure" was assigned when no new/working telephone number was obtained for the student or the student did not otherwise initiate contact with staff. All responses to reconnection attempts were tracked and were dated and counted separately.

The four retention strategies used were evaluated for all of the students who were overdue for completion of the 12-month follow-up survey and categorized as "unable to contact." Each retention attempt and the result was dated and recorded in the tracking database. For each student, we counted whether or not the attempted strategy was successful. In general, strategies were attempted one at a time. Because students could be categorized as "unable to contact" multiple times during the study period, it was possible for students to be contacted by more than one strategy. For this analysis, multiple responses to one strategy were counted as one success for that strategy; e.g., whenever a student responded twice to a Facebook request, the two responses counted as one success for Facebook for that student.

Logistic regression models were used to describe the association between participant characteristics and completion of the 12-month follow-up survey. The odds ratio and its associated 95% confidence interval (CI) were estimated for each of the following

characteristics collected via self-report during the baseline or follow-up survey: student's age, gender, smoking status, and physician diagnosis of asthma. Classification of asthma "severity" was accomplished using self-report of nighttime and daytime symptom frequency, health care utilization for asthma symptoms, medication use for symptoms, and activity restriction due to symptoms according to *Expert Panel 3: Guidelines for Diagnosis and Treatment of Asthma*.^{22, 23} Other characteristics analyzed included student's Medicaid status, home computer ownership, mother's level of education, and mother's report of household income.

When comparing reconnection strategies, we used a "mailed reminder letter" as the reference category, as this strategy was considered a relatively traditional method of retention¹³ (does not require participant having a telephone or computer) and a relatively passive one (does not require verbal contact with participant). Total time spent in tracking was calculated as the number of days between the first and last attempted telephone calls or between the first attempt and date of the 12-month follow-up survey completion. Successes per student were tabulated for all four methods. In addition, a generalized estimating equations (GEE) approach to logistic regression²⁴ was used to predict the proportion of successful contacts per student for each strategy. The GEE method was employed because any student could have from one to four successes/failures, depending on how many strategies were attempted for that student. The odds ratio and corresponding 95% confidence interval (CI) were calculated to evaluate the potential association between each strategy and "success." A linear logistic regression model was used to predict success in obtaining a working telephone number using Facebook. The odds ratio and its associated 95% CI were estimated for each covariate.

In general, confidence intervals that did not include 1.0 were considered to indicate statistically significant associations. SAS V9.2 (Release 2, Cary, NC, USA) was utilized for all analyses.

RESULTS

Participant Characteristics

Of the 7878 students surveyed in the six participating high schools, 1668 reported experiencing asthma symptoms (with or without a physician diagnosis) and were eligible to participate in the RCT. Among the 1668 students who were eligible, 422 (25.3%) subsequently enrolled in the RCT. Of the 422 participating students, 59.7% were girls, and the mean age among all participants was 15.9 years (s.d. $\pm$ 1.2). Of the 422 students enrolled, 2 had missing data on race and 379/420 (90.2%), self-identified as Black.

12-month Follow-up Survey Completion

Among the 380 students who ultimately completed a 12-month follow-up survey, 233 (83.1%) completed the 12-month follow-up survey within 30 days of the due date. None of the covariates of interest, including participant gender, physician diagnosis of asthma, asthma severity, household income, or mother's level of education, was associated with completion of the 12-month follow-up survey (Table 1). Computer ownership, which

showed some variability across schools, was not related to completion of the 12-month follow-up survey.

Attempting to Reconnect

The four retention strategies were applied to a total of 125 participants who were overdue for the 12-month follow-up survey and had been categorized as “unable to contact.” These 125 participants were tracked for a mean of 98.0 (± 107.0) days. Across the four retention strategies, 196 total attempts were made to “reconnect” to the 125 students in order to notify them of the overdue 12-month follow-up survey (Table 2). Of the 196 attempts, 82 (41.8%) were successful in reconnecting (unweighted total). These 82 successful reconnections represented 21.6% of all 380 students who eventually completed the 12-month follow-up survey.

Using as the reference category “mailed reminder letter,” which was successful in 31.8% of attempts at reconnecting, re-dialing the non-working telephone number and outreach on Facebook succeeded in 67.9% and 47.1% of attempts, respectively, and were statistically significantly related to “success” in reconnection (Table 2). Obtaining assistance from school administration was successful in 57.1% of 7 attempts at reconnecting. Additional information was available for 26 (92.3%) of the 28 students whom we attempted to contact by telephone. Of these 26 students with whom we reconnected by telephone or another strategy, over the course of the follow-up period, the average number of re-dials that did not reach a working telephone number was 2.85 per student. A mean of 3.95 ± 4.37 telephone calls were needed (range= 1 to 18) to reconnect with the 26 students by telephone.

We further explored the association of student characteristics listed in Table 1 with response to our Facebook outreach efforts. None of the characteristics was associated with reconnection via Facebook (data not shown). The small number of Facebook respondents and non-respondents precluded meaningful use of multiple variable logistic regression models to characterize respondents to Facebook outreach.

DISCUSSION

Of the four retention strategies employed in our trial, re-dialing non-working telephone numbers on a weekly basis was the most successful strategy, based on the number of reconnections per attempt, in reconnecting with trial participants whose 12-month survey was overdue. This particular strategy resulted in “success” in 67.9% of 28 attempts. Thus, even in this era of social media, telephones remained an important source of communication for our teenage participants.

Although completion of the 12-month follow-up was not the outcome targeted by this analysis, we note that in this study population of urban teenagers, completion of the 12-month survey was not influenced by demographic, socioeconomic, or asthma characteristics, collected by self-report. This finding suggests that students’ ongoing participation and completion of the study components may have been influenced by intrinsic factors, such as finding the intervention informative or enjoyable, altruistic reasons for participating, or extrinsic factors, such as financial incentives.^{25, 26}

Based on frequency alone, telephone number re-dials were more likely to lead to success; given that urban students frequently had disconnected telephones, we believe re-dialing earlier non-working telephone numbers at least weekly was a low-cost method of reconnecting with participants. The average number of days spent tracking the students included in this analysis was approximately 98 days, or a little over three months. Telephone numbers were found to be restored usually after fewer than 5 re-dialing attempts. A mean of nearly three telephone number re-dials were required to reconnect, similar to the number reported by others.^{27–29}

In our analysis, outreach on Facebook was effective in providing a simple and low cost method of locating some students. In our study, 47.1% of 51 outreach attempts on Facebook resulted in reconnecting with enrolled participants, a finding similar to that reported by others.^{11, 12} For urban youth in particular, there is often a concern about access to computer and Internet resources.^{30, 31} As reported previously, social networking may be more common among African American and Hispanic youth than among Caucasian youth.^{13,14}

Finally, obtaining school administrator assistance proved to be a useful strategy in 57.1% of 7 attempts to acquire a working telephone number for the student. School personnel are a valuable connection for investigators working in schools, but this resource should not be misused. Students initially were contacted by school staff who asked them to contact Puff City staff. To our knowledge, ours is the first study to publish results on the use of school administration as a research participant retention strategy. The limitation to generalizability of our success using this strategy is the small number of students to whom this strategy was applied.

Our analysis has other limitations. Our approach to the analysis was to count the number of attempts for each strategy and for each student. Moreover, while we are able to determine which strategy resulted in a successful contact with the student, we are unable to determine whether there was a student preference for a particular strategy, because several strategies may have been used per student. Finally, because the trial and our analysis were conducted among a relatively homogeneous group of Black teenagers from low-income households, findings may not be applicable to other study populations. The relatively low attrition in this trial resulted in a small number of students on which to base our analyses of strategies for reconnecting, further limiting generalizability.

SUMMARY AND CONCLUSION

We reconnected with 82 (66%) of 125 high school students enrolled in an RCT of an asthma management program for urban teenagers with asthma who had overdue 12-month follow-up surveys by using several strategies in order to achieve a 90% 12-month retention among 422 participants, despite the tendency for this population to be highly mobile.^{4–6} Beyond the financial incentives, routine reminders and services offered in this study,^{20, 29} other strategies were needed to contact students and control attrition. Weekly re-dialing of earlier non-working telephone numbers was the most successful strategy for reconnecting with students categorized initially as “unable to contact;” outreach on Facebook and assistance from school administration personnel were found to be useful tools in this population.

Several methods may be necessary for optimal retention,^{19, 32} but social networking, due to its relative accessibility, broad reach and integration into the daily lives of many youth, warrants consideration as an approach to engaging and retaining youth in longitudinal research. Retention strategies must be evaluated periodically as social and cultural trends evolve.

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Table 1

Characteristics of students who completed or did not complete the 12-month follow-up survey for a randomized trial of an asthma management program (Puff City) and associations with survey completion (N=422)

	Not Completed (n=42, 10.0%)	Completed (n=380, 90.0%)	OR (95%CI)¹
Mean Age in Years (sd)	15.7 ± 1.1	15.9 ± 1.2	0.87 (0.66 – 1.15) ²
Gender, n (%)			
Boys	21 (50.0)	149 (39.2)	0.64 (0.34 – 1.22)
Girls	21 (50.0)	231 (60.8)	
Race, n (%)			
Black	39 (92.9)	340 (89.9)	0.69 (0.20 – 2.34)
Other	3 (7.1)	38 (10.1)	
Household Income			
<\$40,000	23 (88.5)	268 (85.4)	0.76 (0.22, 2.64)
\$40,000	3 (11.5)	46 (14.6)	
Mother's education, n (%)			
<High school grad	6 (17.6)	59 (17.8)	reference
High school grad	16 (47.1)	107 (32.2)	1.47 (0.55 – 3.96)
>High school grad	12 (35.3)	166 (50.0)	0.71 (0.26 – 1.98)
Medicaid, n (%)			
Yes	23 (54.8)	200 (53.1)	0.93 (0.49 – 1.69)
No	19 (45.2)	177 (46.9)	
Physician diagnosis of asthma, n (%)			
Yes	33 (78.6)	300 (81.7)	1.21 (0.56 – 2.70)
No	9 (21.4)	67 (18.3)	
Asthma severity ³ , n (%)			
Mild intermittent/persistent	33 (78.6)	285 (75.0)	0.82 (0.38 – 1.77)
Moderate/severe	9 (21.4)	95 (25.0)	
Teen Smoked, n (%)			
Yes	4 (9.8)	31 (8.2)	0.82 (0.28 – 2.43)
No	37 (90.2)	347 (91.8)	
Computer at home (6 month), n (%)			
Yes	15 (88.3)	258 (76.3)	0.65 (0.18 – 2.29)
No	3 (16.7)	80 (24.7)	

¹ Odds ratio and 95% Confidence interval

² OR for every year increase in age

³ Based on symptom frequency and classification of asthma severity and cut-offs adapted from "Figure 14. Classification of Asthma Severity (> 12 years of age)", using nighttime symptoms from Expert Panel 3: Guidelines for Diagnosis and Treatment of Asthma

Strategies used to reconnect with urban youth enrolled in a randomized trial of an asthma management program and having a non-working telephone number as of December 2008 (N=125/)

Table 2

Strategy	Total Attempts	Failed Reconnection	Successful Reconnection	OR (95% CI) ²
		n	n (%)	
Letter mailed to home	110	75	35 (31.8)	reference
Facebook	51	27	24 (47.1)	1.94 (1.01–3.73)
Retry “bad” telephone number	28	9	19 (67.9)	4.60 (1.8–11.81)
School admin assistance	7	3	4 (57.1)	2.91 (0.58–14.50)
Unweighted total	196	114	82 (48.8)	

¹ One or more strategies, each used one or more times, may have been employed to attempt contact with a student. Some strategies may not have been attempted for some students.

² Odds ratio (OR) and 95% Confidence Interval (CI)