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Randomized Study of Survey Recruitment Strategies for Parents of Autistic Children

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Abstract

Introduction: This study aimed to compare phone, email, or text message recruitment strategies for engaging parents of autistic children in an online survey.

Method: In this randomized study, a sample of 1,624 parents of autistic children spectrum disorder (autism) from an integrated health system in Southern California were sent an initial mailed letter and email simultaneously for baseline survey outreach. Then, participants were randomly assigned to one of three follow-up recruitment groups: phone, email, or text message. We compared the efficacy of recruitment strategies in multivariate models.

Results: All three follow-up methods were equally effective for eliciting a survey response. Parents of girls were less likely to respond to survey outreach attempts than parents of boys.

Discussion: Multiple modalities of survey recruitment, including digital and mobile approaches, effectively recruit parents of children in research.

Keywords

Survey; autism spectrum disorder; Internet research; recruitment

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SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.pedhc.2022.05.008>.

INTRODUCTION

Recruiting families of children diagnosed with autism spectrum disorder (autism) to participate in research can be challenging. Assumptions about autistic people (e.g., communication differences, social function, disability status) can lead to overt exclusion from some types of studies, whereas other exclusions may occur because of stigma (Cascio, Weiss, & Racine, 2021; Russell et al., 2019). General negative attitudes toward intellectual disabilities and autism may lead to reluctance for parents of autistic children and autistic people to identify themselves for research participation (Thompson & Phillips, 2007). Some studies suggest that parents of autistic children may be uniquely motivated to participate in genetic research on autism but not necessarily other types of autism research. Involvement in genetic research may be used by parents to alleviate guilt, contribute to improved knowledge and awareness of autism, family planning, and hope for scientific advancements in diagnosing and treating autism (Fletcher-Watson et al., 2017; Trottier et al., 2013).

In autism research, there is limited understanding of evidence-based strategies for increasing the participation of parents of autistic children in survey research. Recruitment of racial/ethnic minorities and girls in autism research is a particularly high priority for methodologic studies, given their longstanding underrepresentation in autism research and evidence for disparities in real-world autism service delivery (Eilenberg, Paff, Harrison, & Long, 2019; Imm, White, & Durkin, 2019; Karpur, Lello, Frazier, Dixon, & Shih, 2019; Shefcyk, 2015; Zamora, Williams, Higareda, Wheeler, & Levitt, 2016). One recent survey of parents of autistic children found generally favorable attitudes about participation in research, with some demographic variability in preferences for survey participation modalities (Becerra et al., 2017). Most families in the survey indicated that they wanted to be contacted for research via email (70%) and that they wanted to participate in research via the Web (83%), but among Hispanic parents, 75% of parents preferred to be contacted by telephone (Becerra et al., 2017). Other studies of online survey participation in autism research have found lower odds of response among non-White parents, parents with lower educational attainment, single-parent households, and parents with more than one autistic child (Kalb, Cohen, Lehmann, & Law, 2012). Participation in survey research is sometimes motivated by values and a desire to contribute to new knowledge but is also strongly influenced by the convenience of participation modalities (Haas et al., 2016). Optimal strategies for survey recruitment with this population are still unknown.

Given limited evidence on recruitment strategies for autism survey research and research participation preferences of diverse families, there is a need for a more systematic approach to determining effective research recruitment strategies. Identifying which contact methods work best for recruiting parents to participate in autism research may improve the representation and quality of research data and eventually improve and refine autism service delivery. This study aimed to compare the efficacy of phone, email, or text message recruitment strategies for engaging parents of autistic children in an online survey of coronavirus disease 2019 (COVID-19) and telehealth experiences. We hypothesized that text message recruitment would most effectively elicit survey responses.

METHODS

Participants and Setting

The study took place from May to July 2021 at an integrated health system in Southern California and was approved by the Institutional Review Board at the health system. A random sample of 2,000 children diagnosed with autism from a health system autism registry was selected. This sample reflected known gender differences in autism, in which more boys are diagnosed with autism than girls (boys: $n = 1,544/77.2\%$; girls: $n = 456/22.8\%$; Maenner et al., 2020). The registry was created using electronic medical records, outside claims, and clinician reports. Once the children were selected, they were linked to their parents' names, addresses, and contact information. Parents were eligible to participate in the survey if they had at least one child with a diagnosis of autism and at least one autism-related behavioral therapy referral (behavioral therapy, speech therapy, occupational therapy, physical therapy) in 2020, as the survey was intended to assess family experiences with therapy. Findings from the survey are reported elsewhere. This resulted in 1,624 parents who were eligible for random assignment. Parents were randomly assigned to one of three outreach methods using R software (version 4.1.2, R Core Team, 2020): email ($n = 474$), phone ($n = 520$), and text ($n = 630$). Three hundred and twenty-two unique parent—child dyads across all three recruitment groups responded to the survey following completion of the survey outreach protocol (20% response). Parents who responded to the survey for more than one autistic child ($n = 42$) were counted as unique respondents for a final analytic sample of 1,666.

Procedures

Once randomized, all parents were sent a baseline email and mailed letter simultaneously informing them of the study and the opportunity to participate in the Web-based survey. We used two methods of outreach at baseline because there is conflicting evidence about the efficacy of letter versus email contact for achieving survey response (Brtnikova et al., 2018; Kaplowitz, Hadlock, & Levine, 2004). After the baseline outreach, two follow-up recruitment attempts were made, including two emails, two text messages, or two phone calls, depending on randomization. For all three groups, the follow-up recruitment attempts involved reminding participants of the opportunity for study participation and informing them how to access the survey. The first follow-up was 1 week after the initial contact; the second and final recruitment attempt was 3 weeks after the initial contact.

Links to the survey were provided directly to participants in a text message and email follow-up contacts, and the baseline letter and email. Those randomized to phone follow-up were offered the opportunity to receive the link again via email or text after the phone call. If potential participants did not answer phone calls, voicemail messages were left asking for a callback.

All survey responses were recorded electronically via REDCap. A \$30 check was provided to parents who completed the survey as a participation incentive. All parents provided electronic informed consent to participate in the study. Parents who had more than one autistic child had the option to complete the survey for each child up to four children.

Outcomes

The primary outcome was overall survey response versus nonresponse for the three recruitment groups. We also examined the response time (baseline, follow-up).

Predictors

The primary predictor was randomized recruitment group assignment (email, phone, text). We also examined the following covariates: gender, age, ethnicity, and insurance type of the child. These data also came from the health system autism registry.

Analysis

Analyses were performed using R software. We descriptively compared survey responders versus nonresponders by demographics (age, ethnicity, gender, insurance type) within each recruitment group. Bivariate χ^2 tests were used to compare differences in response time by recruitment group (email, phone, text). A Kruskal—Wallis rank-sum test was used to test for the main effect of the recruitment group, followed by a multiple logistic regression model to estimate the likelihood of survey response from the recruitment group adjusted for demographic variables.

RESULTS

The overall sample was primarily parents of boys ($n = 1,284$; 76.2%) who were Hispanic ($n = 834$, 49.5%) and commercially insured ($n = 995$, 59%; Table 1). Demographic details of the sample within recruitment groups are shown in the Supplementary Table. In bivariate tests, phone recruitment resulted in the greatest survey completion during the follow-up period ($n = 57$ responders; 46.7%), compared with text message ($n = 43$ responders; 37.1%) and email ($n = 15$ responders; 17.6%; $p < .01$).

After adjusting for sociodemographic covariates, phone recruitment was no longer significantly different from text messages or email. There were no significant differences in survey response by recruitment group ($p = .07$) in the Kruskal—Wallis test or the multivariate model (Table 2). However, parents of girls had had lower odds of survey response compared with parents of boys (odds ratio = 0.68; 95% confidence interval, 0.50—0.92).

DISCUSSION

Using a randomized recruitment approach to a survey regarding COVID-19 and telehealth experience for parents of autistic children, we found that phone calls, text messages, and email were equally effective as follow-up methods for eliciting survey responses. We also found that parents of girls were less likely to respond to survey outreach attempts than parents of boys, leading to an underrepresentation of girls in the study. Digital and mobile survey recruitment methods may interest autism researchers as an alternative to potentially time-intensive phone calls or mailed letter survey recruitment.

Prior research with health care providers has found that mailing letters yield a higher survey response rate in comparison with email, but there is limited research about optimal

follow-up modalities for encouraging survey participation and no such research that we are aware of with parents of autistic children (Murphy et al., 2020). Our study suggests that multiple modalities of follow-up recruitment can be effective for follow-up recruitment in survey research. All three follow-up approaches included sharing the survey link digitally, which may explain the similarities in response rate across study groups. Although prior studies have suggested that Hispanic families prefer phone call participation in research, we did not identify significant differences in response by parent ethnicity when using phone calls, emails, or text messages in adjusted models (Becerra et al., 2017).

Strengths of this study include the geographically representative sample and the randomization design for follow-up methods for a survey response. Prior studies of autism have had a limited representation of racial/ethnic minority groups. However, our sample was representative of the demographic area sampled in Southern California, which included 50% Hispanic participants. The study is limited by an overall modest survey response rate. The survey was conducted from May 2021 through July 2021, which occurred during the ongoing COVID-19 pandemic. Studies suggest that parents of autistic children have been stressed and overwhelmed during the pandemic, which could lead to parents having less time and interest to participate in additional activities outside of the demands of their daily routine (Kalb et al., 2021). Because autism is four times more common in boys than girls, the representation of girls in autism research has been a longstanding challenge (Mademtzi, Singh, Shic, & Koenig, 2018). Our study did not identify any follow-up survey recruitment methods that were more successful at eliciting participation from parents of autistic girls; thus, more tailored recruitment methods should be considered in future studies to capture this group.

In summary, phone calls, emails, and text messages can all be effective methods of eliciting survey responses during follow-up outreach for parents of autistic children when completing an online survey. Parents of autistic girls were underrepresented in survey responses across all groups. Future research should investigate how to increase the participation of autistic girls and their families in research studies.

We are grateful to the parents and families who participated in this survey. The authors use identity-first language to describe autism spectrum disorder in this paper because this is the language that is often preferred by autistic individuals. However, we acknowledge that such language is not preferred by all individuals in the disability community and that there is heterogeneity in how individuals with autistic traits and their families prefer to identify themselves, including both identity-first and person-first language. Clinicians should always refer to patients in the language the patient prefers.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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This study was approved by the Institutional Review Board at Kaiser Permanente Southern California. All participants gave informed consent.

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TABLE 1.

Sample description

Gender	n (%)
Boy	1,284 (76.2%)
Girl	382 (22.7%)
Age	
0–3 years	637 (37.8%)
4–6 years	496 (29.4%)
7–12 years	417 (24.7%)
13–17 years	112 (6.6%)
Race	
White	352 (20.9%)
Black	143 (8.5%)
Hispanic	834 (49.5%)
Asian	225 (13.3%)
Other	112 (6.6%)
Insurance type	
Commercial	995 (59%)
Medi-Cal	458 (27.2%)
Both	70 (4.2%)
Other	143 (8.5%)
Recruitment group	
Email	474 (28.4%)
Phone	520 (31.2%)
Text	630 (37.8%)

Notes. n = 1,666 autistic children from an integrated health system in Southern California whose parents were contacted for a research survey in Spring 2021. There were 1,624 families originally contacted; because some parents (n = 42) responded to the survey for more than one autistic child, there were 1,666 unique parent–child dyads in the final sample.

TABLE 2.

Associations of recruitment type and child demographics to survey response

Predictor Variables	Odds Ratio (95% Confidence Interval)
Recruitment type (reference: email)	
Phone	1.31 (0.96–1.80)
Text	0.99 (0.72–1.36)
Female gender (reference: male)	0.68 (0.50–0.92)
Child age (reference: 0–3 years)	
4–6 years	1.03 (0.77–1.39)
7–12 years	0.75 (0.54–1.04)
13–17 years	0.83 (0.48–1.38)
Child race/ethnicity (reference: White)	
Asian	1.23 (0.82–1.84)
Black	0.73 (0.43–1.21)
Hispanic	0.75 (0.55–1.04)
Other	1.21 (0.71–2.01)
Insurance type (reference: commercial)	
Both	1.65 (0.90–2.9)
Medicaid	1.32 (0.99–1.76)
Other	0.93 (0.58–1.45)

Notes. Logistic regression model estimating odds of survey response from participant demographics in a sample of 1,666 parents of autistic children in Southern California who were contacted to participate in a research survey in Spring 2021. There were 1,624 families originally contacted; because some parents responded to the survey for more than one autistic child, there were 1,666 unique parent–child dyads in the final sample.