

Respondent Driven Sampling Method of Recruitment for a Case Control Study of Gastric Cancer Risk

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Abstract

Objective: Gastric cancer (GC) disproportionately affects ethnic minorities in the US including Asians and Pacific Islanders. Research with minority groups who are at high risk are needed to provide more effective treatment. Successful recruitment of minorities to research must overcome obstacles of language, access, fear and mistrust. Respondent Driven Sampling (RDS) is a sampling strategy designed to recruit underrepresented minority populations using social networks. However, there are no reports of RDS being used for a case-control study. **Methods:** Our pilot study examined the feasibility of using RDS as a recruitment strategy to enroll a large number of participants to develop a GC screener. Our preliminary work showed that 750 cases and 5,250 controls would be needed to fully develop this tool. GC cases, who also served as the seeds, were asked to refer 2 more people to participate as controls in our study. Our pilot goal was to recruit 8 GC cases (as seeds) and 112 controls using three waves of referrals and recruitment. **Results:** Twenty-seven GC cases were contacted of which 10 refused, 4 expressed interested to participate in the survey but were unwilling to recruit controls. Thirteen cases were recruited but only 5 Complete the survey. Of these 5, 3 cases did not pass on referral coupons and only 2 of the participants gave coupons to 3 potential controls. **Conclusion:** Our study revealed the limitations of using RDS with cancer patients to support recruitment. GC patients' constrained social networks, inadequate incentives or other factors may have contributed to the lack of success with using RDS in this setting.

Keywords: Minorities- stomach- early detection

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Introduction

Respondent Driven Sampling (RDS) is an effective sampling strategy to recruit "hidden" and hard-to-reach populations such as injection drug users, sex-workers, as well as underrepresented minority populations (Magnani et al., 2005; Yancey et al., 2006; Shaghghi et al., 2011). It is a link-tracing sampling method that starts with an initial sample of study participants who serve as "seeds". Seeds or the first wave of participants recruit a limited number of acquaintances who comprise the sample's "second wave." The second wave then recruits the next wave, expanding in a recursive manner until the desired sample size and heterogeneity are both reached (Johnston et al., 2008a; Johnston et al., 2008b).

Gastric cancer (GC) disproportionately affects ethnic minorities including Asians and Pacific Islanders in the US and their recruitment to any study must overcome obstacles of language, access, fear and mistrust. RDS is widely used to engage hidden or stigmatized groups in research. However, there are no reports of RDS being used for a cancer case-control study. The aim of this study was to examine the feasibility of using RDS as a recruitment

strategy to enroll a large number of controls (persons without cancer) using the GC patient or survivor as the seed. Our team previously conducted a pilot study to lay the groundwork for a large-scale case-control study to develop a survey-based GC screener to identify high-risk persons. Results from the pilot showed that 750 cases and 5250 controls would be needed to fully develop this screening tool. The pilot study had also demonstrated the difficulty in recruiting controls using phone call recruitment of primary-care patients as well as in-person recruitment at primary care clinics and community centers. Given the large number of controls needed to develop a high-risk GC identification tool, we believed an innovative recruitment method such as RDS would allow (a) rapid and efficient recruitment of a large number of non-cancer participants and (b) effective recruitment of minorities and immigrants. We hypothesized that successful adaptation of RDS methods for our study would greatly enhance our ability to recruit participants into large-scale studies (Johnston et al., 2008a).

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Materials and Methods

A trial of RDS was conducted between June 2018-January 2019 to recruit subjects for a gastric cancer (GC) Diet and Lifestyle survey study. Our goal was to recruit 8 GC cases (as seeds) and 112 controls. Going out to three recruitment waves would have allowed us to reach our recruitment goal of 112 controls using the RDS methods. No oversampling was done. This pilot study had limited funding and was intended to test our recruitment feasibility and the expected attrition rates.

GC patients diagnosed between 2013-2017 were selected from the hospital database for recruitment. Recruitment of GC cases were done over the phone or at the cancer care clinic during their follow-up visits. Based on their preferences, surveys could be mailed, completed on-line, or provided in person during visit. GC cases, who also served as the seeds for the first wave, were asked to refer 2 more people to participate as controls in our study. The cases (seeds) were provided with a study flyer containing brief description about the study and a coupon with a unique ID to be given to the persons they considered suitable for the study. The eligibility criteria for controls were: (i) Ages 40-85 years, (ii) No previous history of cancer diagnosis, (iii) No known personal or family history of genetic syndromes associated with increased risk of stomach cancer, (iv) Not a blood relative of the person referring, and (v) Not live in the same household as the person referring. Referred persons were instructed to contact the study team to enroll using the study contact numbers provided on the flyer and coupons. Once the referred person contacted the study team, the recruitment process and eligibility criteria were explained in detail. Recruits were then asked to complete a mailed paper version of the survey or web-version provided through email. Recruits that had not completed surveys were followed up once in 1-2 weeks for up to 3 times. Participants were offered \$15 for completing the survey and an additional \$10 for each control they recruited.

Results

Twenty-seven GC cases were contacted of which 10 refused, 4 expressed interested to participate in the survey but were unwilling to recruit anyone as controls for the study. Thirteen cases were recruited but only 5 completed the survey. Of these 5, 3 cases did not pass on referral coupons to anyone and only 2 of the participants gave coupons to 3 potential controls. One case didn't complete the survey but gave the coupons to 2 others. A total of 5 people received referral coupons but never contacted the study team. During final follow-up calls with the cases, we identified 2 major hurdles; (1) cases reported difficulty (no eligible person in their social circle) and reluctance in recruiting non-relative controls, and (2) referred controls were not motivated to participate in the study. We reasoned that inability of GC cases to recruit controls may be due to the GC cases being in different social circles than persons without cancer. To test this hypothesis, we decided to recruit healthy caregivers of non-GC patients at the cancer clinic to act as seeds who could refer other healthy

volunteers to our study. We expected that this relaxed eligibility criteria, using caregivers of patients instead of patients themselves, would afford better recruiting using individuals having broader social networks for the RDS methods than individuals with GC. The incentive for completing the survey was also increased to \$20 from \$15. We were able to recruit 7 seeds, however, we were not contacted by any caregiver-referred person for participation.

Discussion

Our trial study revealed the limitations of recruiting controls by this method for cancer studies. Similar difficulty was also observed in a study attempting to utilize lung cancer patients to enroll family members and friends who are smokers (Bastian et al., 2011). The reasons for unsuccessful recruitment is not entirely clear. One of the explanations could be that the seeds were too sick to recruit others. Three of our seeds were undergoing chemotherapy and had frequent hospital admissions due to various complications. One participant, unfortunately, died 2 weeks after recruitment. Another reason could be dwindling social networks due to significant changes in lifestyle after a cancer diagnosis. Since no referred controls reached out to us, the reasons for not being motivated to participate in the study were undetermined. Further research such as focus group studies is needed to understand the acceptability of recruitment using referrals for cancer studies.

Author Contribution Statement

Conception and design of study: HI, BR, KC; Development of study materials and acquisition of data: HI, SS, MR, GU, KC; Analysis and interpretation of data: HI, SS, BR, KC; Editing and drafting of the manuscripts: ALL; All authors gave final approval for the manuscript to be published

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The study was not approved by any scientific body and was not part of any approved student research.

Institutional Review Board Approval

The Einstein Human Research Protection Program, Montefiore Einstein Office of Clinical Trials IRB #2015-4763.

Availability of Data

Data is available on demand by reaching out to the author Dr. Haejin In by email at: Haejin.In@rutgers.edu

Conflict of Interest

The authors have no potential conflicts of interest.

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