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Challenges in Researching Racially Sensitive Topics in HMOs

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Introduction

When research designed to close the disparities gap is conducted in real-world health care settings, unique sensitivities may arise, particularly when race is the focus of interventions. We encountered this issue in the course of a randomized trial investigating the influence of ethnic identity (EI) among African American (AA) study participants. The study was conducted by the research programs at three health maintenance organizations (HMO) and the University of Michigan Center for Health Communications Research, as described in this issue of the journal (Resnicow et al, in press). This commentary describes the research partnership's concerns for the racially sensitive nature of the study and the precautions undertaken to mitigate them. Our experiences may be informative and insightful for health plans and research centers invested in health disparities research.

The research study, Eat for Life, tested whether tailoring a fruit and vegetable (F&V) intervention based on individual EI would enhance program impact beyond that of social cognitive tailoring alone (Resnicow et al., in press). EI refers to the extent to which individuals identify with, and gravitate to, their own and other racial/ethnic groups (Cross, 1991). EI was captured using a unique survey instrument that measures components of EI, such as racial

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salience and cultural mistrust, and classifies respondents into discrete EI subgroups (Davis et al, under review; Resnicow et al., in press).

Although this study was a randomized controlled intervention trial, its hypothesis was more akin to basic science than the outcomes research that health plans tend to undertake. The experimental hypothesis was centered on the conceptualization of discrete types of ethnic identities within one race. With the goal of conducting research on EI as a potential factor influencing health behaviors, the research team was concerned about reactions to this intervention by AA health plan members, particularly when race and ethnicity were manipulated variables in the intervention. As we developed the Eat for Life study, we became increasingly concerned that some of our enrollees might react negatively—for example, by perceiving that they were being targeted for a racially-specific intervention. All sites agreed to take great care to reduce risks during this research study, while pursuing this important scientific question.

The Ethnic Identity Survey and Tailored Intervention

Developing a practical instrument to classify participants into EI subtypes was a central component of the research and the core reason for many of the precautionary measures undertaken. The HMOs had not previously asked AA members such overtly race-relational questions. Some survey items queried respondents' views about their relationships with persons of other races and their trust or mistrust in the government. We recognized these could be sensitive questions and, if mishandled, could generate a serious customer relations problem for the participating HMOs.

The researchers invested heavily in reviewing the scientific soundness and potential offensiveness of candidate EI survey questions. We engaged independent reviewers such as non-study affiliated AA health plan staff, University of Michigan AA graduate students, consultants specializing in Multicultural Health and experts in black identity theory, most of whom reviewed survey items. In addition, focus groups were conducted with AA adult members of the HMOs to explore EI survey item comprehension, acceptability and potential offensiveness. Although time-consuming, the team reworked many survey items to promote clarity and reduce sensitivity and excluded others deemed too incendiary or confusing.

In order to verify the psychometric properties of the EI instrument, a pilot test was conducted using the revised instrument. Factor analysis effectively streamlined the survey from 57 items into a concise and reliable tool of 32 “safer” yet psychometrically sound items, leaving the research partnership investigators with fewer reservations (Davis et al., under review).

Writing the tailored intervention newsletters to match the EI subtypes was another important development activity for which we took precautionary measures. The study's investigators were uncertain how to communicate about dietary information tailored by EI in a convention that would seem honest when delivered from an HMO business enterprise. This source of concern was compounded by the extent of EI diversity among AAs themselves - what offends one AA may not offend another.

Newsletter text and graphics were pre-tested in focus groups with AA members of the HMOs. Using our EI survey, we classified groups by EI type and tested whether they gravitated towards newsletters tailored for their type. The results affirmed that our classification system and tailoring approaches were valid. In addition, our independent reviewers scrutinized EI newsletter renditions to illuminate possible areas of risk. Messages, testimonials, quotes from Black activists, and graphics were examined. AA reviewers advised, for example, that language about slavery was acceptable but a reference to Tuskegee should be removed, and that we avoid referencing typical AA food stereotypes.

Maximizing and Assessing Respondent Acceptance

The research team deliberately scripted recruitment, consent and survey materials to resonate with the respondents. The scripts were forthright. For example, the invitation letter said: *We would like to get your opinions on what being Black means to you, and how you make decisions about your diet and health.* Similarly, the introduction to the EI scale prepared respondents for the sensitive nature of those items: *These questions may be sensitive for you, and you may even find some of them disturbing. Please remember that we are asking these questions because there is a very wide variety of attitudes, backgrounds, and opinions about race within our community.*

To maximize rapport and promote candor, the researchers elected to utilize only AA interviewers to conduct the telephone survey. They introduced themselves as "...part of a team of AA interviewers," and had the latitude to use inclusive language, such as "we," and referenced "our community". While this was a crucial action, employing AA interviewers required successfully addressing Fair Labor Practice regulations in order to implement it. The research team also developed a document of interviewer *Recommended Responses* for such possible respondent queries as "What does race have to do with a F&V study?" and "Do you think it's just AAs who don't eat enough F&Vs?"

The telephone survey concluded with probes to capture participants' reactions to the survey itself. For both the pilot and full trial, participants' responses were encouraging. Nearly 70% of all responses were positive, and less than 10% were negative. Many respondents were pleased that the health plan was concerned, for example: "It lets me know that health care providers at [the HMO] have an interest in the Black community and are willing to adapt a program to motivate people to better eating habits." Some respondents were struck by the unexpected nature of some questions; however they generally enjoyed the challenge of considering those concepts.

Conclusion

Undertaking sensitive race-focused research in a business environment requires substantial effort to minimize risk. We gained immeasurably by involving a multitude of stakeholders, by careful preparation and testing of intervention materials and methods and by assessing participants' reaction to the research. This deliberative approach, although time-consuming and sometimes costly, fostered confidence and fewer reservations. Key lessons learned include the value of strategies used to avoid sensitivities in AA populations and the need to ensure that studies are aligned with the values and internal business needs of the participating organizations.

Though it would be easier to undertake less labor intensive and risky research projects, we are confident that we did not offend members, and we gained knowledge from approaching disparities research by directly addressing race in the content of the intervention. Our hypotheses, though theoretical, practically reinforce the notion that one size does not fit all—the heterogeneity of the AA population justifies tailoring around important differences. Our findings demonstrate the utility in thinking beyond a single AA audience and justify taking on these research risks. If our goal is to eliminate health disparities, culturally-appropriate health promotion, no less than health care, is a valid strategy for health care systems and practitioners, and will be better achieved when armed with evidence-based approaches.

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