

The challenges of exploring the impact of genogram construction on an Appalachian family's health consciousness

Dilip Nair, MD¹, Indira Bhavsar, BS², and Nafeeza Hussain, BS, MPH²

ABSTRACT

PURPOSE: Appalachians exhibit high rates of chronic disease-related behaviors which might improve with heightened health consciousness. Knowing one's family history can be an important health maintenance tool. Appalachians' health attitudes are shaped in large, closely knit extended families in which matriarchs play central roles. We sought assistance from West Virginian grandmothers in a family medicine practice in engaging their extended families with their genogram to assess the impact on family members' level of health consciousness.

METHODS: The family physician identified West Virginian grandmothers in his practice. We sent each of them invitations to participate, along with their extended family, in constructing a genogram. However, none of the thirty-four women contacted agreed to participate. We explored the reasons for their non-participation. We mailed a follow-up survey to all the potential participants. We made follow-up phone calls after sending a reminder letter. Twenty-seven women responded. We collated and arranged in order of frequency their reasons for non-participation.

RESULTS: The most frequently cited reason for non-participation was that the respondent perceived her extended family to be too busy or to live too far from one another to participate. Her own sense of not feeling up to what was being asked of her was the second most frequently expressed reason, almost as often as the first.

CONCLUSIONS: The hypothesis that family physicians might improve health consciousness of Appalachian extended families by engaging them with their genogram remains untested. Testing it will require being mindful of several methodological lessons regarding recruitment of subjects, use of written materials and inclusion criteria. The researcher will be wise to adopt a collaborative, collegial approach such as employed in participatory research.

KEYWORDS

genogram, Appalachian, health consciousness

INTRODUCTION

The Appalachian Region, as defined by the United States Congress, includes West Virginia and parts of 12 other states.¹ It is burdened by significant health disparities. Compared to the rest of the U.S., the region has higher mortality from heart disease, stroke, diabetes and all cancers including specifically lung cancer.² Behind these statistics lie behavioral

risks which are also notably prevalent in this region.³ Appalachian counties exhibit higher prevalence rates of obesity, cigarette smoking and physical inactivity as well as lower rates of fruit and vegetable consumption than non-Appalachian counties, in aggregate. Additionally, rates of cancer screening in Appalachian counties are lower than those in the rest of the nation. West Virginia, lying entirely within Appalachia, mirrors the characteristics of the larger

Author affiliations are listed at the end of this article.

Correspondence to:

Dilip Nair, MD
Marshall University
Joan C. Edwards
School of Medicine
nair@marshall.edu



region.³ The extent to which Appalachians (people indigenous to Appalachia possessed of a distinct cultural identity) are health conscious (i.e. aware of and placing value on their health)⁴ is a crucial consideration in any health improvement effort in the region. In reporting her ethnographic study of rural Appalachian women in western North Carolina, anthropologist Carol Stephens has criticized skeptics of the strength of Appalachians' health consciousness as being ethnocentric.⁵ The women in her study not only placed a high value on health but also drew a tight connection between healthy life and healthy living. Whether or not these findings successfully refute the assertion to the contrary, it is notable that Stephens' study informants indicated that having their extended family members living near each other under the leadership of the matriarch was highly important in their pursuit of health. Other researchers have also underscored the importance of large, closely knit extended families in which mothers and grandmothers play central roles, in shaping health attitudes of Appalachians.^{6,7}

Family health history was highlighted with the launching of the Surgeon General's Family Health History Initiative in 2004.⁸ This public health initiative encouraged all Americans to learn more about their family history as an important tool in health maintenance. The Surgeon General urged family members to talk about and record "health problems that seem to run in their families" when they gathered, for example, on Thanksgiving Day. One way to depict these health problems is to construct a genogram, a "tree" diagram in which family members are depicted by squares or circles depending on gender and their relationships demonstrated by interconnecting lines. A family member's health problems are noted on or adjacent to their corresponding shape on the "tree." Since researchers have posited a key role for large, closely knit, matriarchal extended families in shaping Appalachians' health attitudes, it is reasonable to hypothesize that if an Appalachian family were engaged with their genogram when assembled together as a family, this might have a meaningful impact on their health consciousness. It is also conceivable that this project might be particularly successful if it were conducted under the leadership of the family matriarch. To our knowledge, no studies

have examined this hypothesis. Family-centered approaches to promoting healthy behaviors have been applied successfully⁹ and indeed have been strongly advocated.¹⁰ However these approaches have not involved the assembled extended family viewing their genogram together.

Family physicians often care for multiple members of an extended family or are familiar with their patients' family members. They provide continuous comprehensive care over time to the families. Therefore, they are well-suited to engaging the family as a whole with its genogram. The use of genograms as preventive medicine tools by family physicians was described long ago.¹¹ Furthermore, much has been written about qualitative research conducted by primary care physicians in their own practices.¹²⁻¹⁴ However, to our knowledge, the family physician's exploration of the effects of engaging their patients' extended families with genograms is also novel. Therefore, we proposed to assess, by quantitative and qualitative means, the impact on health consciousness of gathering a family to view a genogram to which individual family members had previously contributed. To accomplish this goal we hoped to gain assistance from the matriarch of the family.

However, research on the National Survey on Drug Use and Health (NSDUH), an annual survey sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA), has shown that the task of recruiting older persons for research purposes is a challenging one.¹⁵ In the 2003 survey, persons over 50 years of age had a response rate of approximately 70% compared with 90% in the 12-17 year old group.

METHODS

We obtained approval for the project from the Institutional Review Board (IRB) overseeing social and behavioral research at our institution. The lead investigator (DN), a family physician, selected from a list of his female patients over the age of fifty-five years, those whom he knew, by means of previous conversations, to be grandmothers native to West Virginia with influence in their extended families



regarding health matters. We sent each of thirty-six women, thus selected, a mailing consisting of an invitation letter and an informed consent. The letter explained the purpose of the study and described how it would be conducted. It asked each woman to consider if the living members of her extended family spanned at least three generations, together comprising at least six adults of sound mind who lived within two hour's drive of the investigators and were frequently in contact with one another. Finally, the letter requested the recipient to notify the investigators if it appeared that her family members fit the criteria and was willing to participate. While one patient initially expressed some interest in participating, she subsequently declined. We did not receive any other responses. We then sought to explore the reasons for the lack of participation in the study.

We secured approval for the project revision from our IRB. We sent new mailings to the women. Each mailing consisted of a letter, a survey and an informed consent form. The letter explained the revised goal of the project and invited the recipient to complete a survey in which she was to rate each of ten possible reasons for non-participation on a Likert scale regarding degree of importance (Table 1). The survey also provided the option of adding other reasons, explaining the answers further and of receiving a follow-up phone call.

After a week's interval, we repeated the mailing. Finally, after waiting another week, we (IB and NH, both medical students) attempted to make telephone contact with the recipients who had not responded. When we were able to speak with a recipient we referenced the previous mailings including the informed consent and sought permission to complete the survey with the recipient over the telephone. We informed each informant that they were free to terminate their participation at any time during the telephone conversation. In addition to addressing each of the possible reasons listed in the survey to determine its weight for that informant, we made note, verbatim when possible, of any

salient explanatory comments made by the recipient. However, the conversations were not recorded or transcribed.

We then collated the results of the surveys so as to identify the frequency with which a given reason for non-participation was identified as being of importance. We also grouped narrative comments according to the reason given.

RESULTS

From the original list of thirty-six women we sent surveys to thirty-four women. One patient on the original list had died and another had moved out of state. We received seven surveys back by mail. One of these was anonymous and so could not be attributed to a particular participant. Another four recipients mentioned the reasons for their non-participation to their physician (DN) in the course of interactions regarding patient care, two during office visits and the other two over the telephone. We were able to contact seventeen more women by telephone. We were unable to contact seven women because they did not answer their phones or respond to voice messages (Figure 1).

The most frequently cited reason for non-participation, mentioned fourteen times, was that the respondent perceived her extended family to be too busy or to live too far from one another

1. I am not a grandmother.
2. I am a grandmother but I do not feel I have much influence with my extended family regarding health matters.
3. I was not clear on what my responsibilities would be.
4. I did not feel up to what was being asked of me.
5. My extended family has too few members.
6. I felt my extended family was too busy or lives too far from each other.
7. Members of my extended family were not comfortable with participating because:
8. I felt the nature of the relationships in my extended family would make it difficult for us to participate.
9. I personally did not feel comfortable with my health information being made known to my extended family.
10. I personally felt uncomfortable sharing my health information outside of a visit with my doctor.
11. Other:

TABLE 1: Reasons for non-participation listed in survey

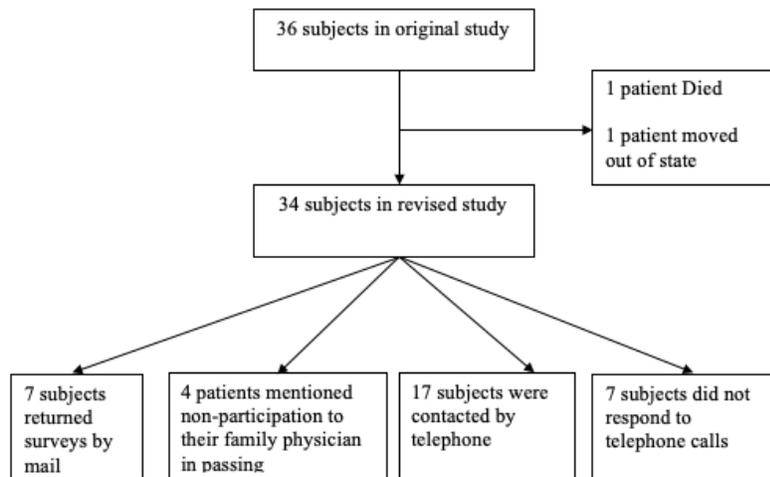


to participate. Her own sense of not feeling up to what was being asked of her was second, being cited thirteen times. Two additional concerns, that her extended family had too few members and that she was not clear what was being asked of her completed the most frequently cited reasons, being mentioned nine and six times respectively (Figure 2).

We did not gain any further insight as to why the extended families were too busy. When the respondents offered an explanation for why their extended families had too few members it was that several family members had died.

Ten of the thirteen women who cited not being up to participating provided explanations for this. Seven of them described having higher priorities competing for limited time. Two of these seven women pointed to job commitments, one of them lamenting that the summer had been her busiest and that she had not had the time to do more than skim the mailings. Most often, the women who gave reasons for not feeling up to participating cited responsibilities caring for family members, often in illness. One representative written statement put it: "I am sorry but I am so busy taking care of my husband ... Sorry but I'm run to death I just don't have time." Three individuals explained that their own diminished capacities contributed to their feeling unable to participate. While health problems were brought up in two of these cases, the third mentioned that she was in the process of moving homes.

We received clarifying comments from only one of the six respondents who stated they were not clear on what we were asking. This respondent complained there was "too much paper" being sent and intimated this was overwhelming. Another woman, while she did not cite lack of clarity as a reason for non-participation, nevertheless wrote, "As you can see I hate filling out forms. I always fail them." Finally, as many as six women expressed unsolicited support and interest in the aims of the project.



Note: One mailed survey was returned anonymously. She was also counted among the 7 subjects who did not respond to telephone calls. Therefore, numbers in the four categories add up to 35, not 34.

FIGURE 1: Results of recruitment efforts

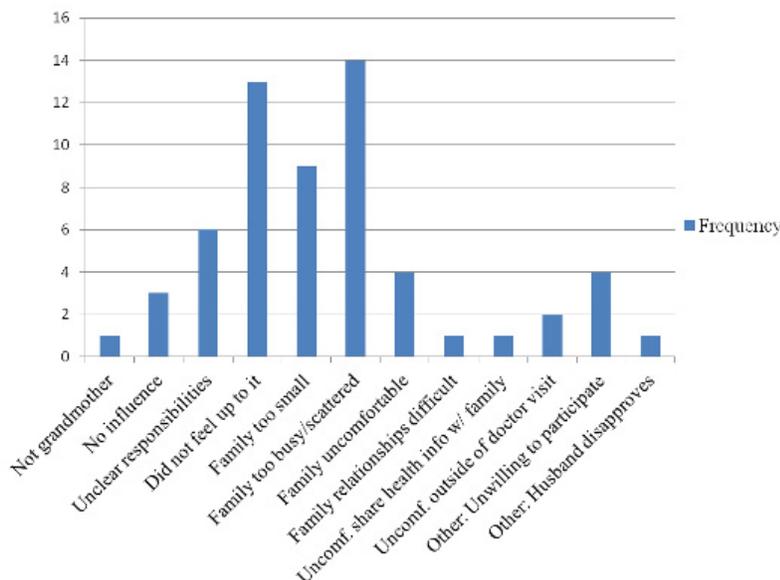


FIGURE 2: Tally of frequency with which reasons for non-participation were identified as important or extremely important



DISCUSSION

The 0% recruitment rate in this group of thirty-four is striking and worthy of exploration. We based our research endeavor on two assumptions that, while apparently plausible according to some previous research findings,⁵⁻⁷ may not have been true for the patient population from which we tried to recruit subjects. In the first place, we anticipated that the grandmothers in this family medicine practice would serve as liaisons and advocates with their families on our behalf. Secondly, we expected the extended families would be geographically clustered and large enough to meet our inclusion criteria.

Our post-hoc exploration suggested three reasons for the grandmothers' non-participation. Firstly, the data portray these women as being deeply engaged in daily commitments, especially care-giving for family members, with little time or energy to spare. Secondly, six of the women surveyed admitted that they were not clear about what was being asked of them. Furthermore, some of the women who stated that they did not feel up to participating may have done so because of poor comprehension or misunderstanding of what we were requesting. In fact, several women actually stated that they would have felt differently about their ability to participate in the original project if they had understood what our expectations were. This possible explanation for the grandmothers' lack of participation calls into question the readability of our initial mailing which contained an invitation letter slightly shorter than two single-spaced pages as well as a four-page standard informed consent. The documents were written at a grade level of 10.4 and 8.9 respectively according to the Flesch-Kincaid readability test.¹⁶ We are unable to more precisely explore the impact of the readability level of our mailings because we did not collect the respondents' educational and employment histories in our follow-up surveys. Finally, the grandmothers perceived their family members as unlikely to prioritize participation in this health consciousness project because they lacked enough time or resources to spare for the project.

Another methodological reason for our unsuccessful recruitment effort was our invitation process. British researchers, conducting a systematic review of randomized controlled trials of methods to

enhance response rates to mailed questionnaires, found benefit in including monetary incentives, making contact with participants before and after the mailing as well as employing brief personalized questionnaires mailed by registered mail.¹⁷ We did not utilize all these strategies because either we judged them to be inappropriate (monetary incentive) or unnecessary (registered mail) in view of the physician-patient relationship. An analysis of patient satisfaction studies has demonstrated that a face-to-face approach to subject recruitment yielded a significantly higher response than recruitment by mail.¹⁸ In our case, neither the family physician nor his co-investigators made any appeals in person. We deliberately confined our recruitment methods to more impersonal mailings because we were sensitive to the risk that the physician might coerce the patients to participate by virtue of his authority and power in their relationship. It is possible that by foregoing a face-to-face conversation between physician and patient we also lost an opportunity to give a clearer and more compelling invitation to participate in the research project.

Our follow-up survey had limitations of its own. The most important of these are the methodological decisions we made that necessarily limited the data we were able to collect. We sought to be careful not to convey any disappointment or disapproval towards the patients we had contacted. For example, when study subjects mentioned their non-participation to their family physician in passing while conversing about health concerns, the physician would, instead of probing their comments further, hasten to reassure them about their decision and pass on to patient care. Additionally, to maximize participation in our survey and limit its burden and intrusiveness, we limited the scope and depth of our questions. Neither did we employ a more open-ended interview format. We also refrained from further exploration of the written responses we received. Finally, we did not record our phone conversations with the respondents for transcription.

Despite all these limitations, however, we maintain that our hypothesis that the health consciousness of an Appalachian extended family might be positively affected by their being engaged together as a family with their genogram, at their family physician's invitation, remains worth testing. What we have



shown in this study is that researchers who endeavor to test this hypothesis will need to be cognizant of several potential methodological pitfalls. First, the recruitment of subjects might be better done in person by the physician, with respectful follow-up by other members of the research team. Second, care must be taken to ensure that any written materials used are of appropriate readability for the participants being recruited. Third, it might be preferable not to seek a liaison in a specified family role but rather to invite a broader array of patients. Fourth, it might be more productive to not restrict family eligibility by criteria of size and geographical and relational proximity.

Projects of this nature depend on the collective knowledge and participation of the family and entails an activity that would potentially benefit the family. Therefore, more fundamental to success than simply avoiding the methodological errors listed above is that the family physician researcher engages with the extended family, learning from and working with its members. Success would be more likely if the hierarchy and division between researcher and subject were lessened, if both parties were seen as co-researchers. As such, a research project of this kind would be well-situated in the field of participatory research, oriented as it is to “a process of sequential reflection and action, carried out with and by local people rather than on them.”¹⁹ The next step then, is to apply these methodological lessons to testing the hypothesis.

AUTHOR AFFILIATIONS

1. Professor, Department of Family and Community Health, Marshall University Joan C. Edwards School of Medicine
2. Marshall University Joan C. Edwards School of Medicine

REFERENCES

1. Appalachian Regional Commission. The Appalachian Region. Available at: http://www.arc.gov/appalachian_region/TheAppalachianRegion.asp. Accessed on September 3, 2015.
2. Halverson JA. An analysis of disparities in health status and access to health care in the Appalachian region. Available at http://www.arc.gov/research/researchreportdetails.asp?REPORT_ID=82. Accessed on September 3, 2015.
3. Centers for Disease Control and Prevention. Chronic disease indicators: state/area profile. West Virginia compared with the United States. Available at:
 4. <http://www.nccd.cdc.gov/cdi> Accessed on October 10, 2015.
 5. Gould SJ. Health Consciousness and health behavior: the application of a new health consciousness scale.
 6. *Am J Prev Med.* 1990;6(4): 228-237.
 7. Stephens, CC. Culturally relevant preventative health care for southern Appalachian women. 1st ed. Keefe SE, editor. Knoxville (TN): University of Knoxville Press; 2005.
 8. Coyne CA, Demiean-Popescu C, Friend D. Social and cultural factors influencing health in southern West Virginia: a qualitative study. *Prev Chronic Dis.* 2006;3(4):1-8.
 9. Francis SA, Katz ML. The HPV Vaccine: a comparison of focus groups conducted in South Africa and Ohio Appalachia. *Matern Child Health J.* 2013;17(7): 1222-1229.
 10. U.S. Department of Health and Human Services. Surgeon General’s Family Health History Initiative. Available at: <http://www.hhs.gov/familyhistory>. Accessed on October 10, 2015.
 11. Rodearmel SJ, Wyatt HR, Barry MJ, Dong F, Pan D, Israel RG et al. A family-based approach to preventing excessive weight gain. *Obesity.* 2006;14(8):132-1401.
 12. Kardia SLR, Modell SM, Peyser PA. Family-centered approaches to understanding and preventing coronary heart disease. *Am J Prev Med.* 2003;24(2):143-151.
 13. Allerdice PW, O’Leary E, Ficken S. Updating genograms in the practice of preventive medicine. *Can Fam Phys.* 1988;34: 849-855.
 14. Muller JH. Narrative approaches to qualitative research in primary care. 2nd ed. Crabtree BF, Miller WL ed. *Doing Qualitative Research.* Thousand Oaks (CA): Sage Publications, Inc.; 1999.
 15. Murphy E, Mattson B. Qualitative research and family practice: a marriage made in heaven? *Fam Pract.* 1992;9(1):85-91.
 16. Britten M, Jones R., Murphy E, Stacy R. Qualitative research methods in general practice and



- primary care. *Fam Pract.* 1995;12(1):104-14.
17. Murphy J, Schwerin M, Eyerman J, Kennet J. Barriers to survey participation among older adults in the National Survey on Drug Use and Health: the importance of establishing trust. *Survey Practice.* 2008;1 (2).
 18. Readability Formulas. The Flesch Grade Level Readability Formula. Available at: <http://www.readabilityformulas.com/flesch-grade-level-readability-formula.php>. Accessed on September 3, 2015.
 19. Edwards P, Roberts I, Clarke M, DiGuseppi C, Pratap S, Wentz R. Increasing response rates to postal questionnaires: systematic review. *BMJ* 2002;324:1183.
 20. Sitzia J, Wood N. Response rate in patient satisfaction research: an analysis of 210 published studies. *Int J Qual Health Care* 1998;10 (4):311-7.
 21. Cornwall A, Jewkes R. What is participatory research? *So Sci Med* 1995;41(12):1667-76.

