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When Family Means More (or Less) Than Genetics:

The Intersection of Culture, Family, and Genomics

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Abstract

There is renewed interest in the use of family history to predict individual disease susceptibility, and as a result, standardized online family history tools are being developed and marketed as a “new genetic test.” It is not known how cultural variations in definitions of family influence collection of these data or what is the best format to use. This is significant given that the populations who carry the greatest burden of the target diseases have not been considered in efforts to test these tools. A qualitative study with a convenience sample of 19 Japanese Americans and Samoan Americans, two groups at high risk for type 2 diabetes, was conducted to explore the process of collecting family history. A particularly strong finding was the high degree of acceptance experienced by the participants with the process and their pride in visualizing their family graphically displayed in pedigrees. It was also found that Samoans included those linked by nonbiological ties in their families, which reflects their cultural practices. Further research is needed to assess the most effective and efficient way to gather family history given the complexities surrounding the deceptively simple concept of family.

Keywords

Pacific Islander; Samoan; Japanese American; family history; genetics; diabetes

Family history has long been recognized as a risk factor for many diseases, and it is now being marketed as a new genetic test that provides “a window into a person’s genome” (Guttmacher, Collins, & Carmona, 2004; U.S. Department of Health and Human Services, 2004). Early predictions for a “genomic era” with the promise of technologic advances to alleviate disease have scaled back (Bell, 2003), but, although characterized as lowtech, there is great interest in applying family history as a tool to identify disease (Rich et al., 2004), including in Third World countries where other diagnostic means are lacking (Bloom & Trach, 2001). It offers great potential for clinical use with individualized disease prevention efforts, as well as for public health purposes as an efficient population screening tool. Family history reflects both underlying genetic susceptibility and shared environment, which makes it a particularly powerful tool. These benefits are significant for those at risk for complex chronic disorders that are associated with positive family history, such as diabetes, and thus, clinicians are being encouraged by governmental institutions and professional organizations to collect accurate family history for risk assessment purposes. In light of this, creative approaches are being developed, with computer-based tools being the most popular. These are thought to be more efficient and practical for use in busy clinical settings. However, we do not know if they are equally effective across all populations, with a concern in particular with those populations

who carry the greatest burden of the target diseases. Online or computer-based tools may be problematic in groups with poor access to computers, who experience a lack of comfort with interactive software, or whose culturally based definitions of family differ from a genetic definition. Although many cultural groups have practices around sharing genealogy, they do so within an oral tradition.

The purpose of this study was to explore the process of collecting family history using a culturally familiar style with two groups who are at high risk for diabetes. We wanted to investigate any differences between the groups in the acceptability of providing medical family history, the degree of comfort, and the conceptualization of “family.” We are interested in comparing a computerbased process with an oral method, and this study is a preliminary step in that larger research.

Background

Family History and Chronic Illness

It has been proposed that “old-fashioned” family history, through the use of modern technologies, such as home computers, can be used to stratify risk for common chronic diseases and inform recommendations for lifestyle changes and screening tests based on resulting risk categories. Chronic diseases that have been associated with a positive family history include breast cancer, colon cancer, heart disease, stroke, diabetes, and depression and other psychiatric illnesses (Guttmacher et al., 2004; Hariri et al., 2006)—conditions that result in the greatest morbidity and mortality burden in the United States and that are often resistant to prevention strategies. Family history is cost-effective because it allows clinicians to target higher risk individuals than is possible with general population screening, and it has the ability to identify other family members outside of the clinical encounter who may be at risk. Family history is also seen as providing patients an opportunity to be more active and involved in their own care (Guttmacher et al., 2004).

Although the collection of family medical history information has been used in clinical settings for decades, recent interest in the United States can be traced back to 2002 when the Office of Genomics and Disease Prevention at the Centers for Disease Control and Prevention launched an initiative to evaluate the use of family history. The family history working group concluded that until molecular genetic tests or biomarker measures are available to identify susceptibility genes and environmental exposures, family history information “may be an effective means for predicting our risk of future diseases” (Yoon et al., 2002, p. 408). As part of this ongoing effort, the working group developed an instrument to collect family history information, created algorithms to estimate risk based on reported family medical history data, and shaped recommendations for using this information to stratify risk of chronic diseases and personalize individual prevention strategies (Centers for Disease Control and Prevention, National Office of Public Health Genomics, 2006). A family history collection tool, Family Healthware, is currently being tested in clinical trials across the United States (Centers for Disease Control and Prevention, Office of Genomics and Disease Prevention, 2005). Following this, in 2004, the U.S. Office of the Surgeon General launched a national public health campaign, “The U.S. Surgeon General’s Family History Initiative,” and declared Thanksgiving as “National Family History Day” to increase awareness of the medical value of the family history. Central to this campaign was the development and promotion of a Webbased tool, “My Family Health Portrait” (U.S. Department of Health and Human Services, 2006). The purpose of this initiative is to encourage families to access the tool online; learn more about their family health history, including heart disease, diabetes, and cancer; record the information on the online tool; and then share this with their clinicians. This information could potentially be used as a tool for combining population-based interventions with family-based interventions. The Web-based tool is very popular and has been downloaded more than 360,000 times.

Multiple Meanings of “Family”

One challenge in using family history as a health technology is that the geneticist or clinician defines family based on biology, whereas individuals often include those linked socially. The outcome of the former is a genetic pedigree; the latter results in a family genealogy. These two records of the kinship meet very different needs. When there is a lack of congruence between a health provider and patient meanings around “family,” the result can be miscommunication (Hunt, Emslie, & Watt, 2001; Maradiegue & Edwards, 2006). One way to avoid this problem is to be aware of the multiple meanings of family and not assume shared understanding.

Kinship studies in anthropology demonstrate the great cultural variation in how family is conceptualized around the world (Schneider, 1980; Stacey, 1998; Strathern, 1992; Waxman, Medin, & Ross, 2007). The definition of family is dynamic, with change over time and within group variation. For example, the Western postmodern family has looser kinship ties than in the past, with relationships that are diverse and fluid (Stacey, 1998). Blended, adoptive, and gay families, as well as those resulting from a variety of assisted reproductive technologies, place an emphasis on choice rather than genetics. For many, family is about social relationships and not solely concerned with the transfer of genes from one generation to the next (Finkler, 2001; Lévi-Strauss, 1969; Peletz, 1995). Nonbiological social factors, such as role behavior, determine family membership, so that a mother’s sister’s son who has been raised with you is your brother (Finkler, 2001). Both formal and informal adoptions are traditional practices and very common in certain societies: Polynesia often being presented as the exemplar (Brady, 1976; Carroll, 1970; Levy, 1973).

Although bilateral descent is the norm in Western societies, it is not universal and there is variation with cultural practices around lineage. In certain societies, individuals place greater importance on (and have greater knowledge about) one side of the family than another (unilineal descent). Thus, individuals in patrilineal groups trace relationships through males only so that your father’s brother’s children are members of your family, but not your father’s sisters (Kottak, 2007). They are members of their husband’s group or family. Efforts to create a family pedigree may be hampered if the participant is not familiar with her mother’s relatives, but her mother’s brother’s children (her cousins) may be able to supplement her overall family history. Knowledge about the cultural system of unilineal descent avoids assuming the universality of bilateral descent. Cultural beliefs such as these also have implications in the conduct of genetic research in terms of confidentiality and autonomy (Benkendorf et al., 1997; Wertz, 1997). One cannot assume that the named proband is in a position to speak for the extended family in agreeing to participate in any genetic research (DudokdeWit et al., 1997).

Beliefs around inheritance are salient when considering the place of family history in health promotion. The meanings individuals bring to their understanding of family history of disease risk are a product of collective experiences and traditions, which in turn influence family roles, norms, interactions, and responses to life events (Peterson, 2005). In their study with middle- and working-class families, Hunt et al. (2001) document ambivalence and uncertainty about inheritance of disease. They found that although individuals recognized that heart disease runs in their family, they did not feel personally at risk if they identified differences with the affected relatives. The belief that one is more at risk if there is a resemblance (physical, personality, disposition) with the side of the family or individual with the disease has been found in a number of studies (Marteau & Richards, 1996; Weil, 2000).

In summary, more research is not needed to document that culture influences illness beliefs and practices, and we know that the completeness with which family history is collected is influenced by ethnic-specific cultural practices and beliefs (Maradiegue & Edwards, 2006; Matthews et al., 2000). We do need more data and guidance on how to incorporate cultural

beliefs into a system of collecting family history so the information is accurate and the process acceptable.

Methods to Collect Family History

Online methods for collecting family history information may be entirely appropriate for many consumers, but they are not for everyone. Public health research tells us that “one size does not fit all” when it comes to risk reduction and health promotion programs. Rather, these programs are more effective if they are culturally tailored to reflect the social context, knowledge, and practices of the target group (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003).

Researchers who evaluated five Web-based tools found that in addition to problems of computer access, computerized tools may be challenging for those with lower literacy levels, particularly lower health literacy and computer literacy, and make the following recommendation:

To meet the goal of Healthy People 2010 to eliminate health disparities, tools that have extensive testing in those from underserved population and in groups with lower general, health, genetic, and computer literacy and in those with lower numeracy are needed. Tools should also become increasingly culturally appropriate. (Kelly & Sweet, 2007, p. 82)

Risk stratification algorithms that lead to tailored behavioral modification and/or screening recommendations are based on data that assume accurate recall in terms of biological family relationships. Clearly, classification of family relationships based on social and cultural definitions has the potential to influence the analytic and clinical validity, and clinical utility, of these tools. Studies on family history indicate mixed results when accuracy is measured (Bensen et al., 1999; Williams, Gray, & Beynon, 2007). Various demographic factors have been found to affect accuracy and completeness of family medical history collection, several of which were evident in our study. One concerns the location of the relative’s death (King, Tong, Pack, Spencer, & Amos, 2002; Williams et al., 2001). This is significant in this study with highly mobile Samoan Americans who all reported family members residing outside the United States. Many cultural groups similarly practice circular migration or return home frequently, and so would be challenged to be certain of relatives’ illness history or cause of death.

Is there another way to collect family medical history information that is more congruent with everyday practice? People articulate their lives through stories or narratives. There is a rich tradition in medicine of using patient narrative to increase clinician understanding of the patient’s experience of illness (Frank, 1995; Kleinman, 1988; Zaner, 2004). Narrative accounts of genealogies also allow increased understandings of complex relationships as family history acts to join an individual’s ancestors, descendants, and potential descendants into a linear living unit (Finkler, 2005), although sometimes with mixed blessings as when the potential for genetic inheritance of disease risk is revealed.

Sharing genealogy is a common practice in many cultures where the first question when two people meet is “Who are your people?” This is followed by a back-and-forth exchange of finding connections based on kinship. This is the tradition among Pacific Islanders overseas as well as in their diasporic communities. Extended kinship ties are also common among Pacific Islanders, with distant relatives or adopted individuals being part of the family. We know that in Asian cultures the place of ancestors is very important. In this study, we hypothesized that the Samoan participants would have great knowledge of horizontal links in their family tree (cousins and beyond) and include social links within the family and that the Japanese

participants would have great knowledge of vertical links in their families (grandparents and beyond) based on their respective cultural values and norms.

Whether described as narrative, biography, or story-telling, the practice of telling another person about one's illness increases patient understanding of their own behavior to motivate some change (Charon, 2006). One study in this area added a visual dimension by giving cameras to young adults with type 1 diabetes to document their own health-related behaviors. They suggest that combining biomedical and biopsychosocial data may help patients reflect on correlations between behaviors and health and thus serve as a motivator for change (Smith, Frost, Albayrak, & Sudhakar, 2006).

Before standardizing online family history tools for clinical practice, we need to learn more about the process of collecting family history with populations who may serve to benefit most from this health technology. We suggest that, for some populations, transforming the collection of family medical history closer to storytelling and sharing genealogy, along with adding the visual element by collaboratively drawing the family tree, will increase awareness of the link between family history and disease. In turn this awareness then leads to increased engagement and greater ownership of the individual's health and the health of his or her family members. In this way, appropriate family history offers the potential to have an impact on health disparities. Many ethnic groups who are at highest risk for chronic diseases that are associated with familial risk have little access to genetic specialty services; however, a strength of their cultures is strong kinship ties with a high sense of solidarity with their kin. Viewing personal health not as individual risk but rather in the framework of the family may be a very compelling public health message. Family history offers a culturally relevant way to deliver this message.

The aim of this study is to test this method of collecting family history information in two groups that are at high risk for type 2 diabetes, who both have traditions of honoring their genealogies: Samoan Americans and Japanese Americans. The goal is to understand salient cultural features, including differences in definitions of family, relevant to collecting family medical history information as pilot data for a future study comparing the effectiveness of online family history tools with a storytelling method.

Method

Study Design

From January to June 2000, a convenience sample of 19 participants—9 Samoan Americans and 10 Japanese Americans—were recruited. Eligible participants were males and females aged between 21 and 75 years who self-identified as Samoan American or Japanese American living in the Seattle Metropolitan area. There were no other inclusion criteria; those who did not speak English were excluded. The sample was recruited after consultation with respected community leaders who used community organizations or personal contacts to advertise the study and solicit volunteers. Potential study participants who agreed to be contacted received a mailed invitation to participate in the study, with a follow-up phone call to set up an appointment for consent and the in-person interview. The acceptance rate was 100%.

Data Collection

Qualitative interviews were conducted over 1 to 2 hours in participants' homes or offices. All interviews were in English and audio-taped for future transcription. After collection of basic demographic information—age, gender, place of birth, and highest level of education completed—the interviewer asked study participants (probands) to “tell me about your family.” This broad question was purposefully used to follow the cultural practice that is common when sharing genealogy and is in contrast to the structured enumeration of first-degree relatives,

followed by more distant family members that is typically used in a genetic pedigree interview. Each participant was queried about increasingly distant relatives until no additional relatives could be identified. The pedigrees were hand drawn by the study interviewer, with the participant actively observing and correcting during the process. Following this, the interviewer called attention to each relative listed and asked about their health histories and vital statuses. The participants were asked specifically about the presence of diabetes, heart attack, stroke, and “other kinds of heart disease” in their families. However, participants frequently volunteered additional family health history information such as the occurrence of cancers and psychiatric illnesses.

Collection of family history data was followed by a series of open-ended questions that explored the individual’s level of comfort with disclosing family information, aspects of the family history that were particularly interesting or helpful, and those topics that were difficult. Participants were also asked their preferred format for providing family information (in person, by telephone, or via a self-administered written or online form). Additional open-ended questions served to guide a discussion about how family is defined, family inheritance of illness, beliefs about the role of genetics in disease, and issues concerning informed consent and genetic research.

Data Analysis

Qualitative data were analyzed using content analysis (Holsti, 1969) to identify recurring themes as well as diversity of views and opinions about genetics and the process of constructing family medical history. The interviews were independently reviewed and coded by the investigators to identify issues, concepts, and themes. Codes were then generated, which were interpreted based on the original research objectives as well as on the themes that emerged from the data. The family history data were entered into a computerized pedigree software drawing program, Cyrillic, Version 2.1 (Cherwell Scientific, Oxfordshire, U.K. 1997, available at <http://cyrillicsoftware.com>). An additional copy of the computerized pedigree was prepared with all health-related information and information removed that was identified by the study participant as sensitive or confidential. This was then printed on high-quality paper and mailed to the participant as a family keepsake along with general information about genetics and inherited disease. The University of Washington Institutional Review Board approved all procedures, and informed consent was obtained for each participant.

Findings

Our sample consisted of 12 females and 7 males, with an average age of 47 years. All the Japanese Americans reported being married (three reported their spouses as deceased), whereas less than half of the Samoan Americans interviewed reported being married. The highest educational level reached varied from 12th grade/GED to postgraduate education, with the majority of participants having completed some or all of college.

Reported family size was similar for both groups. Samoan American families averaged 45 persons (median = 47; range = 20–73). Japanese American families averaged 43 members (42; 22–69). Although all but one of the Japanese Americans interviewed were born in the United States, more than half of the Samoan Americans were born overseas (American Samoa, Samoa). All the Samoan American families currently had some members living outside the United States (Samoa, New Zealand, Australia), and half of the Japanese Americans had relatives living in Japan.

Recalling names and ages of four generations was not difficult for these study participants. They were able to report the disease history and cause of death for many relatives; however, these reports were not confirmed with medical record or death certificates to validate the

accuracy of this information. As could be expected, when the person died overseas, or long ago, a specific diagnosis was rarely available. Many grandparents died of vague causes, such as “was sick then just dropped dead” or “stopped eating and died.” Even though the inclusion criteria did not specify the presence of diabetes, of the 9 Samoan Americans interviewed, 6 reported having diabetes themselves or having a first degree relative with diabetes, and among the 10 Japanese Americans interviewed, 7 reported diabetes within their families.

When Samoan American participants were asked, “tell me about your family,” persons fulfilling social roles were described by that relationship. For example, an individual raised as a brother was identified as a brother whether or not there was a biological basis to the relationship. Similarly, individuals adopted in to or out of a family were described as the children of the family in which they were raised, not as offspring of the biological family. When further questioned, the participants could identify the biological link. But even when the biological relationship was known, the Samoan Americans reported family relationships based on social rather than biological ties. In contrast, Japanese Americans in this study defined family based on biological ties.

One Samoan American participant initially denied any diabetes in his family. As he and the interviewer were finishing up and ready to leave, he mentioned something about his grandfather who had died a number of years ago. This led to a conversation about the grandfather and it emerged that the man had diabetes. Initially in the interview his death had been attributed to “old age.” The young man explained that to him diabetes is just one of those things that most old people get; it is a part of life, part of getting older. For this research participant, diabetes did not fit into the category of “illness.” We do not know how prevalent this attitude may be. It is not clear whether this individual would have volunteered this medical information if he were completing a standard family history using a generic tool, but he did share it in an interview context.

A particularly strong finding in this study was the high degree of acceptance with the process of collecting family history data. All participants enjoyed seeing their family displayed in a visual pedigree. The question “How was it for you to do this family tree with me?” elicited statements such as the following:

I can show this to my children, they should know their family.

It feels good to know my family is so big.

It’s fun to see it and then really just to help me to remember the connections to all my relatives. I’m real visual anyway, so it’s good to do this.

It made me proud to see such a big family.

The prompt “Can you imagine this interview or parts of it making anyone you know feel uncomfortable?” yielded the following from 3 participants:

Only my dad who has passed, and my auntie. Talking about that reminds me of them, and you know, I feel sad.

I look at my sister’s daughter and I want to find her (daughter was adopted out).

With *Nisei*, you would find them much more suspicious about people who want to know anything about their family. It’s the Internment and this led to mistrust for anything associated with the government. My parents told me that they were told the census was confidential, but then that was used to track down family members to send them to relocation camps.

The preferred format for providing family information was in person for all respondents. Knowledge of genetics was mixed, ranging from full understanding to a lack of basic

knowledge about the link between disease and genetics. When asked who in their family would need to give informed consent for a genetics study, the majority of participants said just themselves, but several, as they understood the complexity of the question, replied that they would need to think more about it. One woman said her parents would need to be involved in a decision that concerned the whole family. A practical problem in this case is that her parents live in a small village in Samoa, so contacting them for consent would pose real challenges.

Discussion

Geneticists have long understood the ability to recognize patterns of disease susceptibility and identify inherited disorders through pedigree analysis. Recently, this process has taken on renewed importance in public health and primary health care. With the introduction of new Web-based tools, collection of family medical history is being publicized as an accessible, efficient, and effective genomic tool. Downloading a family history collection tool from the Internet and completing it prior to a health care provider visit has the advantage of allowing people to confer with their relatives or even review family medical or death records, potentially improving the reporting accuracy and completeness. However, the utility of this process has not been fully determined, particularly in non-Caucasian samples.

In the study reported here, there was a high degree of acceptance with the process of reporting and recording family history. Participants enjoyed seeing their family graphically displayed in pedigrees. They commented that this process made them realize that the presence of diabetes was more common in their family than they thought. This elicited questions about their own risk, and that of their children or nieces and nephews. Knowledge of risk is one factor to motivate behavior change, but it is not the only one. Whether adding the opportunity to collaboratively create a visual family tree with medical history further increases positive behavior change is a question appropriate for future research.

Although the My Family Health Portrait formally acknowledges that “no form can reflect every version of the American family” and encourages families to use the tool “as a starting point and adapt it to your family’s needs,” there is potential for use of a single limited tool to become standard clinical practice. There is diversity in how family is defined. Polynesian culture emphasizes extended kinship ties, and this was confirmed in this study as Samoan Americans did not privilege biological links over social ties. The families included adopted children, cousins raised as brothers, and aunts functioning as mothers. When asked to identify blood relations, they were able to do so, but that meant that some individuals previously drawn as siblings had to be moved to a more distant space, and those who had left the family were artificially reunited with their kin in the family tree.

Also relevant to knowledge and recall are the methods of communicating family history. Many cultural groups in the United States have rich oral traditions and share family history through the practice of storytelling. An interview process that honors storytelling more closely mimics this practice, and thus may yield better information than an online or paper questionnaire.

There are practical issues of inaccurate data if a single tool becomes the clinical standard, but there are also social and cultural implications of a movement toward a narrow, biomedical definition of the family. Stressing genetic transmission emphasizes particular notions about family relations. This is counter to the changing patterns of family in many societies. A definition of family that is exclusively biological does not reflect the reality of modern multicultural populations and contemporary social practice. There are consequences with widespread use of a family history tool that is out of step with how many define their family. This raises questions about the acceptability of such a tool with many members of society.

This preliminary work represents an initial step toward further research to understand how family history can be used to help those who may need it the most. There are limitations to this study. The small size of the sample and method of convenience recruitment do not allow generalizability of the findings. The sample size allowed us neither to compare the groups nor to test our hypothesis about cultural differences in the breadth of knowledge regarding extended kin in one generation or knowledge of ancestors. Because we did not include an online format, we are unable to make comparisons between the two methods. However, we interpret our findings as indicating benefits with a culturally targeted approach. This study indicated the need for future research with larger sample sizes, diverse populations, and controlled comparison of methods of collecting family history for accuracy and acceptability.

In conclusion, despite the noted limitations, this study supports the positive role of family history in public health efforts, including the elimination of health disparities. Appropriate use of family history tools has the potential to be beneficial to populations who have the highest burden of the target diseases and limited access to other genetic technologies, but also have strong extended kinship ties and thus value family connections. Results of this study support current recommendations to include racial, ethnic, and cultural factors in the assessment of family medical history tools and have implications for public health professionals and health care providers, in particular, recognizing the importance of identifying basic assumptions about who makes up a family and recognizing the cultural and social nature of kinship. The promise of beneficial outcomes is moderated by cautions against normalizing a single biomedical view of the family and ignoring the rich variation in family that is part of modern society. Before protocols are written and clinical standards adopted, it is worthwhile to step back and deconstruct the concept of family as having both biological and social elements and to find ways to leverage both types of information to achieve improved population health.

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