

Analyzing the Use of Race and Ethnicity in Biomedical Research from a Local Community Perspective

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Most discussions of the use of race and ethnicity in biomedical research and clinical care focus on broad national and transnational populations.¹ Looking at the problem from the perspective of large populations, however, misses the rest of a continuum that runs from the global human population to local communities. If race and ethnicity are fundamental categories for biomedical analyses, they should be informative at all points along that continuum, much as the definition of a gene remains unchanged whether analyzed in the context of an individual, a group, or the total human population. By examining the utility of racial and ethnic categories at a local community level, we can better evaluate whether those categories are indeed fundamental units for analysis. Alternatively, these categories may be analytic proxies useful primarily for approximating aggregate biological and social features of large populations at national and transnational levels of analysis.

Investigating the usefulness of racial and ethnic categories in local interactional communities is useful because those communities are the primary sites where inherited and environmental factors combine to contribute to the health status of individuals.² “Interactional community” refers to the everyday social territories within which people reside and work and have access to face-to-face encounters.³ While there are many other kinds of communities (such as occupational communities, communities of identity, and religious communities), it is within interactional communities that we generally find the most influential factors contributing to health. Put simply, place has a huge impact on health, for a variety of reasons. There are, of course, highly mobile individuals whose life histories or lifestyles transcend the boundaries of everyday interactional communities. Indeed, increasing globalization may weaken the cumulative effects that place has on health. Nonetheless, many people still reside and work in the same place for many years. This pattern is particularly pronounced in rural areas.

Ethnographic Examples

Individual interviews, ethnographic participant-observation, and focus groups were used to investigate health practices in three rural, predominately African-American communities, and three rural tribal communities, all in Oklahoma. The African-American communities ranged in size from 200 to 800 residents,

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while the tribal communities ranged from 2,000 to 3,000 members residing within twenty miles of one another. One hundred individual interviews were conducted across the three African-American towns and ten focus groups were conducted in each town. Fifty individual interviews and twelve focus groups were conducted in each tribal community. Two of the tribal communities are located in proximity to the three African-American towns and share some members.

These studies were designed as an investigation of practices that were common among community members, using life history and illness narratives. That is, participants were asked for self-structured narratives of their lives and also for self-structured narratives of their most recent illness. The comparative analysis presented here demonstrates the utility and value of investigating local, community-specific health practices. The comparison offers a local critique of associations traditionally made among disease, transnational categories of race and ethnicity, and socioeconomic status defined without reference to a local community.

Members of each local community organized their health beliefs and behaviors along two primary vectors: (1) interactions with Euro-American outsiders (who represent the dominant political economy) and (2) intra-community interactions.

Not surprisingly, interactions with Euro-American outsiders were framed primarily as economic transactions. Moreover, these interactions tended to be interpreted as ones in which community members believed themselves to be at an inherent disadvantage because the economic process and its primary benefits remained outside the community. This created difficulties that often aligned with race; that is, a minority identity based on ancestry was predictive of difficulties that study participants encountered in interacting with members of the majority population, and so was used to structure practices to cope with those difficulties.

The African-American members of each local community had developed health-related practices that minimized their dependence on interactions with outsiders. An example of one such practice was the continued use of practical herbal knowledge by traditional herbalists to treat symptoms. Individuals also tended to minimize signs of illness, delaying resort to biomedical providers until symptoms were sufficiently severe to limit or disrupt everyday mobility. When community members finally sought care, they tended to bypass clinics and hospitals in nearby, predominantly Euro-American towns in favor of more distant urban

locations where providers were used to seeing larger numbers of African-American patients.

Members of the tribal communities showed similar patterns. While community members had local access to the Indian Health Service (IHS) (indeed, two of the communities used IHS clinics and hospitals that had

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been contracted out to tribally-run health systems), they nonetheless saw IHS services as extra- rather than intra-community services. This was because many of the health professionals were from outside the community and because IHS services were modeled on Euro-American rather than Native systems of care. Like the African-American community members, Native people in these three communities developed alternative strategies for using biomedical resources. These strategies included shopping among different clinics and hospitals based on word-of-mouth about the fluctuating availability and quality of services, as well as extensive use of traditional health practices and practitioners.

In both the African-American and tribal communities, the practice of trying to minimize use of extra-community health resources seemed to have significant consequences for how community members recognized signs of illness and sought care. These practices, in conjunction with structural barriers to health care such as lack of health insurance, may have contributed to later presentation of disease to external health providers, more severe disease symptoms, poorer patient compliance, shorter survival, and higher mortality rates for many diseases. At the same time, the economic disadvantages shaping health care access, patient perceptions, and patient decisions may have contributed to disease etiology and severity by supporting (among other factors) higher risk dietary practices, residential proximity to environmental toxins, and employment in risky occupations.

Arguably, classifying people using large-scale categories such as "African-American" or "Native American" can be helpful in understanding community practices with respect to external sources of care, because such practices are based on conditions of discrimination and economic disparity that are more or less consis-

tent throughout the United States. Thus many of the practices relating to external sources of care are relatively similar across the different African-American and Native American communities in this comparison. It is possible, however, that local African-American and Native American communities (particularly ones that are more geographically distant from one another than those in this comparison; that is, outside the state of Oklahoma) may construct varying practices to deal with those similar conditions.

In contrast to the consistency found in how communities dealt with external sources of care, there was substantial variation among localities in how community members interacted with one another. For instance, one local African-American community was constituted primarily by five church congregations. Reciprocal assistance (including help in making health care decisions and in providing mutual care when needed) occurred mainly within each of those congregations. Another local African-American community, however, was organized primarily by a number of extended families, within each of which similar mutual assistance occurred. Relations among those extended families tend to be organized by economic status, a process that increased the solidarity within a family while distancing its members from other families. Yet a third local African-American community was organized by households, with those households that had similar levels of resources tending to ally together. There were redistributions of wealth from higher to lower status households, entailing hierarchical social and, especially, political obligations (relating primarily to election for town trustee) on the part of those receiving help.

Each of these different modalities of intra-community interaction entailed different health consequences; each affected contributors to disease such as stress, diet, access to care, and symptom recognition. The community organized by church congregations, for instance, offered a wider range of individuals to consult about illness signs and to provide transportation to clinics or hospitals. There also was an extensive reliance on homegrown vegetables and hunting and fishing in this community, with households reciprocally sharing those locally produced foodstuffs. The community organized by extended families, in contrast, had more limited social networks for mutual assistance and reciprocal exchange, which may have restricted diet to processed foods and limited access to biomedical care (among other implications). At the same time, greater family solidarity may have had consequences for stress levels that were different from those in the first community. The third community, organized primarily by economic status, seemed characterized by larger dif-

ferences in the practices of individuals who provided resources and those who receive them, which may have had health consequences different than those of the other two groups. Unlike the other two communities, for example, the third evidenced a more pronounced division of labor, with individuals having different everyday routines that entailed different physical exposures.

Interestingly, each of these predominantly African-American communities also *included* Euro-Americans and Native Americans who were local residents. While those numbers were small in each town (no greater than ten percent of the total population in each), those individuals were included in local practices. That inclusion demonstrated that locality can be more important than racial or ethnic identity in determining health status and intra-community health practices. However, the Euro-American co-residents displayed very different extra-community health practices than their African-American and Native American co-residents, such as tending to make earlier and more frequent use of nearby health care facilities in predominantly Euro-American towns. Thus, with respect to external practices, racial or ethnic identity can be more predictive than locality.

Intra-community health practices also varied among the three American Indian communities. In one Native community, social practices through which intra-community health care and advice were provided centered on membership in traditional ceremonial grounds or Christian church congregations. Persons who were recognized as being ill were visited, transported, provided food and wood or other material for heating, as well as monetary support by fellow members of a ground or church. This mutual assistance reinforced the solidarity of those extra-familial social units. These social units also attempted to resolve any social conflicts that could be blamed for the group's ill health.

In contrast, in a second community in which members were also divided between traditional ceremonial grounds and Christian church congregations, there was a strong sense that communication about health status as well as demonstrations of mutual concern and mutual assistance should cross those religious boundaries. This density of interrelationships was characteristic of the way in which this second Native community was organized, just as greater boundaries dividing constituent social units was characteristic of the first Native community.

In a third Native community, members carefully limited their discussion of health status and illness to close family members of the same gender, beginning with elder family members. In those discussions, etiology typically was not specified. Implicit associa-

tions between the personal power of an individual and well-being were indicated, such that illness was seen as a symptom of loss of personal power, but these were not further developed into explicit explanations that accounted for the occurrence of illness. In public encounters, even those community members who were ill presented a facade of well-being. Intra-community interaction was a careful dance to maintain and, if possible, enhance each person's own face as well as the

Social scientists have critiqued biomedical uses of race to predict health status, arguing that most, if not all, of the effects attributed to race are actually the result of being a member of a disadvantaged economic class.⁴ This is a valid criticism with respect to analysis of national and international populations. However, community-level analysis suggests that class or socioeconomic status may not necessarily be predictive of localized health disparities. The comparison above shows

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faces of others. Attempts at degrading the faces of others were rare because of the cooperation that was necessary for the successful negotiation of the everyday encounters that comprised social life in the community.

As in the predominantly African-American communities that included local Euro-American and Native American co-residents, these three predominantly Native American interactional communities (which are premised on shared standards for social encounters rather than tribal enrollment) included some African-American and Euro-American co-residents (again, no more than ten percent in each community). Much as intra-community health practices were shared by co-residents in the African-American communities, internal practices were also shared in the Native-American communities by some members who had alternative claims to Euro-American and African-American identities. For example, Native healers and herbalists in all three communities had Euro-American and African-American patients in addition to Native American patients. Again, this suggests that locality matters more than large racial and ethnic categories when studying intra-community health practices.

When health disparities result primarily from practices internal to local communities rather than resulting from the workings of large racial and ethnic categories, only community-level study will illuminate them. Indeed, the ways in which local practices are integrated into a lifestyle or *habitus* make them inaccessible to analyses that aggregate participants by large-scale identities such as race and ethnicity. Local variations in practice tend to be lost in large multi-site analyses. Moreover, some local practices cross racial and ethnic boundaries, as shown in the comparisons above.

that external health practices varied among African-American and Euro-American co-residents with similar economic status and that intra-community health practices varied among local communities with similar economic status. Economic disparities thus seem to be among the factors (including race) that shape an integrated set of community-specific practices with respect to health. Consequently, to understand how socioeconomic status or class (or race or ethnicity or culture or lifestyle or gender) affects the health of individuals situated in specific localities, it is necessary to identify the community-specific health practices and how they help constitute a communal *habitus* in a particular ecological setting.

Race and Ethnicity in Local Context

Clearly, local variation with respect to intra-community interactions and practices can be glossed over by aggregative racial and ethnic categories. Some local practices contributing to health status and outcome may cross racial and ethnic categories. Some of the underlying structural conditions that contribute to those community practices will also cross racial and ethnic categories. Most biomedical research studies, though, tend to ignore local contexts in analyzing results, either to gain statistical significance by aggregating sites or by treating locally-recruited participants as "typical" examples of larger racial and ethnic populations.

Contextualization, however, requires community-specific research. Such research uses labor-intensive, qualitative methods to acquire the background knowledge necessary to interpret local contexts.⁵ These studies have the disadvantage of using small numbers, so their conclusions often do not have the imprimatur of

statistical significance. The analyses presented here, for example, are based on extensive qualitative ethnographic participant-observation carried out over several years, rather than quantitative closed-end surveys conducted over a period of days or weeks. Community-based research also requires the collaboration of local community members, not only in participating in a study, but increasingly in helping to plan and carry out studies and analyze data.⁶

In collaborating on these studies with African-American and Native American community members, it was clear to us that local community members were aware of the significance of broader racial and ethnic categories for making the case that health disparities exist and increased access and resources are needed. Racial and ethnic categories can be particularly important in securing resources to reduce structural barriers to prevention and care, especially where racial and ethnic categories are embedded in health care and research infrastructure and policy. Thus, it can be helpful to use racial and ethnic categories in gathering and reporting disease incidence and mortality and to use tribal membership to access IHS and tribal clinics and hospitals.

Members of local communities were also aware of the ways in which racial and ethnic categories were used against them in the form of discrimination and stigmatization. Those adverse uses crossed communities and probably accounted for the similarity in the ways that African-Americans and Native Americans related to extra-community health resources. At the same time, though, members of local communities were concerned that the larger racial and ethnic categories would gloss over those intra-community practices that they valued and that may be more immediately relevant to their health status and outcomes.

Race and Ethnicity as Analytic Units

How, then, do examples from local communities inform the debate over the use of race and ethnicity in biomedicine? The comparison presented here suggests that race and ethnicity as analytic categories are even more heterogeneous when viewed from the perspective of local communities than when considered in the context of national and trans-national populations. This suggests that racial and ethnic categories are not fundamental social or biological units of analysis. Instead, these categories should be treated either as proxies for factors influencing health in large data sets (though a case must be made in each study for the validity and utility of doing so) or as social forces that can affect individuals' behavior. Using racial and ethnic categories as proxies should not be relevant to local level analy-

ses, but studying racial and ethnic categories as social forces certainly is relevant. Race and ethnicity were most apparent in local African-American and Native American communities included in this comparison in how those very labels were imposed externally by others on their members, and so in how members constructed relationships with outsiders. Indeed, based on intra-community interactional practices, even labeling these communities as "African-American" and "Native American" is somewhat misleading. It is evidence of the extent to which externally imposed, aggregate racial and ethnic categories have permeated the way we conceptualize local places. If, instead, we were to think about the localities in our study as multi-racial or multi-ethnic everyday communities, the finding that internal health-related practices are shared across multiple identities held by people with common socioeconomic statuses would not be surprising.

Understanding contributors to health is a multi-level problem that cannot be reduced to a single, static typology. Nor, in the case of community-based research, can it be left to a single methodology. Arguably, the dominance of racial and ethnic categorization in biomedical research can be directly linked to the dominance of quantitative approaches that depend on aggregating large numbers of individuals into a small number of analytic categories to attain significance. Qualitative studies of health-related practices in local communities provide an important alternative view of complexity and heterogeneity.

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