



Modeling health inequities research in context and the minority researcher's role

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Modeling health inequities research in context and the minority researcher's role

Abstract

Current health inequities research templates are flawed and self-defeating because they do not include historical inequalities as the central context that points to the root causes of health inequities. The context includes structural malformations which are products of the history of colonization and slavery that created racial separation and hierarchies which established Whites as the dominant group and non-Whites (minorities) as the subordinate group. Consequently it is difficult for mainstream researchers to capture the minorities' core knowledge necessary for the creation of relevant and effective interventions for fundamental and sustainable improvement of their health. This paper proposes a health inequities research model that captures the context of health inequities and the essential and unique role of minority researchers.

Keywords

Discrimination in medical care; Health inequalities; Health services accessibility; Minorities – Medical care – Research; Minority representation



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ABSTRACT

Current health inequities research templates are flawed and self-defeating because they do not include historical inequalities as the central context that points to the root causes of health inequities. The context includes structural malformations which are products of the history of colonization and slavery that created racial separation and hierarchies which established Whites as the dominant group and non-Whites (minorities) as the subordinate group. Consequently it is difficult for mainstream researchers to capture the minorities' core knowledge necessary for the creation of relevant and effective interventions for fundamental and sustainable improvement of their health. This paper proposes a health inequities research model that captures the context of health inequities and the essential and unique role of minority researchers.

Key Words: health inequalities; minority representation

INTRODUCTION

A concerted effort to end health inequities has met with little success. Despite the expenditure of substantial resources and the establishment of numerous programs with the sole purpose of ending health inequities, there are indications that not only do inequities persist (Jha, Fisher, Li, et al., 2005) but that the gap might be growing (Centers for Disease Control and Prevention, 2005; Hambidge, Emsermann, Federico, & Steiner, 2007; Halm, Tuhrim, Wang, et al., 2009; Holmes, Arispe and Moy, 2005; Mead, Cartwright-Smith, Jones, Ramos, Woods, & Siegel, 2008; Silventoinen, Pankow, Jousilahti, Hu & Tuomilehto, 2005; Polednak, 2004;). It is imperative that these programs be constantly monitored and that all aspects of these programs are critically re-examined and revamped to improve their effectiveness in reducing health inequities. Moreover, the sordid history of abuse of non-Whites in health care and medical research (Davis, 2006; Smith, 2005; Lawrence, 2000; Washington, 2007) mandate regular and careful surveillance of mainstream research structures and templates.

The purpose of this discussion is to examine current research templates in the context of minority health inequities. We contend that current health inequities research templates are flawed and self-defeating because they do not include historical inequalities as the central context that points to the root causes of health inequities. In our view, the problems of minority health inequities remain unsolved, because as outsiders who were historically excluded from designing programs and institutions, minorities receive what they are given, based on what the giver assumes they need, therefore, their real needs can never be fulfilled to their satisfaction. Their participation in these programs is a form of "domination" in that they "play" according to the design of the dominant group. Therefore, research on health care inequities is ill-served by approaching the task as if the institution being studied was ideology-free. We believe that, as a starting point, it is important to be honest and acknowledge the fact that the American civilization was not originally intended to serve the interests of everyone. As well documented in the history of the United States of America (Zinn, 1980), White-Americans imposed their ideology in a manner that "included" their viewpoints and, simultaneously, "excluded" the non-White viewpoints in the design of the American civilization. It should be noted that we use "non-White" and "minorities" as identical terms although we prefer the former because, whether intended or not, the term "minority" metaphorically, insinuates "inferiority" intended or not. We also acknowledge our simplification of grouping all White-Americans as the "privileged" people. We know that there are White people who are poor, which can be explained by how every ideology has sub-ideologies such that within a given group there are hierarchical categories of people in power (included) and people outside of the power (excluded). We are applying racial/ethnic grouping because as we discuss later, historically there has been a separation of the races leading to differences in experiences, perceptions, expectations, and cultures. It is not an exaggeration to state that even today most powerful institutions are run by White males, and that even poor White people do feel "superior" and different from non-Whites.

Lehman (1992) points out that "all researchers, implicitly or explicitly, chose sides in social conflicts" (*Accounting's changing role in social conflict*. New York & Princeton, NJ: Markus Wiener, p.54). She goes on to elaborate that, consequently, researchers "assume interests to advocate, perpetuate, and support" (p.54) particular ideological positions. She is critical of the traditional research that assumes a conflict-free collective existence.

We concur with Lehman (1992). Rather than a collective existence, society is composed of actors positioned on different planes of the hierarchical order; some are the dominant while others are the dominated; consequently if there is any bargaining, it is among people of unequal positions. While changes have occurred over time, minorities' unrelenting socio-political and economic disadvantages are not accidental but a product of domination in the original design. In our view health inequities research approaches tend to ignore this fact. We believe that our starting point as researchers is to explicitly recognize the origins of the socio-political-economic context of health inequities. To do so is to incorporate the power differential at the core of research.

It is important to recognize that research templates affect the quality of data collected, the analysis and interpretation and, consequently, the quality and effectiveness of the resulting interventions and their application methods. Where inequalities are not factored in as part of the research approach, then research templates made up of the dominant ideology (from the mainstream) are inappropriately imposed on minority settings. Therefore we advocate for research templates that are cognizant of the context of health inequities and that allow experience to inform inquiry so that data gathered are relevant and useful in creating effective interventions.

BACKGROUND

Power, socioeconomic (SES) and health inequities

The history of slavery and colonization resulted in power inequalities with minorities experiencing more oppression, imposition and exclusion. Consequently, a minority person has a higher likelihood of experiencing poverty than an individual from the dominant population. The US has some of the highest income disparities in the world with minorities experiencing high levels of poverty particularly in the inner-cities (Bourgois, 2002). Research documents that poor people experience worse health than the rich do and that income inequalities exacerbate health inequities (Lynch, Smith, Kaplan & House, 2000; Rodgers, 1979; Wilkinson, 1997; Wilkinson, 1992; Wilkinson, 1989, Marmot, 2005). Similarly, research also indicates that socioeconomic status (SES) is a more consistent predictor of health, disability, and access to care than minority status (Mwachofi & Broyles, 2007; Mwachofi & Broyles, 2007; Mwachofi, 2006; Wilkinson & Marmot, 2003) and that the socioeconomic gradient in health is also evident within minority populations (Subramanian, Smith & Subramanyam, 2006; Rodriguez, Sciacca, Dies-Roux, Boden-Albala, Sacco, Homma, et al., 2004). Low-income minorities experience the most acute care access barriers (Lillie-Blanton, Leigh, & Alfaro-Correa, 1996). Therefore, low-income minorities experience double health jeopardy - consequences of poverty and of discrimination in health care and in other facets of American life.

Consistent with the history of power differential, there is differential treatment and access to health care when White-Americans are compared to minorities (Institute of Medicine, 2002). There is evidence of segregation in health care. For example, research in cardiovascular health indicates that there is segregated health care (Kressin, 2005). Skinner, Chandra, Staiger, Lee and McClellan (2005) conducted a large prospective cohort study of 1,136,736 fee-for-service Medicare patients treated in 4,289 hospitals for acute myocardial infarction (AMI) between 1997 and 2001. These researchers found that risk-adjusted mortality after AMI is significantly higher in US hospitals that disproportionately serve Blacks. A reduction in overall mortality at these hospitals could dramatically reduce Black-White disparities in healthcare outcomes.

There are indications that the effects of political systems and priorities shape health disparities. In a review 45 such studies Beckfield and Krieger (2009) found that the studies clustered around four political structures: the transition to a capitalist economy; neoliberal restructuring; welfare states; and political incorporation of subordinated racial/ethnic, indigenous, and gender groups. Evidence from the reviewed studies suggests that the first two structures might increase health inequities, the third has an inconsistent relation to health disparities and the fourth factor might reduce disparities.

Consistent with our view of power, Fausto-Sterling (2008) argues that the social produces the biological in a system of constant feedback between body and social experience. A study conducted in Sweden further illustrates how the social produces the biological. The study purpose was to analyze the association between perceived discrimination and refraining from treatment-seeking and the contribution of socioeconomic disadvantage. Both perceived discrimination and socioeconomic disadvantage were independently associated with refraining from seeking medical treatment. Experiences of frequent discrimination even without any socioeconomic disadvantage were associated with three to nine-fold increased odds for refraining from seeking medical treatment. Experiences of discrimination combined with socioeconomic disadvantage were associated with a multiplicative effect on refraining from seeking medical treatment. The researchers concluded that the goal of equitable access to healthcare services cannot be achieved without public health strategies that confront and tackle discrimination in society and specifically in the healthcare settings (Wamala, Merlo, Boström & Hogstedt, 2007)

The compounding effects of socioeconomic status and ethnicity are not felt in the US alone. They also appear in other countries. Vokó, Csépe, Németh, et al., (2009) investigated whether the association between Roma ethnicity and health is fully mediated by socioeconomic status in Hungary. They found socioeconomic status to be a strong determinant of health that fully explains their worse health status but only partially determines their less healthy behaviors. They conclude that efforts to improve the health of Roma people should focus not only on their socioeconomic status, but cultural differences must be included in developing public health interventions. Another study investigating ethnic disparities in stillbirth risk and infant mortality in Denmark (Villadsen, Mortensen & Andersen, 2009) found that the Turkish, Pakistani and Somali population had substantially higher fetal and infant mortality compared with the Danish majority population, while the Lebanese and former Yugoslavian minorities were at the same level as the majority population. The excess risk was not attributable to socioeconomic conditions. It is for these reasons that we believe that any attempt to address inequities should take a broad view that recognizes the role of ideology, power, and domination in examining the sources of - and finding the solutions to - health inequities.

In a study conducted in the relatively egalitarian state of Kerala in India, Mohindra, Haddad and Narayana (2006) tested two hypotheses that low caste and lower socioeconomic position is associated with worse reported health status, and that the associations between socioeconomic position and reported health status vary across castes. Their findings indicate that women from lower castes reported a higher prevalence of poor health. There was evidence that the associations between socioeconomic indicators and health vary across castes ("magnifying" effect among the backward castes and a "buffering" effect among the forward caste). These researchers concluded that even in the relatively egalitarian state in India, there are caste and socioeconomic inequalities in women's health and that to attain equity, interventions must address both socioeconomic and caste status.

SES is a product of ideology with the dominant/subordinate dichotomy. In this context, instead of throwing money at the problem, it makes sense to take a deeper look at the governing structure in order to highlight the power differentials that are the root cause of the problem. Some solutions are workable when the dominated group is empowered rather than when they are merely spoken for and dependent on the dominant system. Accepting the programs created by the dominant system can mean more domination of minorities even when giving is considered a benevolent act.

Separation of the races

Legal instruments such as Jim Crow laws and treaties with American Indians separated minorities from the dominant population while structurally disadvantaging minorities. The separation ranges in degree from mild to extreme, from neighborhoods to reservations. In most of the US today, minorities still live separately from the dominant population, with different experiences, cultures, perceptions, challenges and expectations. This separation is so persistent that it endures even among the poor homeless heroin injectors and is described by ethnographers Bourgois and Schonberg (2007) as "intimate apartheid". They have observed, "...In fact, African Americans and whites often sleep, inject, smoke and drink side-by-side in the very same encampments, but remain worlds apart."(p.28). They go on to explain, "Marginalized by bourgeois and working class society, homeless drug users are nevertheless still embroiled in the larger field of power informed by racism in the US – especially those dimensions that are dynamized by the particular US obsession with phenotype."(p.28). These ethnographers show that "intimate apartheid" on the street operates at the micro-individual level but at the macro-level it manifests itself in devastating practices that fuel ethnic disparities such as: African American men had six times higher murder rates than

White men; seven times higher incarceration rates; higher unemployment, and the serious health disparities. These ethnographers further argue that most people in the US are convinced that "... the behaviors that propel these ethnic disparities are caused by individual moral flaws that stem from defects in character and/or culture and genotype. They treat ethnic hierarchies as a natural racialized fact They are blind to structural and ideological forces around racism since in everyday interactions individuals – and more importantly categories of individuals defined by skin color – confirm to themselves and others that they deserve their fate..." (p. 29) This separation and resultant perceptions pose a research challenge for mainstream researchers who are expected to articulate the nature and scope of the minority predicament yet they belong outside the realm of the minority experience.

After applying the non-traditional participant observer research approach for ten years, Bourgois and Schonberg (2007) were able to gain deeper insights and to appreciate the differences in the behaviors of individual ethnic groups on account of their historical legacies. For example they understood that because of their historical past, African American men did not want to stoop as low as to be begging for a day job that pays below-minimum wages, under the table and subjects oneself to another "master." Such insights are the product of non-traditional participant-observer research that is cognizant of the larger systemic context that includes history and power differentials and allows for the insiders view and experience instead of the traditional observer view. (We will return to this topic in the proposed the model). In contrast, traditional researchers would likely observe from the outside (surveys) while applying their internalized convictions about minorities' "individual moral flows that stem from defects in character". Such perceptions are bound to affect research agendas, methods, substance and interpretations.

Minority under-representation in the health professions

Again, consistent with our discussion of ideology, power, and domination, minorities are severely underrepresented in the health professions. This fact is particularly true for African Americans, Latinos, and American Indians. Based on these findings, Grumbach and Mendoza (2008) make a strong case for diversity on the grounds of civil rights, public health and educational benefit, and business gains. They advocate for multiprong strategies to improve diversity by addressing the educational pipeline, admissions policies and the institutional culture at health professions schools, and in the broader policy environment. It is our view that even these suggestions for "multiprong" strategies do not amount to much because as long as the fundamental ideologically-imbedded power differentials are ignored those inscribed as inferior will always remain "inferior" and, in fact, the process of minorities accepting those programs is the very process of affirming and legitimizing the hierarchy in the system – that is domination. Minorities are not the originators or participants in the origination of the program, the program is being granted to them because the dominant people are the "benevolent" granting some help to the indigent. This is the sense in which ideologies re-produce their legitimacy, ironically, even in the process of attempting to be fair. It is an example of how, as an aspect of domination, minorities are spoken for.

Crowley, Fuller, Law, et al., (2004) show that African Americans, Hispanics, and American Indian/Alaskan Natives remain severely underrepresented in science and academia despite significant efforts to increase diversity. They illustrate how members of majority and minority groups may perceive climate differently and advocate for attention to the institutional social climate to improve the minority representation. They argue that the benefits of diversity include: a commitment to social justice, a broad diversity of perspectives leading to greater opportunities for scientific advancement, and a potentially enhanced focus on understanding and eliminating the health disparities among different racial and ethnic groups. These ideas are echoed by Jeste, Twamley, Cardenas, et al., (2009)

who also show the widening disparity between the proportion of ethnic minority Americans in the population and the number of researchers. They argue that present academic settings are not optimal for development and sustenance of researchers from underrepresented minority ethnic groups and that there is need for joint effort by universities, medical schools, and funding agencies to implement national- and local-level programs to help develop and reward mentors of junior scientists from ethnic minority groups. Again, this is an example of how minorities are spoken for. Stoff, Forsyth, Marquez, et al., (2009) describe recent epidemiological trends associated with HIV infection in diverse populations. They demonstrate the need to study programs aimed at disparities, and the ongoing mentoring programs supported by the National Institutes of Health targeting investigators underrepresented in the workforce. There is no doubt that viewing health care inequities as an isolated phenomenon is myopic at best.

The Association of American Medical Colleges (AAMC) also recognizes underrepresentation of minorities in the medical profession and in medical education as an obstacle to reducing health inequities (AAMC, 2005; 2006; 2008). AAMC defines under-represented minorities as four racial and ethnic groups: African Americans, Mexican Americans, mainland Puerto Ricans, and Native Americans (AAMC, 2006). Data indicate that although minorities comprise 26% of the total population of the United States only 6% of practicing physicians are Latino, African American and Native American. Only 4% of U.S. medical school faculty members are from these minority groups. However, minority physicians are more likely to treat minority and indigent patients and to practice in underserved communities than are White physicians. They are also more likely to conduct research to help reduce racial disparities in health care (AAMC, 2005). AAMC discusses several advantages of having minority representation in the medical profession including: improved access and quality of health care for minority patients; greater patient choice and satisfaction, and better educational experiences and benefits for all medical school students. Diversity in medical education is also beneficial because it improves cognitive, intellectual, and social outcomes for medical students of all ethnicities (AAMC, 2008). AAMC further shows evidence from research that indicates that minority researchers provide varied perspectives and experiences that may increase the understanding of health and disease patterns in racial and ethnic minority communities (AAMC, 2008). These observations are echoed by the National Academies (2007) which finds that of the 4,396 doctorates awarded in the biological sciences in 2005, only 158 went to African Americans, 227 to Hispanics, and 12 to American Indians

Given these facts about inequities in health status, access to care and representation in health professions in service provision and in research, our view is that a deeper understanding of the sources of these differences can provide interventions that will bring fundamental sustainable changes rather than unsustainable programs that only touch the problem superficially. It is indeed true that the greater the number of minorities in the various programs, the more likely they are to increase the impact of such programs. It would, however, be even better if minorities participated in the initial design of such programs as in the bottom up approach. Providing minorities with room at the table where agendas are set and programs are designed would reduce the power differential thus allowing minorities to be true partners in working to end health inequities.

Some Definitions

We take the view that cultures or civilizations are ideologies. Ideologies, as Hall (1985) points out, "are the frameworks of thinking and calculation about the world – the 'ideas' which people use to figure out how the social world works, what their place is in it and what they ought to do" (1985, p. 99). In agreement with Hall (1985), we take the position that, in actuality, culture or civilization is an ideology because it represents the thinking of the proponents of the dominant people. Ideology is the umbrella under which sub-ideologies are formed and being reformulated on an ongoing basis

as different interest groups push for their agenda or interest. The US is a civilization founded on the colonization of the land of the native people; that process entailed the replacement of the previous civilization with that of the conquerors. The indigenous ideology was supplanted by the European ideology and from there on institutions that represent the interests of the Europeans were created and maintained.

So far, in the context of this discussion, we have attempted to illustrate the point that, by "power," we do not mean power at the superficial level. We are referring to a system that determines how human players interact within the institutions we build and how such institutions serve the interests of certain people while ignoring the interests of others. This kind of power links culture, metaphor, and language at the mind-control level. Institutions, social capital and metaphors that control thought also control action because thought precedes action. Thus the power differential between Whites and minority populations is not only in the superficial level represented by the numbers and faces in high political positions and scene but in the civilization (institutions, metaphors, social infrastructure and human capital).

In this discussion we differentiate between mainstream or mainstream-oriented research and researchers and minority or minority-oriented research and researchers. According to the American Heritage dictionary mainstream is defined as the prevailing current of thought, influence, or activity or the representation of prevalent attitudes, values and practices of a society or group. In this discussion we apply this meaning with an emphasis on the power that the mainstream wields often to the disadvantage of the minorities. Thus mainstream refers to the prevailing research institutions that run and control research structure, methods, paradigms, focus and funding. In the context of this discussion, mainstream research is research according to the White-American design. If we examine this design from the afore-discussed role of ideology, power, and domination we recognize its limitations when applied to minorities. If we view the mainstream research design as "innocent," we will mostly appreciate the benevolent act of funding the research and we lose the diverse viewpoints and opinions of minorities who have a unique perspective to contribute toward the design of the research agenda.

It is important to note that mainstream institutions have a long history in the field with a powerful and well defined infrastructure that is supported by powerful metaphors, human and social capital. The mainstream includes federal and academic research institutions that have been at the helm of US health research for centuries. Such institutions have produced many researchers who support the system and who make necessary adjustments that ensure perpetuity of the mainstream research system and agenda. More fundamentally, there is power in the mainstream. Its perceptions, paradigms, metaphors and methods are accepted as the norm by which everything else is extolled or condemned.

Minority researchers can be defined superficially as researchers from minority populations. However, more fundamentally, minority-oriented researchers are those who conduct research from the minority perspective rather than the mainstream perspective. Such researchers are cognizant of the power differential and of minority experience and of minority perceptions and expectations that are born of the minority experience. Thus, theoretically, it is possible for a White researcher to be a minority-oriented researcher and for a minority researcher to be mainstream-oriented. We could make a case that the research by Bourgois and Schonberg (2007) illustrates a minority-oriented research.

Flaws in Current Research Templates and Discourse

We recognize two major flaws in current health inequities research templates: First, there is no recognition of ideology, power, and domination that make appreciation of historical inequalities

(not merely as relevant factors but as the central context that points to the root causes of health inequities) possible. Second, there is the over-reliance on “objective science” (waMwachofi, 1993) and simultaneous eschewing of lived experience (subjectivity).

By accepting as legitimate, the exclusion of minorities in health care programs and research agenda formulations, it becomes possible to see that their absence is a contributing factor to the failures listed earlier. Consequently we can break the vicious cycle of throwing money into programs and then more money to find out why its does not seem to work. Recognition of the historical context would not only highlight the need to understand health inequities from the minority populations’ perspectives, it will also allow for the possibilities of creating interventions and application methods that would be culturally and structurally appropriate and effective.

When we place objectivity at the core of research, inquiry becomes the end rather than the means for interrogating the nature and scope of health inequities. Human experience, which should be at the core of inquiry, is relegated to the periphery. Consequently health inequities research has several potential negative side effects including: debilitation, dependency, perceived imposition, resentment, sabotage, and perpetuation of the differences and artificial race hierarchies instead of seeking for similarities between ethnicities. Such side effects could be avoided through research templates that are inclusive, cognizant of the context of health inequities, and which place human experience at its core. Now that we have presented the role of ideology, power, and domination let’s look at research roles in the social sciences.

Typical Field Research Roles in the social sciences

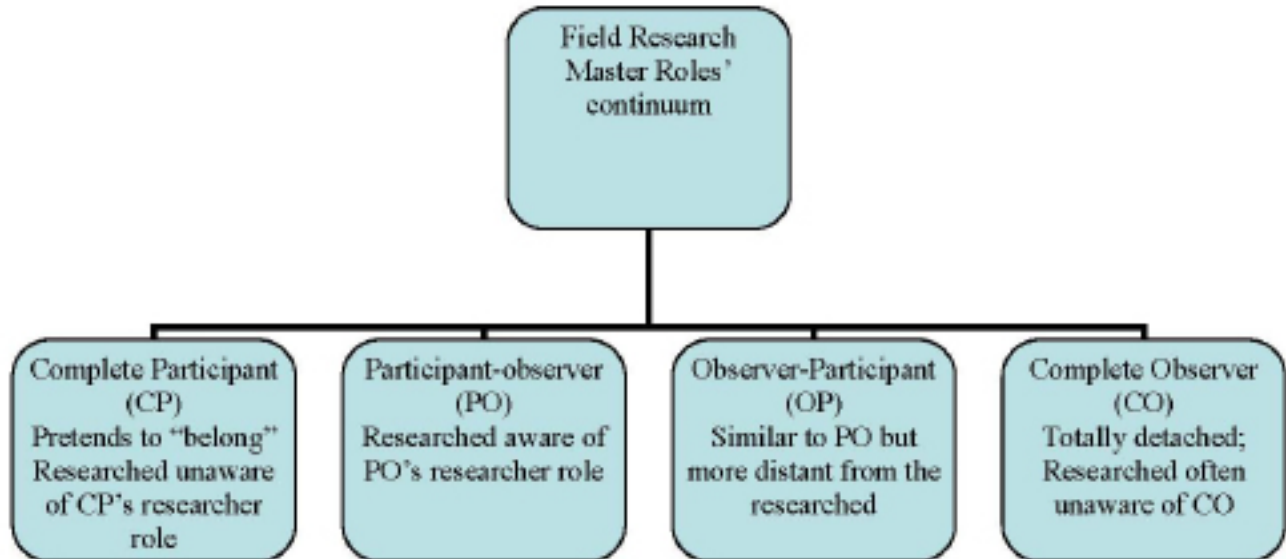
In the social sciences, the “objectivity-oriented” field research template has two major protagonists: the observer who is collecting information and the informant (IN) who is the object of research and from and about whom the information is gathered. Within this context, Gold (1958) defined four master roles on a continuum as depicted in Figure 1. On the one extreme is the complete participant (CP) and on the other is the complete observer (CO). Close to the participant is the participant-observer (PO) and close to the observer is the observer-participant (OP). These roles are defined by the degree to which the researcher participates in the activities of the researched and the distance between the researcher and the researched.

From Gold’s (1958) perspective, each role has its advantages and limitations. The role the CP takes is steeped into the informants’ daily activities so that the informants are unaware of his/her role as a researcher. The advantages are that there is effective communication with the informant. From the perspective of “objectivity” the CP has a disadvantage of over-identifying with the informant or “going native” leading to a distortion of the researcher and analyst role. The PO is further removed from the informant who is fully aware of the PO’s research role. It is also possible for the PO to “go native” or to become too far removed from the informants so that he/she is de facto an observer.

The Observer-participant is unlikely to “go native” but is likely to have ineffective communication with the informant and therefore, might misunderstand information gathered. The complete observer (CO) is even further away from informants and might be guided more by pre-existing target concepts and expectations and is therefore likely to misinterpret what is observed. Because of the distance between the CO and informants, one might assume that there will be a greater likelihood of “objectivity” in observation and analysis. However, it is also possible that the weight of the observer’s pre-existing definitions, concepts and expectations might mar the observer’s ability to understand what is observed or to be objective. What is observed is what was expected to be observed and the conclusions from the observation are mere confirmations of the observer’s expectations. On the other extreme, participants might lose “objectivity” and “go native” but they have a greater in-depth understanding of the informant’s position and of the information gathered from the informant. Thus

the analysis and conclusion might be purely from the informant's perspective but they are based on a clear understanding of the facts of the informant's life experiences, perceptions, expectations and circumstances.

Figure 1: Gold's social sciences field research continuum of master roles



Adapted from Gold, 1958.

This model is based on a research template that ignores the historical context of health inequities and has a heavy stress on "objectivity", at the expense of "native" knowledge, thus the fear of CP or the PO "going native". It also ignores the role of the informant in research – the individual from the focus population. This research template gives a heavier weight and legitimacy to knowledge acquired by the "objective" individual who is not "native" to the situation being studied. Because of the heavier weight and legitimacy given to knowledge acquired by the "objective" observer than the weight given to "native" knowledge, this template perpetuates the differential power structure in health disparities research. It necessarily reinforces the mainstream research agenda and questions at the expense of the "native" minority population's agenda and questions. It has a stress on inquiry versus experience and gives the mainstream observer more say than the minority informant thus perpetuating the mainstream view and power over the minorities by speaking for the minorities. Moreover, interventions created from this research template will reflect not the needs and perspectives of minorities but the perspectives of the mainstream. From the minority person's perspectives such interventions might be viewed as more imposition on minorities, and therefore might be met with resentment and sabotage rendering them ineffective in improving minority health and reducing disparities.

However, they facilitate cementing the power differential when seen from the perspective of the "benevolent superior" helping the poor. Viewed from this perspective, such interventions create debilitation and dependency among minorities. Debilitation and dependency come from creation and reinforcement of the view that change in minority communities has to come from outside such communities. Thus instead of empowering minorities these research templates reproduce the ideology that creates dependency.

Researchers come to the research scene guided by their culture, experiences, structured protocol, target concepts, definitions, perceptions and a continuum of expectations (Mahoney, 1997). This fact necessarily implies that the social and economic status and demographics of the individual

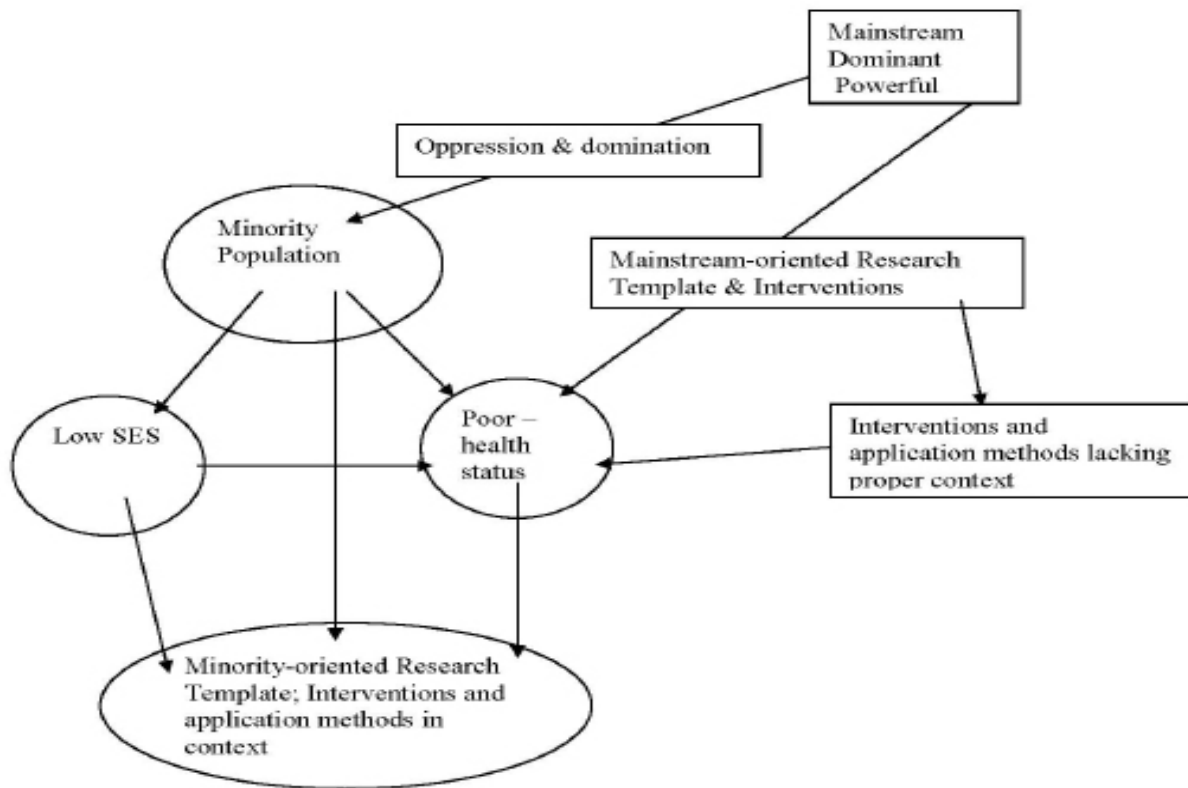
researcher have a direct bearing on the research agenda, structure, process and perspectives taken and therefore on observations made, the analysis, interpretation and the conclusions that follow. Therefore, it is difficult to achieve objectivity. Moreover, objectivity defined as following a strict predetermined research protocol to the exclusion of informants (“research subjects”) experiences and visions is not necessarily a desirable feature in health disparities research. Such a protocol might serve only as a “blinder” especially for a mainstream researcher in a minority setting.

Health Disparities Field Research Roles in Context

In order to understand and appreciate the roles of health disparities researchers, it is important to remember that the ideology of domination has created and nurtured, through metaphors, the “minority status.” In the study of health disparities, it is crucial to recognize that the ideology of inclusion and exclusion has culturally constructed the “dominant-subordinate dichotomy”.

Figure 2 depicts the context with the differential power structure that gives the dominant population an advantage over minorities resulting in disparities such as experienced in health and health care. Recognition of this context leads to the glaring controversy about domination and oppression, emanating from the fact that, historically, rather than speak for themselves, minority people are generally spoken for particularly in policy formation and practice in health where they are grossly underrepresented. Such recognition also makes it obvious that it is important for minorities to define and describe the reality they live and breathe rather than have it described for them by “experts” from the mainstream.

Figure 2: Context of health inequities and research templates

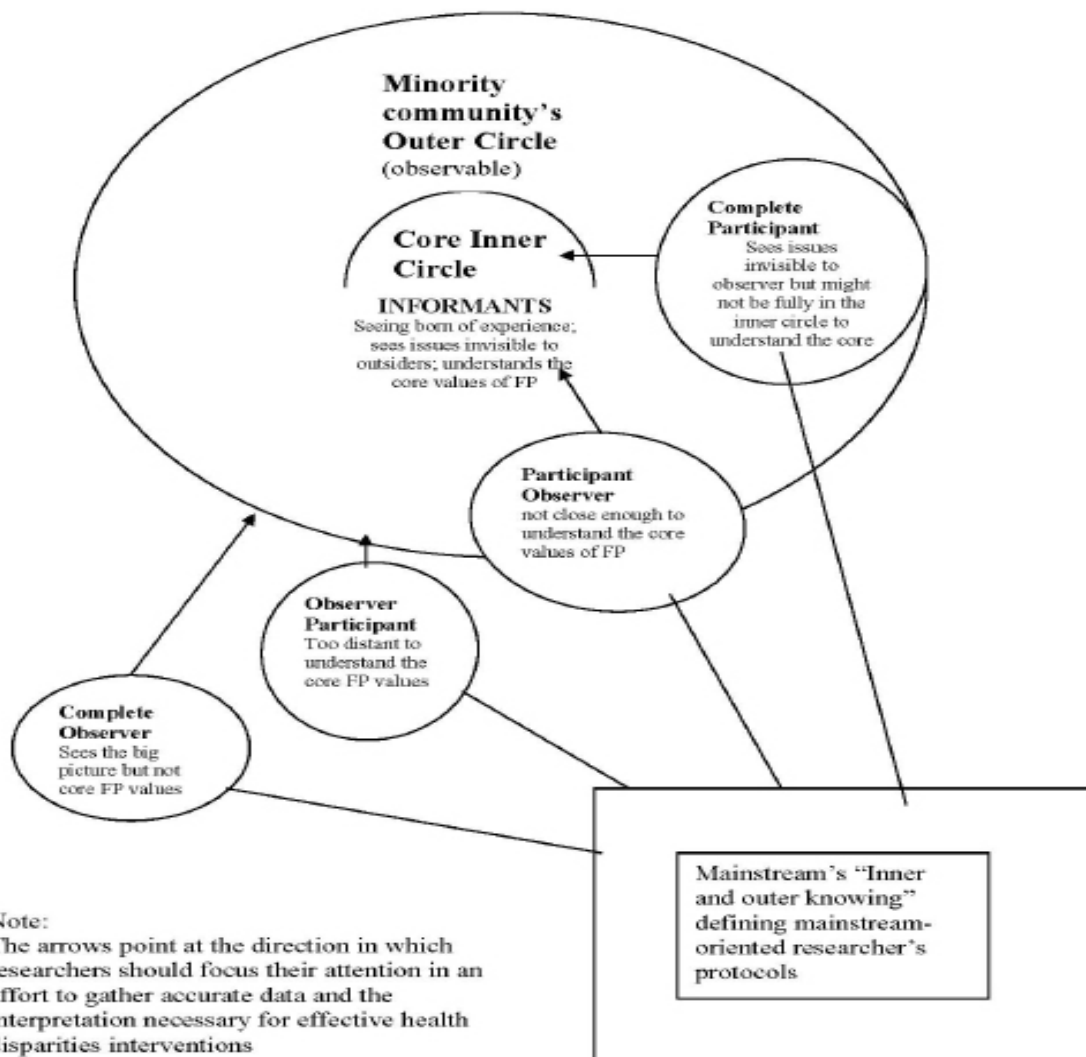


Note: Legal instruments such as treaties and Jim Crow separated minority and majority populations ranging from extremes (reservations) to less extreme neighborhoods. They have different experiences, cultures, perceptions and expectations and therefore, different research templates/modes or modes of seeing and knowing

Given the historical power dichotomy, and the separation of minorities from the mainstream, this model recognizes that racial/ethnic minorities, who are the focus population (FP) in health inequities research, have knowledge that is accessible from the outside by any observer and an inner-core of experiences, values and expectations that provide context and meaning to the outer/superficial observable knowledge.

These are depicted in Figure 3 as two "circles of knowing" – the outer observable information and the inner-core that is not readily accessible to individuals from outside the focus population. Although the outer circle of knowing has a higher degree of accessibility to observers, accurate interpretation of what is observed in this outer circle requires information from the "core" the inner circle of knowing that holds the fundamental core values. Without the inner values, interpretations can be shallow or outright wrong. The inner circle includes core values that are born of the culture, history, experiences, perceptions and expectations of the FP. This inner circle contains potent information about what inspires and drives the FP. Such information is critical to the creation of relevant, effective, and dynamic interventions in health.

Figure 3: Social sciences field research context and roles



However, accessing it requires not only gaining trust of the FP but an understanding that often is born of experience from living the conditions of the FP. Because the inner-core gives meaning to and an accurate interpretation of the readily observable, it should be the researchers' aim to tap into that inner-core. Thus in our model, objectivity becomes subordinate to capturing that inner-core of knowledge about what makes the FP tick. Unlike the weights given in Gold's (1958) model, in this model "native" knowledge has a greater weight than the "objective" knowledge gathered without proper context by observers using protocols created by the mainstream.

Unlike Gold's (1958) model with four roles in a continuum, this model recognizes five roles placed in an insider-outsider dichotomy within the "circles of knowing"; the four defined by Gold (1958) and the informant's role (IN). The informant (IN) has the unique position of accessing both circles of knowing. IN "lives and breaths" the social conditions of the focus population (FP) and therefore can draw from experiences and insights not available to the researcher from outside the FP. The IN is an insider and is privy to knowledge and understanding of and from the inner-core. The IN has full access to the culture, experiences, perceptions and expectations of the FP and has a pivotal role in research (Fox, 2004). The researcher from outside the FP can observe the superficial outer circle of knowing but will only get accurate answers by tapping into that inner-core that will inform interpretation of observables.

The question of whether the research agenda and design is created from within (evolved) or from outside (imposed) illustrates ideology, power, and domination in that researchers from outside have perceptions, experiences and expectations formed outside the FP. Such perceptions and expectations are likely to mar their vision and interpretation of the readily observable, making accurate information and interpretation inaccessible. This fact would be particularly true of mainstream-oriented researchers who are guided by their "dominant" culture with its research agendas, protocols and expectations. It is also true of researchers who are unable to gain trust of the FP. In such instances, a research protocol from outside that is not cognizant of the context becomes a "blinder" so that mainstream-oriented researchers only see what they are looking for and expect to see. Their observations, analyses and conclusions only serve to confirm what the researchers brought to the field. No matter their good intentions, they simply do not live the realities of the informants who might still view them with suspicion as part of the repressive system. Again, this is the inevitable product of the fundamentals we raised at the beginning, inclusion and exclusion of some group in the original design of the system/civilization.

As another example of inclusion and exclusion, the resulting interventions might be sterile lacking potent insider input and the potent energy and fertilization that comes from evolving interventions on the informants' needs, resources (such as social and human capital), expectations, experiences, and visions so that they are persuasive, relevant and applicable without need for adjustments. Imposed interventions created by outsiders without insider input face potential "tissue rejection" (Holliday, 1994).

Non-White ("Minority") Researcher's Position

In this analysis, bear in mind our earlier position that, in a fundamental sense, focus on ethnic differences outside of the large issue of class differences is not particularly useful. It creates the false impression that all Whites are enfranchised and non-Whites are disenfranchised. Ideally, the disenfranchising nature of ideology, power, and domination should be the starting point such that race does not become an issue. But the historical facts with institutions that "rhetorically constructed" (waMwachofi, 1993) race hierarchies have made this possibility unlikely.

The minority researcher (MR), studying minority health inequities simultaneously fits in several positions. As a minority person, she/he is directly affected by factors that perpetuate inequities.

Likewise, her/his needs, experiences, expectations, and visions are shaped within the context of being a minority person in the US. As such she/he can fit in the IN role. As an informant, the MR has access to the "core inner circle of knowing", the "insider" information not readily accessible to a non-minority person. As a researcher seeking a better understanding of health inequities, the MR can also take the other four roles with varying degrees of success depending on her/his ability to be removed from the IN position. Because of their training, it is safe to assume that minority researchers are, to some extent, more capable of stepping away from their IN roles and to observe, and to gather and analyze data about minority health and health inequities. As such they can be participants, participant-observers, observer-participants or complete observers.

This needs to be seen as a partial solution in that the question of who designed research agendas and protocols still matters; there are cases where a minority person may be seen as "acting White", precisely because they are identified as purveyors of the "dominant" values. We are aware that even a minority person who was born and raised in a upper class White neighborhood and went to Ivy league school may face similar problems as a White researcher – further proof of the need to understand the complex link between class and race (see Roediger, 1991).

There are major differences between the minority researcher in these roles and the non-minority researchers. For example, a minority researcher in the participant role will not have to pretend to be a participant because in essence she/he is a participant and that role will be easier for her/him to take because she/he already has the necessary insider information that will allow her/him to fit in. On the other hand the non-minority researcher might have difficulties fitting in and pretending to be a participant. There might be some visual signs that will inform IN that the non-minority researcher pretending to be a participant does not really belong in their group.

The most important difference between the MR and researchers from outside is that the MR always has the insider information. Such information supports and informs the MR in other roles. As participant observer, observer participant, the minority researcher will always have that insider information that will allow for more effective communication with the informants, a great depth and clarity of understanding and more accurate interpretation of what is observed. In the complete-observer role, the minority researcher will have the advantage of insider information and thus will be able to interpret what she/he observed more accurately. More importantly, the MR's pre-existing target concepts, definitions and their continuum of expectations were formed under the influence of being a minority individual in the US. As such, their expectations and definitions are more in-tune with the FP.

At the very least, the minority observer will have a greater in-depth understanding of the informants' needs, experiences and expectations. However, the minority observer might have difficulties being far removed enough to be a complete-observer because, in essence, she/he is always an insider, a participant and an informant. So to be a complete observer she/he has to pretend to be such. Whereas the non-minority researcher has to pretend to increasing degrees as she/he moves toward the inner circle of knowing, the MR has to pretend as she/he moves away from the inner circle and the IN position.

In the context of minority health and health inequities, research objectives should include a genuine need for creation of culturally sensitive and relevant interventions that will improve minority health and thus reduce health inequities. Given such objectives, research templates should emphasize the need to tap into the inner-core. Such templates need minority researchers because their experiences and insights would enrich and inform research.

The end result of research on minority health inequities should be effective interventions for improving minority health and thus end inequities. In order to create such interventions it is

necessary to collect good quality data. Johnson, Avenarius & Weatherford (2006) list factors that facilitate collection of quality data: freedom of movement among the various identifiable groups and subgroups; access to information; type of informant relations; types of information availed to the researcher; need for specialized knowledge; neutral status ability; information reliability; reliance on key informants: extent to which researcher must depend on key informants for collecting data; power and autonomy associated with a given active role. Because of the history of race relations in the US, a minority researcher is more likely to meet these conditions than a majority researcher. For example, it would be easier for a minority researcher to move between the different social groups in a minority population than it would be for a majority researcher. They will also be able to access information, create relationships with informants and key informants, and to build trust. As such the minority researcher is critical to the success of research on minority health inequities and to the creation of effective interventions.

Current Attempts to Overcome Power Differential in Research

Recently, researchers in the US have attempted to overcome past over-emphasis on objectivity that relegated life experiences to the periphery. One such attempt has been community-based participatory research (CBPR) and the other is the participant-observation applied by cultural anthropologist/ethnographers. Each one of these attempts faces challenges but they have made some headway. They still face the ideology and power differential that makes it difficult for outsiders to gather more accurate data in minority communities. The participant –observer approach has probably been more effective than CBPR in getting insider information from minority communities.

Community-Based Participatory Research (CBPR)

Leung, Yen and Minkler (2004) explain that CBPR facilitates community representatives' participation in the definition of the research problem, interpretation of the data, and application of the findings. Epidemiologist can gain a better understanding of the social context in which disease outcomes occur, while involving community partners in the research process, and ensuring that action is part of the research process itself. Thus CBPR can help epidemiology overcome its limitation in its ability to explain why certain outcomes occur and to generate the kind of findings that can be translated into programs or policies to improve health. Israel, Parker, Rowe et al (2005) also advocate the use of CBPR a powerful tool for understanding and addressing the multiple determinants of children's health and for research on complex multifactorial issues that result in children from low-income communities experiencing a disproportionate burden of incidence rates, morbidity, and mortality for a number of health problems. Other researchers praise CBPR for trust building in research especially among minority populations and for its facilitation of a seamless translation of research findings into practice (Mwachofi & Bryant, 2009)

However, CBPR faces some challenges. This method does not overcome the power imbalance or the imposition of agendas of the mainstream on minority populations. Consequently, there are questions of sustainability of the partnerships created through CBPR. Israel, Krieger, Vlahov, et al., (2006) recognize the challenge of sustaining CBPR partnerships past funding. They recommend a focus on three areas: sustaining relationships and commitments among the partners involved; sustaining the knowledge, capacity and values generated from the partnership; and sustaining funding, staff, programs, policy changes and the partnership itself. To overcome the challenges of CBPR in disparities research Trinh-Shevrin, Islam, Tandon, et al., (2007) recommend that three principles be followed in creating community partnerships: creating and sustaining multiple partnerships; promoting equity in partnerships; and commitment to action and research.

Freeman, Brugge, Bennett-Bradley, et al., (2006) conducted two case studies of major research projects that were partnerships between universities in Boston and community based organizations

and city agencies. They report that a key issue for both projects was ensuring that the projects were true partnerships especially with respect to funding mechanisms and distribution of resources. They also found that both academic and community partners may harbor stereotypes and generalizations about each other. There were challenges encountered in aligning objectives and expectations and tensions between research and service delivery. They conclude that open and frank discussion and a transparent process up-front about project direction, finances, expectations, and other dimensions are necessary but not sufficient to address the inherent challenges in CBPR. The researchers recognize that even with all the up-front preparations, there would likely to be differences in perspective in such partnerships that require honest negotiation throughout the process of the project.

Corbie-Smith, Williams, Blumenthal, et al., (2007) conducted interviews with thirty three investigators to examine the range and nature of investigators' communication and relationship building as they recruit minority participants in research. The relationships found ranged from study-related, short-term interactions geared solely to facilitate recruitment to longer term relationships extending beyond a particular project. The data suggest that a range of relationships is important as investigators seek to include minority populations in research. These relationships can both facilitate the recruitment process as well as aid in the interpretation of research findings. It was not clear to these researchers if the CBPR approach overcame the differential power structure between minority communities and researchers.

More revealing is the study of cultural attitudes and competence of clinical investigators seeking minority participation in research (O'Brien, Kosoko-Lasaki, Cook, et al, 2006). These researchers hypothesized that lack of investigators' understanding and skill in effectively communicating with members of minority cultures is a barrier to enrolling minorities to clinical trials. They assessed the cultural competency of faculty and staff involved in clinical care and research. They found that the majority said they were reasonably culturally competent, respectful and had reasonable knowledge of the several cultures of the patients for whom they provide care and with whom they conduct research. However, they found a need for continued cultural sensitivity/competency training to enhance understanding of certain aspects of minority cultures, group and interpersonal relationships, perceptions of disease and wellness and to improve their access to minority communities. Some of their findings are particularly relevant to the power-differential thesis at the heart of this discussion. For example: "... Attitudes expressed by the participants clearly show that a significant majority believe that assimilation of immigrant and minority groups to American norms and values is good ... This could be interpreted as a lack of respect for other cultures or alternatively, as recognition that assimilation of American norms and values is a pragmatic approach to enabling people to get along and succeed in a large, complex and diverse society..." (pp. 667-668).

Furthermore, the faculty and staff expressed frustration about the effects of culture on compliance or understanding of disease states or understanding and compliance with schedules, particularly appointment times. Thus these researchers conclude that although there were expressions of respect for other cultures, they must be interpreted in light of the existence of unconscious bias and stereotyping that lead to differences in communication and treatment. This conclusion clearly echoes power imbalance and the internalized perceptions of mainstream researchers on minorities that clearly affect research.

Related to this discussion, we need to make a critical point about ideology, power, and domination. The dominant system (discourse) once put in place and followed by everyone becomes the cultural norm because it is "reified" (frozen) (waMwachofi, 1993) such that it is not to be questioned. It should be no wonder that most critiques of success or failures of research

approaches or intervention programs do not focus on the dominant discourse. Instead, as shown by above literature review, they focus on people and individual failures. Ideology, culture, community, or institutional failures do not register as questionable in the minds of people. Ideology is power, precisely because of its "oblivious" nature. Thus, programs aimed at training people to become sensitive to the unique experience, past or present of minorities are common while ideology goes unquestioned. Once reified, ideology, power and domination function in ways that the originators of the inequity and the dominant structure become the norm and escape scrutiny. In our culture, systems are seen as "natural" and "neutral" so if there is a problem, it has to be due to individuals' attitudes or ignorance and the logical solution is "education."

It is our view that this focus toward the individual and away from the power structure is at the core of the problem. It fails to recognize that humans, as social actors participate in a social world where the rules are already made and the assumptions are taken for granted and unquestioned. The assumption of race "superiority," for example, is not questioned; if anything, it is taboo to talk about race. So as a society, we suffer a form of schizophrenia where, on the one hand we call for diversity, meaning we are acknowledging that some people were excluded; but on the other hand we want to punish anyone who claims that their individual ethnicity gives them a unique perspective into their world. And that is because we are always clamoring to be objective, neutral in a scientific fashion (waMwachofi, 1993).

Minority investigators have unique perspectives and experiences that can enhance research potential for understanding sources of health inequities, yet relatively few minority investigators are funded by the National Institutes of Health (NIH). A study of barriers to minority investigator NIH funding identified potential barriers as: inadequate research infrastructure, training and development; barriers to development as independent researchers; inadequate mentoring; insensitivity, misperceptions and miscommunication about the specific needs of investigators involved in research with minority communities; institutional bias in NIH policies; unfair competitive environment; lack of institutional support; lack of support for research topics/methods relevant to research with minority communities; and social, cultural and environmental barriers (Shavers, Fagan, Lawrence, et al., 2005).

Data from both the concept mapping and the meeting discussions suggest the need to use a multilevel approach to increase minority representation among funded NIH investigators. Specifically, the NIH should use strategies that overcome barriers at the home institution, within NIH and at the investigator level. Again, as we have attempted to show, this seems like a discussion of how "outsiders" can be admitted into the citadels of power, an admission that there is something wrong. In our view inequity would be tackled more effectively if ideology, power and domination are a central part of health disparities research and analysis.

At the same time, there is evidence of difficulties communicating about disparities in health, health research, and health care access. Kaplan and Bennett (2003) describe three challenges faced by researchers, clinicians and policy-makers: accounting for the limitations of race/ethnicity data; distinguishing between race/ethnicity as a risk factor or as a risk marker; and finding a way to write about race/ethnicity that does not stigmatize and does not imply a we/they dichotomy between health professionals and populations of color. They show the important role of journals in setting standards for research and policy literature. The other relevant difficulty that is not really discussed is the fact that most journals are controlled by the mainstream. All the more reason to engage the background of ideology to explain why this is the case.

Cultural Anthropologists' Participant – Observation

Cultural anthropologists are not governed by quantitative methods. Rather than conduct surveys and correlate discrete statistical variables, they try to explain why and how social relations occur within their respective contexts. They make the effort to build “organic” long lasting relationships based on mutual respect before they begin conducting research (Bourgois, 2004). The goal of this approach is to obtain a holistic perspective on the internal logic and the external constraints of the social setting they study. This approach requires a long-term physical presence residing at the focus neighborhood and the perseverance that helps build the acceptance or entry into the focus community. The organic relationship with the community makes possible for the participant observer to gather useful information from the inside and from the perspective of the focus community. This approach comes closest to the undermining of ideology, power and domination as the primary basis for inquiry.

This research approach can be effective but it does not overcome the power differential because the research agenda is created outside the community so that the researcher comes into the community to be a participant observer of particular issues in the community. What those issues are or what the focus main issue is determined without the community input. So the fact that the researcher is focusing on a particular issue does not mean that the focus community views it to be worthy of research. They might view something else as deserving of such attention. Furthermore, even in the participant role, the participant observer might not be able to fully divorce themselves from perceptions and expectations that they brought in from a different culture. Moreover, their participation-observation success is, to some degree, dependent on how much the community allows them entry and how much of the core knowledge they are allowed to see. These limitations are also true of the CBPR approach.

CONCLUSIONS

A concerted effort to end minority health inequities has met with little success. Research templates affect the quality of data collected, the analysis and interpretation and, consequently, the quality and effectiveness of the resulting interventions and their application methods. Therefore we advocate that there be new research protocols that are cognizant of the context of health inequities and that allow experience to inform inquiry so that data gathered are useful in creating effective interventions. Without explicit recognition of the context of health inequities, research templates from the mainstream are inappropriately imposed on minority settings. Such imposition jeopardizes research effectiveness and that of the subsequent interventions.

Effective interventions require a solid understanding of the sources of inequities, minority populations' needs, resources (including social and human capital), experiences and expectations. Given the historical marginalization and cultural differences, such information is not readily available to the mainstream. Minorities have the critical information necessary for creating and applying effective interventions for ending health inequities. The process of gathering such information from the field requires tapping into minorities' inner circle of knowing so that observables are accurately interpreted and that interventions are culturally appropriate built from the ground up and not imposed from the outside. Such an approach is useful for creating interventions capable of infusing fundamental changes in minority communities so that there are sustainable interventions leading to better minority health and an end to health inequities.

For this to occur there has to be appropriate research templates such as: those that allow experience to inform inquiry while avoiding perpetuation of the power differential and the potentially debilitating side effects of health inequities research; templates that are cognizant

of health inequities context and recognize “native” knowledge as critical in creating effective interventions; and research templates that are minority-oriented (not imposed on minorities) so that they form the basis for the creation of effective, and sustainable interventions from the ground up.

We have presented a basic skeleton of a research model that explicitly recognizes the context of health inequities. This skeleton can be built-upon to create more effective research templates that address health inequities. We have attempted to demonstrate the sense in which majority good faith research approaches focus on the symptoms of the problems and omit the root causes of the problems. We have argued that the major reason for this is that proponents of those research approaches have not come to appreciate the role of culture/ideology in shaping our perceptions of ourselves and our society. We presented a logical argument of how culture that we have conceptualized as ideology, power, and domination acquires a “challenge-proof” characteristic. We are caught in a world of taboos where we cannot discuss concrete facts such as race inequalities freely. We need to examine the paradoxes in which, for instance, objectivity allows us to have theoretical equality while we talk about concrete inequalities. We think that in identifying the dynamics, honestly, by explaining the actual reality of events that account for present day inequalities, we offer a more robust approach that begins to address inequalities from the root.

Due to time and space limitations, we could not do much in the way of explaining the psychological nature of persuasion and the role that language plays in affirming the everyday systems of power but we introduced the idea of ideology, metaphor, power, and domination for that purpose. We accept the fact that although our aim was to look into the origins of this problem, in this specific activity, we are nevertheless, inevitably operating on the surface structure in examining our current state of affairs. That is because the history of domination has occurred for several centuries and we are indeed operating on the aftermath of those structural malformations. Finally, if we have raised more questions than answers, then we have succeeded in our endeavor.

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