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Exploratory Health Disparities Research: The Need to Provide a Tangible Benefit to Vulnerable Respondents

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Abstract

This article examines the responsibilities of researchers who conduct exploratory research to provide a service to vulnerable respondents. The term “service” is used to denote the provision of a tangible benefit in relation to the research question that is apart from the altruistic research benefits. This article explores what this “service” could look like, who might be responsible for providing it, and the challenges associated with such a service. The article argues that not providing a tangible benefit to vulnerable research participants is inconsistent with the principle of social justice that undergirds much of the rationale for conducting health disparities research.

Keywords

health disparities; service; benefit; ethics; social justice; vulnerable

This article examines the responsibilities of researchers who specifically conduct descriptive research to provide a service immediately following data collection to marginalized, disenfranchised, and vulnerable respondents. The terms “service” and “tangible benefit” are used interchangeably and denote the provision of a concrete benefit that is consistent with the research question and is distinguishable from any altruistic benefits that research participants might receive from participation in exploratory research. A tangible benefit could range from providing the respondent with a list of applicable services to the actual provision of services, such as cancer screenings, stress management workshops, health screenings, and so on. This tangible service should be an integral part of the research implementation and a necessary option offered to the respondent *after* data collection has occurred.

This article examines what this “service” could look like, who might be responsible for providing this service, and the challenges that are associated with providing a tangible benefit. In this article we argue that not providing a tangible benefit is inconsistent with the principle of social justice and the ethics of working with marginalized groups (Berkowitz & McCubbin, 2005; King, Vigil, Herrera, Hajek, & Jones, 2007). Indeed, it is the very subject matter of various types of exploratory health disparities research (HealthyPeople2010, 2008), which can initiate a level of anxiety in the most vulnerable respondents (Richards &

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Schwartz, 2002). This anxiety is often discernible by respondents' questions such as, "How can this (cancer, high blood pressure) affect me? What are you doing to help people like me? Where can I go for assistance?"

Beyond informally assisting the individual respondent who expresses the most need, researchers have an ethical responsibility to systematically address the kinds of anxieties that research can evoke. Aside from the issue of evocation of anxiety brought upon by the research question, there are various compelling ethical reasons including social justice, respect for others, and beneficence reasons that oblige health disparities researchers' to explore the question of a tangible benefit beyond the data gathering phase. Furthermore, the issue of withholding information about available services or referring individuals for help, regardless of whether they will follow up on it, is also another critical ethical concern for health disparities researchers. Finally, given the current absence of provisions for tangible benefits from many funding agencies, the level and type of benefit that can presently be provided to respondents will ultimately depend on organizational resources and commitment. Systematic changes to address the potential burden that exploratory research can have on vulnerable respondents must start with the conceptualization of the research design, the writing of the grant budget, and ultimately the conduct of the research itself.

SOCIAL JUSTICE AND HEALTH DISPARITIES RESEARCH

The ethics literature has been vastly influential in informing the concept of social justice. According to the *Belmont Report* (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979), a milestone document on the effort to protect humans in research, justice involves equality in distribution or what is deserved. Injustices take place when, without proper reason, researchers deny an individual a benefit she or he is entitled to. Social justice is an important component that motivates the conduct and urgency of health disparities research (Berkowitz & McCubbin, 2005; King et al., 2007; O'Connor & O'Neill, 2004; Ottenritter, 2004; Stark & Watson, 1999). Similarly, the elements of social justice, provides ample justification for health disparities researchers to offer a tangible service to their target research audience. Equality and social justice are burgeoning topics in health disparities research, as many researchers and academic programs are beginning to incorporate the pedagogy of social justice into their training (King et al., 2007; O'Connor & O'Neill, 2004; Ottenritter, 2004; Stark & Watson, 1999). Well-established organizations, such as the Center for Research on Minority Health, conduct workshops and hold educational training sessions on health disparities and social justice (King et al., 2007). *Healthy Campus 2010*, a subset of HealthyPeople2010, integrates classes on service learning to teach undergraduate students how to use social justice to better serve the community and address health disparities (Ottenritter, 2004). The significance of focusing on social justice is further exacerbated by the well-documented mistrust that many minority communities have of research and their perceptions of researchers merely conducting "helicopter" or one-sided research (Allen, 1994; Corbie-Smith, Thomas, Williams,&Moody-Ayers, 1999; Gamble, 1993).

HEALTH DISPARITIES AND EXPLORATORY RESEARCH

The health disparities researcher explores conditions that are largely, but not only, shaped and perpetuated by inequities such as lack of information and lack of access to care (Flaskerud et al., 2002; Hall, 1999; Hall, Stevens,&Meleis, 1994). Consequently, in health disparities research, the target audience is, by definition marginalized, and is already, or has the potential to be, disparately affected by the illness conditions being studied. These individuals often consist of racial and ethnic minorities, many of whom are women, and others with various illnesses or disabilities (Flaskerud et al., 2002; Vasas, 2005).

Furthermore, health disparities research by definition is conducted with vulnerable populations who experience a disproportionate amount of gaps in services because of social, economic, political, and personal reasons (Flaskerud et al., 2002). For the person from the low-income or underresourced community who may be uninformed about the extent, scope, and nature of the health disparity, the research questions may open up a “Pandora’s box” of concerns that were not salient prior to study participation (Richards & Schwartz, 2002).

Exploratory research typically attempts to better understand the myriad factors that may impact health disparities and is a necessary part of developing innovative conceptual frameworks and interventions to effectively address health disparities (Campbell et al., 2003; Casebeer & Verhoef, 1997; Nocon et al., 2003; Stevenson, Baker, Farooqi, Sorrie, & Khunti, 2001; Thorne & Paterson, 1998; Thorne, Harris, Mahoney, Con, & McGuinness, 2004). However, exploratory research often does not address the immediate needs of the present respondents, and most often such research is conducted to address the target groups’ needs at a *later* stage, pending future funding.

A CONTINUUM OF TANGIBLE BENEFITS

The range, breadth, and depth of delivering a service beyond the act of data collection can take many forms. The type of benefit that can be provided will depend on the research content area, the known needs of the targeted audience, and an informed anticipation of how the research questions might produce anxiety, questions, or concerns among research participants. Arguably, those who participate in descriptive research ought not to have any expectation of benefits beyond a possible sense of feeling altruistic. After all, the institutionally reviewed and approved consent form clearly explains the limitations and benefits of the research. Nonetheless, the perception and need of the vulnerable respondent is quite the opposite and should be based on their reality. Researchers who conduct exploratory research are often confronted with expression of need and anxiety directly precipitated by the research focus. Furthermore, monetary compensation, although not seen by Institutional Review Boards (IRBs) as a direct benefit for participating in the research, to many low-income and poor individuals, can and does influence the decision and ability to participate in research. However, even in terms of stipends, low-income participants want these stipends to be tailored to their specific needs (Mosavel & Oakar, 2009). Monetary stipends, if not considered carefully and tailored appropriately, can indeed perpetuate the image of research as a transaction with a monetary compensation. This image of research will be unable to effectively move forward the health disparities agenda among those most disenfranchised.

Next are two examples of research (hypertension and cervical cancer) in which the respondents themselves identified needs beyond the scope of the descriptive research.

In a study to examine the social contextual factors of hypertension among low-income individuals, 20 patients with poorly controlled hypertension were randomly selected to take pictures of the factors in their environment that they perceived as barriers to treatment adherence.¹ These photovoice participants met with researchers in two separate groups of 10 over the course of 4 weeks. The research goal, stated in the written consent form and explained face-to-face, was to understand the social contextual factors related to hypertension. During the data collection process, however, participants repeatedly expressed their need to address their hypertension beyond providing the researchers with detailed descriptions of their struggles. They indicated that their immediate needs included stress management skills, anger management, exercise, and finance counseling. As a response, the

¹Hypertension study funded by NIH–National Center on Minority Health: 5 P60 MD00265.

researchers developed a skill-building workshop titled “Art of Living.” There were no funds in the research budget to accommodate this workshop; therefore, the research team involved several community leaders to provide many of the needed services. The workshop included stress management techniques such as drumming and Tai Chi. Various motivational speakers provided suggestions on how to effectively address some of the stressors influenced by race, culture, and gender. Furthermore, participants had access to a medical professional to answer their specific hypertension questions. Additional services such as massage, meditation, and financial advice were also provided.

The second example refers to exploratory research conducted in South Africa on beliefs and attitudes about cervical cancer and the potential of daughters to influence their mothers’ screening behavior² (Mosavel, Simon, van Stade, & Buchbinder, 2005). Mothers and daughters separately participated in in-depth interviews. The purpose of the research was explained in the consent forms, and each person had a face-to-face meeting prior to agreeing to participate in the study. The randomly selected sample-pairs were asked why they were interested in participating in the study. Although the study goal was aimed at finding out what they knew about cancer, the majority indicated that they wanted to *learn* more about cancer and about the mother–daughter relationship. In addition, during the pilot testing of the survey, field workers who were selected from the community reported that participants were becoming anxious about cancer because of the research focus. Furthermore, for many of the study participants, it was the very first time they were in a setting where they were specifically asked to focus on their concerns, health, or otherwise. Not only did participants have anxieties about a health disparity, in this case cancer incidence and mortality, but they also were asked in the interview to focus on their social networks, which resulted in a focus on their difficult life circumstances. In an attempt to address these needs, the researchers, in collaboration with community partners, developed a tailored package highlighting both cancer screening and counseling resources that were available but not necessarily known to community members. All research participants were provided with specific names of professionals located in their community that they could contact.

The two examples present different parts of the continuum that is possible in the attempt to address needs revealed by the research question. In the hypertension study, the service was more extensive in that it was a 1-day workshop, which required several resources and utilized community partnerships. On the other hand, in the cancer study, the service was minimal in that a simple referral list was compiled and provided to participants. However, this referral list was tailored and specific to the neighborhood, as opposed to a list of a more generic nature. Nonetheless, the South African example represents a baseline minimum in the type or amount of services that should be directed at research participants living in marginalized communities.

The two examples also illustrate how, on the continuum of tangible benefit provision, it may be necessary to identify a needed service prior to data collection. In the South Africa study the needs were identified during the pilot testing, whereas in the hypertension study participants’ needs emerged in the context of the research process. In the cancer study, utilizing fieldworkers who were community insiders and conducting a pilot study proved useful in highlighting some of the participants’ needs. In the hypertension study, the participants’ needs were not anticipated or discussed prior to study implementation, and researchers responded to participants’ questions post–data collection of, “What now? What do you give us now that you have what you need?”

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CHALLENGES ASSOCIATED WITH PROVIDING A SERVICE

There are various additional responsibilities and challenges associated with prolonging researcher interaction with a research community beyond the data collection. Even if a researcher believes that providing some type service is necessary, there are numerous challenges that make this difficult, although not impossible, to implement.

Budget constraints play a significant role in impeding the viability of service delivery. With respect to federal funding, there are several restrictions and guidelines that have to be followed when spending research funds (Minkler, Blackwell, Thompson, & Tamir, 2003). The fact that most research dollars “are tied up in congressionally restricted vertical silos of categorical disease earmarks or line items in agency budgets” (Green, 2003, p. 416) presents a particular difficulty for the researcher who would like to provide some type of service as part of the research process. Sufficient and flexible funding is required to facilitate the recognition of participant needs that might arise when conducting descriptive research. Such funding priorities make it impossible for the researcher to provide any sort of follow up or immediate short-term give-back to research participants. Funding is required that takes into account the period needed for building relationships with research participants and the varied problems that may emerge once the relationship is established and the research process unfolds. This is especially true of research that is more community based, involving more than one interaction with participants or involving interactions that may be in-depth such as interviews on personal health issues. Increased success has been shown in programs that are not tied to restricted preplanned budgets and have “braided funding streams,” allowing the researcher to address the emerging needs of the participants (El-Askari et al., 1998).

The question of when the service will be delivered and by whom is an important consideration. The issue of time and budget are linked. If researchers get involved with service delivery, then it may take away time from “research,” which in turn may make it difficult for them to complete the research in the amount of time specified in their funded protocols. Partnering and providing service delivery to communities require time and sustained financial commitment. These objectives may not fit with the agenda of those who are seeking short-term objectives and have clear funding goals (Israel, Schultz, Parker, & Becker, 2001; Minkler et al., 2003). The binary responsibility of service and research can be eased by partnering with community organizations and public health agencies (Flicker, 2006; Green, 2003). These community organizations can serve as a bridge between the researcher and the researched by playing a pivotal role in providing service delivery. Establishing an advisory committee prior to the start of the research can also assist with anticipating some of the individual needs of participants that might arise from participating in the research.

CONCLUSION

This article essentially examines the health disparities researcher’s ethical responsibility when conducting exploratory research within marginalized communities. It makes the argument that many health disparity content areas may evoke a level of concern or anxiety about a research issue among participants. However, anxiety is not to be seen as the sole reason for delivering a service but is instead an additional one. Research conducted according to a principle of social justice would look beyond the potential for emotional trauma and would take the position that all research has an obligation to provide some level of service regardless of whether or not anxiety has been triggered. The conventional paradigm of data collection that has no immediate tangible benefit, beyond receiving a stipend, when conducting exploratory research is severely limited and out of sync with the

culture of conscience that the public increasingly demands from contemporary health disparities research. The ethical responsibilities of researching health disparities require a benefit beyond the promotion of altruism. The researcher ought to approach the question of benefit in a systematic and thoughtful way that is consistent with the social justice value that permeates much of the rationale behind conducting disparities research. The provision of a tangible benefit to the individual respondent is one such response that addresses the immediate needs of those most vulnerable. A tangible benefit is a resource or a service that specifically addresses the major issues that might be opened up by the research questions and provides the respondent with the opportunity to (a) be informed about the issues and (b) receive help to address the issues.

For example, community-based participatory researchers understand the importance of considering needs regarding the sustainability of a project *prior* to implementing the research (Lantz, Viruell-Fuentes, Israel, Softley, & Guzman, 2006; Minkler et al., 2003; Shediach-Rizkallah & Bone, 1998; Viswanathan et al., 2004). Similarly, the researcher who engages in exploratory research with marginalized communities must consider the individual needs of that participant, as it relates to the concerns that may be precipitated by the research question, prior to conducting the research. Most important, researchers need to document the need for tangible assistance that respondents might express and to inquire from participants and from community stakeholders as to what these needs might be and then make this narrative a part of their request to funders. Health disparities researchers need to assist funders in understanding the importance of this ethically propelled service or benefit to members of marginalized communities. This needs to be a central consideration in grant applications for descriptive research.

Exploratory research has significance and relevance in that it has the potential to inform paradigms and create more comprehensive conceptual frameworks that can ultimately help to reduce health disparities in the most vulnerable communities (Flaskerud, 2002; Sandelowski, 2004; Sullivan-Bolyai, Bova, & Harper, 2005). The researcher's role is continually evolving, and the heightened focus on health disparities and on developing culturally coherent paradigms makes it necessary to consider the ethical obligations beyond gathering information from marginalized communities.

It is clear that more dialogue and critical thinking is needed on the subject of conducting exploratory research and addressing the heightened needs of those most disenfranchised. In particular, there are important questions remaining about (a) the role of the IRBs in establishing guidelines for addressing the needs of participants beyond the data collection phase, (b) the advantages and disadvantages associated with the IRBs role in regulating postresearch community involvement, (c) the role of funders in enforcing postresearch services, and (d) who else might be ethically responsible besides the principal investigator to provide this tangible service to participants?³ These are just some of the questions that a discussion such as this initiates, thereby indicating that this is only the genesis of a much-needed discourse in health disparities research.

It is beyond the scope of this article to provide the level of analysis demanded by these important questions. However, we do note that there are potential advantages and drawbacks to the idea that IRBs and/or research sponsors ought to be involved in mandating the imperative to provide concrete benefits to research participants and communities. Uniform enforcement of this imperative is, clearly, one advantage of having IRBs involved. Alternatively, involvement by research sponsors may have the effect of mandating this imperative far enough upstream so that IRB involvement need not be required. However,

³We thank the anonymous reviewer for his or her insightful comments.

this is a somewhat unrealistic option, as research sponsors include academic and private, industry-based, and other entities that are not uniformly bound by current research protection regulations and practices. Thus, IRB involvement will likely be required if official regulation of this imperative is going to be sought. Within this paradigm, there is a case to be made for having standard IRB review committees address this issue, as it is at this level that the overall ethics of the research are deliberated. Moreover, having a separate committee dedicated to this issue would require a duplication of resources that few centers can afford. Notwithstanding these administrative issues, the real question that IRBs will need to address is what level of benefit investigators will be required to deliver if their research qualifies under this imperative? In so doing, should IRBs take into account the budget sizes of the research? Should allowances be made for academic versus industry sponsored, or short-term versus long-term research? Furthermore, many investigators already view IRBs warily; what effect may efforts to regulate their obligation to provide benefits have on their trust and confidence in IRB functioning? Could such efforts promote “IRB shopping,” and thereby undermine other important functions of the IRB?

The fact that this brief discussion has raised more questions than answers suggests that, first and foremost, more consideration is needed of the potential impact of regulating benefits on the ethical review of scientific research as a whole. IRBs as well as investigators, research sponsors, research participants and communities, and other stakeholders ought to be consulted on the question of regulating benefits. This consultation process will facilitate the building of an evidence base of multiple voices that could then serve as a starting point for addressing the question of whether regulation ought to go ahead, and how this should happen. The issue of providing tangible benefits beyond the data collection phase is fundamentally driven by justice and respect for persons; so, too, ought the issue of regulation be driven.

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