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Community-Based Participatory Research: An Ethical and Practical Model for Academic Public Health and Clinical Research

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ABSTRACT

Community-based participatory research (CBPR) is a strategy for performing health-related research in vulnerable communities that have been exploited by traditional research in the past. CBPR focuses on mutual collaboration between the community and the researchers involved. This form of research is ethically compelled to instill transparency and trust into the research enterprise. CBPR envisions the involvement of the community in all aspects of the research: design, implementation and dissemination of research results. This collaborative process necessitates an analysis of ethical considerations because it implies additional moral principles beyond the traditional ethics enunciated in the Belmont Report, the foundational guideline for moral biomedical research. In the Belmont Report, the ethical principles of respect for persons, beneficence, and justice are traditionally applied to only the actual research participant. CBPR would require that these principles be extended to the community to empower the community. Also, reciprocal justice should be considered as an additional measure for further assurance that a community receives a just benefit in return for its participation in the research. These ethical considerations, which are made apparent through CBPR, will empower and build the capacity of marginalized communities.

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BACKGROUND

Community-based participatory research (CBPR) is a relatively novel means to facilitate research in communities that have historically been considered vulnerable to the exploitative processes of traditional forms of research. In the United States, these vulnerable communities most notably include HIV/AIDS patients, Native-Americans, and African-Americans. As an example, from 1932 to 1972, the African-American community of Tuskegee, Alabama was subjected to research involving the non-treatment of syphilis in male subjects for the purpose of observing the natural course of the disease. The community received minimal benefits during the course of the research and was neither privy to the rationale for the research nor outcomes of the research. In fact, the research subjects were deceived about their participation and allowed to endure horrible effects of the disease, such as blindness, mental defects, and death. The “Tuskegee Syphilis Experiment,” as it is called, was a historical atrocity perpetuated on a vulnerable community and has been noted as one of the greatest ethical failures in research in the United States (Jones, 2008, p.86). This event led to a lasting

distrust of medical research in the African-American community.

In response to this reprehensible research, the United States addressed the ethics of human research through the federally appointed National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, which published the Belmont Report in 1979. This paper will examine the ethical rationale, based upon the Belmont Report and other ethical principles, for performing CBPR in historically vulnerable communities to further public health and garner trust in communities that have been exploited by research in the past.

ETHICAL FOUNDATIONS

Belmont. The Belmont Report provides an ethical foundation for human research. The report emphasizes three ethical considerations that should be incorporated into all research with human subjects: the principles of respect for persons, beneficence, and distributive justice (The Belmont Report). These three principles ensure that the self-determination of the research participant is preserved, that a benefit-versus-risk analysis is performed, and that no one group is made to bear most of the burdens of participation in

research while other groups receive most of the benefits. These concepts have been incorporated into U.S. Federal Regulations (45 CFR 46). These principles provide a well-established framework for biomedical research; however, they are individualistic in nature and do not consider risks to a group. The “group” aspect is especially critical when a member of a vulnerable community is involved in research because potential negative outcomes may be attributed to the entire group and result in the stigmatization and perpetuation of stereotypes. Also, communities provide a wealth of “local” knowledge that may better inform research priorities and assist in the identification of potential benefits and harms that may be unknown to research participants. Such knowledge, arguably, deserves compensation (either monetary or through skills learned) as reciprocity.

Group & community factors-reciprocal justice.

We do not exist in a vacuum. People who self-identify with a group, in some ways, define themselves by that group in terms of values, beliefs, and perspectives. In fact, culture-specific practices of members of such groups may be an extension of the group’s values, beliefs, and perspectives, and may contribute to common health-related issues experienced by the individual and the group. The symbiotic relationship between the individual and his community necessitates an ethical analysis by researchers and an incorporation of the group into resolving such issues. Also, reciprocal justice, an additional ethical principle, must be considered when collaborating with vulnerable groups that have had non-beneficial relationships with the research enterprise in the past.

The incorporation of group ethics and reciprocal justice into the research paradigm ensures that exploitation of the community will not occur, as the community is guaranteed a just benefit. As Wallwork (2008) notes, “[a] community that bears the burden of health research has a claim to some reasonably fair compensation for its contribution” (p. 73). Community-based participatory research incorporates the principle of reciprocal justice. Wallwork (2008) states that “[j]ustice as reciprocity is extended to groups when the issue is what a group deserves in return for what its members contribute to a joint undertaking” (pp. 72-73). For example, the community involved in the Tuskegee Experiment was economically disadvantaged, largely uneducated, and located in the South- an area historically known for racism and animosity towards African-Americans. These truths coupled with the fact that the research subjects were exploited by not receiving a fair benefit from the research justifies the CBPR approach in similar communities today. Thus, although reciprocal justice is a departure from the Belmont’s narrower focus on justice, it is justified as a vehicle for increasing trust in research performed in marginalized

and vulnerable communities by ensuring that a benefit will be had through the increase in the overall capacity of the community and a lessening of the chance for exploitation.

Community-based participatory research.

Community-based participatory research (CBPR) is a paradigm that encourages the study of disease in both an individual and group context. Such a context improves the quality of the research as it allows the researcher to address the community’s definition of its health-related issues (Wallwork, 2008; Baldwin, Johnson, & Benally, 2009; Israel, Schulz, Parker, & Becker, 1998). With community-defined issues, community members are more inclined to act on the research findings (Baldwin et al., 2009). In CBPR, the community is involved at all levels of the research process, which allows for transparency. In the end, the community is empowered, having directly benefitted from the research through employment opportunities offered, health interventions provided, new skills gained, and possible methods instituted for attaining better health, as well as, a new trust of the research community that caused “like-groups” harm in the past (Baldwin et al., 2009; Israel et al., 1998).

Ethical rationale for community-based participatory research.

Ernest Wallwork (2008) defines the key aspect of CBPR ethically and scientifically as “an investigation involving a vulnerable community [that] draw[s] on the distinctive contributions that each of the parties—community and researcher(s)—can bring in order to arrive at a mutually beneficial undertaking that [equally] respects the partners’ [potentiality to have] very different beliefs, values, interests, preferences, capabilities, purposes, and agendas” (p. 58). The author also notes an ethical framework for performing CBPR that incorporates and broadens the concepts enunciated in the Belmont Report. This “extension model,” Wallwork explains and applies the individualist principles of respect for persons, beneficence, and justice to the community involved in the research (2008, p. 66). Thus, the group’s respect and consent, assessment of the risks and benefits, and social and reciprocal justice are considerations in CBPR. The “group” notion requires the participation of the community in all aspects of the research. Israel, Schulz, Parker and Becker (1998) note, “a fundamental characteristic of community-based research...is the emphasis on the participation and influence of nonacademic researchers in the process of creating knowledge” (p. 177). Community participation will inculcate trust and a sense of ownership into the research venture. Because of the required “sharing” of roles and responsibilities, an ethical foundation will be established that requires the development of research guidelines that respect the community as non-scientists and as members of a

vulnerable group previously subjected to exploitation. Therefore, elements of transparency, open communication, and acknowledgement of partner value to the research are imperative to a successful partnership.

ACTION GUIDS/SPECIFIC PRINCIPLES AND JUSTIFICATIONS

Relationship building and partner selection. Baldwin, Johnson, and Benally (2009) developed an approach to CBPR in the context of indigenous communities that has universal application. Baldwin et al.'s approach is as broad as it is because it addresses issues experienced by all vulnerable groups, such as a need for cultural sensitivity, capacity building in the community, and use of local knowledge to identify and solve health issues. Baldwin et al. (2009) noted the importance of developing a true and "sustaining" relationship between the researcher(s) and the community, the need to plan the research with the community partners, and the benefits of implementation and evaluation of the research with the community (p. S79-S80). Israel et al. (2007) also offer additional recommendations for the formation of a CBPR that minimizes ethical dilemmas. Paramount among these recommendations is the need to identify community leaders who are "respected community members who have credibility and visibility, and who are well-integrated in their community" (Israel et al., 2007, p. 187). The establishment of an advisory board with community leaders is important because this group will be the community's "voice" in all decisions concerning the research and will provide the transparency needed to garner trust in the research endeavor.

Operating principles. After the community representatives are identified, Israel et al. suggest the development of operating principles that promote "attentive listening, openness, caring, inclusiveness, agreement to disagree, identifying and addressing conflicts, opportunity for all to participate, negotiation, compromise, mutual respect, and equality" (2007, p. 185). These elements encourage the development of trust by the community in the research project. The operating principles and their justifications are as follows:

Method of decision-making. The method of decision-making should be determined by both researchers and community members after group representatives have been identified. Whether by majority or consensus, the voting method should be decided upon and adhered to as a means of preventing misunderstandings and promoting a democratic way of resolving issues. This is a fundamental element in the research relationship as it "respects the community" as equal to the researchers in the project.

Identification of research issues and goals. The participation of community members in the identification of their needs and issues "minimizes the likelihood of research that is irrelevant or insensitive to community concerns" (Flicker, Travers, Guta, McDonald, & Meagher, 2007, p. 480). Input from the community will decrease the likelihood of harm to the community because a "benefit" is assured through relevance of the issues explored. The principle of beneficence is upheld.

Determination of methods for performing, analyzing, and disseminating research results.

- (1) *Informed consent.* Informed consent documents should be developed based upon the literacy level of the population. Community members are uniquely vested with local knowledge of this fact and should be of great value in this assessment. Also, community members should be involved in explaining the research to the participants.
- (2) *Minimization of barriers to participation.* A concerted effort should be made to encourage research participation. Flexibility in meeting times for assessments, focus groups, and interviews should be allowed. Also, transportation and child care issues should be addressed. Community members should be hired to transport participants to research sites and to provide child care assistance during research activities when applicable and with reasonable remuneration.
- (3) *Development of training and empowering opportunities.* Community members should be trained and paid to conduct research related activities. For example, if research is related to hypertension, activities could include blood pressure checks, medication compliance tool training, and healthy cooking demonstrations. These activities are related to blood pressure control and will serve the community well after the research project has ended. Also, community members should be involved in research design and methodology determinations and assist with data analysis, presentation of research progress and results, and publication activities. These activities will empower the community to understand the research, act on the research, and use their new skills to seek out areas for future research deemed beneficial to the community (Israel et al., 2007).

All of these operating principles have a foundation in respect for the individual and the community, beneficence realized by the participant and the group, and/or social and reciprocal justice. Respect for the

individual/community is revealed in the informed consent process that values community interaction. Moreover, the principle of beneficence is manifested through the knowledge gained by the community concerning the management of a prevalent communal disease state. And, social and reciprocal justice is expressed by the many modes utilized to build capacity in the community, such as training in research methodology and other employment opportunities.

As an additional note, reciprocal justice should be infused throughout the research project. As Wallwork notes, reciprocal justice acknowledges that “benefits are owed a community for providing access to members; use of its institution, local knowledge, and skills; and the time and energy of members that might otherwise be used for other important communal projects” (2008, p. 73). Other examples for incorporating reciprocal justice into the project are provision of immunizations in exchange for data input, honoraria for clerical assistance, and participation by community members in national presentations of the research (Wallwork, 2008).

OBJECTIONS

Objections to community-based participatory research exist. Critics of CBPR warn of the possible coercion of the individual research participant by their community and thus, a diminishing of the participant’s autonomy. But, as Wallwork notes, voluntary acceptance of a “collective decision [can be considered] ‘a legitimate source of direction’” and protocols can contain further measures of protection of the individual participant such as confidential “opt-out” provisions (2008, p. 70). Other critics may question the motivations of community leaders; however, this concern will be diminished early in the process by the substantial researcher time spent within the community. Some detractors note that the inclusion of reciprocal justice in CBPR is a departure from the justice anticipated by the Belmont Report, but with CBPR, reciprocal justice is justified as a public health measure to empower historically marginalized

communities. Finally, community-based participatory research has been depicted as being incredibly costly, time consuming and overall “not worth it” to the researcher seeking publication, tenure, and promotion (Wallwork, 2008, p. 60). However, efforts are being made to support CBPR as seen by an increase in funders of such research (Wallwork, 2008). In the end, the most ethical method that should be used to perform research in vulnerable groups is community-based participatory research.

CONCLUSION

As presented, the best ethical framework for research within vulnerable populations where “like” communities have experienced exploitative research in the past is the community-based participatory research model. CBPR involves a hands-on, in the field approach to research wherein all involved (participant, community and researcher) are equally empowered. This model respects the individual research participant and his community. Beneficence is shown toward the individual and the group. Also, reciprocal justice promotes trust in research and is justified as a means to atone for past research transgressions that caused exploitation of similar communities. Most importantly, as Flicker et al. (2007) notes, CBPR allows for:

The development of research questions that better reflect health issues of real concern to community members; improv(es) researchers’ ability to achieve informed consent and address issues of costs and benefits to the community; improve(s) cultural sensitivity, reliability, and validity of measurement tools through high-quality community participation in designing and testing study instruments; and increase(s) relevance of intervention approaches and thus the likelihood of success (p. 481)

These research benefits justify the time, cost, and relevance of community-based participatory research in marginalized or vulnerable communities.

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