Re-Conceptualizing the Belmont Report: A Community-Based Participatory Research Perspective

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ABSTRACT. University-based researchers must seek Institutional Review Board (IRB) approval when their projects meet the human subjects regulations’ definition of research. Regulations guiding IRBs are informed by the Belmont Report’s (1979) ethical principles of respect for persons, beneficence, and justice. Debates exist about whether these principles apply to all research approaches. These debates prompted this study involving interviews with 10 community-based participatory researchers (CBPR). Interviewees identified ethical issues relevant to their research, interpreted the Belmont principles, and reflected upon the appropriateness of these principles. Constant Comparative Method guided data analysis. Differences exist between CBPR and the Belmont Report’s conceptualizations of the ethical principles. The discussion includes suggestions to
address these differences with the aim of strengthening the IRB process’ relevance.

**INTRODUCTION**

University-based researchers must seek Institutional Review Board (IRB) approval when their projects meet the human subjects regulations’ definition of research. The IRB process aims to strengthen research ethics and prevent exploitation of research participants. The Federal Policy for the Protection of Human Subjects Regulations (45CFR46, Subpart A) specifies the conditions related to the requirements of an IRB review. These regulations are informed by the ethical principles articulated within the Belmont Report (1979): they include respect for persons, beneficence, and justice.

The Belmont Report’s analytical framework operates from an ethical paradigm referred to as principlism, the dominant system within bioethics (Evans, 2000). Ethical principles are derived from moral theories. Beauchamp and Childress (1997) view principles as:

> both prima facie binding and subject to revision. So understood, a prima facie principle is a normative guideline stating conditions of the permissibility, obligatoriness, rightness, or wrongness of actions that fall within the scope of the principle. The latitude to balance principles in cases of conflict leaves room for compromise, mediation, and negotiation. (p. 145)

Beauchamp and Childress (1994) distinguish principles from rules: “Principles are general guides that leave considerable room for judgment in specific cases and that provide substantive guidance for the development of more detailed rules and policies” (p. 38). Commonly acknowledged benefits of principlism include its ability to justify moral judgments of “this action is ethically wrong” or “this research methodology is ethically questionable” (Macklin, 1999, p. 33).
Debates within the literature question whether the Belmont Report principles as applied by an IRB are culturally bound and adequate in scope (Vanderpool, 1996). Carrese and Rhodes (1995), for example, conducted a study with Navajo key informants who identified cross-cultural limitations with Western bioethics. The informants indicated that a traditional Navajo perspective sees a connection between voicing negative outcomes and an increased likelihood for harm. This belief contrasts to Western thinking where disclosure of risk is heralded as ethical practice. Respect for persons has also been criticized for its individualistic focus. Tai and Lin (2001) state that the Western concept of autonomy focuses on the right of the individual, which contrasts to how certain Asian cultures consider autonomous decision making.

Principlism also is critiqued for its tendency to oversimplify ethical considerations (e.g., Jonsen & Toulmin, 1988). Oversimplification occurs when establishing key principles eliminate “extraneous” information from ethical analysis (Evans, 2000). For example, De Laine (2000) claims that the regulations inadequately question the broader impact or value of research, whereas Sherwin (1992) advocates for a review process that evaluates research “not only in terms of its effects on subjects of the experiment but also in terms of its connections with existing patterns of oppression and domination” (p. 174). This emphasis is not reflected in the Belmont Report’s conceptualization of justice. The ethical principle of justice instead initially assumed a protectionist stance that reflected the historical context in which it was written, a period during which research exploiting vulnerable populations was brought to the public’s attention. Later, justice considerations expanded to include the risks of excluding certain groups from research. The feminist movement, for example, argued that an understanding of women’s health issues required study samples comprising women and not just men. In essence, justice, as conceptualized in the Belmont Report and applied by the IRB, focuses on sample selection but remains relatively silent on the social justice issues as advocated by Sherwin. In response to the perceived narrowness of the principles, Macklin (1999) argues that the Belmont principles represent only the bare minimum of ethical considerations. Furthermore, Macklin cautions that oftentimes people critique the principles, when in actuality they are critiquing the rules associated with the principles. As Beauchamp and Childress (1994) explain, rules are more specific and offer less flexibility than ethical principles.

Additionally, questions remain as to whether the human subjects regulations, which are informed by the Belmont Report, adequately anticipate ethical considerations relevant to non-clinical approaches (e.g.,
These debates prompted the current exploratory study that examined the perceptions of community-based participatory researchers. Community-based participatory research (CBPR) was selected as it differs from clinical approaches where the experimental design is regarded as the gold standard. CBPR oftentimes involves partnerships between community and university or government representatives to address a community-identified or supported concern. CBPR typically focuses upon non-clinical questions and involves communities that have been marginalized. Key principles guiding CBPR include “builds on strengths and resources within the community,” “facilitates collaborative partnerships in all phases of the research,” and “integrates knowledge and action for mutual benefit of all partners” (Israel, Schulz, Parker, & Becker, 1998, p. 178).

The study entailed asking CBPR researchers what core ethical issues are relevant to their work as well as what their interpretation and critique is of the Belmont Report. The project’s intent was to assess the degree to which CBPR ethical considerations are reflected within the Belmont Report’s conceptualization of the guiding ethical principles and to provide recommendations on how to re-conceptualize these principles to better reflect guiding CBPR principles. Greater consistency between CBPR and the Belmont Reports’ conceptualization will likely increase the IRB review’s relevancy to participatory research. An overview of the Belmont Report is presented prior to discussing the study’s methodology.

**BELMONT REPORT**

In 1974, Congress passed the National Research Act that provided budgetary support for a National Commission to examine issues for the protection of human subjects. The Tuskegee Syphilis Ad Hoc Panel and public outcry over other unethical research endeavors demanded a congressional response (Jonsen, 1996). One outcome of the National Research Act was a mandate that all biomedical and behavioral research receiving federal dollars undergo an IRB review. The National Commission also produced the Belmont Report.

The Belmont Report articulated three ethical principles that “provide a basis on which specific rules may be formulated, criticized and interpreted” (Ethical Principles and Guidelines, ¶ 2). These principles are respect for persons, beneficence, and justice. Respect for persons states, “Agents should be treated as autonomous agents, and . . . persons with diminished autonomy are entitled to protection” (Basic Ethical Principles,
2). An autonomous individual is defined as “capable of deliberation about personal goals and of acting under the direction of such deliberation” (Basic Ethical Principles, ¶ 3). The report recognizes that self-determination may be challenging for certain groups (e.g., children), and consequently these groups require additional protection. This first principle is actualized through the guidelines established for the informed consent process. As written, “Respect for persons requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them” (Applications, ¶ 2).

The second principle, beneficence, has two layers. First is the concept of “do no harm”; second is to “maximize possible benefits and minimize harm” (Basic Ethical Principles, ¶ 7). Beneficence addresses how harm can affect individuals and/or groups differentially based upon such key demographics as gender and ethnicity. Some interpret the conceptualization of beneficence as adhering to a utilitarian philosophy that reflects the notion of greater good to the greater number or that “right actions are those that produce the best possible social consequences” (Goodman & Prineas, 1996, p. 294). To actualize this principle, IRB members conduct a risk-benefit assessment that accounts for individual and societal-level considerations.

Justice asks, “Who ought to receive the benefits of research and bear its burdens?” (Basic Ethical Principles, ¶ 11). The principle reflects a position of distributive justice and offers guidance on how to assess whether the burdens and benefits are justly distributed. The Belmont Report acknowledges that even through just selection procedures, injustices may occur due to the “social, racial, sexual, and cultural biases institutionalized in society” (Applications, ¶ 21). The Belmont Report outlines justice considerations at the individual and social level. The individual level specifies “fairness” whereby the researcher “should not offer potentially beneficial research only to some patients who are in their favor or select only” undesirable “persons for risky research” (Applications, ¶ 20). The social level, referred to as social justice, “requires that distinction be drawn between classes of subjects that ought, and ought not, to participate in any particular kind of research, based on the ability of members of that class to bear burdens on already burdened persons” (Applications, ¶ 20). McGough (2001) summarizes the current IRB application of justice as determining whether the research benefits the community, avoids exploitation, includes all affected populations, and considers demographics as well as access issues.
METHODOLOGY

Purposive sampling was used to recruit participants that met the study’s inclusion criteria. The sample included 10 CBPR researchers from across the United States. All participants submitted at least one minimal risk or full review human subjects’ application within the past five years to a University-based IRB. Additional inclusion criteria required that the researcher viewed the community as an agent of change and had a formalized collaborative process. Sample size was determined by saturation, which was reached once concepts converged and when recruitment efforts were unable to identify additional participants (Lincoln & Guba, 1985). Participants were identified through Web-based searches and snowball sampling.

The interviews lasted approximately one hour. The primary interview questions included (1) If you were to train a new researcher on your team, what are the critical ethical issues you would want covered in the training?, (2) What does respect for persons/beneficence/justice mean to you?, and (3) Do these three principles cover the scope of ethical considerations in your research? All participants consented to have the interview audiotaped. The audiotapes were transcribed verbatim and imported into QSR N6, a qualitative data software package. Constant Comparative Method (Lincoln & Guba, 1985) guided the data analysis. A committee of researchers was consulted throughout the design and analytic process. The committee was instrumental in strengthening the study’s validity and reliability.

FINDINGS

The findings represent a piece of a larger study (Shore, 2004). Findings are organized in the following manner: Core Ethics, Interpretation of Belmont Principles, and Critique of Belmont Principles.

Core Ethics

All the interviewees identified the critical ethical issues relevant to their research. The three overarching themes that emerged from the interviewees’ responses referred to “ethics of involvement,” IRB purview, and the interrelationship between scientific and ethical considerations.

Interviewees expressed values and beliefs about the ethics of partnership building, which one interviewee defined as the “ethics of involvement.” These ethical considerations reflect what is required of
academic-based researchers to effectively and ethically engage in CBPR. Academics need to account for the community’s historical experience—specifically, whether mistrust exists due to past involvement in research that failed to produce community benefits. A core underlying value of “ethics of involvement” is a commitment to create equitable and inclusive partnership processes. There is also a need for academic researchers to have sensitivity to potentially complicated partnership dynamics and the skills to navigate these dynamics. As one interviewee commented, competing agendas can exist in communities, which requires researchers to be aware of the political nature of community work and be comfortable and skilled in working through conflict. Other required skills to build and sustain partnerships included the ability to balance listening and offering input, and to negotiate rather than impose expectations and roles. Recurring words or concepts that surfaced in the discussion of “ethics of involvement” included: negotiate, inclusion, time-consuming, commitment, mutual regard, equal sharing, and accountability.

Interviewees also identified core ethical issues that reflect traditional IRB considerations. Issues discussed related to consent, confidentiality, risk, deception, coercion, and HIPAA. These topics are not necessarily considered unique to CBPR. For example, one interviewee spoke broadly about the ethical consideration of “systematically protecting the lives and reputations of the people you are working with.” Descriptions were also provided regarding how traditional IRB ethical concerns are addressed throughout the research process among the research team. The following statement illustrates this tendency and describes how ethical discussions impact the research design.

Be constantly aware of confidentiality issues and they come up in discussions on a regular basis with my students . . . we exclude whole ranges of questions from surveys that the organization would like us to have because they create too much risk for the individual responding.

Other interviewees talked about how research skills and ethical reflection should be considered together as the two are interrelated. As an example, an interviewee posed the following question: “Do you know how to do an interview in a way that preserves the integrity of the individual?” Strategies to determine an appropriate methodology were another example demonstrating the relationship of scientific and ethical considerations. Researchers must be open to community partners’ input regarding effective and community-appropriate ways to gather data. For example, one interviewee described how community partners prevented the use of Likert scales because these scales were considered culturally inappropriate. More appropriate data collection strategies will
increase the quality of information collected, which can lead to stronger science. Selection of a research method, therefore, should take into account the research questions posed by the partnership, the community’s input, and the researcher’s knowledge of various methods. To paraphrase one interviewee, the methods used should be the ones that are “best for the community itself” rather than just what is most familiar to the researcher. The interviewee’s comment was intended to reinforce the notion of how academic researchers engaged in CBPR should not impose their expertise onto a community and assume their knowledge trumps community experiences and insights. Determination for what is “best” requires the partnership as a group to critically consider the context of the project and its aims, which is facilitated when partners have established mutual trust and a shared vision.

**Interpretation of Belmont Principles**

Interviewees were asked for their interpretation of respect for persons, beneficence, and justice. Some of the themes that emerged in their interpretations of the Belmont principles were consistent with the responses to what are the core ethical issues relevant to CBPR. These included a focus on partnership dynamics and ethical considerations traditionally focused upon by IRBs. In their interpretations of the principles, the interviewees also strongly emphasized the importance of producing community benefits such as using study findings to enhance advocacy efforts.

**Respect for Persons**

Given many of the responses, respect for persons could be renamed respect for partnerships. Respect entails acknowledging and valuing the different skills and experiences within the partnership. Respect also entails a commitment to empowering practices, which include creating participatory processes where all partners have a voice in decision making and where there is a commitment to translate findings into actual community benefits. As one interviewee commented, “If you are bringing someone on as a partner, they are treated as a partner.” In other words, community involvement should not be relegated to token participation. Respect for partnerships takes time to actualize and sustain. This interpretation of respect coincides with interviewees’ discussion related to “ethics of involvement.”
Respect for persons can have multiple meanings for study participants, research partners, and IRB reviewers. In order to honor the varied interpretations, “people [should be able to] define what respect means to them.” Care must be taken that respect is conveyed in both written and oral communication. This may entail reviewing survey instruments or other documents to assure that the language used “respects gender and race, and the dignity of individuals.” Cultural differences may account for some of the variation in the interpretations of respect, yet differences in interpretations can exist both within and across cultural groups. Cultural considerations are elaborated upon in the Critique of Belmont Report Principles section.

Differences in interpretation may represent sites of tension that are not easily negotiated. In certain contexts, respect for persons requires community-level considerations that might conflict and supersede individual-level considerations. As an example, one interviewee stated that in some instances, “if a tribe denied me access to do research, [an individual member of that tribe] could not legally give permission to be a part of my study.” If the tribal review process believes that a project presents too great of risk or does not have any community benefits, the tribe may deny the research proposal. Denial by a tribal review board must be understood within the historical context, which is riddled with people “ripping off Indian country and doing really terrible research and falsely interpreting data and spreading all these terrible, horrendous false impressions of Indian country.”

Overall respect for persons “varies from project to project and from community to community.” The challenge is to understand that multiple meanings exist and to figure out how to honor different interpretations. In other words, respect for persons is “respecting differences among participants.”

Interpretations of respect for persons also included aspects traditionally considered by the IRB, such as providing individuals with sufficient information so they can make an informed decision regarding study participation. Study information should include that participation is voluntary and participants have a right to withdraw at any time. One interviewee infused the traditional meaning of respect for persons with CBPR values of partnership and sensitivity to context. He stated:

People should not be used as a means toward your end, so that treating people as full actors, as equivalent if not identical participants in the process, having respect for their historical experience, their current reality, their response to that reality, their opinions,
their views, their different forms of intelligence, their different
skills and so forth.

**Beneficence**

Interviewees’ interpretation of beneficence emphasized empowerment, subjectivity, and traditional IRB considerations. Discussion of beneficence from an empowerment perspective emphasized research outcomes, which included “building the power of collective action” and strengthening the community’s ability to solve their concerns. From this perspective, there was a clear commitment to generating knowledge and translating findings into action. These outcomes reflect how beneficence “goes well beyond the focus on the individual.” In reaction to the IRB’s stance of risk/benefit analysis, one interviewee declared, “I would just twist it and say it’s not do no harm, it’s actually you better do some good.” From this perspective, a CBPR project has failed if it does not result in community benefits. As an example of beneficence from an empowerment perspective:

If our research does not help the community organizations that we’re working with improve their condition that brought them to us, then we haven’t done our jobs . . . we have to be able to provide some product that will help them think more critically about what they do everyday, or leverage resources or solve a problem.

Beneficence is complicated given that individuals and/or groups have varied interpretations of what constitutes a benefit. In thinking about what is a community benefit, researchers need to be self-reflective and to think critically about the community and research context. Working from a position of good intention does not guarantee sensitivity to or awareness of what others may view as an actual benefit. Beliefs regarding research benefits may vary depending upon cultural differences, a community’s historical experience with research, and other contextual factors. This notion of variance reflects the beliefs expressed under the interpretation of respect for persons. One interviewee described experiences where “out of good faith, myself and other members of our team were doing things we genuinely believed were in the best interest of the community and its residents, but the community had a very different interpretation of the potential impact of our research.” Given the complexity of beneficence, the partnership should “take [beneficence] as a
subject of inquiry and a discussion point.” Engaging in conversations with community partners can reduce the likelihood of imposing one’s own notions of beneficence onto others.

Interpretations of beneficence also included aspects that are directly related to what the IRB considers within its risk/benefit analysis. Reflections included how minimization of harms is potentially easier than producing actual benefits. Judgmental statements emerged that suggested CBPR is better positioned than non-participatory approaches to actually produce benefits for the study participants. As one interviewee shared, “one of the criticisms I have of non-community kind of research, particularly the way we tend to do it, is that the relationship between helping people and doing research is so distant that it’s hard to say that beneficence is there.” To clarify this judgment, the interviewee provided an example of a well-funded smoking cessation project. If the intervention project cannot be replicated in other communities or sustained due to the withdrawal of funds, positive findings only reflect special well-financed circumstances that are not applicable to real-world conditions. In other words, “it might work, but you spent $5000 per person to get them to quit smoking, which is completely unreasonable.”

Justice

Interpretations of justice included a focus on equitable research processes, social change, and traditional IRB considerations. The first two foci are not mutually exclusive. As one interviewee stated, “Justice would mean using the research process and outcomes to the extent possible to alter the distribution of resources, power status, and opportunities in the interest of greater social equity.”

An equitable research process requires partnerships that are inclusive where there is a “leveling of the playing field.” A leveled field creates an environment where all the stakeholders’ voices are heard and respected throughout the research process from designing the study, to gathering the data, to disseminating the findings. The emphasis on process and relationship dynamics reflects the sentiments voiced in the “ethics of involvement.” One interviewee described CBPR as “an inclusive process that helps enhance the sense of equity and opportunity for knowledge . . . generation and the application of the knowledge.” An equitable and just process does not occur if stakeholders are invited to participate, but their participation is relegated to the role of advisor rather than decision maker. The following comment summarizes this interpretation of
justice and demonstrates how research processes can become unjust even when community participation is solicited.

Justice means that people have equal access to decision making. And you can have community members participate all you want, and if all they are doing is sharing information and not feeling like they are influencing policy and decision making, then that is a very unjust and very unequal level of participation.

An underlying value of CBPR is its commitment to action. This sentiment is illustrated through the following statement that describes non-CBPR researchers as “more concerned usually just about furthering the body of knowledge about a certain topic. We’re involved in that too, but we better be involved around social change and social justice.” From a social justice perspective, research entails challenging unjust structural or macro-level problems. As part of the social justice commitment, researchers acknowledge the political nature of CBPR and are not silent regarding their intentions to challenge the status quo and disrupt social injustices. A commitment to social justice also influences the types of projects appropriate for CBPR. These typically include working with marginalized communities to address a social inequity, such as health disparities or inadequate housing. As one interviewee shared:

Justice really is not about helping people; it is about changing the social conditions that cause them to need help to begin with. And ideally, this form of research shouldn’t be just about working again at an individual level of analysis. Ideally, at some point, it moves to collective action at a structural target, whether that target is racism, sexism, or classism, or whatever.

Only one interviewee specifically talked about sample selection. Her discussion reflects the questions traditionally posed by the IRB. The intent of the IRB questions is to assure that a study population is not selected and potentially exploited due to their marginalized status and perceived ease of access. In instances where a particular study population is targeted, researchers must justify their sample criteria and demonstrate that there is a “scientifically valid reason for why somebody is included and somebody else is not included.” The interviewee’s case example described studies that seek participation of a particular ethnic group. In order to assess whether the study sample was constructed following the principle of justice, she would ask researchers, “Why do you need American Indian specimens per se?”
Overall interviewees’ responses touched upon IRB considerations yet pushed the regulatory framework by introducing the “ethics of involvement” and emphasizing social change and community-level considerations.

Critique of Belmont Report Principles

Some interviewees were satisfied with the scope of ethical considerations covered by the Belmont principles. In part, this was due to the meaning of the principles being sufficiently abstract to allow for flexible interpretation, or having been schooled in the Belmont principles and, consequently, unable to think of other principles. While the level of abstraction represented a benefit for some of the interviewees, others advocated for greater specification of the current principles. Some of these interviewees pointed to ethical concerns that may already be subsumed under the current principles, but given their importance these concerns were not viewed as sufficiently explicit. For example, one interviewee believed that the notions of truth-telling already were subsumed under beneficence, but given its lack of explicitness, the importance of truth-telling was obscured.

There was also a call to clarify the language in order to make the meaning of the principles more accessible and less confusing. As one interviewee reflected, the Belmont principles’ language “is sort of old school . . . very academic, and obviously were written for people who are doing more traditional research.” Greater explication of the principles also could help reduce problems caused by IRBs and research teams interpreting the principles differently. A tension, therefore, exists between keeping the principles at a level of abstraction to allow for flexibility, with a desire for greater specification that would allow for more consistent application. This tension is interesting given that many of the interviewees spoke strongly about the need to honor the varied interpretations of beneficence or respect. If a specified definition becomes the standard, one group’s worldview may supersedes another group’s interpretation. In other words, specification may strengthen the norm while marginalizing other interpretations.

Other interviewees either suggested additional ethical principles for research in general or the development of ethical guidelines specific to CBPR projects. The suggested new principles that the IRB should consider included equitable decision making; community collaboration; access to data and disclosure of information; and cultural considerations. There was no consensus as to whether the principle of community
collaboration should be applied to all research approaches or just to projects that claim to be community-based. Some of the suggested principles reflect a value orientation more closely aligned to CBPR, and consequently their application to non-participatory projects may be resisted. An example of a suggested additional principle is presented later.

Shared decision making in the research process, and that I think, that will take years and years and years for us ever to see that happen because a lot of traditional researchers are really ambivalent or unwilling to share power because they think that is sort of the fatal flaw with this type of CPBR work.

Ethical guidelines specific to CBPR projects included all the partners being upfront with each other, fair distribution of resources, and active participation. Speaking more broadly, one interviewee discussed the notion of establishing “norms for the group.” The underlying assumption was these norms would evolve within the partnership process and that the partnership, rather than the IRB, is in the position to assess whether these norms are upheld. Partnerships, therefore, need to assume (or maintain) the responsibility of assessing the “ethics of involvement.” Given that community collaboration was named as a new principle, however, the IRB was also seen as having a role in the assessment of the “ethics of involvement.” Perhaps the unspoken difference in roles is that the IRB should look for broader indicators of community participation, while the partnership should be responsible for the negotiation and application of group norms. If guidelines specific to CBPR are to assist the IRB, recommendations included providing scenarios to help the IRB understand participatory research and defining key terms to increase the likelihood of shared meaning. As an example, one interviewee pointed out how multiple interpretations of “community-based research” exist. For some “community-based research” refers to partnership work, while for others it refers to research where the community acts as a site for data collection.

One interviewee recommended shifting from the principle-based mode of ethical analysis as challenges can surface when the ethical principles do not provide consistent guidance on how to proceed. As an example, the interviewee described how compensation could be viewed as either ethical or unethical depending upon whether the argument is made from a respect for persons versus a justice perspective. Furthermore, the interviewee advocated for a model of ethical analysis that better anticipates the research process’s short- and long-term consequences. As the interviewee pointed out, research involvement may result in immediate
risks associated with participation as well as long-term risks based upon the impact of the research findings.

Interviewees were prompted to consider whether their discussion of the Belmont principles required additional consideration if research activities were occurring with diverse communities. Overall, there was a perceived need to consider an individual’s membership in his/her social identity groups given the potential for exploitation that continues to occur under the name of research. The consideration of group memberships, however, must be done in a manner that avoids paternalistic measures. Interviewees reflected on how one must find a balance between respecting an individual’s agency and accounting for the potential vulnerability of certain groups to research exploitation. Interviewees also elaborated upon the necessity to carefully consider issues of trust and honor cultural differences.

In working with diverse communities, interviewees expanded upon the need to build trust, which includes accounting for the possibility that communities may feel over-studied and frustrated with previous research experiences. One interviewee reflected upon his experiences, and shared

There is so much distrust in any situation where an outsider comes in but particularly when the outsider is of a different demographic background from the members of the community. And particularly when the institution that the outsider represents is one that has had very suspect relationships with that particular community, where the community sees itself as an object of exploitation, not as an equal partner.

As indicated by the comment, lack of trust can extend beyond the researcher to include the university as a whole. Community-University tension can result if the university is perceived as taking over local resources and/or not reciprocating to the community. Other interviewees pointed out that the current principles and review process do not adequately account for the historical and continued problems communities may experience with both researcher and university interactions.

Overcoming distrust is difficult, or as one interviewee stated, “Building and sustaining that trust is perhaps the biggest challenge in doing participatory research.” The research process can engender greater community trust by recognizing community strengths, respecting cultural differences, and involving communities in meaningful ways. This requires that the university and/or the researcher maintain a positive presence in the community that extend beyond the life of a single project.
A focus on relevant and useful benefits reflects many of the interviewees’ interpretations of both beneficence and justice.

In the context of working with diverse communities, interviewees reiterated the notion of subjectivity voiced earlier in the discussions related to respect for persons and beneficence. The ethical principles as applied by the IRB hold the potential to overlook how different cultural groups may have varied interpretations of these principles. Differences in interpretations will also exist within cultural groups, which may reflect differences in class and/or gender. Given the subjective nature of the three principles, creating a more specific and standardized definition risks operating from a perspective that is culturally bound and too rigid to allow for alternative perspectives. The question becomes who has the power to define. Both the IRB and researchers need to avoid the potential of imposing a single or dominant worldview on groups that may have varied interpretations of the principles. In the spirit of negotiating meaning, one interviewee noted, “The interpretation of those principles is not simply that of the researcher but that equal weight is given to the interpretation of what those principles mean to the people who are so called subjects of the research.” As an example, one interviewee discussed how cultural differences are not fully recognized in the actualization of respect for persons, the informed consent process. For this interviewee, informed consent represents one of “the best examples of white privilege” as the underlying assumptions of consent is independence, which runs counter to the “vast majority of immigrant cultures here [who] are interdependent.” In order to address this problem, this interviewee described a “translational process” where the actual individuals who interface with study participants modify their approach to create a more culturally appropriate interaction. The concern is that IRBs may require researchers to translate a consent form, but this does not guarantee that the informed consent process occurs in a culturally appropriate manner. Several interviewees considered “cultural competence” as an ethical issue, yet acknowledged how IRBs do not routinely seek information regarding a research team’s level of cross-cultural understanding.

**DISCUSSION**

Overall, interviewees infused their empowerment orientation into their ethical commitments to both the research process and outcomes. The influence of an empowerment perspective was evident by the references to
building trust, creating equitable partnerships, challenging structural inequities, and translating findings into action steps relevant to the community. Concordant with the empowerment perspective, interviewees stated that researchers should resist the tendency to assume that the Belmont Report’s or their own interpretation of the ethical principles is applicable across all research contexts. Honoring varied beliefs requires that researchers are self-reflective and cognizant of cultural differences as well as other contextual factors (e.g., a community’s historical experiences with research).

Interviewees also named some of the ethical considerations traditionally focused upon by the IRB. In the spirit of participatory processes, these traditional considerations were often discussed amongst the research partners and at times infused with CBPR values. Differences between the Belmont Report and interviewees’ conceptualizations of the principles also emerged. For example, the Belmont Report’s interpretation of respect for person focuses more on the individual’s ability to make an autonomous decision. The researcher-researched relationship in the Belmont Report is presumably vertical rather than the partnership-oriented framework described by the interviewees.

In terms of beneficence, the Belmont Report considers both individual and societal-level benefits. As an example of societal benefits, the Report describes research with healthy children who are not the immediate beneficiaries of a study. The children’s participation instead produces societal benefits that include improvements in treatment and/or prevention of childhood illness in general. Interviewees’ also named benefits that impact more than just the individual participant. Interviewees’ conceptualization of community benefits, however, emphasized building collective action and leveraging resources where the community represents an actor in the change process. The Belmont Report suggests a framework more consistent with traditional research where the researched are more representative of objects that passively contribute to the researcher’s understanding and ability to produce individual and/or societal level benefits.

Longres and Scanlon (2001) offer a useful way to distinguish the different interpretations of justice articulated within the Belmont Report and the interviews: distributive and relational justice. The Belmont Report’s conceptualization reflects more of a distributive justice orientation. This orientation focuses upon the distribution of social goods (e.g., a project’s risk and benefits) with a focus on outcomes and/or outputs. The Belmont Report refers to social justice by stating that there needs to be “an order of preference in the selection of classes of
subjects (e.g., adults before children) and that some classes of potential subjects (e.g., the institutionalized mentally infirm or prisoners) may be involved as research subjects, if at all, only on certain conditions” (Applications, ¶ 20). The interviewees’ commitments coincide more with relational justice. A relational justice stance encourages research partners to reflect upon decision-making processes as well as their own and others’ social identity group memberships. These reflections help partnerships recognize whether inequitable power dynamics are disrupting the research process. In terms of socially just outcomes, research is viewed as a means to create social change.

In looking overall at the Belmont Report, one can see how the orientation to research in general differs from some of the core underlying values of CBPR. For example, the Belmont Report refers to study participants as “human subjects,” which connotes a vertical relationship with the researcher occupying the position of greater power. The final footnote in the Belmont Report also indicates that biomedical and behavioral research represent the focus of the report, and that ethical considerations relevant to “social experimentation” require separate consideration. Implicit in this footnote is a conceptualization of research more aligned with the positivist paradigm. The Belmont Report’s discussion of the boundaries that exist between practice and research further reflects this particular conceptualization of research.

The question that remains is whether the Belmont Report principles can be re-conceptualized or broadened to account for the interviewees’ different perspectives. Some interviewees believed that the ethical principles were sufficiently abstract to allow for flexibility in interpretation. This viewpoint coincides with Macklin’s (1999) argument that the challenges related to flexibility surface in the application of the principles. Mirroring the debates in the bioethics literature, however, other interviewees discussed the potential for the Belmont principles and their application to be culturally bound and inadequate in scope. Some of these interviewees identified additional ethical principles or CBPR specific guidelines. The responsibility of assuring adherence to these principles and/or guidelines was not relegated to the IRB. Some interviewees instead suggested that partnerships often have the expertise or sensitivity to better assess the community-relevant ethical issues.

As one interviewee suggested, perhaps the model of ethical analysis needs to shift to better account for CBPR considerations. The relationship paradigm proposed by King, Stein, and Henderson (1999) brings to the surface many of the ethical issues raised by the interviewees. The development of the relationship paradigm was in response to the lack of
fit between principlism and more collaborative research approaches. For example, King et al. (1999) state, “If the principlist paradigm implies that relationships in research are vertical, then the researcher-subject relationship can only be seen as either dominated by researchers, or dominated by subjects—not as a horizontal relationship of equals” (p. 218).

The relationship paradigm does not advocate for the elimination of the Belmont Principles, but instead suggests that the ethical analysis be expanded to foreground contextual factors, including cultural, gender, ethnic, and geographic considerations. King et al. (1999) claim that the relationship paradigm widens the ethical frame of reference as compared with the regulations’ tendency to focus primarily on the individual human subject. The relationship paradigm broadens this focus by considering what the other relevant relationships are. For example, in CBPR, some of the relationships include the different partners, as well as the research team and funders. Considerations of these relationships require an analysis of power dynamics, which is an influence of feminist ethics. Feminist ethics instructs researchers to acknowledge positions of power and vulnerability, as well as to account for structural factors.

The relationship paradigm also challenges assumptions regarding the value and meaning of research. Rather than taking the value of research as a given, the relationship paradigm encourages society to critically reflect upon “what [research] is, what it is good for, and why researchers do it” (King et al., 1999, p. 219). This line of questioning motivates society to think about the purpose of research and its underlying commitments. Given the emphasis on power dynamics, the relationship paradigm could prompt researchers/reviewers to consider the knowledge production process and how communities are involved. King et al. clarify that not all projects have to be participatory; rather by asking these questions more projects may begin to see the value and benefits of developing more collaborative approaches. By not challenging some of the research assumptions, key policies will maintain their bias towards conventional approaches that do not include horizontal relationships.

Basically the relationship paradigm prompts research teams and IRB reviewers to ask different questions than they might under the principlist paradigm. King et al. (1999) state that the relationship paradigm is a “vision tool not an action guide.” A more procedural-oriented “action guide” may offer more standardized and transparent rules to guide an IRB review process. This transparency may be valued given the fear of liability and the tendency to privilege more objective approaches. The relationship paradigm’s shift from a more procedural approach potentially allows for more space for subjectivity. The protest several years ago over the
National Institutes for Health’s funding of certain projects represents an extreme example of a particular set of values trying to dictate what constitutes allowable research. Diversity amongst the IRB committee could help minimize this possibility. For example, presence of individuals involved in CBPR could counterbalance any assumptions regarding the relationship between the researcher and the researched. The goal is not to create a process that privileges one way of conducting research, but rather a process that is open to a fuller range of methodologies.

A recommended next step for CBPR partners is to generate a set of guiding questions aimed at enhancing the IRB process. These questions could help orient IRBs to CBPR, as well as provide guidance for CBPR partnerships as they grapple with their own ethical considerations. Based upon study findings, presented later are provisional questions. These are not intended to replace the questions derived from the Belmont principles, but rather to broaden the scope of ethical considerations. The italicized questions reflect relationship paradigm considerations, while the bulleted items reflect some of the ideas generated by the interviewees. Ideally, these questions will spark conversations amongst CBPR teams, resulting in an expanded guide.

What are the relevant relationships specific to this project?
• Is there community involvement? And if so, (1) how was the partnership formed, (2) who are the different partners, and (3) how are the different partners involved?
• Partnerships should also identify relationship questions related to “norms for the group.” As discussed by the study interviewees, these questions may be best addressed within the partnership rather than by the IRB (e.g., how are decisions made, how are resources distributed?).

What are the relevant contextual factors?
• What are the historical considerations relevant to the partnership and proposed research project?
• What measures have been taken to assure culturally sound research processes and outcomes?

What are the potential impacts of this research project?
• Who benefits, and what are the short- and long-term benefits (accounting for both individual and community level)? Who determines what constitutes a “benefit?”
• What are the short- and long-term risks (accounting for both individual and community level)? What steps are taken to minimize these risks? Who determines what constitutes a “risk?”
How will the findings be used? Will findings be used to effect social change?

**FUTURE STUDY DIRECTIONS**

Suggestions for future research include exploring how CBPR researchers grapple with ethical dilemmas in the field, assessing CBPR researchers’ reactions to the relationship paradigm, and broadening the study sample. Several interviewees described how they approached ethical dilemmas encountered in their work, even though this question was not explicitly asked within the interview. Interviewees described consulting with their partners (e.g., community members and students) as well as being critically self-reflective. They did not mention consulting with the IRB or referring to the Belmont Report. In a previous paper (Shore, 2004), CBPR interviewees identified challenges with the IRB, including a tendency for IRB reviewers to not understand their methodology (e.g., the role of an emergent study design). They did not specifically name differences in ethical considerations as a source of challenge. It would be valuable, however, to explore researchers’ perceptions of the relationship paradigm, and whether this approach would better assist the IRB and the research team in identifying and working through ethical dilemmas.

The study findings are based upon in-depth interviews with 10 individuals. Replicating the study could help determine whether the findings are reflective of other CBPR researchers. Suggestions for broadening the sample also include involving community partners and IRB reviewers. Given that CBPR strives for equitable involvement, it is critical that community partners have a voice in future studies.

**REFERENCES**


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