

Ethical Issues in Patient-Centered Outcomes Research and Comparative Effectiveness Research: A Pilot Study of Community Dialogue

Journal of Empirical Research on
Human Research Ethics
1–9
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sagepub.com/journalsPermissions.nav
DOI: 10.1177/1556264614568426
jre.sagepub.com


Howard Brody¹, Sharon A. Croisant¹, Jerome W. Crowder¹, and
Jonathan P. Banda¹

Abstract

Community bioethics dialogues were held on the topic of patient-centered outcomes research (PCOR) and comparative effectiveness research (CER). Participants were 65 and older and represented either a lower income, African American group (A) or a higher income White group (B). Participants were presented with a variety of background reading and study materials. Meetings were held 2 hr per week for 6 weeks. The groups showed both independence in judgment from the investigators and diversity of opinion between the two groups. Group B addressed more topics than Group A and in some instances explored additional policy nuances. Members of Group A appeared more cognizant of issues of social justice that affect vulnerable populations and appeared leery of approaches that suggested possible disrespect for their own personal experiences. Future plans call for both repeating the dialogue with additional, diverse community groups and repeating community bioethics dialogues on new topics with the same groups.

Keywords

community bioethics dialogue, patient-centered outcomes research, comparative effectiveness research

Introduction

Community bioethics dialogue is a potentially powerful but little-utilized method of consulting the general public about ethical values relevant to health care issues. Beginning with Oregon Health Decisions in the early 1980s, addressing justice and access to care, such dialogues have more recently been used to address values around genetic screening and genetic privacy (Bonham et al., 2009; Crawshaw, Garland, Hines, & Lobitz, 1985; Garland & Hasnain, 1990). In this latter instance (Bonham et al., 2009), the dialogue method was shown to be as effective with lower income, minority communities as with middle-class White participants.

Survey and focus-group research elicit public opinions about bioethical issues at a single point in time and do not, in general, attempt to inform subjects about the existing bioethical debate on the topic being studied nor provide insight into how their views change over time. Other methods of rational democratic deliberation may feature intensive education on the topic and culminate in a vote on policy notions (Carman et al., 2013; Goold et al., 2012). We sought to inform participants about the bioethical topic and to foster sustained, rational discussion, but to seek as an outcome a clear articulation of the group's ethical values that might guide future policy rather than an actual vote on policy options.

Our dialogues were part of a larger project on patient-centered outcomes research (PCOR) in the elderly and, as such, sought to involve a pool of subjects aged 65 and older. The federal PCOR Institute has expanded the definition of PCOR so that it includes comparative effectiveness research (CER; Wu, Snyder, Clancy, & Steinwachs, 2010). The PCOR Institute imagines that PCOR will address several questions from the patient perspective:

Given my personal perspective, characteristics and preferences, what should I expect will happen to me? What are my options and what are the benefits and harms of those options? What can I do to improve the outcomes that are most important to me? How can the health care system improve the chances of achieving the outcomes that I prefer? (Washington & Lipstein, 2011, p e31(2))

Our goal is eventually to replicate the bioethics dialogue among four to six groups representing diverse

¹University of Texas Medical Branch, Galveston, USA

Corresponding Author:

Jerome W. Crowder, Institute for the Medical Humanities, University of Texas Medical Branch, 301 University Boulevard, Galveston, TX 77555-1311, USA.

Email: jw.crowder@utmb.edu

communities in the Texas Gulf Coast region. Here, we report on the pilot phase that involved two community groups, one African American, predominantly lower income (Group A), the other White and predominantly higher income (Group B).

Method

We adapted our dialogue process largely from the work of Fleck and colleagues (Brody, 2009; Fleck, 2006) modifying it only to meet the needs of our specific groups. We sought partnerships with long-standing community organizations with which the investigators had pre-existing contacts and whose members were likely to have an interest and desire to engage in the research process. Given that the chosen project began with the investigators as opposed to being derived from the community, the dialogue process did not use a pure community-based participatory research (CBPR) approach to the research. However, adhering to CBPR's underlying tenets and principles was important for the success of the work and yielded unexpected community and individual benefits. We view CBPR as a collaborative process that fully engages members of the community in the process of research design (Hacker et al., 2012; Israel et al., 2005). The process of preparing for the dialogues thus began with a series of encounters with representatives of the community organizations geared toward eliciting local knowledge. From the beginning, it was clear that we had significant obstacles to overcome before we could begin to broach the actual research itself. We discussed potential cultural and racial barriers, the shared desire to create and foster a relationship of trust and respect, and collectively redefined the "target community" as one whose efforts were considered equal to and integrated with those of the project staff in each stage of the research process, that is, during the design stages, organizing the groups and arranging all logistics, providing data and continual feedback, and, of course, developing the report. While our initial effort sought to equalize the academic and community power differentials to facilitate open and honest communication, the result was a genuine partnership based on shared experiences and a more complete understanding of each other's needs. The mutual consensus was that the established relationships were not only sustainable but also highly desired (Wallerstein & Duran, 2010).

Following the initial set of meetings, each organization was asked to form an advisory board for the project to meet regularly with the academic investigators. The boards were consulted about the topics for discussion, the timing and conduct of the dialogues, and the forms of informational material that would be most suitable for participants. The boards were asked to recruit dialogue participants from among those considered to be members

or affiliates of each organization and to identify suitable meeting spaces. No effort was made to recruit individuals who were viewed as representative of any larger group, and it was emphasized that the participants spoke for themselves. Participants were offered modest remuneration (\$20 per session) for the time spent in dialogue, and each organization was paid an administrative fee for their assistance in the project. The project received institutional review board (IRB) approval, and participants provided written consent.

The investigators reviewed the bioethics literature on PCOR and CER and prepared three sets of information materials—a collection of articles; one-page summaries of the major points in each article; and a set of audio recordings in which the staff discusses the articles, repeats key points from the written summaries, and engages in brief back-and-forth discussion about some controversial points. Additional written commentaries to clarify controversial issues were prepared by project staff. Case studies were also developed for use during Dialogue Sessions 1 to 5.¹ All participants were given copies of the one-page summaries, staff commentary, and case studies, and the remaining materials were provided for participants at their request. Table 1 outlines the weekly topics and their corresponding case studies. Dialogue sessions were held for 2 hr once weekly for 6 weeks.

One of us (JPB) served as the facilitator for Group B, as requested by Group B; the Group A advisory board requested that a member of their group be trained as a facilitator. Facilitator training was carried on over two sessions by another investigator (HB) using a written manual developed for the project. Group A was made up of 10 persons (male/female = 5) and Group B of 11 persons (male = 6/female = 5). The training focused on encouraging group members to speak and moving the overall process forward while maintaining neutrality on controversial issues. One investigator (JWC or JPB) served as the recorder for each session and made audio recordings. HB took notes that focused on ethical issues raised in discussion.

Participants were encouraged to read the articles and/or summaries relevant to each dialogue session, review the case study for that session, and discuss the issues in between sessions with family and friends. Group B participants occasionally reported engaging in independent research between sessions on the discussion topic.

Prior to Session 6, we reviewed notes and developed lists of statements of ethical values from Sessions 1 to 5. We plan to address the ethnographic content of these discussions in a separate paper. At Session 6, participants were presented with these lists and asked to refine or modify any statements as they wished or to propose new statements, to indicate general agreement or disagreement with the resulting statement, and finally to rank each

Table 1. Topics and Case Studies for Various Weeks of Bioethics Dialogue on PCOR/CER.

Week	Topic	Case study
1	Is there ethical mandate to contain health care costs?	ALLHAT study of hypertension, cheapest drug found most effective, later debate claimed to be guided by commercial interests Use of Medicare Part D to favor or oppose use of cheaper generic drugs
2	What are implications of PCOR/CER for patient autonomy?	Should treatment of spinal compression fracture with vertebroplasty be covered by HMO?
3	What are pros and cons of using CER as a rationing criterion?	Fast-track approval of gefitinib for lung cancer based on limited evidence of effectiveness
4	What are the inherent limitations of PCOR/CER for cost containment?	Proton beam vs. standard radiation treatment for localized prostate cancer
5	What ethical values should guide policy decisions about PCOR/CER?	Use of new, expensive, marginally beneficial drug for advanced cancer (e.g., cetuximab for lung cancer)

Note. PCOR = patient-centered outcomes research; CER = comparative effectiveness research; ALLHAT = Anti-hypertensive and Lipid Lowering Treatment to Prevent Heart Attack; HMO = health maintenance organization

Table 2. Demographic and Socioeconomic Characteristics of Groups.

	Group A (N = 10)	Group B (N = 11)
Gender	Male, 5 Female, 5	Male, 6 Female, 5
Marital status	Single, 1 Married, 4 Widowed, 3 Divorced/separated, 2	Single, 0 Married, 9 Widowed, 2 Divorced/separated, 0
Age (M)	73.3	71.6
Race/ethnicity	Non-Hispanic, African American, 10 Non-Hispanic, White, 0	Non-Hispanic, African American, 0 Non-Hispanic, White, 11
Highest school level	High school, 3 Some college, 5 Bachelor's degree or greater, 2	High school, 0 Some college, 3 Bachelor's degree or greater, 8
End-of-month finances	Excess, 4 Sufficient, 3 Insufficient, 3	Excess, 9 Sufficient, 2 Insufficient, 0
Health insurance	Medicare only, 3 Medicare advantage, 2 Medicare and supplemental, 5 Other, 0	Medicare only, 0 Medicare advantage, 0 Medicare and supplemental, 9 Other, 2

statement with which they agreed as high, medium, or low priority. Based on these rankings, we assembled draft final reports for each group, circulated the drafts, and reconvened for a final review session approximately 1 month after Session 6. At the review session, participants were reminded that they had the options of agreeing on a final report, submitting no final report, or registering dissents and writing individual minority reports. Both groups elected to approve a final report and to make it available publicly.² At the final review session, a survey questionnaire, modeled after earlier work by Timotijevic and Raats (2007), was also distributed requesting basic demographic information as well as feedback on the dialogue process.

Results

Table 2 shows the demographics of the two groups. The groups did not differ significantly in the reported use of the

informational materials. Most participants in each group reported reading almost all the one-page summaries and complete articles, but few listened to the audio recordings.

For assembling the draft final reports, we divided the individual statements of ethical values into two categories. We classified as widely agreed-on values those for which the group unanimously agreed and where the vast majority (usually all but one or two) ranked the statement as high priority, with the remaining classifying the statement as no lower than medium priority. All other statements were regarded as potentially more controversial. We then classified all ethical value statements according to general themes.

Provider–Patient Relationship

Both groups agreed that PCOR and CER, to be ethically utilized, required ethically solid relationships between physicians (or other health professionals) and patients, as

captured by the term *patient-centered care*. They agreed that providers should take time, listen to patients, and provide information needed to make informed choices and that patients should become informed about their health issues and if necessary, bring a patient advocate with them to visits. Both groups agreed that the results of PCOR and CER could inform such relationships. Group B added the proviso that even though cost containment was an important ethical objective, providers should inform patients of all treatment options, regardless of cost, and quality of life should be a more important consideration than cost in how the provider approaches the patient.

Health Systems

In addressing the implications of PCOR and CER for the health system as a whole, the values expressed by the two groups assumed somewhat different tones. Group A expressed concerns that the present system treated patients too often as “cash cows,” that the profit motives of insurance companies and drug and device manufacturers exert too prominent a role, and that generally the rich get better health care than the poor. Group A, while generally agreeing with the need for cost containment, expressed the view that we have enough money presently to provide much more health care for more people, if only the money were more justly and efficiently distributed. Both groups generally agreed that PCOR and CER provided ethically suitable methods for cost containment—that is, if we have to start somewhere to control costs, we should begin by eliminating the least effective treatments, as measured according to the outcomes that matter most to patients. Both groups also agreed that such judgments could be made based on reasonable, available evidence, and we need not wait for some time in the future when supposedly ideal evidence would be forthcoming.

Group B added further value statements about health systems issues. They were more concerned that CER results would be used in a “one size fits all” manner that ignored individual differences. They were concerned to protect an individual’s right to purchase a more expensive, and presumably less effective treatment with his or her own funds, insisting that in such a case, the insurer should pay a sum equivalent to that of the lower cost treatment, with the patient being responsible for paying only the difference.

Both groups disagreed with any policy that attempted to separate CER from costs of treatment, urging instead that results of CER be used to make appropriate decisions about the cost-worthiness of treatment.

Commercial Interests

Both groups agreed that commercial interests presented serious ethical problems in health care. Group B offered specific value statements regarding commercial interests, suggesting a neutral organization as a suitable clearing

house for evidence-based information about the effectiveness, safety, and costs of medical treatment, and full transparency regarding commercial ties in all aspects of the health system.

Rationing Health Care

Both groups discussed limitations on access to health care because of costs. Group B spent time debating the use of the term *rationing* in relation to PCOR and CER, without reaching any consensus. Some urged that the term be avoided completely while others saw it merely as an acknowledgment of decisions already being made daily within the health system. Several definitions of “rationing” were offered by various participants, but none received general endorsement.

Free Choice Versus Cost Containment

Initially, Group A appeared to be adopting statements that favored free choice of any health services alongside other statements accepting the desirability for cost control, without confronting any tension between these two ethical values. The investigators eventually felt obligated to intervene in the dialogue to request that the group address this tension explicitly, to be sure that the draft report reflected their considered values. On further discussion, the group suggested a distinction between treatments for which scientific evidence showed a lack of likely benefit and treatments for which scientific evidence showed a possibility of at least some benefit. The group endorsed the health system limiting access to the former but not the latter set of treatments in the name of cost containment, recommending shared decision making between provider and patient in the latter cases.

Group B similarly debated the appropriate limits of free choice in the name of cost control. Many agreed with the principle of limiting patient access to treatments shown to be minimally effective, so long as a fair and transparent process was used to identify these treatments. Others, however, continued to dissent. There was broad agreement that “patient-centered” did not mean “whatever the patient wants,” and some patient decisions were viewed as emotionally based and ill informed. There was considerable, but not unanimous, concern that patients given too much free choice would make end-of-life decisions that sought minimal if any life extension at very high monetary cost as well as at the price of the individual’s quality of remaining life.

Science Versus Individual Testimony

In constructing one of the case studies (“Insurance Coverage for Treatment of Spine Compression Fractures”), we inserted what we assumed at the time to be a straw-man argument,

that a treatment shown by scientific evidence to be ineffective might be approved simply because of the personal testimony of a patient who had undergone the treatment and attributed a “cure” to it. Rather to our surprise, Group A engaged in an extended discussion of this point. The group appeared to understand, first, that “patient-centered” refers to outcomes considered by patients to be of real value in their lives and not to the idea that patients have, through personal experience, a privileged view of what treatments work, and second, that such personal testimony is generally rejected by scientists as anecdotal and hence nonrepresentative of the total population. Nonetheless, many participants were reluctant to discount such personal testimony, and many continued to interpret “patient-centered” as requiring respectful attention to this testimony. The group also held that these value commitments did not signal a rejection of scientific standards of evidence, though they also expressed some skepticism about the reliability of scientific studies in medicine and how their results can be over-interpreted and over-extended.

Commercial Interests at the Table

One article in particular that addressed the role of commercial interests in setting PCOR and CER policy stimulated extended debate within Group B (Selker & Wood, 2009). A majority appeared to favor excluding such interests from a voting role in any policy board overseeing government funding of PCOR and CER. This faction thought that any valuable information representatives of such interests could provide could easily be obtained through a non-voting role or through ad hoc testimony. A smaller faction, informed by their experience with local government boards, argued that such non-voting arrangements actually assured that the voices and views of industry would not be heard at precisely the point in the debate where they could be most informative. This latter faction argued that so long as commercial interests did not hold a majority of seats on any policy board, there could be no danger in giving them voting status.

Personal Responsibility For Health

Group B alone discussed at several junctures whether one way to control health costs would be to assess higher premiums or deny coverage based on individuals’ unhealthy lifestyles and assumed personal responsibility for ill health. These views were hotly contested, and in the end, no consensus was reached.

Provider Incentives

Group B alone also discussed, but failed to reach consensus about, the question of paying incentives to providers who applied evidence-based CER results to their practices. It was argued on the one hand that practical use

of CER should be encouraged and that incentives could be effective and on the other hand that the use of evidence-based standards was simply good practice, which should be expected routinely and not seen as requiring additional incentives.

The participant surveys, completed at the last session, generally showed strong agreement that the conclusions were independent, that the process was well understood by participants, that interchanges were respectful, and that the overall process was effective and meaningful. Table 3 shows those questions that revealed the greatest diversity of views. Several participants thought the materials presented to the group displayed systematic bias, though we were unable to explore this further. Group A agreed more strongly than Group B that the final report accurately reflected their individual views and the views of their community. Groups were more divided on whether they felt that their dialogues would have an impact on future health policy.

After both reports were completed, we called a press conference to announce the availability of the documents and with the intention of having the local newspaper publish an article about the process (University of Texas Medical Branch, 2014). Members from both groups attended the press conference and answered questions from the audience about their experience in the community ethics dialogues, and were able to comment to each other about their findings. Everyone attending this press conference witnessed a remarkable conversation unfold between these seemingly disparate communities, which agreed that the process was very meaningful and the return on their time in the dialogues was significantly more than expected.

Discussion

While there is an extensive and wide-ranging literature on measuring success in democratic decision making, its criteria do not focus on ethics and therefore do not temper our definitions of “success” in the community bioethics dialogue. Instead, we refer to Fleck (2006) and results from deliberations during our community advisory board meetings to set the measure for success. We suggest two—first, whether the conclusions of a group appear nuanced and insightful, without the value statements having been spoon-fed to the group by the investigators, and second, whether different groups with different background and experiences reach at least somewhat different conclusions. We believe that this pilot can be judged at least a partial success based on these measures.

We feel reasonably certain that we did not predetermine the value outcomes for the groups, because of the process followed for conducting and facilitating the dialogues. It was interesting, though not definitive, that some of us

personally disagree with at least some of the statements

Table 3. Survey Questionnaire Items Showing Greatest Diversity of Response.

Question	Group A (N = 10)	Group B (N = 11)
The material that was given to us to read or listen to was credible and trustworthy	Strongly agree, 8 Agree, 1 Neutral, 1 Disagree, 0 Strongly disagree, 0	Strongly agree, 2 Agree, 7 Neutral, 2 Disagree, 0 Strongly disagree, 0
The materials we were given to read or listen to were biased in a particular direction	Strongly agree, 3 Agree, 0 Neutral, 1 Disagree, 2 Strongly disagree, 4	Strongly agree, 0 Agree, 1 Neutral, 4 Disagree, 1 Strongly disagree, 5
I occasionally changed my own views as a result of the discussion	Strongly agree, 3 Agree, 4 Neutral, 2 Disagree, 1 Strongly disagree, 0	Strongly agree, 0 Agree, 8 Neutral, 2 Disagree, 1 Strongly disagree, 0
Talking to others outside the group, during the week between group sessions, helped me to form my own opinions	Strongly agree, 3 Agree, 0 Neutral, 1 Disagree, 1 Strongly disagree, 4	Strongly agree, 0 Agree, 4 Neutral, 5 Disagree, 1 Strongly disagree, 1
The final report reflected my own views accurately	Strongly agree, 10 Agree, 0 Neutral, 0 Disagree, 0 Strongly disagree, 0	Strongly agree, 1 Agree, 9 Neutral, 1 Disagree, 0 Strongly disagree, 0
I believe that our final report represents the ethical views of my entire community—not only those who directly participated in the dialogue	Strongly agree, 4 Agree, 3 Neutral, 1 Disagree, 0 Strongly disagree, 1	Strongly agree, 1 Agree, 6 Neutral, 3 Disagree, 0 Strongly disagree, 0
I believe that the views I expressed in the dialogue will affect future health policy	Strongly agree, 3 Agree, 4 Neutral, 2 Disagree, 1 Strongly disagree, 0	Strongly agree, 2 Agree, 4 Neutral, 3 Disagree, 1 Strongly disagree, 0
I believe that our group's report will affect future health policy	Strongly agree, 2 Agree, 6 Neutral, 1 Disagree, 1 Strongly disagree, 0	Strongly agree, 2 Agree, 3 Neutral, 4 Disagree, 1 Strongly disagree, 0

made in the final reports of each group. In addition, it was clear at the outset that some members were critical of any bias they perceived in the articles. Each group appeared to grapple seriously with the ethical issues and to accept the challenge to back up their ethical statements with reasoned arguments. (We will address the processes followed by the two groups in more detail in a separate report.)

There were also a number of differences between the final reports of the two groups, as well as between their processes of dialogue. Group B addressed more topics than Group A and, in some instances, explored additional policy nuances. This is consistent with the generally higher educational level of the participants. In contrast, members of Group A appeared more cognizant of issues of social justice that affect vulnerable populations and appeared

leery of approaches that suggested to them possible disrespect for their own personal experiences as well as those of their families and neighbors. This would seem reasonable for a community that has been subjected to extensive past discrimination in health care as well as in society generally.

The end results of the partnerships themselves were multi-faceted. While we anticipated the product, that is, the group reports, would yield important information related to the ethical values of the communities involved, the process seemed to be just as important and mutually beneficial to both investigators and community members. The initial planning meetings contributed to a sense of group ownership and capacity building, and throughout the process, group members displayed an uncommon

commitment to the effort. One evening, for example, the weather was frigid, with high winds and icy rain, and yet the members of Group B braved the storm to attend the dialogue. Likewise, Group A's meetings were also consistently well attended, despite the fact that transportation was many times an issue for attendees—overcome in some instances by an investigator providing transportation to and from meetings. However, perhaps the most poignant of our “results” were the unintended benefits. One elderly man, who was both disabled and several years prior forced to retire due to chronic illness, reported during a “debrief” session that participating in the series of dialogues had dramatically changed his outlook and behavior. He indicated that due to his illness and disability, he had lost the sense that he had the ability to meaningfully contribute to his community. He also stated that through the dialogues, he had come to appreciate that his opinion was well respected and that his participation was valued by his peers. Consequently and subsequently, he had begun to volunteer in the community. Likewise, another participant reported that at the outset of the dialogue process, she had been completely dependent on others for transportation, not because she was physically or legally unable to drive, but rather that with aging, she had lost the confidence over time to be more active and independent. She reported during the debriefing meeting that confidence she gained through the process convinced her that she was capable of doing many more things than she had previously believed, and thus renewed her license and began to drive her own car again. These experiences led the research team and its community partners to understand that the results of participating in the process itself were beneficial in ways not previously anticipated.

All the limitations inherent in the method of community bioethics dialogue are of course reflected in our outcomes. As noted, there can be no claim that the views in these reports “represent” the views of the respective communities, or even those of the members of the specific organizations from which the participants were drawn. Nevertheless, we believe that the pilot has shown the value of community consultation using methods such as this. Issues were raised in the dialogues that have not yet been raised in the academic bioethics literature, most notably the focus among Group A on personal testimony about medical efficacy.

Another limitation of our method is that while both groups reported similar utilization of the educational materials, it appeared that comprehension levels were not uniform, raising the question of whether inter-group differences are a reflection of some participants having more information than others about the topics discussed. However, it may also be the case that some participants simply chose not to read all the material or perhaps had difficulty accessing technology that would have allowed them to further investigate topics under discussion. Use of

technology clearly differed between groups; for example, while the majority of communication with participants in Group A was conducted via phone and (paper) mail, Group B participants, for the most part, preferred communication in electronic format and appeared to conduct more online research regarding the session topics. Moreover, these group differences may reflect the failure on our part to appropriately operationalize the advice of the community organization advisory board in packaging the desired information in culturally sensitive ways to meet the groups' needs. Further refinements will evolve as the dialogues continue.

Best Practices

Lessons learned through the dialogue process have led us to a deeper understanding of barriers to communication posed by the investigators' assumptions about the community members' literacy. Despite our efforts to present topics and materials in multiple formats, including audio recordings, to make them more accessible and comprehensible, it became clear over time that closer attention to language was necessary. We have determined in moving ahead to adopt as a best practice the effort to rework all reading materials to reflect third- to eighth-grade reading levels. We will utilize a newly convened community board, representing all groups, to read the documents we want to share with the broader groups and translate them back to us. If they cannot accurately understand them such that they cannot tell us what they mean, then we will adjust our levels accordingly.

We must also ensure that any facilitator selected from the community be a bona fide representative of the convened group. In this instance, the facilitator for Group A was appointed by the director of the sponsoring community organization but was unfamiliar with group members and slightly younger than the members themselves. We believe that this delayed the development of group cohesion, as was evidenced by dialogues later in the process that seemed to be much richer and more thoughtful than those conducted earlier. If such a representative is not to be found, then we will conduct several meetings prior to the dialogues themselves to build capacity and facilitate an environment of trust.

We also acknowledge that at the beginning of the project, we lacked full cultural understanding of our community groups. We believe it to be essential to engage in conversations prior to the dialogues to identify issues potentially related to race, education, and power differentials both within groups and between groups that would preclude honest and transparent communication. In this process, we did so with Group A at the behest of the director of the sponsoring organization, which changed the group dynamic substantially in a favorable way. Simply by acknowledging that we might discover differences based

on these factors facilitated their inclusion in the dialogues. We will continue this practice as we begin new groups.

We anticipate that future rounds of dialogues will be richer still. Ideas for topics will be generated by the groups themselves, which is more closely aligned with a community-based participatory approach to research. It is our hope and intent that these discussions will be instrumental in identifying community values and priorities and thus may be used to better inform health care practices in our communities.

Research Agenda

Following this promising pilot phase, we plan to extend the work in two directions. First, we hope to enlist more community organizations, representing a diversity of cultural and ethnic backgrounds (particularly, Hispanic residents), to conduct dialogues on the same topic, ethical issues in PCOR and CER. We will then further compare all dialogue results for both similarities and differences in process and outcomes.

Second, we hope to return to these existing dialogue groups and seek their participation in future dialogues on new bioethics topics, including those suggested by the groups themselves. We hope to study the effect of experience and training in how the groups approach future bioethical issues. To our knowledge, this facet of community bioethics dialogue has not been explored in previous work, with the majority of community dialogue groups being assembled to address one specific topic of interest and then disbanded. Our hypothesis is that a network of community dialogue groups, representing diverse populations within a region, can engage in a series of dialogues over time and hence provide a valuable resource to an academic bioethics center.

Educational Implications

Numerous educational opportunities exist in conjunction with this project, only some of which were realized. The preparation of selected articles and case studies permit both the investigators and the study participants to become educated about the ethical issue. Few public observers were present at the actual dialogue sessions, however, although preparation had been made for them. Also, efforts were made to interest local high school and community college staff in the dialogues. Ideally, students could have read the background materials and case studies, observed the sessions, and then engaged in the follow-up discussion in the classroom. As dialogues proceed with these and with other groups, we will attempt further to mine the dialogues to their full educational extent.

As far as further educational implications for researchers wanting to engage communities, we feel that we have addressed the “take-aways” in the “Best

Practices” section and furthermore feel that we are still too early in the process to have findings that are generalizable enough for our colleagues to implement in their own work.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This work was supported by the Agency for Healthcare Research and Quality grant #1R24-HS022134.

Notes

1. See [http://www.utmb.edu/pcor/App_Assets/assets/StVincent-Report-FINAL.pdf\(SECURED\).pdf](http://www.utmb.edu/pcor/App_Assets/assets/StVincent-Report-FINAL.pdf(SECURED).pdf), accessed August 9, 2014, and http://www.utmb.edu/pcor/App_Assets/assets/GAIN-GCPA-AA-ReportFINAL.pdf, accessed August 10, 2014.
2. See <http://www.utmb.edu/pcor/proj3.asp>, accessed August 9, 2014.

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Author Biographies

Howard Brody is former director of the Institute for the Medical Humanities at the University of Texas Medical Branch, Galveston (currently on leave). He is trained in family medicine and philosophy, with special research interests in bioethics, physician-patient relationship, and the relationship between health policy and medical practice.

Sharon A. Croisant is currently in the University of Texas Medical Branch's Department of Preventive Medicine and Community Health. She is an investigator for the NIEHS Center in Environmental Toxicology and serves as both director of the Community-Based Research Facility and director of the Center's Community Outreach and Education Core. She has established long-standing, ongoing collaborative relationships with community stakeholders with a vested interest in using research findings to direct community-based intervention and outreach activities.

Jerome W. Crowder is a medical and visual ethnographer at the Institute for the Medical Humanities who works with community groups to understand their decision-making strategies and the societal structures that affect health disparities. In the capacity of this research and paper, Crowder served as an investigator and principal ethnographer in documenting the ideas expressed by the members of the community organizations and analyst of the qualitative data.

Jonathan P. Banda is a third-year medical humanities PhD student at the University of Texas Medical Branch, with an emphasis in social medicine and history of medicine. He has professional experience in human subjects research compliance and institutional review board administration. His current research interests include the history and ethics of human subjects research, the social determinants of health, and the politics of public health interventions in relation to race, gender, class, and sexuality.