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SPECIAL ARTICLE

Optimizing Community Bioethics Dialogues: Reflections on Enhancing Bi-directional Engagement on Health Care Concerns

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Abstract. This article reviews our experience and observations from conducting six Community Bioethics Dialogues (CBD) with elderly residents in diverse communities in Galveston, Texas, from 2014 through 2016. CBD is a mixed method that combines focus groups, instruction, ethnography, and community-based research. CBD brings together select community members for 3 hours once a week for 6 weeks to identify values. We employed CBD to investigate how participants think about and react to issues surrounding Patient-Centered Outcomes Research (PCOR), Comparative Effectiveness Research (CER), and mental health. We offer a methodological approach for conducting and optimizing meaningful dialogues with community groups.

Keywords. Community Bioethics Dialogues (CBD), Comparative Effectiveness Research (CER), Deliberative Democracy, Health Care, Patient-Centered Outcomes Research (PCOR), Values

Background

Unlike more conventional questionnaires or surveys, focus groups provide investigators with multiple perspectives from representative individuals on specific topics within a relatively short time frame, revealing dimensions of understanding. Generally, focus groups require structured questions and offer a dialogue between group members in which they can explore and clarify their views (Kitzinger, 1995; Powell & Single, 1996). Sometimes participants need more time to learn about the subject matter or to become more comfortable with discussing particular topics. In this article, we provide evaluations, insights, and suggestions related to the methodology of Community Bioethics Dialogues (CBD), a method that combines the intimacy of a focus group with the instruction of a seminar, the ongoing participation of ethnography, and the advocacy of community-based research. CBD is a bi-directional form of research, and therefore somewhat different from other small group–oriented qualitative methods. The major difference is that the dialogues are structured to serve as a learning vehicle for the participants as well as a methodology for researchers to glean values on various health care topics. While the CBD method enables researchers to understand the values of communities as represented by a small segment of their population, it also empowers the participants to implement change in their communities.

In a recent survey by Morning Consult, one third of the respondents did not know that Obamacare and the Affordable Care Act are the same thing (Dropp & Nyhan, 2017). In considering complex health issues, it is difficult to know how public understanding, much less consensus, can be achieved. In the United States, there is a history of town hall meetings in which communities have regularly gathered to consider important topics; as our population has grown, however, we have largely abandoned that format, primarily due to the size and scope of many communities and the plethora of issues that present themselves daily. The loss of such open community dialogue has diminished our ability to talk to each other about important topics.

The concept of deliberative democracy, a town hall–like forum, reintroduces the opportunity for community members to gather and discuss current issues in a format that encourages education about the issues and provides a platform for sharing ideas and values (Jennings, 1988; Guttmann & Thompson, 1996; Weeks, 2000; also see Brody, 2009).[1] Such conversations are grounded in the work of Jürgen Habermas, who emphasizes the role of discourse ethics as a means to arrive at a more humane, egalitarian society (1981/1984) and contends that public life only flourishes if matters of public importance are discussed (1987). Deliberative democracy is intended to empower participants to work with community leaders to implement policy changes. Even the World Health Organization (1986) advocates for citizens' right to participate in decisions and policy information regarding health matters in their communities. While deliberative democracy has different formats, each contains the common thread of participants spending time learning about a topic and discussing it in an open forum (see Gastil & Levine, 2003).[2] The goals for deliberative democracy can be internally grounded (e.g., to build consensus) or externally focused (e.g., to inform policy).

Recent work in community-based participatory research, stakeholder engagement, and public deliberation provides promising methods for eliciting stakeholder input, but these methods can be strengthened further by incorporating lessons from the tradition of "grass-roots bioethics" that has been shown effective in articulating commonly held ethical values in both majority and minority communities (Wallerstein & Duran, 2010).

The model for the Community Bioethics Dialogues (CBD) process has evolved over the years, beginning with Bruce Jennings (1988, 1991) and his "democratic consensus," which informed the first round of grassroots bioethics activities in the late 1980s. Jennings argues that community dialogues require a safe space for people to meet and discuss within a larger democratic context, that all participants are free and equal, that they are aware that the dialogue may change their perspectives, and that they do not consider any position "irrational."

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[1] *We note that these dialogues are not intended to be representative for later generalization of results in presenting a larger community's values, ideas, or sentiments. The results of the dialogues are the views of the people who participate in them, with the aim of accounting for how particular residents respond to a variety of topics at the time of discussion. For research purposes, or even policy formation, it should not be assumed that the groups are assembled with representative intent. The groups will be composed of community members who are invited by community leaders and who want to participate.*

[2] *John Gastil and Peter Levine provide an excellent anthology of various deliberative democracy methods in The Deliberative Democracy Handbook: Strategies for Effective Civic Engagement in the Twenty-First Century.*

From the meetings, the participants produce a set of prioritized moral values that is useful for informing and directing policy. Leonard Fleck (1994) added features to the model: the dialogue is informed by accurate, scientific information and guided by trained facilitators, and participants broadly represent the community. The outcome of the dialogue is an explicit, binding choice; the participants agree to live with the consequences of their values and priorities as expressed in the CBD. Catherine Myser's (2004) additional features assure that the dialogue process is democratic in a deeper sense, by emphasizing diversity through the inclusion of minority groups. Myser also urges that professional "experts" collaborate with the community groups to define the questions to be addressed by the dialogues and that the products of the dialogues are disseminated for the use and benefit of all parties. One unique characteristic of this approach is that the dialogues are bi-directional: both participants and researchers benefit from the process as they share their knowledge and insights regarding specific health issues.

CBD, then, is an extended version of deliberative democracy that applies many of the above techniques to the health care arena (see Brody, 2009). In this article, we offer suggestions for optimizing the process based upon our experience conducting six dialogues with diverse local communities in Galveston, Texas. The goal of our research was to elicit and prioritize the ethical values of importance for future policy planning around Patient-Centered Outcomes Research (PCOR) and Comparative Effectiveness Research (CER). PCOR enables patients and their caregivers to "communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options" (PCOR, 2012); CER is "the direct comparison of effective interventions and their study in patients who are typical of day-to-day clinical care" (Sox & Greenfield, 2009, p. 203). These two types of research were included as part of the Patient Protection and Affordable Care Act to assure that provided treatments were those that would be best for specific patients and consistent with the latest research. Our 2013 grant from the Agency for Healthcare Research and Quality (AHRQ) supported the administration of the dialogues as well as the research to determine whether the community dialogue is an effective way of engaging communities on topics such as PCOR and CER. The funding also supported a second round of dialogues on a topic of the communities' choosing.[3]

The Galveston Dialogues

Dialogues began in the spring of 2014 and continued to the end of 2016. Brody et al. (2015) described the ethical issues in PCOR and CER as part of a study utilizing CBD with two groups in Galveston, Texas, in early 2014. We will elaborate on the vitality of the original dialogues and those subsequently held, describe the detailed methodology and offer insights for conducting meaningful dialogues with community groups, and provide selected outcomes from these sessions as examples of what can come from such a method. More specifically, we discuss the administration of and results that came from two additional groups that completed the initial PCOR/CER program and two groups with representatives from the first round that discussed mental health and aging (what we call "Round 2"; see Table 1). We make general observations about the process of conducting and administering CBD and close with some examples of the types of value statements gleaned from the process. We encourage readers to review the reports that have resulted (for example, see www.utmb.edu/pcor/proj3.asp).

The dialogue process that we implemented was largely influenced by Fleck (2009). We believe that the dialogue process is an effective way of educating members of the public on various health care related topics and further improving communication between communities and policy-making bodies. For investigators, the method allows regular and ongoing engagement with community members to

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[3] *Information on the other projects supported by the AHRQ grant is available on UTMB's Web site at https://www.utmb.edu/pcor/.*

Table 1

CBD conducted in Galveston for UTMB AHRQ/PCOR study

	YEAR	COMMUNITY GROUP	THEME
Round 1	2014	St. Vincent's	PCOR/CER
	2014	GAIN/GPCAAA	PCOR/CER
	2015	GICRAC	PCOR/CER
	2015	LULAC	PCOR/CER
Round 2	2016	St. Vincent's	Mental Health and Aging
	2016	GAIN/GPCAAA	Mental Health and Aging

verify their positions on contested topics. Several tangible outcomes can result from the CBD process:

1. A final community report, detailing the value statements participants made regarding the issues at hand, that can be shared with local, regional, and national leaders and representatives, family and friends, and neighbors. Such a report can inform press releases and op-eds about the process to help generate further community engagement.
2. Dialogues can engender conversations at home and within the community, ideally educating those who do not attend and inspiring some to become advocates for change.
3. Research findings published in peer-reviewed journals inform other researchers and health care professionals about community issues that affect decisions and perspectives on health care.

We found that once groups have experienced and completed a dialogue, they will be primed to take on other topics and will generally inquire about opportunities for future dialogues.

Methods

As with any community-based method, preparing to conduct CBD requires significant amounts of time and flexibility for scheduling meetings with community group leaders and members. We provide a general timeline for how the CBD process unfolds because understanding the timing of activities within the process is critical for implementing any methodology.

Example of a general timeline for community bioethics dialogues (CBD)

1. *Identify and invite community group participants. (1 week to 2 months)*
   We contacted leaders of community organizations representing a wide variety of backgrounds, ethnicities, and beliefs in Galveston, and followed up with those who were interested in having their groups participate in the dialogue process.
2. *Meet with group leaders to discuss topics and agree on responsibilities; sign a participation agreement that outlines the duties of both community leaders and the research team. (Variable)*
   The groups took different amounts of time to become comfortable with the dialogue process and understand their expectations, responsibilities, and outcomes. Some groups required only two meetings, while others needed four or five to work through all angles of the dialogue process.
3. *Develop a curriculum and syllabus and gather all materials. (2 days to 2 weeks)*
   The research team is responsible for finding resources (print, video, audio, digital) related to the topic. Depending on the topic and the team's familiarity with the material, a skeleton syllabus may be developed in a day or two and fleshed out in a week.
4. *Engage group leadership in selecting a facilitator, recruiting participants, establishing a meeting calendar, and distributing the syllabus and reading materials. (2 weeks)*
   The community group is responsible for the above tasks, although the research team may be consulted if necessary. It is imperative that the group trust the facilitator. Group

leaders can best identify those members who will best function in a dialogue setting: those who are vocal, respectful, and engaged.

5. *Attend weekly dialogue sessions. (7 weeks)* Ideally, the dialogue group will meet every week for 7 weeks, allowing for a week off between the final dialogue session and the voting on the values meeting, and another week before the final report is presented.
6. *Assist group in reviewing values identified during the discussions for the final report. (1 week)* The research team works with the group facilitator to summarize the values expressed throughout the dialogues and develop a list to present back to the group for discussion and voting on priorities.
7. *Meet with the group to review the final report; elicit testimony on learning from the dialogue process. (1 week)* Once the group members have prioritized their values, the research team and facilitator will compose a summary report. This report is then presented to the group for edits and approval.
8. *Assist with report dissemination: publish online and distribute to the community through participants. (1 week to several months)* The community group may have a Web site for immediate distribution of the report or may need support from the research team to distribute it over the Internet. At the final meeting, the research team will discuss with the group specific audiences that they have in mind for the report and suggest contacts and ways to distribute it to neighbors, relatives, representatives, and other officials.

Since Galveston has a diverse population, the research team contacted local community organizations that reflect such diversity and invited them to consider participating in the dialogues. As UTMB has a history of working with some specific groups and organizations, our colleagues identified persons to call who would be familiar with university research projects and willing to engage with us. However, we also approached some organizations that had not previously worked with university researchers. Our original grant proposal stated that we would work with community organizations representing different ethnic, economic, and social statuses. Preliminary meetings were then held with representatives from the organizations that responded. The representatives reviewed the recruitment parameters, dialogue formats, and materials being considered. The latter task provides the group leaders with an opportunity to confirm the topics that will be studied and discussed, and to suggest the best ways of presenting the material to their community.

While it appears that this process is somewhat top-down, we argue that presenting the opportunity to engage in discussions is not limiting. The group leaders were welcome to decline such an offer, which several did. Once the community leaders agreed to participate, they became the local actors responsible for recruiting participants, identifying a facilitator, and securing a locale. Our task as researchers was to understand how the general populace engages with the concepts of PCOR and CER as medical care moves in that direction. We felt that the bi-directional characteristic of the CBD method made it an ideal approach. As participants became further educated about the health care system, they could establish value statements concerning their care. Simultaneously, the research team benefitted from recognizing how different groups conceptualized the topics and evaluated a topic based upon their values. A more specific explanation of the methodology follows.

The format for the community bioethics dialogues

Our CBD series consisted of 2-hour meetings each week for 6 consecutive weeks. Each of the first five meetings centered on a health-related theme; related readings and a case study were provided to help participants elaborate on the issues at hand. The sixth week was used to summarize the groups' values emanating from the previous discussions, from which the final report was written. The research team wrote the initial draft of this report to reflect the group's values, and a few weeks later held one additional meeting to obtain group members' feedback for the final version.

There are no specific requirement regarding the duration of the dialogues.[4] The length of time for discussion is determined by the complexity of the topic as well as group members' availability. Dialogues are most effective within a period of 4 to 8 weeks, so must be concisely defined in order to fit comfortably within the time frame. One session should be reserved for reviewing values, with no new material presented. Topics requiring more time may need to be broken down into multiple dialogue periods.

Community groups, leadership, and facilitators

Since not many organizations are aware of deliberative democracy or CBD, we approached a variety of community groups, including adult education organizations, churches, and any others whose membership might wish to consider health care policy. This step requires multiple discussions with group leaders and members to educate them on the dialogue process and help them discern the value in sponsoring dialogues for their organization. Even researchers maintaining a good rapport with community groups may still find this process lengthy. Ideally, everyone present must understand the reason for conducting a dialogue and the potential outcomes that could result. In our case, we were familiar with the leadership of two groups and depended on our health research colleagues working in Galveston to introduce us to leaders with whom they had previously worked on other research projects. One advantage we had was that our grant provided funds to reimburse participants for their time, which made the project particularly attractive to underserved community groups.

Our grant funding, however, did place restrictions on certain aspects of the CBD process. All participants in our dialogues had to be age 65 or older. We also had a specific purpose for comparing the outcomes of groups from historically different demographic and ethnic constituencies, as Galveston continues to be home to a variety of economically and ethnically diverse populations (see Brody et al., 2015). One of the initial two groups consisted of African Americans affiliated with St. Vincent's House, an organization that provides a wide variety of services to disadvantaged and underserved populations in the city, including a collaborative health care clinic. The second of the initial two groups drew representatives from two community organizations, Galveston Alliance of Island Neighborhoods (GAIN) and the Galveston Citizens Police Academy Alumni Association (GCPAAA).[5] For additional participants in the PCOR/CER dialogues, we later sought representation from Galveston's Latino community and approached the local representatives of the League of United Latin American Citizens (LULAC), who welcomed the opportunity to participate in the dialogues. We attained further representation from the African American community by inviting an organization that broadly serves as an Institutional Review Board (IRB) for that community, the Galveston Island Community Research Advisory Committee (GICRAC). Both LULAC and GICRAC maintain active constituencies that responded favorably to learning more about health care and the selected research topic of patient-centered outcomes and comparative effectiveness research, providing an excellent opportunity for these groups to engage and learn.

Group selection and size

Groups can be selected using various criteria (e.g., demographic, ethnic, geographic, religious, social). In some cases, a group may need to be homogeneous in order to represent the values of the larger community. In other cases, a diverse selection of participants may reflect the larger population; it

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[4] *For example, author Determeyer developed a 3-week "mini-dialogue" as part of her dissertation work to examine the use of community bioethics dialogues and educating communities on aging and end-of-life planning.*

[5] *For Round 1, Brody et al. (2015) labeled St. Vincent's as "Group A" and GAIN/GPCAAA as "Group B."*

depends upon the topic of the dialogue. Results of the CBD process are meant to reflect the values of that group and not to be generalized to a larger population. In our experience with persons 65 years and older, even though the various groups may have been relatively homogeneous in terms of ethnicity or class, the perspectives they shared were diverse, and consensus was not achieved on many of the points that they raised.

The partnering organizations are responsible for recruiting dialogue participants and selecting their facilitator. Ideal participants are those who are interested in the topic, willing to engage with the materials, and comfortable expressing their ideas and opinions in a group forum. Leaders may personally invite specific persons to participate given their work experience or skill set, while recruiting others for their knowledge of or leadership history in the community.

We strongly encourage leaders to keep the groups to a manageable size, as determined by the ability of the facilitator; we recommend 8 to 15 people as optimal. We have witnessed that smaller groups can become dominated by one or two individuals, and larger groups tend to subdivide and develop ongoing side conversations instead of focusing on one theme. Facilitators must be able to maintain the discussion under any circumstances and must have the trust and respect of the participants. Furthermore, they must be able to allow all voices to be heard, for no matter how tight a community may be, there are always dissenting ideas to share, making for robust conversations and helping participants to reflect upon and identify their values about a topic in greater depth.

Leadership

The participation agreement that each community group executes with the research team must designate when the dialogues begin and state that community leadership is responsible for recruiting participants, identifying an individual to facilitate the discussion, and securing a venue for conducting the dialogues. For researchers, maintaining strong relations with group leadership is fundamental to a successful dialogue, as leaders know the community members who will best take to the materials and who will speak most readily with others about the topics and share what they have learned with family and friends. In our experience, the group leaders both participated in and observed the dialogues. Some leaders felt that they needed to be involved so the other members would see that they were invested in the process. Others, however, felt that their presence stifled conversations, so they served as observers for the first and final meetings. Either way, once the dialogues begin, the leadership's primary role remains administrative, contacting participants about changes to the meeting calendar or paying out their compensation.

Facilitators

The community group and their leadership choose facilitators. We feel that this responsibility requires careful selection, as candidates must demonstrate characteristics similar to those of good teachers as well as strong leaders. For example, facilitators must be skilled at speaking in groups, listening to participants, and demonstrating empathy while directing conversations. While they do not need to know each member of the dialogue group personally, they must be able to get along with different personalities and maintain order in the discussions. Equally important, facilitators must have an interest in the topics and demonstrate their experience in effectively leading discussions.

Consequently, it is important to identify facilitators who understand that the focus is on engaging all of the participants in the discussions rather than serving as a principal educator for the group. That is, they must willingly allow the discussions to unfold naturally, with all perspectives represented in the dialogue, rather than promote particular agendas of their own. While power dynamics are common in any group activity, the fundamental objective here is to have everyone participate. Participants must have the ability to disagree without being disagreeable. All of the participants should agree on this premise at the beginning of the dialogues, and the facilitator is charged with supporting and encouraging positive behaviors. Furthermore, we encourage each group to establish ground rules that outline how participants will engage and interact with each other during the forum. Writing these guidelines out on a large sheet of paper and taping them to the wall at the beginning of the discussions reminds participants about their terms of engagement.

As the research team, we provided guidance (training) to the facilitators for collating the materials, reviewing each week's reading selections, integrating the information effectively in their discussions, and encouraging the use of current events to provide examples. We identified terms used in the materials to develop a glossary to which participants could refer. Some weeks were more intensive than others during the facilitators' training, which was completed on their own schedules. For some, it was more convenient to undergo the training in one or two intensive sessions; with others, we met throughout the sessions to discuss the upcoming week's materials. We found that these methods were equally effective and that both honored the time of the individuals. It is important to work with the specific needs of each group and its leaders, and to include contingency plans in case of absence. For example, since unforeseen circumstances made one leader unable to attend and facilitate a meeting, a research team member did so instead. Since we were well into the dialogue, this was not a problem because the participants were familiar with this individual and were comfortable with their leadership for that meeting. The importance of planning for the unexpected cannot be overemphasized, especially when working with community groups. This applies equally to the participants, who may sometime miss a session; such an occasional absence is not a problem as long as most of the participants can meet at the appointed time.[6]

Choosing topics

The themes for our first round of dialogues—patient-centered outcomes research (PCOR) and comparative effectiveness research (CER)—were specified by the terms of the research funding. When these initial dialogues ended, and the reports were written and posted on the university's PCOR Web site, we then asked the groups' membership to decide on the theme that they would like to explore next (Round 2). After multiple meetings over nearly 6 months with representatives of both original groups present, the theme for these new dialogues—mental health and seniors—was selected. At each meeting, the groups brainstormed potential broad topics, suggesting medications for seniors, end-of-life issues, mental health issues, and social justice themes. Together, the groups decided that mental health represents the most critical of those issues for seniors living in Galveston. Once the topic was established, additional meetings were required to identify specific topics within the arena of mental health most immediate to the group's situation. During the final planning session, the groups agreed on the following five topics: an overview of mental health among the elderly, followed by specific discussions of brain decline, caregiver matters, medications, and downstream community issues. They also asked that a guest speaker, an expert on the theme, be included each week to discuss how they engage with each issue in their daily work. It was then up to the research team to develop the curriculum, create the glossary, and contact the experts.

Since this decision-making process was rather time consuming, we recommend determining a specific topic to discuss so that participants in groups forming for the first time can learn the process. Future dialogues can then include topics selected by community leaders and dialogue participants; we consider this important in pursuing discussions that are of interest to the community, as individuals

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[6] *It is important to note that in our case a specific research protocol was employed. As a result, we had the engagement of the University of Texas Medical Branch Institutional Review Board (IRB), which approved the overall research process. Groups that are meeting independently and are not part of a formal research protocol would not need to undergo this process.*

would be more apt to participate and then discuss with neighbors and family members. It is at this point that the dialogues return to the initial intent of deliberative democracy and the idea of town hall meetings. As participants share their knowledge with others in terms that are meaningful to them, they generate conversations beyond the walls of the meeting room and spread understanding throughout the community.

Materials

For our original dialogue on PCOR/CER, Brody and his team compiled materials from the bioethics literature to be considered for use in the community dialogues. Once the specific themes were selected for each week, the investigators prepared 1-page summaries of the major points in each article as well as audio recordings of discussions about the readings, so that those participants who might not be familiar with the jargon of academic writing and dense material could listen to others discuss them. Our experiences with the readings for the original two groups indicated that some of the articles were too complex and academic for the participants to fully comprehend the major issues in the allotted time between meetings (see Finch, Lewis, & Turley, 2013, p. 227; Powell & Single, 1996). Therefore, during preparations for the 2015 PCOR/CER dialogues with LULAC and GICRAC, the materials were modified to include very few academic journal articles. Instead, we integrated materials from governmental and professional organizations that most of these participants are more likely to access and be able to read (e.g., articles and essay from the *New York Times* and *TIME* Magazine). For the sessions on mental health and aging, as mentioned above, participants requested that a guest expert speak about each week's key topic and were willing to stay an hour longer when such presenters were arranged. The selected experts for these sessions presented and then participated in the dialogue sessions.

Before arriving at the designated venue, the participants should be given the reading materials so that they can familiarize themselves ahead of time with the topics being discussed, enabling a more lively discussion. In our case, group leaders were responsible for copying and distributing the materials to their members. Although it is not always possible for everyone involved to get through all of the assigned readings, at the very least the participants should be able to discuss the topics with a basic understanding of the critical issues. Sometimes summaries of the readings, or a "roadmap," can be developed for approaching more challenging articles to support the members as they read materials that may be unfamiliar to them. We have also met participants who eagerly devoured the readings and further explored the topics on the Internet, bringing the articles that they discovered to the meetings on the topic at hand.

In preparing for the 2015 set of PCOR/CER dialogues, one of the groups requested that we compile a glossary of terms as a resource for participants to access while reading or discussing. As the dialogues unfolded, we found that the glossary became an invaluable tool to which the participants regularly referred during the discussions. The glossary also provided a common denominator for all of the discussions by establishing a foundational vocabulary, as some of the words, terms, and concepts were difficult for laypersons to understand. Therefore, as mentioned earlier, for those considering conducting a community dialogue, providing a glossary of key terms is critical.

In addition to the glossary, we included a case study for each of our dialogue group meetings that the participants used to discuss the numerous elements gleaned from the week's readings. We consider the case study to be central to the process because it illustrates the points being made concerning the problem or policy issue at hand and provides the means for discussing all of the pros and cons, as well as helping to elicit values from the members. Each case employs a real-life scenario of the topic that integrates the different aspects of the problem, and changes can be implemented when necessary. For example, in the original set of PCOR/CER discussions, we used a case on kyphoplasty (an osteoporosis fracture treatment, usually for vertebral compression or augmentation) to represent a problem that offers different treatment approaches.

We found this case to be difficult for the participants to conceptualize because the procedure is not well known and few have experienced it. Instead, for the 2015 PCOR/CER dialogues, we offered a case study about meniscus tears, a knee problem commonly experienced by seniors that has multiple potential treatments and outcomes. Making the problem more tangible elicited significantly more discussion, as the risk of meniscus tears is relevant to seniors' daily lives and the participants could easily understand the different treatment choices that some of them had personally experienced. Case studies provide participants with an opportunity to grapple with the terms and issues by working through a problem together and using their readings, discussions, and glossary to arrive at a position on its resolution. Including a case study helps the participants to think through the practical aspects of a problem, a process that can generate many value statements and help them understand the issues or policies at hand.

Other administrative issues

Several administrative issues should be addressed when forming CBD. Nagel (1992) proposes that participants in deliberative democracy groups, of which community bioethics dialogues represent one model, be compensated for their time. Although our grant funding included a modest remuneration, we do not believe that such compensation is mandatory; it depends upon the particular group that is sponsoring the dialogues and its capacity for providing this incentive. It is more important to provide individuals with the opportunity to discuss critical issues than with compensation; however, the modest amounts provided to group members on fixed incomes helped remove barriers to their participation.

For each of the dialogues, the sponsoring group selected the location of the meetings. In one case, the location was suboptimal, in our opinion, because the air-conditioning fan noise often made it difficult for participants to hear each other's comments clearly. In evaluating a potential meeting locale, environmental factors must be considered to determine whether or not they will be conducive to good discussions; we recognize, however, that various groups have different capabilities for providing such locations. Furthermore, when meetings last longer than two hours, food and beverages will sustain participants' energy levels, especially if they have medical conditions such as diabetes. These are simple administrative matters that can be tailored to each group's needs.

Conducting the research

As researchers, our responsibilities are many: first, we are there to support the community leadership and participants, in whatever way necessary, to ensure that they have a successful experience during the dialogues. Success, in our eyes, is determined by the group completing the process, producing a report, and communicating that participants have gained something from the dialogue experience. Such success is furthered measured by repercussions for participants in the future (e.g., how they apply what they learn to their everyday lives to improve health care decisions and treatment, or how the report impacts upon their neighbors, friends, and elected officials). In addition, we must collect and analyze the different types of qualitative data being generated during the dialogues: the values and other comments expressed by individual members; observations of members' behaviors and their expressions and reactions to each other during the discussions; and our own reflections, analysis, and positioning as participant observers of the entire process. We are then responsible for sharing our observations with the group and the leadership for their response and comments for further discussion and examination—did we accurately see, hear, and feel what they did, said, and thought? Since this research is bi-directional, we must recognize that what we believe to be a finding or an important observation may not be all that important or impressive to the group members themselves. Having a conversation and sharing our data with the participants enables us to clarify and distill our values from theirs, which in and of itself is an important reflexive exercise.

Because we were conducting research on the CBD method itself as well as supporting the dialogue sessions, at the first meeting we explained the dialogue process and obtained informed consent from all participants. In preparing for each dialogue session, we reread and discussed the designated articles and case study. We confirmed that we had a large tablet with enough paper, colored markers, and an easel for writing key points and value statements in situ so that participants could follow the discussion more closely. We also checked the audio recorder for new batteries and sufficient disc space to record at least 3 hours of conversation so that we could later review the recording and ensure that value statements were inscribed as accurately as possible. Once in the venue with everyone seated and ready, we would make announcements to the group and field questions about housekeeping issues. We then turned the session over to the facilitator to lay out the ground rules and run the dialogue. One researcher would stand by the tablet and record the value statements made by each participant as the group discussed the issues. The second researcher sat and took notes about the dialogue itself.

Dialogue fieldnotes ranged from observations about how participants reacted to each other or to the material, to direct quotes about a specific idea, and to nonverbal actions taking place throughout the meeting. We reviewed the notes when we assessed the audio recording and looked for themes. Crowder (2013) used a "Livescribe" pen that audio recorded while writing on the page, allowing the team to return to a moment when a note was made in order to listen to what was being said. The searchable digitized files made by such instruments are also useful as a back-up recording.

A note on video data

Researchers may be inclined to video record the dialogues, as visual data can provide rich information for those interested in nonverbal communication, language, kinesics, proxemics, and oculesics inherent in facilitated group discussions. However, they should do so only if they have a specific question that can be answered using visual data. Not knowing what to expect from these sessions, we initially refrained from video documentation. However, before the second round of discussions began, one of the groups requested that videos of each session be made for later distribution to members of the community. The participants' request went to their group leaders, who could not find equipment or personnel. The participants then asked us for such support, which we were able to provide albeit with the additional strain on our research responsibilities of setting up, capturing, and processing the files. While some may be tempted to place a static camera in the corner and let it roll throughout the meeting and see what comes of it, we recommend employing a dedicated videographer, as the other two research positions require full-time attention.

Implementing and Disseminating Outcomes

One of the primary objectives of conducting CBD is to empower the participants to implement change in their communities. Throughout the dialogue process, we take notes on the various value statements made by participants, which we then compile and present to each group. After the fifth and final dialogue, the research team creates a list of all of the value statements made over the five weeks, organized by theme. Each member takes this list home to review and rank by personal preference before returning for the sixth meeting, when the group votes on which values should receive top priority. This voting and ranking process provides the information needed to prepare the summary report that is reviewed and vetted by the members (usually at a seventh meeting). Such a collective report reflects the key values expressed during the discussions. The identified value statements are intended to represent those held by a majority of the participants in the dialogues as well as to identify those most important to the group. But even if only one or two individuals hold a particular value, they may contribute a minority perspective that is included in the report (Brody et al., 2015). The final report serves as a summary of the discussions held during the dialogues and provides evidence of the context in which they were made. Participants can share this report with whomever they want to inform about their positions on such issues. For example, after the dialogues described here were completed some community members sent copies to officials such as city council members and state and federal representatives, as well as to health care and pharmaceutical executives. We are not aware of how such officials have valued the reports. We do know that friends and relatives of the groups' participants have remarked that sharing such documents with those in power enhances their sense of being heard and makes them feel that they are less likely to be forgotten.

In order to promote awareness of the communities' values, our dialogues included basic activities such as posting each report on the University's PCOR Web site, arranging a local press release and editorials (e.g., Crowder & Determeyer, 2017; Taylor, 2014; UTMB, 2014), and encouraging the continued discussion of topics with friends and family members following each session. New ideas for distributing the information have been suggested by a number of participants: for example, creating materials for younger adults in the community as they approach 65 years of age. The participants believed that there were many issues their children and grandchildren were not well prepared to deal with as they aged, in terms of both health complications and dealing with the "system," especially the health care changes associated with Medicare eligibility and enrollment. Another group wanted to introduce the dialogue process to the leadership of their national organization, so that they could begin offering dialogues at different chapters across the country. Several of the groups have discussed ways of distributing the outcomes to elected officials at the local, state, and federal levels to help them understand the values held by their constituencies regarding health laws and policies.

Observers

As stated earlier, one of the fundamental principles of CBD is that the discussions be open to all residents and persons from the community so that they can attend and witness the process as it unfolds. Each group has allowed observers at their dialogue meetings, but few have taken advantage of the opportunity. We believe that providing residents with an opportunity to be in the audience offers yet another means of educating the public on the issues being discussed. The idea is that the observers would, in turn, promote the dialogue process through discussion with others and consider forming groups of their own. Observers were encouraged to keep back their comments and observations until the weekly dialogue was completed, at which time they could address the group at large. In one case, we contacted the local high school and invited teachers and students to attend and then take the discussions back to their classrooms, but the scheduling of the community meetings conflicted with the academic calendar.[7]

Participants' personal perspectives

At the end of each dialogue series, participants were invited to provide a qualitative assessment of their experience. They commented on what they had learned and how the dialogues impacted upon them personally in addition to critiquing the process itself. After the first round of discussions (PCOR/CER), all of the participants expressed their appreciation for the dialogue process, noting that they learned a great deal about the importance of being their own health care advocates. Moreover, they acknowledged the need to take notes during physician visits, bring a trusted friend or relative to listen, and obtain second opinions for serious matters. One participant cited the changes that occur when one turns 65 and expressed a desire to prepare information for her fellow church members. For the second round (mental health), the participants acknowledged the importance of learning about mental health issues and resources.

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[7] *We also considered having high school students tape the sessions for subsequent school and community education, but were unable to coordinate the schedules.*

In addition, several of the participants noted the critical need to complete advance directives and talk with family members about treatment choices and wishes before the end of life. One individual who worked as an assistant manager of an apartment complex scheduled a meeting of all residents and family members to instruct them about directives and other important documents as people age. Encouraging individuals to think about their health concerns proactively is an important community effect of the dialogues.

To evaluate the process, we developed a simple questionnaire for the participants to complete during the final meeting, asking them to reflect on their sense of knowledge gained, the effectiveness of the facilitator, the appropriateness of the space where the meetings took place, and the quality and amount of materials to review before each meeting. Most respondents were quite happy, if not exuberant, about the work of their facilitators. In only one case, during the first round, were participants disgruntled with the facilitator, who struggled with the concepts and with conducting a small group conversation. After that incident, the research team changed how we supported the facilitators by meeting them when and how they felt they could best make use of us. We also became more vocal after each meeting, helping the facilitators identify aspects of their work that could use polishing.

We asked willing participants to share aloud their observations about the dialogues and the revelations that they experienced with the group. By far these were the most profound moments of the dialogue process as members stood and addressed their colleagues: sharing stories of what they did with the material they were learning, how they conveyed these ideas to their families and friends, and how they manifested such knowledge in taking action locally. Furthermore, participants lauded the organizers and community leadership for offering them the opportunity to participate in the dialogues and asked to be included in the next dialogue that would take place; some even offered themes or topics to explore in a future round. It was also at this moment that we asked the participants how they felt their report could best be distributed and used, acknowledging that a copy of it would appear on the UTMB/PCOR Web page.

Although we did not formally follow up with the members of each group, we did receive anecdotal evidence from some who had sent copies of their report to ranking officials in their national organizations and even to elected persons in the county and city governments. Several suggested that as researchers who wielded more "power" than they did, we should convene a final meeting between the groups and local officials to present and discuss the reports in an open forum. While we held press conferences and sent out releases at the end of each round, those did not suffice in seeding a larger conversation about these issues in the city. Instead, we are now working toward developing an open meeting protocol whereby participants and invited elected officials (and anyone else they feel should be included) meet to discuss the results of reports and propose ideas for addressing their values through policy, awareness, or even acknowledgment at that level. We had expected a greater urge to distribute the reports by the participants themselves, but for the most part they relied upon the research team to do that for them, a miscalculation that we will address in our next round of grant proposals.

In the round discussing mental health with seniors, the researchers provided a Likert-type questionnaire regarding perspectives on mental illness. At the end of the sessions, the same questionnaire was again provided to participants, giving the researchers additional data to analyze on perspectives. It is also possible to obtain quantitative information by asking participants to complete a short rating form on various aspects of the dialogue experience.

Conclusion

The community bioethics dialogues (CBD) process is a powerful means of educating community members while also conducting research to obtain perspectives on a wide range of health care topics. At the end of each of our sessions, participants commented on how much they appreciated knowing more about the material and the importance of the knowledge they gained during the discussion process. Members expressed how they had become more empowered to be thoughtful health care consumers and to ask questions of their caregivers, both for themselves and for their family members. At a time when health care expenditures continue to grow, it is important that health care users understand the information that they access. A platform such as CBD provides community members an opportunity to discuss key health care issues in a safe environment, planting the seeds for cultivating a better understanding of some of the care and policy issues that will affect every member of their larger group. Due to the success of our dialogue sessions, we expect that other groups will adopt this model to help educate their constituencies on various health care matters and encourage them to share that knowledge with their families and communities.

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