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Deliberative Discussion Focus Groups

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Abstract

This article discusses a new approach for the conduct of focus groups in health research. Identifying ways to educate and inform participants about the topic of interest prior to the focus group discussion can promote more quality data from informed opinions. Data on this deliberative discussion approach are provided from research within three federally funded studies. As healthcare continues to improve from scientific and technological advancements, educating the research participants prior to data collection about these complexities is essential to gather quality data.

Keywords

focus groups; qualitative; deliberative discussion; education; USA

Introduction

Focus groups are a unique and effective modality for capturing in-depth data about a topic of interest determined by the researcher (Morgan, 1997). However, the ability to capture quality data from the participants is also dependent on how knowledgeable the participants are on the topic of the discussion (Cobb, 2011; Guttman, 2007; Kitzinger, 1995). If a focus group is used to gather feedback or reactions about a new product or marketing plan, little information needs to be communicated to the participants before the focus group discussion. In addition, if the purpose of a focus group is to obtain opinions or attitudes about their understanding of a social phenomenon (i.e., what does genetics mean to you?), little information can be presented prior to the discussion. However, the use of focus groups has grown exponentially over the past two decades to include ever-increasing complex, health topics.

This growth of focus groups in health research parallels the growing recognition about the importance of including public opinions in healthcare, science, and technology projects (Cobb, 2011). Public opinions are a reflection of values and attitudes that are not only comprised of individuals' immediate and more general social-environmental factors but also

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include pre-existing knowledge, attitudes, and opinions (Sanz-Menendez, van Ryzin, & del Pino, 2014). As such, they are an important stakeholder not only for the development of interventions but also as support for healthcare and public policies. For example, focus groups are often used before and after a randomized controlled trial to gather information on how best to implement the intervention, the content of the intervention, and/or how well the intervention worked (Campbell et al., 2000; Jemmott, Sweet Jemmott, & Fong, 1998; Oakley, Strange, Bonell, Allen, & Stephenson, 2006). Another example of the growing use of focus groups in health research is the identification of what healthcare consumers want to know about clinical or research activities such as biobank consent preferences and return of genomic results (Bollinger, Scott, Dvoskin, & Kaufman, 2012; Lemke, Wolf, Hebert-Beirne, & Smith, 2010; Murphy et al., 2008; Streicher et al., 2011; Whitley, Kanellopoulou, & Kaye, 2012). When public opinions are not included with new technological developments in health and science, public backlash may occur as was evident with the public rejection of genetically modified foods (Gaskell, Baurer, Durant, & Allum, 1999; Pew Research Center, 2015). In addition, when the public is not knowledgeable about the topic, support for science or healthcare-related topics also declines (Pew Research Center, 2015). As such, not only the inclusion of public opinion but also education is essential for adequately involvement of this stakeholder group.

Little emphasis has been placed on how to inform or educate focus group participants prior to the group discussion within these multifaceted health contexts. The process of informing and discussing the topic of interest by the researcher is similar to the concepts of deliberative discussion (Fishkin, 2011). Deliberative discussion is a conceptual framework for how discussions should be structured to gather higher quality data based on five premises (Fishkin & Luskin, 2005). The first premise of a deliberative discussion is that participants should be (a) informed to make accurate statements but they should also be supported. The information presented should be (b) balanced and incorporate both the pros and cons of the topic of interest as well as (c) comprehensive. The discussion must include individuals who are (d) voluntarily engaged in the discussion, and their statements should be evaluated on their (e) merit and not the person talking.

Deliberative discussions are a key component within deliberative democracy (Fishkin & Luskin, 2005). Growing support for deliberative tools such as deliberative democracy sessions and town halls is the recognition that the public has limited knowledge on topics related to science and technology. This has fueled additional efforts to include the public in a meaningful manner through improved education and deliberation prior to collecting opinions (National Science Board, 2010). One of the primary advantages of deliberative discussion is the ability to inform, interact, and then assess public opinion. This process is valued over other methods of public opinion research because it is assumed to generate more thoughtful data because public opinion is derived after education, interaction, and discussion of the topic (Cooke, 2000).

Deliberative public opinion data are highly valued because the participants are able to learn about the unique circumstances and interests of competing arguments through this process. As participants engage and become more knowledgeable, more thoughtful and informed statements are expected to emerge, leading to better quality data (Gastil & Levine, 2005).

Overall, deliberation can be described as a sophisticated version of talking, listening, and reasoning, which is ideal within the focus group setting. Small groups are ideal for promoting deliberative discussions because of the ability to share and hear opinions along with reasons for these opinions (Hamlett & Cobb, 2006).

To continue the use of focus groups as an effective modality for obtaining in-depth data within these newer and more complex health and research contexts, more information and education is required of the participants to engage in a productive focus group discussion. Two key additions to the typical focus group experience help facilitate a deliberative discussion focus group approach and include an educational presentation prior to the group discussion and the addition of an expert co-moderator. Prior to using the educational presentation, a separate set of respondents evaluated the presentation for content and balance between the pros/cons of the topic. It is important to use a separate set of respondents that are not included in the development of the educational content or focus groups to address some of the potential influence of the researchers' beliefs into the study data and to gather feedback on the education for understandability and balance. An independent review of the pre-determined question route for the focus groups is also of importance to ensure neutrality of the questions and to capture if opinions changed during or at the end of the discussion.

Immediately following the presentation, participants are reminded about the role of the expert co-moderator and her or his experience in this domain. Then the participants are specifically asked for questions about the presentation, the topic of discussion, or anything that may be unclear. We remind participants that they may also ask questions during any part of the discussion, but we encourage some questions to be asked in the beginning. Using this format, in the first minute of every focus group discussion, a question has been raised by a participant. The co-moderator is highly descriptive in providing the first answer to not only demonstrate expertise but also openness to answer any and all questions by the participants. The primary moderator then begins the questioning route that is pre-determined within the semi-structured focus group guide after all of the initial participant-driven questions are answered. Toward the end of the focus groups, the moderator will ask for participants' final opinions about the topic of interest and how their opinions may or may not have changed from earlier in the group experience. We have published articles from approximately 60 focus groups utilizing a deliberative discussion format (see Table 1).

Case Examples

Three examples are described below to capture how we created a deliberative discussion focus group approach with the use of an educational presentation and an expert co-moderator. Of note, our research utilized a qualitative descriptive framework (Barbour, 2005; Sandelowski, 2000). Congruent with a qualitative descriptive framework, content analyses were used to analyze focus group data in these studies. A distinguishing feature of content analytic approaches is the use of a consistent set of codes to designate data segments that contain similar material. Once a template for coding is generated, the researcher systematically applies the coding template to the data, with the option for open coding to capture data that may have been missed initially when the template was created (Elo & Kyngas, 2008). After coding is complete, the codes are summarized along with

recontextualization of the data to identify patterns (Miles & Huberman, 1994). This approach was used to analyze the data in the following examples. For more details on this analysis and recruitment, please see articles listed in Table 1. Institutional review board approval was obtained for all of the studies.

Example 1. Public Attitudes Regarding the Use of Electronic Health Information and Residual Clinical Tissues for Research (see Table 1).

We sought to understand public attitudes regarding access to electronic medical records (EMRs) and residual clinical biospecimens through focus groups (Botkin, Rothwell, Anderson, Stark, & Mitchell, 2014). Use of EMRs and residual clinical biospecimens has become important for the conduct of biomedical research. Currently, human subjects protection regulations permit much of this research to be conducted without individual informed consent, posing a risk to biomedical research from public objection. Twelve focus groups with 131 participants were conducted in Utah, Washington, Arizona, and Minnesota.

To provide background information to the group participants, we created a 12-minute video about research with EMRs and access to residual biospecimens collected through clinical and research contexts. This video was developed by the Genetic Science Learning Center. The video is available at <https://vimeo.com/album/3301573/video/83887646>. The purpose of this video was to inform focus group participants about the research and issues related to population-based research, use of EMRs and stored biological materials for research, protections for privacy and confidentiality in population-based research, and information about the proposed option to opt-out of research access to their data or biospecimens. The video was shown at the beginning of each group.

One of the researchers experienced with focus group research moderated the groups. The other moderator was an expert on the topic and answered questions from the participants. The most interesting outcome of this approach is that the final opinion of the participants in this study was inconsistent with some surveys of general population (Simon et al., 2011), in that, many of the participants were supportive of an “opt-out” approach, as opposed to “opt-in” (signature). Many of the reasons provided were related to the intricate details about population research that could have only come from information about competing opinions and further clarification to questions asked by the participants from the expert co-moderator. The most common questions (see Botkin, Rothwell, Anderson, Stark, & Mitchell, 2014), if answered sufficiently, may allow more public support for an opt-out approach to population-based research.

Example 2. What Parents Want to Know about Storage and Use of Residual Bloodspot Retention (see Table 1).

The second example of a deliberative discussion focus group approach was the development of a public health education intervention about residual newborn screening bloodspots (Botkin, Rothwell, Anderson, Goldenberg, et al., 2014). We conducted 11 focus groups across four states. We sought to seek feedback to determine what parents want to know regarding the retention and use of residual newborn screening dried blood specimens to make informed choices regarding this practice. Prior to the group discussion, each group watched a short video about newborn screening (NBS) based on the “Seven Things Parents

Want to Know About Newborn Screening” (Davis et al., 2006) and a second video about the management of residual dried bloodspots. Both movies can be viewed at <https://vimeo.com/album/3301573/video/62966764> and <https://vimeo.com/album/3301573/video/65186474.spot-videos/>. The focus groups were moderated by two moderators, and one was introduced as an expert on the topic of discussion.

Based on the items consistently identified by participants in all of the focus groups and the analysis of experts, we developed seven key items parents want to know about residual newborn screening dried blood specimens for state health departments. We believe that the final items were generated from more thoughtful and informed opinions of individuals who were able to engage in a lengthy discussion about the topic of interest. Without the deliberative discussion approach in these focus groups, two important items would have been missed. First, despite having two educational videos, participants in the focus groups assumed that extra heel pricks were performed to gather more blood beyond the purpose of newborn screening. Without the stated expectation of participant-driven questions and the open environment, participants may not have asked for this clarification and made their opinions based on this erroneous assumption. Second, participants assumed that all results would be personally communicated back to them if their infant’s blood was used in research. This is a nuanced detail that required further clarification about de-identified samples and the use of a high number of samples for population-based research.

Example 3. Public Attitudes Regarding a Pilot Study of Newborn Screening for Spinal Muscular Atrophy (see Table 1).

To assess attitudes about a pilot study of newborn screening for spinal muscular atrophy (SMA), six focus groups were conducted within the states of Utah and Colorado (the same states that were proposed to be included in the population-based research study; Rothwell, Anderson, Swoboda, Stark, & Botkin, 2012). Prior to the conduct of the focus group, an educational video was created to give information about SMA, newborn screening, population-based research, and the pros and cons of two decision-making approaches for research participation (opt-in vs. opt-out; <https://vimeo.com/album/3301573/video/122124948>). Two moderators facilitated the focus groups, and one of the moderators was introduced as an expert in the domain of interest.

One of the most interesting and unexpected aspects of this deliberative discussion approach within this study as well as the other two examples provided above was the significant amount of participant-driven questions. Using the data analysis technique described above, two separate content analyses were conducted. The first analysis focused on all coded data that did not include participant-driven questions. The second analysis was a content analysis on participant-driven questions. The analysis of the participant-driven questions was conducted independently and after completion of the first analysis. The second analysis was used as a comparison to the results in the first analysis.

Participant-driven questions were the most frequently occurring code with 240 questions across the six focus groups, and the next most frequently occurring code was on ways to inform/educate people about the research with 137 incidences. Although the results of the study were informative, the value of including representative examples of the participant-

driven questions further contextualized the focus group discussions and provided specific examples of what information the participants asked. The additional analysis of the participant-driven questions provided concrete examples of the participants' information needs about these complex screening programs and rare diseases as well as provided detailed information of what may be important for improving public knowledge about this topic. Second, it provided data about potential information that a study might include in education materials, consent forms, websites, and so on. Depending on the purpose of the study, the participant-driven questions could also be analyzed to reflect how to improve the process for parental decision making and the role of providers in this process. Without creating an environment that encouraged learning, some of these details would have been missed.

Discussion

As technological advancements in healthcare and health research continue to increase, helping research participants understand these complex topics is needed for more thoughtful and informed opinions from research participants (Cobb, 2011). Health research is changing, and existing paradigms of research to gather public opinion need to adjust to these changes to gather quality data. Increased involvement of participants in research as co-collaborators and/or citizen scientists is growing (Hand, 2010; Trumbull, Bonney, Bascom, & Cabral, 2000). Identifying ways to improve research processes and/or tools for gathering *informed* decision making may benefit from the input of deliberative discussion focus groups. These participants have been educated and offered opportunities to ask questions and engage in an extensive dialogue on the topic. The more informed research participant may lead to better outcomes that can influence patient care and policy.

For example, in our research with focus groups on public attitudes about newborn screening, many of the participants misunderstood what was newborn screening and/or did not know that these programs existed despite the mandatory nature of them (Botkin, Rothwell, Anderson, Stark, & Mitchell, 2014). To address these problems, an educational presentation was presented to inform participants about the accurate details of newborn screening and the pros and cons about current newborn screening programs. We also included an expert co-moderator to answer questions before and during the focus group discussion. The addition of an expert co-moderator along with educational materials significantly increased participant understanding and the value of the focus group data.

One of the most interesting aspects to emerge from our work with the deliberative discussion focus group approach was the large number of questions raised by the participants. Questions initiated by participants using this method were the most frequently occurring code in all the three data examples (Botkin, Rothwell, Anderson, Goldenberg, et al., 2014; Rothwell, Anderson, Goldenberg, et al., 2012; Rothwell, Anderson, Swoboda, et al., 2012). The participant-driven questions also enabled participants to gain knowledge and refine their opinions as well as serve as another source of data to verify and reinforce interpretations of the discussion data. The participant-driven questions also provide evidence for the importance of education and the ability to ask questions during the focus group discussion to gain clarification or further information. This amount of question-seeking raises some

concerns about the current conduct of research. More effort on part of researchers may need to occur to adequately engage research participants not only during the informed consent but also during their participation in the on-going research. Finally, the participant-driven questions also serve as a data source for the type of questions the public may have about a topic. Greater public implications may spill over from deliberative discussions such as the potential to empower individuals to seek more involvement in other public service activities or research.

Another benefit of promoting participant learning during the focus group experience is the assessment of the participants' *final* opinions and if they changed from the beginning of the group experiences. Unlike the informed consent process, participants read the document and can agree to participate as the study as designed or choose not participate. Within deliberative discussion focus groups, participants are able to provide reasons for why they would or would not participate in the research after discussing the topic for up to 2 hours.

Finally, one of the key assumptions for why focus groups are effective tool for research is because they occur within a social context. By promoting learning, participants can hear and discuss issues that may not have arisen without someone else first asking the question. Individuals do not make healthcare decisions in isolation, but they often discuss them with friends or family prior to the final decision. Deliberative discussion focus groups allow this type of discussion about pros and cons of a decision to be heard. In addition, most utilized deliberative discussion groups typically require several days of participation. Conducting several deliberative discussion focus groups may be an alternative that can allow informed data to be captured by a greater diversity of participants who cannot spend multiple days volunteering for a research project. In summary, promoting learning through the use of an educational presentation and an expert co-moderator can significantly enhance participant understanding and increase the utility of focus group data.

Limitations

The inclusion of an education presentation that includes the pros and cons as well as an expert to help answer questions can promote a more informed, thus more valuable context for data collection. However, a presentation of information about the topic of discussion may bias the discussion and/or project toward the desired outcomes of the research. It is important to present both the pros and cons or positive and negative outcomes of the topic of discussion to the participants. Although the education presentations in these studies were aimed to provide both the pros and cons of a topic, information we presented could have biased participants. For example, we stated in one project that the risks are empirically low for biobanking and actually stating that the risks are low may have biased the conversation. This is a similar problem with consent forms. Consent forms may imply potential benefits to individuals as opposed to science and society, thus promoting therapeutic misconception (King et al., 2005). The point is you can overstate risks and/or overstate benefits in an attempt to be neutral about an issue. How to balance these issues is problematic and more importantly, is this appropriate?

However, as with all focus group research there are elements to consider such as reflexivity, and trust in participant's capacity to engage in dialogue. These concerns should be discussed

among the research team as well as in the development of the questioning route for the semi-structured focus group guide. Review of the questioning route by researchers not associated with this study can help address these concerns. Along with these considerations, appropriate review and training for focus group research should be addressed prior to any research activity.

With any research design, biases remain, and often participants are forced to make an assumption that is unknown to the researchers. Promoting learning and question-seeking during focus groups highlight these participant assumptions. Second, within any focus group context, the influence of the moderator is ever-present, and bias can be projected. It is important that the lead moderator creates an open context where participants can not only make an informed decision but also express disagreement. Without providing an opportunity and support for participants to learn and ask questions before the group discussion, focus groups may not be as effective within these ever-increasing complex, health contexts.

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Table 1

Publications of Focus Groups Using a Deliberative Discussion Approach (Educational Intervention and an Expert Co-Moderator).

Name	Number of Groups	Total Number of Participants
Concerns of Newborn Blood Screening Advisory Committee Members Regarding Storage and Use of Residual Newborn Screening Blood Spots (NIH; R01-HG004970)	4	39
Policy Issues and Stakeholder Concerns Regarding the Storage and Use of Residual Newborn Dried Blood Samples for Research	3	21
Assessing Public Attitudes on the Retention and Use of Residual Newborn Screening Blood Samples: A Focus Group Study (NIH; R01-HG004970)	14	128
Public Attitudes Regarding the Use of Electronic Health Information and Residual Clinical Tissues for Research (HRSA; D1-BRH20425)	15	13
Public Attitudes Regarding a Pilot Study of Newborn Screening for Spinal Muscular Atrophy (NIH; R01-HD69045)	6	70
What Parents Want to Know About the Storage and Use of Residual Newborn Bloodspots (NIH; R01-HD062762)	12	104

Note. NIH = National Institutes of Health; HRSA = Health Services Research and Administration.