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Advantages, Disadvantages, and Lessons Learned in Conducting Telephone Focus Groups to Discuss Biospecimen Research Concerns of Individuals Genetically at Risk for Cancer

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Abstract

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Keywords

Focus Groups, Qualitative Research, Telecommunication

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Advantages, Disadvantages, and Lessons Learned in Conducting Telephone Focus Groups to Discuss Biospecimen Research Concerns of Individuals Genetically at Risk for Cancer

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Advances in telecommunication technology allow biomedical researchers to explore new, inexpensive opportunities for conducting focus group research. This article reports our experiences using such technology to engage individuals genetically at risk for cancer about biospecimen research. Telephone-based focus groups were conducted with a total of 40 individuals, and participants were asked about their experiences and perceived benefits and limitations of participating in a telephone focus group about biospecimen research. The lessons learned can effectively be applied to other areas of health research. In particular, this method may be most useful to engage individuals who are less apt to speak in public, and/or when there are concerns over privacy if face-to-face discussions methods are used. Keywords: Focus Groups, Qualitative Research, Telecommunication

Focus groups are a qualitative research method used for exploring a specific population's knowledge, attitudes toward, and behaviors regarding a given topic (Krueger, 1998). Whereas focus groups are typically held as in-person meetings, geography, time, and resources may serve as major barriers to this encounter (Ross, Stroud, Rose, & Jorgensen, 2006). For these reasons, researchers have sought alternative methods to conduct focus groups that allow participation of broadly dispersed populations as well as those who, for health or other personal reasons, are unable to leave their homes. White and colleagues were among the first researchers to describe the use of the telephone as the communication channel to conduct focus groups, and their rationale for using this channel was to encourage group discussion of sensitive topics while maintaining participants' anonymity (White, Coverdale, & Thomson, 1994). Since then, researchers have used telephone focus groups (TFGs) to explore a variety of health-related topics, including training needs, education disparities, and health practice evaluation (Cooper, Jorgensen, & Merritt, 2003). However, as a methodology, TFGs have received limited attention as much focus is still placed on face-to-face focus group interactions (Cote-Arsenault & Morrison-Beedy, 2004).

Smith and colleagues (2009) conducted a systematic review of articles related to TFGs published between the years 2003-2007. They located 11 health-related studies and summarized the access to wide geographical location, increase in participation rate, logistical efficiency as the advantages and loss of nonverbal cues and sampling bias due to technological requirements as the disadvantages of using telephone focus groups. Similarly,

Cooper and colleagues (2003) conducted a systematic review of using TFGs in health research and identified the need to explore the difference in focus group dynamics of in-person and telephone-based focus groups. They also identified a lack of detail in the reported methods of TFGs such as focus group size and duration (Cooper et al., 2003).

The current study focuses on the methodology used to conduct TFGs with a geographically disparate sample of individuals genetically at risk for developing cancer. The purpose of the TFGs was to discuss perceptions of participating in biospecimen research, privacy and confidentiality concerns, and topics in which biomedical researchers should understand prior to administering informed consent with this population. We report on the process of conducting the TFGs, lessons learned, and reported advantages and disadvantages of using TFGs to conduct research related to biobanking with individuals genetically at risk for cancer. This information may be useful for researchers who work with rural and/or geographically dispersed populations, for whom it is not feasible to conduct their studies on site.

Biobanking Research

In biobanking studies, biomedical researchers collect human biospecimens such as blood, tissue, and other bodily samples, and break down these samples to study disease prevention and control at the molecular level. Research using biospecimens has led to the development of new cancer drugs and treatments and is predicted to lead to personalized medicine (Hewitt, 2011). Cancer patients are often asked to donate blood and tissue (biospecimens) that were removed during cancer treatment surgeries (National Cancer Institute, 2011). Researchers seeking to study genetic differences in the development of cancer among family members are beginning to approach cancer patients' family members who do not have cancer but have tested positive as genetically at risk for cancer to also donate biospecimens (Hewitt, 2011). Thus, for both research and practice it is critical to understand cancer patients' and their unaffected, genetically at-risk family members' concerns about donating biospecimens and biospecimen research prior to requesting for their donations.

Past research has demonstrated the general public's concerns about biospecimen research. For example, Luque and colleagues (2011) found that one community's main concerns related to donating biospecimens included fear of privacy loss (e.g., information leaked to insurance companies and employers), donors' anonymity, accidental discovery of diseases detected in the donated biospecimen(s), and the possibility that researchers would sell their biospecimens for profit.

We explored the bioethical concerns of biobanking in two distinct groups. First, we explored a national sample of individuals genetically at risk for cancer. We also assessed biomedical researchers' perceptions of bioethical concerns of potential biobanking donors and educational preferences for training researchers on these concerns. We chose to conduct TFGs for this exploratory study due to participants' potential concerns about privacy and anonymity as well as their geographic dispersion. We examined the advantages, disadvantages, and lessons learned regarding the use of TFGs to conduct research with the at-risk population.

All authors, at the time of this study, were employed by Moffitt Cancer Center and had received National Institute of Health (NCI) funding to conduct the larger study. Authors played various roles in the TFG study. As a group, we planned the overall study to identify the similarities and differences in concerns about participating in biospecimen research between individuals with a family history of hereditary cancer and bio-behavioral and basic science researchers who use biospecimens in their research. We examined the possibilities of data collection methods keeping in mind the need to collect data from a nationally

representative sample in an interview type format yet maintain confidentiality, particularly with the community group. We did not consider Skype or other video recordings as we wanted the opportunity for the high risk participants to remain anonymous. We also considered other web-based platforms such as Adobe Connect but determined this may add additional costs to the study as we would still have to pay for transcripts of the audio files. The study was conducted over the period of one year. Future directions for this larger project are to develop an on-line curriculum to improve researchers understanding of high risk community member’s concerns about bio-banking. Additionally, we plan to use telephone focus group methodology in future research given the positive experience we had with this technology.

Methods

When designing the study, we created a systematic roadmap of steps (i.e., assessment, planning, implementation and evaluation) that documented our use of the TFG methodology. Table 1 shows a snapshot of these steps and the questions that we considered that supported our use of this methodology. In the upcoming sections, we describe each step in more detail.

Table 1: Systematic Steps to Select and Evaluate the Use of Telephone Focus Groups

Steps	Description (Questions to ask)
Assessment	<ul style="list-style-type: none"> • What research questions are we trying to answer? • What population/sample are we trying to reach? • What methodology will allow us to reach this population? • Are the exploratory research questions seeking sensitive information? • Do the researchers prefer seeking the views of one participant at a time, or do they prefer dialogue among a group of research participants? • Will the selected methodology fit the goals of the study and the needs of the population?
Planning	<ul style="list-style-type: none"> • What resources are needed to carry out the telephone focus groups? • What communications are needed to recruit the sample? • What logistics (e.g., time zone, technology) are needed to achieve goal? • What is the best method to administer and collect informed consent? • What staff is needed to plan and conduct the study?
Implementation	<ul style="list-style-type: none"> • What procedures and processes are needed to conduct TFGs? • What are the expectations for the research participants?
Evaluation	<ul style="list-style-type: none"> • What lessons did we learn using this methodology? • What worked well? • What did not work well? • Were the participants satisfied with using this method? • Were the staff members satisfied with the results? • Would we use this method again?

Assessing

When selecting our research method for this exploratory study, we assessed the needs of our participants. We evaluated time constraints for participating in this study, geographic dispersion of the study sample, as well as the possible sensitivity of the topic, donating biospecimens. Although biospecimen donation with healthy controls was not a sensitive

topic in one community (Luque et al., 2011), we believed individuals at genetic risk for a hereditary cancer may have concerns specific to their health status and family history. We considered conducting telephone in-depth interviews; however, we wanted to encourage cross-communication of research participants. Although we believe that some questions may be viewed as sensitive information, we believed that the lack visually identifying other individuals genetically at risk for cancer may ease any discomfort in the group (Cooper et al., 2003). Based on these considerations, we selected TFGs as our methodology.

Planning

Next, we began planning the use of TFGs for our research study. Individuals genetically at risk for developing cancer were recruited from a national network of cancer genetic registries. An electronic informational flyer was distributed to these individuals via the hereditary cancer database listserv, and those interested in study participation were asked to call a study hotline number to receive more information and to verify eligibility. Participants were sent a demographic form to complete and return via FAX or email. The University of South Florida Institutional Review Board granted a waiver of documentation of informed consent for this study.

A master database identifying possible focus group dates was created to house all communication and scheduling information for the project. When scheduling the focus groups, the sample's geographic distribution among multiple time zones was taken into consideration, and all focus groups were scheduled in Eastern Standard Time to avoid confusion. Researchers created their own data file to document communication with participants about the collection of demographic information, selection of participation dates, and mailing and receipt of participant honorariums. In a few instances, some TFGs were cancelled, rescheduled, or merged if there were insufficient number of participants for the TFG. We aimed to recruit 60 individuals genetically at risk for cancer with no more than 8 participants per TFG. However, after we had recruited 40 individual and examined the data collected thus far, we determined we had reached saturation – we were no longer hearing new information and thus it did not appear to make sense logistically or financially to continue to recruit.

Determining the best software or multimedia application to use for conducting the TFG session was just as critical to the success of the study as effective recruitment, development of the focus group guide, and selection and training of the focus group moderator. Choosing a software system that offered state-of-the-art technology, reliable recording, accurate transcription, and competitive pricing was essential. Other factors considered were ease of use, accessibility, limitations of the software, and data security if audio recordings and transcripts are to be housed on the software provider's network. For the purpose of this study we reviewed three independent software vendors and rated them based on the aforementioned criteria. Although all met the general criteria, we ultimately selected the company that offered a verbatim transcript of the focus group within 24 hours of the call. The company recorded the conference using their own telephone recording software, charging a fee of \$100 per transcript.

Implementation

Participants were able to access the TFG session by one of two methods. They either called a toll free number and entered a passcode provided by study staff; or researchers provided the communications company participants' phone numbers for the company to call them directly the day of the focus group session to connect them to the conference call. The

call began with moderator and co-moderator introductions and the description of the study's purpose. Researchers then provided the following instructions asking participants to:

1. Introduce themselves by any name they wished to be called during the focus group with the reminder that the call was being recorded;
2. Be cognizant of the "delay" in telephone transmission, particularly on a large conference call;
3. Observe the standard focus group etiquette of allowing everyone a chance to speak freely; and
4. Speak one at a time, and respect others participants' comments.

As with traditional in-person focus groups, the moderator followed a semi-structured interview guide to pose questions to the group. Respondents were invited to answer directly or comment on other focus group members' discussions. During the call the moderator and study team were able to log onto a website provided by the communication company to access unique audio conferencing services which included a list of study participants, status of their connection, and strength of the connection to identify participants who may be experiencing dropped calls or poor service, audio controls (e.g., mute, stop, cancel or record), and the ability to chat or message other study staff regarding internal information. The messaging capability allowed the moderators to communicate privately with comments such as "Ask the respondent for an example" and, "Do you think [name of participant] is adequately engaged in the conversation?"

Evaluation

To evaluate the use of our telephone methodology, towards the end of each focus group, study authors (GQ, CDM) asked participants about their satisfaction with participating in the TFG. They also asked participants if, based on their experience in this focus group, they would be likely to participate in another TFG in the future. At the completion of the TFG interviews research staff downloaded the audio recordings as an mp3 file from the communication service's website. The communication company also mailed a CD of the audio files and a complete verbatim transcript to research staff within 24 hours of call completion. The principal investigator stored audio and transcript files on her computer and the corporate firewall-protected shared drive. These procedures were approved by the institution's IRB.

Results

A total of 40 individuals recruited from the Cancer Genetics Network Registry participated in one of seven TFGs with an average of six participants per call (range of 4-8). All participants were non-Hispanic Whites. Most participants were female (n=37, 92.5%), married (n=37, 87.5%), over the age of 45 years old (n=28, 70%), and had earned a college degree (n=34, 85%). When reviewing the recorded focus groups and audio files for accuracy, we noted the high quality of the transcriptions. Qualitative results of this study reflected participants' evaluation of using TFGs to discuss ethical concerns of biobanking.

Advantages of Using the Telephone Focus Groups

The majority of participants were pleased with the ease of use, increased accessibility/geographic reach, and convenience of TFGs. Several participants noted their

own behavior changed during the focus group because of the format, indicating they were more conscientious of listening to other participants and were not as preoccupied with thinking about their next response. Others believed the size of the group contributed to the positive experience. “The size of this group is small enough where each of us was able to contribute equitably.”

Participants stressed how the convenience of the TFG influenced their decision to participate in the research study. One participant responded, “[it] *saves a lot of time of travel and coming to a location.*” When participants were asked about their willingness to participate in future TFG session, all confirmed, noting the ease of participation as the primary factor for their positive experience. “*I thought it was very convenient. I got to hear others’ thoughts and give mine, too, from the comfort of my home.*”

Participants noted that the TFG allowed them to share confidential information and personal thoughts about their risk status in an anonymous setting. One reported, “*Given the subject matter (hereditary cancer risk) and concerns about privacy I worry about all the time, I was relieved to discuss this over the phone.*”

Further, at least half of the participants said the opportunity to discuss issues related to their genetic risk status in a private setting, knowing that other participants were “*in the same boat*” as they were, was “*comforting*” and “*a relief*”. Another participant described her preference for this method due to her fear of speaking in public. “*It’s actually easier to do it on the phone if you are shy or if you fear of public speaking.*” Another participant reported, “*I could say things I might not have said face-to-face with others. I felt free to disclose personal thoughts.*”

Disadvantages of Using the Telephone Focus Groups

Limitations of using telephone focus groups identified by the participants included the lack of traditional focus group elements such as visual cues, body language, and focus group member dynamics. One participant stated,

“I can’t see everybody, I can’t see facial expressions. I think one interesting thing about [in person] focus groups is that you build rapport with the other individuals in the group.”

Another noted, “*It was difficult to get to know the others over the phone but this didn’t prevent me from saying what I thought.*”

Concerns for time management and lack of group rapport were also expressed. One participant stated, “*I felt rushed to say what I wanted to because we only had one hour for the call*”. Participants also described how technical challenges such as background noise, cross-talk and connectivity issues, including a disconnection served as distractions during the TFGs. However, participants said the benefits of the TFG outweighed the limitations.

Conclusion and Lessons Learned

Our experiences suggest that TFGs are well suited for hosting group discussions with individuals living in various geographic regions. Consistent with past research, it is also a useful approach for maintaining anonymity of research participants and encouraging discussion on sensitive topics (Smith, Sullivan, & Baxter, 2009, Tolhurst & Dean, 2004). The benefits of using TFGs outweighed the limitations (e.g., not being able to assess non-verbal cues) described by participants. Research suggests that respondents felt more relaxed and willing to discuss sensitive information over the telephone when compared to face-to-

face interactions (Novik, 2008). TFGs are, thus, most relevant in selected situations when participants are geographically dispersed and it is not feasible to convene regional face-to-face focus groups; face-to-face focus interactions are not essential to the topic under study; and anonymity is presumed or deemed necessary. Other key considerations and lessons learned of using telephone focus groups include:

1. When researching and reviewing various telecommunication companies to host the calls, inquire about call recording and transcription abilities. Identify if there is need and opportunity to monitor the calls audio features (e.g., mute) via the Internet as well as the need for moderators or the study team to communicate privately on this same site.
2. To keep the participants' attention, limit the focus group call to 90 minutes or less. Calls longer than 90 minutes tend to becoming tiring for participants.
3. Restrict the number of focus group guide to 10-12 questions for a 60-90 minute call.
4. The most popular time for the individuals genetically at risk for cancer was during the lunch hour, and some could only stay on the call for an hour.

Researchers should evaluate the relative merits and applicability of this methodology before selecting a given approach. Future expansion of this technology to incorporate video and other interactive components may ameliorate the concerns about non-verbal cues; however, overall, this was not perceived as a significant barrier by the participants. Increasing the quality of such communication technologies (e.g., better connections, less "noise") may also improve the use of this methodology. In conclusion, this often overlooked but rather straightforward communication technique opens up the opportunity for biomedical researchers to explore health topics (e.g., genetic testing) on a national scale, allowing for demographically diverse and broader geographic populations discuss sensitive topics such as donating biospecimens for the advancement of cancer prevention and treatment.

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