Conducting focus groups in Second Life® on health-related topics

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ABSTRACT

The "Mrs. A and Mr. B" research project uses focus groups conducted in the virtual world Second Life® to collect qualitative data on healthcare equitability as experienced by persons with and without disabilities. Novel methodological adaptations to traditional focus group methods include avatar consent, text discussion, participant advance preparation and disability accommodation. In this project, focus group findings are used to enrich and clarify results obtained from the analysis of a quantitative administrative dataset derived from Medicare data. In this article, advantages and challenges of using virtual world focus groups are highlighted.

1. INTRODUCTION

The "Mrs. A and Mr. B" project (www.healthcareequitability.org) examines disparities in healthcare from the perspectives of persons with disabilities. While disparities have been examined related to gender, racial/ethnic group, economic status and education level, less is known about the quality of healthcare received by persons with disabilities and the effects this has on their life outcomes. The "Mrs. A and Mr. B" project (Penn Medicine, 2013), funded by the Patient Centered Outcomes Research Institute (PCORI) in 2013, uses a mixed methods approach to address this question. A parallel mixed methods design is being used to quantify how access and quality of health care impacts the progression of disabilities and survival alongside a qualitative exploration of ways that people with and without disabilities experience healthcare in their daily lives. The quantitative portion of the study includes an in-depth analysis of ten years of administrative data from more than 30,000 adult Medicare beneficiaries. The qualitative arm of the study includes focus groups conducted in the virtual world Second Life®and in a face-to-face format. People with a wide range of disabilities add a stakeholder voice to the interpretations. The purpose of this article is to highlight the novel features of virtual world focus group functioning. Improved understanding of disparities related to disability from multiple perspectives may inform public policy and clinical practice.

2. FOCUS GROUPS IN VIRTUAL WORLDS

Traditionally, focus groups have been used in business for feedback on perceptions, attitudes, and opinions toward products or services being proposed or offered. During the introductory cycle of Second Life, when mainline businesses such as Nike and Nissan were exploring virtual worlds for traditional marketing purposes, virtual world focus groups were tried and found to be less effective than face-to-face market test groups, although some industry professionals still recommend them, with appropriate modifications. Focus groups are particularly useful when the purpose of the research is to observe in real time how participants interact around a given topic. The focus group facilitator creates a script with open-ended questions to guide the discussion. The role of the facilitator includes generating discussion, encouraging participation from all members, preventing monopolization by one individual and protecting all members from risks of breaches of confidentiality, premature disclosure or dysfunctional group dynamics. Recently, focus groups with an academic focus have been attempted in the virtual world Second Life. Stendal (2014) conducted usage studies with persons with disabilities to determine level of participation and interest in virtual worlds. Input into the Access Board's public commentary about accessibility of medical diagnostic equipment was collected from focus groups in Second Life (US Access Board, 2010). The "Mrs. A and Mr. B" project will hold 4-6 virtual focus groups regarding disability and healthcare during each of the three years of the study.

3. METHODS

A team-based approach to research involving multiple stakeholder groups is recommended in order to increase the likelihood of improving healthcare. The "Mrs. A and Mr. B" project team involves members from the University of Pennsylvania Perelman School of Medicine and the Virtual Ability community in Second Life. Stakeholders are involved in all aspects of the research. The project team has worked to adapt the focus group methodology to the virtual world setting. Novel adaptations include: tailoring focus group facilitator training to fit an on-line format in a way that accommodates all persons with disabilities, establishing recruitment and consent procedures that assure protection of confidentiality, avoid coercion and enhance opportunities for participation, and developing procedures to facilitate participation for persons with all forms of disability.

3.1 Focus Group Facilitator Selection and Training

Focus Group Facilitators are trained in the virtual world Second Life by project staff. Criteria for selection include having previous experience as a researcher using Second Life and having excellent written English language skills. Facilitators must be comfortable working with diverse people, able to think quickly in social situations, and willing to act with discretion regarding personal health information.

All current trainees and trainers are very familiar with communicating through an avatar in a virtual world, with no less than 62 months of experience. All staff participated in an online Collaborative Institutional Training Initiative (CITI) course ("Biomedical Research, Basic Course"). Facilitators received training specific to their role. Task-specific training includes generic focus group facilitation knowledge and skills for roles both as a focus group leader and as an assistant. Trainees develop knowledge of common virtual world disability-related accommodations. The final steps in facilitator training involve conducting mock focus groups with participants. The actions of the trainees are observed and evaluated by project staff. At the end of each training session, project staff debrief both the trainees and the mock participants, allowing further modification of the procedures to improve virtual world focus group processes.

3.2 Virtual World Focus Group Procedures

The project design includes both face-to-face and virtual focus groups. While these two types of focus groups cover identical content, the procedures for the two formats vary. Recruiting and consenting for participation in focus groups in Second Life is initiated through multiple means including the exchange of on-line Project Information notecards, the virtual world equivalent of text documents. The notecard presented to potential participants explains the research process and describes what research participation means to the potential focus group member. The information may also be provided orally in a group or individual setting. Project staff are available through instant messaging (IM) or email to answer questions before consent is obtained.

Potential participants give their consent by typing their avatar name of choice and the date on a notecard that is attached to the Project Information notecard. Demographic information (but not participant name) about the participant behind the avatar is maintained in a database separate from the focus group information. The necessity to obtain and type on this notecard and return it to a project staff member mitigates unintentional consent. These research protocols were approved by the University of Pennsylvania Institutional Review Board (IRB).

Focus group meetings take place in a secure location, 1000 meters in the sky above a Second Life island designated for research. (See Figure 1.) The virtual land that the meeting space is over can be made private so that only specified avatars (focus group facilitators, participants, and project staff) can enter the area. The virtual space is set up similar to a physical focus group space. (See Figure 2.)
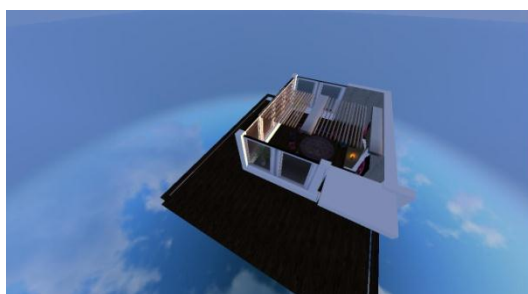

Figure. 1. *Focus Group Room floating far above virtual land surface.*

Figure 2. *Focus group session showing interior of virtual Focus Group Room and poster of topics to discuss.*

The focus group facilitator has the text of the focus group script on a notecard, from which individual segments can be copy/pasted into the text chat stream. This allows the facilitator to follow the IRB-approved script while still maintaining the flexibility to insert additional probes, clarifications, or other material as needed, akin to the flexibility of a face-to-face facilitator.

3.3   Progress to Date

As of the end of July 2014, three virtual world (Second Life) groups (11 participants) and one face-to-face group (5 participants) have been run. Transcripts from all focus groups are de-identified to remove all names and potential personally identifiable health data.

The Mixed Methods Research Laboratory at the University of Pennsylvania receives the de-identified transcripts, enters the transcripts into NVivo 10.0 software (a qualitative data management program) and applies codes to the transcripts in order to identify themes across focus groups. Initial analysis indicates emerging ideas of patients' perceptions about their healthcare. Trends include the importance of self-advocacy, the impersonal nature of doctor-patient interactions, and the lack of communication among healthcare providers indicating system fragmentation.

4. DISCUSSION AND CONCLUSIONS

Conducting focus groups in a virtual world setting requires some additional adaptations beyond those needed for face-to-face focus group facilitation. Both formats confront similar barriers: recruitment of an appropriate representative pool of participants, the need to support candor in participant responses, and concerns about privacy, confidentiality, and the potential for revealing personally identifiable health data.

4.1   Dealing with generic issues specific to virtual worlds (Second Life)

Within Second Life, it is possible to identify peer support communities of persons with disabilities from which to recruit a population similar to the population from which the quantitative Medicare data was drawn. The use of avatars to conceal actual identity has been known to increase candor (Broitman, 2007). Privacy is ensured by conducting the sessions in a physically isolated skybox. Two methods are employed to deal with concerns about personally identifiable data: collect demographic data on participants separately from their focus group contributions; and de-identify focus group transcripts before submission for analysis.

4.2   Novel features of virtual world functioning

Several significant adaptations occur because these focus groups are held in a virtual world. First, the consent process is significantly different from those in face-to-face groups, as described above in Section 3.2. Also, the focus groups are conducted entirely in text. Some individuals participating in focus groups require Americans with Disabilities Act (ADA) accommodations in order to participate. The participants experience some advance preparation.

The facilitator and participants communicate by typing rather than orally, as text is more readily accessible by most participants, including those who access their computers using assistive technologies. (See Section 3.2 above.) Individuals for whom typing or reading is impaired by their disability request accommodations ahead of time. We assign a typist for persons wishing to give their input orally. Similarly, a reader is assigned to persons who cannot see or read aloud the text chat. These helpers are all CITI certified.

Participants are given a notecard with the questions to be addressed when meeting arrangements are made. They are encouraged to type out responses to these questions on the notecard in advance, so that they can easily copy/paste them as appropriate. Of course they can also then type additional comments or responses to what others shared. Advance preparation accommodates those for whom typing is laborious, or who require additional time to think through their responses. It also allows more time for discussion, since spontaneous typed responses take more time to transmit than do spoken responses. Moreover, responses prepared in advance can be submitted after the focus group has been completed so that ideas that did not have a chance to emerge during discussion may still be captured.

4.3   Advantages of conducting focus groups in virtual worlds

The advantages and disadvantages of collecting qualitative data through face-to-face focus groups are well documented. Virtual world focus groups have somewhat different advantages and disadvantages.

For the "Mrs. A and Mr. B" project, the major advantage of conducting focus groups in a virtual world is that it allows much easier access to our target audience—people with disabilities. People with disabilities make up a

significant portion, perhaps as high as 20% (Information Solutions Group, 2008), of those in virtual worlds. In virtual worlds, they can participate more freely in public events such as focus groups. In a virtual setting, they do not face logistical issues to attend meetings, such as transportation or the need for meeting organizers to provide medical or assistive technology equipment. Additionally, international participation is much easier, and the facilities for conducting research in virtual worlds are inexpensive. The existence of dialog as text is helpful, as no transcription is necessary.

4.4   *Disadvantages of conducting focus groups in virtual worlds*

One disadvantage of conducting focus groups in a virtual world is that the population accessed must be both computer literate and possess a high-end computer. This population is not representative of disabled people at large, nor is it representative of the population in the Medicare administrative dataset that we are using in the quantitative arm of the project. To mitigate this in the "Mrs. A and Mr. B" project, we include face-to-face focus groups with members of an urban community who have lower literacy skills and are not computer users.

Avatars do not provide nonverbal information such as gestures or tone of voice. These sources of information, often gleaned from face-to-face focus group meetings, are missing, but with the topic we are interested in, we feel that this is less important than the text content.

4.5   *Conclusion*

Overall, the advantages of using virtual world focus groups outweigh the disadvantages. People with disabilities like to help others and wish to give back to their communities. Many participants welcome the ability to be able to be heard in a forum in which issues about which they care deeply are discussed. The focus groups held in Second Life effectively involve them in academic research. The "Mrs. A and Mr. B" project is demonstrating the utility of this novel method of collecting qualitative healthcare data.

With increasing use of virtual worlds for product design, testing, and prototyping, as well as educational and therapeutic endeavours, collection of data by focus groups in virtual worlds will also increase. To fully leverage the unique affordances of a virtual world setting, typical face-to-face focus group protocols must be modified (Houliez and Gamble, 2012). Therefore our experiences with focus groups for the "Mrs. A and Mr. B" project can help improve the quality of data collected in future virtual world projects.

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