

BRIEF REPORTS

Expanding Participatory Data Analysis: An Innovative Strategy for Engaging Community Advisory Board (CAB) in Qualitative Research Data Analysis Virtually

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This brief provides an innovative and practical manner in which to better engage community advisory boards (CABs) with data analysis. A growing number of scholars are interested in better integrating the community into the data analysis of community based participatory research, community engaged, and/or participatory action research. Participatory data analysis with the community is a critical way diverse communities with lived expertise can inform analysis and interpretation of data grounded in community's voice, perspectives, and meanings. We describe the cervical cancer project, whereby a community advisory board (CAB) was integrated into qualitative data analysis starting by focusing on the codebook, an integral part of data analysis. This brief provides three specific ways in which participatory qualitative analysis can improve the manner in which research engages the community. We outline one opportunity for scholars to actively engage community partners virtually in the data analysis using the codebook with specific strategies to facilitate participation. We encourage researchers to consider these strategies for disruption when re-thinking the practice of CBPR especially during the analysis stage particularly when it comes to research with black, indigenous, and other people of color (BIPOC), under-represented, or marginalized communities with limited English, literacy and/or education levels.

INTRODUCTION

There are several approaches to engage the community in research including Community-Based Participatory Research (CBPR), Participatory Action Research (PAR), Community-Based Participatory Action Research, Community Engaged Research, among others (Balls-Berry & Acosta-Pérez, 2017; Vaughn & Jacquez, 2020; Wallerstein et al., 2017). These approaches share core principles of elevating and engaging with the community to enhance the impact and rigor of the research (Holkup et al., 2004; Israel et al., 2020). The ultimate goal is to develop research methodologies where investigators partner with community members (e.g. youth, patients, marginalized communities, consumers) - providing them with ownership, perspective, and expertise in the scientific process. As a research community, we have increasingly recognized the importance of integrating community

involvement ideally *at each* stage of the research: partnership, design, data collection, analysis, dissemination, and subsequent action (Vaughn & Jacquez, 2020). A plethora of research on partnerships have merged across the nation with several integrating careful reflection and assessment of their diverse partnerships (Boursaw et al., 2021; Taffere et al., 2024; Wallerstein & Duran, 2010). Despite the growing interest and engagement, few scholars engage the community in *all* phases of the research process, particularly with regards to the data analysis stage (Cashman et al., 2008).

Community and participatory data analysis has often been a challenging area for many projects and scholars. Despite the intention to involve the community at every stage of a research initiative, community partners engage in data analysis and interpretation far less frequently than in other phases, often due to varying levels in ability, time, and resources. This results in missed opportunities for community members, regardless of their educational background or research experience, to engage with data analysis beyond being involved in the data collection or recruitment. This paper describes our innovative community-engaged analysis process and offers lessons learned and concrete strategies for other teams to engage the community more holistically and comprehensively in the data analysis stage.

Overview of the Cervical Cancer Case Study for Innovative Participatory Data Analysis

The Cervical Cancer Project's goal is to uplift the diverse experiences of middle to older age Latina women diagnosed with cervical cancer. Cervical cancer disproportionately impacts Latinas (Austin et al., 2002; Heintzman et al., 2018; Zeno et al., 2022). Our team is comprised of five women of color including two Latina undergraduate students, two master level research assistants, and the PI, a bilingual 1.5. generation Latina. Using the Database of Individual Patient Experiences (DIPEX) Methodology, which is described elsewhere in detail (Herxheimer et al., 2003; Ziebland & McPherson, 2006), we conducted 60-90-minute audio and video recorded patient interviews. We worked with a diverse community advisory board (CAB).

CAB members were either self-selected, invited, and/or were referred for participation. We presented the project to multiple community organizations and recruited from nearly twenty community events inviting folks to be part of this group. The CAB is composed of 15 members, representing a multi-community with intergenerational perspectives across the lifespan. This includes community members, undergraduate students, graduate students in medicine, clinical faculty, researchers, former participants of the project who were interviewed, as well as government sector representatives and staff from various community healthcare centers. Approximately 80% of CAB members speak Spanish, 50% identify as Latina and/or immigrant, and 30% have personal or familial experience with some type of cancer. Given the

diverse background in research and education levels among CAB members, we drafted an agenda that fostered connection between the entire community and the project (see Appendix I).

The CAB was invited to participate in a data analysis meeting scheduled for 3 hours, allowing ample time for meaningful engagement. During this meeting, we employed three focused strategies to ensure successful community participation in data analysis. We first built community rapport through creating psychological safety. Second, we established a common language for qualitative data analysis by leveraging common social media language. Third, we utilized a dynamic visualization board to keep the community engaged throughout the process. Our stakeholder community group convened on July 14th, 2023, to participate in a data analysis activity. The community had previously met twice to provide feedback on interview instrument and recruitment strategies. As an established group that had guided the project over the past year, the CAB was well position to contribute to this third gathering where the primary goal was to inform the data analysis by providing direct input on the codebook. About ¼ of the transcripts have been analyzed in NVIVO that informed the development of the codebook presented. During this meeting that was in English, the CAB's role was to review the codebook presented in both English and Spanish at a third grade reading level to answer what might be missing, what they liked, and what was unclear.

Strategy 1: Building a Psychologically Safe Virtual Space

We informed the CAB from the outset that they would be involved in all aspects of the research process for this project. Each time we met we focused on a specific part= of the research process. The goal was to ensure their voices and perspectives were included, regardless of their individual background or comfort level with research. We are aware there are often negative and strong emotional reactions among students and faculty, let alone among non-academic communities, with regards to “data” “research” or “analysis.” Therefore, to address this real and perceived unequal power dynamics among this diverse group of community advisory board (CAB), we continued to intentionally schedule additional time at the beginning of every meeting, building rapport with an activity that would: a) increase vulnerability b) demonstrate safe space, and c) normalize being on a growth edge (Brown et al., 2020; Wennerstrom et al., n.d.). They were all compensated for their time on the CAB.

At this third gathering, we engaged in an activity called: *What Do You Carry with You?* Each person shared an item that they carried with them in their purse, pocket, and/or near them to share with the team. We had people share a meaningful painting behind them passed down in their family; we had others share a picture they carried in their wallet of their family members.

This activity invited learning about each other and about our family and history as well. This set the tone for our gathering by establishing emotional psychosocial safety.

Strategy 2: Leveraging social media organizational structures

Because data analysis is less familiar to many of the CAB members, we took extra care and effort to ensure everyone was speaking the same language. After setting the tone, we guided the community into data analysis jargon. While our team first provided an overview of qualitative analysis and coding definitions as well as an example of the software used (NVIVO 14), we took the additional step of translating qualitative research analysis jargon to common everyday real-world experiences. We intentionally used the term “hashtag” instead of coding and gave an example of posting a picture on Instagram or Facebook. For example, we communicated with the group, “On social media, to describe a picture, we use hashtags, to categorize and describe that photo. So, in parallel we do the same with codes and the transcript data.” This guided the stakeholder group into reflection and conversation with each other on the coding tree, allowing them to provide feedback and co-create. Our team felt strongly that starting with the codebook was the ideal entry point for data analysis (Ando et al., 2014; DeCuir-Gunby et al., 2011). Codebooks serve as the guiding map for analysis, and by re-purposing the term “hashtag,” we were able to effectively convey our goal for today: reviewing the codebook and providing feedback that informs data analysis.

Their feedback on the codebook could significantly influence the direction of the analysis and shape the themes that emerge. By involving CAB members in the coding tree development process, we facilitated their active participation in data analysis in a less intensive manner such as learning to line by line code. Using the term “hashtag” helped enable their understanding of the codebook, allowing them to provide more effective feedback. The approach helped the CAB conceptualize how the codes would generate relevant information, which would then serve as the foundation for interpretation and the generation of themes.

Strategy 3: Utilizing visualization software for dynamic review of codebook

During our 3-hour meeting we innovatively utilized a platform called Miro board to engage the CAB members. A coding tree or codebook is defined as the categories used to organize and analyze data in a qualitative study. Coding trees are often created using inductive and deductive processes. Inductive consist of reviewing the data to ensure the voices of the participants guide the development of the coding tree. Deductive or a-priori processes consist of reviewing the literature to ensure the already well-established patterns and/or themes that are part of the evidence-based research. The research team reviewed all 22 transcripts, coded ¼ of them, and engaged with the literature over a 3-month period to ensure we came up with a comprehensive list of

both deductive and inductive codes. We condensed the list and brainstormed ways to share with the stakeholder community in a manner that was open to co-creation and co-refinement of the code book.

Miro board allows for an interactive and visually appealing presentation of the coding tree (see Figure 1, 2 and 3). For the community data analysis portion, we shared two versions of the coding tree and provided examples of a de-identified transcription section from actual participants in this study to illustrate how the coding tree is applied. CAB members were invited to navigate to the Miro board and review the codebook together. We stayed in a larger group rather than divide up into smaller groups for the sake of time. Although CAB members had the option to add and rearrange items on the Miro board themselves, they chose instead to engage in an open discussion about what they were observing, while my team made the changes and edits as we discussed.

While other researchers have involved community members in the actual analysis of the text (see Jackson, 2008), we focused on including them in the creation of the categories that inform the analysis. Overall, their involvement led to four concrete changes. The first was the addition of three new parent code around family history and family experiences with cancer, cervical cancer knowledge and education, and a code focused on stigma and shame. The second was the addition of fertility/family planning under the impact code and non-formal interpersonal relationship under social support as well as adding money financial under cervical cancer journey factors. The final change was the addition of children and other non-formal interpersonal relationships under social support as important subcode to capture.

Despite having limited time, different technology background, and a diverse linguistic and educational background CAB, the three strategies utilized facilitated an active and fruitful discussion on the codebook informing analysis (See Appendix II).

CONCLUSION

Involving the community in data analysis can seem to be overwhelming, excessive, or impossible. However, we facilitated community engagement by using the codebook and presenting it in everyday language, incorporating hashtag with visuals. We are just beginning to explore how to effectively involve the community into qualitative data analysis (Hess et al., 2022). What is clear is that their insights and modifications to the codebook can significantly influence the direction, perspective, and content that we, as a research team, focus on during the more formal traditional coding process in NVIVO. It is not necessary to train community members in NVIVO or have them line-code the transcripts to capture their voice. By inviting their input through the codebook, we can engage them in a direct and meaningful manner. The next step will be to return to the CAB with the emerging themes to refine the outcomes of our in-depth analysis. This process could also include evaluating their experiences in this collaborative effort.

Figure 1: Miroboard visual of main 16 parent codes.

1.Latinidad: Includes the common and shared beliefs, morals, thoughts, and experiences in the Latina community. This also includes the focus and/or any mention on assumptions, roles, beliefs, attitudes of Latina women.	2.Sexuality: Any and all mention about their upbringing and/or values, attitudes, as well as knowledge and experiences with sex and sexuality.	3.Preventative and Screening CC Services: Behaviors as well as values, attitudes, and knowledge around exams, vaccines, shots, lab tests, specifically PAPs and HPV testing. Any before and after changes with cervical cancer specifically.	4.CC Diagnosis: Any and all discussions about the actual diagnosis process and/or experience.
5.CC Treatment: Includes experiences and understanding of treatment; side effects; unexpected events/complications (infections, allergic reactions, etc.); experiences with surgery and aftercare.	6.CC Impact*: Any and all physical as well as emotional and/or psychological.	7.Health Care System: Interactions, experiences, and/or perceptions with the HCS both positive and negatives.	8.Coping with CC: Discussion of hobbies, self-care, and mechanisms used to overcome struggles and difficulties.
9.Social Support*: Both positive and negative as well includes descriptions of relationships with others including impact of dx and tx on relationship, support, and challenges to that relationship. Discussion of their our cancer journey too that may or may not have helped participant.	10.CC Journey Factors*: Includes discussions of immigration status, distance to treatment, racism, neighborhood, language, insurance, childcare, etc.	11.Surveillance/Survivorship: Focuses on the health and well-being of a person with cervical cancer from the time of dx until the end of life.	12.Violence: Any and all experiences of trauma and/or abuse as a child, adult, and/or related to CC if at all.
13.Interventions: Any ideas or suggestions to effectively increase screening and reduce late diagnosis among Latinx women for cervical cancer.	14.Lessons/Messages*: Includes personal takeaways from cancer dx as well as descriptions of what they would like other folks to know about it.	15.Key Quotes: Message or phrases or terms that are moving, insightful, and/or powerful.	16.Uncertainty for Coder: Passages where we are not clear but know it is substantive (as a team go back and decide on this code, make a note in the memo on this too for now)

Figure 2:

Miroboard visual of 16 parent codes and their sub-codes.

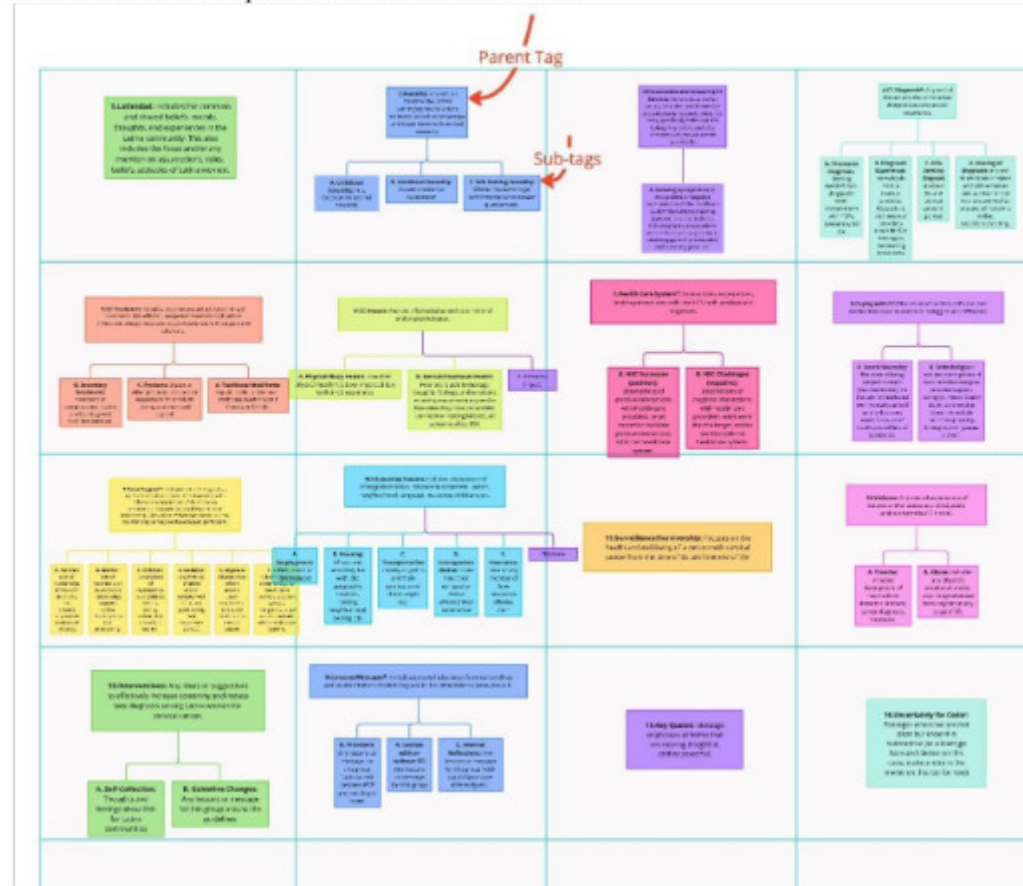
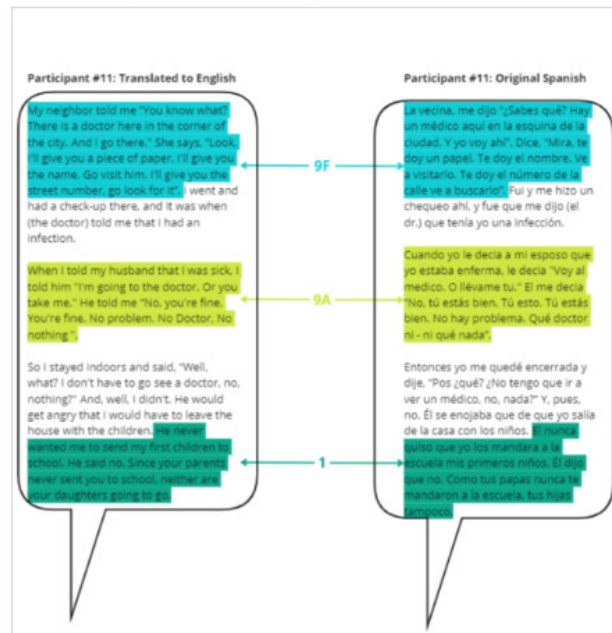


Figure 3:

Miroboard example with Participant 11 using codebook.



We hope other community-centered projects can learn and implement more innovative qualitative community data analysis techniques that engage community members. While progress has been made, more work is needed to fully involve community partners in all aspects of the research (Cashman et al., 2008; Jackson et al., 2018). We shared one innovative approach in which community partners can in an important part of qualitative data analysis, rather than being limited to validity and reliability checks. While some studies involve the community in creating the categories, that can be time consuming. Input at the codebook level is also critical: inclusive, community stakeholder-informed codebooks can significantly change the direction and outcomes of data analysis. Importantly, community members do not need to learn NVIVO to be part of data analysis. They can still play a crucial role in guiding and informing the themes that emerge from the research findings by actively participating in decisions about which codes are applied during line-by-line analysis. The diverse roles and skills of the community members - whether students, patients, clinicians, or academics- complement each other. We suggest that including CABs in refining the codebook enhances the data analysis process, ultimately enriching the insights and findings.

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Conflict of Interest

None

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Supplementary Materials

Appendix I

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Appendix II

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