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Community-Guided Focus Group Analysis to Examine Cancer Disparities

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Abstract

Background—Accountability for Cancer Care through Undoing Racism and Equity (ACCURE) is a systems-change intervention addressing disparities in treatment initiation and completion and outcomes for early stage Black and White breast and lung cancer patients. Using a community-based participatory research approach, ACCURE is guided by a diverse partnership involving academic researchers, a non-profit community-based organization, its affiliated broader-based community coalition, and providers and staff from two cancer centers.

Objectives—This paper describes the collaborative process our partnership used to conduct focus groups and to code and analyze the data to inform two components of the ACCURE intervention: 1) a "power analysis" of the cancer care system, and 2) the development of the intervention's training component, Healthcare Equity Education and Trainings, for cancer center providers and staff.

Methods—Utilizing active involvement of community and academic partners at every stage in the process, we engaged Black and White breast and lung cancer survivors at two partner cancer centers in eight focus group discussions organized by race and cancer type. Participants were asked to describe "pressure point encounters" or critical incidents during their journey through the cancer system that facilitated or hindered their willingness to continue treatment. Community and

academic members collaborated to plan and develop materials, conduct focus groups, and code and analyze data.

Conclusions—A collaborative qualitative data analysis process strengthened the capacity of our community-medical-academic partnership, enriched our research moving forward, and enhanced the transparency and accountability of our research approach.

Introduction

A core principle of community-based participatory research (CBPR) is for community and academic partners to be equitably involved throughout all stages of the research process.[1,2] In many research projects, however, community members are more involved in data collection and less involved in data analysis.[3,4,5,6,7] Not being involved in data analysis excludes the diverse expertise of community members from key interpretation decisions[5,7] and affects partnership transparency and accountability. There are benefits of including community members in the data analysis, such as increasing the communities' capacity to undertake research and evaluations.[1,3,4,5] Community members can provide context to the data[3] to enhance academic researchers' understanding of the issues. Participating in the analysis may deepen communities' understanding of the problems, which helps them make more informed decisions when designing and implementing action steps and interventions to address the complex issues affecting their health.[3,5] Some CBPR studies have provided opportunities for community partners to collaborate on data analysis and interpretation; ranging from informal data analysis using imagery and facilitated discussions to training community members in qualitative analysis skills, such as reading, coding, and analyzing transcripts.[3,4,5,6,8] To make data analysis and interpretation accessible for all partners, it is critical to combine traditional data analysis techniques with methods tailored to each community.[3,4,5,6,8] This paper contributes to this emerging body of literature by describing collaborative data analysis process and interpretation procedures, developed by our CBPR partnership for conducting Accountability for Cancer Care through Undoing Racism and Equity (ACCURE).

Partnership Approaches to Address Cancer Disparities

ACCURE is a systems-change intervention addressing disparities in treatment initiation and completion that result in poorer health outcomes for early stage Black breast and lung cancer patients than for White. Guided by principles of CBPR, ACCURE builds on a longstanding community-academic partnership, the Greensboro Health Disparities Collaborative (GHDC) (www.greensborohealth.org), a broad-based community coalition involving academic researchers from the University of North Carolina at Chapel Hill (UNC-CH) and affiliates of an anti-racism training organization, The Partnership Project (TPP), by including as partners the providers and staff from two cancer centers. Undergirding both GHDC and ACCURE is a commitment to the language, history and principles of Undoing Racism™ (www.pisab.org), a framework that facilitates critical analysis of structural racism; focusing on the concepts of institutional "transparency" and "accountability" as mechanisms of systems-change. All GHDC members and ACCURE investigators are required to attend an

antiracism training based on the Undoing Racism™ approach, to ensure a common language and lens for examining racial disparities in the healthcare system.

GHDC has met monthly since its 2004 founding, with and without funding, and has developed infrastructure to support its mission, govern its partnership, and advance equitable decision-making in research.[9] GHDC's first CBPR project was Cancer Care and Racial Equity Study (CCARES), which used a novel data collection procedure, called Critical Incident Technique interviewing, to explore whether Black and White women with breast cancer received the same cancer treatment and, if not, determine the differences and possible reasons.[10] Our second study, ACCURE, is informed by the findings from CCARES through:

1. Extending GHDC membership to include the healthcare institutions involved as partners in ACCURE.

2. Applying Undoing Racism™ concepts to design components of the ACCURE intervention.

3. Developing and implementing a community-guided focus group data analysis procedure.

Objectives

Findings from focus group interviews with patients who completed their care within the past year were used to inform two components of the ACCURE intervention: 1) a "power analysis" of the cancer care system, and 2) the development of Healthcare Equity Education and Trainings (HEET) for cancer center providers and staff. The goal of ACCURE's "power analysis," a concept drawn from Undoing Racism™ was to illustrate the path patients navigate from diagnosis through surgery, treatment, and return to the community from the perspectives of Black and White breast and lung cancer survivors. The "power analysis" also assisted with identifying issues in the cancer care system that may have resulted in unequal treatment. We engaged twenty-seven survivors in eight focus groups organized by race and cancer type. The purpose of this report is to describe the CBPR procedures used to equitably involve community, academic, and healthcare providers in analyzing the focus group data.

Methods

Our collaborative designed an inclusive, intentional analysis process that explicitly addressed racial equity and power sharing between community and academic partners. As in all aspects of the ACCURE study, we developed each step in this process to reflect the principles of CBPR and Undoing Racism™, including the use of a flexible timeline to accommodate the CBPR process. The focus group protocol described here received approval from the two Institutional Review Boards (UNC-CH and University of Pittsburgh) overseeing the ACCURE study.

1. Focus group development

In Table 1: Focus Group Process, steps 1–8 enumerate the active involvement of community and academic members of the GHDC in all stages of planning and execution of the focus groups. As a first step in launching our qualitative data analysis process, GHDC members

were offered an alternate human subjects research ethics training, developed and approved by UNC-CH's Institutional Review Board for non-traditional investigators.[11] This training provided a community-friendly set of slides that covered the human subjects protections content of web-based Collaborative Institutional Training Initiative and was delivered by an ACCURE co-Principal Investigator (co-PI) with examples that were specific to the ACCURE study. Twenty-six GHDC participants completed the training, indicating strong community interest in contributing to qualitative data analysis.

A GHDC committee, including community, academic, and healthcare system representatives, led the development of the focus group guide and of a visual chart of the cancer care system to post during focus group interviews to facilitate discussion. Both were then refined by the entire GHDC.

The GHDC guided the selection of focus group moderators and supervised their practice in piloting the script and diagram in a mock focus group with five volunteer breast cancer survivors from Sisters Network Greensboro, an African American breast cancer survivorship organization.

Male and female focus group participants were recruited from our partner cancer centers and organized by race and cancer type: 1) Black breast cancer, 2) White breast cancer, 3) Black lung cancer, and 4) White lung cancer. To be eligible, participants must have completed treatment for stage 1–2 breast or lung cancer in the previous twelve months. A Black moderator facilitated the focus groups with Black patients at each center, while a White moderator took notes. They reversed roles for the White focus groups. We audio-recorded and took field notes at each focus group session and recordings were transcribed verbatim for content analysis.

2. Coding process

The remainder of Table 1–Focus Group Process, steps 9–13, shows the timeline and participation from academic and community members of the GHDC in coding and analysis of the transcripts. The Coding Coordinating Team (CCT) that included the lead community partner from TPP, the academic partner overseeing ACCURE's process evaluation, and a research assistant (RA) developed a step by step explanation of the basic method for coding and retrieving relevant text from transcripts.[13] The inclusion of a CCT, a departure from conventional coding methods, was designed to oversee collaboration with the broader GHDC, ensure that both academic and community perspectives were involved in coding the transcripts, and interpreting meaning of retrieved coded text.

Prior to launching the coding process, the CCT developed and conducted training with GHDC members to provide an overview of qualitative analysis, and the specific goals and proposed uses of this analysis for the ACCURE study. The presentation described focus group analysis, differences between topical and interpretive codes, procedures for identifying text relevant for each specific code and interpreting themes from coded text. The CCT proposed a modified code and retrieve method that would be consistent with ACCURE principles on ensuring transparency and accountability, as described below.

Sixteen volunteers from the GHDC were organized into biracial community-academic coding pairs to analyze an assigned focus group transcript. Matching coders was an intentional process not typically done in conventional coding and retrieving procedures. The lead community partner on the CCT, a founding member and secretary of the GHDC, carried out this matching since she was familiar with all members. To prioritize diverse perspectives, she matched pairs with consideration of race, experience (academic/medical/community), personality style (to avoid having one person's voice overpower another), and length of involvement in the GHDC (to match long-timers who knew the GHDC's history and have been steeped in antiracism principles with newcomers to ensure that these principles were at the forefront of the process).

Each coding pair was assigned one transcript to review together to agree on the assignment of *topical* codes, developed directly from the focus group guide prior to the analysis, and on the creation and definition of *interpretive* codes, which emerged from the coders' reading of the transcripts. The initial codebook provided to coding pairs is found in Table 2: Codebook, with subsequent changes added in italics. This was a six-step process:

1. Each pair member read the transcript independently before coming together to review and discuss the stories and experiences participants shared.

2. Each pair member applied a second independent reading to focus on and answer five guiding questions: What are recurring themes? What is similar about people's experiences? What is different about people's experiences? What information is missing? What should have been asked?

   This information was recorded in Summary Table A, with a column for each member of the pair to record their answers.

3. Different from conventional coding and retrieving, the pair discussed their respective answers to these questions before assigning codes to the transcript text to allow each pair member the opportunity to acknowledge similarities and differences in their perspectives, come to agreement on assigning topical codes, and begin defining interpretive codes that represented their different perspectives. For example, one community coder with a history of breast cancer recognized emotions of feeling "empowered" or "disempowered" that were expressed in the transcript during doctor appointments, blood work, chemotherapy, radiation, and unexpected hospitalizations. After discussing her perspective with the academic coder, both were better able to: 1) interpret the topical codes related to decision-making and side effects, 2) identify and define new interpretive codes related to insurance/billing and treatment completion and aftercare, and 3) apply codes to the transcript. Thus, coding by community-academic pairs contributed to deeper understanding of concerns expressed by the focus group participants.

4. Each pair member carried out a third reading to independently assign topical and interpretive codes and sub-codes to the text by completing

Summary Table B, created from the codebook to assist with organization of individual and group findings by allowing side by side comparison of the codes and text lines each person had designated.

5. The pair reconvened to discuss their respective assignments of each code and sub-code to the text and reach consensus. For example, for the code, "Discouraged Continued Treatment," an academic coder identified one instance of relevant text, whereas a community coder identified ten instances. Discussion of this discrepancy revealed that the academic coder applied this code to patient-doctor interactions only. The community coder also included conversations among patients waiting for appointments about lack of information regarding transportation and billing errors. When the pair shared their rationales for coding, they came to consensus on ten instances that reflected "Discouraged Continued Treatment."

6. Finally, each pair reached consensus on the definition of interpretive codes and sub-codes utilizing the language of the focus group participants. For example, Black members of several coding pairs stressed the need to add a separate category that captured family and spiritual support systems as facilitators, so we added the interpretive code "Empowering from natural/cultural/social supports."

In summary, deliberate diverse pairing of coders enhanced their ability to identify and define interpretive codes.

3. Analysis and Generation of Emerging Themes

Because the focus group interview transcriptions were completed and sent to the coding pairs at different times, CCT modified the coding procedure based on feedback from early coders with suggested additional codes, recommended revisions to the instructions, and two summary tables (A and B as referenced above) to help coders organize their findings. The recommended changes added clarity for the community members who were coding transcripts for the first time.

Upon receiving each group's coding summary, RAs entered coded text lines into ATLAS.ti Version 7 and prepared code reports from each focus group session. The CCT reviewed the code reports and created a consolidated codebook (see Table 2: Codebook) with input from the co-PI, an RA, and the ACCURE Project Manager. This represents a departure from conventional methods to facilitate a smooth transition from interpreting findings to their application to the ACCURE intervention. Using this codebook, the combined team worked in face-to-face meetings to summarize and interpret the meaning of the codes within, as well as across, race and cancer type to generate preliminary themes for further refinement with the GHDC. The transcripts from cancer center A were completed and the analysis begun before the transcripts from cancer center B were complete. The comparative analysis was an iterative process during which lessons learned from the analysis of cancer center B were used to revisit the findings from the transcripts of cancer center A, and vice versa.

4. Development of the Power Analysis and HEET Curriculum

The CCT presented emerging findings to the GHDC, including cancer center administrators and staff, who provided feedback and shared their perspectives on incorporating these findings into the HEET by brainstorming questions which could be posed to the staff to convert patient concerns into system changes. The GHDC suggested that the CCT pinpoint critical incidents that might be related to differential treatment by race, utilizing the language of "Critical Incident Technique" derived from our CCARES research. For ACCURE we defined *critical incidents* broadly to include positive and negative, major and minor events that stood out as meaningful to the focus group participants, as well as occurrences that CCT members interpreted to have had an impact on care. We added more GHDC members to the CCT, with experiences and perspectives relevant to potential critical incidents (e.g., former cancer patients, medical providers, etc.). We devised an iterative, three-step critical incident analysis process:

1. We discussed what created a critical incident, and whether individuals, healthcare system processes, or both, had contributed to its occurrence.

2. We revisited the manner in which the text was coded and reviewed the different ways the incidents had an impact on patients and on their care.

3. We visually mapped where incidents had occurred on the cancer journey diagram, using a different diagram for each focus group and color-coding positive and negative events. This provided a visual tool that facilitated comparisons of participants' collective experiences across race, cancer types, and cancer centers.

This in depth analysis, made possible by our collaborative process, was critical to understanding the "pressure points" encountered by cancer patients during treatment, and to revealing subtle but important differences as experienced by Black and White patients. Pressure points can be incidents that either discourage patients from continuing care or encourage them to continue care. For example, one patient was deeply encouraged when a physician of another race took her hand and talked to her about faith. Another patient was tempted to discontinue her radiation treatments prematurely because of the severe side effects and a callous response by the doctor supervising her care. The ACCURE intervention is integrating these findings on critical incidents into specific sessions of our Healthcare Equity Education and Training to engage cancer center staff and providers in discussing the pressure points identified by patients and ways to change the system to improve treatment outcomes.

Lessons Learned

CBPR co-investigators have been struggling to find meaningful ways to engage community partners in all phases of the research process, particularly the data analysis phase[3,4,5,6,7]. For ACCURE, identifying pressure point encounters within a cancer care system required full involvement of community, academic and medical partners in collecting, analyzing, and interpreting focus group data, and then applying the findings to our systems-change intervention. Our use of coding pairs for the analysis and the CCT for interpreting the

themes through an iterative process illuminated four key lessons that strengthened our collaborative approach to data collection and analysis:

1.   CBPR recognizes the value and expertise that all partners contribute,[2] but it is critical to build community capacity to facilitate equitable participation in research.[8] Similar to previous studies,[6,12] we found that some community partners considered the academic partners to be the "experts" in qualitative data analysis and therefore, better suited to lead and complete this step in the research process. Given this dynamic, it was important to develop a process to enable GHDC members with diverse perspectives, training, and experiences to work in tandem on data analysis and interpretation. The in-depth training on coding was useful as conceived, but strengthened considerably over time with refinements suggested by non-academic members of the GHDC, resulting in a clear instructional guide, a timeline to help move the process forward, and summary tables to assist with capturing the coded data.

        The careful matching of coding pairs enhanced the success of the process and different perspectives offered within each pair enriched the interpretation. Our protocol for matching coders was refined over time. We initially used four coders in two pairs who then came together. The process was unwieldy and did not add significantly to the analysis, so we utilized two coders for our second set of transcripts. Thoughtful planning and our flexibility to refine and improve the process as it unfolded put all partners at ease about qualitative analysis and increased the community partners' confidence with coding data. We are incorporating this qualitative data analysis method into a NIH Diversity Supplement we were awarded that will conduct focus groups with an additional breast cancer patients. With the lessons we have learned, we will be able to adapt the community-guided analysis process described in this paper to learn more about racial differences in breast cancer patients' experiences with pain and symptom management.

2.   Allotting sufficient time to complete the data analysis process was essential for full community participation. The project timeline required multiple revisions to allow for participation of all partners. As noted by Kieffer et al.[8] strict, inflexible research timelines do not respect the time commitment and constraints of community or academic partners. The atmosphere of responsiveness and an efficient, yet flexible timeline for completing the analysis promoted a space where everyone's feedback was valued and members chose their own level of commitment.

3.   Acknowledging community members' unique perspectives and establishing specific ways they could contribute to the research process created opportunities for all partners to shape the analysis and contribute to the interpretation of the data. Careful selection of pairs that acknowledged personality, as well as race and community or academic

standing enhanced the conversations. This collaborative approach ensured that all partners were involved in deciphering and identifying key concepts within the data, while holding each other accountable to the aims of the research and to the cancer care systems examined for ACCURE.

4. The ACCURE study is unique in weaving together Undoing Racism™ and the CBPR approach to design and test a new systems-change intervention for narrowing the gap in Black and White breast and lung cancer patients' quality and timely completion of treatment. Our collaborative's commitment to both CBPR and Undoing Racism™ provided a solid foundation for ongoing partnership, and enabled us to have a common language to discuss the findings from the qualitative data. CBPR and Undoing Racism™ also provided a lens to examine the critical incidents in the cancer journey from a racial equity perspective, and identify how components of the cancer care system worked together to promote (or against one another to inhibit) healthy outcomes among cancer patients. Our CBPR approach, bolstered by Undoing Racism™ framework, provided our partnership with a complex yet meaningful perspective to push forward current dialogue around cancer diagnosis, treatment, and care in eliminating racial inequities.

Conclusion

The qualitative data analysis process described here strengthened the capacity of our community-medical-academic partnership, enriched our research moving forward, and enhanced the transparency and accountability of our research approach. Through this process our partnership has become increasingly comfortable with holding each other accountable and ensuring that all partners' expertise and voices are acknowledged in every aspect of our research process. Recognizing the importance of sharing our lessons learned with other researchers, we have formally discussed our collaborative analytic process on three different occasions: 1) a two-day CBPR workshop offered through the Qualitative Research Summer Intensive; 2) a workshop with faculty at the University of North Carolina at Wilmington; and 3) a graduate course on CBPR at the UNC-CH. Our goal is to continue to adapt our data analysis process to future projects and build on the strengths of all members of our partnership to deeply analyze our research data from both CBPR and Undoing Racism™ lenses.

We are fortunate to have a partnership that has worked together for more than eleven years, but we believe that the iterative nature of this process, including a clear outline of the steps, would lend itself well to a newer CBPR partnership. Pairing community and academic partners allows for co-learning that enhances the interpretation for all parties and may lead to more nuanced and comprehensive qualitative findings. Finally, the details of our systematic procedure can add to the growing literature on how to tailor conventional qualitative data analysis methods to make optimal use of the multiple perspectives and experiences, inherent to CBPR partnerships.

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Table 1

Focus Group Process

Activity	Date	Participants	
Location		Academic	Community
1. Human Subjects Ethics Training	10/12, 12/12	7+ PI, PM	19
2. Development of focus group guide	7/12–11/12	2 + SC	4
3. Development of journey diagram	9/12–1/13	1 + SC	3 + SNG
4. Selection of focus group moderators	1/13–2/13	2	4
5. Mock focus group with SNG	2/13	3	3 + SNG & 2 Mod
6. Focus group recruitment			
Cancer Center A	4/13–5/13	2	0
Cancer Center B	8/13/-9/13	2	0
7. Conduct of focus groups			
Cancer Center A	4/13–5/13	4	3+ 2 Mod
Cancer Center B	9/13	2	2 Mod
8. Transcription - CCA & CCB	4/13–10/13	2	
9. Development of coding process template (later revised by GHDC)	5/13	2 + SC	
10. Qualitative Analysis Training	6/13	8	16
11. Coding of transcripts by community-academic pairs			
Cancer Center A	6/13–9/13	8	8
Cancer Center B	12/13–2/14	4	4
12. Analysis of transcripts			
Cancer Center A	9/13–6/14	5	3
Cancer Center B	2/14–6/14	6	1
13. Presentation of analysis to GHDC			
Cancer Center A data	11/13	1	1
Cancer Center B data	3/14	1	1
Combined data	6/14	1	1

Throughout the project, regular monthly GHDC meetings were held and project activities were discussed and modified by consensus of the Collaborative. Simultaneously, the steering committee conferred weekly to ensure that the process was carried out as planned.

SC – Steering Committee

CCA – Cancer Center A

CCB – Cancer Center B

SNG – Sisters Network Greensboro

GHDC – Greensboro Health Disparities Collaborative

PI – Principle Investigator

PM – Project Manager

Mod – Moderator

Table 2

Codebook

Code: Topical and Interpretive • Sub-Code Name	Code/Sub-Code Definition
Why Cancer Center A/B?	Events, conversations, thoughts, or actions that led them to start cancer treatment at Cancer Center A/B.
• Consideration of other cancer centers/medical facilities	Events, conversations, thoughts or actions that made them consider being treated at other locations for their cancer.
Barriers	Barriers to care that are not captured in the sub-topical codes below. (e.g., staff titles, support services, financial strain, support for side effects)
• Disempowering	Events, actions, character traits, processes, procedures, interactions, and/or conversations that discouraged them from feeling understood, adequately educated and/or prepared for experiences or situations, respected, in control, or otherwise empowered.
• Discourage Continuing Treatment	Incidents and/or points that made them want to stop treatment, including actions, processes, procedures, interactions, or communications.
• Discourage Decision-making	Experiences or communication that discouraged them from taking part in making decisions around their care and/or associated actions, processes, procedures, interactions, or communications.
• Discomfort	Perceptions of discomfort or strange, unexpected encounter.
Facilitators	Enhancements to continue care that are not captured in the sub-topical codes below. (e.g., primary care providers, other institutions)
• Empowering by the institution	Events, processes, procedures, conversations, or actions that encouraged them to feel understood, educated, respected, in control, or otherwise empowered by the institution.
• Empowering from natural/cultural/social supports	Events, processes, procedures, character traits, conversations, or actions that encouraged them to feel understood, respected, in control, or otherwise empowered from natural/cultural/social supports.
• Encourage Continuing Treatment	Incidents and/or points that made them want to continue treatment, including decisions, actions, interactions, behavior changes and/or communications.
• Encourage Decision-making	Experiences or communication that encouraged them to take part in making decisions around their care, including instances when participation seemed welcome or "invited" and/or associated actions, processes, procedures, interactions, and/or communications.
• Comforting	Perceptions of familiarity or comfort.
Treated Differently Due to Race	Positive or negative treatment due to their race, culture, or ethnicity, including processes or procedures, actions, quality of care, interactions and/or communications.
Nurse Navigator	Positive or negative reactions to the services of a Nurse Navigator, including being offered/referred to Nurse Navigator, frequency and content of communications, quality of interactions.
Desired Changes	Desired changes to the cancer diagnosis and treatment system, including barriers, facilitators, processes, procedures, interactions, and/or communications.
Inadequate Education	Experiences or situations that may have been expected by the medical team, but for which the patients did not feel they had adequate education or preparation. (e.g., postoperative, drug side effects, etc)
Post-treatment follow-up	Experiences or situations which occurred after completion of their chemotherapy and/or radiation therapy that affected their sense of being cared for by the system