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Utilizing Community-based Participatory Research Principles in a Safety-Net Hospital to Develop a Research Partnership

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Summary:

Research at safety-net hospitals may require additional planning to ensure the ethical conduct of research with vulnerable populations. This report discusses application of the principles of community-based participatory research and bioethics to establish a research partnership with a safety-net hospital in the southern U.S.

Keywords

Community-based participatory research; safety-net hospital; ethics; health disparities; vulnerable populations

Past unethical and intentional medical and research practices that were performed on minority populations continue to have salient effects on the receipt of timely health care and participation of minorities in research, particularly among African Americans.¹ These unethical occurrences have been linked to distrust among minorities about the intent of medical studies.² However, minorities who visit safety-net hospitals perceive the care they receive as patient-centered, of quality, and trustworthy, and describe the hospitals as institutions that understand the community.^{3,4}

Safety-Net Hospitals/Community Health Centers

Safety-net hospitals (SNHs), also known as community health centers, specialize in care for patients with multiple comorbid conditions, and complex social and economic circumstances (many of which have negative health consequences). In most SNHs, more than half of those served are members of vulnerable groups and almost two thirds live at or below the federal poverty level.⁵ This is important as people with lower socioeconomic status (SES) have higher cancer death rates than those with higher SES.⁶ These populations may stand to benefit the most from clinical and biomedical research. However, the health, social, and economic status of patients cared for in SNH settings renders them vulnerable to exploitation, abuse, and other harms of commission or omission. Safety net hospitals were established in the U.S. in response to the lack of quality health care for individuals residing in urban settings, with most revenue generated through Medicare and Medicaid reimbursement.⁷ With the mission to serve a high-risk medical population with complex medical conditions and limited access to quality health care, SNHs are ideal to develop and conduct health disparities research and to identify effective strategies for addressing low minority participation in research and Cancer Clinical Trials (CCTs).⁸

The research team for the work discussed here comprised investigators of the National Cancer Institute Center to Reduce Cancer Health Disparities-funded Partnerships to Advance Cancer Health Equity (PACHE) Morehouse School of Medicine/Tuskegee University/O'Neal Comprehensive Cancer Center pilot study, *Increasing Minorities Participation in Clinical Trials 2.0*. The investigators approached the leadership of the Georgia Cancer Center of Excellence at Grady Memorial Hospital, a SNH located in a major urban city in the southern U.S., to understand their capacity to conduct cancer research and CCTs.⁹ Part of the mission of the cancer center at the SNH is a focus on research to improve patient outcomes, as well as basic, clinical, and population-based studies.⁹ Given the vulnerability of the patient population, the leadership of the cancer center and the academic research team used principles of community-based participatory research to develop a partnership to enhance the capacity to conduct cancer research and CCTs.^{10,11}

Community-Based Participatory Research

Community-based participatory research (CBPR) is a philosophical, social, and ethical framework that informs and shapes research design, implementation, data use, and dissemination.^{10,11} The core value of CBPR is reciprocity, which stipulates that community members and academic partners design, implement, analyze, and interpret results

collaboratively to the mutual benefit of both partners.^{10–11} In CBPR, the community's voice and expertise are essential. Undergirded by cornerstones such as trust and communication, CBPR has been used to examine cancer disparities among various populations.^{12–18} It serves as a useful set of tools for assessing cancer screening knowledge and behaviors, promoting cancer screening, establishing academic-community partnerships, developing culturally responsive interventions and instrumentation, and discovering new areas for scientific inquiry.^{12–18} The purpose of this report is to describe the application of CBPR principles to develop the capacity for research in a cancer center at a SNH.

Addressing Bioethical Concerns

We applied CBPR principles to address ethical concerns for conducting research within the SNH introduced above. Based on the vulnerability of the patient population and the location of the SNH in a southern region of the U.S. with a history of research abuses, racism, and discrimination, we applied principles of CBPR to develop a partnership with the SNH to address distrust African Americans have with the conduct of government-sponsored research and medical systems.^{19–20} The historical abuses of the *U.S. Public Health Service Study of Untreated Syphilis in the Negro Male* (conducted in Tuskegee, Alabama) remain a guiding light in many African Americans' perception of interactions between academic institutions and local communities.²¹ Through the application of the principles of CBPR, the following bioethical concerns were addressed in developing the partnership with the cancer center at the SNH: beneficence (doing good), non-maleficence (preventing or mitigating harm), fidelity and trust within the fiduciary investigator-participant relationship, personal dignity, and autonomy pertaining to informed, voluntary, competent decision-making, and the privacy of personal information.²²

A hallmark of CBPR is its commitment to action in translating research into practice. In Box 1, we demonstrate how we operationalized CBPR principles in establishing a partnership with the cancer center at the SNH to facilitate the conduct of research, and to address any bioethical concerns that might adversely affect the conduct of research. The principles of CBPR were used to guide the structure of project meetings between the academic research team and the cancer center leadership, to inform the process to develop the capacity to conduct research, and to address any ethical concerns germane to the patient populations. This approach ensured equal voice and full disclosure of study activities to the cancer center leadership.

Conclusions

Utilizing the principles of CBPR to establish a research partnership with the Georgia Cancer Center of Excellence at Grady, a SNH located in the southern region of the U.S., was critical to addressing bioethical concerns. Although the process could be deemed time and labor intensive, it proved beneficial in addressing bioethical concerns among the patient population. By utilizing principles of CBPR, Georgia Cancer Center of Excellence at Grady was able to contribute its expertise and share in responsibility and ownership of the research infrastructure. Application of CBPR enabled the academic research team collaboratively to develop effective strategies for conducting research in the SNH. Building trust and

establishing rapport with the Georgia Cancer Center of Excellence at Grady leadership and administrators involved a series of meetings, collaboration on community- and hospital-based events, transparency in describing the partnership purpose, and having a plan to share the knowledge generated from research and how it would be used.⁸ Through the CBPR approach, a joint process can be established to interpret, disseminate, and translate the data into interventions and/or policy. This report presents an approach to assist future health disparities research developed in partnership with SNHs. When planning a study, researchers should follow CBPR principles to establish trusting relationships with the hospital board, its staff, and the community and patients, to encourage study participation, and to address ethical concerns prevalent as a result of unethical historical treatment.

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Box 1.**TRANSLATING CBPR PRINCIPLES INTO ACTION**

CBPR Principle	Concept	Application	Ethical Concern Addressed
CBPR acknowledges community as a unit of identity. ¹⁰⁻¹¹	Recognize, distinguish, and respect the community as a unique and vital partner in the research process. ¹⁰⁻¹¹	Identified and established a formal process for defining the SNH as a 'community.' Engaged and received continued direction from the cancer center leadership and the patient and family advisory board, and leadership from a state cancer organization. Worked closely with the Outreach Department and the Patient Navigators of the cancer center in the SNH.	Respect, Autonomy, Trust
CBPR builds on strengths and resources within the community. ¹⁰⁻¹¹	Listen to, learn from, and identify what each partner brings to the process; build on strengths; and find solutions to challenges. ¹⁰⁻¹¹	Established processes for the partnership to share their perspectives through various communication platforms, beyond quarterly meetings. Ensured that there was a structured balance of power; no decisions were made without the approvals of the cancer center leadership, the director of research, and the patient and family advisory board in the SNH.	Respect, Beneficence, Non-Maleficence
CBPR facilitates a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process. ¹⁰⁻¹¹	Enable fairness and equality at each step of the research process. ¹⁰⁻¹¹	Developed structural ways (regular-face to-face meetings) to check-in with the partnership, given the sensitivity of the research being conducted with a vulnerable population, and to engage in a dynamic process of building trust.	Autonomy
CBPR fosters co-learning and capacity building among all partners. ¹⁰⁻¹¹	Ensure that all partners learn, grow, and share throughout the process. ¹⁰⁻¹¹	Routinely had update meetings with the SNH leadership as to what their needs were and how we might assist. Developed a dissemination plan for the partnership, including IRB approvals, process for development of consent forms, patient engagement models, and communication regarding what was learned from other stakeholders (physicians, nurses, research staff, and patients).	Autonomy, Trust
CBPR integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners. ¹⁰⁻¹¹	Work towards a balance between research and action so that all partners benefit. ¹⁰⁻¹¹	Communicated from the start about expectations, the need to establish processes for research staff, and understanding the barriers and facilitators to clinical trial participation. Discussed why each partnership member was involved and how the research would assist in developing interventions in clinical and non-clinical settings. Developed a feedback loop and instituted strategies for addressing challenges.	Beneficence, Non-maleficence, Autonomy, Respect
CBPR focuses on the local relevance of public health	Know local and relevant health problems; learn	Sought to learn the historical and current health status of the population served in the SNH	Beneficence

CBPR Principle	Concept	Application	Ethical Concern Addressed
problems and on ecological perspectives that attend to the multiple determinants of health. ¹⁰⁻¹¹	about and respect the community's history and wide-ranging factors that affect their health and well-being. ¹⁰⁻¹¹	through sponsoring and participating in cancer outreach events. Understood the interconnections of the patient's lives and how they affect well-being and how the context affects their health outcomes.	
CBPR disseminates results to all partners and involves them in the wider dissemination of results. ¹⁰⁻¹¹	Share findings and lessons learned with all partners in meaningful ways to meet the goals of all partners. ¹⁰⁻¹¹	Co-developed a dissemination plan to provide ready access to the findings in clear language through the development of briefs and reports. Allowed for and encouraged the partnership to feel invested in the data and findings through transparency in data collection efforts and engagement of stakeholder groups. Formulated dissemination plans beyond publications and scientific presentations.	Trust, Respect, Beneficence, Privacy
CBPR involves a long-term process and commitment to sustainability. ¹⁰⁻¹¹	Commit to a long-term process through investment of time and resources. ¹⁰⁻¹¹	Ensured steady visibility and easy access to research staff by securing an office at the SNH. Financially and intellectually supported annual events at the SNH, such as Survivorship Day and Colorectal Cancer Awareness Week.	Trust
CBPR involves systems development using a cyclical and iterative process. ¹⁰⁻¹¹	Ensure that the partnership draws on competencies of each partner in a cyclical, iterative process in all stages of the research process. ¹⁰⁻¹¹	Developed a system to elicit feedback from leaders at the SNH and the academic institution.	Beneficence, Trust, Respect
<p>Note</p> <p>CBPR = Community-based participatory research.</p>			