Identifying Barriers to Care:
Using The Community-Based Participatory Research (CBPR) Approach To Qualitative Analysis Of Coding Cancer Navigator "Real Time" Communications

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Abstract

The Accountability for Cancer Care through Undoing Racism and Equity (ACCURE) study employs the community-based participatory research approach to collectively examine the nature and frequency of support that nurse navigators provide breast and lung cancer patients. A team of academic and community members partnered to develop a codebook based on the ACCURE navigator protocol, coded and analyzed navigator notes, and shared findings with the navigators to strategize for improvements. Our findings suggest that the interpretation of data is enriched by involving community partners' perspectives and cultural or contextual knowledge in the analysis process. Using the CBPR approach to analyze and code data has its challenges, but it serves to broaden the "relevancy and authenticity" of emerging data that can be useful in revealing disparities in cancer treatment.

Introduction

African American cancer patients, as compared to their White counterparts, continue to initiate treatment later and remain less apt to complete care, fueling worse outcomes, including shorter survival. ACCURE is a 5-year NCI-funded intervention study aimed at achieving equity in quality and completion of care among African American and White early stage breast and lung cancer patients at two cancer hospitals. For the randomized control trial portion of the study, we are evaluating two innovations: 1) the "real-time registry" (RTR), an electronic warning system tool; and 2) a unique "nurse navigation" program to determine whether these interventions support breast and lung cancer patients' receiving appropriate and timely treatments, and if they help to narrow the racial disparity in completing treatment.

Purpose

To identify barriers in cancer care while assessing navigator interventions to improve the quality and completion of care and to do this by combining community and academic partners' expertise in analyzing nurse navigator notes.

Objectives

➢ To explain the use of the CBPR approach in qualitative analysis of ACCURE nurse navigator notes.
➢ To define the facilitating factors or barriers that patients have in completing cancer treatment.
➢ To identify (both benefits and challenges) of involving community members in a qualitative analysis of navigators' documented communications.

Methods

Coding Analysis Process:

➢ Two dyads of a community and academic partner were each assigned to analyze half of the 1230 navigator note entries.
➢ Within each dyad, the partners read and assigned codes, and then came together to come to a consensus on any discrepancies.
➢ A qualitative analysis was conducted using deductive and inductive coding.
➢ A codebook was developed based on the ACCURE Navigator Protocol (deductive codes) and the notes were reviewed more than once to identify emerging codes from the text (inductive codes).
➢ The notes were coded via Excel spreadsheet in paragraph clusters.

Results

CBPR Benefits

➢We found that some of the notes were coded based on what was implied rather than explicitly stated. These differences illustrate and highlight the diverse opinions and level of expertise brought to the analysis process.

Example: Interpretation of the meaning of **"emotional support"**
" Patient encouraged to call health nurse if pain not controlled" **(Implied Code)**
"RN offered self, acknowledged her anxiety and provided upcoming appointment dates." **(Explicit Code)**

➢We also found that academic partners' interpretation of the data, which was based on theoretical or scientific knowledge, was balanced well by community partners' cultural or contextual knowledge. Having both perspectives led to a clearer understanding of the role of navigators in enhancing patient-provider communication.

CBPR Challenges

➢Although community members served to enhance the analysis process, allowing community members to code from an Excel spreadsheet produced challenges in coding accuracy. For instance, coded portions of the text were not highlighted, making it difficult to know what text was coded a certain way, and why that code was assigned.
➢The lack of pre-training and procedural development created challenges in the coding process.
➢ Time constraints between community and academics lessened the number of available meetings to discuss relevant issues and concerns throughout the analysis process.

Results (continued)

Below is a specified list of guidelines for ACCURE navigators to follow in order to provide the type of support needed by patients to improve treatment completion rates.

Initial visit (MD visit or 72hrs)	3 businesses days after initial contact	Visit 2 (10-21 days)	Visit 3	Visit 4	No show
Review surgery/adjuvant treatment	Active listen	Engage discussion on patient concerns/questions	Repeat initial visit protocol	Ask patient "Who is a major support person?"	Assess fear
Teach back on basic facts	Offer social support	Answer questions	Establish goals	contact support person	Assess mistrust issues
Assess feelings about treatment options	Answer questions	Explore barriers and assess Trust		Enlist support person help	Assess barriers
Patient-centeredness	Review surgery/treatment facts	Use patient-centered model		Reassess patient priorities	

The ACCURE codebook illustrates the barriers and facilitating factors identified using the CBPR approach to qualitative data analysis.

ACCURE Code-book	Codes	Descriptions
1	System Barriers-Inside/Outside the health system	When patient discusses barriers, such as lack of communication, transportation, financial, etc.
2	Pain	Code when navigator assists with management of pain
3	Type of support emotional	When navigator provides support or resources for emotional support. E.g.. Counseling
4	Perceived Racism	Patient discusses experiences with racial prejudice or discrimination.
5	Unclear	When notes are unclear. E.g., abbreviated terms

Conclusion

➢ The CBPR approach is becoming a recognizable and acceptable approach in addressing health disparities in cancer prevention (Strickland, 2006, p. 230). It offers tangible outcomes for all partners involved, but tends to present some challenges when analyzing qualitative data. In ACCURE's process analysis of two interventions, it served to deepen the relevance and authenticity of findings on how navigators can enhance a cancer care system's accountability for equity in quality and completion of care.

➢ Overall, the CBPR approach helped in the identification of barriers and facilitating factors, such as system barriers, type of emotional support, pain, and perceived racism.

Recommendations

Moving Forward:
➢Organize pre-training sessions with community and academic partners involved.
➢Establish a coding review board to evaluate the success and limitations of the coding process.
➢Provide an incentive to community partners for their time and effort.
➢Choose community and academic partners based on their availability, knowledge, and experiences with cancer or health disparities.
➢Create a code tracking sheet.

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