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COMMUNITY ACCESS, THE GATEWAY TO COMMUNITY ENGAGEMENT RESEARCH: BEST -PRACTICES FROM CAPTC COHORT STUDY.

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ABSTRACT

Community engagement can be defined as the process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being. Community engagement research will enable researchers to effectively incorporate critical insights into their research questions and also

conduct research that can translate more easily to real world settings and impact health. Regrettably, the knowledge of community engagement research is still poorly understood in most nations in Africa.

The main objective of this study is to highlight the roles of community engagement in promoting research outcomes.

This research work was designed as part of the CaPTC Transatlantic Cancer Familial Project which is an on-going cohort study of prostate cancer in men of West African ancestry. The first phase of the project was a questionnaire-based survey which was designed to be administered in diverse community settings. Prior to the administration of the questionnaires, the community leaders were contacted and co-opted as important stakeholders.

The turnout and the willingness of the members of the community to participate in the survey was very impressive. The respondents agreed to participate in future researches including clinical trials if contacted.

Community engagement in research may enhance a community's ability to address its own health needs and health disparity issues while ensuring that researchers understand community priorities. Therefore, there is great need to explore community engagement research in Nigeria.

Keywords: Community access, community engagement, community leaders, research**.**

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INTRODUCTION

Community engagement can be defined as the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. [1] The aims of Community engagement are to build trust, enlist new resources and allies, create better communication and improve overall health outcomes as successful projects evolve into long lasting collaborations. [2-3]Community-based research is rapidly

gaining recognition as an important tool in addressing complex environmental, health and social problems. [4]

In particular, researchers and practitioners need to understand the cultural dynamics of specific groups and institutions in order to build relationships and identify ways to effectively collaborate, and build respect and trust. This is an on-going effort for all involved in the community engagement process. [5-7] Communities are not homogeneous entities; they are made up of diverse groups with different histories, social structures, value systems, and cultural understandings of the world.

The purpose for engaging community in health promotion, policy making and research is because certain indices such as lifestyles, behaviors', and incidence of illnesses are shaped by social and physical environment. [8]If health is socially determined, then health issues are best addressed by engaging community partners who can bring their own perspectives and understandings of the community life and health issues to a project. Therefore, if health inequalities are rooted in larger socioeconomic inequalities, then approaches to health improvement must take into account the concerns of communities and be able to benefit diverse populations. [9] In addition, community engagement helps the health professionals, community leaders and policy makers to open up to new opportunities as they face new challenges. [10]

Community engagement research is not a popular concept in most nations in West Africa. Many researchers in West Africa conduct research without the knowledge of the applicability of the researches in their immediate environment. Many of the researches are institutional based with little or no involvement of the hosting communities. This probably explained why translational researches and cohort clinical trials are still at primitive stages in West Africa. To reverse this trend, CaPTC Transatlantic Prostate Cancer Familial Project with the international headquarter based at the University of Florida, introduced the concept of community engagement research at all research sites in West Africa .

MATERIAL AND METHODS

The CaPTC Transatlantic Prostate Cancer Familial Project is an active, ongoing cohort
study of 2,000 West African men to investigate the genetic, environmental and behavioural aetiology of prostate cancer in West African men.

Community Access and Community Engagement Research

Prior to the administration of the questionnaires in communities, institutions and places of religious worships such as churches and mosques, the community leaders, opinion leaders and community mobilizers and religious leaders in various community settings both rural and urban, were identified. These categories of people are well respected in West Africa. Prior advocacy visits to the traditional leaders, religious leaders, head of health and educational institutions, professional groups and opinion leaders were carried out. The aims and objectives of the study including the benefits to the participants and the society at large were communicated to the community leaders. The community settings where the questionnaires were administered, include the following: hospital facilities (Primary Health Care Centres, Private Facilities, General Hospitals, Federal Medical Centres and University Teaching Hospitals), Educational Institutions (Colleges of Education, Polytechnics, Universities), Other settings within the communities (Markets, Shops/ City Centre/ Business District, Churches, Mosques, House to House Outreaches. During our engagements in the communities, we embarked on health talks, distribution of handbills and customized T- shirts as part of our community engagement activities. The actual date of visit to the communities was jointly decided by members of the CaPTC and the community leaders at our various research sites.

Study Participants and Recruitment

Study participants were Nigerian and Cameroonian Black men resident in the US, Nigeria,
and Cameroon. The study inclusion criteria were: (1) West African men regardless of history of prostate cancer diagnosis; (2) men between the age of 35 and 70 years; and (3) men who
consented to completing the study survey. Using a flyer, participants were recruited at multiple settings, including clinics and diverse community settings such as restaurants, social organizations, churches, mosques, and health events.

Data Collection

Prior to data collection, Institutional Research Board approvals were obtained for all study sites in the US, Nigeria and Cameroon. University of Florida served as the coordinating center for the study. Other participating institutions in Nigeria were Ahmadu Bello University, Covenant University, Ekiti State University Teaching Hospital, Federal University of Agriculture Abeokuta, Lagos State University Teaching Hospital, National Hospital Abuja, University of Calabar, University of Ilorin, and University of

Maiduguri. The institution in Cameroon was University of Yaounde.

Participants who met the eligibility criteria were recruited at these sites for the study. First, informed consent was obtained from participants prior to participating in the study. Next, participants completed the survey through self-administration or with assistance from a research assistant using the study instrument. The survey was administered in English or West Africa "Pidgin" English, a simplified means of speaking communication for people who have not acquired western education. "Pidgin" English is widely spoken in West Africa for easy communication.

RESULTS

The community access and the acceptability of members of our team were encouraging because of the prior community sensitization and mobilization visits that were carried out. On the actual date of administration of the questionnaires and taking the necessary blood and saliva specimens from the participants. The participants were already mobilized by the community leaders and they were gathered at a point in the community waiting for the arrival of members of our team. We also utilized the opportunity to carry out a health talk on prostate cancer and other related health issues before proceeding to administer the questionnaires to the participants. The turnout was very impressive and all the members of the community that were recruited participated in the study. The participants also agreed to participate in future researches including clinical trials on human subjects. The details of the participants were recorded and they will be contacted for future follow-up studies including clinical trials.

The members of the CaPTC Research Team enjoyed unrestricted community access during the concluded phase 1 of the project.

DISCUSSION

Center for Disease Control (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) in their booklet titled" Principles of Community Engagement" defined community engagement as "the process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being" .[11] Community engagement involves a physician or other health provider or researcher moving into a community based on the realization that a particular problem identified is enormous and requires a multifactorial approach to resolve. [12] This involves partnering with the

community to improve the health of the dwellers, [13] thus avoiding using the community only as guinea pig without any benefit whatsoever .

Thus, it is now widely accepted that involving the community representatives in an early and sustained manner in the design, development, implementation and distribution of research results and collaborating with its members are cornerstones of efforts to improve public health. Community engagement helps cultivate a sense of community ownership that builds trust and deepens knowledge of local realities. A review of literature suggested that the effectiveness of any community engagement approach stipulated on the population and the health behaviour,[14] Swainston and Summerbell[14] conducted a rapid review of the evidence on the effectiveness of community engagement approaches for health promotion interventions. The two research questions were: what community engagement approaches are effective for the planning, design, or delivery of health promotion interventions? What are barriers to using community engagement and what interventions have successfully overcome these barriers?

Another review reported on the adverse impact an engagement initiative can have on its participants, [15] such as causing physical, psychological, and financial stress. Findings from primary studies and position papers suggested that while different approaches and models exist for community engagement, the evaluation of these have been sparse or undocumented. Concepts such as diversity of stakeholders, deliberative methods for consensus building, and equitable representation were identified as points for reflection when designing and implementing a community engagement initiative. Based on the findings of this report, it is recommended that:

1) A community engagement approach should be tailored to the population of interest and the target health behavior

2) Potential adverse effects of a community engagement initiative must be considered and mitigated

3) Community-based organizations must be involved in any engagement initiative

4) The inclusion of diverse stakeholders should not be at the expense of consensus building

5) Community engagement approaches should be evaluated.

A report addressed the impact of community engagement on participants of initiatives focused on social determinants of health with information drawn from multiple disciplines such as urban renewal,

service planning, and civic participation.[15] The initiatives in their level of engagement, from consultation, to delegated power in planning and design, to co-governance or co-production. Interestingly, none of the initiatives were controlled solely by community members. [15] 'Engaged' individuals reported positive changes in their physical health, psychological health, self-confidence, self-esteem, sense of personal empowerment, and social relationships .[15] However, some adverse outcomes, such as exhaustion, stress, financial burden, consultation fatigue, and disappointment were also reported. [15]

The National Institute for Health and Clinical Excellence in the United Kingdom developed a set of 12 recommendations to guide effective community engagement. [16] These recommendations were based on the analysis of various types of data: reviewing government policies; systematically reviewing literature on community engagement approaches and the experience of community engagement; modelling the economic cost of community engagement; and incorporating program theory and evaluation principles. [16] Together, the recommendations cover four major components: prerequisites for success, infrastructure to support implementation, approaches and increase levels of community engagement, and evaluation.

Using the NICE recommendations, [17] offered a four-step practical guide based on their work with Black and minority ethnic (BME) communities:

a. Making sure everyone is ready

b. Consulting

c. Moving from talking to action

d. Obtaining feedback and follow-up

They discovered that in making sure everyone is ready for the research, a local Organization must be willing to collaborate. To avoid selecting an organization whose views may not reflect that of the greater community, the authors suggested spending sufficient time within the community in order to decide which organization to engage with. While it is important to develop a meaningful partnership with a community, this process can be challenging for health agencies [17]. Indeed, barriers in access to and acceptance by communities may hinder the early establishment of common goals. Other factors to consider during this stage of the engagement include recognizing culture-specific beliefs about health, ethical concerns, timing and commitment of consultation events, and interpretative services (if applicable).

Also in their review [17] highlighted two essential elements for consultation phase.

These are; practical considerations – informing participants of what is required of them, and frequency of consultation events. The authors advocated for one-to-one sessions with participants, wherever possible, to avoid domination by some community members. [17]

It has been reported that policymakers and research funders have shown concern that clinical research system produces new knowledge that may not be translated effectively into the clinical practice. [18] Acquisition of evidence base health care through clinical research carried out in tertiary care academic health centers is a barrier to translation of research into practice .[19] Thus, raising concerns, such as external generalizability of findings as most research population is just a fraction (0.1 %) of the total community. [19] Hence, to advance clinical research and make it translational, and to reduce health disparity, it must integrate significant representative samples of the population who received care outside the immediate academic health centers of a single location; it must not only be health focused but must also integrate the social, economic, cultural, ethnic and geographic identity of the study participants. [20] Practice-based research is a model that combines scientific investigation and education with community engagement. [21] Community engagement involves networking among a collection of people to understand the community, its members and identify key informants, community leaders, potential stakeholders and sources of support. [21] The communities involved in practice-based research have not been limited to a single geographical location, region or neighborhood, or to single racial, ethnic, religious groups, collection of patients with the same diseases or a population defined by multiple characteristics such as vulnerability in relation to social and clinical attributes or virtual community linked by email or social media. [21] Methods of community engagement or interactions in the US include identifying communities interested in collaboration, meeting and establishing communication with community members and leaders, understanding the health concerns/interest of the community, establishing feasibility and recruitment strategies and becoming involved in the community. [21] Community engagement activities include community outreach, support and education between the research team and the community. [22] Recruiting local businesses, churches, schools and other support groups to endorse or support the study has also been used by research groups in the developed countries. [23]

Thus, from the first phase of the CaPTC Project, a lesson emerged that, community access is indeed is very crucial to community engagement research. This led to the declaration of two of the sites; Ekiti Site and Hebron International Diagnostic & Molecular Pathology Centre in Ilorin as centers of excellence in community engagement research. These two sites work in collaboration and have been scheduled with the responsibility of consolidating the gains achieved thus far in community engagement research, hereby preparing the platform for future engagements with communities in other research areas including clinical trials.

CONCLUSION

community engagement is indeed, the gateway to community research if positive result is the ultimate. However, community engagement approach should be tailored to the population of interest as well as the target health behaviour, as there is no evidence to suggest that one approach is sufficient across all communities.

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