

Viewpoint

Developing conceptual framework and methodological considerations in community-supported chronic disease management

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This article describes the conceptual and methodological foundation of community-supported chronic disease management. A community-supported approach recognizes the diversity of community residents' participation outcomes and attempts to maximize self-mobilization to manage chronic diseases in community settings. This paper argues that incorporating ethnographic research to understand a community holistically and promoting an inclusive community organization through a systematic approach has the potential to facilitate community support and improve sustainability in chronic disease management in resource-limited settings.

Chronic diseases contribute significantly to the global burden of diseases. The World Health Organization (WHO) estimates that chronic diseases cause 41 million deaths yearly, and 77% are from low and middle-income countries.¹ Under-resourced healthcare systems, lack of sustaining partnerships with communities, and hierarchical and centralized governance structures make the marginalized communities in low and middle-income countries particularly vulnerable to the adverse effects of these diseases.²

To address chronic diseases, advocates of community-based participatory research (CBPR) and other community-based approaches promote the importance of building equitable community partnerships and promoting community-owned solutions.³ While the idea is commendable, Cornwall, Arnstein, and others highlight the problem of variable forms such participation can occur. It can range from simple tokenism, where the residents are informed and consulted to a limited degree while organizations make the primary planning and implementation decisions, to self-mobilization, where residents plan and act to effect change.⁴ For example, two recently published Randomized Control Trials, HOPE 4 and COBRA BPS, compared community-based management against traditional office-based management of hypertension. Both trials showed improved blood pressure control with community-based management. However, on a closer look, it appears that both trials designed studies in which critical decisions, such as selection, support, and accountability of health workers, key components of the study, primarily came from the health systems with patients as passive recipients (tokenism).^{5,6} Furthermore, a 10-year meta-review done by McFarlane et al. suggests that the researchers will need to be more transparent and describe accurately and thoroughly the nature

of the partnership with members of minority communities.⁷

There is no consensus regarding how the community representatives for partnership are selected. Many CBPR projects partner with local churches or NGOs without knowing the nature of the relationships between such organizations and the community's rest of the members. Such partnerships leave the question of whether the representatives reflect the general will of the residents, particularly the marginalized within the community. Wallerstein et al. describe individual characteristics of partners, such as motivation, cultural and religious values, and reputation.⁸ Still, such identification does not solve the problem of identifying individuals or organizations that authentically represent potentially diverse and conflicting community residents' needs and preferences.

While designing community-based interventions to address chronic diseases, studies tend to reduce the community descriptors to area, number of facilities, and distance from tertiary centers.^{4,5} Such characterization excludes factors important to the sustainability of the intervention, such as the relationship between representatives and recipients, particularly with regards to trust, respect, empathy, familiarity, relevance to community felt needs, incorporation of local context/belief systems, regular and visible support from members, community leaders, and health systems, adequate training, and secured career pathway for the health workers.⁹ Such a reductionist approach to the community may give short-term treatment outcomes but will fail to generate continuous coverage.

For the above reasons, we attempted to conceptualize and highlight the methodological requirements of a community-supported approach to chronic disease management. A community-supported approach recognizes the di-

versity of community residents' participation outcomes and attempts to maximize self-mobilization to manage chronic diseases in community settings. Key concepts and methodological considerations of the approach are described below.

CONCEPTUALIZING COMMUNITY-SUPPORTED APPROACH

To begin conceptualizing the community-supported approach, we first asked the question, what is a community? Defining a community in reductionist terms (e.g., mean population, area, number of facilities) does not adequately explore the interconnectedness and social and historical context that may shape resident behavior and expectations. Such an approach will fail to garner local resources, connections, and ownership, which are critical in building long-term sustainability.

We borrow sociologist Aday et al.'s definition of community: "We regard the community as clusters of interpersonal ties with geographic location and identity and socio-political, historical, economic and other shared or contested characteristics. Communities have more or less fixed, permanent, and permeable boundaries. Those who share Community co-location likely participate in and may contest cultures and histories. Communities cannot be reduced to the individuals that comprise them because they are distinct from any specific individuals and the groups of individuals that exist at any given moment in time."^{10,11}

When we understand the community as a structural and connected entity, we recognize that change requires an integrated effort promoting individual and collective benefits. Individuals influence the community but are also shaped, restrained, and empowered by the community's existing discourse, belief systems, traditions, and practices. By understanding and galvanizing these structures, processes, and networks of relationships, we hypothesize to develop an intervention that is well-integrated and, to an extent, supported by the community.

Management of Chronic diseases, such as diabetes and hypertension, can benefit from such a support system. Patients with chronic diseases usually have to take multiple medications, make lifestyle changes, and follow up with doctors regularly. Here, much beyond the doctor's prescribed drugs and advising lifestyle changes, patients must "own" their care by ensuring medication compliance, overcoming financial burdens, and changing dietary and activity habits. Facilitating a support system where patients live has the potential to sustain such behavioral change.

In our view, the "ideal form" of this support system is the one that pursues agency. Borrowing from Bhattacharya, the agency is defined as restoring the capacity of a people "to create, reproduce, change, and live according to their meaningful system."¹² This means that the community's residents should be able to control and manage the project as much as possible with only limited and necessary intervention from external influence, including the research group. By actively pursuing agency, we believe that the project's vulnerability to the availability of government/

non-governmental funding and national and international stressors, such as a pandemic, war, famine, and inflation, can be reduced, promoting interventions' sustainability in resource-limited settings.

METHODOLOGICAL CONSIDERATIONS ETHNOGRAPHIC RESEARCH

An ethnographic research approach may help us understand the community holistically. Ethnography is an approach to learning about the social interactions, behaviours, and perceptions within teams, groups, organizations, and communities by situating the data-gathering effort within the worldview and experiences of those studied instead of the researcher's personal or professional judgment. It necessitates direct engagement with the world, which the researcher aims to examine to document an empirical portrayal of people's nature, viewpoints, and lived realities. Ethnographic researchers employ participant observation, field notes, and structured or semi-structured interviews.^{13, 14}

Ethnographic research is inclusive in its approach to defining and understanding a phenomenon. If the effort is to "get inside" the way each group sees the world, the researcher must "let go" of their own subject and objective viewpoints to embrace the participants' subjective and objective views. Such an approach can help identify resources and people that residents view as trustworthy. Furthermore, it can promote the intellectual openness and humility necessary to understand the felt need authentically, a critical step in nearing the ideal of agency.

DOOR-TO-DOOR APPROACH TO SELECT REPRESENTATIVES AND ACCOUNTABILITY

Going door to door to each household in the community geography identified by residents via ethnographic research as opposed to the geography determined by government institutions (such as adopted by the COBRA BPS study) would help identify trusted and legitimate leaders more reflective of the general will of the residents.⁵ Going door to door will enable the residents to express their viewpoints and, thus, more ownership of selecting "trusted individuals." Furthermore, we are obtaining consent from participants in the project, increasing the legitimacy of "trusted individuals." This contrasts with the pick-and-choose approach, where the researcher picks a partner and relies on individual characteristics instead of a systematic and inclusive approach.

To mitigate internal marginalization and conflict, an inclusion committee will need to be formed by going door to door. The inclusion committee's role is to respond to corruption, violence, marginalization, and conflict from and within the community.¹⁵ We imagined that while the health committee would help conduct the daily activities of the health workers, the inclusion committee and inclusion workers would ensure that the service reaches everyone, including the most marginalized. If any dispute happens among workers or residents in the community, there will be a trusted body to give as impartial guidance as possible.

Furthermore, better intra-community accountability will provide greater confidence in negotiating with external stakeholders and promote agency.

CONCLUSIONS

In this paper, we attempted to conceptualize a community-supported approach. The approach advocates building an empirical understanding of the community via ethnographic research, which can help identify appropriate contexts and resources to promote a support system that directly impacts patient care. A door-to-door approach to selecting representatives and promoting accountability via forming an inclusion committee can provide legitimacy and inspire confidence among residents to move towards the agency, which is an ideal worth striving for. We conducted a pilot project with a detailed protocol at the Khorigapara Community in Bangladesh. Details of the project will be described in a separate paper.

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