

Assessing chronic disease management strategies through community based participatory research

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[Abstract] Comprehensive chronic disease management (CDM) strategies aim to improve such aspects as continuity of care, health-related quality of life and, overall population health. Here, consideration is made of how CDM may be enhanced through a more integrated and holistic health care system by incorporating a community based participatory research (CBPR) approach. This has the potential to provide meaningful participation by citizens in public health policy development. That CBPR may garner improved assessment of the effectiveness of existing CDM strategies, as imbedded in such practices as (regulated) complementary/alternative medicine (CAM), public health, and transcultural health care initiatives, should not be overlooked.

[Key words] public health; community based research; chronic disease management

INTRODUCTION

Depicted in Figure 1 are three domains (of many) which may have a role in the provision of a chronic disease management (CDM) strategy. Here, a community based participatory research (CBPR) approach is presented as having a potentially positive influence towards improving CDM initiatives. Through CBPR, care professionals may garner community input regarding CDM initiatives plus develop community partnerships. By doing so, health care planning and client-centered care may be enhanced.

As denoted by Wallerstein and Duran^[1] CBPR is an orientation to research that focuses on relationships between community and academic partners, with principles of mutual benefit, co-learning and long-term commitment. It is research that seeks to equitably and actively involve community members, organizational representatives, and researchers in all aspects of the research process. From such, community members are provided opportunities to contribute their expertise and/or life experiences to help others (e.g. health care providers) better understand a given phenomenon, such as their real or perceived health care needs. In turn,

community knowledge and insight is gained and integrated into care practices, for the benefit of the community involved^[2]. In turn, knowledge brokering and knowledge transfer between providers and recipients is enhanced.

Chronic disease management (CDM) is defined here as a holistic and comprehensive approach to health care that emphasizes ways to maintain independence and keep as healthy as possible through prevention, early detection and management of chronic conditions^[3]. As a multifaceted construct, CDM strategies call for diverse intervention strategies, which is essential as members of a given community or society are by no means homogeneous. Yet worldwide, there remains a dominant focus and provision of acute health care services which, overall, are said to be doing a disservice to addressing the care needs of older individuals with long-term, incurable chronic health conditions. Indeed, chronic illness care needs to be emphasized more if we are to appropriately address the real needs of aging populations^[4]. Moreover, continual assessment of a given community's health and social needs is required so that practical and potentially more cost-effective

CDM initiatives may be updated, developed and more effectively implemented. Towards this objective there is need to integrate a community based participatory research (CBPR) approach, so as to better ascertain from a community perspective what works and what does not. While there are limitations to a CBPR approach, such that mainly those who are healthy enough to participate are provided opportunity to have input, it is nevertheless a start towards improving existing CDM strategies.

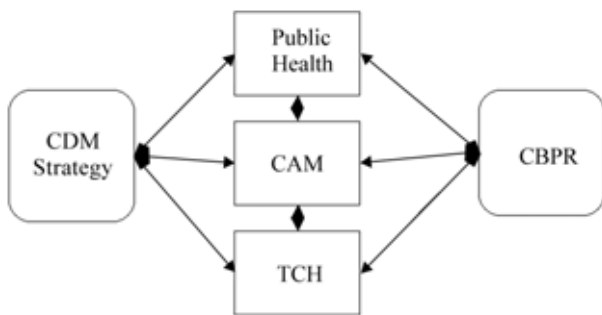


Figure 1 Dialectical strategies to enhance chronic disease management

Legend: CDM = chronic disease management, TCH = transcultural health care, CAM = complementary and alternative medicine and, CBPR = community based participatory research

INTEGRETING A COMMUNITY BASED PARTICIPATORY RESEARCH APPROACH

Kodner and Kyriacou^[5], as cited in Hébert, *et al.*^[6], consider integrated care as “a discrete set of techniques and organizational models designed to create connectivity, alignment and collaboration within and between the cure and care sectors at the funding, administrative and/or provider levels”. Absent from such definitions is allowance for public participation, of those affected within communities for the purposes of education and taking action or effecting social change. To address this exclusion a community based participatory research (CBPR) approach is needed^[7].

By providing independent community members opportunities to indicate their needs and preferences, this may help to identify gaps in existing services. Moreover, community input can help identify barriers to obtaining services and support, and systematic inequalities. Rather than being ignored, CBPR enables clients/

patients and communities to be empowered and be seen as partners in their own care. To this end, improved focus and support for self-care initiatives (*e. g.* health promotion) may also be enhanced. A further benefit of deploying CBPR is that such has the potential to enhance effective communication between health care professionals and the patients and/or clients they serve, thereby potentially improving holistic and patient-centered health care.

As noted in Rogers, *et al.*^[8], patient-centeredness is predicted on an understanding of the client/patient as a unique human being, and refers to doctor-patient encounters that are characterized by responsiveness to patient needs and preferences, using the clients/patients knowledge to actively guide the interaction and information giving, as well as shared decision making. Further, deploying a patient-centered emphasis permits the autonomy of others to be more respected. Agich^[9] argues that human development is not only biological but psychosocial as well, necessitating human psychosocial interaction. Meaningful autonomy enables psychosocial interaction, in turn providing a means from which diverse psychosocial needs of people may also be addressed. As psychosocial needs are often culturally determined through such powerful societal forces as socialization, there is benefit in using a transcultural health care approach so as to better ascertain and meet cultural specific health care needs.

INTEGRATING A TRANSCULTURAL HEALTH CARE APPROACH

Improved chronic disease management can be aided by using a transcultural health care (THC) approach. THC places emphasis on recognizing and understanding the values, beliefs and health practices of diverse cultures, so as to provide health care in a more culturally competent manner^[10]. As North America experiences a dramatic increase in the number of foreign-born residents^[11], such populations will increasingly expect to receive health and other services that are culturally sensitive. Collins^[12] is noted as saying: “Health care providers are faced with an enormous challenge to respond to the needs of culturally diverse clients. If they are to achieve the ultimate goal of preventing or dela-

ying disease in high risk populations and decreasing the rates of morbidity and mortality associated with chronic diseases, health care providers must ensure that their care is based on a consideration of cultural factors. ”

Systems lacking a transcultural health care approach can lead to many problems including: (a) inadequate recognition of patient health problems due to language barriers; (b) a lack of effort in identifying resources that are culturally appropriate; and (c) a lack of rapport with care staff which could contribute for some patients to their fear, social isolation and depression^[13]. Collectively, these type of problems can prevent effective management of illness and disease. Improved collaboration and partnerships with culturally diverse communities, through CBPR, could help alleviate such problems and promote cultural competence.

That diverse cultures use eclectic health care practices to address their chronic disease needs cannot be overlooked. Indeed, varied cultures have significantly contributed towards the establishment and accelerated growth of what is often referred in North America as “ complementary and alternative medicine ” (CAM).

CAM AS A POTENTIAL CHRONIC DISEASE MANAGEMENT STRATEGY

A person’s culture often impacts an individual’s perception of what health and wellness is and, the manner in which illness and disease is to be treated. Chronic conditions in general are predictors of seeking out medical and social care, including the use of complementary and alternative medicine (CAM). Yet research on the use of specific forms of CAM by those with chronic health conditions remains lacking^[14 - 16].

CAM is increasingly utilized by all age groups worldwide. In Canada alone, more than fifty percent of all its citizens are estimated to use some form of CAM every year^[17]. Here, CAM is defined as diagnosis, treatment and or prevention strategies that complement mainstream (biomedical) medicine by satisfying a demand not met by conventional approaches^[18].

A common form of CAM that addresses musculoskeletal disorders is massage. As populations age, there is an increased prevalence of such conditions. Since

musculoskeletal disorders have a major impact on society in terms of long-term disability, morbidity and economics^[19], there is increasing need to consider the potential regulated (licensed) CAM modalities could have within a CDM framework.

Information that can elicit why members of a given community use CAM may be derived using a CBPR approach. Such information would be useful for health care professionals and others to be more informed as to how patients/clients self-manage their chronic disease conditions. Moreover, as the reported use of CAM to doctors is low and perceived effectiveness by its users is often high, arguably increased awareness and understanding about CAM therapy use, via CBPR, is imperative. Such improved understanding could aid health care professionals to be more responsive to patient’s needs plus, assist policy makers to create more relevant and effective policies.

PUBLIC HEALTH

As community based participatory research is community driven and an action-oriented approach to (health) research, such is regarded as highly consistent with the core values of public health^[7]. As public health aims to inform, educate and empower people about health issues^[18], it is situated in a unique position to support vulnerable (and other) populations to have a voice, so that policy and resource allocations better reflect community priorities. Argued here, the provision and/or enhancement of this “ voice ” may be augmented by integrating CBPR within public health initiatives. Doing so could further support social justice, as exemplified and/or characterized by improved fairness in the delivery of care as well as greater inclusion and protection of the vulnerable^[4,20]. Yet, inequities persist, as found in the manner monies and the existing infrastructure perpetuates the dominant provision of acute care services while simultaneously hindering the provision for chronic care (rehabilitation). This speaks of the necessity for public health to be more proactive towards meeting community health care needs^[18]. Presented here, CBPR could support public health personnel towards this goal.

SUMMARY

While the domains of transcultural health care, public health, and complementary/ alternative medicine have been addressed here at a surface level, the hope is that this commentary will serve as a springboard towards a deeper analysis of how such domains could use CBPR to better address chronic disease management concerns. Their potential dialectical synergy as partners, via a CBPR approach, could help to improve population health using their combined efforts to maximize and/or sustain human health as best as possible. Yet, fragmentation of services still predominates.

Input by communities through a CBPR approach has a further potential to enhance continuity of care which refers to the organized, coordinated and steady passage of individuals through a system of care and services^[21]. However, existing infrastructural resources in Canada and other countries to carry this out are lacking, as is research on such facets as hospital-community collaboration^[22].

Enabling and empowering community input, in partnership with health care professionals, to improve health care planning and decision making continues to be problematical as barriers to develop a CBPR approach remain daunting. Poland *et al.*^[22], for example, indicate that while hospital and community collaborations are widespread, there remains an unfavorable policy environment and hospital institutional culture that inhibit collaborations to transpire. Moreover, this group of researchers has determined that for such collaborations to flourish or exist at all crucially depends on the presence and ongoing enthusiasm of one of more “champions” within a given hospital and a commitment of both communities and hospitals to overcome their ideological differences. Persistence is needed as CBPR requires a substantial time commitment over a long period, as well as equitable sharing of resources^[7].

As CBPR matures, tensions associated with such aspects as relations of power, privilege, participation, community consent and the role of research in social change will become increasingly recognized^[1]. Amidst such conflict rests opportunity for policy changes that would support values that guide good health care, such as being more accessible, ethical, patient-centered and

accountable, while also having much greater public input. Indeed, such goals are becoming more emphasized through such initiatives as the Romanow Commission^[4]. In such countries as the United States and Canada there has been little research to date as to how community-based participatory research can affect public policy^[22]. Therefore, more reflection and work in this area is encouraged, as is support for improved infrastructures to enhance self-care^[23 - 26].

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