Evaluation and Program Planning xxx (2016) xxx–xxx

Contents lists available at ScienceDirect

Evaluation and Program Planning

journal homepage: www.elsevier.com/locate/evalprogplan

Concept mapping methodology and community-engaged research: A perfect pairing

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ARTICLE INFO

Article history:
Received 3 August 2016
Accepted 22 August 2016
Available online xxx

Keywords:
Concept mapping
Participation
Community engagement
Community-based participatory research

ABSTRACT

Concept mapping methodology as refined by Trochim et al. is uniquely suited to engage communities in all aspects of research from project set-up to data collection to interpreting results to dissemination of results, and an increasing number of research studies have utilized the methodology for exploring complex health issues in communities. In the current manuscript, we present the results of a literature search of peer-reviewed articles in health-related research where concept mapping was used in collaboration with the community. A total of 103 articles met the inclusion criteria. We first address how community engagement was defined in the articles and then focus on the articles describing high community engagement and the associated community outcomes/benefits and methodological challenges. A majority (61%; n = 63) of the articles were classified as low to moderate community engagement and participation while 38% (n = 39) of the articles were classified as high community engagement and participation. The results of this literature review enhance our understanding of how concept mapping can be used in direct collaboration with communities and highlights the many potential benefits for both researchers and communities.

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1. Introduction

Concept mapping (CM) is a research methodology that is uniquely suited to engage many types of communities in broad aspects of research from project set-up to data collection to interpreting results to dissemination of results (Burke et al., 2005; Walker, Jones, & Burke, 2014). Since Trochim's 1989 article where he outlines the refinement of CM as a research methodology, CM has been applied in numerous fields and various contexts (Behar & Hydaker, 2009) and has received growing attention as a participatory research method useful for community health (Burke et al., 2005). An increasing number of research studies of health topics have utilized the methodology for exploring complex health issues in various communities [i.e., cancer screening (Ahmad, Mahmood, Pietkiewicz, McDonald, & Ginsburg, 2012), strategies to increase physical activity (Kelly, Baker, Brownson, & Schootman, 2007), youth development programs (Urban, 2008), health disparities (Risisky et al., 2008), obesity and bullying interventions for youth (Vaughn, Jacquez, & McLinden, 2013), strategies to address HIV/AIDS (Abdul-Quader & Collins, 2011; Szaflarski, Vaughn, McLinden, Wess, & Ruffner, in press), and immigrant experiences (Haque & Rosas, 2010)]. However, to date, there has been no review of peer-reviewed CM literature in health research across the continuum of community engagement in terms of application and methodological challenges.

How "community" is defined in community-engaged approaches to research can be a point of much confusion. The most basic definition is "those who have a shared unit of identity" and describes community as an expansive and inclusive concept (Burke et al., 2013). For example, under this definition, patients with a shared experience (e.g. seniors living with chronic pain) are

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http://dx.doi.org/10.1016/j.evalprogplan.2016.08.013
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Please cite this article in press as: L.M. Vaughn, et al., Concept mapping methodology and community-engaged research: A perfect pairing, Evaluation and Program Planning (2016), http://dx.doi.org/10.1016/j.evalprogplan.2016.08.013

considered a community. In addition, those who live in the same neighborhood or geographic location are considered a community. Communities can be affluent or disadvantaged, small or large. The word "stakeholder" may sometimes be used interchangeably or simultaneously with "community" in research. A stakeholder may be part of a community, or an entire community may be considered a stakeholder. As Burke et al. note, defining who a stakeholder is in research is difficult—there is no standard definition and definitions range widely (2013). In research, and in CM, it is necessary to define community and/or the range of stakeholders to be included at the onset of the project.

Community engagement and participation in research can be considered to occur along a continuum (Clinical and Translational Science Awards Consortium (CTSA) & Comunity Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011; Winer & Ray, 2000). Depending on the project and the stakeholders, community engagement in research varies in the community's level of involvement, decision-making about project design and process, and communication. The continuum ranges from *outreach* (some involvement, one-way communication) to *consultation* (more involvement, two-way communication, connections), to *involvement* (participatory communication, partnership), to *collaboration* (community involvement, partnership/trust building), to *shared leadership* (strong bi-directional relationship, joint decision-making, trust) (Clinical and Translational Science Awards Consortium (CTSA) & Comunity Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011). Another model of participation in research is comprised of four modes: *contractual* (people in the community are contracted to take part in researchers' experiments); *consultative* (people in the community are asked for their opinions by researchers); *collaborative* (researchers work with the community on projects that are researcher-driven and designed); to *collegiate* (researchers work with the community as colleagues in a process of mutual learning with the research process driven and controlled by the community) (Biggs, 1989).

On the partnership, collegiate, and shared decision-making end of the continuum lies community-based participatory research (CBPR). CBPR is a collaborative approach to research that equitably involves all partners, including researchers and community members, in all aspects of the research process (Blumenthal, 2011; Israel et al., 2005; Minkler & Wallerstein, 2008). Over the past decade, it has become increasingly apparent that a CBPR approach is critical to the translation of research findings into action and practice (Wallerstein & Duran, 2010). Though often incorrectly classified, CBPR is not actually a specific research method. Rather, CBPR is an approach to research that seeks to empower communities and stakeholders as partners in the entire research process, from idea generation and data collection to dissemination and implementation of research findings (Minkler & Wallerstein, 2008). CBPR stands in stark contrast to many traditional research approaches which are researcher-driven and lack shared decision making with community partners (Minkler & Wallerstein, 2008; Szaflarski & Vaughn, 2014). Compared to research that is conducted *on* the community by outsiders (usually well-intentioned academic researchers), CBPR emphasizes co-research, empowerment and capacity building, partnership, and bi-directional leadership and decision-making in collaboration with communities who have traditionally had little input to the research process (Vaughn, 2015). In CBPR, the community members are viewed as valuable experts instead of being seen as disinterested or unqualified to partner in research due to lack of formal research training (Vaughn, 2015).

Community members have unique insights that should be used to enhance our understanding of a given phenomenon. Involving community members from the start of a research project also helps to ensure that the data collected reflects their lived experiences and can be effectively translated into practice (Jagosh et al., 2012). According to Burke, Trauth, and Albert (2014) "when appropriate, based on the intent of the project, enhanced community inclusion into the research process can enrich a study" (p. 14). Many studies use the nomenclature of CBPR and community-engaged research. However, there is wide variability in the extent to which the community serves as a reciprocal partner with the academic researchers (Jacquez, Vaughn, & Wagner, 2013). In addition, the confusion is amplified due to terms that are often used synonymously in the literature—community-based participatory research, action research, citizen science, community-engaged research, community-partnered research, participatory action research, and participatory research (Jacquez et al., 2013; Jagosh et al., 2012; Viswanathan et al., 2004). See Table 1 for definitions of these related terms.

CM is uniquely suited to directly engage multiple types of community members at each step of the process "so that they become research collaborators, contributing more than responses to questions" (Burke et al., 2005, p. 1394). Beginning with the preparation step in CM, community members can be partners who share leadership with researchers to define the community/appropriate stakeholders and decide on a focus prompt that will answer the research questions and fulfill project aims. In the subsequent steps of CM, community members can collect, organize, analyze, interpret and prioritize data. Stakeholders can provide data in both individually and in group settings. The visual representations of CM data (e.g. point maps, cluster maps, pattern

Table 1
Nomenclature and definitions of various models of community inclusion in the research process.

Action research is a broad family of social research methodologies that aim "to contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration within a mutually acceptable ethical framework" (Rapoport, 1970; p. 499). Introduced by Kurt Lewin in 1946, action research was intended to generate theory while the researcher simultaneously acting on or in to change the social system (Susman & Evered, 1978).
Citizen science is the involvement of the public or nonscientists in research (Bonney et al., 2009; Purdam, 2014). Citizen science ranges in the degree to which the public actually participates in research (contractual, contributory, collaborative, co-created, collegial) (Shirk et al., 2012).
Community-based participatory research is a collaborative approach to research that equitably involves all partners, including researchers and community members, in all aspects of the research process (Blumenthal, 2011; Israel et al., 2005; Minkler & Wallerstein, 2008).
Community-engaged research involves "inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership of people affiliated with or self- identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community of focus" (Ahmed & Palermo, 2010, p. 1383).
Community-partnered research is an approach to research that involves academic researchers working in collaborative partnership with communities with the emphasis on community perspectives, recommendations, and goals for research (Barnett et al., 2003).
Participatory action research is an approach to addressing societal issues by adapting to the needs of marginalized communities, enhancing knowledge and facilitating action (Brydon-Miller, 1997; Kemmis, 2010; Kidd & Kral, 2005).
Combining social investigation, educational work and action (Hall, 1985), participatory research is a "bottom-up" approach to research that focuses on "knowledge for action" and active engagement of local priorities and perspectives (Cornwall & Jewkes, 1995). Jagosh et al. (2012) define participatory research as "the co-construction of research through partnerships between researchers and people affected by, and/or responsible for action on, the issues under study" (p. 312)

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