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Editorial

Creating culturally relevant and sustainable research strategies to meet the needs of vulnerable populations

ADELINE NYAMATHI, DEBRA JACKSON*, BERNIE CARTER⁺ AND MARK HAYTER[!]

School of Nursing, University of California, Los Angeles, CA, USA; *Faculty of Nursing, University of Technology, Sydney, NSW, Australia; *School of Health, University of Central Lancashire, Lancashire, UK; 'Faculty of Health and Social Care, University of Hull, Hull, UK

t the core of community-based participatory Aresearch (CBPR) is the principle that culturally relevant and sustainable research heralds a mutually intense engagement between researchers and the populations which they are servicing. The Institute of Medicine (IOM) (2002) argues that communities must be involved in the design and implementation of interventions in an effort to effectively reduce health disparities. CBPR is known to integrate these dynamic processes as the empowerment of the community and advancement of scientific knowledge is needed to address health disparities (Coker-Appiah et al., 2009) among vulnerable populations. Seminal authors have defined vulnerable populations as those who are known to experience higher than average patterns of morbidity, mortality and reduced life expectancy as a result of fewer resources and increased exposure to risk when compared to the general population (Flaskerud & Winslow, 1998).

For the last 30 years, several theoretical models have successfully guided research among vulnerable populations. For instance, the vulnerable populations conceptual model (VPCM) is one model which has considered the interrelationship among resources, relative risk, and health status (Flaskerud & Winslow, 1998). Correspondingly, the rigorously tested comprehensive health seeking and coping paradigm (CHSCP; Nyamathi, 1989), originally adapted from Lazarus and Folkman (1984). Stress and Coping Model and the Schlotfeldt (1981) Health Seeking Coping Paradigm, has guided dozens of research publications incorporating the gamut of qualitative methodology to clinical trials, conducted with at-risk populations including homeless and drug addicted populations (Nyamathi, Flaskerud, Bennett, Leake, & Lewis, 1994; Nyamathi et al., 2012) to impoverished populations living with AIDS

in rural villages in India (Nyamathi et al., 2011a, 2011b). The CHSCP considers a broad array of factors that impact vulnerability – some of which include: situational; personal; resource-related; cognitive; and coping strategies; all of which impact outcomes (Nyamathi, 1989). Regardless of the model utilized, theoretically driven interventions must be culturally sensitive and build on the strengths and skills of the community in order for them to work effectively and empower populations to improve overall health and well-being.

At the nucleus of CBPR is the belief that interventions that incorporate cultural beliefs and values of the participants are critical to impacting effective outcomes. Key principles include respecting the diversity and identity of the community, reducing social inequities by empowering and promoting colearning opportunities, and enhancing community capacity by building on community strengths and resources (White-Cooper, Lewis, Green-Moton, Grunbaum, & Gray, 2009). In addition, seminal writings of Israel, Schulz, Parker, and Becker (1998) set in stone the principles that define CBPR today. These include: (1) recognizing the community as a unit of identity; (2) building on the strengths and resources within the community; (3) facilitating collaborative partnerships in all phases of the research; (4) integrating knowledge and action for mutual benefit of all partners; (5) promoting a co-learning and empowering process that attends to social inequities; (6) involving a cyclical and iterative process; (7) addressing health from both the positive and ecological perspectives; and (8) disseminating findings and knowledge gained to all parties.

When utilizing CBPR research, respecting the diversity of the community is an integral element of successful interventions. One population of prime importance globally and one of the most vulnerable are those behind bars, in part because of the high rate of illicit drug and alcohol use (California Department of Corrections and Rehabilitation (CDCR), 2009; Substance Abuse Mental Health Services Administration, 2011). Contributing factors to lack of successful community reintegration include ongoing substance use (CDCR, 2009), loss of support from significant others and engagement of coping behaviors that while successful in keeping inmates alive while in prison, no longer are appropriate in a community-based sample. Guided by an understanding of the needs and culture of long-term inmates, culturally sensitive interventions designed by parolees and focused on reducing drug use, recidivism, and promoting positive coping behaviors is currently under investigation. Inclusion of peer coaches, successful ex-parolee role models, to promote skills, non-violent communication, and guide problem-solving when in risky situations is a result of community involvement. Further, the integration of nurse case managers has been requested in terms of ensuring health screening, health education and health promotion.

Among indigenous cultures around the world, namely Aboriginals and Torres Strait Islanders in Australia and rural women living with HIV in India, social inequities and factors which heighten transmission of communicable disease abound. In Australia, as the burden of hepatitis in Indigenous populations is disproportionately high, as compared to their non-indigenous population counterparts (Menzies, McIntyre, & Beard, 2004), creative and targeted strategies need to be considered (Menzies & McIntyre, 2006). The need for these populations to be integrally involved in the design of interventions will contribute to the success of the outcomes to be achieved (Couzos, Lea, Murray, & Culbong, 2005). The notion of inclusion is widely recognized and has been the catalyst for considerable work around Indigenous research participations and the development of specific methodologies (Henry & Pene, 2001).

Among rural women living in Andhra Pradesh, India, ART excessive barriers to antiretroviral medications have resulted in unnecessary and premature death. With 2.47–5.2 million people affected with HIV in India (NACO, 2008; Ramchandani et al., 2007), the importance of integrating lay village women in the support network of this vulnerable subgroup has led to significant increases in adherence to anti-retroviral treatment (ART) CD4 levels, and enhancement of physical and psychological health (Nyamathi et al., 2011a, 2011b). These inclusions have naturally come from the women themselves who suffer the ravages of HIV/AIDS.

Similarly, in Taiwan, a deeper recognition of cultural beliefs about health and parenting have enabled health care providers to become aware of the burden of ill health amongst the under-researched Aboriginal communities and subsequently develop services and interventions in partnership with those communities (Chang & Hayter, 2011; Chang, Lo, & Hayter, 2011). Gaining trusted access to conduct meaningful research with such communities is an essential part of health care evidence gathering – and is *the* key to improving health amongst marginalized, culturally diverse populations.

Building community capacity involves first recognizing, then building on the strengths and resources of the community in an effort to create and sustain effective interventions. Each community is unique and successful negotiation requires the understanding that 'no one size fits all in terms of planned intervention. Researchers need to build community capacity by partnering with community-based organizations, establishing advisory boards made up of community partners, working with the community to clarify the critical research questions, refine study protocols, and interpret and disseminate research findings. This collaborative working relationship is a catalyst for co-learning opportunities between researchers and the communities in need, and enables the development of most effective strategies. For populations with significant social inequities, such as homeless and drug- or alcohol-addicted populations, it is imperative that researchers partner with gate keepers, health care brokers and community partners in an effort to empower and promote facilitation of health care.

Children likewise constitute a marginalized and often overlooked population who have specific needs and have the right to be included in research which will affect them (Carter, 2009, 2011). In the context of community-based research, children are an important group to engage with as they represent the future of the community and could contribute to shaping policy (Carter, 2002). However, despite the rhetoric in the western world, the inclusion of children in research remains patchy with 'pockets of participation' (Franks, 2011, p. 18). Twum-Danso's (2009, p. 379) exploration of the impact of culture on children's participation suggests it is particularly difficult where the 'concept that children have opinions and qualities that can contribute to their communities is also perceived as contentious'. Children's knowledge of their lives, their communities and their health needs can contribute in a fundamental way to meaningful and sustainable community research.

Equally important, it is imperative to understand and respect the limitations with certain systems of care and learn how to ardently maneuver structures to link clients with care (Hayter, 2005). Researchers and health care providers may face challenges in terms of linking clients into care, in such cases, it is imperative to be driven by the mission of providing quality provision of healthcare for patients despite the barriers which may thrive in certain communities.

In sum, CBPR is a powerful tool and method for researchers to utilize when working with vulnerable populations, as well as, those who are hardto-reach. Theoretical frameworks help to guide community-based intervention research which may ultimately uncover antecedents, mediators, moderators and outcomes. In so doing, researchers will be better equipped to address social inequities and disparities among vulnerable populations in an effort to improve health care outcomes.

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