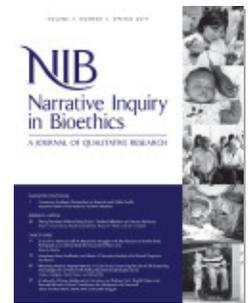




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Engagement and Quality of Life in Under-represented Older Adults: A Community-Based Participatory Research Project

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Community-based Participatory Research (CBPR) is defined as a collaborative approach to research that involves all partners equally in the research process and recognizes the unique strengths that each partner brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving some kind of change in the community partner’s program and certainly improves knowledge for the academic partner. In addition, commonly acknowledged benefits of CBPR to the academic and researchers include an increased investment in and commitment to the research process by the study participants and facilitated participant recruitment and retention. Benefits for the community partner include assuming the role of “partner” rather than “subject”, and having a voice in both setting the study objectives and the design of the project, thus ensuring respect for the culture and goals of the community. Both partners gain from the increased likelihood that the project will be successfully completed. The CBPR model was used to guide our collaborative research project, entitled “Engagement and Quality of Life in Underrepresented Older Adults” at Indiana University with our community partner, Catholic

Charities Indianapolis and their Senior Companions Program (SCP). The Corporation for National and Community Service is the Federal agency that administers SCP nationally and is the major funding source for this program. As the elderly population increases so does interest in ensuring their health and function. The SCP, a volunteer based program of seniors providing companionship to vulnerable community dwelling elders is an excellent example of civic engagement. CBPR is especially relevant in research with underrepresented groups (URG) because the community partner is typically integrated well within the URG. The SCP recruits, trains, supports and matches volunteers aged 55 and older with frail adults in need of support and companionship. SC provide support and touch the lives of adults needing extra assistance to live independently in their homes. SC serve frail older adults, adults with disabilities, those with terminal illnesses and their presence offers respite to family caregivers at no cost to the clients or caregivers.

Our CPBR project was designed to determine elements of wellbeing, physical health and quality of life in the minority elderly participating in the SCP. Understanding the Senior Companion (SC) role and the impact of the SC on the client and, conversely, the client’s impact on the SC has provided valuable information and insight on the effect of meaningful engagement on minority elderly. 60 SC participated in one of 9 focus groups designed to learn more about how the SCP impacts their quality of life as well as that of their clients. SC shared rich stories and examples of how the SCP keeps them motivated, distracts from their own problems as they help clients in need. While our project was designed to understand the elements of participating in the SCP that contribute to and improve quality of life for both the Senior Companions and their clients, the nature of the relationship among the members of the research team, the academic and community partners, is crucial to the success of our work.

Fundamentally, CBPR succeeds when community–academic partners share equal responsibility for the project. While we certainly agree that these elements of CBPR described above are important, we found that the following qualities in our team and working closely together to meet

the requirements to complete the project have been critical to the success of our research:

Positive Partnership Experience

Mutually respectful relationship among the partners and long-standing collaboration existed prior to the initiation of the CBPR. The community-academic partner co-leads undertook the CBPR with a strong foundation of mutual respect and trust built upon a respectful, professional relationship spanning two decades. An essential element of the collaboration was that both partners wanted to learn more about the SCP and what makes it work so well. The community partner knew that rather than collecting data for purely research purposes, they would gain useful information about their SCP that, when applied, will improve both the SC and clients' experiences in the program. The academic partner was careful to create an interdisciplinary team with each member contributing their area of expertise as peers and true collaborators, each open to learning from one another in a congenial, respectful and positive atmosphere. The success of such a relationship would likely struggle within a traditional hierarchical structure if one partner served as the single leader.

The study subjects themselves were very engaged from the beginning. Similarly, during the focus group activity, SC understood that they possessed a wealth of knowledge to share based on their individual experience about becoming an SC and were able to express their unique volunteer experience. Equally important was the fact that SC also played a direct and important role in developing the psychological well-being survey that they were asked complete as part of the pilot project. Four SC reviewed the individual items on the questionnaire designed to measure well-being and selected those items they felt would be most acceptable to the SC to answer. Having SC involved in the design of the project from the beginning increased their interest and excitement for it. Additionally, SC commented on the focus group process as one that "made me feel that what I do as a Senior Companion is important", they felt that the research team "listened to what I had to say", "I could speak the truth" and "felt supported."

Demonstrated commitment and passion to serving the elderly is evident in team members and impacts the nature of our work. The interdisciplinary team, which included social service providers from the community and SCP, medical students, interdisciplinary faculty (psychology, psychiatry, nursing, public health), have had long histories working with and serving the elderly in our community. Our commitment and passion to the population made the project exciting and an extremely positive experience for the team and the team members. The collaborative experience far exceeded the research goals *per se*.

Challenges

Time commitment. The partnership demanded more time than anticipated, particularly in the area of research preparation and follow up. In retrospect, we wish we would have or could have spent more time preparing the facilitators in the use of protocols prior to holding the focus groups. Having sufficient time for the research team to fully plan, implement and analyze the data and successfully manage the resources and budget was a challenge for our team. All good intentions aside, it is very difficult for all team members to be available for all team meetings, data analysis and preparing our work for dissemination.

Support from community leadership. The community partner agency or governing entity must be supportive of the CBRP from the beginning. Without agency support, the demands on the community partner's time could become problematic. In our project, the community partner's agency recognized the benefits of participating in the CBRP—deriving untapped qualitative data to improve program services and the volunteer experience while contributing to the common good through academic research and data analysis.

Collaborative Institutional Training Initiative (CITI). Unlike our previous collaborative activities, the most significant challenge for our community partner was the CITI research training requirement for all members of our team. Our community partner gave some serious thought to pulling out of the project before it even began as the web based modules

about the conduct of research to be completed were daunting. The long standing relationship of the academic and community partner co-leads prevented this from happening as the academic partner worked closely with the community team members to successfully complete the research training.

While it is clear the necessity of assuring all members of the research team are held to the highest standards of research ethics, our non-academic community partner felt that their team was at a distinct disadvantage. The research conduct course appeared to be derived from graduate level material about the conduct of research including complex policies about the ethical conduct of research with which they did not have previous experience. The expectation that community partners from various backgrounds, different areas of expertise, and academic achievement must complete the CITI training prior to the project beginning can create a major obstacle. We believe that that academic partner and funders must reach out to community partners and provide more direction and help with this expectation or the expectation of the training needs to be re-considered as does who really needs such training. We realize that this is a universally accepted and utilized training requirement, academia needs to understand that what was developed within the academic community, when applied to the greater community, puts the greatest burden on the community and quickly places the community at a disadvantage and diminishes egalitarianism so important for building team. While our team was able to support each other as we completed the CITI training requirements, there may be other partnerships that fail or never begin because of this onerous expectation.

Summary

The collaborative nature of the CBPR worked extraordinarily well in our project. It led to a greater sense of collaboration and understanding, not only between the staff members of our community partner and the faculty of our academic partner but also between staff, faculty, and this remarkable group of Senior Companions who were the focus of study. It certainly left us with the goal of continuing our

partnership. The disadvantages were relatively minor, usually associated with trying to impose programs designed for academic settings, for example the CITI training requirement, to the community settings. We look forward to continuing our work together.

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A Belgian Story of CBPR Among People with a Migration Background

Charlotte De Kock

About three years ago, I decided I was in need of a new professional challenge. At the time I had been working as a practice oriented researcher in the social work field for about four years. My previous projects were practice based and policy oriented and involved studying people with a migration background, acceptance of difference in society and fair integration of these people in elderly care and education. These projects also involved amplifying the voices of vulnerable people with a migration background, to open communication about inequalities in general society. In 2015, the Institute of Social Drug Research (Ghent University, Belgium) hired me to conduct and help coordinate a community-based participatory research project on substance use and treatment for addiction in people with a migration background. A challenge indeed because this type of research had never been conducted in Belgium and the topic of the research is understudied in Belgium. We worked with a team of four researchers, each