PROJECT MUSE®

Using a Clinical Outreach Project to Foster a Community-Engaged Research Partnership With Somali Families

Sarah Miner, Dianne V. Liebel, Mary H. Wilde, Jennifer Carroll, Sadiya Omar

Progress in Community Health Partnerships: Research, Education, and Action, Volume 11, Issue 1, Spring 2017, pp. 53-59 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/cpr.2017.0007>

➔ *For additional information about this article*

<https://muse.jhu.edu/article/661292>

Using a Clinical Outreach Project to Foster a Community-Engaged Research Partnership With Somali Families

Sarah Miner, RN, PhD¹, Dianne V. Liebel, RN, PhD², Mary H. Wilde, RN, PhD², Jennifer Carroll, MD, MPH³, Sadiya Omar⁴

(1) NYU Rory Meyers College of Nursing; (2) University of Rochester School of Nursing; (3) University of Colorado, Department of Family Medicine; (4) Refugees Helping Refugees

Submitted 14 December 2015, revised 27 July 2016, accepted 27 August 2016.

Abstract

Background: Community-engaged research partnerships build the capacity of community and educational organizations to work together toward addressing important health issues and disparities for vulnerable populations, such as refugees or immigrants. A critical step for building a community-engaged research partnership is the first contact or *entrée* into the community.

Purpose: The purpose of this paper is to describe how a successful home health community-engaged partnership became the *entrée* and foundation for a community-engaged research partnership to explore the home health needs of Somali older adults and their families.

Methods: A number of strategies were used to engage the Somali community, initially in a clinical home health project and subsequently in an academic research study.

Lessons Learned: Valuable lessons were learned on delivering home health care (HHC) services to Somali older adults and their families as well as conducting research with this

population. The most important lesson was that none of the work could be done without the involvement of the Somali community. The partnership described is one of the first to address the home health needs and experiences of Somali older adults and their families. The project illustrates a mutually beneficial relationship that can occur when a community-engaged clinical project expanded to address an issue of importance to the community through research.

Conclusions: This foundation served to create an opportunity for more comprehensive community-academic partnerships with the potential to improve the delivery of HHC to Somali older adults, as well as open avenues for research in other areas that are relevant to the Somali, medical, and academic communities.

Keywords

Nursing, community health partnerships, community health research, process issues, community health services, refugees, community health worker

Community-engaged research partnerships combine the assets of academic institutions with leadership from the community to address complex health, social and economic issues. Prior research has shown they can build the capacity of community and educational organizations to work together toward addressing important health issues and disparities for vulnerable populations.^{1,2} Community engagement also facilitates the translation of research findings back to the community, decreasing the gap between health research and practice.^{1,3,4} Such partnerships are of particular value when

attempting to address the needs of vulnerable and under-represented populations, such as refugees or immigrants.^{4,5}

Somali older adults in the United States confront difficult health risks, including increased risk of chronic illness and depression when compared with other immigrant groups.⁶⁻⁸ Their lack of familiarity with Western medical practices, health care infrastructure, and differences in religion, language, and culture also limit their ability to access health care and treatment.⁹⁻¹¹ In summary, a growing population of Somali older adults are at risk for decreased health care access and

poor health outcomes; therefore, there is a need to investigate further how to decrease their vulnerability.

Conducting research with Somali older adult populations can be challenging, but community-engaged research has been used successfully to explore health issues and foster collaborations among Somali communities. Many of these partnerships have focused on female and reproductive health issues,^{12–14} physical activity,^{15–17} or the health needs of Somali refugees in general.^{10,18–20} Few studies have focused on the health needs of Somali older adults,^{11,21} and none have looked at the use and perception of home health services, which is particularly relevant given that HHC is designed to meet many of the health needs with which Somali older adults struggle. There is limited but promising evidence that the use of HHC can improve health outcomes for Somali adults^{22,23}; however there are persistent disparities in access to HHC particularly among foreign born populations.^{24–26} Underuse of HHC for groups like Somali older adults may contribute to continued health disparities and poor health outcomes, and therefore needs to be explored further. Additionally, although the use of a community health worker (CHW) with refugee and immigrant populations in the United States and other countries is a well-established practice, less is known about the effectiveness of their role in adult HHC.^{27,28} Further community-engaged research exploring the health of Somali older adults, as well as the value of CHWs in HHC, is warranted. The purpose of this paper is to describe how a community engagement project between a community organization and a HHC agency became the entrée and foundation for a community-engaged research project to explore the health needs of Somali older adults and their families.

THE PARTNERSHIP

In 2002, members of the Somali community in upstate New York recognized that their older adults were suffering with problems affecting their well-being. This led to the establishment of Refugees Helping Refugees (RHR), a 501-c3 community organization dedicated to providing a range of social services to refugees in the community. As the agency grew, members identified they needed help addressing the medical issues of their older adults, and in 2012 RHR leaders contacted a local home health agency. HHC delivers health services in the home and is designed to serve health care needs of patients while incorporating family members and caregivers.^{29,30} The

services offered by the HHC agency matched with many of the Somali older adults' health needs, resulting in establishment of a community-engaged partnership that leveraged resources, expertise, and potential benefit for the HHC agency as well as the Somali community.

The community-engaged partnership between the HHC agency and RHR took place from 2013 to 2014. An interdisciplinary team consisting of a nurse, medical social worker, physical therapist, occupational therapist, and a Somali CHW was established. RHR helped the HHC agency to recruit a Somali community leader for the CHW role who spoke English, was a certified nursing assistant, and had experience in case management. The CHW was particularly important because the HHC agency did not have personnel from the Somali community, which is not funded by insurance. Because of this, the agency applied for and received a small grant to fund this position.

To better understand Somali culture and refugee health issues, the CHW provided training to the HHC team. The team also met with prominent refugee community groups, advocacy organizations, refugee resettlement workers, and health providers for the Somali and refugee communities to discuss strategies for better delivery of HHC services. Collaboration with these groups improved the HHC team's understanding of health needs at the individual and community levels from the perspective of the Somali families, their health care providers, and other community members. It resulted in a network of cross-referrals, where the HHC agency could coordinate referrals for services outside of HHC, and personnel at these programs could refer patients for HHC services. In particular, the CHW role was essential in facilitating HHC with Somali older adults. She arranged for and participated in co-visits with the HHC team, provided guidance on all cultural matters, taught the Somali community about HHC services, and identified and advocated for Somali community members who would benefit from HHC.

Evaluation is a key aspect of community engagement and the success of this community-engaged partnership resulted in one of the nurses involved in it wanting to explore the issues further through her PhD dissertation research.^{4,5} A first step was to examine the clinical outcomes of the patients who had received HHC to determine the effect of this partnership on health outcomes and to provide feedback to the commu-

nity about the impact of the partnership. The results of this community-engaged partnership are explained elsewhere, but these efforts revealed that refugee patients' management of pain, oral and intravenous medications, and functional abilities all improved over the course of their HHC episodes.³¹ The improved clinical outcomes demonstrated the potential for HHC to positively impact the health of Somali older adults, but further research on this topic was needed.

CREATING AND IMPLEMENTING A RESEARCH PROJECT WITH THE SOMALI COMMUNITY

A critical step for building a community-engaged research partnership is the first contact or *entrée* into the community.⁴ The success of the clinical community-engaged partnership established a foundation of trust, respect, and mutual benefit, facilitating the incorporation of research. As a doctoral student, the researcher had the support of the university and her doctoral committee, but the next step to establishing a research partnership was approaching RHR. The researcher met on multiple occasions with members of RHR to gather feedback on the design and method for the research study and to determine the extent of RHR's role in the partnership. The researcher chose to conduct a qualitative, descriptive study exploring Somali older adults' and their families' perceptions of HHC services. The aims of the study were to explore factors influencing the use of HHC by Somali older adults and their families and to describe their perceptions of and experiences with the care and the services offered by HHC. RHR agreed to assist with recruitment of participants and consultation on cultural matters related to data collection and analysis. After discussion with RHR members, the term "older adult" for the study was defined as 50 years or older because it was more consistent with their expectation and their life experiences. The researcher agreed to submit the research proposal to the RHR Institutional Review Board in addition to the University of Rochester Institutional Review Board and to be respectful of RHR time commitments and activities.

Data collection for the study was done with semistructured interviews and home visits. The language of data collection was English or Somali and required an interpreter. Interpreters may have a number of different roles, but it was clear from the community-engaged partnership and the literature that using *per diem* interpreters would not be effective for this

type of community-engaged research partnership.³²⁻³⁵ Rather than hire an interpreter, the researcher chose to hire the CHW previously involved in the community-engaged partnership, understanding how advantageous this would be for continuity and trust. Another added benefit was the CHW had participated in qualitative research before, and hiring a CHW for this role meant she would be able to interpret interviews; help with recruitment, data collection, data analysis; and consult and advise on cultural matters related to the research process.

Preparation for involvement in the community-engaged research partnership by the CHW necessitated completing an on-line human subjects' training module. Although the CHW had formal higher education and was fluent in English, the highly academic language and research vocabulary of the course and the need for computer access all posed challenges for completing it independently. Because of this, the researcher and CHW completed the training module together and used it as an opportunity to teach the CHW about research in general, and this study in particular. They discussed the research questions, aims, methods and the importance of maintaining confidentiality. They also explored possible ethical situations that could arise in the current study and cultural issues and beliefs the CHW could help the researcher to understand. The researcher developed an initial interview guide using concepts from the HHC literature, experience with the community-engaged partnership, and a conceptual model used in previous research with Somali populations.¹² These questions were pilot tested with the CHW to ensure comfort and understanding of interview style and interview questions.

Recruitment for the study was done in partnership with RHR, but the CHW quickly became the main force for recruitment and was instrumental in identifying Somali families who had received HHC from other agencies outside of those involved in the community-engaged partnership. This also meant the timing and flow of participant recruitment was controlled much more by the CHW than the researcher. Once a family was identified, the CHW would call and speak to them to explain the project, and if they were interested in participating, she would arrange a day and time to meet with the researcher, herself, and the family for the informed consent process.

The informed consent process involved a thorough discussion with the participants to ensure they felt safe and understood the process and expectations of their participation

in a research study. Many of the participants were not able to read or write in Somali or English and may not have been comfortable signing papers; therefore, the study was approved to use a verbal consent process. Consent was often done in the home in a group setting with family members present so that all could ask questions, regardless of whether they were going to participate in an interview or not.

Once the informed consent was completed, data collection focused on conducting home visits and interviews. Home visits occurred first, and their purpose was to become familiar and comfortable with the families, and for them to become familiar with the researcher and CHW. During these visits, the researcher used field notes to collect data relevant to their HHC experiences. After home visits, semistructured interviews were conducted, mostly in the families' homes, and for interviews the CHW and researcher used a consecutive style of interpreting where only one person spoke at a time.

Debriefing sessions with the CHW after interviews and home visits was another important form of data collection. Debriefing is a technique used to gain information about cultural and language issues that cannot be discussed during interviews and to document the CHW's observations and opinions on the research process.^{32,36–38} The content discussed during these sessions ranged from technical issues related to recording devices to issues with families that were important in understanding home dynamics. Although the CHW did not participate directly in data analysis, these debriefing sessions were used to provide feedback to the researcher on emerging ideas, possible codes and themes, and as a means of checking and verifying the researcher's understanding of the data.

LESSONS LEARNED

Importance of the Community-Engaged Partnership as a Foundation for the Research Study

The success of the research partnership built on the momentum of the clinical community-engaged partnership. The community-engaged partnership was vital to the transition to the research partnership because the HHC agency took the time and energy needed to form a foundation of trust with the community. Had the community-engaged partnership not been well-regarded, it is more than likely the research study would have encountered larger barriers than it did. Affiliation

with a university and doctoral research was perceived as positive among the Somali community and assisted in maintaining the same level of trust and respect during the research partnership as in the community-engaged partnership. This level of trust and respect was paramount to ensuring that other projects can be done in the future. Members of RHR, the HHC agency, and the research team have co-presented at conferences and continue to participate in manuscript development and publication in relation to the partnership.

Flexible Research Method and Design

Incorporation of community input and compromise on research questions and procedures requires flexibility, beginning with understanding that it was the Somali community that should decide the extent to which they wished to participate. Collaborative discussions focused on how to think about RHR's participation and development of the research study that would include their perspective but also respect the time needed for work with other projects. It was particularly important for this partnership that the researcher teach Somali families about the goals of the study and for the researcher to learn about their beliefs and expectations related to the research process. Families were less interested in understanding about the confidentiality of research and more interested in how it would benefit their older adults. Some families did not like being recorded and having a variety of data collection options, recorded and unrecorded, was crucial to better understanding of Somali families' perceptions of HHC and research. Debriefing sessions with the CHW were invaluable, providing insights essential to informing the research method, data collection, and analysis.

Importance of Using a CHW for HHC and Research

Using a CHW for the community-engaged partnership helped Somali families to learn about and ultimately accept HHC services, and later facilitated their participation in the research partnership. It also clarified the importance of using the right CHW. Beyond language skills, the person had to be active in the community and someone who could be trusted with personal information. Use of a CHW who was recognized and trusted in the community meant families would give the CHW information they never would have shared with the researcher or an unknown interpreter. Likewise, the CHW

could share background information or cultural nuances that affected how and what families disclosed.

Another important lesson was learning how providing paid work to a community volunteer could inadvertently create a power imbalance, negatively affecting the researcher's relationship with the agency and the community. Work on the research partnership was paid, and another community leader at RHR wanted assurance that involvement would not prevent the CHW from doing her volunteer work for the community. If the paid work was given precedence, the researcher could have been perceived as preventing the CHW from performing her work with RHR and the Somali community. Recognizing this and finding a way to address it respectfully was crucial to engaging the community in research and keeping the partnership intact. Thus, the researcher and CHW had a number of discussions leading to a schedule where the CHW could perform her duties at RHR while participating in the research partnership. Using a CHW from the community with a number of additional responsibilities required more flexibility on the part of the researcher, but clearly aligns with current directions in cross-language research.^{34,38–40} The CHW was essential for collecting higher quality data and to the success of this partnership, but more research is needed to explore the use of this role in both clinical and research settings, especially with refugee populations.

Incorporating Somali Cultural Values into HHC and Research in the Home Setting

Somali families valued HHC, but wanted it to be more supportive of their traditional beliefs and family structure. They wanted HHC providers and researchers to understand that caregiving of older adults was an expectation of younger family members and perceived as emotionally fulfilling for those who did it. This was even more important given that, as refugees, many of these families had been separated by war or the refugee resettlement process. The concept of health for these families was holistic, and the ability of families to care for older adults at home was viewed as being as important as medicine, if not more so, to the health of their older adults. They perceived the role of HHC to be important to understanding medication and illness, and their role was to ensure the older adult felt connected to the community and supported by their family. In this way, they wanted HHC

agencies and Somali families to work together for the overall health and well-being of older adults. They understood that HHC providers would not be Somali, but wanted them to understand basic aspects of their culture and Muslim faith. Families expected shoes to be removed when entering the home to keep the floor clean for prayer. Somali Muslim families prayed five times a day, and during this time they would not answer the door or phone. Traditionally, Somali men went to the mosque on Friday, and some (not all) Somali men and women preferred not to be touched by someone from another gender. Entering a Somali family's home, whether for clinical or research purposes, meant being a guest of the family, considered to be very important in Somali culture, and families often expected guests to share food or drink with them. It also meant that telling a guest to remove their shoes or not to touch a member of the family would have been perceived as rude, which is why families wanted HHC providers to understand this before they came to the home. Whether used for scheduling home HHC visits or research interviews, this cultural information was critical to facilitating the process and improving the experience for both Somali families and those who were visiting them in their homes.

Community Engagement as a Cultural Expectation

The final and most important lesson was that neither the clinical project nor the research could have been done without the involvement of the Somali community. This was echoed in HHC interactions, discussion with RHR staff, and with the CHW. Somali families have a cultural expectation that access to services and communication should happen through their community leaders. The process of community engagement for these families was familiar, even if accessing HHC or participating in research was not and using community-engaged approaches gave credibility to the clinical and research partnership.

CONCLUSIONS

The partnership described is one of the first to address the home health needs and experiences of Somali older adults and their families. Conducting community-engaged research is essential to creating and sustaining authentic community-academic partnerships based on accountability and fairness between the partners.^{4,5,41} The community-engaged

partnership described here illustrates how a mutually beneficial relationship can occur when a community-engaged partnership expanded to address an issue of importance to the Somali community through research. Researchers and academic institutions interested in conducting CBPR may want to consider collaborations and partnerships that already exist in the community and explore how research could be added in a way that is meaningful to the community. The foundation created by this community-engaged partnership created an opportunity for more comprehensive commu-

nity-academic partnerships in the future with the potential to improve the delivery of HHC to Somali older adults, as well as open avenues for research in other areas that are relevant to the Somali, medical, and academic communities.

ACKNOWLEDGMENTS

This research was funded by The Transcultural Nursing Society and The University of Rochester School of Nursing. The authors would like to thank HCR Homecare and Refugees Helping Refugees for their participation and support.

REFERENCES

1. Kauper-Brown J. Community-academic research partnerships for health. In: Centre for Urban Health Initiatives Annual Planning Workshop, Community-Campus Partnerships for Health, Seattle, Washington. Powerpoint presentation, Presented May 3, 2004. Retrieved from http://depts.washington.edu/ccph/pdf_files/p-cuhiToronto4.pdf
2. Dixon CG, Rasch JD. Engaging minority populations through community outreach and engagement. *J Rehabil Admin*. 2006;30(1):33–46.
3. Seifer DG. Transformation through partnerships. *Prog Community Health Partnersh*. 2010;4(1):1–3.
4. Handley MP, Potter M, Goldstein OG, et al. Community-engaged research: A quick-start guide for researchers. In: Fleisher P, editor. UCSF Clinical and Translational Science Institute (CTSI) Resource Manuals and Guides to Community-Engaged Research. University of California San Francisco: Clinical Translational Science Institute Community Engagement Program; 2010.
5. Southern California Clinical and Translational Science Institute Office of Community Engagement. A quick start guide to conducting community-engaged research [updated 2012]. Available from: http://oprs.usc.edu/files/2013/01/Comm_Engaged_Research_Guide.pdf.
6. Njeru J, Tan EM, St Sauver J, et al. High rates of diabetes mellitus, pre-diabetes and obesity among Somali immigrants and refugees in Minnesota: A retrospective chart review. *J Immigr Minor Health*. 2016;18:1343–9.
7. Bureau of Refugee and Immigrant Assistance, New York State services to older refugees request for proposals and application. New York State Office of Temporary and Disability Assistance. Albany, NY. 2013. Retrieved from <http://www.otda.ny.gov>.
8. Mirza, M. Unmet needs and diminished opportunities: Disability, displacement and humanitarian healthcare. Research Paper No. 212 UNHCR Policy Development and Evaluation Service. United Nations High Commissioner for Refugees, Geneva, Switzerland. 2011.
9. Morris MD, Popper ST, Rodwell TC, et al. Healthcare barriers of refugees post-resettlement. *J Community Health*. 2009;34(6):529–38.
10. Pavlish C, Noor S, Brandt J. Somali immigrant women and the American health care system: Discordant beliefs, divergent expectations, and silent worries. *Soc Sic Med*. 2010;71(2):353.
11. Deckys C, Springer PJ. The elderly Somali Bantu refugees' adjustment to American healthcare. *Online Journal of Cultural Competence in Nursing and Healthcare*. 2013;3(1).
12. Johnson CE, Ali SA, Shipp MP. Building community-based participatory research partnerships with a Somali refugee community. *Am J Prev Med*. 2009;37(6 Suppl 1):S230–6.
13. Carroll J, Epstein R, Fiscella K, et al. Knowledge and beliefs about health promotion and preventive health care among Somali women in the United States. *Health Care Women Int*. 2007;28(4):360–80.
14. Johnson-Agbakwu CE, Helm T, Killawi A, et al. Perceptions of obstetrical interventions and female genital cutting: Insights of men in a Somali refugee community. *Ethnicity Health*. 2014;19:440–57.
15. Wieland ML, Weis JA, Palmer T, et al. Physical activity and nutrition among immigrant and refugee women: A community-based participatory research approach. *Women's Health Issues*. 2012;22(2):e225–32.
16. Mohamed AA, Hassan AM, Weis JA, et al. Physical activity among Somali men in Minnesota: Barriers, facilitators, and recommendations. *Am J Mens Health*. 2014;8(1):35–44.

17. Marinescu LG, Sharify D, Krieger J, et al. Be active together: Supporting physical activity in public housing communities through women-only programs. *Prog Community Health Partnersh.* 2013;7(1):57–66.
18. Filippi MK, Faseru B, Baird M, et al. A pilot study of health priorities of Somalis living in Kansas City: Laying the groundwork for CBPR. *J Immigr Minor Health.* 2014;16(2):314–20.
19. Culhane-Pera KA, Allen M, Pergament SL, et al. Improving health through community-based participatory action research. Giving immigrants and refugees a voice. *Minn Med.* 2010;93(4):54–57.
20. Springer PJ, Black M, Martz K, et al. Somali Bantu refugees in southwest Idaho: Assessment using participatory research. *Adv Nurs Sci.* 2010;33(2):170–81.
21. Raymond NC, Osman W, O'Brien JM, et al. Culturally informed views on cancer screening: A qualitative research study of the differences between older and younger Somali immigrant women. *BMC Public Health.* 2014;14:1188.
22. Miner S, Liebel D, Wilde MH, et al. Meeting the needs of older adult refugee populations with home health services. *J Transcult Nurs.* 2015.
23. Nguyen D, DeJesus R. Home health care may improve diabetic outcomes among non-English speaking patients in primary care practice: A pilot study. *J Immigr Minor Health.* 2011;13(5):967–9.
24. Davitt JK, Kaye LW. Racial/ethnic disparities in access to Medicare home health care: The disparate impact of policy. *J Gerontol Soc Work.* 2010;53(7):591–612.
25. Kirby JB, Lau DT. Community and individual race/ethnicity and home health care use among elderly persons in the United States. *Health Serv Res.* 2010;45(5 Pt 1):1251–67.
26. Scharlach AE, Giunta N, Chow JC, et al. Racial and ethnic variations in caregiver service use. *J Aging Health.* 2008;20(3):326–46.
27. Lewin S, Munabi-Babigumira S, Glenton C, et al. Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases. *Cochrane Database Syst Rev.* 2010;(3):CD004015.
28. Lewin SA, Dick J, Pond P, et al. Lay health workers in primary and community health care. *Cochrane Database Syst Rev.* 2005(1):CD004015.
29. Zander V, Müllersdorf M, Christensson K, et al. Struggling for sense of control: Everyday life with chronic pain for women of the Iraqi diaspora in Sweden. *Scand J Public Health.* 2013;41(8):799–807.
30. National Association for Home Care and Hospice. Basic statistics about home care. [cited 2010 May 31, 2016]; Available from: http://www.nahc.org/assets/1/7/10HC_Stats.pdf.
31. Miner SL, Wilde M, Carroll J, et al. Meeting the needs of older adult refugee populations with home health services. *J Transcult Nurs.* 2016. In press.
32. Wallin AM, Ahlstrom G. Cross-cultural interview studies using interpreters: systematic literature review. *J Adv Nurs.* 2006;55(6):723–35.
33. Ogilvie LD, Burgess-Pinto E, Caufield C. Challenges and approaches to newcomer health research. *J Transcult Nurs.* 2008;19(1):64–73.
34. Liamputtong P. Doing cross-cultural research. New York: Springer; 2008.
35. Hsieh E. “I am not a robot”! Interpreters’ views of their roles in health care settings. *Qual Health Res.* 2008;18(10):1367–83.
36. Fryer C, Mackintosh S, Stanley M, et al. Qualitative studies using in-depth interviews with older people from multiple language groups: methodological systematic review. *J Adv Nurs.* 2012;68(1):22–35.
37. Wong JP, Poon MK. Bringing translation out of the shadows: Translation as an issue of methodological significance in cross-cultural qualitative research. *J Transcult Nurs.* 2010;21(2):151–8.
38. Shimpuku Y, Norr KF. Working with interpreters in cross-cultural qualitative research in the context of a developing country: Systematic literature review. *J Adv Nurs.* 2012; 68(8):1692–706.
39. Squires A. Methodological challenges in cross-language qualitative research: A research review. *Int J Nurs Stud.* 2009;46(2):277–87.
40. Squires A. Language barriers and qualitative nursing research: Methodological considerations. *Int Nurs Rev.* 2008;55(3):265–73.
41. Ahmed SM, Palermo AGS. Community engagement in research: Frameworks for education and peer review. *Am J Public Health.* 2010;100(8):1380–7.