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## The Mother–Daughter Health Collaborative: A Partnership Development to Promote Cancer Education

**Maghboeba Mosavel,**

Department of Social and Behavioral Health, Virginia Commonwealth University, School of Medicine, McGuire Hall Annex, 1112 East Clay Street, Richmond, VA 23298, USA, mmosavel@vcu.edu

**Teleangé Thomas,**

Sisters of Charity Foundation of Cleveland, 1228 Euclid Ave, Cleveland, OH 44115, USA, Tthomas@socfdncleveland.org

**Kimberly Sanders,**

NorthEast Ohio Neighborhood Health Services, Inc., 8300 Hough Ave., Cleveland, OH 44103, USA, faithhealer777@aol.com

**Lydia Hill,** and

Mental Health and Substance Abuse, Cleveland Department of Public Health, 1925 St. Clair Avenue NE, Cleveland, OH 44114, USA, lydiahill911@mac.com

**Marcia Johnson**

Haven 4 Hope, 1480 East 196 Street, Euclid, OH 44117, USA, haven4hope@yahoo.com

### Abstract

Creating meaningful partnerships with community partners to address cancer disparities remain challenging and a work in progress. This paper examines what started as the traditional formation of an academic–community partnership and evolved well beyond the initial research tasks. We evaluate the partnership process, which includes assessments by the members of the Mother–Daughter Health Collaborative, focusing on how partnership involvement in the data analysis process contributed to a sense of ownership and urgency about providing cancer education. The work of partnership is ongoing, fluid, and challenging.

### Keywords

Health disparities; Academic–community partnerships; Cancer education; Mother–daughter communication; African-American; Low-income; CBPR

### Introduction

While cervical cancer is considered a cancer control success story, disparities continue to exist in mortality rates [1] and access to preventive services [2]. Low-income, minority populations are less likely to engage in screening and are more likely to have their cancer diagnosed at a later stage [3]. African-American women continue to have the highest rates of cervical cancer mortality, despite the general decrease in cervical cancer incidence [3, 4].

The need to establish innovative partnerships is critical to addressing cancer disparities. In their report on overcoming cancer health disparities, the National Cancer Institute (NCI) advocates innovative community-based solutions to improving cancer health outcomes in under-served populations. The goal of this paper is to demonstrate the evolving nature of a community-academic partnership to address cancer disparities among African-American mothers and daughters. In particular, this paper illustrates how the commitment to partnerships often becomes evident through participation in the data analysis process. We demonstrate how the process of being engaged in data analysis of focus group data played a significant role in providing the partners with a more comprehensive understanding not only of research but more in-depth information even about the complexity of needs within many of their own communities of service. In this paper, the focus group data is merely used to provide a backdrop to, and a rich context for, the evolution of the partnership.

### Community-Based Participatory Research and Partnerships

Theory tends to portray an ideal of community-based participatory research; however, the reality for many researchers is that they are able to effectively engage the community and establish partnerships with varying degrees of success [5-7]. This paper reports on the evolution of a creative research partnership with a specific group of stakeholders—community service providers. These are usually paid professionals affiliated with a community organization. They often have extensive experience working with a community or health issue and can be especially instrumental when designing and conducting research [8].

Increasingly, academic researchers are acknowledging the necessity of forming community partnerships [9]. In fact, many funders now expect the development of meaningful and sustainable partnerships [10, 11]. However, many of these partnerships are still initiated by the academic researcher, which may be considered by some to be inadequate [12]. This paper argues that not all academic research-initiated partnerships should be dismissed. The specific manifestations of partnerships are determined by a combination of the researcher's and the community's needs. Nevertheless, partnerships are best sustained by the passion and commitment of their members. While researchers have recognized the importance of sharing results, relatively little has been written on the practice of knowledge transfer to the community [13-15]. We discuss how our collaboration of community service providers established and transformed its identity by translating academic research results into an accessible format of cancer education in underserved populations.

### The Process of Partnership

**Data Sources**—The context for establishing this partnership was to guide the development and implementation of research to address cancer disparities. In particular, the goal was to examine the cultural feasibility of utilizing the adolescent daughter to provide her mother with cancer screening information. Data sources for this paper include documented reports by each member of the collaborative. We asked each member of the collaborative to: (1) examine the reasons for their involvement in the group, (2) identify the factors that strengthened their commitment to the collaborative, and (3) describe the challenges of being part of this group. Each member provided written feedback. The majority did so via email, except for one partner who wrote her feedback in longhand. The written feedback from individual group members was combined with notes from meeting minutes accumulated throughout the partnership.

**Development of the Partnership Team**—The choice for members of the partnership team was determined by the cancer focus group and its impact on low-income African-American mothers and daughters. Members were asked to describe how they became

involved. Prior to the formation of the collaborative, the PI and first author, MM, and TT (co-author) had a strong collaborative, mutually beneficial working relationship. Both MM and TT were part of group reviewing current and upcoming community-based cancer research projects. Based on this working relationship and TT's strong community involvement, the PI approached TT to help her start an advisory community. These two then identified other providers whose work focused on youth, advocacy, women's health, community outreach, and/or cancer education. They intentionally identified some service providers who lived and work in the targeted communities. Initially, a total of six providers were invited to an introductory meeting. Two stopped attending after two or three meetings, and it was subsequently learned that one made a job change and one was retrenched. Two were from the targeted neighborhoods. These service providers represented organizations that worked with minorities on neo-natal care, mental health, substance abuse, and access. One of the organizations provided services that include conducting home visits with young mothers and linking them to various resources that supplied the family with necessities, such as diapers and baby food. Another organization provided chemical dependency treatment to adults and also offered a youth drug prevention program. Similarly, one of the services providers worked with neighborhood youth and had a peer-to-peer mentoring network. Another organization served a community health center that offered accessible, comprehensive primary care to families and also provided ancillary services to low-income African-Americans in the neighborhood.

In response to the question concerning how they decided to become involved, everyone indicated that it was the strong previous work relationships with other members of the collaborative combined with their interest in cancer education that motivated them to join and then to continue to attend. In particular, one member said that she became serious about her involvement after the PI wrote a letter of support, and she subsequently received funding, for a mother–daughter retreat in the community. Members said that it was the sense of purpose and camaraderie that they had with each other that motivated them to be part of this group. They also said that they benefited personally and professionally from being part of this group. In this regard, one member said: *being a part of the MDHC has strengthened my community networking skills. It also gave me women in my life to add to my sisterhood.*

**Being part of the data analysis:** The PI decided to ask the members of the collaborative to become involved in the data analysis of the focus groups data (N=12, six with mothers and six with adolescent girls). The goal was to provide members of the Collaborative the opportunity to interpret the findings but also to provide their organizations with formal feedback on the concerns of mothers and daughters. The focus group data had no identifiable information attached to it and any location information was removed. Collaborative members were instructed to read the focus group transcripts and to make summaries of the themes. At each meeting, the group discussed two transcripts. Recognizing that reading transcripts would require a bigger time commitment, members were offered a small stipend. However, they all chose to have their stipend routed to a mother–daughter retreat hosted by one of the members.

Being part of the data analysis process initially appeared intimidating to one member. She said: *I didn't know what to think. I never participated in data analysis. Working with youth I had only collected data—someone else always took it from there.*

All four members of the collaborative indicated that it was being part of the data analysis process that fully emphasized to them the urgent needs of the community about cancer education and also the communication needs of mothers and daughters. Up to this point, they felt that they really knew the issues but at least three members described the reading of the transcripts as being an “eye opener”. One said: [*Being part of the data analysis process*]

was informational on a personal level and also letting me know that the work I'm doing is important. Involvement in the rigors of the data analysis process helped several of them to develop a stronger appreciation for the integration of research and practice. One member said that she gained a broader understanding of research: *I learned that research is not just science based, it is also history based. I also see how it connects the past to the future.*

**The data analysis process might have influenced the group name:** The name of the group itself was a work in progress. It was only after a year of working together and specifically after engaging in the data analysis process, that the group spontaneously decided on a name. At first, the group named itself the Mother–Daughter *Cancer* Collaborative. However, several members later expressed concern about the name they had chosen. Most of the concerns about the name of the group surrounded the usage of “cancer” in the name. One member said: *The word cancer tends to be very scary and intimidating in the African-American community. When African-Americans hear “cancer” they instantly think of death. Most people in general do not want to hear about something that could affect them to the point of death. Most people would rather if it is going to happen then just happen quickly.* Another member cited her involvement with the data analysis that made her sure that simply focusing on cancer was a limited approach. *Although cervical cancer and HPV are our primary focus, the research [findings] also indicates that our efforts would be futile if our approach simply addressed cancer without addressing the many ailments that affect women in general.* Another example is captured with this member’s comment: *Cancer is still taboo in the African-American community. Additionally, fear and negativity are associated with the word. African-Americans still associate death, dying and hopelessness with cancer. We did not want to deter potential participants from attending the data dissemination or any future programs: it was mutually agreed that the word “cancer” would limit initial engagement and buy-in from the community. Subsequently, the group changed “cancer” to “health” and since then this partnership is known as the Mother–Daughter *Health* Collaborative.*

**Data analysis highlights the need for mother–daughter cancer education:** At the final meeting, one member asked a question which, in fact, determined the future path of the collaborative. She essentially asked the group: *“Now that we are done with data analysis, how can we tell our people what we found?”* The group expressed a strong motivation to disseminate the research findings to other low-income African-American mothers and daughters. The group organized and held a one-day workshop, which they promoted as a “Research in Action Day.” The objective was to take the findings and to do something practical with the data. The Research in Action Day program focused on key themes such as, cervical cancer screening, human papillomavirus, African-American attitudes towards cancer, and the mother–daughter relationship. The cancer education event showcased the individual strengths and skills of the Collaborative members, such as one member’s extensive experience working with youth, another’s capacity to establish rapport with large community groups, and another’s ease working with women in community-based health promotion. One member admitted that she initially had some skepticism about translating data into something practical. *My initial thoughts ranged from skepticism about how the mothers and daughters would view the researchers to excitement of how much information could be gotten out to the community through youth.*

Since the “Research in Action” day, the collaborative has organized and hosted three additional cancer education workshops with mothers and their adolescent daughters. Thus far, the collaborative have provided cancer education to more than 60 mother–daughter pairs.

**Challenges**—The time commitment was a challenge for most members. As one person indicated: *Being a member of the mother–daughter collaborative can be very time consuming when you have many things to complete with your regular job, (and) then try to incorporate activities with the MDHC.* Similarly, the evening and weekend cancer education workshops posed some difficulty to even the most committed members. Moreover, some members regarded their involvement in the data analysis process as challenging. “My challenge was keeping my ‘service provider hat’ on. I kept thinking with my ‘old school parent hat’ when reading the comments of the participants.”

## Discussion

This paper illustrates an effort to engage a specific stakeholder voice that of community service providers, to partner on a research project. What emerged from this partnership was an ownership of the cancer agenda and a strong motivation to expand the research focus to include cancer education workshops for mothers and daughters. The context for the formation of this collaborative was driven by research that set out to examine the cultural feasibility of utilizing the adolescent daughter to provide her mother with cancer screening information. While the research results clearly indicated the potential for such a paradigm shift [16], the data analysis experience propelled the collaborative to become proactive about disseminating cancer education as well as providing skills to support and strengthen the overall communication with mothers and their adolescent daughters.

Community-based participatory research is ideally intended to be jointly initiated by the community and academia [17, 18]. In practice, however, it is often the case that academics for various reasons initiate the research [17]. Academic-initiated research does not necessarily mean that it cannot have genuine elements of community engagement and participation. This paper illustrates the evolution of the Mother–Daughter Health Collaborative. While this group was indeed initiated by an academic it was able to develop a meaningful group identity and purpose that was much broader than the initial research agenda. The success and impact of this group was marked by the sense of shared responsibility, acknowledgement of each individual’s expertise and a commitment to the well-being and elimination of cancer disparities among African-Americans. It was only during the data analysis process that the cohesiveness of the group was formed. Their rich, multi-layered perspectives brought complexity, yet versatility to the analysis, and involvement in the data analysis was enlightening to the providers themselves. The community service providers’ involvement in the data analysis process also reassured and reaffirmed their passion about their respective community work within the context of their organizational affiliation.

Despite the role of the PI in initiating a partnership, the identity and impact of this group remained fluid and group-driven. It is important to acknowledge that the Mother–Daughter Health Collaborative does not exemplify the ideal community-based participatory type of partnership. However, the strength of this partnership is in how it was able to transform itself and develop its own identity. Another criticism may be that the group did not start with a clear agenda beyond that of the investigator-initiated research question. However, this may in fact be one of the positive elements in that the group was then able, through exposure to the focus group data, to develop its own agenda. Furthermore, while this group engaged in a modified and simplified data analysis process, the benefits of being involved in this process were very useful to members individually and organizationally. Another criticism might include to what extent paid professionals, i.e., community service providers, represent low-income, African-American communities. This is an important and valid question. These community providers were carefully chosen not only because of their knowledge of the community, but also because of their level of grassroots involvement with the targeted

group. Community service providers, even if they live in the targeted neighborhoods, may not have the same insights as community residents. However, they are an important group of stakeholders, which in this case demonstrated that they can disseminate and translate research into practical and tailored cancer information.

The evolution of an academic-initiated research agenda into a community cancer education agenda is possible. This Collaborative illustrates how such a partnership developed into a meaningful collaboration that now extends beyond the original research agenda. This paper supports findings that suggest partnerships are created through meaningful engagement and the acknowledgement of local expertise [19, 20]. It is crucial to recognize that community service providers are a unique group of stakeholders; they do not completely represent the community, but they do represent an important voice and a valuable resource. The Mother–Daughter Health Collaborative was functional beyond simply providing credibility to the research, developing into an active group that translated findings into tangible and tailored education for underserved mothers and daughters.

In conclusion, since the formation of this group, this collaborative has continued to conduct cancer education workshops for mothers and their adolescent daughters. Significantly, two of the members have received funding with the PI and are listed as Co-PI's on these grants. Furthermore, all four members of the collaborative are paid consultants on a federally funded grant with the academic researcher. These examples clearly illustrate the evolution of this collaborative and the types of partnerships that are possible when all members are valued and meaningfully engaged.

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