WORK IN PROGRESS AND LESSONS LEARNED

Using our Strengths: Establishing a Community-academic Partnership to Tackle Menstrual Health Concerns in Philadelphia

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ABSTRACT

Background: Menstrual health is a secretive, stigmatized, and understudied topic in the US. To begin addressing this stigma requires understanding menstrual communication patterns in the community; however, few studies have applied community-based participatory research to explore menstrual health stigma.

Objectives: To describe the team and lessons learned building a community-academic partnership aimed to explore menstrual health stigma and communication in Philadelphia, PA.

Partnership: A menstrual health non-profit and a social-reproductive epidemiologist forged a community-academic partnership using a unique program that encourages partnerships between researchers and community organizations.

Lessons Learned: Three lessons are described: (1) take time to build trust; (2) be patient and respectful navigating challenges and unforeseen difficulties; (3) ensure equitable distribution of project resources and benefits.

Conclusion: Our partnership accomplished impactful work by acknowledging the unique resources, skills, and networks that each partner possessed.

KEYWORDS: Community-Based Participatory Research, Health promotion, Community health partnerships, Women's Health, Menstruation

Background

Each day, 800 million people are menstruating worldwide.¹ Despite being a normal, anticipated aspect of human physiology, menstruation is a highly stigmatized topic.^{1,2} People who menstruate often intentionally conceal their menses or suppress communication about their menstrual health experiences to promote their social acceptance and make those around them feel comfortable.² These menstrual taboos are dangerous to overall health and wellness as they deter menstruators from discussing their menstrual health concerns with family, friends, and healthcare providers.² This is concerning, as 1 in 4 menstruators report irregular cycles, such as abnormal menstrual bleeding and/or dysmenorrhea³; further, 1 in 5 menstruators lack sufficient resources needed to manage menses, a growing epidemic known as period poverty.⁴⁻⁶ Therefore, work is imperative to destigmatize menstrual communication to improve menstruator's quality of life.²

However, beginning to de-stigmatize a topic as under studied and shrouded in social secrecy as menstruation is difficult without further research. To promote widespread and stigma-free menstrual health communication, we must first explore and understand current communication patterns surrounding menstrual health experiences at the community level.

Therefore, we used a community-based participatory research (CBPR) model to design a qualitative study to investigate menstrual health stigma and communication practices among women in Philadelphia, PA.

CBPR employs community-academic partnerships to conduct research driven by community needs, not academic interests. CBPR employs specific principles encompassing a myriad of tenets, from respecting the community's preexisting identity to creating a community-academic partnership that allows for equitable collaboration to solve community public health

needs beyond the scope of a single project.⁷ Through combining the academic and community partners' unique skills, talents, and resources, CBPR can be a powerful tool in implementing positive social change⁷ and should be considered during the conceptualization of projects in public health and other social sciences. To our knowledge, few studies have applied CBPR principles to menstrual health research in the USA nor critically reflected on such a partnership between a menstrual health agency and its academic-based partner.

Thus, we developed a community-academic partnership to address menstrual health communication practices among women in Philadelphia. Our aim is to share the lessons learned during the creation of our partnership and implementation of our project, including how the community and academic partners built trust, respectfully handled challenges and unforeseen difficulties, and distributed resources and benefits equitably during our collaboration. By highlighting how to promote the development of future ethically sound and sustainable community-academic partnerships, we hope that this information will be used to further promote CBPR in menstrual health research and other similar areas of women's and reproductive health.

CBPR Principles

Nine core principles underpinning the development and success of CBPR partnerships have been identified by Israel et al.⁷ These principles apply to every stage of CBPR project conceptualization and execution and ensure that community-academic partners engage in fair and ethical research efforts. We will explain which principles were utilized and how they were directly operationalized throughout our work (Table 1).

Partnership Development and Project Cultivation

Community Partner: No More Secrets Mind Body Spirit Inc.

The community partner was No More Secrets Mind Body Spirit Inc. (NMS), the nation's first sexuality awareness and consultative organization and one that launched the only feminine hygiene bank and in-home delivery service in Philadelphia.⁵ NMS is a black-woman-led, grassroots organization founded and operated by a mother-daughter duo (LM, NM), with the mission to "decrease stigmas, silence, and secrecy by increasing self-esteem, socialization, and self-love." Together, NMS spreads awareness about period poverty and advocates for menstrual equity and equal access to menstrual products for all through their missions, including the distribution of over two million menstrual products last year. In February 2021, NMS opened "The SPOT Period," the nation's first menstrual hub. The SPOT is not only used for the storage and distribution of menstrual hygiene products, but also serves as a community safe space where menstruators can feel comfortable participating in vulnerable conversations and educational seminars regarding menstruation; feminine health and hygiene; uterine care; bodily autonomy; and more. The SPOT Period has even inspired satellite menstrual hubs sponsored by NMS, including The Periodt* Menstrual Supply Hub in Lincoln University, PA.

Opportune Meeting

The academic partners include an epidemiologist with expertise in community health outreach and education, and women's health and wellness, currently working in a Department of Family and Community Medicine (ARC); and her medical student-mentee (BK) who has interest in women's community medicine. The relationship between the academic partners (ARC, BK)

^{*}No More Secret's satellite hub "The Periodt Menstrual Supply Hub" uses the intentional misspelling of "period" as "periodt". "Periodt" is a slang term used to emphasize the conclusion of one's thought or emphasize a point, and in this instance, it also serves as a play on word related to menstrual health."

and the community partners (LM, NM) developed from a set of chance events. In July 2019, ARC read a *Philadelphia Inquirer* article⁶ detailing NMS' mission and feminine hygiene delivery program; as a social-reproductive epidemiologist, ARC was thus inspired to expand her women's community wellness research to include menstrual health and hygiene topics. In December 2019, ARC encountered LM at Philadelphia's 2019 Community Driven Research Day (CDRD).⁸ The event was intended to connect academic researchers and community leaders to foster community-academic research partnerships and fund project proposals to answer community-driven questions.⁸ It was set up like a research poster session, where community leaders presented posters detailing their organization and/or initiatives. When ARC encountered LM's poster defining period poverty and how NMS' delivery program works, the two immediately connected over their shared interest in menstrual health awareness and expressed mutual desire to collaborate on a CDRD proposal.

Partnership Progress and Project Conceptualization

Work on the CDRD proposal began in January 2020. During the first proposal brainstorming meeting, LM told the story of NMS, including their motivation for creating the feminine hygiene bank and what concept areas NMS would like to explore through a pilot grant. LM shared anecdotes from the community, noting that most struggle to even say, "I have my period" aloud. She expressed concern and frustration that menstruation is infrequently discussed, despite menstruators' need to talk about their menses. Given NMS' passion for improving menstrual experiences, the team decided that focusing on menstrual communication, including menstruators' discomfort engaging in it, should be the project motivation.

Later that month, the team attended CDRD's Research Readiness Day together, a workshop for fledgling partnerships to learn more about developing successful communityacademic partnerships, creating a community-driven research proposal, and working with community research participants. This session enabled us to finalize our partnership mission, solidify our project approach and methodology, and discuss additional long-term goals we would like to explore together. Although the shared project goal was defined as, "explore the menstrual health experiences and communication norms of women in Philadelphia," the team agreed that this project was only one small piece of our overarching aspirations to normalize menstruation. Therefore, an expanded partnership mission was developed: "to understand menstrual health and hygiene norms, routines, and needs among menstruators in Philadelphia, and use this information to (1) develop and implement educational workshops and outreach programs that improve menstrual experiences and decrease menstrual stigma and shame; and (2) advocate for menstrual equity policies and influence change at the local and state level." The advocacy component was added because NMS advocates for menstrual health awareness and resource support at the local and state levels, visiting with Philadelphia City Councilmembers and Pennsylvania State Representatives (Table 1; CBPR principle 6).

Over several months, we prepared a full proposal with LM and ARC as co-principal investigators (submitted in April 2020). Our award was funded by the Jefferson College of Population Health at Thomas Jefferson University, Philadelphia, PA, in May 2020. Since then, the community and academic partners have been working together and meeting weekly (NM, Executive Director of NMS, and BCK, ARC's Medical Student Research Assistant) to complete our CBPR project - a qualitative study to explore menstrual health communication norms within the catchment population NMS serves in Philadelphia.

Project Setting and Approach

Philadelphia is home to almost 1.6 million people (52% female),⁹ with 25.8% of residents living below the poverty line and about 22% of females ages 18-44 considered to be living in poverty (~88,183 individuals).⁹ NMS serves anyone with menstrual health and hygiene needs; however, its catchment population tends to be women living in Philadelphia neighborhoods with the highest concentrations of poverty, particularly North and West Philadelphia zip codes.

To explore the menstrual health experiences and communication norms of this population qualitatively, we conducted in-depth interviews of cis-gender women aged 18-45 from Philadelphia (N=20) to: (1) describe their menstrual experiences; (2) explore their menstrual health and hygiene communication norms among friends and family, the community, and healthcare providers; and (3) understand the relationship between menstrual communication norms and menstrual experiences. The interviews followed a flexible, semi-structured guide of pre-determined questions and question probes. Through these interviews, we learned about the menstrual health experiences of individuals NMS serves and how women communicate about their menstrual health and hygiene needs, which will be used to inform community resources, educational sessions, and interactive workshops aimed at improving menstrual experiences through improved menstrual communication. We structured the interviews to follow a flexible, semi-structured guide of pre-determined questions and question probes. Upon completion of each interview, participants were given a \$5 Walmart gift card and a 3-month menstrual supply bag.

Strengths-based Role Delineation

All partners worked together through conceptualization; data collection; coding and analysis; manuscript writing and dissemination; and general project administration. We quickly identified how to best differentiate roles and assign different individuals as the lead for various tasks to further foster a collaborative environment, a hallmark principle of a CBPR approach⁷ (Table 1; CBPR principle 3). LM, an educator and skilled communicator with close connections to the catchment population, conducted most interviews. NM, a diligent, organized manager, managed finances and ensured that participant remuneration was fulfilled and consent forms were filed. ARC walked the team through the coding process and ensured the methodology was sound throughout development, implementation, and analysis. BCK, a bright, eager student, reviewed background literature, conducted a few interviews, and drafted sections of manuscripts. Throughout the process, these roles were revisited and revised regularly to adjust to the everchanging environments where we work and live. All partners were involved in finalizing manuscripts produced from our work, including the present paper, and worked together to conceptualize drafts, suggest edits, and give final approval before submission for publication.

Lessons Learned: Ethical and Sound Development of Community-Academic Partnership

Reflecting on the entirety of our collaboration, the community-academic partners identified three key lessons that not only helped us to develop and maintain our partnership, but also fostered team growth. The lessons include: taking time to build trust among each other and within the community; demonstrating patience and respect while navigating unforeseen challenges; and ensuring the equitable distribution of project resources, individual efforts, and benefits.

1. Take Time to Build Trust

Community-academic partnerships collaborate under the expectation that both teams will contribute different, but equitable, parts to the completion of a research project. However, power-struggles may unintentionally exist between the two groups. ¹⁰ Community partners may regard large academic institutions with skepticism and distrust, ¹⁰ deterring research participation. Similarly, academic partners may approach CBPR with a preconceived agenda and without proper consideration of the community's needs. Therefore, to ensure the success and sustainability of our community-academic partnership, we needed to invest in building a foundation of trust between the two teams. 10 Previous community-academic partnerships have demonstrated that trustworthy researchers employ certain strategies to promote fairness and communication among teammates and research participants. These strategies include shared decision making, being approachable and respectful, and ensuring equitable distribution of resources. 8 With these qualities in mind, the academic partners spent time listening to the community partner, asking questions, and learning about what the community needed—rather than imposing an agenda—to collectively finalize the research topic and approach. Furthermore, we designated each meeting as a safe space where members of the partnership were encouraged to ask questions about the research process and could learn from one another's expertise without judgement (Table 1; CBPR principle 4). In the end, the community partner learned more about the nuances of research, the research process, Institutional Review Board (IRB) approval, research ethics, and academic research dissemination, while the academic partners learned more about community engagement and interaction and translating academic results to more conversational, digestible pieces of information that can reach community members. This fostered a sense of co-learning across the team (Table 1; CBPR principle 4).

Trust also needed to be cultivated between the academic partners and members of the community. Initially, we planned to use email recruitment to identify participants; however, NMS receives most of its customer requests through social media, via text message, and through individual word-of-mouth. NMS shared that within this catchment, social vulnerabilities are plenty, but community members are more likely to share personal information regarding why they are reaching out and details on the types of products they need through casual communication on their preferred platform, subsequently opening lines of menstrual communication. NMS' connection with individuals in the community of interest made recruiting research participants a fairly easy process as community members trusted them. Through this association with the "period ladies" at NMS, the academic partners became people the community could trust as well, rather than just an imposing and intrusive institution, when discussing sensitive topics such as menstrual experiences.

Overall, trust also served as our primary collaboration and engagement strategy for our partnership. At the beginning of our partnership, we connected based on our shared interest in bringing awareness to menstrual health and hygiene issues. We were so eager to begin our work that we never fully identified an engagement strategy for developing our partnership, only the specific project goals. However, in retrospect, our primary strategy for growing our partnership and completing our project was based on placing trust at the forefront of everything we did. We trusted in ourselves and in each other. We admired and respected the skills we each brought to the table and were not afraid to speak our minds. We listened to each other, valued each other's thoughts and feelings, and trusted that we would flourish if we cultivated our partnership using these principles.

2. Be Patient and Respectful Navigating Challenges and Unforeseen Difficulties

Community-academic partnerships are not immune to the inconveniences experienced in other research realms. Similarly, our partnership had to navigate the complexities of administrative work required to begin our research, including Collaborative Institutional Training Initiative (CITI) training, Institutional Review Board (IRB) requirements and delays, and accessing safe, ethical computer programming to store and share participant contact information. Overcoming these challenges required patience and respect from each partner. For example, when we experienced unforeseen delays in our proposed schedule due to institutional issues with secure file sharing, the community partners expressed understanding and patience, rather than frustration, as the academic partners worked to resolve these administrative aspects.

Most importantly, in accordance with CBPR principle 1,⁷ health and wellness of community members were the top priorities for both the community and academic partners and trumped any project deadlines or expectations we may have had. Our interviews were conducted via telephone, giving participants greater flexibility than in-person interviews would provide while also keeping everyone safe during the early days of the COVID-19 pandemic. Throughout the project, we often paused our interview schedule due to the social and civil injustices affecting the community. City-wide protests in the wake of blatant racial injustices, a volatile political environment, gun violence, and widespread suffering from the effects of COVID-19 superseded our project – as we understood that we could not ask community members to focus on extraneous tasks such as research interviews while racial identity, basic human rights, and safety were actively being threatened in their neighborhoods.

Unexpected events in interviewee's lives, including changing work schedules, also presented challenges in completing interviews and often required us to reschedule.

Understanding where people stand in the community and respecting that position is a key principle to success in ethical community-academic partnerships and CBPR as a whole. Promoting the health and wellness of the community being studied must be the single most important priority for all parties involved.

3. Ensure Equitable Distribution of Resources and Benefits

The CBPR model not only expects equality among partners during project design and implementation but also in the distribution of resources and rewards. Early in our collaboration, we discussed equitable distribution of resources and benefits among both partners and the community. We had frank conversations about money, salary, and participant remuneration. To allow for more direct funding access, the \$10,000 grant funds were issued directly to NMS as three lump sums to be used for participant incentives, transcription costs, NMS stipends, and a small stipend for our student research assistant. ARC took no salary support or financial assistance. Given that we would be asking intimate questions about their menstrual health, incentives included a traditional NMS menstrual hygiene bag, filled with three-months' worth of products personalized for the participants' needs, as well as a Walmart gift card. However, COVID-19 restrictions prevented us from conducting in-person focus groups, requiring more funds be allocated for longer transcription costs for interviews, thereby decreasing gift card amounts from \$15 to \$5. While not ideal, we did everything possible to maintain the equitable distribution of monetary funds for NMS and for the community members themselves.

To ensured equal benefits for everyone involved in the project, we created a traditional academic-based dissemination plan that included peer-reviewed manuscripts and poster presentations (N=4 academic research papers on our partnership and qualitative interview

findings). Further, we have a conference presentation on qualitative findings and a joint CBPR overview and project findings presentation for the academic partner's institution forthcoming. Also, we developed a specific community-based dissemination plan to share project findings with the population NMS serves (Table 1; CBPR principle 2; principle 3; principle 8).

Since the catchment population uses social media, the team decided to share project findings in a series of Instagram, Facebook, and Twitter posts. Recently, NMS has also become active on Tik Tok; thus, we plan to create a series of short video clips as conversation starters around menstruation. Further, the team will present the project findings at the 2022 Menstrual Hygiene Day event (2021 event postponed due to COVID-19). Additionally, the team is working together to develop an infographic summarizing the findings, to be shared with the community and used during NMS advocacy initiatives, including visits with legislators. This community dissemination plan not only benefits NMS' mission but will help to educate and bring awareness to menstrual health and hygiene issues in their community and potentially further given the wide reach of social media (Table 1; CBPR principle 5).

Sustaining Successful Partnerships

A sustainable community-academic partnership means the partnership does not begin or end with one project (Table 1; CBPR Principle 9). From the beginning, we wanted to have an evolving partnership, reflective of our lives and careers. This included working with each other outside of the project and supporting each other's goals and mission. For ARC, this meant donating menstrual products, attending fundraising events, and sharing NMS' social media posts and updates within her institution. For LM, it meant being able to call on ARC with large and small questions, asking about ways to secure grants for more menstrual products, discussing

ways to connect menstrual health conversations in medical education and medical care, and having her serve as a member of NMS' Community Advisory Board. For both partners, this is easy to do when you truly believe in someone and the work they are doing. ARC will continue to work with NMS to advocate for the inclusion of menstrual products in Medicaid and Supplemental Nutrition Assistance Program (SNAP) benefits in Pennsylvania state legislation. The community and academic partners plan to work together to create additional menstrual and sexual health workshops and educational meetings for community members; develop evaluations for the refinement of these classes; and grow NMS's Community Advisory Board (Table 1; CBPR Principle 7). These efforts are not only a testament to the value of community-academic partnerships in research, but also an example of the far-reaching impact these partnerships can have when appropriately founded and nurtured.

For those looking to initiate partnerships, we recommend exploring events that encourage academic-community agency networking (similar to CDRD). Another way to build a partnership is for academics to get involved with community organization, volunteering and/or and attending advisory board meetings or town halls. This would help to better understand the agency, their structure and mission, and provide insight on their stakeholders and strategic plans for improving the community. Importantly, academic researchers can learn more about the community themselves – touching on CBPR principle 1: acknowledging community as a unit of identity. However, not all communities or organizations will welcome partnership with the intent of scholarly work, and researchers must approach potential partnerships with respect for community-based colleagues. A more in-depth discussion on facilitating partnership establishment for interested community organizations is available from Darling et al. 11

Conclusion

To examine the effects of menstrual stigma on communication norms and menstrual experiences, we developed a partnership using CBPR. Our results will influence the development of educational workshops and community resources through our community partner, NMS. Our community-academic partnership accomplished its most impactful work once we acknowledged the unique resources, skills, and networks that each partner possessed. This partnership offers a model approach for community-based research.

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Ta	Table 1. CBPR Principle and Application in Partnership for Menstrual Health.				
	CBPR	Principle	Principle Operationalized in		
	Principle ^a	Description ^a	Our Partnership		
1.	Acknowledges community as a unit of identity	Sense of emotional connection in a group; may be defined by geographic area or shared sense of identity.	The health and wellness of the community was of upmost importance throughout the project. In the face of the COVID-19 pandemic, local and national political unrest, racial injustices, and general suffering within the community, the CBPR partners understood that community identity and healing were far more important than the CBPR project and project deadlines and methods were adjusted to honor this principle.		
	Begins with and builds on strengths and resources within the community	Build on what already exists; identify, support, and enhance community strengths, skills, and/or networks.	Participants in this CBPR project were asked to share vulnerable information on their menstrual health experiences. Information sharing of such an intimate nature was made possible by NMS' established relationship with the community and extensive social network. Additionally, data gathered from the study will be used to enhance and support NMS' mission through the creation of accessible educational materials, community workshops, and advocacy events at their menstrual hub, The Spot Period.		
3.	Promotes collaborative, equitable partnership in all aspects of the research, involving an empowering and power-sharing process	Partners equally share control and decision-making power over processes; community expertise acknowledged, understood and equitably incorporated.	Each partner's individual skills were identified and roles were assigned accordingly to ensure equitable and unique contributions from each person. This included acknowledgement of NMS' expertise interacting with community members and understanding their communication preferences. To ensure equitable power-sharing, equal access to resources and project benefits were granted to each partner and all project deliverables were given final approval from each individual author.		
4.	Facilitates co- learning and capacity building among all partners involved	Mutual knowledge exchange and colearning between partners; strengthen team effort and partner relationship.	Each meeting between the partners was designated as a safe space for learning and information sharing. Mutual knowledge exchange throughout the project improved each partner's understanding of CBPR: the community partners learned the academic research and data dissemination processes, and the academic partners learned about community engagement techniques and how to disseminate research results as casual and conversational pieces of information accessible to the community.		
	Combines and creates a balance between research and action for the mutual benefit of all partners.	Create new knowledge, while simultaneously contributing to community health and/or action; may include translating research into strategies of community interest.	This project allowed for a new and thorough understanding of the menstrual health communication norms among NMS' catchment population. This knowledge will be used to develop community workshops and educational materials to improve the health and wellness of the community.		
6.	Focuses on local relevance of public health problems and	Topic is relevant to the community and will address community	Our partnership mission was to "understand menstrual health and hygiene norms, routines, and needs among menstruators in Philadelphia" to allow for the development and implementation of		

ecologi	cal	health determinants	community resources to improve menstrual experiences and meet community-identified needs			
	ches that	from an ecological lens.	including period poverty and improved menstrual health communication.			
	the multiple					
	inants of					
	and disease.					
7. Facilita	•	Partnership systems	Partners were able to collaborate to solve expected and unexpected problems throughout the			
-	oment through	developed are able to	entirety of this project by addressing each other with mutual respect, patience, and			
a cyclic		engage in problem-	understanding. These values have contributed to the development of a sustainable partnership.			
iterative	e process	solving processes (e.g.,	Future projects between the community and academic partners include: advocating for the			
		all aspects of project)	inclusion of menstrual products in SNAP benefits, the creation of menstrual and sexual health			
		and for subsequent	workshops and educational meetings for the community, and further developing NMS'			
		projects.	community advisory board.			
-	inates results	Disseminate finding to	Two dissemination plans were carried out to ensure transparency of results to all partners and the			
	artners and	all partners; all partners	community. The dissemination plan for the academic partners includes peer-reviewed			
	s them in the	as co-authors of project	manuscripts and poster presentations. The dissemination plan for the community partners			
dissemi		deliverables and	includes a presentation for National Menstrual Hygiene Day 2022, social media posts to share			
process	•	outcomes.	project findings with NMS' followers, and an infographic summarizing our findings to be shared			
			with the community during NMS advocacy initiatives. All partners are co-authors of these			
0 D	1 ,	E 4 11' 1 4 C	project deliverables.			
	es a long-term	Establishment of	The community and academic partners have fostered a supportive and collaborative relationship			
process		partnership that extends	that extends beyond the completion of a single CBPR project and are committed to continuing			
commit	ment.	beyond single project.	their work both in the community and the state level. Outside of our research endeavors, the			
			partners support each other by attending NMS' community and fundraising events, academic			
D 1	T 1 . 12		presentations, and sharing menstrual health and NMS related social media posts.			
a. Based or	a. Based on Israel et al's principles described in <i>Encyclopedia of Health and Behavior</i> . ⁷					