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FIRST PERSON ACCOUNT

"Just because I have a medical degree does not mean I have the answers": Using CBPR to enhance patient-centered care within a primary care setting

Rachel Siegal[1] | **Andrew Nance**[2,3] | **Atalaya Johnson**[3] | **Andrew Case**[1,4]

[1]Health Psychology Doctoral Program, University of North Carolina at Charlotte, Charlotte, North Carolina, USA

[2]Atrium Health Primary Care Cabarrus Family Medicine, Kannapolis, North Carolina, USA

[3]Community Free Clinic, Concord, North Carolina, USA

[4]Department of Psychological Science, University of North Carolina at Charlotte, Charlotte, North Carolina, USA

Correspondence

Rachel Siegal, 9201 University City Blvd., Colvard 3022, Charlotte, NC 28223-0001, USA.
Email: rsiegal@uncc.edu

Abstract

Patient-centered care (PCC) is a health care delivery model that is considered a means to reduce inequities in the healthcare system, specifically through its prioritization of patient voice and preference in treatment planning. Yet, there are documented challenges to its implementation. Community-based participatory research (CBPR) is seemingly well-positioned to address such challenges, but there has been limited discussion of utilizing CBPR in this way. This article begins to address this gap. In it, we present three diverse stakeholders' perspectives on a CBPR project to enhance PCC within a primary care clinic serving low-income patients. These perspectives provide insights into benefits, challenges, and lessons learned in using CBPR to implement PCC. Key benefits of using CBPR to implement PCC include increasing the acceptability and feasibility of data collection tools and process, and the generating of high-quality actionable feedback. Important CBPR facilitators of PCC implementation include intentional power-sharing between patients and providers and having invested stakeholders who "champion" CBPR within an organization with empowering practices.

KEYWORDS

community-based participatory research, health inequities, patient-centered care

KEY POINTS

- Community-based participatory research (CBPR) holds promise for addressing healthcare inequities by enhancing patient-centered care (PCC)
- In this project, CBPR reduced perceived pressure on the provider and increased patient voice and confidence in decision-making
- CBPR improved program implementation, evaluation, and subsequent recommendations
- A reflexive approach that centered humility and building trust was important for using CBPR in PCC
- Individual champions and organizational readiness seem to be key facilitators of CBPR effectiveness

Eliminating healthcare inequities—unjust differences between populations in healthcare access, use, quality, and outcomes—is a critical focus of health equity efforts (Gómez et al., 2021). Community-involved research can inform the implementation of equity-enhancing efforts and increase the likelihood of their success (Baumann &

Cabassa, 2020). Indeed, community-based participatory research (CBPR) has been used in a variety of healthcare settings such as mental health care, service organizations, and community coalitions to address inequalities in a range of health outcomes from HIV prevention and treatment to violence exposure and mental illness (Case et al., 2014; Hartmann et al., 2021; Stalker et al., 2020; Tapp et al., 2013). Findings suggest CBPR's promise for addressing healthcare inequities lies with its utility in increasing patient engagement, inclusion in decision-making, and health behaviors.

Primary care is "the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community" (Institute of Medicine [IOM], 1978; IOM, 1996). It is a main entry point to the U.S. healthcare system and an important site for health equity efforts. For example, even when access to care, level of need, and sociodemographic factors are similar, Black and Hispanic/Latinx communities report lower rates of health service use and poorer health outcomes than White communities (Manuel, 2017; Sealy-Jefferson et al., 2015). In this context, patient-centered care (PCC) has emerged as an approach to promoting equity in primary care (Epstein et al., 2010).

PCC prioritizes patient voice and preference in treatment planning and, as such, may help eliminate inequities in primary care (Epstein et al., 2010). Yet, challenges exist to implementing PCC in this setting. These include providers being uncertain of how to adapt PCC strategies, lacking the time to learn and use strategies, and having difficulty building relationships with patients who distrust the healthcare system (Blaum et al., 2018; Elliott et al., 2018). While research exploring CBPR use within primary care exists (Tapp et al., 2013), there is a lack of inquiry into *how* CBPR may enhance PCC in this setting. This article begins to address the gap. In it, we present diverse stakeholders' perspectives on a CBPR project to implement PCC within a primary care clinic serving low-income patients. These perspectives provide insights into benefits, challenges, and lessons learned in using CBPR to implement PCC.

PCC: PROMISES AND CHALLENGES

Health care inequities are complex, multifactorial, and interact with other determinants of health to have a disproportionate impact on specific populations that have been marginalized by healthcare systems, including racial/ethnic minority groups and communities with fewer resources (Baumann & Cabassa, 2020). Importantly, these health care inequities are maintained by factors such as a lack of service affordability, a lack of cultural competence, and policy and practices that have fostered patient mistrust (IOM, 2003).

PCC is positioned to help address factors undergirding health care inequities (Epstein et al., 2010). One of IOM's six aims for improved health care (IOM, 2001), it is a model of care which emphasizes respect and responsiveness to patient preferences and needs, transparency, and patient-guided clinical decision-making around evidence-based treatment (IOM, 2001). The dimensions of PCC include respecting patients' values; providing information, communication, and education; and coordinating and integrating care (IOM, 2001). Adaptation of PCC strategies is associated with greater trust and satisfaction with clinical encounters, improved understanding of treatment regimens, and increased adherence to provider recommendations (Rathert et al., 2012; Shay & Lafata, 2014).

Although promising, PCC can be challenging to implement. Studies of primary care providers (PCPs) highlight several barriers to PCC implementation. Notably, these challenges are not wholly distinct from drivers of health care inequities as they are embedded in delivery system structures and the culture and legacy of healthcare (Olfson, 2016; Starfield et al., 2005). Some providers report not knowing how to effectively use PCC strategies and, if using PCC strategies, not using PCC well (Elliott et al., 2018). Others report not having time to implement aspects of PCC such as information exchange and joint decision-making (Elliott et al., 2018), though some reports suggest time might be only a perceived barrier (Sinaiko et al., 2019).

Barriers also exist in traditional health care approaches that PCC is meant to supplant in some ways. Historically, U.S. healthcare has been hierarchical, with providers situated as experts and patients as recipients of providers' expertise (Friedman, 2013). From this perspective, the main issue faced in health care is patient compliance. However, patients engage in better decision-making about care, have greater satisfaction with treatment, and report better health-related quality of life when providers share decision-making power (Ernst et al., 2013; Keating et al., 2002). Furthermore, when hierarchical relational patterns meet provider biases the result can be differential care. A recent national study on advanced care planning (a key component of patient-centered end-of-life planning) found that when providers presumed that their patients would not want to discuss end-of-life issues, they were more likely to side-step the planning process (Ashana et al., 2021). This was often the case for providers working with Black, Hispanic/Latinx, and religious patients. This finding is consistent with other research that suggests that patients who demonstrate greater knowledge of biomedical vocabulary, a proactive disposition toward their health care, and the skill to communicate effectively with their health care providers benefit most from PCC (Nimmon & Stenfors-Hayes, 2016; Rubin et al., 2018). Thus, PCC as an equity-enhancing model of health care may not be equitably delivered across patient populations.

For some patients, lack of trust in a specific provider or the healthcare system is a barrier. In a medical setting, trust reflects the belief that providers or health care organizations will act in one's best interest (Mechanic, 1998). Systemic failures erode trust in providers and negative patient experiences with individual providers can be generalized to the larger system (Smith, 2017). For some patients, medical mistrust has its basis in atrocities such as the Tuskegee Syphilis study and forced sterilization programs, as well as discriminative encounters (Alsan & Wanamaker, 2017; Cuffee et al., 2013). Medical mistrust has important consequences including reduced rates of utilization of health services, engagement with care, and adherence to care recommendations (LaVeist et al., 2009; Williamson & Bigman, 2018). It is higher among Black and Latinx patients compared to White patients, patients of a lower versus higher socioeconomic status, and patients living in rural versus urban areas (Jaiswal & Halkitis, 2019).

CBPR TO ENHANCE PCC IMPLEMENTATION

In principle, CBPR is well-suited to address barriers to PCC implementation. As Baumann and Cabassa (2020, p. 2) argue, "…partnerships with stakeholders from vulnerable contexts are not only ethical, but also enable the development of interventions and implementation strategies that are equitable for all." The goal of CBPR is to involve the community in all aspects of the research process, such that research is conducted "with" rather than "on" or "for" the community (Wallerstein et al., 2019). By involving the community throughout the research process, CBPR can help address key challenges to PCC implementation. Specific CBPR principles lend themselves to challenging counterproductive hierarchies and dynamics in healthcare, including reflexive engagement, redistributing power, and building trust.

Reflexive engagement

Reflexivity in CBPR is focused on navigating the influence of positionality on the research process. Through reflexivity, researchers "turn the gaze on themselves," by questioning their privilege in knowledge production and determining what knowledge is valued and who makes those decisions (Wallerstein et al., 2019). Many CBPR projects have illustrated the power of ensuring that "expert" knowledge and role do not further marginalize nonacademic partners (Haapanen & Christens, 2021). At the same time, a recent commentary calls for a distinction between involvement in the research and opportunities to control or inform certain phases of the project (Haapanen & Christens, 2021). For example, some community partners may have different expectations for a partnership, and reflexivity can be used to identify partners' desired degree of involvement throughout the research process, instead of making assumptions (Haapanen & Christens, 2021).

Redistributing power

CBPR has been used in community research partnerships to address power differentials (Muhammad et al., 2014). Research partners who use reflexivity to understand how their identities and positions impact their power, inform how the research is conducted, and inform how knowledge is created may be better positioned to engage in sustainable, more equitable research partnerships (Muhammad et al., 2014). Specifically, building on reflexive insights, research partners can acknowledge personal and institutional histories of racism, power, and privilege, as well as the historical context of the research. This may include individual and organizational reflection on identity and positionality, equitable funding distribution, and sustainable and equitable community capacity building (Muhammad et al., 2014). Partners may engage in deliberative communication that recognizes community expertise and integrates community knowledge, while also paying attention to academic or research jargon and hierarchies to reduce power imbalances (Muhammad et al., 2014). Other power redistribution strategies include sharing knowledge, validating community partners' experiences, and prioritizing community members' research goals (Wallerstein et al., 2019).

Building trust

Trust is an essential element of CBPR and PCC. Some individuals and communities engaged in CBPR have previously experienced being researched "on" rather than being researched "with" and have subsequently lost trust in working with traditional researchers (Rodriguez Espinosa & Verney, 2021). Trust can be conceptualized as both a process and outcome that can change over time (Lucero et al., 2017). Authenticity, listening, commitment, and recognizing the expertise of the community are all ways that outside researchers can build trust with communities (Lucero et al., 2017). Being present in the community, upfront about expectations, and accountable to those expectations can also facilitate trust-building (Lucero et al., 2017).

CURRENT STUDY

The goal of this study was to illustrate how CBPR, as described above, can be used in primary care to enhance PCC, with a specific focus on CBPR addressing barriers to PCC implementation including traditional hierarchies and medical mistrust. To do so, we describe a CBPR project within a primary care clinic and highlight three stakeholders' perspectives: PCP, academic researcher, and health care patient. These perspectives highlight perceived benefits of CBPR-implemented PCC, as well as adaptation challenges experienced, and lessons learned.

CONTEXT

The Community Free Clinic is in a predominantly urban county in North Carolina and serves patients who have at least one chronic illness, a household income at or below 125% of the federal poverty line, and who do not have private health insurance but do not qualify for Medicare or Medicaid. Before this project, the clinic administration and staff had implemented several procedures to increase patient involvement in care including the creation of a patient advisory board and conducting motivational interviewing. The project that is the focus of this paper emerged through discussions between the PCP, Dr. Andrew Nance, and community psychology faculty for the purpose of an applied class project for a community psychology graduate trainee, Rachel Siegal. The project was supervised by a faculty member, Dr. Andrew Case. A clinic patient, Atalaya Johnson (Laya) joined at the beginning of the intervention and with Rachel and Dr. Andrew Nance, formed the research and implementation (R&I) team.

In July 2019, before Rachel or Laya joining the R&I team, Dr. Andrew Nance received a grant to adapt a Lifestyle Medicine intervention to the clinic. Lifestyle medicine is an evidence-based approach to health care that emphasizes the treatment and prevention of chronic disease through positive changes in health behaviors including nutrition, stress management and relationship building. With grant funding, the clinic implemented a cooking program and food pharmacy to address nutrition, and a healthy living program to address stress management, sleep hygiene, and tobacco cessation.

Following receipt of this grant, health care providers used motivational interviewing with patients to identify potential participants for the Lifestyle Medicine program. If patients' goals aligned with any of the available interventions (e.g., the cooking program, the food pharmacy, the healthy living program), providers enrolled clinic patients in the program. Patient enrollment started in August 2019, and the cooking class and other interventions started the following month. The cooking program took place at the clinic and was designed as a series of 2-h classes, once a week, for 3 weeks. During each class, patients observed a program-trained cook prepare three meals and tasted each of the meals. At the end of each class, patients visited the food pharmacy to receive groceries to recreate the meals at home. Fifteen patients were enrolled in each iteration of the cooking program. Although nutrition and stress management programs were readily implemented, the clinic did not have a program to help patients develop relationships, a core aspect of Lifestyle Medicine. Here, we describe how we used CBPR to develop and pilot the relationship-building program and improve the clinic's PCC approach.

Using CBPR

Rachel joined the R&I team in September 2019. After the first cycle of the cooking program, anecdotal feedback from participating patients suggested that they were already building relationships within the program. To leverage this mechanism for relationship-building, solicit patient participation in the development, pilot, and evaluation process, and engage in the program as a co-learner, Rachel began attending the cooking program in October 2019. Upon joining the class, she discussed the project with patients and asked for volunteers to join the R&I team. Two patients asked to hear more, and one joined the R&I team alongside Rachel and Dr. Andrew Nance.

The R&I team met weekly to develop and pilot a relationship-building program and conduct a pilot evaluation of it. This process was iterative with members participating in steps and parts aligned with their goals and strengths (see Table 1 for varied roles of team members).

STAKEHOLDERS' PERSPECTIVES

The narratives below represent the perspectives of three stakeholder groups on the project and highlight how CBPR was used within this primary care setting and the benefits and challenges of the approach. The order in which these narratives are presented reflect the timing of the individual's entry into the project and is not a reflection of role importance or contribution.

Primary care provider: Dr. Andrew Nance

In a lot of ways, our clinic was primed to use a CBPR approach. We already had a patient advisory board, which met once a month to provide input on clinic decisions. PCPs also were using a motivational interviewing approach, which centers the patient's goals in decision making about their health care and emphasizes provider acceptance and compassion. For example, when patients visited me in the clinic to address their chronic medical problems, I would gauge their interest to make lifestyle changes with a question such as, *"from 1 to 10, with 10 being the most motivated you could ever be, and 1 being not interested in making lifestyle changes, what number are you currently?"* Some patients gave multiple

TABLE 1 Stakeholders' participation in the CBPR process.

Process	Physician	Patient on research team	Other patients in the program	Researcher
Problem identification	X			
Program selection	X			
Grant application	X			
Implementation of CBPR approach				
Program adaptation	X	X		X
Measurement development				
Pre/postsurvey	X	X	X	X
Interview guides	X	X		X
Focus group guides	X	X		X
Data collection				
Pre/postsurvey				X
Interviews		X		
Focus group				X
Data analysis and summary				X
Interpretation	X	X	X	X
Dissemination	X	X		X
Local stakeholder buy-in (e.g., meetings, newsletters)	X	X		X

Note: The researcher was invited to work with the physician following receipt of the grant, at which point the researcher described CBPR to the physician, and they agreed to use a CBPR approach moving forward.

Abbreviation: CBPR, community-based participatory research.

reasons why they could not make the lifestyle changes at this time, but most patients responded with an 8, 9, or 10. When a patient self-identified as highly motivated, I would discuss the Lifestyle Medicine program and ask their permission to place the referral. I often would mention that the information they learn during these classes can help them lower the number of medications and improve their quality of life. I believe that using motivational interviewing in the clinical setting—even in referring patients to the program—set a foundation for the relationship-building that occurred during the Lifestyle Medicine program.

Although I was worried that patients referred to the Lifestyle Medicine program would not show up, they not only showed up, but they often asked to meet more often. What became evident early on was that patients in the program were creating relationships with one another, which included providing accountability to implement the lifestyle changes they learned. At the same time, I was forming stronger relationships with patients while helping to provide accountability. Throughout the program, I would call patients 1:1, or call into a group activity, to check-in on how they were doing and provide accountability for continued involvement. Using a CBPR approach built naturally on the relationships I was already cultivating with patients and strengthened them because, as I'll explain next, using CBPR gave patients more power over their health care decision making.

Although the Lifestyle Medicine program was already being implemented by the time we started using a CBPR approach, we were still developing aspects of this program, and figuring out how to adapt the program to our clinic. At the start, I convened a program development, research, and implementation team (R&I team), composed of Rachel (the community psychology graduate student), and a medical student intern. In using a CBPR approach, we invited patients to join our R&I team. Patients who were interested began meeting with our team weekly. As part of this weekly meeting, they were able to provide immediate input about how the Lifestyle Medicine Program could be improved, what aspects needed to be adjusted, and collaborate on the data collection tool development and implementation. For example, based on input from the patient member of our team, we extended the program to 12 weeks instead of 3 and we began starting the weekly programming with getting-to-know-you activities. Prior to using a CBPR approach, these decisions would not have been made with patient input, and we likely would not have even thought of the ideas.

Engaging patients as team members to participate in the decision-making process about the implementation, adaptation, and evaluation of the Lifestyle Medicine program as it was occurring was new to my practice. This approach built on the patient advisory board the clinic had, and it gave patients even more decision-making power, by engaging patients at a programmatic level. In using CBPR, patients were involved in the decision making as soon as a question arose, because they were already in the room with the health care providers and program staff. Not only did using a CBPR approach mean that patients had more power in their health care decision making, including program development, implementation, and evaluation, but it also had significant benefits for my practice as a PCP.

In using a CBPR approach, where patients were part of identifying solutions, I didn't need to come up with the answers myself, something that is often expected of doctors and other health care providers. Instead, we empowered patients to make decisions about their health care, which optimized health care delivery and, I believe, improved health outcomes. It seems simple when you say it out loud, but this is not often how medicine is taught. In plain words, using CBPR was also more fun and less stressful than my traditional practice. Although using CBPR can take more time, I found myself feeling less symptoms of provider burnout when I used a CBPR approach, because I didn't feel that I only had to rely on myself—I had partners with lived experience engaging in decision making throughout the process. For me, this approach meant that just because I have a medical degree did not mean that I needed to have the answers. Prior to using a CBPR approach, I often felt like I needed to create the perfect program. Using CBPR meant that I could bring my medical expertise to the conversation, patients could bring their expertise, and together we could develop a successful program.

Through this process, I now think about using my role as a PCP to be facilitative and supportive, rather than prescriptive. In my future work, I plan to engage patients more throughout the entire program design—from grant application, to program development and implementation, through data analysis and dissemination.

Community psychology graduate student: Rachel Siegal

This project occurred for me in the context of a class project for a graduate course in community psychology, where I was simultaneously learning about community psychology values and conducting a project aligned with these values. Prior to this project, I had minimal experience using CBPR and very little experience conducting research in healthcare. Using CBPR allowed me to enter the healthcare setting with expertise as an academic and community psychologist-in-training, including growing expertise in research methods such as CBPR. At the same time, I could rely on Dr. Andrew Nance for his expertise in a medical setting, and on Laya for her expertise as a patient. As a student, using CBPR allowed me to enter this new setting with confidence that together we could implement and evaluate the Lifestyle Medicine program.

When I first started on the project, Dr. Andrew Nance's plan was to assign patients to activities in the community so that they could build relationships. As he described, this top-down approach is common in health care and is often reinforced by the idea that the physician has to have all the answers. Informed by CBPR, we instead invited patients to be part of decision-making. To do so, we first invited patients to join the R&I team. As part of our initial R&I team meetings, we discussed our identities which were most salient as part of this project (e.g., physician, patient, researcher), and how these identities influence our perceptions and experiences of power. Through this conversation, we were able to adjust our team's practices, to mitigate some of the power differentials. For example, we changed our meeting time to directly after the cooking class occurred, to reduce travel expenses to and from the clinic. We also reduced our reliance on email communication and opted to bring printed copies of anything that we needed the team to review. These changes—albeit minor—made participating on the R&I team more accessible and equitable.

Creating structures for patient involvement in decision making resulted in near-immediate, positive, changes to the program and evaluation. For example, rather than assign patients to activities (a very prescriptive, top-down, approach), Laya suggested that we start with activities that could take place at the beginning or end of each cooking class. These activities were financially and geographically accessible to all patients, which likely increased their feasibility for patients.

Involving patients and clinic staff (i.e., Dr. Andrew Nance) as members of the research team also improved evaluation of the program because we were each able to use our varied perspectives to inform the evaluation. For example, when developing measurement tools (pre- and postsurveys, and interview and focus group guides), I used my training in program evaluation, while also leveraging my access to the university library. Dr. Andrew Nance identified measurement tools that the clinic already used and made recommendations based on his understanding of the time and resource pressures physicians and clinic staff operate within. At the same time, Laya provided insight into what was important to her to learn about this program, as well as how patients may interpret the questions used in the data collection tools. Additionally, Laya conducted the interviews, because of her insider status as a patient and participant in the Lifestyle Medicine program. She reported that participants would often share something that mired her experience, which would trigger a follow-up question from her. Alternatively, when planning the focus group, Laya indicated that she would prefer to be a participant in the focus group, to ensure that her voice was heard as a patient, rather than as a researcher. So, her engagement as a participant-researcher varied throughout the process.

Patients were also involved in data interpretation. To facilitate data interpretation, I brought handouts of preliminary project results to share with the cooking class, and we discussed patients' questions and feedback. For example, while results suggested that participants' feelings of loneliness decreased, results also showed that participants' did not report any increased feelings of community. In interpreting these findings, patients discussed that a lack of accessible transportation out in the community prevented them from building on the relationships they formed in the class. Patients suggested that a future iteration of the program should enroll people from nearby neighborhoods, so that relationships could be easily maintained outside of the clinic. By incorporating patient and physician insights, we were able to make recommendations to clinic leadership about how to adapt, scale, and sustain the program.

Beyond acting in my role as evaluator, I provided additional support throughout the project. For example, I attended and participated in all of the cooking classes and completed additional tasks like rearranging tables and chairs, bringing snacks, or cleaning up after a cooking class. My participation in the cooking class and contribution to additional tasks helped me to develop relationships with patients and the clinic staff. I believe it also conveyed my commitment to the success of this program and participants' well-being, that I wasn't just “here to collect data”. Although using a CBPR approach involved a large amount of time, I found that this level of engagement resulted in stronger relationships with the R&I team and other participating patients and improved the quality of my work.

Patient: Atalaya Johnson (Laya)

Being a patient at the clinic, a member in the cooking program, and a researcher on the R&I team changed my life. Like other patients at the clinic, before coming here I used the emergency room for health care because I did not have health care insurance. I was thinking about a serious surgery to help control my health and I felt alone with my health care challenges. All of that changed when I joined this program.

First of all, the clinic itself is a community. The health care providers talk to you and treat you like a person; the doctors actually listen to you. When I joined the cooking program and Rachel advertised the research position for a patient, I knew I wanted to be part of the team because of how much the clinic had already changed my life, and I wanted to be part of that for others. What's funny is that as a patient who was now a researcher, I didn't feel confident. But Dr. Andrew Nance would ask for my opinion and with Rachel sitting next to me, I found my voice. Not only that, but I realized I could be a voice for other patients in the cooking class.

In the first few weeks, I would talk to other patients, ask them what they wanted in the cooking class, ask them what they wanted to change and then would share that back with Dr. Andrew Nance and Rachel and we would work to make those changes. After I did the interviews with everyone in the class, people started coming up to me even more and asking about things like help with transportation or needing clarity on a medical question that they wanted me to ask Dr. Andrew Nance about. Being a patient and peer helped them feel comfortable sharing these things with me, and being a researcher ensured that I could relay their concerns to the right people and integrate their feedback into data collection and analysis.

As part of the research team, Dr. Andrew Nance and Rachel asked me to brainstorm activities for each class, and even though they were easy, quick activities, people loved them! One time, Rachel and I were running late, and people in the class had already started the activity without us, because they were so excited. These activities helped us build new relationships because they broke the ice, we could start talking with one another, and then build up a friendship from there. By the end of the program, if someone didn't attend class that day one of us (patients) would text them to check in. We cared about each other.

Dr. Andrew Nance and Rachel really pushed me to step out of my comfort zone as a patient. After the class said that we wanted to do gardening and would love to keep having cooking classes, I went with Dr. Andrew Nance and Rachel to meet with people at the church next door, to talk about the cooking program. The church had a beautiful, stainless steel kitchen that would allow us to meet there and have more people in the class, which would mean providing more support and more food for more people. But I was really nervous about talking with the church members. Dr. Andrew Nance encouraged me and helped me practice, and when I shared my story, my role as a patient and researcher, and the impact I had seen this program have, the church members agreed to partner with us. I was so excited to bring the news back to the class.

Even as a researcher, it was really important to me that I still be seen as a peer to everyone else in the class. People trusted me and felt more comfortable with me because I was their peer. This trust and comfort allowed them to share their stories with me, and with their permission I would bring those back to Dr. Andrew Nance and Rachel so that we could make adjustments. Trust was important between Dr. Andrew Nance, Rachel, and me, too. By working together each week, we got to know each other. Dr. Andrew Nance was still my physician, but he also became a friend. Because of this, I felt comfortable raising issues when they came up. For example, at one point, Rachel and Dr. Andrew Nance missed a meeting with me and another patient. I called Rachel and described what happened, including the frustration I felt. Rachel conveyed the situation to Dr. Andrew Nance who called me back to talk about what happened and figure out how we can avoid this happening in the future. While I thought about not calling Rachel, I thought if I didn't, that I wouldn't be able to continue engaging authentically as part of the team. I also didn't want this type of mistake to occur again.

Overall, the cooking class provided a place where we could come together and learn to eat healthy and live healthy lives. Being part of this project helped me become more confident in myself and do things I never thought I could. I'm proud that I was able to be a voice for other patients, and that I've continued to step out of my comfort level beyond the cooking class.

DISCUSSION

These stakeholder perspectives illuminate how CBPR can help implement PCC and thus help reduce barriers to equitable health care. For practitioners, we found CBPR useful in: (a) mitigating the expectation that providers should have all the answers and (b) enhancing patients' confidence and skills. From a research and evaluation perspective, we found that CBPR contributed to improving implementation-specific factors related to data collection, analysis, and recommendations. While we describe commonly named challenges such as limited time and ensuring an equitable partnership (Boursaw et al., 2021; Wallerstein et al., 2019), we reflect on the importance of building long-term relationships grounded in reflexivity, flexibility, and trust as "pre-work" to using CBPR, particularly in health care settings with empowering elements.

Benefits of using CBPR to implement PCC

We observed that through using CBPR, the provider was relieved of the expectation to have "all of the answers" and instead could work with the research team to respond to challenges and co-create solutions. The provider could bring his medical expertise, while the CBPR approach allowed for patients' perspectives, needs, and preferences to drive necessary innovations and adaptations. The result, from our perspective, was an intervention better adapted and more responsive to patients' needs. Other collaborative partnerships have identified liberation as an outcome of CBPR, for both the community and the academic or medical researchers (Muhammad et al., 2014). Indeed, by using CBPR, the medical provider on our team was able to reject individual and cultural biases that can accrue through medical training and within medical systems (Muhammad et al., 2014) and to show up without "all the answers". In the current healthcare context, where there is some concern that there are not enough health care providers, as well as not enough time and support to effectively implement PCC (Sinaiko et al., 2019), this partnership approach may help to reduce provider burnout.

At the same time, patients were empowered as a result of participating on the research team. The patient on the research team described her growth in confidence and self-efficacy, and increased skills in public speaking, research, and advocacy, as a result of participating in this project. In particular, she frequently referred to both the nervousness she felt when meeting with the church members, and the pride when, as a result of her advocacy, the church agreed to partner with the clinic to host future iterations of the Lifestyle Medicine program. A psychological sense of empowerment, an increase in shared decision-making power, and improved advocacy skills, are frequently described short-term outcomes of using CBPR (Oetzel et al., 2018).

The collaborative approach characteristic of CBPR may provide an opportunity for a deeper level of patient engagement in health care decision making. In PCC, patients are encouraged to ask questions, state preferences, and share decision-making about their health care plan with their provider (IOM, 2001). More meaningful patient engagement in decision making about how their health care is delivered can drive improved health care outcomes by increasing the useability (i.e., the acceptability and feasibility) and sustainability of the health care intervention (Ramanadhan et al., 2018).

Using participatory approaches improves implementation of evidence-based practices in real-world practice and community settings (Ramanadhan et al., 2018). In this study, by involving patients in data collection and interpretation, we created better data collection tools and processes that were likely more acceptable and feasible for participants to use. For example, the patient team member made recommendations on how the tools could be shortened and wording changed, to improve the feasibility of using the tool (Minkler & Salvatore, 2012). Similarly, only the patient team member conducted interviews, as someone who shared lived experiences and ascribed identities with the other patients. Matching the researcher identity with that of the interviewee minimizes social distance, mistrust, and barriers, which can increase the acceptability of data collection and ultimately the validity of the knowledge accessed (Muhammad et al., 2014).

In using CBPR, we interpreted the results with program participants, to provide patient-informed recommendations to clinic leadership. By engaging patients in interpretation, we were able to ground the study findings within the local context and identify recommendations, which may increase the intervention's effectiveness (Minkler & Salvatore, 2012). For example, as noted previously, patients expressed that their lack of geographical residential proximity to each other made it difficult to maintain relationships outside the cooking class. We subsequently recommended to the clinic that future cooking classes enroll patients from geographically proximal locations, so that patients could sustain relationships beyond the initial class. This programmatic shift will likely improve the feasibility of relationship-building, and subsequently increase the effectiveness of the program, contributing to longer-term sustainment of health outcomes (Ramanadhan et al., 2018). In summary, in this study, patient involvement in decision making through CBPR likely contributed to improved health outcomes by improving upon key aspects of program implementation: Data collection feasibility and acceptability, as well as data interpretation and subsequent recommendations to increase program effectiveness (Minkler & Salvatore, 2012; Ramanadhan et al., 2018). Future implementation research should consider assessing changes in acceptability and feasibility of data collection tools, processes, and programming because of changes derived using CBPR.

Challenges of using CBPR to implement PCC

The main challenges we encountered in this project were around time constraints and ensuring an equitable partnership among team members. It is worth noting that these are well-documented challenges in CBPR and not specific to PCC or primary care (Boursaw et al., 2021; Wallerstein et al., 2019). Yet there were some unique dimensions of these challenges for this project. For instance, in terms of timing, Rachel and Laya joined the team after clinic leadership and staff had identified a "problem" and the subsequent solution (Lifestyle Medicine). Ideally, clinic leadership and staff would have been involved in partnership with the community earlier, such that the project itself and subsequent solution(s) would have been identified through a participatory process involving patients and clinic staff (Flicker et al., 2017). Also, this project occurred over the course of an academic semester. While it was successful in achieving key aims, a longer timeline would allow for increased time for relationship building, community engagement, and partnership synergy (Foell et al., 2020; Coombe et al., 2020).

Time constraints were also influential in day-to-day interactions. Dr. Andrew Nance, the physician, had 2 days per week at the clinic, with most of those hours delineated for direct service delivery. Moving forward, Dr. Andrew Nance plans to work with his supervisors to advocate for reduced hours of direct service delivery when conducting a project using a CBPR approach. In healthcare organizations, advocates for CBPR have used the CBPR model as a tool to align board members, executive leadership, and donors to shift organizational practices (e.g., re-allocating budgets and staff time) to support a CBPR approach (Chanchien Parajón et al., 2021). This is a promising next step for our project, and one that may be useful to organizations looking to use CBPR to deepen their practice of PCC.

Engaging equitably in the research partnership required an ongoing reflexive attentiveness about what engaging equitably means, for each partner. For instance, bringing hard copies of documents as opposed to transmitting electronic versions made communication and information sharing more equitable between all partners. Additionally, we adjusted expectations for involvement in the project based on each other's willingness and comfort across the various project stages. For example, although Laya was initially nervous to present to church members about the project, with scaffolding from the rest of the team, she developed public speaking skills, presented to church members, and felt empowered as an advocate. Alternatively, during quantitative data collection and for the focus group, Laya requested to be "100% a patient." This changing level of involvement throughout the project aligns with Haapanen and Christens (2021) argument for a more nuanced approach to understanding and supporting partner involvement in community-engaged research, which integrates considerations for partners' interests, needs, and strengths, the context and goals of the collaborative effort, and the specific project phase. A tool to support conversations about shifting levels of partnership involvement could be useful for practitioners and researchers implementing CBPR, particularly for partners new to this approach.

Key lessons learned in using CBPR to implement PCC

A key lesson learned in this project was the importance of reflexivity centered in vulnerability and humility. As noted, reflexivity is an awareness of the ways in which values, biases, and status influence the research process (Finlay, 2002) and has been conceptualized as a tool that helps the researcher identify and anticipate their impact on those participating in research and determine a course of action that upholds the best interests of participants (Case et al., 2017; Gildersleeve, 2010). Yet, reflexivity is not limited to academic researchers. In the context of healthcare, with its traditional hierarchies, it seems particularly important that providers are reflexive. A literature on cultural humility in the medical profession highlights the importance of ongoing self-reflection.

Dr. Andrew Nance often engaged in an interpersonal reflexive process by repeatedly asking other research team members, “what am I missing?” This question had the potential to invite differing opinions and perspectives that highlighted biases or inaccurate assumptions. We believe that this vulnerable curiosity when exhibited by the physician on our team helped to mitigate power differentials between team members, by indicating an openness to and comfort with critical feedback. With time, “what am I missing” became the way the whole team approached the project. We believe this type of reflexivity helped to build authentic relationships where team members felt comfortable calling in other members, to interrogate and challenge problematic values and prejudices (Rauk et al., 2021). Reflective trust, where mistakes can be made, discussed, and managed, is a key element for successful CBPR partnerships (Lucero et al., 2020). In CBPR projects, reflective trust has been associated with improved processes and outcomes (Lucero et al., 2020). For example, when Laya confronted Rachel and Dr. Andrew Nance about missing a meeting, she was building on a foundation of reflective trust. By fostering reflective trust, through an ongoing practice of reflexivity, we were able to overcome mistakes, and continue working towards our collective goals.

Furthermore, as a result of this conversation, we were able to identify how the miscommunication occurred, and adjust our communication processes so that a similar mistake would not happen again. As a team, we were able to build critical, reflective, trusting relationships with one another that allowed us to hold each other accountable and to collaboratively respond to mistakes and challenges that arose (Lucero et al., 2020). The role of reflexivity in moving from other forms of trust (e.g., functional trust or proxy trust) to reflective trust, may inform the existing theory of trust progress developed by Lucero and colleagues (2020).

Our project flourished on grounds that were already tilled, in part, by broader organizational practices reminiscent of empowered organizations. Empowered organizations have internal structures and functions, through which staff can engage in partnering and empowerment practices, as well as external partnerships and relationships to collaborate and share resources (Chanchien Parajón et al., 2021; Peterson & Zimmerman, 2004). For example, the patient-centered belief system, as well as structures through which this belief system was institutionalized (e.g., the patient advisory board and the use of motivational interviewing), were empowering practices already in place in the clinic. As Laya described, “the doctors talk and listen to you, they actually care.” The long-standing relationship with the church, as well as the newly formed relationship between the university and the clinic, provided avenues for collaboration and resource sharing. These empowering organizational practices were key facilitators for using CBPR in the healthcare setting.

Even within an organization with empowering practices, the importance of individual “champions” in using a CBPR approach arose as a clear lesson. Community psychologists or others drawn to CBPR, naturally attend to and maximize on group processes when doing work to enact social change. Indeed, a literature on organizational readiness suggests an organization's motivation and capacity to implement something new is key to social change, and often requires an individual champion (Scaccia et al., 2015; Walker et al., 2020). We found that individual champions–people with the desire, ability, and capital to move important levers–were an important part of organizational readiness and a catalyst for greater readiness and change.

In the current project, Laya was a patient-champion; she was willing and able to commit extra time to support the CBPR project, advocate for other patients, and step into areas of discomfort. She was pivotal to all the team was able to accomplish because she occupied a critical mediating role between patients, the research team, and the organization. As a patient at the clinic, a participant in the Lifestyle Medicine program, and a researcher on the R&I team, she was able to ‘work the hyphen’ between each of these identities (Muhammad et al., 2014), to utilize her status as an insider, as well as her decision making power on the research team. Similarly, Dr. Andrew Nance was able to use his role as a physician and health care leader to mediate between the organization, the program, and the research team. By having an R&I team who reflected different partners in this work and who were champions of this work, we believe we were able to more effectively engage in a CBPR process and achieve improved health outcomes.

A third lesson learned was the importance of building in a participatory approach from the beginning of the research process, when feasible. Dr. Andrew Nance repeatedly remarked on how he wished he had collaborated with patients during the planning stage, when he first learned of the funding opportunity. We propose that this type of relationship-building in preparation for identifying funding opportunities and implementing solutions should occur even earlier, in a pre-planning stage. Often, partnerships engaging in CBPR are established over months or years of relationship building (e.g., Foell et al., 2020). This longer-term relationship-building process can help these partnerships develop synergy over time, where partners are better able to identify problems and subsequent solutions, adapt them to the local context, achieve goal(s), and have a greater impact on health inequities (Coombe et al., 2020; Oetzel et al., 2018). Investing ahead of time in the resources necessary to build relationships and establish participatory processes, improves the developed interventions, research, and health outcomes (Coombe et al., 2020; Oetzel et al., 2018). The need for this commitment to relationship-building over time, using participatory processes from the start, was a key lesson learned from our experience.

CONCLUSION

While we do not want to paint CBPR as a panacea for addressing health inequities within the healthcare system, we maintain that it can play an important role in redressing issues of trust and hierarchies in healthcare that limit patient utilization and treatment effectiveness. Our CBPR process had utility in implementing PCC in a primary care setting that serves individuals who do not have health insurance and who have limited financial means. This process increased patient engagement in intervention development and evaluation while simultaneously shifting the burden the PCP felt in having to be the one with all the answers. Given these benefits of a CBPR approach, we envision CBPR as part of a promising future for primary care in which PCC is synonymous with equitable care.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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