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LESSONS FROM THE RESEARCH FIELD ON PARTNERSHIP IN PEDIATRIC PRIMARY CARE WITH URBAN, LOW-INCOME, AFRICAN AMERICAN PARENTS

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Abstract

Qualitative data collection offers a unique opportunity to partner with research participants. Lessons learned through the process of data collection with urban, low-income, African American parents are reflective of the research findings themselves. Carefully designed research studies can remove barriers and empower participants, broadening the reach and results. Recruitment within communities develops trust, and focus groups offer a more empowering method for interviewing marginalized populations. Parents desire to have solid partnerships with their children's health-care providers so that with their providers' guidance, their children can flourish. The process of implementing the research itself, and not just the results, reveals strategies for improving partnership between parents and health-care providers.

Keywords: Qualitative Research, Partnership, African American, Pediatric Health Care, Focus Groups

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INTRODUCTION

Most parents can attest to the value of a strong and trusting partnership with their children's primary care provider. The ability to openly ask questions and concerns about

their child's health, growth, development, and behavior and in return to receive the relief and comfort of clear guidance and a plan of action is the essence of the ideal pediatric primary care parent-provider relationship (American Academy of Pediatrics, 2012; American Nurses Association, 2008). The ideal setting for pediatric primary care is in a medical home, which is a model of care that promotes the holistic care of children and families with a focus on family-centered partnerships (National Association of Pediatric Nurse Practitioners, 2016). In a medical home, this parent-provider partnership is characterized by "family-centeredness, compassion, and trust" (Nelson et al., 2005, p. 48). A relationship like this can only be established over time. However, only half of the children in the United States have an ongoing, continuous relationship with their pediatric provider, and African American parents reported an average length of relationship with their child's provider of only six to eleven months (Inkelas, Schuster, Olson, Park, & Halfon, 2004; Stevens & Shi, 2002a).

Many parents struggle to find and maintain this type of relationship with their child's pediatric provider; however, the African American population seems to face additional barriers. African American parents report a decreased length of relationship with their child's provider (Stevens & Shi, 2002a) and report lower overall quality of primary care even when controlling for socioeconomic status and health system factors, such as insurance (Stevens & Shi, 2002b). Additionally, African American parents were more likely to report that their child's provider never, or only sometimes, understands their child's needs and how they wish to raise their child (Flores, Olson, & Tomany-Korman, 2005). And while African American children appear to receive the same basic preventive services as their Caucasian peers, the parents are less likely to experience family-centered care (Diao, Tripodis, Long, & Garg, 2017; Stevens, Mistry, Zuckerman, & Halfon, 2005). African American children and parents are more likely to have no usual source of care, have lower rates of access to primary care providers, and are less likely to attend the recommended number of well-child care appointments (Flores, 2010).

Improving the dynamics between the parents and the provider is essential in achieving quality well-child care, and in turn, equitable child health.

While the quantitative data defines this challenge, the context and experiences of health care that parents have lacks the depth needed to more fully understand the true nature of what contributes to the ongoing disparities in care quality. While we anticipated learning about the context and experiences from the qualitative data analysis, what was not anticipated were the lessons that the study implementation process itself would reveal. This brief paper will share lessons learned through the process of qualitative data collection with urban, low-income, African American parents, and how partnering with parents through the research process itself can provide greater contextual understanding of a marginalized population's experiences of pediatric well-child care.

BACKGROUND

Traditionally, the relationship between pediatric providers and parents took on a dominating, paternalistic approach. Any medical encounter, for that matter, has often been viewed as oppressive because of the nature of the provider bestowing health and knowledge onto an individual (Filc, 2006). However, in pediatric health care, parents view pediatric providers as part of their village in raising children, bearing partial responsibility for the outcomes of each child's growth and development (Hill, 1960). In his article in *Pediatrics* describing the role of the provider in health promotion and prevention, Dr. Hill gave an example of when a father of a 16-year-old boy lamented to him on the phone, "We haven't done a very good job on Joe, have we?" after learning that his son had gotten his girlfriend pregnant (Hill, 1960, p. 299).

According to Hill, pediatric providers view themselves as partners with parents in a child's health (1960). Current trends in research of pediatric health-care quality even demonstrate the prioritizing of *partnership* with parents to overcome child health

disparities (Horn, Mitchell, Joseph, & Wissow, 2011). Renowned pediatrician T. Berry Brazelton argues strongly for the supportive, working relationship that a care provider needs to have with the family, and views this as part of the “art” of medicine (Brazelton, 1975, p. 533). The issue of domination and partnership is complicated in health care, and enters into the realms of ethics, personal responsibility, and professional duty.

Nevertheless, the goal of the pediatric health-care provider should aim at the Aristotelean ideal of a flourishing life for the child (Oberle & Allen, 2001). The notion of human flourishing is one that Riane Eisler points out is partially dependent on protecting children from any form of inequity or violence (2014). By building genuine, trusting, and caring partnerships with parents, committed to protecting and loving their children, we build hope and a brighter future.

For marginalized communities, however, such as the low-income African American community, partnering relationships can become mired in the challenges of culture, socioeconomics, and trust. African Americans continue to face the ongoing challenges of systemic racism in health care (Hardeman, Medina, & Kozhimannil, 2016). Racism, a social determinant of health, continues to impact child health through “implicit and explicit biases, institutional structures, and interpersonal relationships” (Trent, Dooley, & Dougé, 2019). The barriers that prevent the fostering of a genuine, trusting, and caring partnership with pediatric health-care providers are many.

A METHODOLOGY OF PARTNERSHIP

Designing a research study to explore strategies for partnering with parents in their child’s growth and development in well-child care required as much care and awareness as entering into a therapeutic relationship in a clinic setting. How to place the researcher into a position in which parents would feel trust and be willing to share

details of health-care experiences and parenting challenges and concerns was the focus of the design. The qualitative research aim, to describe parents' expectations and experiences of well-child visits, comes from constructivism, within the naturalist paradigm. Constructivist research acknowledges that "how people view an object or event and the meaning they attribute to it are what is important" (Rubin & Rubin, 2012, p.19). This approach allows the researcher to understand the lens through which parents view well-child care.

Focus group interviews provided a clear path forward. Focus groups offer a less direct, less dominating form of interviewing compared to one-on-one interviews (Krueger & Casey, 2014). Encouraging greater parent interaction and assuming a less dominant role in the focus group setting acknowledged the parents as the experts; as nursing theorists Chinn and Kramer write, "[T]he people seeking liberation are the experts regarding how their particular injustice is experienced" (2018, p. 83). While they are collective in nature, focus groups do not aim for consensus, but rather seek to gain an understanding of the range of responses parents have to their shared experience of well-child visits (Liamputtong, 2011).

Partnering in Recruitment

Recruiting for any research study can be challenging, but attempting to gather eight to ten parents who identify as African American, are low-income, and meet the eligibility criteria at the same time and place, while coordinating food and childcare, seemed nearly impossible. As the principal investigator, I recruited for and implemented the focus group sessions with consultation from my co-investigator. To be eligible, parents (or primary caregivers) had to be raising at least one child age five or under, who was not born prematurely, and did not have any chronic health conditions or developmental disabilities. What was underestimated, however, was the parents' desire not only to have their voices heard, but also to work with me to make it successful. For example, at one focus group site, the person who arranged for the use of the apartment

complex's community room took it upon herself to share fliers with the community and collect their eligibility surveys without even being asked to do so. Another time, the first participant who was recruited outside of a grocery store later came back and gave suggestions of where else to go and recruit. Experiences in developing recruitment partnerships can be categorized into several themes.

Being Where They Are

Partnering with a marginalized community means being where they are. The most success in recruitment came from the times when I shook hands and talked face-to-face with people in the community. Standing outside grocery stores (with the approval of the store manager) and walking the neighborhoods, apartment complexes, and streets near the focus group venue provided nearly all of the final participants. During recruitment dialogues, highlighting that this event was for *them*, to hear *their* voices and experiences went a long way in winning trust and showing respect. In one focus group, a parent actually remarked that the reason she felt like she wanted to come was because I was there, in this community, as a white health-care professional. She described how important it is for providers to be in the community to share health information. Other participants in the group agreed that they did not ever see their providers in their own community: "You can treat us - our kind - when we come into the facility, but you can't walk in the neighborhood that we're from?" The lesson for recruitment was that by being in the community and sharing through word of mouth, researchers can hear from more people's voices: "Everything is by word of mouth...We came here today. You may be back here in two weeks ... [And] you know what, [I'll tell people] we all went to a focus group and you should come out and try this."

Flexibility and Adaptability

Flexibility and adaptability in recruiting strategies and approaches were critical to successful partnering with participants. The original study plan included recruiting

through fliers with a Quick Response (QR) code, an image that can be read by a smart phone camera, and contact information. Fliers were placed in WIC (Women, Infants, and Children, a government funded supplemental nutrition program) waiting rooms and Head Start centers (government-assisted early childcare and preschool) in the surrounding areas. Weeks in advance, the necessary e-mails, phone calls, and faxes were sent to all of these sites to promote early recruitment. In the end, almost no participants were recruited from these original strategies.

Not only was it important for me to be out in the community recruiting, but the word of mouth from one participant to another also increased the recruitment response. Often I found that participants were more willing to attend if they could recruit at least one other friend to come with them. Whenever one person signed up to attend, I followed that with an invitation to bring a friend or family member who might also have young children and be eligible to attend. Ensuring that they had an extra flyer to share and telling them to have their friend call to verify eligibility and inform me if they would need childcare were all that was needed.

Offering flexibility in how parents could contact me improved access to participate. Potential participants had the option to call, e-mail, go to a website, or scan a QR code. Only one person chose to use the QR code, while the rest chose to call my number and talk directly to me about the study. All participants agreed to provide a cell phone number for text reminders and updates about the focus group, demonstrating a sense of trust and connection from the start.

Incentives and Removing Barriers

Viewing an incentive less as a tool to entice participation, and more as a way to show respect and gratitude is an important distinction when partnering with research participants. Appropriate incentives provided another avenue for strengthening the study. For participants to be able to attend, certain needs had to be met. Free childcare was provided onsite in adjacent rooms by qualified childcare providers, food (a dinner meal) was provided to the adults, snacks were offered to the children, and participants

received a \$40 cash gift card at the end of the study. Additionally, recruitment was kept to areas within a few miles of the site to limit the need for transportation.

PARTNERING DURING THE FOCUS GROUP

Focus Group Logistics

Careful consideration of the logistics in setting up the focus groups was necessary to ensure that the sites could not only provide access to the study population and the ability to collect data, but also be feasible and accessible for participants. Placing their needs above one's own in the planning and execution made the event itself a little bumpy, but in the long run, it was successful. Timing of focus groups for young parents was important to consider. Early evening after work in the middle of the week was successful in this instance. Because of the timing over dinner, a meal was offered to parents and a substantial snack to the children. Using cultural knowledge gained from talking to parents helped me provide food that was enjoyed and appreciated, but also quiet enough to not interfere with the audio recording.

In acknowledging that parents and children are a partnership unit in and of themselves, ensuring that parents could participate while accommodating their children was a key component to the study's success. Childcare in a nearby room with qualified care providers gave parents reassurance and the ability to attend even if their own childcare plans changed at the last minute. Being prepared for all possible outcomes - either no children showing up, half as many children showing up as you planned on, or more children showing up than you planned on - was very important. The ability to adapt to the families' needs throughout recruitment and the evening of the focus group was important, because the members of community I was recruiting from often face many competing demands on a daily basis that require greater flexibility and preparation. In one focus group, two parents who planned to attend did not come; one canceled the

day of the focus group because of a medical emergency, and two additional parents attended who had not contacted me ahead of time.

Fostering Open Dialogue

While a parent-provider relationship in the clinic can develop over the course of several visits, a focus group typically lasts only an hour and a half, giving the researcher only a short amount of time to establish trust and to develop open lines of communication between and among participants. The initial approach during recruitment helped to start open lines of communication and trust. Strategies included clearly explaining the focus group event, what to expect, what the eligibility criteria are, being approachable, and conveying genuine interest in them. During the focus group, following Casey and Krueger's (2014) guidance was helpful in generating dialogue; they recommend beginning with a question that is easy for everyone to answer, and then sequencing questions to flow naturally from general to specific. Parents responded well to this format, and momentum quickly built until it was often difficult to keep participants speaking one at a time in their eagerness to share.

Through the entire process of conducting focus groups, what was readily apparent was the participants' desire to take an active role in having their voices heard, sharing with other parents about the struggles and joys of parenting, and informing healthcare providers about their experiences and expectations of pediatric healthcare. While the study methodology and design were intentionally planned to promote a successful study, the complete success of the data collection stage of this study is owed entirely to the participants.

CONCLUSION

Several times during the planning and proposal process of this research project, the question has been asked by other researchers and colleagues whether Caucasian

persons such as ourselves could do this work with African Americans. While it is important to be cognizant of the historical and sociocultural factors at play when white researchers do research with an African American population, what has become apparent to us throughout this process is the power of partnership to overcome this potential challenge. When research is grounded in the desire to approach participants respectfully, to empower and give voice to the community, and is done in the spirit of humility and service, the racial divide no longer stands as an obstacle, but as an opportunity for building a bridge together. Partnering with parents, in research, and in the clinic, supports them as they build their children's foundation. Collectively, these partnerships at the beginning of life lay the groundwork "for a more peaceful, equitable, sustainable world where all children can realize their capacities for consciousness, caring and creativity" (Eisler, 2014).

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