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Inclusion of Black and Latina Parents With Physical Disabilities in a Qualitative Research Study: A Peer Researcher Training Model

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Abstract

Public health qualitative research has largely failed to achieve full inclusion of people with disabilities and Black people and Latinx/as. Although there is a small, but growing, community of academic researchers from each of these communities, there has been limited involvement of non-academic community members in research. While Community-Based Participatory Research (CBPR) has informed the inclusion of marginalized groups in research for decades, instances of full inclusion of disabled Black people and Latinx/as in public health research have been minimal. One way to ensure the inclusion of Black/Latinx community members with disabilities is to involve them as peer researchers. As part of a qualitative study examining pregnancy experiences of individuals with physical disabilities from Black/Latinx communities, academic researchers trained four peer researchers to conduct interviews and analyze the data. This paper describes our approach, which may serve as a model for training peer researchers in qualitative research methodology for future studies. All peer researchers were women who identified as Black or Latina parents with physical disabilities. This approach was chosen due to the study's focus on the intersections of disability, race, ethnicity, and pregnancy, and applied a disability justice lens. Although CBPR offers important principles for research existing literature suggests CBPR is not always inclusive and power sharing. Therefore, we developed a research training model which places a unique and timely focus on the intersections of CBPR, racial and disability justice,

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the importance of building the capacity of Black and Latina disabled peer researchers, and its importance to building community relationships and trust.

Keywords

peer researcher; training model; inclusion; black and latina parents; public health; qualitative research; pregnancy; disability; race; ethnicity

Background

Members of the disability community and Black/Latinx communities have had limited involvement in public health research. Although there is a small, but growing, community of academic researchers with these intersecting identities, there has been little inclusion of non-academic community members in this work. Community-Based Participatory Research (CBPR) is a research approach that equitably involves community members, organizational representatives, if applicable, and researchers in all aspects of the research process; all partners contribute expertise and share decision-making and ownership (Israel, 2012). While CBPR has created the framework for the inclusion of marginalized groups, instances of full inclusion of individuals who identify as members of both the disability and Black/Latinx communities have been minimal. In an effort to expand this nascent literature, this paper provides an example of a collaboration between academic researchers and disabled Black and Latina peer researchers as part of a qualitative study on perinatal health of Black people and Latinx/as birthing persons with physical disabilities.

CBPR has an overarching commitment to equity and power sharing in the research process. Israel (2012) describes a set of principles including the acknowledgement of community in units of identity; building on strengths and resources within the community; facilitating a collaborative, equitable partnership and involving an empowering and power-sharing process that amends social inequities; and fostering colearning and capacity building among all partners. CBPR also seeks to integrate and achieve a balance between knowledge generation and intervention for the mutual benefits of all partners. Based on these CBPR principles, community involvement and inclusion of collective community was at the center of our considerations in designing this study.

Our study focuses on the unmet needs of Black people and Latinx/as with physical disabilities during pregnancy and birth, and the potential impacts of ableism, racism, and sexism on pregnancy and birth experiences. Understanding the interactions of these “-isms” and the ways they may influence available perinatal information and strategies and pregnancy-related outcomes is an area of great interest to researchers, persons with disabilities, and Black/Latinx communities. Therefore, it was imperative to center the voices of Black and Latina people with physical disabilities and to create a research space that builds upon these principles and a firm commitment to equity and power sharing throughout all phases of research.

The implications of structural racism continue to impact birth outcomes of persons of color. A CBPR-based study on the experiences of women and birthing people of color reported that participants felt unsupported and not seen as an individual during their childbirth experiences (Berry, 2022). Moreover, there are widely documented disparities in pregnancy and birth outcomes, including a maternal mortality rate among Black women that is 2.6 times higher than the rate for non-Hispanic White women (Hoyert, 2023). Much like structural racism, structural ableism impacts pregnancy and childbirth experiences and outcomes for persons with disabilities. Likewise, research has shown marked pregnancy- and birth-related disparities, barriers, and unmet needs in accessing pregnancy health care among women with disabilities (Clements et al., 2016, 2018; Clements, Mitra, et al., 2020; Clements, Zhang, et al., 2020; Horner-Johnson et al., 2021; Long-Bellil et al., 2017b; Mitra, Clements, et al., 2015; Mitra, Clements, K., et al., 2016; Mitra et al., 2017, 2018; Mitra, Iezzoni, et al., 2015; Smeltzer et al., 2016). In previous research, persons with disabilities described experiencing inadequate care during pregnancy, birth, and the postpartum period due to limited clinician knowledge and negative attitudes, physical inaccessibility of health care facilities and equipment, and a lack of information related to pregnancy and postpartum supports (Clements et al., 2016, 2018; Clements, Mitra, et al., 2020; Clements, Zhang, et al., 2020; HornerJohnson et al., 2021; Long-Bellil et al., 2017b; Mitra, Clements, et al., 2015; Mitra, Clements, K., et al., 2016; Mitra et al., 2017, 2018; Mitra, Iezzoni, et al., 2015; Mitra, Long-Bellil, et al., 2016; Smeltzer et al., 2016).

The need to develop a qualitative research approach that enables community members to be co-creators of knowledge emerged from this study’s focus on the intersections of pregnancy, disability, and race/ethnicity. Exploring the presence of racism, ableism, and culturally insensitive care and how they may influence pregnancy and birthing experiences of Black people and Latinx/as with physical disabilities will lend important considerations to the pregnancy research, practice, and policy landscape. Achieving equitable and effective relationships with disabled persons of color and their communities is imperative to understanding intersectional identities and the unique experiences of multiply marginalized persons with disabilities. Therefore, we designed and implemented a peer researcher model, rooted in collaboration and equitable relationships, to conduct a qualitative study examining intersections of disability, pregnancy, race, and ethnicity amongst Black people and Latinx/as with physical disabilities.

Technique

Earlier CBPR studies focusing on the experiences of disabled people have identified several factors that play a role in achieving the principles of CBPR. These include having strong interpersonal relationships and allocating adequate resources such as allowing time for discussion and shared decision-making, funding, and time to support teams of disabled people (McDonald & Stack, 2016). Meeting access needs was imperative to supporting community members within CBPR (Nicolaidis et al., 2015). However, while CBPR holds significant value, the literature also indicates the presence of challenges in establishing equitable and sustainable partnerships. These challenges include engaging the most impacted communities (Sullivan et al., 2005) and aiming to make the research transformative and emancipatory (Barnes, 2002, 2006; Minkler, 2012).

Additional factors that enhance the practice of effective CBPR include elevating community members to be co-creators of knowledge; promoting meaningful conversations that matter to communities; promoting civic engagement, activism, and advocacy; promoting assets- and strength-based approaches to research; and promoting culturally relevant interventions (Lund et al., 2022).

This study examined the pregnancy experiences of Black people and Latinx/as and birthing people with physical disabilities through qualitative semi-structured interviews, informed by a CBPR approach and the disability justice framework. As defined by Sins Invalid, the

> Disability justice framework understands that all bodies are unique and essential; all bodies have strengths and needs that must be met; [we] are powerful, not despite the complexities of our bodies, but because of them; and all bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and we cannot separate them (What Is Disability Justice?, 2020)

For this study we provided training to four peer researchers, all of whom identified as disabled parents and Black or Latina. Their role includes conducting interviews and contributing to subsequent qualitative analysis. A peer researcher is often a community member who has lived experience of the subject area and often possesses limited research experience. As peer researchers, community members offer their expertise to study design and aid in ensuring that the study reflects community interests and that findings are disseminated in a culturally and linguistically appropriate and accessible manner. Peer researchers in our study played an active role in developing the interview guide, crafting the recruitment materials, formulating strategy, and designing the overall study. They will be involved in subsequent analysis.

This model of training peer researchers serves as a guide for fostering culturally inclusive research that respects disability perspectives, while also offering insights into applying a disability justice framework to involve disabled people of color in research and enhance community trust and engagement. The following section describes what is often regarded as the “behind the scenes” efforts involved in CBPR. Our project underscores the significance of making these processes more transparent to ensure the effective functioning of this study and the success of the peer researcher model.

Identification of Peer Researchers and First Steps

From the outset of the research process, it was imperative to foster trust and commit fully to value-based actions such as disability accommodations, shared leadership and decision-making, and co-developed policies (McDonald & Stack, 2016) All the peer researchers were identified at the grant proposal stage and provided letters of support stating that they would serve in the peer researcher role, should the project be funded. The letters underscored their interest in the research topic, willingness to aid in dissemination of research findings, and their shared commitment to a peer researcher model rooted in shared decision-making and learning. These letters of support represented the start of working to build authentic and equitable research partnership.

All peer researchers self-identified as a person with a physical disability with a strong sense of disability pride and connections to the disability and Black/Latinx communities. They were identified through previous work by members of the research team and their lived experience and interest in addressing gaps in knowledge about pregnancy and disability and examining perinatal care, complications, and outcomes for disabled people of color. All peer researchers had been involved as participants in prior research studies and at least one of them had conducted a small number of qualitative interviews in the past. This peer researcher model would enable the research team to build the peer researchers' capacity to conduct qualitative research. The research would be rooted in disability justice and benefit from the knowledge and expertise of peer researchers through their intersecting identities.

The first step once project funding was issued was a kick-off meeting, which included the peer researchers and other collaborators on the project (see Figure 1). This meeting discussed the objectives of the overall grant, outlined training opportunities, and delineated all areas of shared decision-making in order to begin the process of trust-building and establishing a foundation for working together. A subsequent meeting with the peer researchers focused on the specific aims of the qualitative study and formulated a process for including the peer researchers in all phases of the study. During this meeting, peer researchers offered feedback on the entire process including the number of trainings and their accessibility needs. Meeting participants discussed ways to create space for the peer researchers' perspectives in shaping the study design, recruitment, analysis, and dissemination processes.

Peer researchers were all required to complete human subjects research training courses required by the university's Institutional Review Board (CITI Program: Research, Ethics, and Compliance Training, 2023). Human subjects research training is time-consuming and often inaccessible to peer researchers (e.g., written with academic jargon); therefore, we implemented essential supports such as follow-up discussions about the human subjects training to facilitate comprehension of the Institutional Review Board training content and answer questions. This step was valuable for peer researchers to fully engage with the human subjects research training. The human subjects research training is important to help researchers understand the principles that guide research in a way that protects participants, and it led to relevant discussions about how those principles could be applied in our study to protect disabled research participants, in particular.

Qualitative Interview Training and Development of the Interview Guide

Qualitative interview training and development of the interview guide were led and coordinated by researchers with lived experience. Drawing on their lived experience, peer researchers contributed to the interview guide's structure, question content, and wording. Peer researchers revised the interview questions to address experiences of racism and cultural insensitivity throughout pregnancy. They also crafted questions focused on feelings raised by experiences of insensitivity as a way to create space for Black people and Latinx/as birthing people to share their intersectional experiences throughout pregnancy. Interview length was an aspect of the study in which the peer researchers' perspectives were important. The peer researchers felt that requesting participants to be available longer than 1 hour would be too burdensome given they have children and may have other caregiving or work responsibilities. Thus, the interview guide was shortened to reflect a one-hour time allotment and the peer researchers practiced navigating through all the questions in that time frame. The interview guide was iteratively revised with feedback from the peer researchers and other collaborators, fostering collaboration and equitable partnership within the design of the interview guide. Peer researchers approved the final version. Obtaining their approval was an important step as it helped equalize power amongst peer researchers and other members of the research team. The entirety of the process was empowering and power sharing in nature, thus acknowledging the peer researchers as experts in the subject area. Peer researchers also devoted time and labor to drafting the study recruitment flyer, screening instruments, and informed consent document.

Peer researchers participated in a series of trainings to develop interviewing techniques, and they conducted mock interviews to familiarize themselves with the interview process. Training sessions were led by researchers with lived experience and served as a venue for peer researchers to provide input on the development of the interview guide and all study materials, including offering feedback on the recruitment poster design. Peer researchers echoed a need for more questions to explore the intersections of race, ethnicity, culture, sex, and disability.

Recruitment

Peer researchers provided feedback and input on recruitment strategies as well as the recruitment materials. The recruitment strategy reflected diverse outreach including outreach to agencies that serve proximately Black/Latinx communities as well as resource agencies, support and transitional programs, and pillars of the community. Some of their recommendations for recruitment included outreach to disability-centered organizations, Black/Latinx-lead organizations, early intervention programs, faith organizations, food services programs, after-school programs, and reproductive health providers/institutions. Peer researchers echoed the need for the recruitment poster to be easy to read and accessible for potential study participants. They also incorporated feedback on the poster graphic and recruitment language. Peer researchers were asked to share the poster with the many networks within their communities and recruitment is currently ongoing. Recruitment progress will be shared with peer researchers and recruitment strategies will be revisited and modified upon peer researcher request. Peer researchers will also aid in dissemination strategies. Dissemination will cast a wide net given their lived experience and connections to Black/Latinx communities, persons with disabilities, and vast professional networks.

Data Collection

Data collection remains in progress. Peer researchers will conduct interviews and be involved throughout analysis and dissemination of findings. Interviews will last about 1 hour and will be conducted by one of the four peer researchers. Every effort will be made to match peer interviewers with participants who come from a similar cultural community (e.g., Latina interviewers will typically be matched with Latina participants). Interviews will also be conducted in Spanish upon request. Interviews will be conducted remotely using the

Zoom video conferencing platform, and they will be recorded and professionally transcribed for analysis. Interviews conducted in Spanish will be professionally translated into English.

Data Handling/Analysis

We will use Dedoose Version 9.0.17. (2021) to analyze the transcripts using inductive and deductive approaches and iteratively compare concepts and themes as they emerge from data. Peer researchers will participate in a training on the qualitative analysis approach and specific techniques. They will contribute to establishing codes and developing a qualitative codebook as well as engage in discussions about adding new codes or expanding or collapsing codes over time (Patton, 2014). This project's approach to data analysis is resonant with the CBPR approach as it continues involvement of peer researchers in every step of the research process. Peer researchers' initial establishment of the themes via codebook is one way to help ensure that the research team centers the priorities of Black people and Latinx/as.

Findings from this study will be triangulated with findings from other study aims (O'Cathain et al., 2010), for example, secondary data analyses, in order to better understand the perinatal health of Black people and Latinx/as with physical disabilities. Our qualitative data will provide context and insight into disparities identified in other study aims. In collaboration with peer researchers, dissemination products and strategies will be developed based on our findings for a variety of relevant stakeholders, including members of the disability community.

Ethics

There are a number of ethical considerations for this qualitative methods study. Before beginning recruitment, interviews, and data analysis the peer researchers completed two required human subject training courses, which raised some concerns (CITI Program: Research, Ethics, and Compliance Training, 2023).

Training

The first concern was a lack of disability community-centered content in human subjects research trainings. For example, one peer researcher alerted the team to a reference in one of the courses to a researcher with ties to eugenics. Another peer researcher found an optional course about research with people with disabilities, but that course was focused on persons with disabilities as research subjects only and was not included as part of the required training. The acknowledgment of these ethical considerations reflects the CBPR principle to facilitate a collaborative, equitable partnership within all phases of research, involving a power-sharing process that amends social inequities (Israel, 2012). These revelations exemplify a broader need for more inclusive representation of persons with disabilities within all research spaces.

Resources

A second important ethical consideration raised by peer researchers was the need to recognize the unique considerations of disabled people of color and to minimize any potential harm to study participants resulting from the research. Although this is always a consideration of human subjects research, the peer researchers raised the need for additional protection given the intersecting, marginalized identities of this specific study population. Incorporating this consideration acknowledges CBPR Principle 5 related to integrating and achieving a balance between knowledge generation and intervention for mutual benefit (Israel, 2012). While uplifting the stories of study participants is imperative for the study, peer researchers echoed the ethical need to protect participants from emotional harm given that many may have never had an opportunity to share or fully process their experiences as a Black or Latinx/as physically disabled, pregnant person. The peer researchers were concerned about exacerbating trauma related to experiences of poor treatment or complications during pregnancy and childbirth. The peer researchers also suggested a resource list to offer participants who may become upset during the interview, especially if they have had difficult or upsetting pregnancy experiences (such as pregnancy loss).

Peer researchers were also trained to emphasize the voluntary nature of the study and the option to pause or end an interview at any time. Given internalized racism or ableism, peer researchers found it imperative that participants be given space to process their feelings while acknowledging a boundary for an interview not to continue if signs of stress or strong emotional reactions were present. Peer researchers also discussed the importance of their own self-care throughout the interviews given their own potentially traumatic pregnancy experiences. Peer researchers were encouraged to recount any issues that occurred during the interview within their post-interview check-in and team debrief meetings.

Compensation

Fostering equitable partnerships is reliant on fair and adequate compensation. Costs associated with building effective, sustainable partnerships should be planned and budgeted in advance to allow adequate time for partners to learn about one another, develop trust, and establish processes for working together (Hoeft et al., 2014). Compensation of peer researchers is another important ethical concern given that compensation should account for all time spent to foster learning. Allocating the budget to fairly reimburse the peer researchers recognized their expertise as persons with disabilities and Black/Latinx community members, respected their role as researchers, and encouraged trust and true shared decision-making. Peer researchers were compensated for all time in spent training, reviewing study materials, aiding in study design and study recruitment, and conducting interviews as hourly contracted independent consultants. Fair compensation for research involvement is imperative to CBPR and other community-centered research methodologies. However, these costs are not necessarily any greater than what would be incurred for hiring other personnel to conduct the required research activities, and the benefits of community-engaged research far outweigh the associated expenses.

Rigor

We will use established approaches to ensure the rigor of the qualitative analysis: continuing data collection until saturation; clarifying, elaborating on, and evaluating data immediately after collection; and interpreting findings (Patton, 2014). Avoiding tokenization and offering ongoing support to peer researchers will aid in ensuring rigor of the qualitative process and supporting their involvement within the research study.

Avoiding Tokenization

The research team designed the study to avoid tokenization of the peer researchers. The team included disabled people in multiple roles in addition to the peer researcher role. The peer researcher training was facilitated by one of the study investigators who is a White researcher and a mother with a physical disability with extensive experience interviewing women with disabilities regarding reproductive health (Long-Bellil et al., 2017a; Long-Bellil et al., 2017b; Mitra, Long-Bellil, et al., 2016; Smeltzer et al., 2016). The research team found it important that the peer researchers received training from a disabled researcher. Coordination of the peer researcher team was led by a Black, disabled researcher with physical disabilities with extensive experience integrating persons with disabilities within home -and community-based services and other community supports. She conducted check-ins with peer researchers throughout the training process to assess and strengthen the training as well as to identify areas where they would like additional training. This feedback was used to strengthen future peer researcher trainings and will inform the development of the upcoming data analysis training. This model was used to meet the needs of the peer researchers and offer flexibility within training content and study design.

Ongoing Support

Training was centered around acclimating the peer researchers to qualitative research design and study material development and outlined how to conduct a qualitative, semi-structured interview. Within the trainings, mock interviews prepared peer researchers for interviewing. One-on-one check-in sessions were offered simultaneously with training and served as a space for the peer researchers to offer feedback on training design as well as offer additional considerations related to the research study design. Peer researchers also requested accommodations such as headphones and a stand to display the interview guide. These products were ordered and tested during the mock interview process.

Technical support was also provided to the peer researchers. Peer researchers engaged in Zoom practice sessions to aid in their comfort with recording and navigating the platform. They also practiced rapport building and the process for obtaining verbal consent. They will receive assistance from the research team to schedule interviews and upload interview recordings and transcripts.

Members of the research team will meet with the peer researchers after each of the first few interviews to debrief the interview, offer feedback, and discuss any challenges or concerns the peer researchers experienced while interviewing. This ongoing support recognizes the emotional challenges that peer researchers may face when conducting and analyzing interviews given their own personal lived experience. Providing ongoing support has been an important and necessary element of this CBPR study. The frequency of debrief sessions will be determined in collaboration with peer researchers.

Having support staff who are knowledgeable about the population and content area enabled our study to provide ongoing support throughout the research process. For example, support will continue to be provided throughout the interview and analysis phases of the research by a team member who has research experience with marginalized women and children of various racial, religious, and socioeconomic backgrounds. Ongoing support has also meant finding different ways to check in more frequently than with a traditional research team.

Peer researchers will also assist with dissemination. Training will continue and peer researchers will aid in ensuring findings are shared in a culturally informed, disability-centered, and accessible manner, while continuing to uphold a disability justice lens by uplifting the voices and experiences of Black people and Latinx/as birthing people with disabilities.

Conclusion

This peer researcher training model is unique and timely in its focus on the intersections of CBPR and disability justice. While CBPR offers important principles to research, it is important to continue to challenge the principles of CBPR to allow research to be truly community-driven. In response, we developed a peer researcher training model that applies a disability justice lens to meaningfully promote equitable partnership, collaboration, and shared decision-making with disabled people of color. Disability justice has shown how inclusion models position “exclusion” as the problem in need of redress, leaving larger structural issues of inequity unchallenged (Voronka, 2017). By incorporating a disability justice lens this research training model uplifts the voices of Black and Latina birthing people recognizing their expertise as persons with disabilities and their intersectional experiences of race, gender, and disability. This research training model also demonstrates the ethical importance of compensation for completion of trainings and all tasks related to developing and implementing a research study. This research training model fosters equitable partnerships that are inclusive and fosters power sharing by including peer researchers within all phases of study design.

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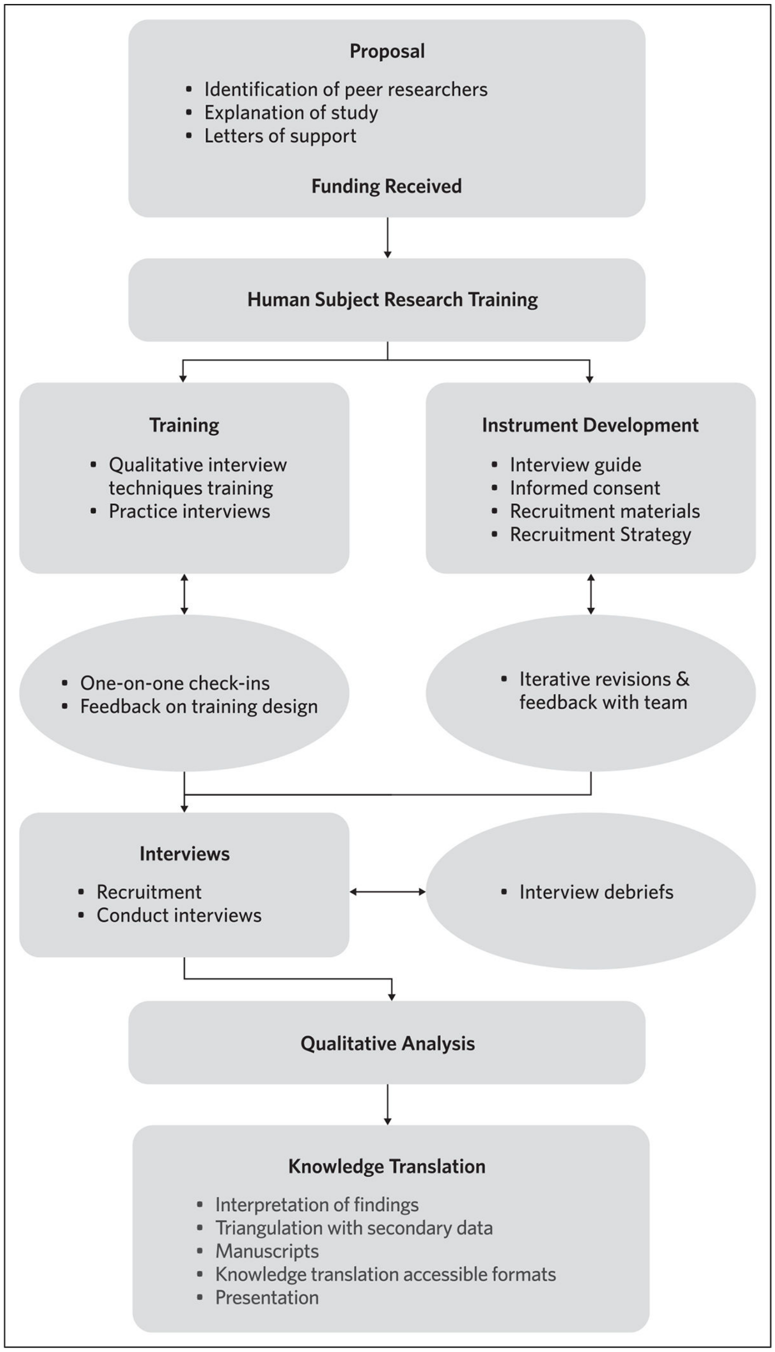

Figure 1.

A diagram of peer researcher process for a qualitative study about the intersections of disability, pregnancy, and race/ethnicity.