

# Qualitative Methodologies and Community Participation in Examining Reproductive Experiences: The Harlem Birth Right Project

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*Objectives:* Racial disparities in health present a challenge to public health because of the complexity of interacting social forces. The Harlem Birth Right Project sought to improve understanding of these forces by using qualitative and community participatory methods. In this paper we 1) describe the process of qualitative inquiry and community involvement, 2) evaluate the impact of community participation, and 3) present a brief summary of the findings on social context as it relates to pregnancy outcomes of women in Harlem. *Methods:* We operationalized the qualitative method by combining participant observation, longitudinal case studies, and focus groups. An ethnographic survey was used to verify and triangulate findings across methods of data collection. We involved the community in the design, implementation, and analysis by collaborating with community-based organizations, setting up a community advisory board, and the use of dialogue groups and community meetings. *Results:* The use of qualitative methods and community partnership uncovered important aspects of the social context of women's lives that may not have emerged through traditional epidemiologic research. We found that pregnancy may serve as a catalyst to increase perception of the magnitude of preexisting social stressors. Several stressors and chronic strains associated with structural forces were identified. For example, the high percentage of households headed by women is seen as one consequence of larger structural forces. While social support networks serve as an important coping mechanism to buffer against the stress caused by these structural forces, the types of support women seek differs by social strata, and some strategies were identified as being substantially more effective than others. *Conclusions:* Qualitative and community participatory research can be successfully conducted to support public health goals and can derive important new information on the social context of women's lives.

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**KEY WORDS:** ethnography; community participatory methods; pregnancy; socioeconomic status; African Americans; stress; social support.

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## INTRODUCTION

Regardless of their socioeconomic position, African American women fare worse in birth outcomes as compared with white women at every economic and education level. (1) Traditional epidemiological methods are limited in their ability to address the complexities of public health (2), and, while quantitative data analysis is extremely useful in forming predictive models (3), it can be limited

in its explanatory capacity since it strives to define single-factor explanations for complex phenomena. Wise (4) observed

... a remarkable proliferation of studies reporting associations between infant mortality and a vast array of singular variables or risks. . . . with little regard for their respective prevalence or how these risks interact to actually determine infant mortality patterns in the real world.

Furthermore, Wise (4) suggests that

... the uncritical interpretation of singular risk associations has led to a kind of tyranny of the “p” value by which statistically significant risk associations push the public debate to the margins and frame the public understanding of infant mortality as the product of deviant maternal behavior. Not only has this “marginalization” played into destructive stereotypes of maternal responsibility for infant death, but it has also helped generate in many communities a host of specialized programs designed to provide services to a relatively small group of “high-risk” women. Although these programs are greatly needed, they distract attention and resources from the basic infrastructure of comprehensive health care and social service provision in these same communities.

The Harlem Birth Right Project sought to identify the social, economic, and political variables that may lead to greater vulnerability to high rates of infant mortality and adverse pregnancy outcomes among African American populations and was designed to examine the broad social context of reproductive health. As the research evolved, exploration of the potential sources of stress and chronic strain became a key focus. The researchers hypothesized that systemic stressors and strains contribute significantly to the overall level of stress women in Harlem experience. To explore how these factors affect the health of African American women, the research team designed an ethnographic study that incorporated standard qualitative research tools, and in addition, developed a strategy for community participation in the research process. The specific objectives of the Project were to 1) use ethnographic inquiry to identify the broad social context of gender roles and pregnancy outcomes in Harlem, 2) involve community members in this research, and 3) to evaluate the community participation process with respect to its utility and impact on data collection. The complete findings from the Harlem Birth Right Project are reported in a forthcoming publication (5). This paper describes the study methodology in detail, and briefly summarizes

some of the findings that pertain to pregnancy outcomes.

## METHODS

The Harlem Birth Right Project was conducted in Central Harlem, a predominantly African American community with population of approximately 100,000 and located in northern Manhattan, New York City. It is a diverse community, containing historic institutions, families with many years of residency, and a stable, if relatively small, and middle class. Though shaped by segregation and discrimination, Harlem has been a vibrant social, political, and cultural axis for African Americans of all classes. Harlem has historically experienced cycles of fluorescence and decline. In the 1970s, 80s, and 90s, Harlem—along with the rest of New York City—was profoundly affected by the processes of global economic restructuring, which was reflected in the shift from an industrial-based economy to one based on the information and service sector. Loss of manufacturing jobs led to decline in the unionized sector of the labor force. These processes interacted with longstanding patterns of racial discrimination, and at the time we conducted the study (1993–1997), Harlem residents faced major challenges, including significant levels of housing displacement (6), disproportionately high rates of unemployment (approximately 60% of residents and 16 years and older were not in the labor force) (7), high poverty levels (more than one third of all households had incomes below the federal poverty level (7), and infant mortality rates that were more than twice that of New York City as a whole (8).

### Operationalizing Community Participation

Participatory action research, the theoretical approach that guided community involvement in the Harlem Birth Right Project, seeks to involve the community in design, implementation, and analysis of research (9–16). When the Project was initiated in 1993, participatory action research was still a somewhat novel concept, although the need for promoting such an approach was generally recognized (17–18). We used four approaches for organizing community participation: 1) recruitment of organizations and researchers with longstanding relationships and commitment to the community, 2) development of a community advisory board, 3) community dialogue groups, and 4) community meetings.

*Recruitment of Organizations and Researchers with Longstanding Relationships and Commitment to the Community*

The New York Urban League was chosen as the general contractor for the Harlem Birth Right Project because of its long-term links with the Harlem community and its involvement in a number of other health-related projects, including overseeing the Harlem Healthy Start program. In addition, all four principal investigators had long histories of residence, activism, or work in Harlem.

*Development of a Community Advisory Board*

To involve a broad cross-section of the community, the research team established a 24-member Community Advisory Board (CAB). This Board was composed of Harlem residents, who met quarterly with the researchers throughout the 4-year research period. In constituting the CAB, the researchers attempted to make it representative of the socioeconomic, occupational, gender, religious, age, and ethnic heterogeneity of Central Harlem. To operationalize this, CAB members were recruited from community organizations, unions, youth programs, and service organizations, and participated as individuals and not as representatives of their organizations. Some members were unaffiliated persons encountered in the course of fieldwork. The CAB actively participated in all phases of the research, including designing and facilitating the research (e.g., selection of the research sites, and development of the focus groups and the ethnographic questionnaire), facilitating research contacts and entry into research sites, representing the project at various public functions, serving as resources in the hiring of personnel (e.g., interviewers) from the community, and helping develop strategies for public dissemination of the project objectives and results. Furthermore, the CAB maintained continuous dialogue with the researchers, providing insight into research problems on the basis of their experiences as long-term residents or workers in Harlem.

*Community Dialogue Groups*

In addition to the CAB, several Community Dialogue Groups (CDGs) of 5–10 persons each were convened during the active field research to discuss specific issues, such as selection of the sites for

intensive ethnographic data collection, selection and recruitment of longitudinal participants, focus group criteria, structure and content of the ethnographic questionnaire, and improved community participation. The CDGs allowed the researchers to involve an even broader group of Harlem residents in the Project, to discuss specific issues in greater depth and to avoid overburdening the CAB members.

*Community Meetings*

Additional participation was elicited through two general community meetings open to the public, which were held to provide information about the Harlem Birth Right Project and to solicit advice. Moreover, ethnographers provided persons at all participant observations sites and public meetings with detailed explanations about the research.

**Operationalizing Qualitative Research**

In collaboration with the CAB and the CDG, the researchers developed an ethnographic research design with four components: participant observation, longitudinal case studies, focus groups, and ethnographic questionnaire. A thorough literature review and pilot fieldwork were conducted over the 6 months prior to initial data collection. Analysis of media reports, archival information, public documents, and academic literature was undertaken throughout the research to situate the Harlem data in a broader social and political context.

*Participation Observation*

Participant observation was conducted at 10 sites, including 3 neighborhood sites, 6 work sites, and the housing court. The 3 neighborhood sites were chosen to reflect differing income and infant mortality rates. The first was a low-income community with the second-highest infant mortality rate in Harlem (the highest rate is in the area that includes Harlem Hospital and is not representative of residents in the area). The second site had a slightly higher income level and a lower level of infant mortality; it included a section of historically elite residents in Harlem. The third site was characterized by occupation and income profiles of the average range in Harlem and one of the lowest rates of infant mortality; this site included a public housing project.

The five original work sites reflected the occupational categories in which African American women are found nationally as well as locally. These sites were a fast-food restaurant (service workers), an office site (clerical and professional workers), a street vending site (informal sector workers), and two social service sites (service and professional workers). After consultation with the Community Advisory Board, two additional locations, the large public hospital and housing court were added as sites for participant observation. Five ethnographers (a senior ethnographer, three graduate student ethnographers, and one of the principal investigators) conducted the ethnographic fieldwork primarily between summer 1993 and fall 1995, generally spending 3–4 months at each site.

At most of the 10 participant observation sites, a team of two ethnographers participated in daily activities and neighborhood events, observed behavior and organizational patterns, conducted structured and open-ended interviews, and collected and analyzed social networks data, life histories, and genealogies. Participant observation in the neighborhood sites facilitated analysis of patterns of family structure, types of stressors, and social support systems and facilitated contact with women not currently employed, on public assistance, or working in the informal sector (that sector of the economy where goods and services are produced and/or sold outside of the regulatory apparatus—e.g., taxation, health and safety, minimum wage laws). Participant observation at the five work sites allowed researchers to directly observe conditions, types of stressors, and coping mechanisms of African American women in different occupational sectors. Both the neighborhood and work sites allowed observation of interactions across work, family, and community settings.

Team ethnography—in which two ethnographers were stationed at each site—allowed comparison of observations and strengthened assessment of validity. Further, it allowed for the interaction of multiple perspectives of “insider/outsider.” The team approach and multiple perspectives allowed for cross-checking of data, comparison of observations, enhanced validity, and increased reliability. The ethnographers met regularly to exchange information and plan strategies.

### *Longitudinal Case Studies*

After 3–4 months of participant observation at the various sites, 26 women of African descent with

varied demographic and socioeconomic characteristics were recruited from the neighborhood and work sites to participate in longitudinal case studies. An ethnographer conducted a preliminary interview with each woman to explain the study and obtain informed consent. Subsequently, the ethnographers interacted with the women and observed their experiences at home and at work, conducted formal and informal interviews, and elicited support network data. These extended case studies were based on maintaining contact over approximately 1 year; 6–20 contacts were made with each participant. Contacts included making home visits, attending health care appointments, visiting prisons, attending various rituals, and meeting at work. Because of circumstances beyond their control (e.g., moving or illness), 4 of the nonpregnant women were not able to complete the study, leaving a final sample of 22 women in the longitudinal study. Of these, 11 were pregnant at the time of recruitment and were followed throughout their pregnancies and some part of the postpartum period.

### *Focus Groups*

Toward the end of the participant observation phase of the research, 11 focus groups were held, in which some of the longitudinal participants also participated. Other focus group participants were recruited from the 10 field sites and from the broader community through flyers, word-of-mouth, and sign-up sheets at block parties, street fairs, and other public events. The mixed composition of the groups enabled the ethnographers to cross-check validity of their field observations and to obtain additional insights into resident’s experiences.

The focus groups generally included 5–10 participants. Topics covered a range of social experiences, for example, budget cuts, bereavement and loss, birth experiences, culture, housing, men, research in the African American community, women heads of households, and youth.

### *Ethnographic Questionnaire*

On the basis of the results from participant observation and focus groups, the researchers developed an open-ended interview that was to be administered to 100 randomly selected women in Central Harlem. A total of 83 participants completed the questionnaire. Development of the questionnaire involved collaboration across the investigative team, the CAB and the

CDGs. The process began with a discussion among the ethnographers and principal investigators of relevant areas to be researched. After an extensive literature review of each topic area, the Project's ethnographic data was reviewed and the topic areas were further expanded based on ethnographic observations. The research team then developed open-ended questions and probes that addressed these topic areas, each time going back to the ethnographic field notes and experiences for insight and additional data. In addition, a CDG was convened to review topics suggested for the questionnaire and to develop specific items within each topic.

Because the questionnaire was based on information from the actual lives of women in the community, this survey likely captured a broad spectrum of the experiences of these women. The final version of the questionnaire covered a range of topics, including social and demographic characteristics, work, family, pregnancy, stress, health, perceptions of the environment, and political participation.

Two different sampling strategies were used to identify potential participants for the ethnographic questionnaire. First, a random sample of 57 women aged 18–65 years who had originally participated in the Harlem Health Survey, a random, population-based survey of households in Central Harlem, was selected. Women were selected randomly from subsamples of women with specific levels of educational achievement (less than a high school degree, a high school degree or General Equivalency Degree, and more than a high school degree) to attain diversity in the sample. Second, women were also randomly selected from Harlem Health Survey participants who lived in neighborhoods that were part of the ethnographic field sites. Other women were given the questionnaire at a homeless shelter and at the work sites.

### Analysis Strategies

Social strata were determined by education level, occupation, and income. For example, middle stratum (or middle class) was used to refer to persons in professional and managerial positions in the occupational structure, persons who have some degree of income security, and persons with postsecondary education pursuing professional careers. Because the preponderance of ethnographic research focuses on low-income populations (19, 20), a unique feature of Harlem Birth Right Project was to also explore the lives of middle-income women to gain insight into

possible risk factors as they affect women across socioeconomic strata, as well as variation within socioeconomic strata.

Throughout the Harlem Birth Right Project, the research design involved maximizing validity by using a range of research operations and methodological strategies (participant observation, longitudinal case studies, focus groups, questionnaires) to facilitate cross-checking of data, observations, and conclusions. Traditional ethnographic techniques of establishing the accuracy of statements and their reliability (verification, validation, triangulation, proof, inference, replication, repetition, and comparison with other studies) were incorporated into the study. Data were assessed through the use of internal triangulation (eliciting the same data in a different way from the same informants) and by comparing accounts given by different study participants and the observations of the ethnographers.

During the field research, the field notes, interviews, and focus group transcripts were coded based on a list of topics developed by the research team. These topics (initially defined narrowly to provide maximum detail) were indexed and cross-referenced. Preliminary analysis of the coded data served to further focus field research and to develop the ethnographic questionnaire. During the analysis phase, the coded data were examined for patterns or themes, and re-sorted into broader categories, such as “social support” or “housing problems.” Once the data were coded and sorted, validity was further assessed through cross-checking field data with data gathered in the focus groups and through the ethnographic questionnaire.

### RESULTS

Women in Harlem experience substantial stressors and chronic strains associated with the environment, housing, economic concerns, health care, and social service delivery. The effects of economic conditions are not clearly distinguishable from the social and political conditions. For example, for low-income women, the effort to piece together income and benefits from a number of sources was a source of chronic strain. For middle-income women, a dominant theme was fragility of status due in part to their disproportionate concentration in the public sector, which is particularly vulnerable to cuts in Federal and state funding, downsizing, and privatization. Many middle-stratum participants appeared to be willing to

exchange one set of stressors for another in that they were willing to live under conditions of systematic neglect of community in exchange for the protective features of living in a black community, including more limited exposure to racism in their neighborhoods.

Also, in the context of these stressors and chronic strains, pregnancy may serve as a catalyst to increase the magnitude of actual and perceived severity of stress. The mechanism appears to be multiplicative rather than additive. The case material demonstrated how pregnancy served to mobilize greater action by women to address housing, environmental, economic, and other social stressors that existed before pregnancy. Active attempts to assess adequate income, job benefits, nutrition, child care, access to quality health care, and a safe environment intensified during pregnancy.

Social networks play an important part in Harlem women's lives. We found that women develop broad networks, often women-centered, that strongly influence economic survival and childbearing decisions. The research identified decline in the percentage of women who are married and rise in the percentage of households headed by women as two consequences of the larger structural forces and changes in the Harlem area. Social support networks are an important adaptative coping mechanism for these consequences. The support systems offer women instrumental, emotional, and informational support, and they help women cope with pregnancy. Family, partners, and extended networks play an important role in the process of decision making. Family and peers, in particular, participate in decisions about pregnancy and influence the context within which pregnancy and childbearing occur. The importance of this social context seems to hold across social strata.

Recruitment of social support networks appeared to differ by social strata. Middle-stratum women tend to rely more on friends and hence may be unable to access the type of instrumental support (such as childcare) more likely to be offered by families. In contrast, low-income women may rely primarily on families, but find that due to resource scarcity generated by worsening economic conditions, all family members have less to give, thereby straining networks. Any intervention from women's reproductive health should be sensitive to the fragility of these support networks and should incorporate resources that reinforce network ties.

We observed that women relate to men in various ways, including through their own consanguineal networks. Despite perceptions in popular media and the

health field concerning relationships among African American women and men, our research suggests that men, themselves strained by economic and social conditions, play more important roles in the lives of women than is frequently recognized. Therefore, interventions to improve reproductive health for women must include men and address men's conditions.

In examining women's experiences with health care delivery, we found that prenatal medical care is only one of multiple strategies for self-care, but it is an important one. All pregnant longitudinal study participants and 91% of respondents to the ethnographic questionnaire who had, at some time, been pregnant reported receiving prenatal medical care. No discernible pattern indicating preference for type of prenatal care facility emerged, nor did there seem to be any significant cross-strata variation in the type of prenatal care facility chosen.

Our data from the longitudinal sample indicated that bureaucratic procedures for obtaining insurance and for enrolling in prenatal care programs at ambulatory clinics and in-hospital clinics could delay the start of proper prenatal medical care for up to 4 weeks. This observation is especially true for low-income women who are working and thus may be just above the upper limit for Medicaid eligibility, but who are not provided health insurance through their place of employment. For these reasons, many study participants frequently did not enter medical prenatal care until their second trimester.

Across social strata, all the women who participated in our study expected quality prenatal care and sought facilities throughout New York City that offered what they perceived as quality care. Perceptions of "quality" varied widely, however, and the case material suggests that the search for quality prenatal care may delay entering into prenatal medical care, and may lead women to transfer from one care setting to another delaying care even further.

We found that health care providers' perceptions of their patients' attitudes and behaviors may be shaped by a complex set of factors, including providers' lack of understanding of the social context in which Harlem women operate (particularly true of low-income women); the providers' own constraints of having to work with limited resources (particularly true at public hospitals and clinics where the majority of our study participants went for care); and providers' assumptions that individual behavior, including high-risk behavior, can be isolated and treated separately from the wider social conditions. These

perceptions were most clearly illustrated in health care providers' inability to understand why their patients might miss prenatal care appointments.

The patients, on the other hand, did not always understand that noncompliance (e.g., missing prenatal care visits) might place them at risk for poor pregnancy outcomes, because they place medical care in the larger context of all their self-care efforts. Harlem women were as likely to be noncompliant for structural reasons (e.g., difficulty in attending clinic at the scheduled hours or bureaucratic obstructions) as for other reasons, including unpredictable life events (e.g., family or job responsibilities, or transportation problems).

Another finding was the substantial variation across social strata in levels of distrust and engagement with the medical system. Among the longitudinal study participants, African American women with more than a high school education seemed more likely to vocalize concerns about the quality of medical care, to control their engagement, and to seek alternative care. In contrast, African American women with less than a high school education seemed less likely to vocalize distrust but to be passive in their use (e.g., through noncompliance) of medical care.

## DISCUSSION

As Baum notes, "Public health has, then, both to describe and to understand communities" (2). The approach taken in the Harlem Birth Right Project—incorporating community participation and qualitative research methodologies—advances that endeavor. In this Project, community participation was critical to achieving new theoretical and methodological insights, and assisted in the ways in which material was prepared for presentation to the community. As many proponents have pointed out, community participation has an important role to play in facilitating access, trust, and implementation. But the incorporation of community participation also has real implications for addressing biases in traditional public health and social science research. The experience in this study forcefully underscored the often implicit emphasis on deficit models and the implications of this emphasis for the community. For example, at one CAB meeting, board members emphasized the importance of presenting a balanced picture of the community instead of using the traditional deficit model approach. The resulting community profile included a balanced representation of what the CAB

members thought were positive indicators (e.g., percentage of persons living above the poverty line) and negative ones (e.g., percentage of persons living below the poverty line). This profile was seen as useful to the community beyond the research project and was widely used in slide shows and fact sheets by CAB members and other members of the community.

CAB members also encouraged the researchers to examine housing court as an additional important site for participant observation. This arena provided the opportunity to observe the tenants who lodged housing complaints, and their lawyers, thereby, yielding a cross-occupational perspective on how the contingencies and problems of daily life of one group (e.g., low-income women, women at risk for homelessness) can affect those of another group (e.g., women lawyers who advocate for the poor) and the resulting potential for exposure to stress or chronic strain for both groups.

Community members encountered by the researchers were generally supportive of the study's approach, which embedded infant mortality within the larger social and economic context, but on several occasions community residents asked why pressing concerns such as high rates of unemployment or income insecurity, the poor quality of education and social services, and environmental problems—rather than infant mortality—were not being addressed. The participation of community members led to important changes in the research design and project implementation. For example, sites for participant observation were added, the sample for longitudinal observation was expanded (e.g., to include women of different ethnic groups), and topic areas for investigation were amplified. Community participation also broadened our areas of inquiry and provided the research team with multiple critical perspectives from which to view health-related exposures and health care delivery. The CAB also contributed to the community profile.

Qualitative research is generally not designed to form predictive models or to determine correlations and causal relationships between variables; nevertheless qualitative data and their analysis can, in addition to producing data as described earlier, guide quantitative data collection by pointing to possible relationships among variables that may then be explored uniformly and systematically. The process of developing the ethnographic questionnaire illustrates how qualitative and quantitative approaches, along with community participation, can be productively used to improve the quality of the overall research. Ethnographic observations allowed the investigative

team to ask questions and explore areas we would not have been familiar with without qualitative research. Consequently, the construction of the questionnaire involved development of a theoretical matrix that broadened the original topic areas and the “concepts of life stress paradigm” previously considered in stress research (21, 22, 23), including the new topic of community life, an expansion of the concept of personal dispositions and coping, a stronger focus on women’s resources and obstructions to prenatal health care, and an expansion of the concept of social networks to include assessment of the broader ways that women participate in many social arenas.

The data collected during the Harlem Birth Right Project suggest that to understand the greater vulnerability of African American women to poor pregnancy outcomes, it is important to consider the larger system of social relationships in which these women are embedded. That is, interventions that focus only on single behaviors (e.g., abstaining, early prenatal care, or “planning” a pregnancy) or isolate physiological or behavioral risks (e.g., risk of vaginal infection, or substance abuse) likely will not be effective because women may be unable to comply with these narrow interventions unless social factors are also addressed.

Thus, in designing public health interventions for the Central Harlem community, the combined effects of various types of social hierarchies (of race, class, and gender) on the lives of residents must be taken into account. In addition, public health interventions must confront the multiple sources of strain women face. These sources include the ways in which gender inequity, racial discrimination, and class inequality impose limitations on access to health care and, perhaps more important, on secure jobs, adequate housing, good nutrition, adequate child care, a safe and healthy environment, and necessary social services—all of which are necessary for good health. Such interventions must also build on and support the protective mechanisms that women and men have developed, such as individual and collective coping strategies around housing, family, and community.

Central Harlem already has a range of community organizations and institutions that overcome tremendous obstacles to render valuable services. Programs developed without reference to the institutions, organizations, and historical and cultural context of Harlem are less likely to be successful and may miss the opportunity to build on the strengths of the community. Intervention programs that listen to the voices of the community and especially the women themselves—both through their own words

and through documentation of their actions—and attempt to address the community’s multiple concerns may be the most successful in improving pregnancy outcomes among African American women in Harlem.

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