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Hearing the Silenced Voices of Underserved Women -The Role of Qualitative Research in Gynecologic and Reproductive Care

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Summary for Indexing

In order to provide effective evidence-based health care to women, rigorous research that examines women's lived experiences in their own voices is needed. However, clinical health research has often excluded the experiences of women and minority patient populations. Further, clinical research has often relied on quantitative research strategies; this provides an interesting but limited understanding of women's health experiences and hinders the provision of effective patient-centered care. In this review, we define qualitative research and its unique contributions to research, and provide examples of how qualitative research has given insights into the reproductive health perspectives and behaviors of underserved women.

Keywords

Qualitative Research; Underserved Women; Gynecology; Fibroids

Introduction

Patient-centered care (PCC) is health care which is respectful, compassionate, equitable, transparent, and responsive to patients' needs and values.^{1,2} Although the concept of PCC has been academically discussed for many decades,¹ it was not until the Institute of Medicine defined PCC as a primary aim for improvement in health care that the concept appears to have been widely integrated into health systems.^{1,2} Since that time, predominantly quantitative research has found that PCC is associated with many positive health outcomes including improved physical and emotional well-being, patient satisfaction,

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treatment adherence, and patient-physician communication.^{1,3,4} However, in order to achieve these positive outcomes, health systems must first understand the unique needs and values of patients; this likely requires the utilization of qualitative research designs which can inform subsequent quantitative studies. It is therefore vital for health-care research to include qualitative analysis of the perspectives and experiences of patients who have historically been overlooked. The purpose of this review is:

1. to describe the strengths and limitations of qualitative approaches and how they differ from the more common quantitative approaches;
2. to describe why this approach is particularly important for underserved communities, and;
3. to review application of qualitative studies to various populations of underserved women.

Qualitative versus Quantitative Research Paradigms

As researchers, we seek to gain knowledge in order to increase insight and solve problems. We may rely on diverse worldviews or paradigms which guide our beliefs about how knowledge is constructed and how it can be discovered. Two common paradigms are the positivist and naturalistic/constructionist paradigms. These paradigms respectively provide the framework for quantitative and qualitative approaches to inquiry.⁵ Although each approach provides valuable insight and data, the naturalistic approach to data inquiry often provides the richest understandings of women's lived experiences and health behaviors.

First, within the positivist paradigm, knowledge/reality is believed to be objective, measurable, and cannot be socially constructed. As a result of the fixed nature of reality, study results can be generalized to other people and situations. Positivist researchers frequently conduct studies to test theories or models using a deductive approach. The theory is chosen a priori and then hypotheses are developed to be tested. Research within the positivist paradigm typically takes a quantitative approach to inquiry. Quantitative research methods include the collection of numeric or categorical data either through experiment or survey which is then statistically analyzed to test the relationship between independent and dependent variables (see Box 1).⁵⁻⁷

Naturalistic researchers on the other hand believe that individuals construct knowledge through engagement with others in the world and that knowledge/reality is subjective as the interpretation of data is influenced by the researcher's beliefs. Their approach to data inquiry is inductive in nature and generates a theory or hypothesis following the examination of participant's perspectives. Naturalistic researchers therefore often utilize qualitative research designs to collect data.^{5,7} Three common qualitative research designs include:

1. phenomenology which is utilized to describe the perspectives of those who have experienced a particular phenomenon,
2. ethnography which involves the exploration and understanding of a specific culture or group, and

3. grounded theory which seeks to construct a theory about how individuals work to resolve problems.⁸

When little is known about a phenomena, qualitative research may lead to increased understanding and the generation of theories of the phenomenon. Quantitative research is therefore guided by the results of qualitative research. Thus although these paradigms are often viewed as competing, they are actually complementary in nature.⁵ Further, the boundary between qualitative and quantitative research is often blurred as quantitative research designs may include inferences about meaning based on the magnitude of study results and qualitative research designs may explore the magnitude of study findings. Additionally, most research includes an interplay between inductive and deductive approaches to inquiry.⁶

For centuries, the positivist paradigm and resulting quantitative research has been the predominant approach to data inquiry.⁵ However, interest in qualitative research has dramatically increased in the last 40 years. The rapid expansion of interest in qualitative research resulted in increased challenges of the assumptions of qualitative research and led to what is referred to as the “paradigm wars”; a war regarding the superiority of quantitative or qualitative research.⁷ As a result of this war, and despite the complementary and often blended nature of qualitative and quantitative research, qualitative research has been criticized and devalued.⁵ This may contribute to the limited number of qualitative manuscripts that are published, the limited publication of qualitative studies in higher impact journals, and the lower availability of funding for qualitative research as compared to quantitative studies.^{9,10}

It has been argued that qualitative research designs are not rigorous in nature and the resulting data collected is neither valid nor reliable.^{5,7,8} This argument appears to be driven by the inappropriate requirement that qualitative research adhere to the same principles and goals as quantitative research. Where research designs in quantitative research seek to control extraneous variables in the prediction of causal or correlational relationships, replicate statistical findings, and seek exactitude; qualitative research allows for variability and may even seek out the experience of outliers, focuses on naturalistic and unstructured contexts, and may not include a focus on causation and replication. Thus, qualitative research has its own goals and criteria which are vital to understanding the rich lived experiences of individuals.^{7,11}

The differences in principles and goals of qualitative and quantitative research are evident not only in research design but also in sample selection, data collection, data analysis, and data interpretation (see Box 1). For example, there are sampling differences in qualitative and quantitative research with sample sizes often being larger and selected more randomly in quantitative research. This is because quantitative researchers often focus on the reduction of sampling error and the power of a study required to detect statistical differences whereas quantitative researchers may desire non-random/purposive sampling in an effort to richly describe the phenomena being studied. Data collection in qualitative research is also appropriately less standardized than what is typically seen in quantitative research. Unlike quantitative research, qualitative research does not rely on tests, questionnaires, structured

interviews, or other closed-ended measures. Rather, data collection in qualitative research relies on open-ended protocols.^{8,11,12} Further, data collection in qualitative research ends once data saturation is reached; when no more new data is able to be uncovered and additional collected data is redundant in nature.^{8,12}

Differences in data analysis and interpretation between quantitative and qualitative research are also apparent. Rather than statistical analysis of quantifiable data and deductive inferences about study results, a common approach to qualitative data analysis is content analysis which inductively examines and explains shared concepts within the data and groups them in codes and then into broader categories. These categories are labeled and then grouped into themes which illustrate the phenomena being studied.^{8,11} Given that the goals of data collection and analyses for quantitative research are often the discovery of quantifiable differences as compared to rich descriptions of phenomena respectively, requiring qualitative research to utilize quantitative statistical analyses would be inappropriate.

Ultimately, both qualitative and quantitative researchers are concerned about the quality of the data generated. However, qualitative researchers use language to describe these concepts that differs from that of quantitative researchers. For example qualitative researchers may use the term ‘credibility’ instead of ‘internal validity’ to represent data that is accurate and they may reference the ‘transferability’ of data, meaning the study results are generalizable (similar to ‘external validity’) to other contexts. Similar to the traditional concept of ‘reliability’, qualitative researchers may discuss the ‘dependability’ of data which indicates that the same results would be discovered if study participants were re-interviewed. Further, ‘confirmability’ is similar to quantitative ‘objectivity’ and reflects that study data reflects study participants experiences and not researcher’s biases (see Box 2). Study rigor of qualitative studies may be ensured via the explicit description of the study design, justification of the use of a qualitative approach to data inquiry, the search for disconfirmatory data, participant review of study findings (“member checks”), inclusion of participant exemplar statements, as well as description and justification of sample population selection, sample size, and data collection. Further, use of trained interviewers, assessment of coder reliability, recorded and independently transcribed interview data, and systematic and reproducible data analysis may serve to increase the rigor of a qualitative study.^{8,9,12,13}

Finally, unlike quantitative research, the validity of qualitative data is not typically based on statistical analyses but rather through discussions with study participants, focus groups, or other researchers to confirm the researcher’s interpretations. Qualitative data, though often rigorously analyzed thematically through computer software programs, is also not typically analyzed through statistical means but rather may be analyzed through multiple approaches depending on the phenomena being studied. However, mixed method studies which combine qualitative and quantitative research approaches frequently include both thematic and statistical data analysis and thus may capitalize on the strengths of both data inquiry approaches.^{8,9,12,13}

Qualitative Research in Clinical Science

Quantitative research methods do not always provide the best understanding of health behaviors.^{7,12} For example, qualitative research may be a more appropriate course of data inquiry when the phenomena being studied is difficult to quantify; when greater comprehensive understanding of the phenomena is desired; in order to generate hypotheses as to relationships and causal mechanisms; and to study populations which may be underrepresented in research due to low literacy and/or marginalization.^{12,14} Multiple examples exist which highlight the value of qualitative research over and above that of quantitative research. One such study qualitatively examined why participants in a quantitative study of health and behavior change following myocardial infarction reported low attendance rates in a recommended rehabilitation program. Subsequent qualitative interview of these participants revealed that patients had low motivation to make behavioral health changes as they believed that survival following myocardial infarction meant that their medical problems were mild in nature. As a result of the findings of this qualitative study, changes can be implemented to create a new and potentially more effective behavior change rehabilitation program.^{15–17} Yet another example of the incremental benefit of qualitative data beyond that of quantitative data can be seen in a clinical case study of a woman from an underserved population who was gang raped. While meeting with a hospital counselor, the patient was advised to engage in coping strategies that were empirically supported as effective by quantitative research but were largely unavailable or otherwise inappropriate to the patient given her specific life context. Through qualitative data collection, the counselor was able to work to better understand the patient and provide coping strategies that would be uniquely effective for the patient.¹⁸

In addition to the general added benefit of qualitative research in understanding health behaviors, it has been argued that quantitative research has historically been monocultural with a focus on homogeneous Eurocentric subject populations. Such research has often excluded the experiences of women and minority populations. Qualitative health research which focuses solely on the experiences of women from majority populations also limits understanding of diverse women's experiences. As a result, what is known about health and behavior change may not be generalizable to these populations and may result in the application of ineffective medical interventions and ongoing health disparities for women.^{14,19} This is particularly true for women who are also sexual minorities, from low socioeconomic backgrounds, and/or women from racial/ethnic minority groups.

Sexual Minorities

Quantitative research confirms that lesbian, bisexual, queer/questioning (LBQ) women and (T) transgender men (individuals who are born biologically female and identify and often present as male) may experience disparate access to and quality of medical treatment, health challenges, discrimination, and harassment.^{20–22} Although limited quantitative research has explored the health needs and experiences of LBQ women, less is known about transgender men's health experiences as their experiences are often inappropriately grouped with LBQ women despite sexual orientation and gender identity being different issues.²¹ Given the

unique health experiences of LBTQ individuals, qualitative research is needed to gain insight into these women's and transgender men's experiences.

Qualitative research on the health needs of LBQ women has found that the use of appropriate language by medical providers is highly important in providing effective care. For example, when caring for a lesbian patient, use of the term "social mother" or "non-birth mother" to describe the female partner of a woman who has given birth may be offensive as it may be seen as minimizing their role as a mother.^{23,24} LB women have also described the importance of a supportive clinic environment (e.g., use of gender-neutral language on clinic forms, use of supportive language, appropriate emotional support) as well as the inclusion of their partners in their reproductive health care.²⁵ For example, in a qualitative study by Wojnar & Katzenmeyer (2013) one lesbian woman described her concern about being treated differently by her physician: "Because we were different ... I felt I had to be perfect ... I dressed neatly and I was really supportive to my partner. I was afraid a nurse or a doctor would come into the room and judge that same-sex couples who decided to have babies are not good to each other or that I don't know how to be a supportive partner in labor or postpartum period."²⁴ Overall, it appears that providing a supportive environment for LBQ women's reproductive care is vital as LBQ women's negative interactions with their health care providers may play a large role in these women not seeking routine gynecologic care.²²

Transgender men also have unique gynecologic concerns as they may take testosterone, engage in breast binding or undergo surgical removal of their breasts, ovaries, and/or uterus. However, limited research has examined transgender men's health experiences or needs. The limited quantitative studies of this patient population have often focused on rates disease prevalence or reproductive hormone levels. Qualitative research on transgender men's health experiences provides far greater insight into these patient's experiences. For example, one qualitative study of transgender men's gynecologic health needs reveals that despite not being fond of receiving gynecological care, transgender men perceive gynecologic care to be important. However, transgender men report experiencing gender dysphoria during gynecologic exams and often report concern about sharing their identity with their physicians as well as concerns related to clinic forms which only ask patient's to identify their sex and not their gender. As one study participant stated: "More options on the forms means there is room in people's minds."²¹

Additional quantitative research on sexual minority women and transgender men has found that many LB women and transgender men want to become parents.^{26,27} Although this is interesting, it does not provide information about the ways in which LBT patients experience family building. LBT patients often must pursue medical treatment to begin family building as they require the use of donor sperm, donor egg, and/or gestational surrogacy. Qualitative research specifically on transgender men's experiences of medically assisted reproduction reveal that for these patients lack of acceptance, problematic clinic forms, fear of mistreatment if they revealed their gender identity or advocated for their own care, and even refusal of treatment.²⁸ Thus, as with LBQ research, research with transgender men indicates that the reduction of barriers in gynecologic care likely involves the use of gender-neutral language on clinic forms or forms which allow transgender men to identify their gender,

supportive clinic environments, and acknowledgement of the emotional complexities involved in transgender men's gynecologic care.²¹

Low Socioeconomic Status

Another group of women whose health experiences are understudied in research are women from low socioeconomic status backgrounds. This is particularly true for low-income housed and homeless women. Limited research has examined these women's gynecologic needs and quantitative research with this population is difficult given that it may be difficult to access a large random sample of low-income housed and/or homeless women, and the transient nature of the patient population. What quantitative research exists has shown that these women are at greater risk of certain depressive and anxiety disorders, sexual assault, sexually transmitted diseases, chronic health problems, and unintended pregnancies.²⁹

Several qualitative studies of homeless women's health experiences reveal that homeless women are often primarily focused on their own survival and that their health needs were often not a high priority. Further, many homeless women were unable to take advantage of the health care system due to transportation, employment, housing, or childcare concerns whereas others had low access to health care needs (e.g., condoms, feminine hygiene products). Other women did not access health care as a result of low health literacy particularly as it related to sexually transmitted infections, concern regarding trauma reactions in vaginal exams, perceived low quality of care, and perceived lack of respect from medical providers which resulted in some women not disclosing they were homeless.^{29–31} For example, in Kennedy et al.'s (2014) interview study of homeless women, one woman stated, "It's just heavy. Say like you don't know where you're going to be living in the next month, day, year, you know. You can't focus on too much other things. And so if I have to just eliminate a couple of things just to keep my mind focused—children got to school, okay, I might have to go to work, I'm trying to get this housing...you can't stop to take care of your health sometimes. So it's very, very, very hard."³⁰ Without this understanding of low-income housed and homeless women's lived experiences gleaned through qualitative inquiry, the implementation of gynecologic and other healthcare which ignored the unique needs of this population would likely prove ineffective.

Racial/Ethnic Minorities

Despite making up an increasing percentage of the population, the gynecological challenges of women of African, Asian, and Native American descent as well as women of Hispanic ethnicity remain relatively understudied. This is largely due to challenges in recruitment of these populations to participate in studies. What little research exists with racial/ethnic minority participants highlights the clinical importance of qualitative findings as qualitative studies have provided important perspectives of these women by giving voice to their gynecological health care experiences and beliefs. In short, while quantitative studies may tell us the "what" of these populations, qualitative studies help us understand the "why".

For example, quantitative research findings regarding racial/ethnic minority women's gynecologic health has found that African American women (AAW) have a higher mortality

rate from cervical cancer as compared to other groups of women; this difference appears to be driven by differences in rates of cervical cancer screening (i.e., “what” is the cause of these differences). A qualitative study by Ackerson et al. (2010), however shows that AAW women who engage in regular screening have supportive mothers and physicians who reinforce the importance screening and explain the medical reasons for screening (i.e. “why” AAW women may not be participating in screening). Thus simply being told to have an annual Pap smear is a less effective mechanism than using family networks and engaged provider that educate patients to effectively encourage AAW women to undergo screening.³² Similarly, for women of Middle Eastern descent, qualitative research has also found that greater medical explanation of the importance of cervical screening is needed. However, as a result of cultural norms regarding modesty, women of Middle Eastern descent may benefit more from the support and encouragement of their husbands rather than their mothers to undergo cervical screening.³³

Quality research has also highlighted important differences and insights amongst minority women seeking infertility or pregnancy care. For example, qualitative research has found that Hispanic women, may desire that their physician not only communicate with them in their primary language, but they also desire physicians who act like they are their friends during treatment.^{34,35} Qualitative research has also found that different cultural and religious beliefs about infertility may result in increased stigma, fear of interpersonal violence or divorce, and reduced treatment seeking for some women. For these women, physician awareness of and sensitivity to different cultural beliefs about health, improved health education, and inclusion of religious and other supports may play a vital role in encouraging women to seek treatment.^{34,36–43} These recommendations are similar to those resulting from qualitative studies of women from racial/ethnic minority groups who historically engage in lower rates of breast cancer screening than white women (CW).^{44–48}

The contributions of qualitative research to the gynecological health of minority women is particularly evident in research focusing on women living with fibroids. Although fibroids have been found to disproportionately affect AAW, research on women’s lived experience with fibroids often includes fewer AAW women than CW (see e.g.,^{49–53}). Quantitative research has identified multiple differences in pathology (e.g., uterine size and weight, number of fibroids, age at diagnosis, and time between diagnosis and surgery), risk factors (e.g., obesity, history of hypertension, family history of fibroids), and potential sequelae (e.g., infertility; heavy menses; disruption in physical activities, relationships, and work) between AAW and CW.^{54,55} It is likely that the aforementioned differences as well as other demographic and cultural differences would influence AAW’s lived experience with fibroids; thus AAW’s voices with regard to fibroids warrant attention.

Results of the few published qualitative studies of women’s experiences with fibroids in which the majority of participants are AAW have provided a richer understanding of AAW’s experiences. In 2015, Ghant et al. published one of the first studies which qualitatively examined primarily AAW’s perspectives regarding fibroids.⁵⁶ This found that women with fibroids experienced psychological stress (including fear of dying) and a sense of loss of control over their body. For example, one woman in the study stated: “I became a little worried because I am like something is wrong with me and I don't understand it. I actually

thought at one point ... am I dying, God am I dying?" Further, women with fibroids reported a decrease in self-esteem as a result of their fibroids and a desire for greater social support surrounding their experience with fibroids.⁵⁶ This study enforced the need for emotional and psychological support for patients with fibroids - largely minority women.

Yet another qualitative study of a large number of AAW's treatment seeking behaviors found that women received delayed diagnoses of fibroids because they inaccurately believed their fibroid-related symptoms (e.g., abnormal uterine bleeding) were normal and many women had low health literacy about fibroids. The limited health literacy regarding the seriousness of symptomatic fibroids is evident in the statement of one woman in the study who reported: "...my period lasted for 30 days and it was heavy and it was horrible. I was wearing pads like the size that you get in the hospital after you have a baby and I was so used to that happening that at that time I didn't call anybody because you know it was like this is normal."⁵⁷ Although some women lacked relevant knowledge about fibroids, others knew something was wrong but actively avoided seeking help for various personal reasons.⁵⁷ Finally, one identified qualitative study examined racial/ethnic differences in lived experiences with fibroids. Results of this study by Sengoba et al. (2016)⁵⁸ confirm the importance of separately examining AAW's perspectives regarding fibroids as AAW in this study reported higher treatment expectations, greater treatment barriers and financial challenges, poorer recovery experiences, and decreased satisfaction as compared to other women.⁵⁸ Overall, it appears that among AAW women with fibroids, increased social and emotional support and health literacy education are warranted to improve the gynecologic care of these women.

Summary

Patient-centered-care requires that health systems understand the unique needs and values of patients. However, historically, clinical health research has often excluded the experiences of women and minority patient populations. Further, clinical research has often relied on quantitative research strategies; this provides an interesting but limited understanding of women's health experiences and hinders the provision of effective patient-centered care. Therefore, rigorous qualitative research exploring women's health and lived experiences needs to be included, encouraged, and funded in order to enable the provision of high quality evidence-based health care to women.

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Box 1**Underlying Assumptions for Positivist and Naturalistic Research Approaches**

Type of assumption	Positivist Approach	Naturalist/Constructivist Approach
Research Design	Quantitative	Qualitative
Epistemology	Knowledge is uncovered by detached scientific observations. Reality is independent of any opinions of the researcher. The researcher tries to minimize subjectivity and to maximize objectivity	Knowledge is socially constructed through interaction of the researcher with research participants. The values of both the researcher and the research participants contribute to knowledge.
Ontology	Reality is singular and objective. Reality is constructed based on cause and effect inferences.	Reality is plural and subjective. Each study participant has a different view on the phenomenon being studied.
Methodology	Deductive reasoning Statistical hypothesis testing Objective and measurable Prediction and estimation Identifying associations between variables Generalization from samples to population Rule-bound Statistical analyses Internal and external validity Reliability Sample is large or random	Inductive reasoning Theory or hypothesis construction Subjective and non-measurable Exploration of participants' experiences Provide rich description of the phenomenon being investigated Generate hypothesis or theory Generalization does not matter Context-bound Content analyses Credibility, transferability, Dependability, confirmability Sample size is often small

* modified from Tavakol & Sandars (2014).

Box 2**Data Quality Criteria for Quantitative and Qualitative Research**

Data Quality Criteria	Quantitative Research	Qualitative Research
Confidence in the accuracy of findings	Internal Validity	Credibility
Generalizability of findings to other settings	External Validity	Transferability
Reproducibility of findings	Reliability	Dependability
Findings are unbiased	Objectivity	Confirmability

Key Points

- Patient-centered care requires that health systems understand the unique needs and values of patients.
- Quantitative research designs provide an important but limited understanding of women's health experiences and needs.
- Limited understanding of women's health experiences and needs can lead to the development of ineffective health care strategies and treatment.
- Qualitative research exploring women's health and lived experiences uniquely helps give a voice to the health experiences of underserved women.
- Qualitative research enables the provision of truly patient-centered care and lays the groundwork for inclusive quantitative studies.