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Authors

McLemore, Monica R
Desai, Sheila
Freedman, Lori
et al.

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Women Know Best—Findings from a Thematic Analysis of 5,214 Surveys of Abortion Care Experience

Monica R. McLemore, PhD, MPH, RN^{a,b,*}, Sheila Desai, MPH^b, Lori Freedman, PhD^b, Evelyn Angel James, CNM, WHNP-BC^b, Diana Taylor, PhD, RNP, MS, FAAN^{a,b}

^a University of California, School of Nursing – Family Health Care Nursing Department, San Francisco, California

^b Advancing New Standards in Reproductive Health, Bixby Center for Global Reproductive Health, University of California, San Francisco, California

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ABSTRACT

Objective: Patient experience is an essential component of quality care. Few studies have comprehensively evaluated patient experiences of abortion care. The objectives of this study were to describe women's experiences of abortion care in their own words, and to determine themes across patient experiences.

Study Design: Data for this thematic analysis, a qualitative method that allows for the identification, analysis, and report of patterns or themes within data, come from a larger study of safety and quality of aspiration abortion care across 22 clinical sites. Participants completed an abortion experience survey including fixed choice questions and an open-ended question: "Is there anything you would like to tell us about your experience?" The data were then categorized by responses to another survey question: "Overall, was your experience about, better, or worse than you expected?"

Results: A total of 5,214 responses were analyzed. Women reported positive abortion care experiences with the majority of women rating their experience as better than expected ($n = 3,600$). Two major themes that emerged from the data include clinic- and patient-level factors that impact how patients rate their experiences. Analysis of the responses categorized in the worse than expected group ($n = 136$) found that women primarily faulted clinic-level factors for their negative experiences, such as pain control and management, and wait time for appointments and in clinic.

Conclusion: This analysis highlights specific areas of abortion care that influence patients' experience. The few women who were disappointed by care in the clinic tended to fault readily modifiable clinical factors, and provided suggested areas of improvement to enhance positive experiences related to their abortion care.

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Positive patient experience is well documented to be associated with improved clinical outcomes such as decreased morbidity, decreased mortality, and better treatment adherence (Institute of Medicine, 2001). Generally, patient experiences of health care provision are measured using validated, well-designed survey instruments such as the Hospital Consumer Assessment of Healthcare Providers and Systems (2014). This

survey was developed by the Centers for Medicare and Medicaid services and is the first national, standardized, publicly reported survey of patients' perspective of their care while hospitalized. The ambulatory care/outpatient version called Consumer Assessment of Healthcare Providers and Systems was developed by the Agency for Healthcare Research and Quality (AHRQ, 2012), and measures patient experiences in four domains using one to two questions each. However, owing to the controversy and stigma that continues to be associated with abortion, this very common, safe and legal procedure has been largely ignored in quality of care studies and only a few have evaluated patient experiences of abortion care beyond general satisfaction or procedural safety (Bird et al., 2003; Dalton et al., 2006; Kaiser, 1999).

Only two studies have prospectively measured women's experiences of aspiration abortion care in outpatient settings. In 1999, the Kaiser Family Foundation and the Picker Institute

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* Correspondence to: Monica R. McLemore, 1330 Broadway Ave, Suite 1100, Oakland, CA 94612, Phone: 415-200-6097; Fax: 510-986-8960.

E-mail address: mclemoremr@alumni.ucsf.edu (M.R. McLemore).

released a report entitled, “From the Patient’s Perspective: The Quality of Abortion Care,” in which a diverse group of 2,200 women across 12 states were interviewed 3 to 4 weeks after their abortion about satisfaction and quality care factors. Generally, women in the Kaiser-Picker study reported high satisfaction, with two notable exceptions: 1) Nausea was not appropriately treated and 2) continuity of care was compromised as women wanted assistance in making follow-up appointments (Kaiser Family Foundation, & The Picker Institute, 1999). Of note, 96% of women stated they would recommend their abortion provider to a friend and the factors influencing the abortion experience of women were 1) information from clinic staff, 2) attention to privacy, 3) treatment by staff, and 4) post procedure assistance (Kaiser Family Foundation, & The Picker Institute, 1999).

A more recent California-based prospective, observational study that evaluated the safety and quality of early aspiration abortion provision in 22 clinics across the state used measures for quality of care based on the findings from the 1999 Kaiser-Picker report as well as federal measures of consumer assessment of healthcare that include patient- and clinic-level factors (AHRQ, 2012; Taylor et al., 2013; Weitz et al., 2013). This larger study, from which the data analyzed in this manuscript come, was designed to elicit patient experiences of abortion care using multiple methods. The findings published elsewhere (Taylor et al., 2013), analyzed fixed-choice survey responses from 9,087 women and found that patient experience scores were very high across the entire sample; almost 90% of women rated their treatment by clinician and clinic staff as excellent, whereas only 60% of the women in the Kaiser-Picker study reported their experience as excellent. The adjusted analysis found that clinical care characteristics were associated with overall patient experience; clinician type was not (Taylor et al., 2013).

Patient satisfaction ratings alone have been determined to be an inadequate measure of patient care experience in the context of abortion care because fixed-choice questions do not allow women to further explain their experience that may influence the quality of care. To better understand how to improve abortion care, qualitative data analysis results in a more in-depth understanding of women’s individual perspectives of clinical care. The objective of this mixed-methods analysis was to extend the quantitative analysis of women’s experiences of abortion care in the larger study by determining themes across patient experiences using a thematic approach.

Methods

Institutional review board approvals were obtained from the University of California, San Francisco; Ethical and Independent Review Services for Planned Parenthood clinics; and Kaiser Permanente of Northern California. Briefly, women at least 16 years of age (18 years at Planned Parenthood sites) seeking a first-trimester aspiration abortion (i.e., facilities self-defined this as ≤ 12 or ≤ 14 weeks’ gestation by ultrasound) and who could read English or Spanish were recruited from 22 clinics providing abortion care in both Northern and Southern California, to participate in the study (Taylor et al., 2013). All women enrolled in the study received a 16-item, de-identified survey during the post-abortion recovery phase from study staff and were left alone to confidentially complete the survey, before leaving the clinic. This survey was adapted from three published instruments (AHRQ, 2012; Kaiser Family Foundation, & The Picker Institute, 1999; Misra, 2001) and included questions about demographic and health characteristics (three questions), access to

abortion care (six questions), and four questions assessed specific Consumer Assessment of Healthcare Providers and Systems domains: 1) Treatment by abortion provider, 2) treatment by clinic staff, 3) clinic wait time, and 4) experience of pain (AHRQ, 2012; Bjertnaes, Sjetne, & Iversen, 2012; Kaiser Family Foundation, & The Picker Institute, 1999). Consistent with recommended best practices (Bell & Krivich, 2000), an open-ended question was added to the survey to elicit patients’ experiences with their care. The final patient experience survey sample was 9,087 women who completed one or more questions on this anonymous survey.

Data for the thematic analysis reported in this manuscript were a subset of responses from this survey, examining responses to two of the questions: A fixed-choice question, number 2 of 16 on the survey, with three response sets—overall, was your experience about, better or worse than you expected?; and an open-ended question—is there anything you would like to tell us about your experience? This represented the final question of the survey and women were provided one quarter of a page to expand on their fixed-choice responses. Usable comments were defined as at least one phrase or sentence in English. Patient experience survey questions including women responding to the four fixed-choice and the one open-ended question are shown in Figure 1.

Analysis

Thematic analysis is a qualitative method that allows for the identification, analysis, and reporting of patterns or themes within data (Braun & Clarke, 2006). Data for this analysis were initially extracted verbatim from STATA version 12 (StataCorp, 2011). The senior author of the study (D.T.) conducted an initial data review to determine if the data were robust enough for more in-depth analysis. The first author conducted the initial thematic analysis under the supervision of a medical sociologist with extensive qualitative methods expertise. Briefly, thematic analysis includes several phases: Familiarize yourself with your data (first and senior author), generate initial codes (first author), search for themes (team), review themes (team), define and name themes (team); and produce the report (team; Braun & Clarke, 2006). More than one code applied to many of the responses in which several issues were articulated. The first author read all 5,214 comments and grouped them in broad categories. The team then determined the final coding scheme, based on the broad categories and all of the comments were re-read by the first author. An iterative process was used to determine the major themes from the data. Finally, the first author developed grids of codes and themes that could serve as exemplars and a second iterative process was used within the team to determine which quotes best represented the themes and could be included as findings. Once the exemplars were identified, several members of the team drafted the first manuscript and a final iterative process was initiated to complete the report.

Results

Of the 9,087 women who completed the patient experience survey in the larger study, 5,255 women responded to the open-ended question. After exclusion for responses that were not at least a phrase or sentence in English, 5,214 usable narrative responses remained (57% of women completing the fixed-choice survey questions). Respondents (to the open-ended question) were on average 25 years old and the majority was non-Hispanic

Figure 1. Flow sheet of survey questions that assess patient experience.

White or Hispanic, and had completed a high school degree or had some college education (Table 1). There were not proportional differences between the groups of women who responded or did not respond to the question assessing if their experience was about, better or worse than expected (data not shown). The women who did not write in comments had a similar demographic distribution, although they were more likely to be

White, and less likely to have completed a college degree or higher (data not shown). Of these 5,214 women, nearly 70% reported their experiences as better than expected; 26% reported the experience to be about what they expected and 3.4% reported their experience to be worse than expected.

Two major categories of themes quickly emerged from the data, namely, patient-level and clinic-level factors that influenced patient experiences. Experiences of shame and/or stigma, pain experience, and interactions with staff emerged as patient-level factors, and perceptions of clinical environment, adequate pain management, and wait time for appointments and procedures emerged as clinic-level factors influencing abortion care experiences. Definitions and exemplars are provided for each of the themes and specific suggestions related to each theme that could improve the abortion care experience are provided in Table 2.

Women's Experiences of Shame and/or Stigma

Shame and/or stigma were coded as reflections on women's abilities to be honest with their provider regarding contraceptive choice, history, or failure, and/or previous abortion. This code also includes comments of embarrassment about having an abortion and future plans: "I vow to never do this again" or "You learn from your mistakes." Many comments included in this code overlapped in the staff code because women were appreciative of

Table 1
Demographic Characteristics of Women Providing Usable Comments ($n = 5,214$)

Characteristic	Sample, % (n)	Mean/Range
Age, y		25 (15–47)
Race/ethnicity		
Hispanic/Latina	39 (2,055)	
White	24 (1,267)	
African-American	16 (828)	
Asian/Pacific Islander	13 (652)	
Other	5 (275)	
American-Indian/Alaska Native	3 (137)	
Total	5,214	
Education		
Still in high school	3 (142)	
Didn't finish high school	7 (382)	
Finished high school; got GED	25 (1,287)	
Some college	44 (2,319)	
Graduated college	17 (930)	
Master's, professional or doctoral degree	3 (154)	
Total	5,214	

Table 2
Patient-Suggested Improvements of the Abortion Care Experience

Concern	Suggestion	Rationale
Shame and/or stigma	Use of a numbers system to call women in crowded/shared waiting rooms	Ensure privacy and acknowledges embarrassment about having an abortion
Staff	Continue to employ empathetic, competent staff who are attentive to patient postoperative care needs	Ameliorates and moderates many of the negative comments regarding wait time and pain
	Have staff frequently check in with patients and to use a team-based and patient centered care in abortion service provision	Improves information sharing with patients and attention to privacy and post procedure assistance
Pain	Manage nausea and vomiting	Provide additional medications
	Improve sedation and analgesia	Patient discomfort reflected 76% of comments in the worse than expected strata
Clinical environment	Entertainment, music, magazines while waiting	Allows for distraction
	Staff check-in	Supports women in their information needs
Time	Keeping women informed	Allows women to plan their time
	Free Wi-Fi and cell phone chargers	Allows for distraction
	Wait time for appointments ≤ 7 days	Minimizes anxiety

not being judged and commented about how helpful the staff was in making women feel supported in their decision. Women associated negative feelings toward themselves about needing to have an abortion, yet concurrently directed positive comments toward the staff in the midst of these experiences. Many women also spoke defiantly about their abortion experience as a singular experience in their lives: “First and last time. So depressed”, or “My experience was something I never thought I would do in my life.”

Women's Experiences with the Staff

The role of the staff cannot be understated in this study. Many of the comments across various codes reflect women's experiences with the staff, identified as the reception and phone staff, the nurses, and the clinicians. All levels of staff are commented on and the women in several cases name specific individuals. Several domains emerged in terms of staff and they include staff demeanor (i.e., kind, rude; “Everyone I interacted with at the clinic was kind, informative, cordial, and patient” or “Receptionist was rude but everyone else was excellent”).

Additionally, many women commented on the staff role (i.e., easing anxiety, comfort measures). Women were aware of both their own emotional state and their behavior: “The staff are what made my experience much easier and less frightening.”

Interestingly, women were able to articulate conflicting emotions and their responses to them particularly the distinction that just because they were having a hard time did not preclude them from making their decision and the key role non-judgmental staff played in the process: “I had a hard time but the doctors were really great,” and “I was a crying, nervous wreck and the staff was friendly and calmed me down.”

Women made a clear distinction between staff and personal support and several commented about the inability to have social support during their abortion experience, particularly of note are women who understood the need for accompaniment owing to possible impairment because of medications administered, but made statements such as: “I really wanted my boyfriend there with me” or “Patients should be allowed to see one person in recovery.” Some women went further to request accompaniment in the rooms and stated: “Allow others to come in procedure rooms, i.e., significant others,” or “I have been given gas before and been able to have a friend in the room, it would be better that way,” and “Was very nervous but then went away with talking to the ladies in the waiting room.”

Women's Perceptions of the Clinical Environment

The theme of clinical environment encompassed several domains, including physical space of the clinic and many women commented on cleanliness and being surprised: “I was pleased about how clean the facility was.” Other women commented about the space among and between patients (some women definitely valued privacy more than others), the resources available in the clinical space (many patients complained about wait time and lack of cell phone chargers, magazines, etc.), and differences in clinical experiences based on geographic location. Examples include reflections on the proximity of patient to each other, the resources available in the clinic, and geographic location: “If possible, a more private waiting room would be more comfortable.” Physical space comments were mostly centered on the warmth or coolness of the examination and waiting rooms, quality of entertainment/magazines; however, detailed comments about the cleanliness, music, and privacy included, “You should put music in the waiting room areas or have better sound barriers installed,” and “The volunteer support staff and music in the parking lot is very much appreciated.”

Women's Perception of Time

The theme of time was mentioned by many women regardless of how they rated their experiences and can be considered as two distinct domains: Wait time for an appointment and wait time in clinic. Women spoke clearly about once the decision to have an abortion is made, that they wanted it to happen as quickly as possible. “The wait time because once you have made up your mind to have the abortion you want it over as soon as possible.” Confounding this reality, many patients associated their abortion care experience as a waste of their time owing to the shortness of the procedure, but all of the preparation that is required to safely perform the procedure: “There was a lot of waiting, and feeling like I was on an assembly line,” and “Schedule appointments more timely.”

An additional component of time was the disconnect of the long wait time for the appointment or in clinic with the shortness of the procedure: “Waiting time is too long but I am very satisfied with your service and how I was treated while I was in the clinic,” or “Its so much wait before, that's what makes it much scarier. But overall it was good,” or “It was very hard to get an appointment. Call center did not get back to me on my cell phone.”

Many women commented that time and specifically waiting contributed to their anxiety, remarking that “The waiting is the hardest part; more communication would be very helpful,” or “The staff is great, but the wait is extremely long and very nerve wracking and uncomfortable,” and “Waiting period made me much more anxious,” and “Four hours to wait for an ‘emotional’ situation was beyond frustrating.” Many women also remarked in the staff category that those staff who checked in with women during their wait were the most appreciated.

The Worse than Expected Responses

In this section, we focus in on the dominant concerns of those who specifically noted their experience was worse than expected, to identify factors that contributed to bad or negative experiences. Three major themes in the worse than expected responses were identified: Clinical care, pain, and wait time. Clinical care was related to comments about multiple attempts at intravenous catheter insertion, problems assessing pregnancy on preprocedure ultrasound, uncertainty about abortion completion post-procedure, and the need for subsequent blood draws and follow-up appointments. Time-related comments addressed wait time for an appointment once the decision to have an abortion was made and time in clinic. However, these comments and the clinical care comments were dwarfed by the high frequency of comments regarding pain, where the majority (103 of 136) of the comments addressed some aspect of pain.

Women's perception of pain

Women who rated their abortion experience as better than or about what they expected also wrote negative comments about their pain levels or type of pain management. Domains of pain included amount and type of medication, amount and type of pain, and associated effects of pain; many women used strong language to describe the pain they felt, such as “Worst pain of my entire life,” or “The shot or whatever it was to my uterus before the suction was excruciating.” Concurrently, many women expressed gratitude for services while experiencing pain or awareness about their own perceptions of pain and pain tolerance: “Great staff! More painful than I expected but I think it's because I have high tolerance,” and “It'd be better if I had the option of complete sedation—even at an additional cost” to “I just wish I was asleep and didn't feel anything.”

Many women made specific comments about the quality of their pain management and used the opportunity to advocate for better interventions: “Don't give medications that induces pain if not prepare to then administer the medicine for nausea and vomiting,” or “It hurt very bad and stronger medication should be offered to those who request it”; some women went as far to understand that pain and or discomfort would be a part of their experience, but distinguished this fact from their experience: “I was told I would feel some discomfort, but instead there was lasting intense pain.” Comments were shared between the clinical environment and pain, particularly if a different clinic offered a type of analgesia and sedation that was more or less effective for a previous abortion. Patients seemed to compare and contrast previous abortion care experiences to rate their current experience: “I have had procedure done seven years ago at different location and my experience there was horrible, this time it was much better” or “I've had this procedure before in 2007 although, but more painful this time.” Patients also commented on medication/pain use as altering their perceptions of time: “In past

procedures, I've been sedated and unaware of what was going on ... it makes the time go faster.”

Discussion

Echoing the very positive patient experience scores as reported from the larger study (Taylor, 2013), this analysis shows that most women found outpatient first trimester abortion care to be about what or better than they expected. Women's experiences described in the open-ended question expand our understanding of what women value in abortion care and how services can be improved. The five themes identified from the women's written comments (shame and/or stigma, staff treatment, clinical environment, pain, and time) are specific to operational realities of providing medical services and are perhaps exacerbated in the abortion context (Kimport, Cockrill, & Weitz, 2011). Additionally, comments reflected many of the domains measured by the fixed-choice questions; however, these narrative data provide concrete suggestions for improving the abortion care experience from the individual woman's perspective.

These data advance our understanding of the abortion care experience in two distinct ways. First, these data give context to the quantitative findings collected in four predetermined domains; second, they provided women with the space to expand their responses, particularly the environment of care. The Kaiser-Picker study asked participants about the cleanliness of the clinic, patient privacy, and treatment, but otherwise did not ask patients about what types of interventions would make their wait times more tolerable or what immediate inexpensive modifications the clinics could make (i.e., phone chargers and free Wi-Fi) to improve their in-clinic experiences.

Management of other symptoms by clinicians including nausea and vomiting was also mentioned in several comments; however, pain management by far was the factor that contributed to women reporting worse than expected experiences. Analgesia and sedation in abortion care has received little attention in the literature and is an area of investigation that should be considered given the intensity and frequency of women's comments. Recent research in abortion analgesia and sedation has focused on second trimester or later abortion (Dean, Jacobs, Goldstein, Gevirtz, & Paul, 2011; Wiebe, Byczko, Kaczorowski, & McLane, 2013; Wilson, Chen, & Creinen, 2008); however, few studies have identified patient-centered pain management as an area of inquiry for patients seeking first-trimester abortions (Allen, Fortin, Bartz, Goldberg, & Clark, 2012; Meckstroth & Mishra, 2009; Rawling & Wiebe, 1998; Renner, Jensen, Nichols, & Edelman, 2010). Future studies should seek to identify patient preferences for pain management and establish evidence-based care for analgesia and anesthesia appropriate for the socio-demographic factors, weeks of gestation, and other variables associated with patient experiences of comfort and pain. For example, providing music in the clinic, entertainment/magazines in the waiting rooms, multiple opportunities for privacy, and increasing involvement of partners and other personal support people along with preparing women for long wait times can be used to improve clinical care and women's experiences of their care.

Limitations and Strengths

There are two limitations to our study and two major strengths. First, data collected for analysis in this study were obtained at the end of patients' recovery time, which for many

patients was the conclusion of a long day. We hypothesize that many participants were eager to leave the clinic, which may be one of many factors that contributed to the low response rate for the open-ended question. Future research should be designed specifically to elicit patient experiences about their abortion care, independent of other factors being studied. Second, surveys were completed post abortion and the potential for sedative/pain effects that influence a woman's responses could account for the large number of comments regarding pain. Two strengths of the study include the large number of written comments ($n = 5,214$) and the use of multiple types of queries to evaluate patient experiences in their own words that resulted in patient-suggested solutions to improve clinical care provision.

Implications for Practice and/or Policy

Incorporating the assessment of patients' experiences of their care is an essential component of quality care. Data from this study suggest areas of clinical improvement that can influence women's experiences related to their abortion care. We provide a list of the clinic- and patient-level factors that emerged from the data with practical suggestions from patients in Table 2. Many of the suggested improvements are low or no cost and can be easily and quickly implemented into existing practice.

Conclusions

Women reported very positive abortion care experiences; almost 70% rated their experience as better than expected. Very few rated their abortion experience as worse than expected (<4%). This qualitative analysis highlights specific areas of abortion care that influence patient experience outcomes and specific areas of clinical improvement that impact patient experience outcomes related to quality care and offer patient-suggested solutions. The few women who were disappointed by care in the clinic tended to fault readily modifiable clinical factors such as pain management and wait time.

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Author Descriptions

Monica R. McLemore, PhD, MPH, RN, is an Assistant Professor in the Family Health Care Nursing Department and a Research Scientist at Advancing New Standards in Reproductive Health, both at the University of California, San Francisco.

Sheila Desai, MPH, was the Research and Evaluation Manager for the Health Workforce Pilot Project at Advancing New Standards in Reproductive Health, University of California, San Francisco.

Lori Freedman, PhD, is an Assistant Professor in the Department of Obstetrics, Gynecology and Reproductive Sciences and a Medical Sociologist at Advancing New Standards in Reproductive Health, both at the University of California, San Francisco.

Evelyn Angel James, CNM, WHNP-BC, is a doctoral candidate in the Community Health Systems Nursing Department and a Research Resident at Advancing New Standards in Reproductive Health, both at the University of California, San Francisco.

Diana Taylor, PhD, RNP, MS, FAAN, is Professor Emerita in the Family Health Care Nursing Department and Director of Research and Evaluation of the Primary Care Initiative at Advancing New Standards in Reproductive Health, both at the University of California, San Francisco.