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"Every Person's Just Different": Women's Experiences with Counseling for Early Pregnancy Loss Management

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A B S T R A C T

Background: Women have strong preferences for their choice of early pregnancy loss (EPL) management. However, current practice patterns suggest that some women may not be offered counseling about the full range of management options. To develop a foundation for quality counseling about EPL treatment, we elicited patients' perspectives regarding their preferences and values for communication during this decision-making process.
Methods: Twenty-one individual interviews were conducted with women who recently experienced EPL. Interviews discussed their experiences surrounding EPL diagnosis, counseling for and support during treatment decision making, and management outcomes, and concluded with questions seeking feedback on a decision tool. Interview transcripts were coded in an iterative and collaborative process by two authors, using constructivist grounded theory analysis.
Results: Women in our study overwhelmingly preferred having options for EPL management rather than being prescribed a single treatment by their provider. Women reported a wide variety of personal priorities that influence decision making for EPL management. They valued providers who engaged in a balanced conversation about these priorities and medical recommendations. Participants stressed the importance of candid counseling about treatment options and expressed frustration with delayed news delivery for EPL diagnosis.
Conclusions: A patient-centered approach to EPL management includes unbiased counseling about the full range of options available. Women may perceive communication during EPL diagnosis as a critical time to initiate these discussions. Women are often weighing personal priorities to make decisions about EPL management and use of a decision aid may offer a systematic approach to identifying women's preferences for treatment.

Early pregnancy loss (EPL), or first trimester miscarriage, is a common experience, occurring in at least 15% to 20% of pregnancies (Sapra et al., 2016; Ventura, Abma, Mosher, & Henshaw, 2008). Because large-scale trials have established that there are a variety of safe and effective options (Trinder et al., 2006; Wieringa-de Waard, Vos, Bonsel, Bindels, & Ankum, 2002; Zhang et al., 2005), management of this condition is a preference-sensitive decision in which the best choice for management depends on how the patient values perceived advantages and disadvantages of the treatment options (O'Connor et al., 2007). The preference-sensitive nature of this decision has been recognized by the American College of Obstetricians and Gynecologists, who in a 2015 Practice Bulletin, state that all eligible patients should be offered the full range of therapeutic options—uterine aspiration, medication management, and expectant care (Committee on Practice, 2015).

Research demonstrates that women managed according to their preferences, as compared to those randomized to treatment, can have improved quality-of-life scores and mental health scores, as well as increased satisfaction with care (Wieringa-De Waard, Hartman et al., 2002). Further, studies show that many patients

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do have strong and variable preferences for their choice of EPL management (Dalton et al., 2006; Smith, Frost, Levitas, Bradley, & Garcia, 2006; Wieringa-De Waard, Hartman et al., 2002). However, estimates of actual treatment patterns suggest that choices of management may be constrained and depend on where women receive care. Specifically, the vast majority of obstetrician-gynecologists use uterine aspiration in the operating room, whereas family physicians and nurse midwives primarily use expectant care, and few providers use office-based aspiration or medication management (Dalton et al., 2006; Dalton et al., 2010; Wallace, Dehlendorf, Vittinghoff, Gold, & Dalton, 2013). Given that many women have preferences for these latter options (Dalton et al., 2006; Smith et al., 2006; Wieringa-De Waard, Hartman et al., 2002), this finding suggests that some women may not be receiving care that allows them to select the option that is concordant with their preferences. Although some of this may be related to training or resource limitations (Dalton et al., 2010; Wallace et al., 2013), it also may reflect inadequate or directive counseling.

Counseling is an essential part of choosing management for preference-sensitive decisions, because supporting a woman to make a treatment decision in line with her priorities and preferences would be expected to improve her ability to make value-concordant decisions and therefore to have better outcomes. As research demonstrates that one-half of women would change their decision for EPL management given a physician's recommendation (Molnar, Oliver, & Geyman, 2000), providers have an influential role in the decision-making process. However, there has been no formative research in the case of EPL management to inform how women wish to arrive at a decision for EPL care and how providers can support them in this process.

To develop a foundation for counseling about EPL management options, we aimed to describe patients' experiences of and preferences for counseling during this decision-making process. Our research aims to inform the development of implementation strategies directed towards improving women's experience of counseling for miscarriage management.

Materials and Methods

We conducted semistructured interviews with women who recently experienced EPL from December 2010 to May 2011. Recruitment took place at a county hospital and an academic medical center in Northern California. All EPL management options are generally available to women at these health centers, with aspiration performed either in an outpatient hospital-based or office-based setting. Eligible women presented to medical care with a diagnosis of EPL requiring management, were at least 18 years old, spoke English or Spanish, and had access to email or phone for personal contact and interview scheduling. We excluded women presenting with an inevitable or completed miscarriage, because they did not require counseling on management options, and women who had medical complications, such as hemorrhage or infection, for whom options were limited.

Clinicians at each recruitment site identified eligible women at the time of diagnosis or management of EPL and discussed the study with interested participants. The research assistant contacted participants who had consented to be contacted, and interviews were scheduled either by phone or email. Most women were interviewed within 4 weeks of EPL management completion.

Private, semistructured interviews were conducted by a member of the research team and used a question guide (Table 1) focused on the participant's experience of events surrounding EPL diagnosis, counseling for management options, and management outcomes, as well as the participant's perception of emotional support from her provider and family or friends during the process. Women were also asked specifically about having choices in medical treatment decisions and their preferences for provider involvement in making these decisions. Each interview concluded by presenting to the participant a draft of a counseling checklist based on compiled EPL preferences research (Wallace, Goodman, Freedman, Dalton, & Harris, 2010) to record impressions and feedback on its usefulness as a decision aid. The checklist was revised in an iterative manner during the course of the study to meet the needs and reflect the preferences of our participants. Figure 1 shows the final version of the tool, Patient Treatment Priorities for Miscarriage.

Table 1
Selected Questions from the Interview Guide

How did you find out you were having a miscarriage?
How did your provider talk with you about what to do about the miscarriage?
Was there anything the provider said that was particularly helpful or reassuring?
Looking back at the whole experience from the time of diagnosis through the decision making, do you think you were given a choice of management?
Do you think a different treatment option would have been better for you? Why or why not?
Do you want your provider just to give options about treatments or tell you what their preference is?
Some people find having choices about medical treatment to be a good thing, and others feel that too many choices can be confusing or difficult. What do you think about having choices, especially choices for miscarriage treatment?

All interviews were audiotaped, transcribed, and verified by written field notes. A bilingual research team member translated the Spanish interview to English for analysis. De-identified interview transcripts were entered into NVivo 9 software. We chose a constructivist grounded theory approach to analyze the data as it provided the flexibility to focus on ideas that emerged during data collection and analysis as well as incorporate predetermined areas of interest (Charmaz, 2006). With a constructivist grounded theory approach, we interpreted our findings to seek understanding of our participants' experiences as situated within the larger social context. We devised a coding structure based both on these preexisting themes of interest (e.g., the importance of having treatment options) and on newly identified ones (e.g., frustration with delayed news delivery). After coding several transcripts independently, the members of the research team met to revise the coding structure as indicated by emerging themes. We drafted memos to document our thoughts about newly identified themes throughout data collection and analysis, and added and revised coding categories as needed in an iterative manner. Two researchers independently read each transcript to apply codes and met to resolve any discrepancies. Ultimately, all interviews were analyzed with a uniform coding scheme using NVivo software. Participant recruitment stopped when thematic saturation was reached.

This study was approved by the Committee for Human Research at the University of California, San Francisco.

Results

Twenty-one interviews were conducted, of which 1 was in Spanish, 12 were by phone and 9 were in person. Participant