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Grief after second-trimester termination for fetal anomaly: a qualitative study

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Abstract

Objectives: We aimed to qualitatively evaluate factors that contribute to and alleviate grief associated with termination of a pregnancy for a fetal anomaly and how that grief changes over time.

Study design: We conducted a longitudinal qualitative study of decision satisfaction, grief and coping among women undergoing termination (dilation and evacuation or induction termination) for fetal anomalies and other complications. We conducted three post-procedure interviews at 1–3 weeks, 3 months and 1 year. We used a generative thematic approach to analyze themes related to grief using NVivo software program.

Results: Of the 19 women in the overall study, 13 women's interviews were eligible for analysis of the grief experience. Eleven women completed all three interviews, and two completed only the first interview. Themes that contributed to grief include self-blame for the diagnosis, guilt around the termination decision, social isolation related to discomfort with abortion and grief triggered by reminders of pregnancy. Social support and time are mechanisms that serve to alleviate grief.

Conclusions: Pregnancy termination in this context is experienced as a significant loss similar to other types of pregnancy loss and is also associated with real and perceived stigma. Women choosing termination for fetal anomalies may benefit from tailored counseling that includes dispelling misconceptions about cause of the anomaly. In addition, efforts to decrease abortion stigma and increase social support may improve women's experiences and lessen their grief response.

Implications: The nature and course of grief after second-trimester termination for fetal anomaly are, as of yet, poorly understood. With improved understanding of how women grieve over time, clinicians can better recognize the significance of their patients' suffering and offer tools to direct their grief toward positive coping.

Keywords: Abortion; Second-trimester abortion; Pregnancy termination; Fetal anomaly; Perinatal grief; Pregnancy loss

1. Introduction

Approximately 150,000 women in the United States are diagnosed with a fetal anomaly each year [1,2]. Between 47% and 90% of these women choose to terminate the pregnancy [3–6]. For many, the diagnosis is devastating and unexpected [7]. One study found that 17% of women undergoing termination of pregnancy for fetal anomaly had symptoms of posttraumatic stress disorder as far out as 2 to 7 years postprocedure, indicating an extremely severe grief response [8]. Because women terminating for a fetal anomaly are often choosing to terminate highly desired pregnancies, it is possible that their grief response may be particularly difficult and thus may require more nuanced counseling [9]. Though most patients in this situation receive counseling [10], there is no evidence-based guide to direct women's expectations with this process.

Few studies have examined how women experience grief over termination for fetal anomaly and how their grief

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Table 1
Characteristics of participants

Characteristics	N (%)
Total	13
Age (median)*	31 (1.5)
Gestational age weeks (mean)*	20.3 (3.1)
Primigravid	6 (46)
Nulliparous	8 (62)
Ethnicity	
White, non-Hispanic	7 (54)
Hispanic	4 (31)
Black	1 (8)
Asian	1 (8)
Reason for termination	
Genetic anomaly	5 (38)
Structural anomaly	8 (62)
Method chosen	
D&E	10 (77)
Induction	3 (23)

* Mean (SD) or median (SE) reported.

changes over time. Previous research in this population has shown that the immediate grief response is different from the grief response several months or years after the event [11]; however, narrative descriptions of how women's grief processes unfold over time have not been described. While it has been shown that shame and guilt are predictors of long-lasting grief after miscarriage [12], the roles of guilt and shame in termination for fetal anomaly have yet to be elucidated. If guilt and shame contribute to grief after termination for fetal anomaly, it will be important to understand the role of stigma in how women classify and process their grief.

We conducted a longitudinal qualitative study to assess how women define and experience grief over termination for fetal anomaly and how this grief changes over time. Improving our understanding of grief after termination for fetal anomaly will aid in the development of an evidence-based approach to counseling women who face this diagnosis, with the goal of promoting healthy coping. It will also help clinicians better address the significance of their patients' losses and provide anticipatory guidance about the course their grief may take.

2. Materials and methods

From March 2012 to October 2013, we recruited women who were undergoing second-trimester abortion for fetal anomalies or other pregnancy complications, such as preterm premature rupture of membranes (PPROM), fetal demise or maternal complications for a longitudinal qualitative study of decision satisfaction, grief and coping. Because grief associated with termination may differ according to the reason for termination, we limited the analysis of the grief response to women terminating for a fetal anomaly. All women were presented with the option of dilation and evacuation (D&E) or induction abortion and were allowed to choose their preferred method. We recruited and consented women at the procedure site the day of or before the procedure. Women eligible for the study were between 14 and 24 weeks of gestation, over 18 years of age and English speaking. We enrolled study participants until we reached saturation of themes. The study was approved by the University of California, San Francisco, Committee on Human Research and University of Michigan Institutional Review Board.

We recruited women from four sites (two outpatient hospital-based clinics that provide D&Es and two inpatient labor and delivery wards that offer inductions) within two academic institutions, one in Northern California and one in Michigan. Although participants' counseling regarding method options before referral was variable, the enrollment sites uniformly offered options counseling about both methods prior to the procedure.

Subjects participated in a longitudinal qualitative study, consisting of three phone interviews over 1 year. We conducted the first interview at 1 to 3 weeks after the procedure, the second at 3 months and the third at 1 year. We asked participants open-ended questions regarding their experiences with receiving the diagnosis, counseling, options discussed, decision factors, and grief and coping after the procedure. This analysis focuses on the themes related to their grief response and how their grief changed over time. We used the same semistructured interview guide for each interview but asked open-ended questions and encouraged participants to direct the interview toward what they felt were salient aspects of their experiences. We chose to conduct individual interviews instead of a focus group because of the personal and stigmatized nature of abortion. We felt that individual interviews would allow women to more fully express their emotions without feeling pressured or judged by other women's responses.

We audiorecorded, deidentified and transcribed all interviews. Two authors (M.M., J.K.) analyzed the interviews using grounded theory approach [13] in QRS NVivo 10.0 software to identify themes as they developed. As novel themes emerged in the analysis, we incorporated them into the interview questions. We compensated study participants with a $20 gift card for each of the first two interviews and a $40 gift card for the final interview.

3. Results

We enrolled 19 participants in the study. Three participants' interviews were not used in the analysis of grief because they terminated for reasons other than fetal anomaly (PPROM and fetal demise). Of the 16 eligible women (12 D&Es and 4 inductions), 3 were lost to follow-up before completing the first interview (2 D&Es and 1 induction), leaving 13 women and 35 interviews for analysis (10 D&Es and 3 inductions) (Table 1). Eleven women completed all three interviews, and 2 women (1 D&E and 1 induction) completed only the first interview.