Qualitative Pilot Study: Longitudinal Perspectives From People Who Had Second Trimester Abortions for Fetal Anomaly

Elise S. Cowley, BS*; Taryn M. Valley, MA*; Kelsey Christianson, BA; Suzanne Walczak, MD; Jessica A. Greenblatt, MD; Laura Jacques, MD

ABSTRACT

Background: We investigated patient experience with abortion for fetal anomaly, about which little is known.

Methods: This qualitative, longitudinal pilot study surveyed 7 patients twice after abortion for fetal anomaly, initially 4 to 5 days after the abortion and a follow-up 3 months post-abortion, at a single Wisconsin hospital from July 2012 to February 2014.

Results: Patients indicated that having a choice to have an abortion and choose the modality is imperative, and they remained certain in their decision-making over time. They also described initially strong, then lacking, social support; processed grief; and identified resource constraints.

Discussion: Patients emphasized the importance of having the choice to choose abortion and the abortion modality, remaining confident in their decision-making over time. This qualitative pilot study provides areas for future intervention to improve care for people undergoing abortion for fetal anomaly.

INTRODUCTION

Nearly 1% of pregnant people have an abortion for fetal anomaly,[1,2] yet little literature examines patient experiences with abortion for fetal anomalies or how patients' needs change over time.[2-4] We studied experiences with second-trimester abortion for fetal anomalies in Wisconsin. The state's abortion legislation is frequently changing, and patients are facing growing barriers when trying to access abortion services.[5,6] In this qualitative pilot study, we examined patients' longitudinal decision-making certainty, emotional experiences, perceived support, and resource needs after abortion for fetal anomaly.

METHODS

From July 2012 until February 2014, we recruited patients at Froedtert Hospital, an academic and community-partnered hospital in Milwaukee, Wisconsin. At the time, barriers to abortion access in Wisconsin included a mandated 24-hour waiting period and consent certificate. Froedtert Hospital only provided abortion services given maternal health risk or life-threatening fetal anomalies. Patients qualified for the study if they were over 18 years old, English-speaking, and 14 to 24 weeks gestation with a pregnancy complicated by a lethal fetal anomaly.

We emailed consented participants 2 REDCap surveys, the first survey 4 to 5 days after their abortion and the second 3 months later (Appendices A and B). Surveys contained multiple-choice, short-answer, and free-text questions. Questions on the initial survey included demographic information, pregnancy history, fetal diagnosis, decision-making factors between termination modalities, and experience interfacing with the health care system. Questions on the follow-up survey included how people were feeling 3 months later about their experience and decision, reflections on modality choice, how their experience has been returning to their normal activities, who they have shared their experience with, and what advice they would give others. We analyzed qualitative data using an inductive-deductive approach, establishing codes then

• • •

Author Affiliations: Department of Bacteriology, University of Wisconsin-Madison (UW-Madison), Madison, Wisconsin (Cowley); Microbiology Doctoral Training Program, UW-Madison, Madison, Wisconsin (Cowley); Department of Obstetrics and Gynecology, University of Wisconsin School of Medicine and Public Health (UWSMPH) Madison, Wisconsin (Valley, Jacques); Department of Anthropology, UW-Madison, Madison, Wisconsin (Valley); UWSMPH, Madison, Wisconsin (Christianson); Department of Obstetrics and Gynecology, Medical College of Wisconsin, Milwaukee, Wisconsin (Walczak, Greenblatt). **These authors contributed equally to this work.*

Corresponding Author: Laura Jacques, MD, Department of Obstetrics and Gynecology, University of Wisconsin School of Medicine and Public Health, McConnell Hall, 4th Floor, 1010 Mound St, Madison, WI 53715; phone 608.890.2053; email laura.jacques@wisc.edu; ORCID ID 0000-0003-2343-8358

Published online June 3, 2024.

Table 1. Themes Regarding Experiences With a Pregnancy Complicated by Fetal Anomaly and Representative Quotes From Initial Surveys Related to Themes and Subthemes

THEME *Subtheme*	Quote No.	Representative Quotes	Modality
Certainty in Decision-Making			
Importance of the ability to choose abortion and certainty around this choice	1	I would have felt trapped in my own body [without the abortion]. It was hard enough for me to have to carry my baby as long as I did after finding out. I think that emotionally I would have been a basket case. I don't quite know how I would have been able to handle it. My husband would have been the same. I don't think that he would have been able to look at me. I had a hard time looking at myself.	D&E
	2	I would be upset [if I had not had the option to have an abortion]. It is an option for people to make when getting the upsetting news that your child will not survive. No one should be able to tell you that you don't have an option.	D&E
	3	It would have been even harder to have to carry my child full term knowing it would not survive. Not having the option for labor induction would have been very upsetting.	IOL
	4	It is a decision we made together and the best decision for us as a couple.	D&E
Emotional Support			
Physician and health care staff support	5	[Doctors] gave us the space that we needed, but were still available for questions. They did not rush us to any decisions.	D&E
	6	The doctors presented the information very well and were all very empathetic. We could not have asked for better people to give us the news.	D&E
	7	The staff was great, from the nurse who checked us in at the day surgery center to the anesthesia team. Everyone was very compassionate and made sure my husband and I both had everything we needed.	D&E
	8	The diagnosis was presented in a medical and somewhat "sterile" way, not very emotional.	IOL
Family and friend support	9	It was a very difficult decision but my family as well as the staff we interacted with made the situation go smoothly. Everyone really helped my husband and I to let our feelings be hear [sic] and really honor the memory of our daughter.	IOL
	10	With the support of my husband as well as our families and friends it was as easy as it could be. They were there to bring food and do things around the house. Getting back to work was just exhausting, but my staff helped a great deal with easing me back in.	D&E
	11	We received great support from family and friends. They provided their own experiences as well as people to talk to when we needed to vent or cry.	IOL
Processing of Grief	12	I was so sad. I hadn't realized how much wanted him until the diagnosis.	D&E
	13	[I felt] numbness at times. Anger and disgust at the baby.	IOL
	14	Of course I felt sadness, but I was surprised at how angry I was. Why was this happening to us?	D&E
Resource Constraints	15	All I could think about was the time to recover and the expense with labor. My insurance covered almost all of the surgery.	D&E
	16	If finance was not an issue, I would have given my precious a service and burial.	IOL
	17	We chose labor induction. It seemed to be the safer option at that point in the pregnancy. I was also told there might not be a place closer than Chicago that offers D&E at the stage of my pregnancy, and I liked the idea of being closer to my home.	IOL

Abbreviations: D&E, dilation and evacuation; IOL, induction of labor.

themes.[7] Four researchers synchronously coded data in NVivo12 (QSR International, Australia), reaching consensus on themes.

RESULTS

Of 36 eligible patients, 12 (33%) opted for dilation and evacuation (D&E) and 24 (67%) chose labor induction. All 36 patients were approached for this study; 10 (28%) enrolled and provided contact information for the surveys. Three patients dropped out before completing either survey, and 7 participants successfully completed both surveys. This resulted in a paired survey response rate of 70% and a follow-up survey response rate of 100%. Among the participants included in the study, 4 chose D&E and 3 chose labor induction.

We identified 4 themes in both immediate and follow-up surveys: patients (1) felt certain in their decision-making, (2) emphasized need for emotional support, (3) shared processing of grief, and (4) noted resource constraints. Below, we discuss these themes using representative patient quotes.

Certainty in Decision-making

Certainty About Having an Abortion: All patients considered the capacity to choose abortion in the setting of fetal anomaly essential—even patients who disapproved of abortion in other circumstances. They said they imagined feeling upset or helpless if they had needed to continue the pregnancy. One patient said, *"I would have felt trapped in my own body [without the abortion]. It was hard enough for me to have to carry my baby as long as I did"* (Table 1:1).

Another patient summarized how choice was essential: *"No one should be able to tell you that you don't have an option"* (Table 1:2);

Published online June 3, 2024.

Table 2. Themes Regarding Experiences With a Pregnancy Complicated by Fetal Anomaly and Representative Quotes From Follow-up Surveys Related to Themes and Subthemes

THEME *Subtheme*	Quote No.	Representative Quotes	Modality
Certainty in Decision-Making			
Importance of the ability to choose abortion and certainty around this choice	1	It was hard at first when my pregnancy suddenly ended and there was no baby to show for it. However, everyone has been really supportive and I am very happy and at peace now with the whole situation.	IOL
	2	I still feel that I made the correct decision [to have an abortion].	IOL
	3	I would still be pregnant if he had not been born on his own. I do enjoy being pregnant but it would be so difficult being pregnant knowing the baby would die when he was born. I felt I needed to end the pregnancy to start my grieving process sooner and not prolong	D&E
	4	I would not have changed my decision. I feel like it was the best thing to do for our family.	D&E
Importance of choice in abortion modality and certainty about chosen abortion method, D&E or IOL	5	A surgical procedure I think would have been a little more stressful.	1OL
	6	I would not like it [D&E] because I want to see my baby regardless of the deformity.	IOL
	7	Labor induction was the right decision for us. D&E makes me uncomfortable.	IOL
	8	I feel good about my decision to have a D&E. It was the best decision for me and my husband.	D&E
	9	I think the entire event would have been much worse if D&E was not available. If I would have had to have gone through L&D (labor and delivery), that would have been much, much worse. It would have taken me much longer to heal, both emotionally and physically.	D&E
	10	Keep you [sic] head up and trust yourself. If your choices are the best for that little baby, then trust yourself that you are doing the right thing. Regardless of what anyone says, you made the right decision if you are putting the needs of your family and that little baby first.	D&E
	11	I think I wish I would have labored to have him so I could have held him. I really wish I could have cuddled him. At the time I made the decision because I didn't want to be with other women delivering healthy babies.	D&E
Emotional Support			
Family and friend support	12	The number of people that ignore or forget what you've gone thru [sic]. I think it's easier for them to not mention it, since they don't want to bring it up/make me feel sad, etc. By them not saying anything, it makes me think they don't care.	IOL
	13	I think just having people, especially our parents, understand that what we went through was hard and that we are not completely over it and when we are ready we will try again. It is not something to just jump back into....there are a lot of emotions still involved.	D&E
	14	I don't think anyone can truly understand besides me. My husband and parents are dealing with the loss of their first grandchild, and my husband with his first child. I was the one carrying her, and no one else can completely understand that. But, I also don't expect them too [sic].	D&E
	15	I don't think anyone can really understand what you are going through unless they went through the exact same thing. There are days when my husband does not even totally understand and he will admit that. I think people try to understand and try to empathize, but they do not really understand.	D&E
Seeking shared experiences	16	Everyone in the support group has gone through a similar experience so they understand.	D&E
	17	My mother lost a child during pregnancy so she was able to share her feelings about that with me.	IOL
Processing of Grief	18	I cried a lot at first and didn't have any interest in life. As time has gone by I had to go back to work and take care of my children. Life has gone on and I have good days and bad days.	D&E
	19	Mentally, at times I find myself thinking about the baby and the what ifs. Physically, I am back to my normal routines.	IOL
	20	I have my good days and my bad days. I just take what I can handle and if I need to step away from an [sic] situation I do and come back when my emotions calm down. Now I have some bad days and then [sic] come unexpectedly. I cry more that I'm not pregnant again then I do about what I had to go threw [sic].	IOL
	21	I still hurt and cry when I think about it, as my baby would be due to be born this month. I have good days but sometimes have days I cry through when I think of him.	D&E
	22	I truly believe that I made the right decisions for my family and my little girl. I am at peace with my decisions.	D&E
	23	It was hard at first when my pregnancy suddenly ended and there was no baby to show for it. However, everyone has been really supportive and I am very happy and at peace now with the whole situation.	IOL
Resource Constraints	24	I'd like to attend a support group at Froedtert, but it's about 45 minutes away. Wish it was closer.	IOL

Abbreviations: D&E, dilation and evacuation; IOL, induction of labor.

and another said it would be difficult to *"carry my child full term knowing it would not survive"* (Table 1:3). Most patients shared that, though difficult, they felt certain their decision to terminate the pregnancy was right for them and their families (Table 1:4).

On follow-up, participants continued to describe certainty in their decision to have an abortion (Table 2:1-3). One patient stated, *"I would not have changed my decision. I feel like it was the best thing to do for our family"* (Table 2:4).

Certainty About Chosen Abortion Method: Participants universally indicated that having a choice between abortion modalities–D&E or labor induction–was critical for them and their families (Table 2:5-8).

Published online June 3, 2024.

"[T]he entire event would have been much worse if D&E was not available. If I would have had to have gone through L&D (labor and delivery), that would have been much, much worse. It would have taken me much longer to heal, both emotionally and physically." (Table 2:9)

Nearly all patients reported feeling that they had chosen the correct abortion method on 3-month follow-up and wanted to reassure others faced with similar choices to trust they would choose correctly.

"Keep you [sic] head up … trust yourself that you are doing the right thing. Regardless of what anyone says, you made the right decision if you are putting the needs of your family and that little baby first." (Table 2:10)

Only 1 patient said they wished they had chosen a different method: labor induction instead of D&E:

"I think I wish I would have labored to have him so I could have held him. I really wish I could have cuddled him. At the time I made the decision because I didn't want to be with other women delivering healthy babies." (Table 2:11)

Emotional Support

Health Care Staff: All patients reported strong support from nonphysician health care staff but varying experiences with physician-provided support (Table 1:5-6). One patient said:

"The staff was great, from the nurse who checked us in at the day surgery center to the anesthesia team. Everyone was very compassionate and made sure my husband and I both had everything we needed." (Table 1:7)

However, a patient said that while the diagnosis of fetal anomaly was given professionally, they wished for more emotional connection with their physician (Table 1:8).

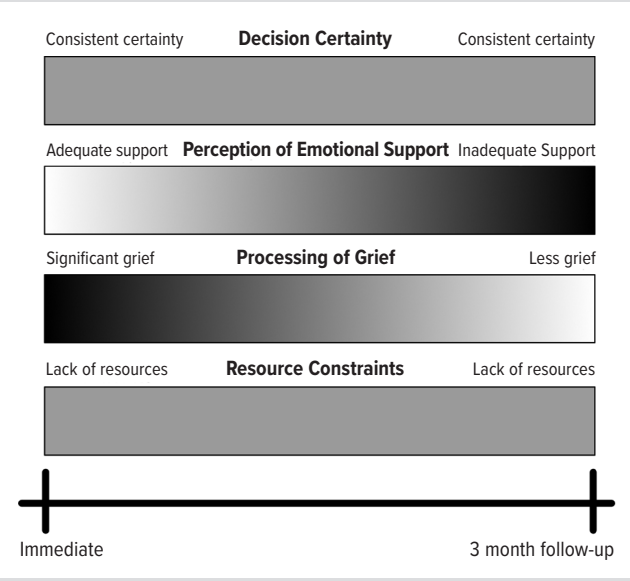
Family and Friends: Immediately after their abortion, patients expressed feeling well supported emotionally by family, friends, and colleagues (Table 1:9-11). Over time, some said they felt that others wished they would move on faster than they were able and couldn't fully understand their experience (Table 2:12).

"I think just having people—especially our parents—understand that what we went through was hard and that we are not completely over it and when we are ready we will try again. It is not something to just jump back into….there are a lot of emotions still involved." (Table 2:13)

On follow-up, respondents reflected on the limits of support (Table 2:14). One patient said:

"I don't think anyone can really understand what you are going through unless they went through the exact same thing. There are days when my husband does not even totally understand, and he will admit that. I think people try to understand and try to empathize, but they do not really understand." (Table 2:15)

Figure. Shifting Perspectives of Patients Immediately and Longitudinally Post-abortion for Second Trimester for Fetal Anomaly



The majority of respondents reported feeling consistently certain in their decision to have an abortion and their choice of modality. Immediately after their abortion, patients reported feeling well supported but later wanted more support. Immediately, people described significant grief. They reported continuing, but waning grief on follow-up. Though the types of resources people needed changed over time, patients consistently detailed how lack of resources limited their decision making.

Seeking Shared Experiences

Relatedly, patients reported seeking people with shared experiences, through structured programs or family connections. When people shared experiences, participants on follow-up reported feeling more supported (Table 2:16-17).

Processing of Grief

Participants uniformly demonstrated attachment to their pregnancy both immediately and upon follow-up. Directly after the procedure, they reported significant grief: *"I was so sad. I hadn't realized how much wanted him until the diagnosis"* (Table 1:12). All patients reported calling the "entity that was lost" by name or "baby." Alongside sadness, sometimes participants expressed anger or numbness (Table 1:13-14).

As time passed, people experienced grief differently than directly after their abortions (Table 2:18-20). *"I still hurt and cry when I think about it, as my baby would be due to be born this month. I have good days but sometimes have days I cry through when I think of him"* (Table 2:21).

Over time respondents said they felt increasingly "at peace" with their abortion decisions, process, and outcome (Table 2:22). One participant echoed many shared sentiments on follow-up:

"It was hard at first when my pregnancy suddenly ended and there was no baby to show for it. However, everyone has been

Published online June 3, 2024.

really supportive, and I am very happy and at peace now with the whole situation." (Table 2:23)

Resource Constraints

Some respondents struggled with logistics surrounding their abortion. They were concerned about finances, including procedure expenses, potential lack of insurance coverage, time off work for recovery, and burial expenses (Table 1:15-16). They also mentioned travel distance for desired modality or accessing support services as obstacles (Table 1:17). One patient said, *"I'd like to attend a support group at Froedtert, but it's about 45 minutes away. Wish it was closer"* (Table 2:24).

DISCUSSION

The themes identified in previous studies on patient experience with abortion for fetal anomalies, such as the importance of emotional support and shared grief processing, the evolving certainty individuals feel about their decision-making over time, and the impact of resource constraints on patient experience, align with our findings (Figure).[2-4,7-11] Moreover, our findings underscore patients' persistent demand for emotional, logistical, and financial support post-abortion.

A key finding in our study is the importance patients place on choice when faced with a pregnancy complicated by fetal anomaly. Participants in our study described the stress and harm they would have experienced without the choice to have an abortion or select the modality (D&E vs labor induction). This finding is particularly relevant in Wisconsin, where abortion for fetal anomalies is restricted and was temporarily banned in June 2022, following the US Supreme Court decision that overturned *Roe v Wade* and removed federal protection for abortion.[5,6,12] This study highlights the need for research focused on understanding the impact of restrictive abortion laws on patients diagnosed with fetal anomalies.

This study has several limitations including a low overall survey response rate, which increases the risk of response bias; a small sample size; and recall bias. Despite these limitations, thematic consistency and response breadth strengthen analysis. Research involving stigmatized behavior and rare conditions draws meaningful conclusions from small samples. This qualitative pilot study provides groundwork for future research about patient experience with second-trimester abortion for fetal anomaly.

Acknowledgements: The authors wish to thank the patients for making this study possible and their individual funding sources, as well as Andrea Zorbas and Amanda Wildenberg for administrative support.

Funding/Support: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. Elise Cowley is a Medical Scientist Training Program (MSTP) student and was supported by a National Library of Medicine training grant to the Computation and Informatics in Biology and Medicine Training Program (NLM 5T15LM007359) at UW-Madison, and in part by MSTP grant T32GM140935. Taryn Valley is an MSTP student who was, during the work on this paper, funded in part by the CORE Lab, funded by a large, anonymous family foundation, and in part by MSTP grant T32GM140935. Kelsey Christianson was supported by the Herman and Gwendolyn Shapiro Foundation through a summer research award and UW-Madison Department of Obstetrics and Gynecology. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Financial Disclosures: None declared.

Ethics Approval and Consent to Participate: The project has been approved by the Medical College of Wisconsin Institutional Review Board (ID# IRB PRO00016460). Written consent was obtained from the original primary investigators, Jessica Greenblatt, MD, and Suzanne Walczak, MD, stating that only deidentified data are being provided for analysis by current investigators.

Availability of Data and Materials: The datasets generated and analyzed during the current study are not publicly available due to the specific nature of the content discussed and possible identifiability of participants from their data but are available from the corresponding author on reasonable request.

Appendices: Available online at www.wmjonline.org

REFERENCES

1. Byrne JJ, Morgan JL, Twickler DM, McIntire DD, Dashe JS. Utility of follow-up standard sonography for fetal anomaly detection. *Am J Obstet Gynecol.* 2020;222(6):615.e1-615.e9. doi:10.1016/j.ajog.2020.01.001

2. Maguire M, Light A, Kuppermann M, Dalton VK, Steinauer JE, Kerns JL. Grief after second-trimester termination for fetal anomaly: a qualitative study. *Contraception*. 2015;91(3):234-239. doi:10.1016/j.contraception.2014.11.015

3. Kerns J, Vanjani R, Freedman L, Meckstroth K, Drey EA, Steinauer J. Women's decision making regarding choice of second trimester termination method for pregnancy complications. *Int J Gynaecol Obstet.* 2012;116(3):244-248. doi:10.1016/j.ijgo.2011.10.016

4. Kerns JL, Light A, Dalton V, McNamara B, Steinauer J, Kuppermann M. Decision satisfaction among women choosing a method of pregnancy termination in the setting of fetal anomalies and other pregnancy complications: a qualitative study. *Patient Educ Couns*. 2018;101(10):1859-1864. doi:10.1016/j.pec.2018.06.012

5. *Core Brief: Post-Dobbs Changes in Abortion Access in Wisconsin and Nationally.* UW Collaborative for Reproductive Equity; April 11, 2023. Accessed April 26, 2023. https://core.wisc.edu/wp-content/uploads/sites/1349/2023/04/Post-Dobbs-changes-in-abortion-access_April-2023-.pdf

6. UW Collaborative for Reproductive Equity update on availability of abortion care in Wisconsin. Collaborative for Reproductive Equity. Published September 14, 2023. Accessed December 10, 2023. https://core.wisc.edu/2023/09/14/uw-collaborative-for-reproductive-equity-update-on-availability-of-abortion-care-in-wisconsin/

7. Bernard HR. Qualitative Data Analysis 1: Text Analysis. In: Barnard HR. *Research Methods in Anthropology: Qualitative and Quantitative Approaches.* 4th ed. AltaMira Press; 2006:463-521.

8. Gammeltoft T, Tran MH, Nguyen TH, Nguyen TT. Late-term abortion for fetal anomaly: Vietnamese women's experiences. *Reprod Health Matters*. 2008;16(31 Suppl):46-56. doi:10.1016/S0968-8080(08)31373-1

9. Korenromp MJ, Page-Christiaens GC, van den Bout J, Mulder EJ, Visser GH. Adjustment to termination of pregnancy for fetal anomaly: a longitudinal study in women at 4, 8, and 16 months. *Am J Obstet Gynecol*. 2009;201(2):160.e1-160.e1607. doi:10.1016/j.ajog.2009.04.007

10. Ramdaney A, Hashmi SS, Monga M, Carter R, Czerwinski J. Support desired by women following termination of pregnancy for a fetal anomaly. *J Genet Couns*. 2015;24(6):952-960. doi:10.1007/s10897-015-9832-x

11. Asplin N, Wessel H, Marions L, Georgsson Öhman S. Pregnancy termination due to fetal anomaly: women's reactions, satisfaction and experiences of care. *Midwifery*. 2014;30(6):620-627. doi:10.1016/j.midw.2013.10.013

12. Dane County Court affirms legal right to abortion in Wisconsin. Collaborative for Reproductive Equity. Published December 7, 2023. Accessed December 10, 2023. https://core.wisc.edu/2023/12/07/dane-county-court-affirms-legal-right-to-abortion-in-wisconsin/

Published online June 3, 2024.