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Documenting moral agency: a qualitative analysis of abortion decision making for fetal indications☆☆

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Abstract

Objectives: We explored whether the decision-making process of women aborting a pregnancy for a fetal indication fit common medical ethical frameworks.

Study design: We applied three ethical frameworks (principlism, care ethics, and narrative ethics) in a secondary analysis of 30 qualitative interviews from women choosing 2nd trimester abortion for fetal indications.

Results: All 30 women offered reasoning consistent with one or more ethical frameworks. Principlism themes included avoidance of personal suffering (autonomy), and sparing a child a poor quality of life and painful medical interventions (beneficence/non-maleficence). Care ethics reasoning included relational considerations of family needs and resources, and narrative ethics reasoning contextualized this experience into the patient's life story.

Conclusions: This population's universal application of commonly accepted medical ethical frameworks supports the position that patients choosing fetal indication abortions should be treated as moral decision-makers and given the same respect as patients making decisions about other medical procedures.

Implications: These findings suggest recent political efforts blocking abortion access should be reframed as attempts to undermine the moral decision-making of women.

Keywords

Abortion; Medical ethics; Stigma; Fetal anomaly

1. Introduction

Modern medical ethics presumes that patients are moral agents who can and should make decisions about their own bodies and lives. Ethicists rejected the earlier “doctor knows best” model of paternalism because only patients can integrate their personal values with the

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relevant medical facts. Therefore, a foundational premise of bioethics is that competent adults must be allowed to take chances and risk pain in pursuit of a better life [1].

However, in some cases the law discriminates against pregnant patients making informed medical decisions. In abortion care, many state legislatures now adopt the paternalistic role formerly held by physicians. State laws that regulate abortion patient encounters differently than other patient encounters [2] suggest women considering abortion are not full moral agents. For example, forced waiting periods suggest that unlike all other surgery patients who are trusted to do independent reasoning, abortion patients might consent to surgery without considering the consequences. Laws requiring ultrasound viewing and counseling scripts communicate that, unlike other patients and physicians, those engaged in abortion care cannot make ethical decisions without the active participation of the State. Paternalistic laws like these reverse decades of progress in the USA toward respect for patients' moral agency in decision-making.

In this article, we focus on the most severe type of restriction on pregnant women's decision making, bans on pre-viability abortions. The US Supreme Court ruled that a fetus is not a "person" under the constitution before birth, and that states cannot constitutionally ban abortion before viability [3,4]. However, in the USA, 17 states have passed laws banning abortion before viability at the time of this writing [5]. This conflict creates a chilling effect on physicians in these states who feel they must stop performing second trimester abortions to avoid penalty. This lack of providers makes it difficult or impossible for women to access abortion services in these states in the second trimester.

Second trimester abortion accounted for only 11% of US abortions in 2010 and only 1.2% occurred at or after 20 weeks, yet second trimester abortion is heavily targeted by legislative initiatives [6]. Women choosing to end a pregnancy for a fetal anomaly are disproportionately affected by these gestational age restrictions, because most are diagnosed in the second trimester [7,8]. These patients have already undergone extensive genetic and perinatal counseling, yet they still must endure the full range of state mandates and restrictions that question their moral agency. Women living in states with pre-viability bans, who either receive a diagnosis late in the second trimester, or need time to react to an earlier diagnosis, are either prevented from accessing constitutionally protected medical care, or must travel long distances across state lines to do so.

Clinical ethicists use ethical frameworks to analyze difficult medical decisions [9]. However, these ethical frameworks have never been applied to qualitative data on the moral reasoning of patients ending a pregnancy for fetal indications. If patient reasoning shares traits with medical ethicists' reasoning, perhaps this documentation of patient moral agency would reduce the stigma patients report they feel around abortion decision-making, and support arguments against legislative interference in the physician-patient relationship. The objective of this study was to explore the decision-making process of patients aborting a second trimester pregnancy for a fetal anomaly, in order to identify whether they used frameworks commonly used by medical ethicists.

2. Materials and methods

2.1. Recruitment

This study is a secondary analysis of a qualitative study designed to explore reasons for termination timing in the setting of fetal anomalies [10]. The primary study recruitment was a non-probability, convenience sample. Eligible participants included all English-speaking women aged 18 and older presenting for abortion for fetal indications between 12–24 weeks gestation at Northwestern Memorial Hospital from July 2011 to January 2012. We defined “fetal indications” as any genetic or structural findings that were the primary reason the patient chose pregnancy termination.

2.2. Interview procedures

One author (L.M.G.) interviewed women prior to pre-operative consultations, before any medical team interactions, and no follow-up study contact occurred. We compensated participants with a \$40 grocery gift card. All participants provided written informed consent under Northwestern University Institutional Review Board approval.

Data collection included a verbally administered demographic questionnaire and a qualitative semi-structured, in-depth face-to-face interview. The study team developed the interview guide through consultation with experts in family planning, genetics, and perinatal loss social work. Questions explored the patient’s decision-making process for genetic screening and eventual termination, support system response, termination beliefs, and other factors. Participants were not specifically asked about moral reasoning. Finally, the study team confirmed diagnoses and gestational age through the computerized medical record and external reports.

2.3. Data analysis

Data analysis for the primary study outcome was previously described [10]. We used both manifest and latent content for secondary analyses of patients’ decision-making responses. We chose three ethical frameworks because the American College of Obstetricians and Gynecologists ethics guidelines state “...enlightened medical decision-making cannot rely exclusively on any single fundamental approach to biomedical ethics” [11]. At least two team members independently coded and iteratively analyzed all transcripts to identify themes or concepts relevant to each of the three frameworks. Many patient responses could have been assigned to more than one ethical framework. We reviewed those quotes within the context of the subject’s full interview and collectively assigned the one framework that was the best fit. [12].

We chose principlism as the first ethical framework, because the principles of autonomy, beneficence, non-maleficence, and justice are commonly used in medical ethics and are a systematic way to analyze the data [13]. Autonomy is defined as “personal rule of self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choices, such as inadequate understanding” [13]. Beneficence is defined as “the obligation to promote well-being in others,” and non-maleficence is defined as “the obligation not to cause harm or injury.” Beneficence and non-maleficence are principles

physicians and ethicists typically apply when considering patient interests, but here we analyzed whether patients applied them to their understanding of the current or future interests of their fetuses [13]. The complex maternal-fetal relationship makes the distinction between “do good” and “do no harm” difficult to make, so the principles of beneficence and non-maleficence were combined into one category in the data analysis. In principlism, the principle of justice typically focuses on the fair distribution of social resources at the governmental level or within the physician-patient relationship, not private decisions about the allocation of economic and non-economic resources within families. Therefore, we chose to analyze themes of relational justice, such as distribution of maternal or family resources, within the second framework, care ethics (discussed below).

Care ethics focuses on the interpersonal relations and personal caring that go into good decision-making [14]. Because reproductive decisions often occur within a family unit, we hypothesized that the focus of care ethics on the relational value of other family members might be relevant to these patients, in contrast to the more individualistic focus of principlism. The third framework chosen was narrative ethics, which focuses not only on the relational, but also the communicative dimensions of moral situations [15]. Narrative ethics is based on the understanding that every moral situation is unique, and that healthcare decisions are justified by how well they fit in the patient’s life story. The narrative approach broadens an understanding of the patient’s life, since the process of the patient telling his or her story involves decisions about which information to include or exclude [16].

Understanding a life as a narrative “deepens our insight into the relationship between the unraveling of human life and moral agency” [17]. The patient’s narrative of his or her life frequently invokes other ethical frameworks within the story.

3. Results

We analyzed transcripts from the thirty study participants. Demographic characteristics are shown in Table 1. We found 100% of the women’s description of their abortion decision-making process fit one or more of three analytic frameworks commonly used by medical ethicists—principlism, care ethics, and/or narrative ethics. As expected, overlap occurred between frameworks. Although we assigned each statement of reasoning to only one framework, reviewing all statements made during each subject’s entire interview reveals that only five women used a single framework (which was Principlism/autonomy). Seven of the 30 fetal anomalies involved in this study are considered lethal (anencephaly, trisomy 18 or 13) and the remainder, though grave, would have a spectrum of potential outcomes. Despite the variation in fetal diagnoses, no major differences were found in the abortion decision-making between the lethal and non-lethal groups—all participants felt they were making the decision to end the pregnancy, as opposed to letting “nature take its course.” Even those with a lethal anomaly felt there was still a decision to be made, and stigma associated with it.

3.1. Principlism: autonomy

At presentation for the abortion, 100% of participants ($n = 30$) reported reasoning that was consistent with the principle of autonomy. Participant reasoning included assertion of their right to determine their own fate, make decisions, and control what happens in their lives

and to their bodies. They said that their views, choices, and actions should be respected, including their decisions to get pregnant, avoid physical risks, and avoid personal suffering involved in raising a child with serious medical needs or watching a child with a lethal anomaly die. The participants all considered their own needs (emotional, practical, and physical), yet only five of the women expressed autonomy as the only reason in their decision-making. This was not just a matter of politics or policy: several patients expressed “pro-choice” beliefs, but commented that being the decision-maker was vastly different from believing the option should be available. (Table 2).

3.2. Principlism: beneficence/non-maleficence

Eleven participants (36.7%) painstakingly reviewed what would be best for their potential child in language that is best classified as an analysis of beneficence or non-maleficence. They discussed their desire as a caregiver to pursue a course of action that carried the least harm, or the most potential to avoid pain. They considered options of life-support and heroic surgeries, but avoidance of suffering in utero, after delivery, and throughout any potential life, were key themes. (Table 2).

3.3. Care ethics

Each participant had different relational needs to consider and 40% ($n = 12$) described decision-making consistent with care ethics. For participants with other children, themes included the just allocation of limited family resources, both economic (e.g., the financial costs of medical care) and non-economic (e.g., time, or the emotional needs of siblings). The potential burden on extended family and aging grandparents was often discussed. The relational priority became the family unit, as participants stated that abortion was the best decision for the family. Despite this conclusion, the importance of the fetal relationship was acknowledged.

3.4. Narrative ethics

Before the abortion was completed, 66% of participants ($n = 20$) had already considered how this decision would fit into their life story. Participants discussed past experiences, and future hopes and dreams such as considering another pregnancy or adoption, or avoiding any more pregnancies. Some never planned to share their loss, while others sought to memorialize and honor their baby. These women contextualized this experience within their life experiences and discussed how this loss affected her and her family presently and going forward.

4. Discussion

This study is novel in the use of qualitative data to explore the decision-making process of patients aborting a pregnancy for fetal anomalies through the lens of accepted ethical frameworks. Although participants were not asked to share their moral reasoning, in a general discussion of decision-making, 100% of participant interviews showed evidence that women were in fact doing moral reasoning; that is, all respondents shared ideas that fit at least one or more ethical frameworks we considered. Women choosing abortion for fetal anomalies universally applied accepted ethical frameworks and, as moral decision-makers,

should be given the same respect and deference as patients making decisions about any other medical procedure.

Different ethicists favor different ethical frameworks. We applied three frameworks because we don't expect consensus on which ethical framework best fits abortion decision-making. There are several reasons the most commonly taught ethical framework, principlism, might be an imperfect fit for abortion decision making. The principle of patient autonomy assumes one patient, and applying it exclusively to the woman masks what some feel is the crux of the abortion debate: whether the moral status of the fetus means there are two patients. The opposite critique can be made of applying beneficence and non-maleficence in the abortion context: toward the woman, the fetus, or both? These three principles do not help answer the underlying question of fetal moral status. However, support for applying the autonomy principle solely to the woman, particularly before viability, is found in the law. Alternatively, in cases where a woman views the fetus as a second patient, the principles of beneficence and non-maleficence may apply. Another critique of the principlist approach is how the individualistic focus obscures social determinants of decision-making. For example, classifying a patient's report that she's unable to raise a child with a disability as "autonomy reasoning" avoids discussion of what resources society does and does not offer potential parents in this situation. Finally, there is also overlap between the surrogate decision-maker role acknowledged in the principle of beneficence/non-maleficence and the maternal role acknowledged in care ethics.

Care ethics or narrative ethics might allow for more nuanced reasoning than principlism, because these frameworks expand the circle of interests beyond the patient, to people and relationships that are affected by the decision. The care and narrative ethical frameworks tend to more fully capture the suffering and difficult decision processes many participants described. The women, who analyzed the needs of their fetuses, conceptualizing the fetus as having autonomy or beneficence/non-maleficence interests of its own, were engaged in surrogate decision-making. Many clinicians believe that a fetal patient with a probable lethal anomaly or severe and irreversible cognitive developmental capacity should be treated as a dying patient [18]. Abortion for severe fetal indications could be considered analogous to end-of-life care in which a surrogate decision-maker acts on behalf of another, weighing risks and benefits. Pregnant women facing legislative restrictions that deny them the time needed to explore higher level consultative services or to make a decision in the context of their family unit are effectively denied the "trial of treatment" many patients and surrogate decision-makers choose to improve the chances of making a decision they can live with. Whether a patient views her decision as one revolving around her own autonomy, the best interests of the fetus, or her larger web of obligations and relationships, integrating medical data and personal values in the context of grief over bad news about a wanted pregnancy takes time. Yet laws imposing gestational age limits for abortion risk rushing a decision when a late fetal diagnosis is made.

The limitations of this study include the convenience sampling of women undergoing a pregnancy termination for fetal indications—this sample does not capture the views of women choosing to continue a pregnancy after diagnosis of fetal anomaly, or women choosing abortion for other indications. All 30 women in this study desired their pregnancies

(and 26 planned it) but new information led them to change their mind about continuing the pregnancy. Their decision-making may or may not be different from women confronting undesired pregnancies. The women studied were primarily white, married, insured, had advanced educational attainment, and spoke English as a first language; therefore their views might not represent those of women of other racial or ethnic backgrounds or of lower socioeconomic status. The application of ethical frameworks in a secondary analysis of established data might not fully represent the responses that would be obtained by a study guide that explicitly probed for ethical decision-making responses. Finally, there are alternate ethical frameworks that could have been chosen and applied to these data.

Despite these limitations, the moral agency of women faced with a diagnosis of a fetal anomaly is evident, especially given the fact these women invoked a range of ethical frameworks without being asked about moral reasoning as a study objective. Only patients can decide the “correctness” of medical decisions for themselves — and sometimes for their families, and in the case of abortion, their fetuses. State mandates surrounding abortion and the stigma they reinforce only add to the difficult process these women must endure. Political efforts to roll gestational age limits back before viability undermine these patients’ moral agency. The family of the fetus diagnosed with a life-limiting prognosis should be allowed the same options available in other medical circumstances, including time to decide the best course of action in their bereaved state.

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Table 1

Socio demographic and pregnancy characteristics of study participants choosing 2nd trimester termination for fetal indications (N = 30)

Participant age	35(26–44)
Race	
White	22 (73.3)
Black	2 (6.7)
Asian/Asian Indian	6 (20)
Hispanic ethnicity	1 (3.3)
Marital status	
Unmarried/In relationship	3(10)
Married	27 (90)
Education	
Some college/College	18 (60)
Above College/Professional	12 (40)
Insurance	
Private	25 (83.3)
Medicaid	4 (13.3)
Self-pay	1 (3.3)
Religious affiliation	
Catholic/Christian	16 (43.3)
Muslim	1 (3.3)
Jewish	3(10)
Hindi	1 (3.3)
None	9 (30)
No. children	
None	12 (40)
1	9 (30)
2 or more	9 (30)
Prior termination	
1st trimester	5 (16.7)
2nd trimester (fetal indication)	3(10)
Current gestational age	20w4d (13w4d-23w5d)
Fetal diagnosis	
Trisomy 13 or 18	5 (16.7)
Lethal anomaly	2 (6.7)
Trisomy 21	6 (20)
Genetic syndrome	5 (16.7)
Neural tube defect	3(10)
Anatomic malformation	4 (13.3)
Renal abnormality/oligohydramnios	4 (13.3)
Intrauterine growth restriction	1 (3.3)

Data are presented as n (%) or median (range).

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Ethical frameworks and supporting qualitative themes and quotes from study participants choosing 2nd trimester abortion for fetal indications.

Ethical framework	Decision-making theme	Representative quotes	Gestational age/ anomaly
Principlism - Autonomy	Preventing personal emotional harm	"...you are nine months pregnant, you go to the hospital, you are into labor, you deliver the baby and then you go home with nothing. Why would I want to wait that long and just have that emotional problem later on."	22 weeks/anhydramnios
		"We're talking genetics- that is what the scary thing is for me and the gamble... there can be heart problems that show up and then, I couldn't go through that heartbreak."	15 weeks/Trisomy 15
	Preventing personal physical harm	"At this point the baby's health is affected anyway and you need to take care of your health."	23 weeks/renal anomaly
	Personal desires for child's quality of life	"...it's not going to have the life it deserves or the life I want it to have." "It is kind of sad but at the same time I am not ready to raise a handicapped child."	15 weeks/cystic hygroma 20 weeks/multiple anomalies suggestive of Trisomy 13
	Parenting concerns	"...that for me was the thing that decided it because I could see struggling with all the other parts, the developmental parts and doing the best that I could but I don't have faith that somebody else would care for this person the way I would [after I'm gone]."	14 weeks/Trisomy 21
Principlism - Beneficence/Non- maleficence	Exercising independent, private decision-making	"It scares me to think that there are lawmakers that want to take away my right to do this. I don't think that anyone should have the right to tell us that we should have to have this baby." "...if they survived and blood transfusions and hooked up to machines and we knew that we did not want to bring a baby into life who was going to suffer so much." "Even though, yes he could survive. It would be a pretty brutal life after that."	18 weeks/spina bifida 17 weeks/Turner's syndrome, hydrops 13 weeks/Trisomy 21
	Preventing suffering of the future infant, child, or adult	"I look at it the way I look at my thoughts on assisted suicide... yes, this is a baby and yes, it's ending a life...I just think it is a humane ending to a life that would have been a lot of suffering." "We have to do justice to this child and not keep our religion a priority but also think about the baby. So in order to avoid this sort of traumatic situation we decided to terminate... my primary goal is that this child should not suffer."	22 weeks/cardiac defect 23 weeks/renal anomaly
	Balancing needs of all family members	"I've got other children and what kind of impact is that going to make on their lives? Are we going to end up spending their college money to take care of a sick baby? Am I going to be able to still work? I was torn up about finding childcare for a normal, non-sick baby. What do you do with a baby that may never grow up? We're in our late 30s. If we're lucky, if you look at it that way, this child outlives us? Then what? Are we burdening siblings to take care of him?"	19 weeks/Trisomy 21
		"...the financial problems we are going to face with insurance with a very sick child. The problems we are going to face with our own children feeling neglected and feeling like they suffered because of having a very critically ill child in the family. There are just so many other things than just the baby's health to consider."	22 weeks/intrauterine growth restriction
		"... we keep reminding ourselves that this is the best decision for us and for our family..."	15 weeks/Trisomy 21
Narrative ethics	Integrating past, present, and future	"I think you just have to find peace. It takes a while but you have to go through the process. Initially you are so devastated and you just have to sit down and review the options and make the best decision that you can make with the information that I have now. Making peace with the first one took about two years. I am going to focus on work and our future adoption efforts to get through this one."	18 weeks/spina bifida

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Ethical framework	Decision-making theme	Representative quotes	Gestational age/ anomaly
		“I think we’ve bounced back from things before and it’s hard to look to the future when you’re still living in the present, but, I mean we’re still hoping we can get pregnant and we’re hopeful that we’ll have a healthy baby someday...”	21 weeks/renal anomaly
	Marking ending of fetus’s story	“We decided that it was worth the emotional closure that we will at least get out of this...to request the ashes or try to get footprints and I felt strongly that was something I really needed...maybe we’re avoiding some mental health costs in the end...”	19 weeks/Trisomy 18