

TITLE:

Relational Decision Making in The Context of Life-Limiting Fetal Anomalies: Two Cases of Anencephaly Diagnosis.

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ABSTRACT:

Life-limiting fetal diagnoses such as anencephaly require families to make decisions where no options offered will lead to the desired outcome of a healthy baby. While informed choice and shared decision making are important aspects of ethics regarding care choices, they have limitations. In this article, 2 cases of anencephaly diagnosis are presented and a relational decision-making model of care is proposed as an alternative for aiding pregnant people and their families in making challenging choices in the context of maternity care.

KEY WORDS

Life-limiting fetal diagnoses

Anencephaly

Decision-making

Prenatal care

Ethics

Informed choice

Shared decision-making

Relational decision-making

CASE 1 SUMMARY

MK is a gravida 1 para 0 at 15 weeks gestation with an uncomplicated pregnancy to date. Following a non-diagnostic “gender reveal” ultrasound, she received a call from her midwife telling her the ultrasonographer suspected the fetus had anencephaly. Her midwife had already called maternal-fetal medicine (MFM) to arrange for diagnostic ultrasound and confirmation that day. MK was familiar with the “incompatible with life” anencephaly diagnosis as she was a health care provider student. The MFM physician confirmed the diagnosis of anencephaly and MK was told there was a 50% chance of stillbirth and a very high probability that the fetus would not survive labor. MK was given the recommendation to return for a 20-week anatomy scan at which time she would meet with a genetic counselor and pastoral care. Termination of the pregnancy was not offered to MK. She knew it was an option and assumed her providers were hesitant to offer it, knowing her religious beliefs. MK had a supportive family including her husband who said “This is your body, I will support whatever you decide.”

MK’s pregnancy continued to be uneventful, and the fetus was active but she woke every day fearing it would be the last that she would feel the baby move. Her birth plan consisted of “spot check” intermittent monitoring, delayed cord clamping, and no amniotomy as she wanted the baby to have as much protection around his head as possible during labor. The majority of the birth plan consisted of funeral arrangements and having the newborn boy baptized immediately after birth. A nun at the hospital played a very important role in the support MK received during the pregnancy.

At 42 weeks gestation, MK and her team made the decision to induce labor. Despite attempts with mechanical ripening, misoprostol and oxytocin, she did not achieve active labor. MK then faced the choice of 2 options she had hoped to avoid: cesarean birth or amniotomy and she chose cesarean hoping for “a live baby”. This was a difficult moment for MK, but she felt very supported by providers and staff.

The newborn cried right away and had Apgars of 7 and 9. MK was able to do skin to skin in the operating room and he was baptized immediately. MK and her family sang happy birthday to him

every hour and at 24 hours of age the unit staff joined in the singing. Hospice met with MK and started preparing everything to go home on day 2. The infant was held almost every minute of his 18-day life and he was in MK's arms as he took his last breath.

CASE 2 SUMMARY

JR was a gravida 3 para 1 who became pregnant after 3 rounds of in-vitro fertilization (IVF). At 10 week's gestation she had an ultrasound performed by a reproductive endocrinologist who told her that the fetus appeared to be anencephalic. JR is a maternity care provider at the hospital where she received care and although she had cared for patients with a fetus with anencephaly, she did not feel she understood the significance of this possible diagnosis during that visit. The reproductive endocrinologist asked JR to come back in a week but also said that the diagnosis was certain and that she should consider stopping the IVF medication to see if a miscarriage would occur spontaneously. She left the office stunned and devastated.

JR returned a week later and the diagnosis of anencephaly was confirmed. The fetus also had an abnormal heart rate pattern. The physician told JR she had waited too long to stop the IVF medication and wrote a prescription for misoprostol at the conclusion of the visit. This visit did not include a discussion about options to continue the pregnancy, provision of statistics regarding the fetus's chance of surviving to term. JR was not given referrals to specialists, neonatology or a social worker. JR's co-workers advised her to take the misoprostol and try again. Her immediate support people also felt like this was the best choice and were confused as to why she would consider carrying a nonviable fetus to term, leaving her to feel alone in the decision making process. An intrauterine fetal demise was diagnosed several weeks later and 8 weeks after the initial diagnosis JR underwent a dilatation and curettage.

INTRODUCTION

Advances in fetal diagnostics have made life-limiting or debilitating anomalies detectable at earlier gestations with increasing accuracy.¹ Anencephaly, wherein a large portion of the brain and skull is absent is one of these rare but devastating diagnoses. Anencephaly is a neural tube defect, in which the cranial end of the neural tube fails to close during fetal development. In the United States, 2.8 per 10,000 live births are affected by anencephaly.² When data from elective termination and fetal demises are added to the calculation, the overall incidence of anencephaly is higher³ and estimated to be approximately 10 per 10,000 pregnancies.⁴ The etiology of anencephaly is thought to be

multifactorial with a combination of genetic and environmental factors involved.⁵ Anencephaly is uniformly fatal. Of those who are liveborn, 86% die within the first 24 hours of life.⁶ Survival beyond 1 week is rare.⁷

For parents experiencing this tragic diagnosis, the decision is essentially whether to terminate/induce labor at the time of diagnosis or continue the pregnancy until the death of the fetus or labor/birth and death of the neonate. Studies in countries where abortion is legal indicate that the majority of parents will opt for termination, although data specific to the United States is not as clear as abortion statistics are not consistently collected.⁵

Providing care when all choices lead to a devastating outcome for a family is an ethical dilemma all maternity care providers will face at some point. While the diagnosis of anencephaly can be devastating, there are services available to assist and support families confronted with this diagnosis. Consultation with maternal fetal medicine physicians or other specialists may be needed, but if they choose to continue the pregnancy, continuing care with the primary maternity provider is appropriate and often preferred. Referral to perinatal palliative care can assist families and providers as they consider and prepare for possible outcomes including intrauterine fetal death, elective termination, or neonatal death.⁸ In areas where this specialized care does not exist, maternity providers must address the unique needs and challenges of these families, drawing from all resources to meet physical, emotional and spiritual needs.

It is challenging to present options to patients who are in a state of acute trauma after receiving devastating news. Emotional stress exerts a profound, yet complex, influence on learning and memory. Research has shown that trauma generally exerts deleterious effects on memory retrieval.⁹ Conversely, snapshots of emotionally arousing events can create vivid memories of the event which can predispose individuals to developing post-traumatic stress disorder.¹⁰ Ineffective communication of bad news can have lasting negative effects on the ways in which patients perceive the care that they receive and the information they were provided.¹¹

A relational-decision making model builds upon the tenets of informed choice and the shared decision-making model but centers the relationships that the pregnant person have with their family, their community, their culture, and their health care team. The model provides a context of care and support to aide pregnant people in making challenging and complex decisions. An understanding of biomedical ethics that are in play during healthcare decision making is a fundamental component of maternity care delivery, particularly in challenging situations and is foundational to relational decision-making.

INFORMED CHOICE AND SHARED DECISION-MAKING

Informed choice (often referred to as informed consent) is a reasoning process that leads to the selection of a course of action among alternatives, a process in which decision makers use various types of evidence to make a choice.¹² The informed choice narrative is a departure from historically paternalistic models of decision-making that do not elicit preferences and may limit the person's involvement to that of consent only.¹⁵ In the informed choice model, there is an expectation that the health professional is the objective agent who provides information and that the patient is left to make the decision with little further input.¹² The four criteria of the informed choice process include 1) patient competency, 2) a reasonable choice from a set of options provided, 3) disclosure of relevant information, and 4) freedom from coercion.¹⁶ On the surface, these conditional elements appear reasonable and appropriate. Within the emotional context of a devastating diagnosis and without a contextual framework of the pregnant person's lived experience the four criteria may, in fact, serve to undermine patient rights and reinforce provider bias.¹⁷ What is missing from the informed choice approach is a lack of understanding of the vulnerability that occurs when "no choice" leads to the desired outcome.

A shared decision-making model of informed choice describes a joint, step-wise process where healthcare providers and patients make decisions together in clinical practice. It is best described as an approach where provider and patient share the best available evidence when faced with the task of making decisions.¹⁸ Elwyn et al describe a three-step model for shared decision-making where the health care provider reassures the patient that their preferences are an important part of the decision-making process prior to discussion of the risks and advantages of each option. The pregnant person's preferences are then discussed collaboratively, the various options are weighed, and together they move toward a decision.¹³ The challenge with the shared decision-making model is that there is still the assumption that decision-making is an unemotional, rational weighing of readily available, easily understood evidence based on information presented to give the best possible outcome.¹² The decision-maker is assumed to be an articulate, well-informed individual who has a range of acceptable options available from which to choose.¹⁹ It also makes the assumption that all choices are equivalent and supported by best evidence, which may not always be the case in complex decision making related to maternity care.¹⁴

Competency is directly correlated with the ability to make rational decisions, one where emotions and rationality are seen as mutually exclusive characteristics. When a pregnant person's opinions are seen as emotionally founded, that person's competence may be questioned and the inclination may be to revert to paternalistic practice rather than engage in a discussion that creates

space for emotionality. In the case of a life-limiting anomaly, none of the options provided may be acceptable, as seen in both of the cases of MK and JR. Lastly, a shared decision-making model of informed choice emphasizes an individual's right to opt-out. In withholding consent, the pregnant person can often be seen as acting contrary to medical advice and deemed "noncompliant." When healthcare providers place judgment on a pregnant person opting out and label the person as non-compliant, that individual may feel judged or coerced into making a different decision.

While the conceptual framework of shared decision-making attempts to equalize the power differential between provider and pregnant person, the emotion and vulnerability that occur after the diagnosis of a life-limiting anomaly can decenter rationality during the initial shock and recognition of the diagnosis. Both JR and MK felt that their providers talked through the option that they were presented with but did not do so in a way in which neither individual felt fully supported.

A RELATIONAL DECISION-MAKING MODEL

A relational decision-making model approaches informed choice by deliberately integrating the position of individual within the array of relations that constitute and inform their life such as family, culture, personal experiences, and socio-political influences. The model centers the discussion around choice within those contexts and identities. A comparison of informed choice and shared decision-making relative to the relational decision-making model is provided in Table 1. Relational decision-making emphasizes those relations as key to the decision-making, informed choice process.¹⁷ This model departs from the assumption that decision-making is a merely a rational weighing of pros and cons with the support of an informed provider. Integrating a relational approach to decision-making does not dismiss the importance of informed choice, but rather reworks how informed choice is conceived and implemented into practice where alliance and relationality are key informers of care.¹⁷

Decision-making is firmly affected by ongoing, dynamic social relationships.²¹ These relationships influence and inform an individual's sense of self and experience as an expectant parent.¹⁷ A relational decision-making model acknowledges the political context in which care is provided and enables consideration of the way in which wider social contexts restrict or open the possibility for certain decisions to be made.¹² In both of the cases presented, JR and MS had the legal option to terminate or continue the pregnancy. However, they felt their choices were hindered because they were not offered the full range of available options. There are likely a number of reasons why all options were not provided to MK and JR including clinical presentation, age of gestation

when the diagnosis was discovered, or availability of support resources in each health setting. However, both JR and MK felt that the limited options or resources provided could have been based on provider biases²⁰ and the information presented may have been circumscribed by previous decisions and a-priori assumptions about the decision they would make in light of the diagnosis. A relational decision-making model of care would have encouraged discussions that placed their principles, values, and life experience within the context of the grief and loss of carrying a fetus with anencephaly. Conversations could have occurred that encouraged JR and MS to examine how influences such as their roles as health care providers might inform their care choice and helped them resolve potential discrepancies between deeply held religious and/or political identities and personal decision-making. The decision to continue a pregnancy or choose to terminate a pregnancy is then made within the pregnant person's understanding of that process and the meaning that they personally subscribe to the experience.¹⁷

Relational Decision-Making and Bioethical Principles

A relational decision-making model is rooted in the bioethical concepts of autonomy, responsibility, accountability, and alliance. It is grounded in the ethical responsibility of maternity care providers to partner with patients to acknowledge their socio-emotional situation when assisting them in making choices for their care

Within this particular context of care, respecting a pregnant person's autonomy involves more than disclosure of relevant information and the facilitation of competent and non-coercive consent.¹⁷ It also means understanding and making explicit that a person's decision to continue or terminate a pregnancy is deeply embedded in that person's broader understanding of pregnancy, family, and personal ethics. Respect for autonomy is at the very core of all health profession's codes of ethics including the American College of Nurse-Midwives (ACNM)²⁶ and American College of Obstetricians and Gynecologists (ACOG).²⁷

Responsibility is the component of a relational approach that is shared with informed choice. It requires the health care provider to actively participate in the process of informed choice and in the facilitation of full disclosure. There may be circumstances in which the provider has ethical objections to care requested by a patient, in which case, the provider has an ethical responsibility to disclose that to the patient. This conflict does not abdicate the responsibility of the health care provider to provide education regarding the diagnosis, prognosis, and options, including termination if that is an option given the gestation of the pregnancy. If then, a person faced with the diagnosis of fetal anencephaly chooses to terminate the pregnancy, the health care provider has the obligation "to

refer the woman to a provider who can render the requested care” in a way that does not place an undue burden on the pregnant person.²⁸

Accountability is the acknowledgment that the process of relational decision-making has been successfully facilitated. Choices need to be subject to periodic re-evaluation and discussion. While the action side of accountability involves a pregnant person coming to a final decision about the progression of care, the health care provider side entails accountability to reflect, to continue to learn, to change when needed, and to revolutionize systems to improve care for the pregnant people they serve.²⁹

Lastly, alliance is defined as the collaborative and affective bond between a provider and patient. It is a dyadic relationship that affects satisfaction with care as well as a sense of self-efficacy, patient voice within the health care system, and patient outcomes.²³ Health care providers’ interpersonal or ‘bedside manner’ is a meaningful and significant component of care and has an impact on outcomes for pregnant people.^{24,25} Alliance is a key component for all health care provider/patient relationships and it is the foundation of support that pregnant persons may rely upon when forced to make difficult choices about pregnancy and birth.

DISCUSSION

The relational component of decision-making is fundamental to providing compassionate care to people who are pregnant with a fetus with a life-limiting diagnosis. Life-limiting fetal anomalies are some of the greatest challenges for health care providers to discuss with patients. They are a devastating diagnosis with no optimal outcome. The midwifery model of care is positioned to provide this type of care as the philosophy of care, as defined by ACNM emphasizes a continuous and compassionate partnership as well as the therapeutic use of human presence and skillful communication.²² Pregnant persons may seek out midwifery care because the philosophy of personal relationship and alliance with health care providers are values they want to be a prominent aspect of their pregnancy experience.¹²

A true informed choice process for life-limiting anomalies must include a discussion about pregnancy termination options and for many providers that challenges their own ethics and beliefs. While both ACNM²⁸ and ACOG³⁰ support the rights of providers to “conscientiously object” to the provision of certain types of care based on the providers’ own beliefs, it is necessary for providers who use this approach to understand the potential impact of that care refusal. It is incumbent upon

maternity care providers to take a personal inventory of what they bring to the care relationship. This personal inventory does not mean a challenge to deeply held values and beliefs but it does involve a reckoning of how those beliefs influence the relationally valued care provided to pregnant people.

MK, now a practicing maternity care provider, recognizes that many families face fetal life-limiting diagnoses without the support and resources that she had:

“When a woman sits in front of me in tears because they don’t know what to do. I listen and support. I reassure them that whatever decision they make, they are making it out of love and I am there with them no matter what. What I have realized is that you really don’t know what you would do until you are forced to make a decision. I ask patients who have experienced or are experiencing similar tragedies if their baby has a name and then refer to the child by that name. Say the baby’s name is the best advice I can give someone taking care of women and families that have experienced a loss because it affirms they lived and mattered. They lived and mattered, even if only for a short time in their mother’s womb.”

JR’s choices surrounding her pregnancy were a surprise to her care providers, her partner and herself. She is disappointed that she was not given the full range of options in a way that would have supported her process in making an informed choice.

“My knowledge as a maternity care provider was enough to support me knowing I could refuse care but the lack of options offered created an adversarial relationship with my providers. Instead of the connected, relational care that I wanted, I was left with the grief of having lost a beloved and wanted pregnancy as well as the grief of feeling unsupported and uninformed. My own approach to providing care to my patients now centralizes the concept of relationship building with pregnant people and their families. The experience of not being provided with all options as a patient reinforced the central component of relationship building in healthcare practice in all contexts, but especially in cases where the choices are hard and not optimal.”

Both MK and JR’s experiences reinforce that the shared-decision making model of care needs to be expanded to encompass a relational component. A relational decision-making model builds upon the values of informed choice and shared decision-making in the transmission of information that is accurate and thorough. In addition, the relational decision-making model values relationships the

pregnant person has with family, culture, and ethics as well as the profound experience of creating emotional connection and building alliance with a person in a state of acute stress and trauma.

Relationship building is key to assuring that the information provided is integrated in a way that truly supports a pregnant person making decisions about their care that are in keeping with their values and experiences.

CONCLUSION

The 2 cases reviewed in this article offer unique insights for maternity care providers, particularly when caring for families with a diagnosis of a life-limiting condition. MK and JR found that their personal experiences have had a profound impact on the way they approach the provision of maternity care to other families. MS and JR were able to use their own personal stories of grief and loss and situate their experiences within the context of what it means to be a maternity care provider and provide relationally centered care. However, all maternity care providers are encouraged to exercise a relational approach to informed choice when counseling pregnant people, particularly regarding options following the diagnoses of a life-limiting anomaly.

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Table 1 – Decision Making Definitions

Model of Care	Definition
Informed Choice	A reasoning process that leads to the selection of a course of action among alternatives through the presentation of various types of evidence. ¹²
Shared Decision-Making	A model of informed choice that describes a joint, step-wise process where health care providers and patients make decisions together in clinical practice and a patient's preference determines the ultimate choice of action. ^{13,14}
Relational Decision-Making	A model that approaches informed choice by deliberately integrating the position of individuals within the array of relations that constitute and inform their lives and where informed choice is conceived and implemented into practice with an emphasis on alliance and relationality. ¹⁷

Sources: Noseworthy DA, et al¹², Elwyn G, et al¹³, King TL, et al¹⁴, Thachuk A¹⁷