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Pregnancies and Fetal Anomalies Incompatible with Life in Chile: Arguments and Experiences in Advocating for Legal Reform

LIDIA CASAS AND LIETA VIVALDI

Abstract

Chile allows abortion under no circumstances. Whether it's fetal anomaly incompatible with life or congenital malformation resulting in little or no life expectancy, all Chilean women are expected to carry their pregnancies to term. In this context, in January 2015 the Chilean Congress began debating a bill to legalize abortion on three grounds, including fatal congenital malformation. The medical community, including midwives, has presented its views for and against, especially on how the law may affect clinical practices; in addition, women, many of whom have experienced a fatal congenital malformation diagnosis, have weighed in. This qualitative study draws on 22 semi-structured interviews with nine certified nurse-midwives, one neonatologist, nine obstetrician-gynecologists, one psychiatrist, one psychologist, and one sociologist who provide care during gestation, pregnancy, delivery, and post-delivery in the public and private sectors, plus three interviews with two women and the former partner of a woman who underwent the experience. These interviews starkly illustrate the plight facing women carrying nonviable fetuses, including women's shock upon receiving the diagnosis, their feelings of bereavement and loss, and the clinical practices used in an attempt to ease their suffering under the weight of exceedingly difficult legal restrictions. These interviews confirmed that compelling women to carry nonviable fetuses to term violates their human rights. They also show that the chances of legislative change are real and that such change will present new challenges to the Chilean health care system.

Lidia Casas, LLB, LLM, PhD, is a professor and researcher at the Diego Portales University School of Law, Chile.

Lieta Vivaldi, LLB, MSc, is a PhD candidate in sociology at Goldsmiths, University of London, UK.

Please address correspondence to Lidia Casas. Email: lidia.casas@udp.cl.

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Introduction

Chile bans abortion even in cases of congenital malformation with little or no life expectancy. As a result, all Chilean women are forced to carry their pregnancies to term. Their only choices are safe termination abroad or safe or unsafe illegal abortion at home. In this context, in January 2015 the Chilean Congress began debating a government bill to legalize abortion on three grounds, including fatal congenital malformation. Since 1999, Chile has been prompted numerous times by United Nations human rights bodies to improve its abortion laws.[1]

This article documents the experience of carrying and delivering fetuses with congenital anomalies incompatible with life and reviews the actions of providers who care for these women during gestation, pregnancy, delivery, and post-delivery. In Chile, published studies on pregnancy termination in this context are few. The plight facing women with a severe fetal congenital anomaly diagnosis differs from that of those who want to terminate a pregnancy in that the former are generally wanted pregnancies and the sense of loss is highly distinct.[2] The literature notes that for women, the autonomy to decide whether to terminate or continue a pregnancy with fetal anomaly is of critical importance, and governments must provide counseling and care tailored to their needs.[3]

The Chilean medical community has taken active part in the legislative debate, speaking out for and against President Michelle Bachelet's proposed bill. They have provided mostly technical opinions, save for midwives who also contributed the experiences of pregnant women. Women for and against the bill who have experienced such pregnancies have provided testimony in Congress and to the media. This article tries to provide a nuanced portrait of women's suffering and of the difficulties confronted by clinicians dealing with fetal malformation diagnoses in a country with an absolute abortion ban.

We draw on interviews with public and private health care providers. To illustrate women's plight, we also interviewed two women and the former male partner of a woman who underwent this experience. While we contacted more women, the vast majority did not wish to be interviewed. Due to these constraints, most insights on women's experiences were provided by their health care providers. These interviews confirmed that forcing women to carry a nonviable fetus to term violates their human rights.

Methods

Our investigation used mixed qualitative methods involving compilation and systemization of information from primary sources (statistical registers) and secondary sources, including a literature review and unpublished reports about women's experiences and overall treatment received. Although not the original intent, this study captures primarily the experiences of health care providers, since most of the women we contacted did not wish to be interviewed.

From July through September 2015, we conducted 22 semi-structured interviews with one psychiatrist, one psychologist, nine certified nurse-midwives, one neonatologist, nine obstetrician-gynecologists, and one sociologist in public and private practice in the cities of Santiago, Valparaíso, and Valdivia. One interview was part of a group session with a multidisciplinary clinical research team that relayed the results of an unpublished study based on a clinical history review and interviews with nonviable pregnancy patients in the Aconcagua and Valparaíso-Quillota public health services. We also interviewed two women and the former partner of a woman who lived through the experience. Questions posed to health care providers centered on medical and personal experiences and on their views on the decriminalization of abortion on fatal fetal anomaly grounds. We asked them when, by whom, and how affected women were told; what overall medical treatment was provided; what the women's reactions were; whether the women requested pregnancy interruption; and what course of action was followed for women who sought abortions. We also queried them on their views on liberalization of the law and its potential effects on clinical practice. The two women and the former partner, for their part,

were asked about medical treatment received, options given during gestation, whether they sought or thought about pregnancy termination, and their views on the decriminalization of abortion on fatal fetal anomaly grounds, as there is evidence that at least some women are given the option of terminating the pregnancy or inducing early labor.[4]

Interviewees were contacted personally or through the snowball technique.[5] We contacted antenatal care professionals who provided names of obstetrician-gynecologists and other health care providers, as well as contacts with the College of Nurse-Midwives. The women were identified with assistance from health care providers and personal contacts. In the case of the male partner, his former wife was not willing to participate. Locating women who had had nonviable pregnancies and were willing to talk was not an easy proposition. Interviews were done in person, digitally recorded, and transcribed for analysis. The research was reviewed and approved by the Diego Portales University Ethics Committee. All participants were fully apprised of the contents, potential risks, and benefits; were assured anonymity and confidentiality; and gave their consent.

Context

On January 31, 2015, the government of President Michelle Bachelet submitted a bill to decriminalize abortion on three grounds: danger to the woman's life, fetal anomaly incompatible with life, and rape. At present, Chile does not allow abortion under any circumstances. In March 2016, the bill passed in the Chamber of Deputies, not before the fetal anomaly clause was reframed as "a pregnancy may be terminated when … the embryo or fetus suffers a lethal congenital or genetic structural impairment." All polls conducted since January 2015 have shown widespread support for decriminalization in cases of severe fetal abnormality. An October 2016 poll by the nongovernmental organization Humanas showed that 75% of female respondents agreed with the fetal anomaly exception. The lowest level of support in any poll stood at 67% for both men and women.

There is no cut-and-dried definition of "fetal anomaly incompatible with life" or a definitive understanding or list of fatal malformations. For the purposes of the congressional debate, local experts proposed one: most fetal anomalies involve fetal or neonatal death.[6] This definition is phrased to avoid tension with organizations of persons with disabilities and the misperception that severe fetal anomalies include Down syndrome. Carmen Astete and Blanca Román note that a fatal prognosis may result from a combination of pathologies.[7] A literature review presented by one of the local experts found a number of recognized fatal pathologies, including bilateral renal agenesis, Potter syndrome, acrania/anencephaly, skeletal dysplasia, trisomy 13 or 18, and alobar holoprosencephaly.[8] Local experts, in fact, went by the inventory in the UK's Fetal Anomaly Screening Program.[9] Hernán Muñoz et al. report that 20% of 23,446 infant deaths in Chile in 2013 involved fetal anomalies.[10] Overall, Chilean infant mortality has fallen, while the number of malformations has remained constant, perhaps due to late and teen pregnancies and alcohol and drug abuse.[11] For 2012, Chile's National Statistics Institute noted a total of 8.6 fetal anomalies per 1,000 live births.[12]

Malformations incompatible with life can be diagnosed at various stages. The Chilean public health system advises ultrasound testing at weeks 11–14, 20–24, and 30–32.[13] Muñoz et al.'s meta-analysis review shows that 51% of anomalies can be diagnosed at weeks 11–14 and 65.7% in the second trimester.[14] All clinicians interviewed agreed that severe malformations, such as anencephaly, become immediately evident at the first ultrasound; if in doubt, further tests can confirm. Other malformations may be detected at later stages.

In the Chilean public health system, biotechnology techniques and a multidisciplinary approach have ensured timelier, more accurate diagnoses. Despite suboptimal infrastructure and a specialist shortage, 68% of fetal anomalies and up to 88% of fatal anomalies are diagnosed prenatally.[15] Muñoz et al. confirm that 80% of all fatal malformations and up to 100% of some fatal anomalies are diagnosed prenatally in Chile.[16]

Findings

Diagnosis and pregnancy

Initial reaction. How and when a diagnosis is reported is key. Women's reactions will vary depending on whether the pregnancy was planned, if they had previously contemplated abortion, if they have a support network, and whether they have other children.

In the public health system, women often hear the results from sonographers or attending physicians. Midwives noted that because of their rapport with patients and their ability to use less technical language, it often falls to them to provide details and explain the pathology. Depending on protocols, women may also be referred to secondary care facilities for confirmation by a geneticist and an opinion on fetal survival.

Data from two public health services in Santiago show that few babies born with a fetal anomaly incompatible with life survive beyond one week.[17] Health care providers noted that most mothers report uncertainty as a key driver of distress. One obstetrician-gynecologist recommended being highly specific with women or couples about fetal death, birth, and survival rates beyond one week. To facilitate informed decision making, he thought legal reform ought to mandate full information and counseling.

In the public health system, information and emotional support is provided at specialist perinatal centers. In the private sector, diagnoses often come from the attending physician or the sonographer. Sometimes doctors disagree on a diagnosis, as the former partner noted, which can lead to either hopes for a positive outcome or further anxiety over the uncertainty surrounding the pregnancy. Disagreement among doctors is in fact a moot point, as abortion is not a legal option and the primary focus for clinicians is to find out whether the fetus can receive antenatal care that could improve its chances of survival.

There was consensus among medical respondents that most affected women experience shock and disbelief. As a female midwife said, it is news no one expects to hear: "'Maybe you're wrong. Maybe I didn't understand right. Miracles happen.'" A woman treated at a private clinic said that she was shocked, yet had only a general idea of the diagnosis. Her gynecologist provided details only a month later. The former partner said:

> *The news was devastating. I was stunned; my ex cried, but stayed strong. I recall making an appointment for a test; they took some amniotic fluid and we got the results three weeks later. But this wasn't the attending; our gynecologist thought the baby was fine, that it was healthy … I breathed easier. I believed him, I was relieved.*

Case management by health care providers after first diagnosis. A confirmed diagnosis triggers a range of feelings that may vary over time but are best described as "a sense of overflowing bereavement," as one of the women interviewed put it. In practical terms, it is the start of a lengthy, uncertain process in which many practitioners interact with varying degrees of coordination. The former partner, whose wife was treated at one of Chile's best private clinics, said it was four weeks between first diagnosis and confirmation, similar to other private clinics. For women in the public system, the process is lengthier due to a shortage of specialists.

Multidisciplinary teams making group decisions, including on fatal malformation cases, have recently started forming across Chile's public health service. In the private sector, cases continue to be handled on an individual basis. One private sector obstetrician-gynecologist said that dealing with these cases is a very personal affair. When faced with a difficult situation, he asks colleagues for a second opinion, but there is no comprehensive approach.

Since specialist maternal and fetal health centers are not available in most of Chile, patients are referred to the University of Chile and the Pontifical Catholic University teaching hospitals and some regional hospitals or private clinics. The aim is to secure a clear-cut diagnosis and determine possible antenatal care, not pregnancy termination. Many respondents agreed that more such centers are needed, as women who live far away have it much

harder: in addition to the expense and emotional toll, they must also travel.

All health professionals noted that the absence of protocols that standardize concepts, processes, and action means that women depend on the judgment, responsiveness, and willingness of the attending team.

One female nurse-midwife felt that the criminalization of therapeutic abortion explains the lack of protocols:

> *Since therapeutic abortion is illegal, there is no training and no protocols. There is merely creativity and instinct by the multidisciplinary team responsible … We have no specially trained people to follow up on cases.*

Living with pregnancy after diagnosis. The sense of disbelief that follows a malformation diagnosis is often followed by feelings of unfitness to be a wife and mother. Women experience denial and self-blame or downplay the situation. As a group of female midwives noted, feelings of guilt, incompetence, and shame are all channeled toward family and partners: "'Why wasn't I able to carry a healthy baby? Why me?'" This, in turn, can lead to searching for clues in one's own or the partner's family. Guilt takes the form of relentless questioning. The psychiatrist said:

> *Many mothers wonder why this happened. They took good care of themselves, yet some people who are into drugs or alcohol have no issues. They even think "it must have been something I ate … maybe that sushi did this to me."*

The psychologist argued that a severely impaired fetus is in itself a traumatic event:

> *There is guilt, self-reproach, dejection, depression, etc. Motherhood is so idealized that we tend to believe the idea of the "super mom." This is a sensitive issue, because there is a sense of grief and self-flagellation that is very persistent over time … "Here is the failed mother."*

The psychiatrist noted that her patients expressed a range of feelings. While there is anguish at not knowing when the fetus will die, some are relieved that it will be spared a lifetime of pain. Others just want it removed to end its suffering or to put an end to a hopeless situation. The psychiatrist and Woman A, who had a nonviable pregnancy, agreed that there is much anxiety over whether the fetus is still moving. Woman B said, "You eat something sweet so that the fetus moves."

She described this complex process:

> *It's torture … At night I feel a lot of anguish, but ten minutes later I'll be laughing my head off, and after that, I'll start crying. It's a process. It helps to think a little bit like a mom, what type of life my baby would even have. It's a relief. If it's for the best [for it to die], OK, then that's how it should be. That calms you down, it helps. It's not that you are happy that your baby isn't OK, but knowing that its life would have been awful, that's a relief. Every sorrow is one's own and one is not more important than another, but if you were to give birth thinking everything was normal and then to have it die, that would be worse. That also makes me feel a little better. I have these months—that can also be torture—to brace for it … We can all die any time, but this is a death foretold. And that is also a relief. When the uncertainty passes, you have peace. I cry a lot, it's hard to get up in the morning, it's hard to fall asleep, it's hard to go to work, but deep down I am at peace.*

Faith and God figure constantly, albeit ambiguously. There is always hope for a miracle, that the diagnosis was wrong, or that God will intervene. But there is also the wrathful God. Interviews with midwives and the psychiatrist, and the results of an unpublished study conducted by another research team, showed that women with unplanned pregnancies who contemplated abortion before finding out that their fetus had an abnormality experienced the most guilt, as they felt it to be the wrath of God. The man interviewed said that his former partner, a devout Catholic, turned to mysticism as a coping mechanism.

Health risks. Almost all health care providers interviewed saw no health risks for the mother in continuing the pregnancy, save for conditions such as a partial molar pregnancy or excess amniotic

fluid. The former can cause a choriocarcinoma—a type of tumor—while the latter can cause placental abruption and increase the risk of post-partum bleeding. Risk to life is considered rare. As some obstetrician-gynecologists suggested, medical practice allows for some form of treatment, and if pregnancy termination occurs, it is the consequence, not the goal.

However, all agreed that the heaviest impact is on mental health. Pregnancy brings exposure, compliments, and questions in public, at work, from relatives, and even from unaware health care workers. Some women turned to Chile Crece Contigo (Chile Grows with You), a nationwide social program for parents and family members that, for these specific cases, offers support and counseling designed to ease guilt and prevent pathological grief.[18]

The psychiatrist said:

> *Only psychiatrists can grant sick leave to mothers dealing with anxiety or anguish, but getting insurers to cover this is hard. They have cut rest periods down from a month to 15 days. A woman carrying a nonviable fetus shouldn't have to go to work because she will inevitably be asked about the baby, with catastrophic results for her mental health. I know of a terrible case of an anencephalic baby who survived for nearly three months. The mother, who was over 40, fully expected it to live and camped out at the hospital. When it died she went into pathological grief. When she had first found out that the fetus was malformed she had threatened to jump in front of the subway if we didn't abort it.*

A public health midwife said that women

> *feel that somehow they have failed; that they are just unable to have healthy children. They dread a new pregnancy and many opt for tubal ligation … Unresolved grief leads to depression but many can't get time off work for therapy. A common result is post-partum depression becoming chronic. While pregnant they have nightmares about carrying a monster, like in the movies. After birth, many don't want to see the malformed baby.*

Her colleagues agreed that after an experience like this, many couples break up. Some have known of men who avoid sex in order to prevent another pregnancy.

Mental health issues are compounded by poorly trained medical practitioners. Female patients in the private health system pay out of pocket for counseling, and costs are steep. A woman related her experience at an expensive private clinic:

> *The doctor said that we needed counseling, and he went on to offer—practically handing out brochures—the services of the clinic's excellent psychologists. I found this tactless and uncaring. Rather than empathy, I felt they were just trying to make money. When we were given the diagnosis we were in shock, but what he said felt almost like "Just go home" … It was very painful.*

What women are offered. Nearly all interviewees agreed that the law grossly restricts latitude; as one midwife noted, "Chile does not allow for a plan B; both therapeutic and non-therapeutic abortion are illegal." Some health professionals are at a loss when women ask to terminate a pregnancy. Most say they understand their plight, but cannot do anything. As one physician said:

> *No one offers anything … no one does [pregnancy termination], the most you can do is a karyogram [a diagram of the features of chromosomes done via an amniotic fluid, placental, or blood sample]. That said, I know for a fact that some doctors in private practice tell women about misoprostol.*

Pregnancy termination options in the public and private sectors are different. A woman seeing a doctor in private practice said that he suggested a safe out-of-country abortion, an option she declined. Although she knew that her daughter would die at birth, she chose to go through with the experience. Abroad she would have no support network, and she was uncomfortable with using an option many Chilean women can't afford. Several interviews corroborated that private clinics often suggest travel abroad, an option that patients in the public health system—who likely cannot afford it—don't often hear about. Travel to countries such as Brazil or Colombia costs at least US$500 per person, plus

living and medical expenses. Cuba or Mexico cost almost twice as much.

The former partner we interviewed said that while their doctor never suggested termination, he did note that most patients do not carry such pregnancies to term.

Among health professionals asked about women who sought an abortion, views and perceptions were mixed. Some obstetrician-gynecologists said that most do not ask. One said:

> *Everyone knows that in Chile abortion is against the law. Most patients don't ask for an abortion and most doctors, if asked, will say no. But that doesn't mean that women aren't going to do it.*

Another agreed that few women ask for an abortion: "Only one out of ten, and then in strict confidence. They don't want their medical record to show that they sought an abortion and risk others finding out."

One physician said that access to the internet and information sharing means women know about misoprostol, which is why they are no longer asking doctors about abortions. One midwife said that she knows some doctors who tell women about misoprostol. Another said, "We gave this woman a misoprostol prescription. We helped her all we could." But misoprostol safety declines with gestational age: "It is less effective because most malformations are diagnosed late, not at 6 to 8 weeks … and its use—or misuse—at that stage can cause severe bleeding, infection, uterine rupture, etc."

An obstetrician-gynecologist in the regional public and private health systems said, "Most women who decide to carry a malformed fetus to term are affluent and devout. Among the disadvantaged, most choose termination."

In Chile, "affluent and devout" are bywords for the usually well-heeled members of ultra-conservative Catholic groupings such as the Opus Dei or the Legion of Christ. But as a public hospital psychologist who specializes in fatal anomalies and treats underprivileged women said:

> *My patients aren't looking to terminate their pregnancies. I know a very specific profile: women who submit to the [gendered] social mandate and don't have the wherewithal to question it. Some want to continue their pregnancy, others don't have a choice.*

Most health care providers feel that women do not ask because they probably sense that doctors will not help them commit an illegal act, because they do not have the kind of rapport that would allow such a question, or because there is family pressure to carry on.

A midwife said that women "are pressured by sisters, mothers, partners, etc. to see things through. They all offer opinions and women feel forced to carry on. These poor women have a really hard time. They can't sleep."

But as some noted, partners or relatives can also help empower women to make their own choices. The psychiatrist observed that men escorting their partners to appointments tend to support them to do as they choose:

> *Women call the shots. There is a sort of respect on the part of these macho men, who sometimes may even be criminals, but feel that women should be able to do what they want, considering that they are the ones who suffer.*

Early induction of labor and delivery. Some medical respondents said that pregnancy termination may be discussed in meetings with department heads and ethics committees as a means to reduce suffering or health risks. However, when done without department heads signing off, early induction of labor and delivery before the fetus can be deemed to be mature or to have reached a certain gestational age can expose practitioners to sanctions.

When asked whether this procedure was performed at their medical centers, interviewees gave disparate answers. Some said no, others that it was common. A review of all interviews shows that each respondent had his or her own definition of "abortion" and of the gestational age at which early induction of labor is an option. One physician said that if a woman requested it, her opinion should prevail:

> *In pregnancies without chance of fetal survival, we support a woman's choice to terminate her pregnan-*

> *cy at weeks 30 or 32. We know the fetus is going to die anyway, so why wait until 40 weeks?*

Another said:

> *[T]he [gestational] age limit allows us to manipulate the law. Up to 15 weeks or 500 grams in weight, it's abortion. Few women ask to induce a preterm birth … Some patients have secondary pathologies; if there is a health risk, termination can be moved up to 33 weeks.*

One midwife said, "Some women ask for termination and the best you can do, if doctors are sympathetic, is ensure that they accept that she should decide, that is, wait for viability until week 34."

Health conditions are also weighed in pondering induction. A member of a multidisciplinary team noted:

> *Some women ask for induced labor, which is technically not the same as termination. … At 35 weeks some just can't take it anymore, but unfortunately the prescription is to complete rather than induce, unless strong medical reasons exist. It is rare for a woman's life to be at risk. If there's a request for induction we will take it to the ethics committee, but it usually doesn't go over well. They argue technicalities that sound more like institutional reasons. The technical aspects aren't trivial, but the real issue is why are such women allowed to get to 37 weeks … You see patients having a really hard time, and you wonder why that wasn't addressed earlier.*

There is duality when handling these situations. A physician noted that

> *one can act after 22 weeks. For example, if you have a patient with a hypertensive crisis and we're at 25 weeks, you act. If there aren't any health issues, you wait until the situation calls for action.*

Another doctor said that obstetric risk protocols are followed "until [the pregnancy] is considered viable, at 35 or 36 weeks, approximately. If you have a nonviable fetus, for example, if the fetus has acrania, we remove it a bit before."

Some argue that the private sector affords more freedom of action, but inducing labor remains a hush topic. And based on interviewees' responses, it is clearly an issue for which there is no guidance or consensual or evidence-based policy.

Delivery and post-partum. Differences in the public and private health systems become especially marked at delivery. For many women, this is a key moment since it is when, maybe for just a few minutes, they will get to see their child before it dies. In the private system, women are usually in a private room, which lets them and their loved ones live the moment in privacy. In the public system, the lack of infrastructure does not allow for a more intimate atmosphere. Caring staff will usually draw a curtain around the bed or otherwise provide some privacy, but this depends both on the particular staffers and on physical capacity. As a midwife noted:

> *Women arriving in their beds are surrounded by other women with babies in arms. You realize what's going on and draw the curtain, but still, next to her there's another mother holding a bouncing baby.*

Physicians and midwives agree that women now have more choices. They can choose delivery methods, whether to christen the baby, if they want to say their goodbyes, and so on. A woman said that holding her daughter until she died in her arms was a big help.

Respondents reported that some maternity care facilities provide areas for women and relatives to practice their beliefs, and even allow them to see or touch the baby if they wish. This helps them go through this ordeal in a more intimate, supportive environment. Yet there is a significant difference between a newborn who lives for a few minutes or hours and one who survives for months. One obstetrician-gynecologist said:

> *When someone says that these pregnancies can be ended ahead of time, some people are opposed just because fetuses can survive a month or two. But is it survival or just extended suffering? If the mother chooses to live through that, OK, that's her option. But if she doesn't, the choice should also be there.*

One midwife remembered a woman from outside Santiago whose son survived, which forced her to travel back and forth frequently because he needed

constant care. She felt that such situations are easier to deal with when the baby dies shortly after birth. When death takes its time, people become afraid of medical costs and feel guilty over wanting it to be over soon, with serious mental health consequences for all involved. One physician said:

> *The real ordeal comes when a baby survives in terrible condition. Sometimes the family has to pay for expensive surgery, and maybe look after a seriously impaired baby for the rest of its life … If you ask me, I would take trisomy 13, anencephaly or microcephaly anytime, because the baby is dead within three days. The problem is when it survives and nobody knows how or why it's still alive, or for how long.*

A midwife reflected on how difficult it is for women to deal with grief and its impact:

> *Many have other children. They don't really have the time to process their grief, because life must go on and in this macho society women are the tower of strength that must bite the bullet. If they stop working, the whole home comes tumbling down. They don't have time to grieve or find a psychologist because the kids have to go to school, have to be fed, etc. Husbands don't deal with this well. They have depressions they never deal with, which often leads to marriage breakup.*

One respondent related the emotional toll taken by holding down a job and caring for her family. The fetus she was carrying died in utero, yet she had to wait two weeks for a surgery slot to have it removed. She chose not to see it. She said that despite the pain of coming home to an empty baby room, it was a great relief knowing that it no longer suffered.

Public system professionals agree that poor follow-up with women beyond the first year is an issue, as they never know what happens with the grieving process afterward. In the private health system, based as it is on individual health risk, most insurers put caps on coverage and women must pay out of pocket for extended mental health care.

Opinions on the therapeutic abortion bill

Almost all medical staff respondents interviewed supported therapeutic abortion on grounds of fatal impairment. They played down the physical or health risks for the woman but agreed that these cases can have a major mental health impact. These firsthand accounts exposed an urgent need to legislate pregnancy termination in cases of fatal congenital malformation or imminent danger to a woman's life or health. The neonatologist noted:

> *The issue put me in a quandary ... Before I started here I was against abortion, but I've seen so much suffering in these mothers that go through nightmarish pregnancies … Those brainless patients that only breathe for three hours and then die, the poor mothers that have to carry those pregnancies to term—it's heart-rending.*

Another said:

> *Having a choice would be quite a relief, even for mothers who decide to go through with the pregnancy. It would mean that they do so because they want to, not because they are forced to.*

A midwife said that the law prevents her from providing care that is consistent with women's sexual and reproductive rights. The psychiatrist added:

> *It's abhorrent that in this country we've made so much progress in biomedicine but still think as if we were back in the Middle Ages … If we have prenatal diagnostics, if medicine has made such progress, then we ought to have therapeutic procedures that are consistent with such progress. A therapeutic abortion ban does unthinkable violence, is unethical, and contradicts the basic principles of bioethics.*

Another midwife agreed with the three grounds in the proposed bill but said that one of the objectives of decriminalization should be to promote health and safety:

> *Since all abortion is criminalized, all abortion is clandestine, and safety will hinge on income level … So it comes down to the right to adequate health care and the right not to be mutilated or die as a result.*

The psychologist commented:

> *The law doesn't merely sanction or ban abortion, it also generates a social narrative in which we are not*

> *allowed to talk about it. And for these traumas, this is a very delicate matter. That is one consequence of the ban. Even if we legislate abortion, and I hope that is the case, we would still have to wait a few generations to be able to speak freely about it.*

Some health care providers who opposed the bill said that most women were strong enough to deal with the experience. Others resorted to convoluted arguments to avoid acknowledging their opposition. One physician felt that the bill fails to take account of the opinion of medical specialists and the reality of medical practice in Chile: "Techniques are available to identify conditions incompatible with life, and the law should require that fetal-maternal specialists provide the diagnosis."

Another saw the potential for conflict with insurers:

> *If the law passes, insurance companies will favor termination, like in Germany or England. If a woman is 12 or 15 weeks along and she is carrying an anencephalic fetus, they'll suggest termination. If she disagrees, checkups, tests, delivery, ICU days—all that will cost a lot of money. So from a purely financial standpoint, insurers will press for termination.*

A midwife felt that the bill fails to offer malpractice protection, adding that if anencephalic babies can survive six or seven days—as she has seen in her practice—even that short time may be enough for some families. Her implicit opposition seems based on a concern that health care providers, especially sonographers, could be held liable for misdiagnoses.

When asked if the current abortion ban affects patient choice, an obstetrician-gynecologist working in antenatal care said:

> *Personally, I don't think so. The problem isn't the law, it's a system that doesn't deliver proper care. This [legislative debate] is a great opportunity for the country to confront the issue and do the right thing, for instance creating [specialized] centers … to deal with these patients and give them the maximum number of choices.*

The two women we interviewed and the man's ex-wife did not terminate their pregnancies. One sought termination, but her physician discouraged it; a midwife recommended another doctor, but the woman was too scared to follow through. All three interviewees agreed that women should have a choice.

Discussion

Our findings match other studies of pregnant women with a fetal anomaly diagnosis in that the primary feelings are shock and disbelief.[19] Forced motherhood in a fetal impairment context is an undue hardship on women and their partners and often leads to breakups. While some of the women in our sample (the women we directly interviewed and patients of the people we interviewed) sought to get pregnant again, fear led most to shun a future pregnancy. Some of these trends have been noted in other studies.[20]

A study that does not directly capture the views of women is admittedly limited. In this regard, we note that the task is especially challenging where abortion is banned, as women have few opportunities to ponder pregnancy termination and health care providers have few options to mitigate suffering, promote overall health, or prevent the risks associated with continuing a pregnancy. Abortion is also stigmatized through gender norms that hold women up as strong caregivers capable of dealing with the experience, as some interviewees noted. Gender issues and the stigma associated with abortion are also observed in countries where abortion is legal.[21] Our findings suggest that the criminalization of abortion reinforces a feeling of ethical or legal wrongdoing. Not all women may wish to terminate their pregnancies, even when legal.[22] The issue is not "pro-choice beliefs." Rather, as one study of mostly religious women and their partners documented, the issue is about having options.[23]

Health care staff, for their part, confront their own dilemmas. They are often untrained to handle these situations, cannot offer women other options, and must resort to circumventing the law to provide early induction of labor, suggest an illegal abortion, or prescribe misoprostol. This state of

powerlessness is a notorious stressor. In a context where abortion is absolutely banned and protocols do not exist, it is not clear whether even sympathetic health care staff know about the correct use of misoprostol in a second-trimester abortion.

In Chile, the formal training of midwives, obstetrician-gynecologists, and other practitioners does not include dealing with these difficult pregnancies. Because of legal restrictions on proper medical practice in pregnancy termination, many are unfamiliar with the technical aspects of second-trimester abortion, which results in suboptimal care. In this regard, the symbolic power of criminal law works in two ways: it steers health care workers away from assisting women and restricts proper clinical practice.

Some women can obtain a safe abortion abroad on the direct advice of their obstetrician-gynecologist. Chile is not at all unlike Ireland, where women obtain abortions abroad, in a practice known as "abortion tourism."[24] But women who lack the means are left to their own devices and must face varying degrees of safety.

In the Chilean public health system, women who seek to terminate a pregnancy after 22 weeks are dependent on medical discretion. Some doctors will perform early induction for the sake of a woman's health and integrity, knowing full well that they may be subject to disciplinary or even criminal action. Pamela Eguiguren et al. note that termination options hinge on sympathy, the views of the health care team, and whether the setting is public or private.[25]

The current legislative debate illustrates the irony of the situation and the challenges facing the Chilean health care system. A senator recently submitted an amendment to the bill requiring that even if the fatal fetal malformation is diagnosed early, the abortion will have to wait until after week 22 or when the fetus weighs above 500 grams, in order to have an early induction of labor following a two-week cooling-off period. The amendment is explicit in referring to this as early termination rather than abortion. As discussed, and all experts agree, fetal anomalies in the bill are associated with fetal or neonatal death—that is, fetuses with little or no chance of survival. The proposed gestational limit speaks to the reluctance of allowing abortion, while delaying early termination inflicts unreasonable suffering on women. Ironically, in Sweden, which allows abortion prior to 18 weeks, abortion after 21 weeks is seldom approved.[26]

The above amendment calls to mind a 2002 case that inspired an unsuccessful legislative motion to decriminalize abortion on fetal malformation grounds. A woman with a partial molar pregnancy publicly requested an abortion. The then health minister, an expert transplant pediatrician, answered that no clinician or government official could help, as abortion was illegal. After the woman underwent an emergency early induction of labor, Chile's main conservative newspaper ran a front-page headline stressing that this was pregnancy termination, not abortion.[27] In 2017, the former health minister who had reminded the affected woman that abortion was illegal signed and sponsored a paid ad opposing Bachelet's bill in the same newspaper.

The abortion ban exposes women to otherwise avoidable risks, and medical practitioners distinguish between obstetric and mental health consequences. Regarding obstetric risks, in previous research, a midwife referred to an adolescent who died as a consequence of delaying inducing labor with an anencephalic fetus.[28] But as many respondents emphasized, inasmuch as health protection is limited to its most basic physical attributes, the risks involved in ignoring the severe mental health effects of enforced pregnancy can only increase. Serious harm to psychological integrity can result in severe and chronic depression, pathological grief, and, as some respondents suggested, even suicidal ideation.

In *K.L. v. Peru*, the United Nations Human Rights Committee found that forcing women to carry a nonviable fetus to term constitutes cruel and inhuman treatment.[29] Women confronted with nonviable pregnancies have varying experiences, expectations, and needs. This should be recognized, and women—whether they choose to continue or terminate—should receive support and care, while states should guarantee appropriate conditions that

allow women to make a very difficult decision.

Failure to acknowledge this issue limits the chances for a humane response. A country that bans all abortion cannot protect the mental or physical integrity of women who choose to terminate their pregnancies, nor does it adequately shoulder the responsibility for mitigating the mental health consequences. And a system of support should seek not to persuade but to provide and organize health care that meets women's needs and rights.

The United Nations Committee on Economic, Social and Cultural Rights has asked states to remove all barriers to the full realization of sexual and reproductive rights.[30] Abortion bans make women unequal, with impacts that differ depending on economic, social, and cultural factors, including the health care available to them.

The Inter-American Court of Human Rights, in ordering provisional measures in *B. v. El Salvador*, required the state to ensure the life and integrity of B., a pregnant woman who had discoid lupus erythematosus and renal failure, compounded by an anencephalic fetus that placed her life, personal integrity, and health in imminent peril.[31] The recommended medical protocol was termination, but El Salvador bans therapeutic abortion, and the courts declined to order access. As a result, the Inter-American Court required the state to

> *adopt and guarantee, urgently, all the necessary and effective measures so that the medical team who are treating B. can take, without any interference, the medical measures they consider opportune and desirable to ensure due protection of the rights established in … the American Convention and, in this way, avoid any damage that could be irreparable to the rights to the life, personal integrity and health of B.*[32]

The paradox in allowing termination on grounds of fetal nonviability is in the language. The viability is used against the law when there is no life expectancy. Chilean midwives and obstetrician-gynecologists use second-trimester induction of labor to provide "a solution" that will not be an abortion from a medical or technical point of view. But since Chilean law does not make any such distinctions, this is still illegal.

This also raises unresolved issues. The exception works under the assumption that the fetus is not viable and that the condition requires certainties that medicine is not necessarily able to offer. While the absence of life expectancy after birth seems to remove the moral weight of allowing a decision to terminate, fear of misdiagnosis exposes the moral dilemma faced by health care providers. Clinicians who disagree with women's right to choose may cite diagnostic uncertainty in order not to apprise women fully and adequately about pregnancy termination. One interviewee suggested telling women of the probable life expectancy of the fetus, consistent with the moral stand that a life is worth living, regardless of length. But fear of liability or of being held accountable for the wrong decision obscures the basic point that women should be able to choose based on all the information science is able to provide.

Conclusions and recommendations

Whenever abortion is banned, women carrying a nonviable fetus face heightened mental anguish and risks to their moral integrity. This is compounded by the stigma and mistreatment involved in depriving women of both a voice and the chance to make an exceedingly difficult decision on their own.

While the severe fetal congenital indication in the proposed Chilean bill may be seen as a medical issue, in fact agency is the key. Women should be able to decide, yet the legislative debate has highlighted the weight of biomedical rhetoric and the medical profession's ability to impede or facilitate pregnancy termination. Accordingly, given the limitations of science and of the health care system, requiring a rock-solid diagnosis could become a barrier.

Respecting women's rights means taking into account the complexities of allowing abortion in cases with little or no chance of survival after birth. It also means supporting women by providing nondirective counseling and compassionate care throughout the whole process and beyond.

A legal regime that bans all abortion does not guarantee women's health or protect their rights to

equality, dignity, and non-discrimination.

In Chile, the legislative debate and any future law reform and policies should address the plight of these women and ensure the protection of their human rights. All women should be treated with dignity and respect and should be empowered to voluntarily choose whether to terminate or continue a pregnancy.

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