



# Prinatal palliative care

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يا حبيبنا

يا مظلوم

فانزلنا في القرآن  
صراطا مستقيما  
بسم الله الرحمن الرحيم

# introduction

- ◎ 23,450 infantile deaths in year
- ◎ 2/3 of which: neonatal period
- ◎ Congenital malformation & chromosomal abnormality : the most common cause (20.6%)
- ◎ Prematurity & LBW (17.4%)

- ⦿ Prenatal diagnosis of fetal abnormality that may be life- limiting
- ⦿ Challenging & complex discussion between patient & health care provider
- ⦿ Individualized care plan

# life-limiting

- ⦿ Lethal fetal condition
- ⦿ As well as others little or no prospect of long term exutero survival without sever morbidity

And

- ⦿ **For witch there is no cure**

# life-limiting

- Severely morbid condition
- intervention is questionable efficacy
- deemed to be unacceptably burdensome to neonate





لَا تُصَلِّ عَلَيَّ مُحَمَّدٍ وَلَا عَلَىٰ أَهْلِ بَيْتِهِ



# بیماری قابل درمان در جنین

درمان در دوران جنینی:

## درمان طبی جنین

مثل هیدروپس جنینی (کمخونی جنین، آریتمی ها)

## درمان جنین با جراحی

- ❑ **Percutaneous Procedures:**  
Cardiac catheter procedures
- ❑ **Ex-Utero Intrapartum Treatment (EXIT) Procedures**



# بیماری قابل درمان در جنین در دوران جنینی

## MEDICAL THERAPY

- Arrhythmias
- Congenital Adrenal Hyperplasia (CAH)
- Congenital Cystic Adenomatoid Malformation : corticosteroid treatment
- Thyroid Disease: Maternal administration

# بیماری قابل درمان در جنین

## **SURGICAL THERAPY** (maternal-fetal surgery)

- ❖ Open Fetal Surgery
- ❖ Fetoscopic Surgery

# بیماری قابل درمان در جنین در دوران جنینی

## Open Fetal Surgery

- Congenital cystic adenomatoid malformation (CCAM): open lobectomy
- Myelomeningocele

# بیماری قابل درمان در جنین در دوران جنینی

## Open Fetal Surgery

- Pulmonary sequestration
- Sacrococcygeal teratoma

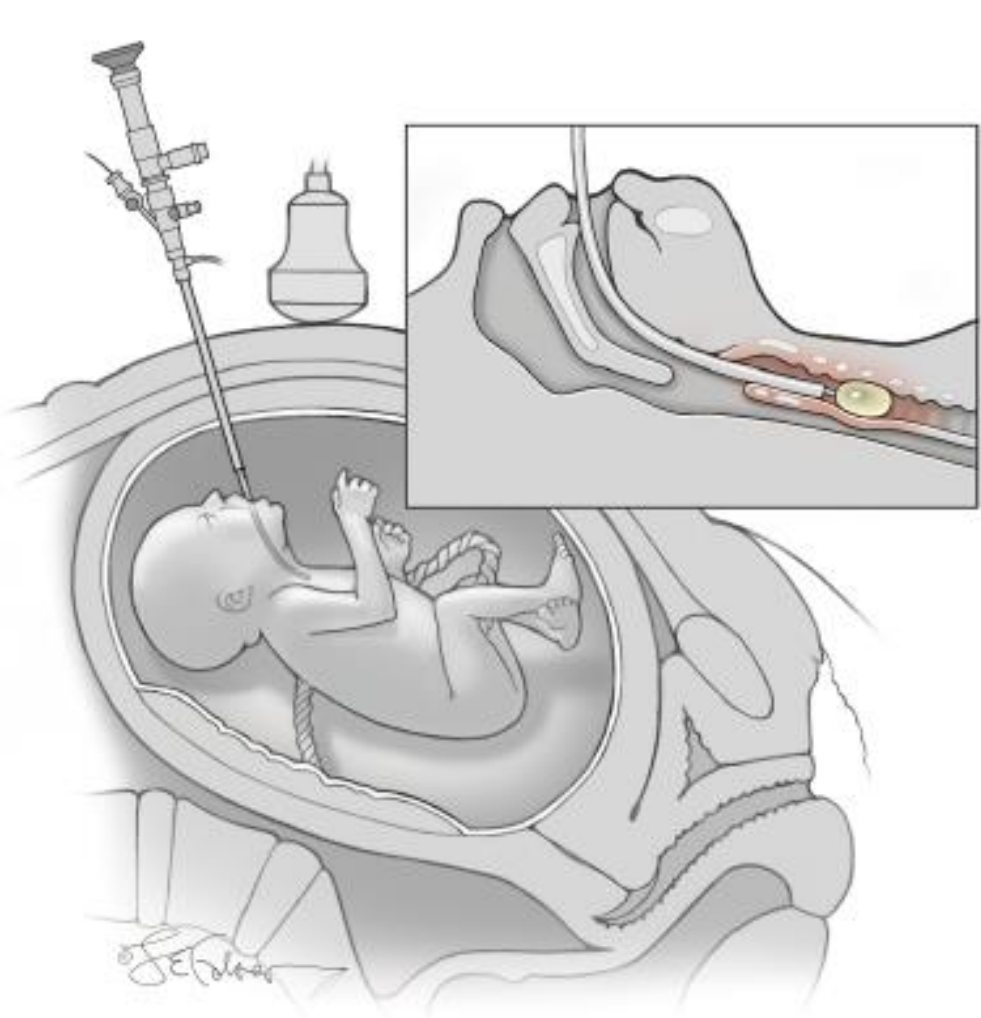




# بیماری قابل درمان در جنین در دوران جنینی

## Fetoscopic Surgery

1. Amnionic band sequence: band release
2. Congenital diaphragmatic hernia (CDH): fetal endoscopic tracheal occlusion (FETO)

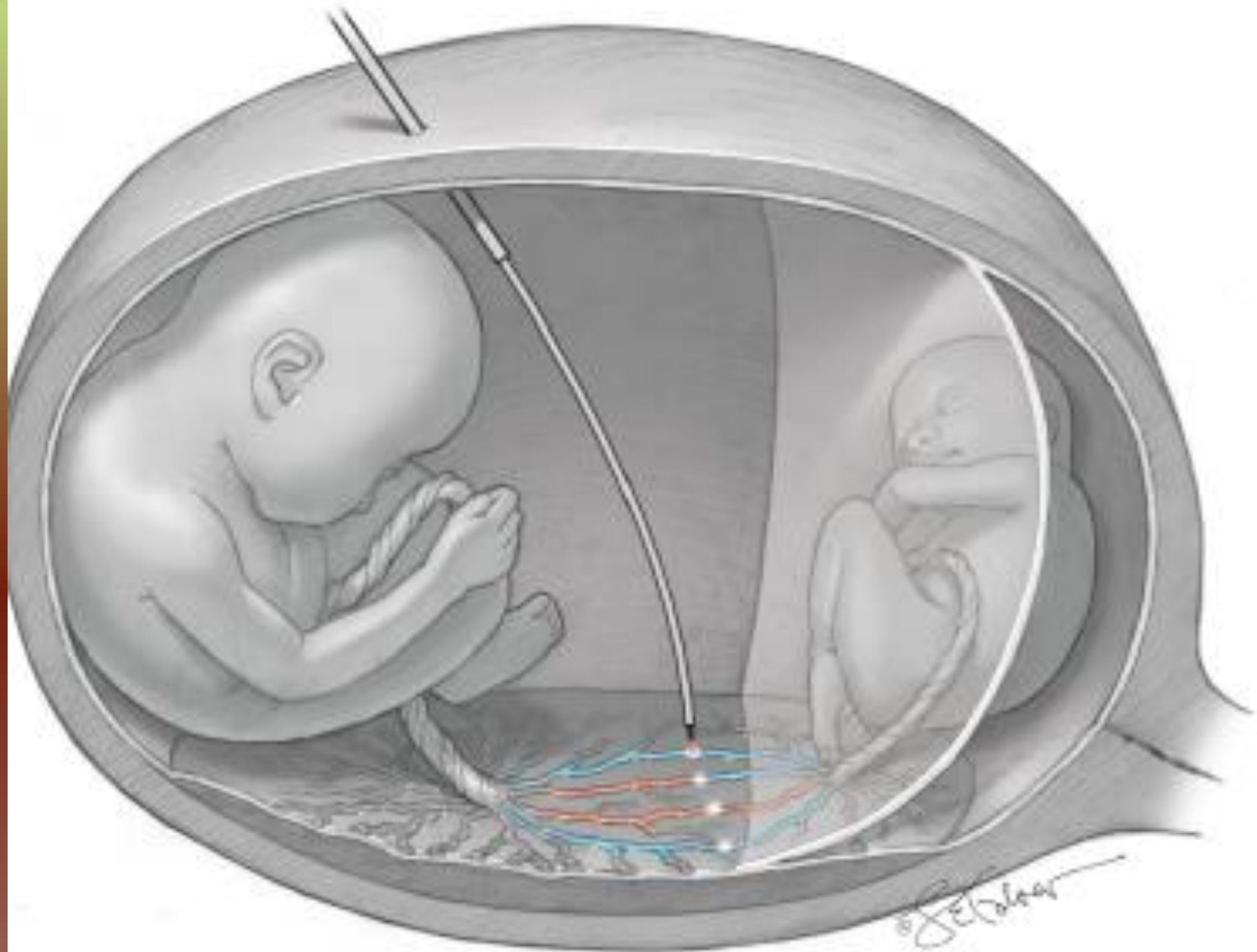


(Reproduced with permission from  
Shamshirsaz AA, Ramin, SM, Belfort MA:  
Fetal therapy. 2017)

# بیماری قابل درمان در جنین در دوران جنینی

## Fetoscopic Surgery

5. Posterior urethral valves: cystoscopic laser
6. Twin-twin transfusion: laser of placental anastomoses



# بیماری قابل درمان در جنین در دوران جنینی

Percutaneous Procedures

Cardiac catheter procedures

- Aortic or pulmonic valvuloplasty for Stenosis



# بیماری قابل درمان در جنین در دوران جنینی

Percutaneous Procedures  
Radiofrequency ablation

- Twin reversed arterial perfusion (TRAP) sequence
- Monochorionic twins with severe anomaly in one twin
- Chorioangioma

# بیماری قابل درمان در جنین در دوران جنینی

Percutaneous Procedures

Shunt therapy

- Dominant cyst in CCAM
- Thoracoamniotic shunt for pleural effusion
- Vesicoamniotic shunt for bladder outlet obstruction

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# Diagnosis of life- limiting

from

- Fetal imaging
- Genetic testing

but require interdisciplinary input from

- ✓ Maternal- fetal medicine subspecialist
- ✓ Geneticists
- ✓ Pediatric subspecialist

## Perinatal palliative care

Ana Martín-Ancel <sup>1</sup>, Alejandro Pérez-Muñuzuri <sup>2</sup>, Noelia González-Pacheco <sup>3</sup>, Hector Boix <sup>4</sup>,  
María Gracia Espinosa Fernández <sup>5</sup>, María Dolores Sánchez-Redondo <sup>6</sup>, María Cernada <sup>7</sup>,  
María Luz Couce <sup>8</sup>; en representación del Comité de Estándares, Sociedad Española de Neonatología

- ⦿ a model of care designed
- ⦿ to prevent & treat physical, spiritual, emotional, & social needs
- ⦿ of fetuses & newborn infants with life-threatening or life-limiting conditions





## Perinatal palliative care

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- ⦿ The care extends to the infant's family
- ⦿ by an interdisciplinary team
- ⦿ to improve **quality of life** from the time of diagnosis (possibly in utero) into death & bereavement (days, months or years later)

# Belgium

- ⦿ When a severe diagnosis
- ⦿ before or after birth
- ⦿ perinatal palliative care (PPC)
- ⦿ to support infant, parents & involved healthcare providers

# perinatal palliative care

- ⦿ a multidisciplinary care approach aimed to improve
- ⦿ the quality of life of patients & their families
- ⦿ through prevention & relief of symptoms, whether physical, psychological, social or spiritual



The American College of  
Obstetricians and Gynecologists  
WOMEN'S HEALTH CARE PHYSICIANS

# ACOG COMMITTEE OPINION

Number 786

## Committee on Obstetric Practice Committee on Ethics

*The American Academy of Pediatrics and the Society for Maternal-Fetal Medicine endorse this document. This Committee Opinion was developed by the Committee on Obstetric Practice with the assistance of committee member Russell S. Miller, MD and the American Academy of Pediatrics' liaison member James J. Cummings, MD; and the Committee on Ethics with the assistance of the American Academy of Pediatrics' liaison member Robert Macauley, MD and the Society for Maternal-Fetal Medicine's liaison member Steven J. Ralston, MD, MPH.*

## Perinatal Palliative Care

- Focus on maximizing quality of life & comfort
- For newborns with variety of conditions
- Considered to **be life-limiting** in early infancy

# with a dual focus on

- ❖ ameliorating suffering
- ❖ honoring patient value





# Perinatal palliative comfort care

- ⦿ one of several options along a **spectrum** of care includes
- ⦿ pregnancy termination (abortion) & full neonatal resuscitation & treatment
- ⦿ should be presented to pregnant patients faced with **life-limiting** fetal conditions

# Perinatal palliative comfort care

- ◉ Without intend to prolong life in the context of life- limiting

# Perinatal palliative comfort care

- initial consultation should include a review of the fetal diagnosis
- introduction to goals of palliative medicine
- review of variety of decisions the woman & her family may face both antenatally & in the newborn period

# Perinatal palliative comfort care

All care option should be discussed:

- ◎ Pregnancy termination (abortion)
- ◎ Prenatal & postnatal intervention intend to promote survival
- ◎ **Perinatal palliative comfort care**



# Perinatal palliative comfort care team

- obstetric care providers
- neonatologists
- health care providers with expertise in pediatric palliative care
- nurses
- social workers
- mental health professionals
- religious counselors
- lactation specialists
- child life specialists



# Components of Perinatal Palliative Comfort Care

- formal prenatal consultation
- development of a birth plan
- access to other neonatal & pediatric specialties, as needed
- **support & care** during prenatal, birth, & postnatal periods, including bereavement counseling

# Initial consultation

- Review of fetal diagnosis
- Introduction goal of palliative medicine
- review of variety of decisions the woman & her family may face both antenatally & in the newborn period

# Initial consultation

- ⦿ can be helpful to identify the patient's preferred terminology (such as “baby,” “pregnancy,” or “fetus”)
- ⦿ inquire if fetus has been given a **name**
- ⦿ by which the fetus may then be referred if favored by patient

# Initial consultation

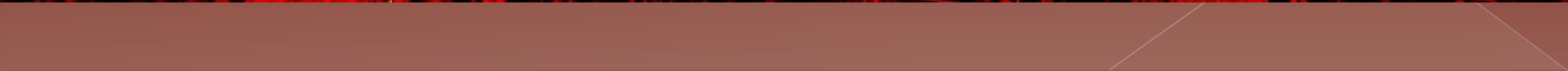
establish the therapeutic alliance for :

- ⦿ ongoing care
- ⦿ validate patient's decision to pursue palliative comfort care
- ⦿ ensure that patient goals align with reasonable expectation for pregnancy





الإلهام العالمان جدي الحسين قتلوا عظمائنا



# Birth plan

Critical prenatal component

- Individualized  
For
- Delivery  
&
- Neonatal care



# Birth plan

- intrapartum fetal monitoring
- Mode of delivery consideration

should be clarified

# Birth plan

There may be scenario

- intrapartum fetal monitoring
- Timed delivery
- Cesarean delivery for fetal indication

May be valid part of birth plan of  
**prinatal palliative care**: well-informed patient  
wishes to have a live birth

# Birth plan

must include plans for assessment & care of **newborn:**

- ❑ **newborn** bonding
- ❑ skin-to-skin contact
- ❑ warmth
- ❑ hydration
- ❑ feeding & lactation
- ❑ management of respiratory distress
- ❑ pain control

# Birth plan

- Ideally discussed with health care provider before delivery
- Placed in medical record
- Available for review





# After delivery

- ◉ Emotional & spiritual support should be provided
- ◉ If infant survive and discharge, PPC team should work with family
- ◉ to determine appropriate disposition
- ◉ At home or
- ◉ in health care setting

# After child death

bereavement counselling





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## “Have no regrets:” Parents’ experiences and developmental tasks in pregnancy with a lethal fetal diagnosis



Denise Côté-Arsenault <sup>a, \*</sup>, Erin Denney-Koelsch <sup>b</sup>

<sup>a</sup> University of North Carolina Greensboro, USA

<sup>b</sup> Division of Palliative Care, University of Rochester Medical Center, USA

- Prenatal diagnosis of life-limiting condition can be very stressful for patient & their family
- eliciting feelings including grief, loss & anxiety



## “Have no regrets:” Parents’ experiences and developmental tasks in pregnancy with a lethal fetal diagnosis



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- Who choose continuing pregnancy,
- although PPC not available to all,
- Majority were happy **to meet their baby after delivery**
- even if the newborn lived only briefly after birth or stillborn

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@samtekhoda3



# Ethical Considerations

- ⦿ **Women should have control over decisions that affect their bodies**
- ⦿ **how to manage a pregnancy complicated by a life-limiting fetal condition** ( Committee Opinion No. 664. American College of Obstetricians and Gynecologists)

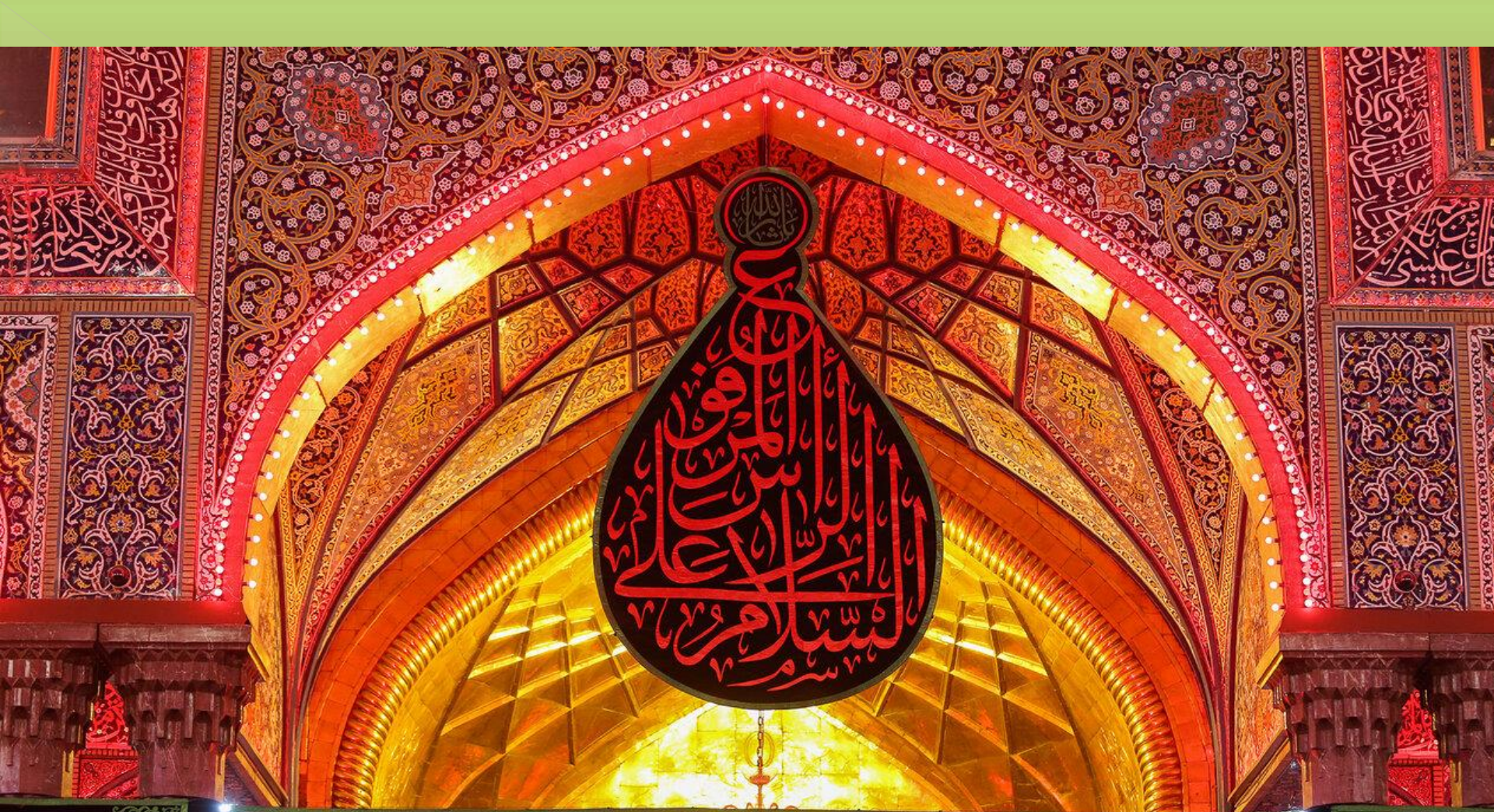
# Ethical Considerations

- ⦿ informed consent require
- ⦿ opportunity to further their autonomy

# conclusion

- ⦿ one of several options along a **spectrum** of care includes
- ⦿ pregnancy termination (abortion) & full neonatal resuscitation & treatment
- ⦿ should be presented to pregnant patients faced with **life-limiting** fetal conditions





قال سيد الشهداء ابو عبد الله عليه السلام مخاطبا ولده زين العابدين

والدين اذ نبت كبريا في جدي نبت عتبات الله المهادي

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