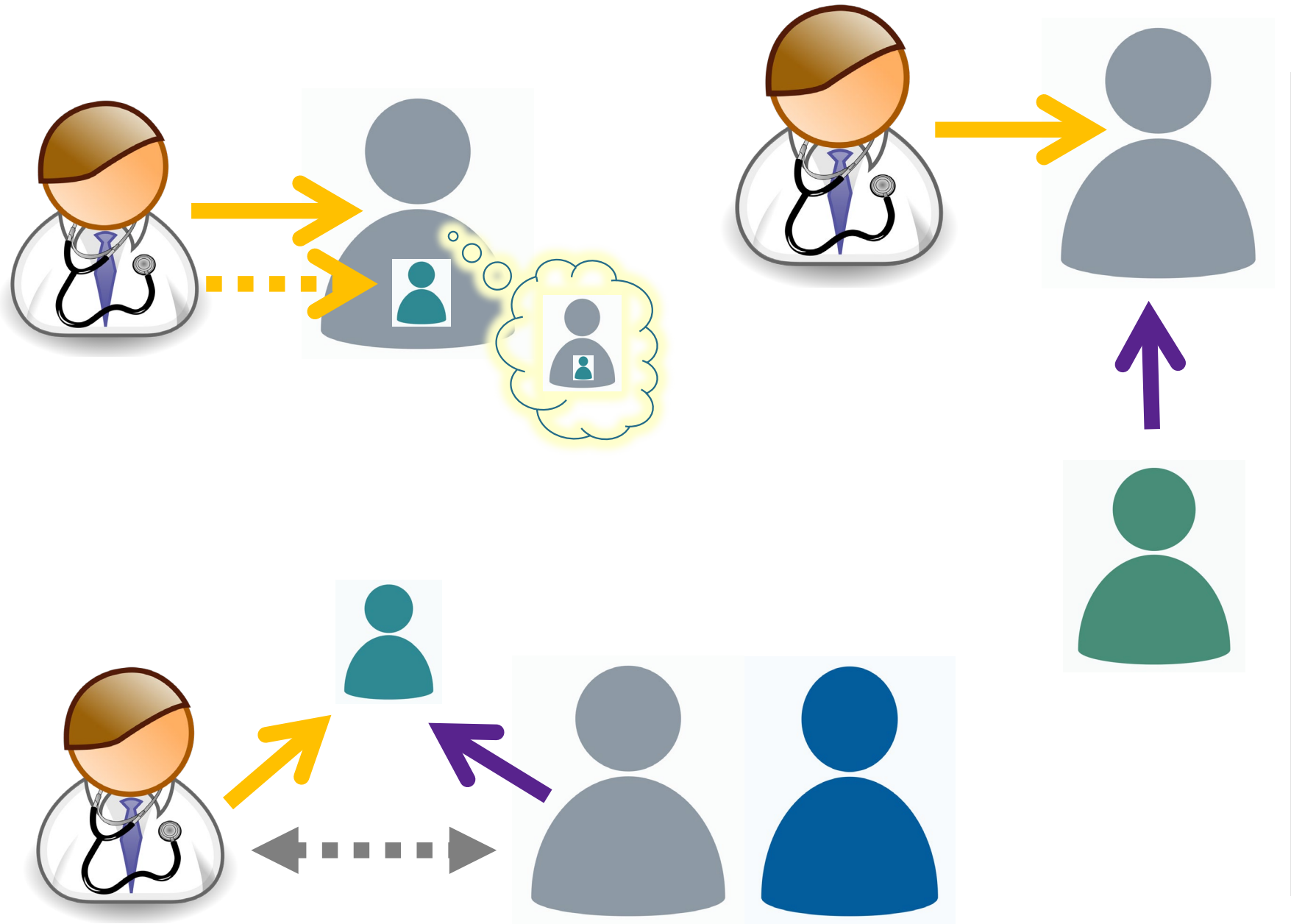


Relationships



MODELS FOR PARENTAL DECISION-MAKING (AND OVERRIDING PDM) IN PEDIATRICS

Best Interests Standard In Pediatrics

- Best interests – “acting so as to promote maximally the good of the individual”
- But parental failure to choose the treatment that is “best” is not the threshold
 - Choice of harmful/unreasonable option(s)
- Courts should apply standard of what is “in the child’s best interest” in determining what to do with the child

Buchanan and Brock, *Deciding for Others* 1989; Kopelman LM, *J Med & Phil* 1997

Harm Principle In Pediatrics

- Best interests are difficult to define, may be perceived differently by parents and medical professionals, and is not the standard used in other spheres
- State intervention is justified when parental decisions “significantly increase the likelihood of serious harm as compared to other options”

Diekema DS, *Theor Med Bioeth* 2004

Constrained Parental Autonomy Model In Pediatrics

- Parents have a “presumptive right to non-interference, a right that is restricted only if they fail to provide for their child’s basic needs.” Child’s interests inextricably connected to family interests
- State intervention only if:
 - Medical experts agree that treatment is appropriate; AND
 - Denial of treatment would deprive child of basic needs; AND
 - Treatment is expected to give child a chance of normal healthy growth or a life worth living (according to the child)

Ross LF, *Children, Families and Healthcare Decision-making* 1998

Treatment Options for Seriously Ill Newborns — Physician's Assessment in Relation to Parent's Preference

Physician's Assessment of Treatment Options*	Parents Prefer to Accept Treatment**	Parents Prefer to Forego Treatment**
Clearly beneficial	Provide treatment	Provide treatment during review process ^{tt}
Ambiguous or uncertain	Provide treatment	Forego treatment
Futile	Provide treatment unless provider declines to do so ^t	Forego treatment

* The assessment of the value to the infant of the treatments available will initially be by the attending physician. Both when this assessment is unclear and when the joint decision between parents and physician is to forego treatment, this assessment would be reviewed by intra-institutional mechanisms and possibly thereafter by court.

** The choice made by the infant's parents or other duly authorized surrogate who has adequate decisionmaking capacity and has been adequately informed, based on their assessment of the infant's best interests.

Monistic (One Concept) Theories: • Duty? (Deontology) • Benefit? (Utilitarianism)	Principlism: • Autonomy (Capacity? Self-Determination?) • Beneficence • Non-Maleficence • Justice
Standards • Best interest of child • Harm • Constrained Parent Autonomy	Parents as Surrogate Decision Makers • Vested interest in child's well-being • Intimate knowledge of child • Social/cultural/religious alignment • Bear consequences of treatment choices
Informed Consent Assent/Consent/Dissent	Other Issues? Gender stereotypes? Global considerations? Effect on health care providers? Conscientious objection?

Patient with capacity?

No

Surrogate available?

Yes

Advance directive?

No

Wishes known?

No

Use best interests

Yes

Patient decides

No

Pursue guardianship

Yes

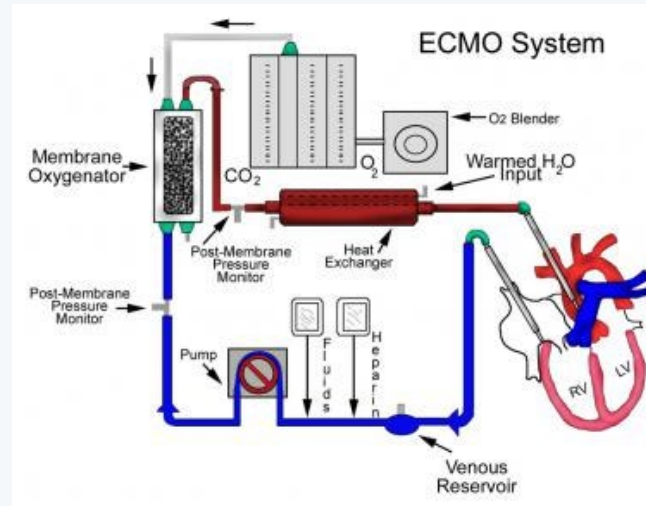
Follow advance directive

Yes

Use substituted judgment

“Agreed Upon” Framework

- Ventilators, dialysis machines, antibiotics, ECMO (Extracorporeal Membrane Oxygenation), etc. have **saved, improved and extended the lives of many**; other times have **prolonged the dying process**.
- For example, **ventilator** can help someone with a collapsed lung or curable pulmonary disease. But for someone with ALS, it increases “the anguish of slow suffocation.”
- CPR can save a patient. But, CPR on an elderly patient who has suffered a major heart attack often results in cracked ribs or restoring an oxygen-deprived brain to a vegetative state.



Technology – Save / Prolong Life

- ***Euthanasia*** occurs when a **physician administers a lethal injection or intravenous (IV) drug to a patient**, resulting in death soon after the administration of the drug.
 - Death occurs as a direct result of administering the lethal injection or IV drug, usually within minutes.
 - Euthanasia is illegal in the United States
- ***Physician Aid-in-Dying (PAD)*** occurs when a **physician prescribes a lethal drug to a terminally ill patient**.
 - Most states in which PAD is legal specify only patients with < 6 months to live may request.
 - Patient fills their prescription at a pharmacy, and is free to take the drug at any point thereafter.
 - Prescribing physician does not need to be (usually is not) present when patient takes the drug, and dies.
 - Death occurs as a direct result of ingesting the prescribed drug, usually within minutes.

PAD/Euthanasia

- **Life Support Termination** occurs when **someone** (who does not need to be a physician) **withdraws life-sustaining devices** for the purpose of ending a patient's life.
 - withdrawing respiratory assistance (e.g. vent); withdrawing nutrition and hydration.
 - death may occur several minutes, hours, or even days (months, years) after terminating life support. death occurs naturally as a result of disease rather than as a direct result of a lethal drug.
 - Life-support termination is legal, and a common practice in US hospitals.
 - Patients have the right to refuse and withdraw life-sustaining treatment, letting illness “take its course”
 - Also called Passive Euthanasia (confusing)
- PAD, Euthanasia, and Removal of LST are classified as **voluntary, involuntary, or nonvoluntary**
 - **voluntary** when death is hastened or care is withdrawn at the request of a competent patient
 - **involuntary** when against a patient's expressed wishes not to hasten their death (this is akin to murder)
 - **nonvoluntary** when the patient is unable to participate in the decision to hasten death (e.g. coma, PVS).

Removal of LST

- **Can let person die (withhold or remove LST)** in clinical/medical practice
- **Death with Dignity/PAD** legal: Netherlands, Switzerland, Germany, Australia (Victoria), Belgium, Canada, Colombia, US states mentioned below
- Washington, D.C., Colorado, Oregon, Hawaii, Washington, Vermont, Maine (Starting 1 January 2020), New Jersey, California, one county in New Mexico, and is de facto legal in Montana.
- **Euthanasia** legal: Netherlands, Belgium, Canada, Colombia, Switzerland, Luxembourg, parts of Australia.
 - Legal in Canada (PAE and PAD) (Bill C-14, June 2016). Restrictions similar to DWD.
 - Illegal in US.
 - Belgium – permits pediatric euthanasia