Shifting Boundaries of Viability: Ethics, Innovation, and the Overton Window in the Care of Extremely Preterm Infants

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0910 – 1010 ET

Presenter

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- Army Lt. Col. Jeanne Krick, MD, MA, FAAP is the Program Director of the Neonatology-Perinatology Fellowship at the San Antonio Uniformed Services Health Education Consortium (SAUSHEC).
- She currently serves as the Consultant the Surgeon General of the Army for Medical Ethics, the Chair of the Ethics Committee for Brooke Army Medical Center, and the Associate Course Director of the pre-clerkship medical ethics course at Uniformed Services University of the Health Sciences (USUHS).
- Lt. Col. Krick was commissioned into the Army through the United States Military Academy in 2008, where she completed her B.S. in Life Sciences. She received her medical education at USUHS (2012), completed a residency in Pediatrics at Madigan Army Medical Center (2015), and a fellowship in Neonatology-Perinatology at the University of Washington (2018). She also completed a fellowship in Pediatric Bioethics through the Treuman Katz Center for Pediatric Bioethics (2018) and a Masters in Bioethics and Humanities at the University of Washington (2018).
- She is active in research in military medical ethics, parent-physician communication, periviability ethics, and medical ethics education.

Disclosures

- Army Lt. Col. Jeanne Krick has no relevant financial or non-financial relationship(s) relating to the course content or with ineligible companies to disclose.
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Learning Objectives

At the conclusion of this activity, participants will be able to:

1. Describe the ethical debates surrounding resuscitation at extremely premature gestational ages.
2. Explore how uncertainty affects decision-making for these infants.
3. Recognize the potential for bias when counseling at extremely premature gestational ages and mitigation strategies.

Care of Newborns - A Little History

- Before the 20th Century
  - Born at home
  - No dedicated care
- Infant Welfare Movement
  - Shifting views on moral status
- Early treatments
  - Incubators
  - Gavage feeding

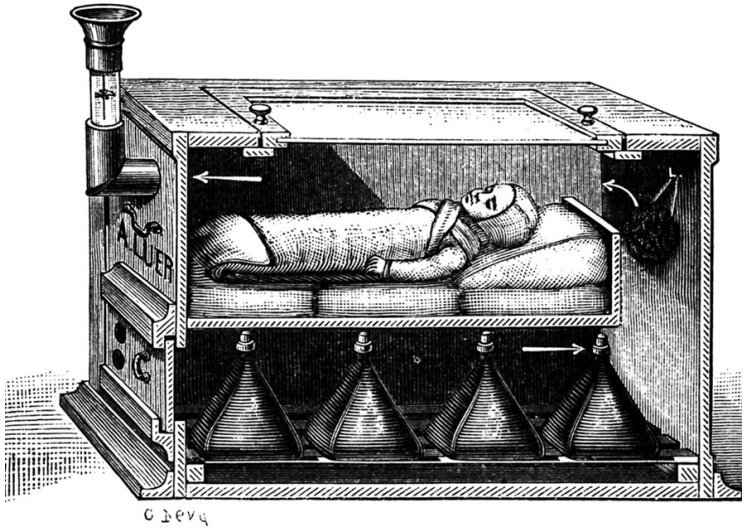


Image of an early infant incubator (1883)

Neonatology - An Evolving Field

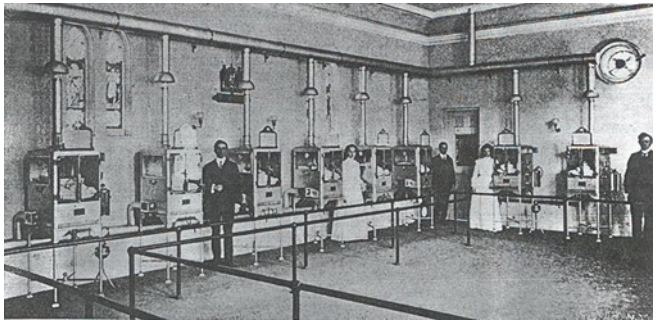


Image of infants in incubators as a sideshow

Image of Patrick Bouvier Kennedy Memorial

Image of Virginia Apgar

Image of premature baby

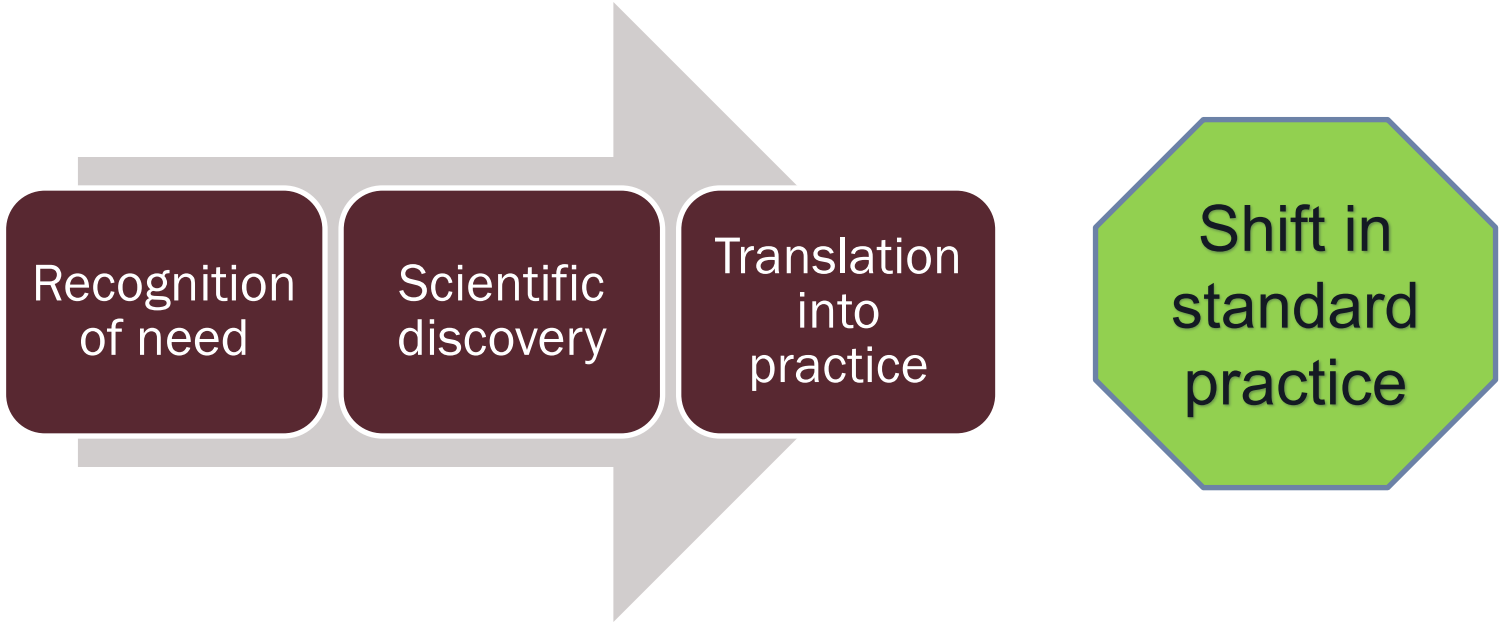


Image source: J Krick, MD

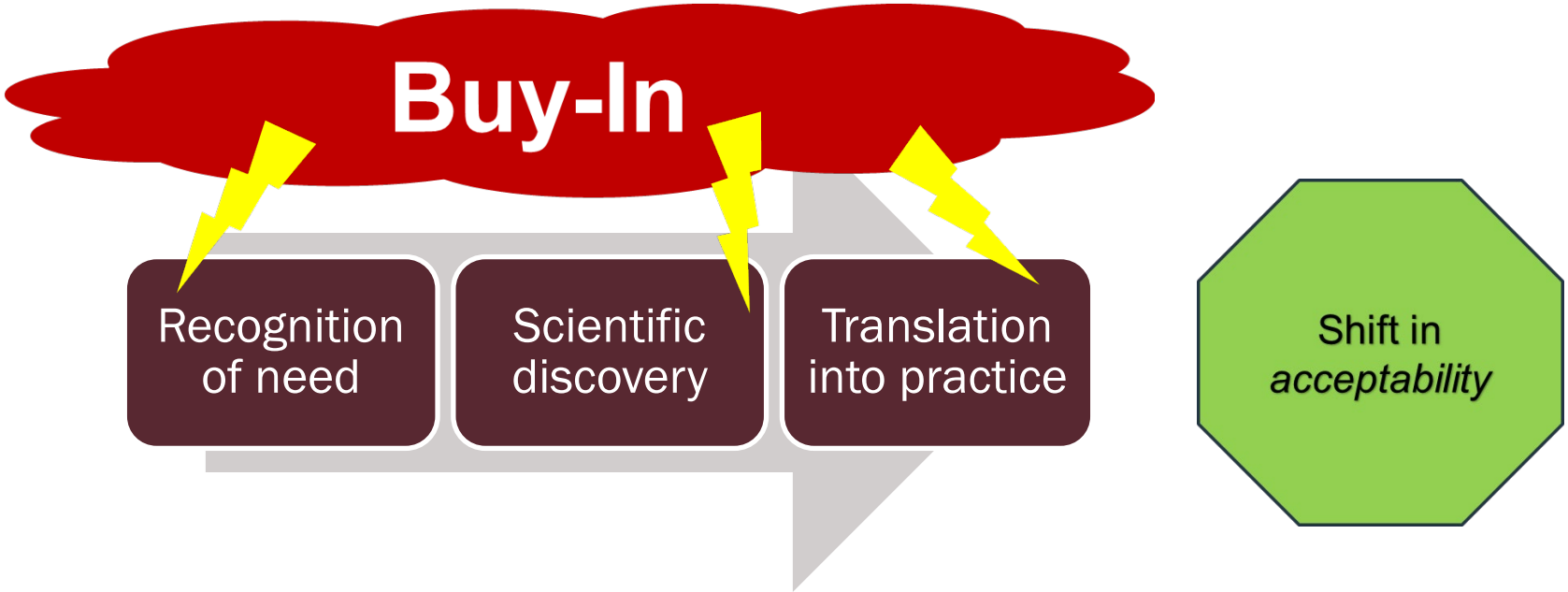
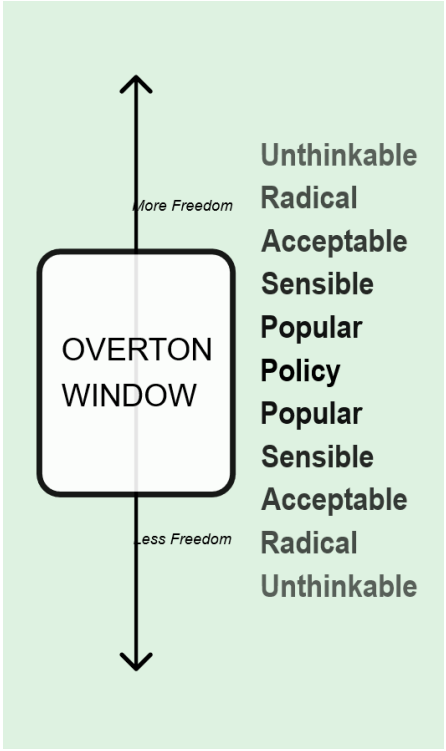


Image source: J Krick, MD

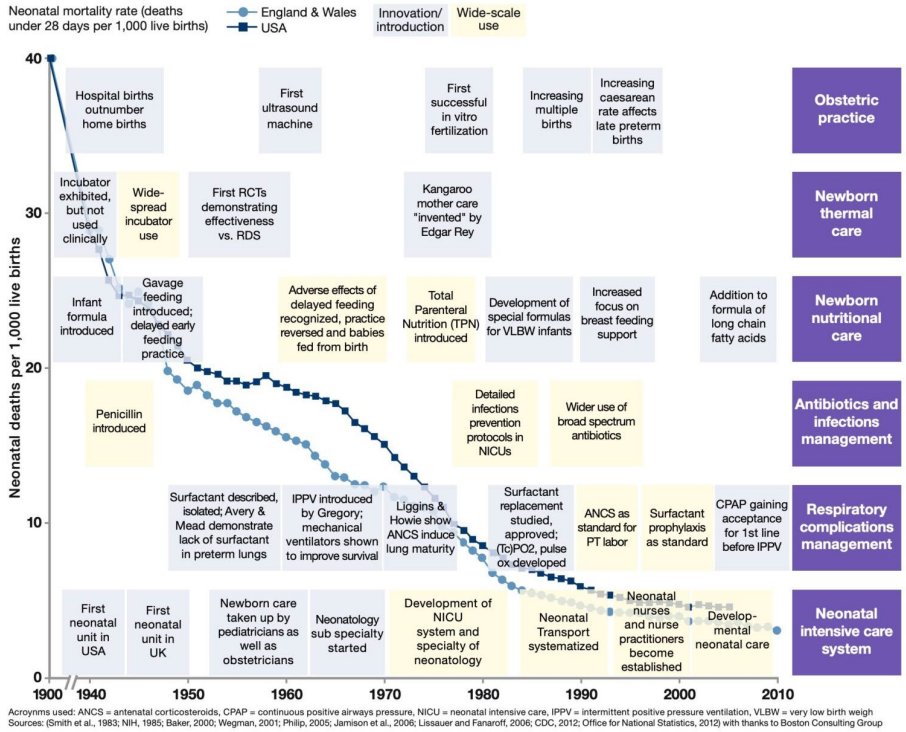
Overton Window

- Public policy
- Range of acceptable ideas/practices
- Shifts over time
  - Public awareness
  - Advocacy
  - Changing perceptions



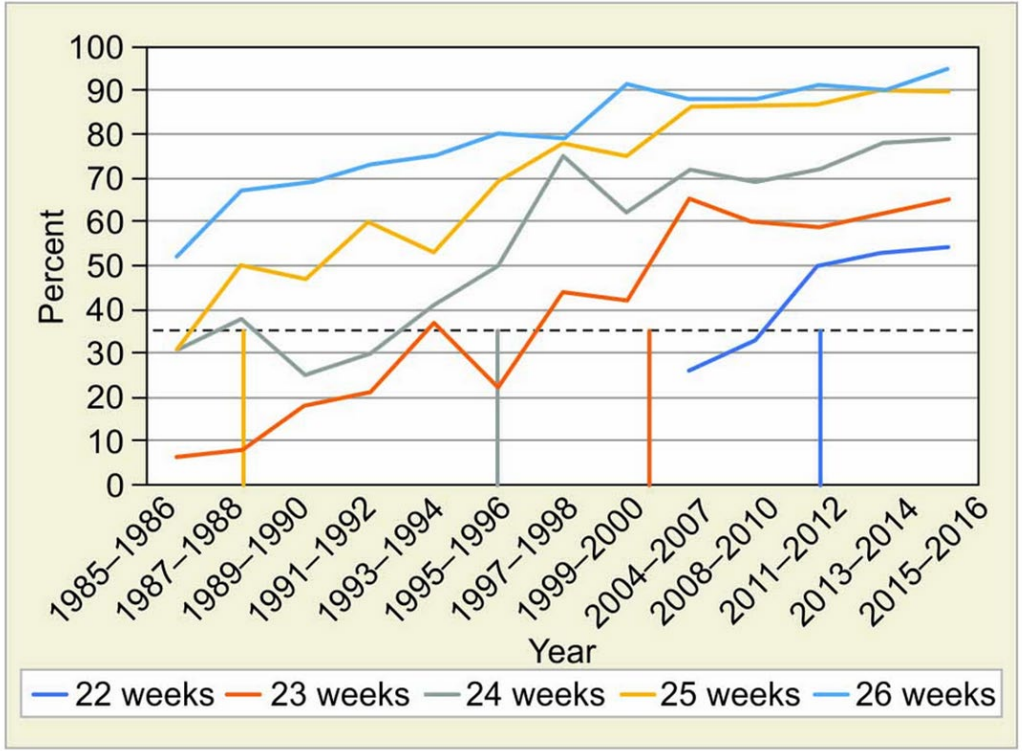
(Krick et al., 2023)

Neonatal Advances

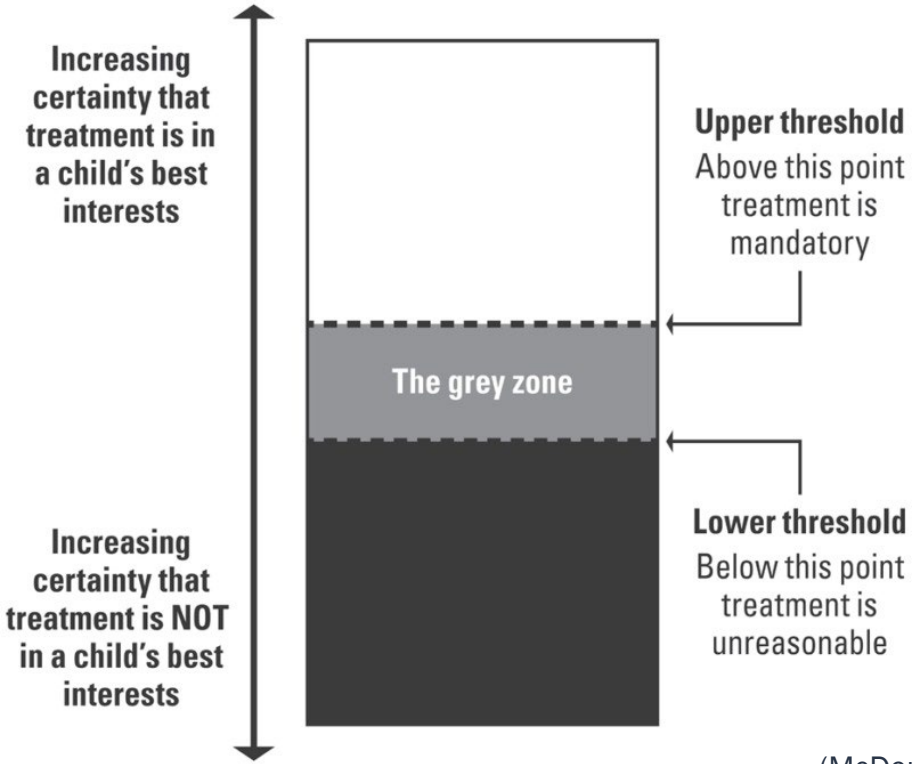


(https://neonatology.net/history/neonatology-timeline/)

Survival at Periviable Ages

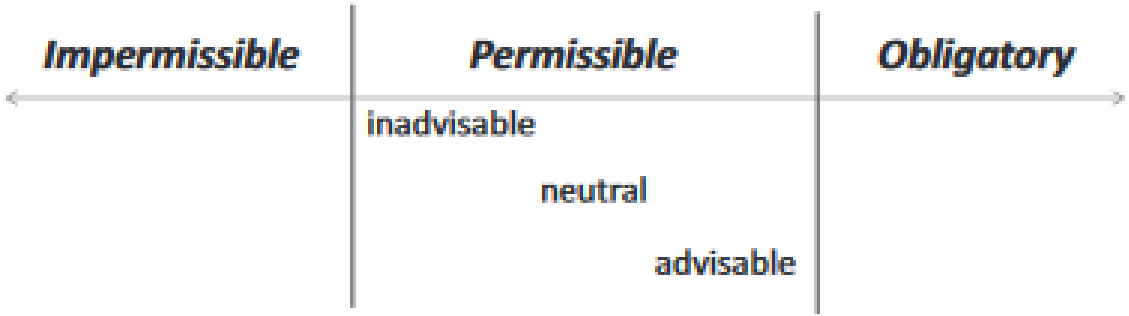


(Stanojevic, 2023)



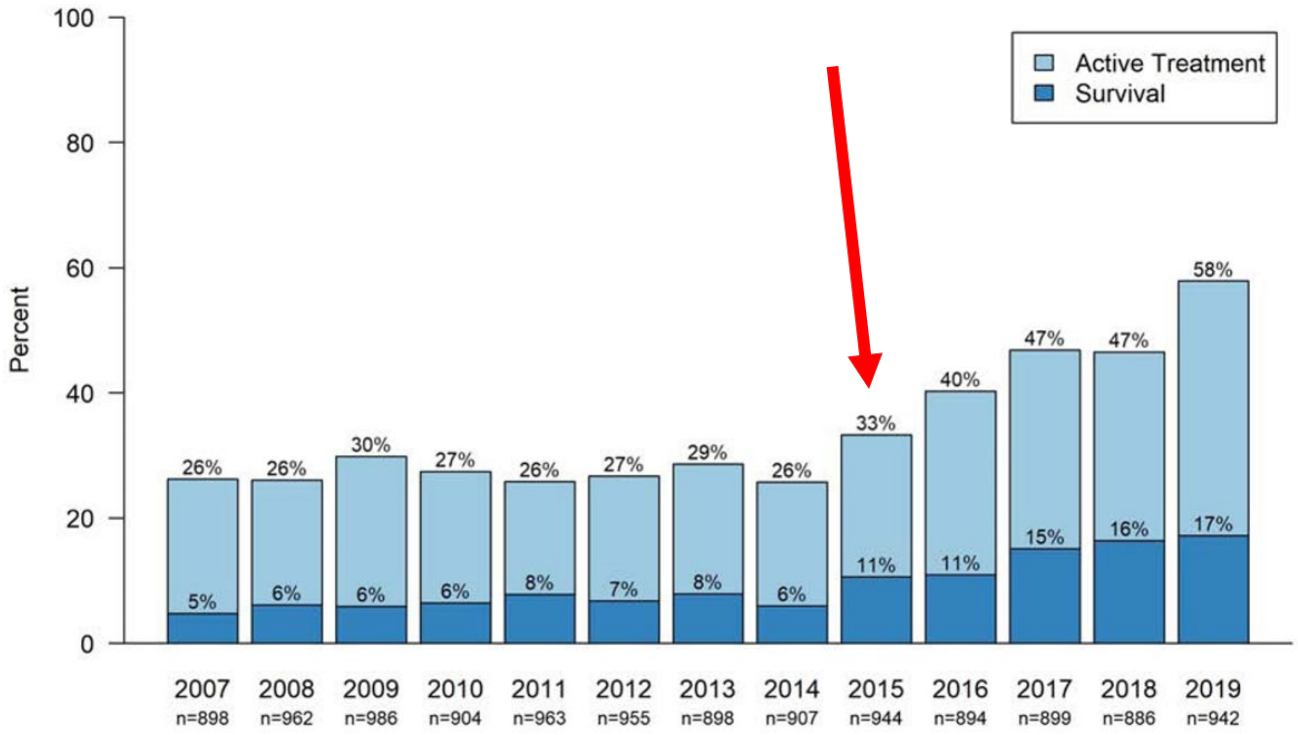
(McDougall et al., ed. adapted from Wilkinson 2012)

I-P-O Framework



(Mercurio & Cummings, 2021)

Outcomes and Treatment for Infants Born at 22 Weeks



(Rysavy et al.,2021)

CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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Antenatal Counseling Regarding Resuscitation and Intensive Care Before 25 Weeks of Gestation

James Cummings, MD, FAAP, COMMITTEE ON FETUS AND NEWBORN

abstract The anticipated birth of an extremely low gestational age (<25 weeks) infant presents many difficult questions, and variations in practice continue to exist. Decisions regarding care of periviable infants should ideally be well informed, ethically sound, consistent within medical teams, and consonant with the

(Cummings, 2015)

AAP Guidance - August 2015

- Antenatal Counseling Regarding Resuscitation and Intensive Care Before 25 Weeks of Gestation- Cummings and Committee on Fetus and Newborn (2015)
  - Fetal gestational age is imprecise
  - 22 weeks is generally accepted as the lower threshold of viability
  - Outcomes in individual cases are difficult to predict and vary from center to center
  - Due to the uncertainty for infants 22-24 weeks, it is reasonable that decision-making regarding delivery room management be individualized and family centered
  - Promotes joint discussions between parents and both obstetrics (OB) and Neonatal Intensive Care Unit (NICU)

Meet the Most Premature and Smallest Babies Ever Born

Learn about some of the tiniest preemies, including the smallest baby ever born. These are kids who defied the odds stacked against them.

Parents Magazine

Viable at 22 Weeks: Just How Low Can Preemies Go?

Time Magazine

UAB Hospital delivers record-breaking premature baby

UAB News

Premature births: Baby born at 22 weeks survives against odds

BBC News

'She's a miracle': Saint Luke's youngest surviving NICU baby heads to 2nd grade

KSHB News

NICU Admission by Gestational Age

Table 1. Standardized NICU Admissions by Gestational Age and Year, 2008-2021

	No. of NICU admissions/1000 extremely preterm birth admissions								
Gestational age, wk	2008-2009	2010-2011	2012-2013	2014-2015	2016-2017	2018-2019	2020-2021	Change, %[a]	*P* value[b]
<22	0.4	0	0.3	0.3	0.5	1.2	1.7	284	<.001
22	6	7	8	8	17	28	28	388	<.001
23	69	61	78	79	80	87	92	32	<.001
24	145	135	136	137	134	134	134	−8	.07
25	166	156	150	160	148	144	158	−5	.01
26	175	175	180	170	178	173	164	−6	.11
27	186	213	207	202	201	200	199	7	.77
28	253	253	241	244	242	234	225	−11	<.001

(Rysavy et al., 2024)

NICU Admission by Gestational Age (continued)

Table 1. Standardized NICU Admissions by Gestational Age and Year, 2008-2021

	No. of NICU admissions/1000 extremely preterm birth admissions								
Gestational age, wk	2008-2009	2010-2011	2012-2013	2014-2015	2016-2017	2018-2019	2020-2021	Change, %[a]	*P* value[b]
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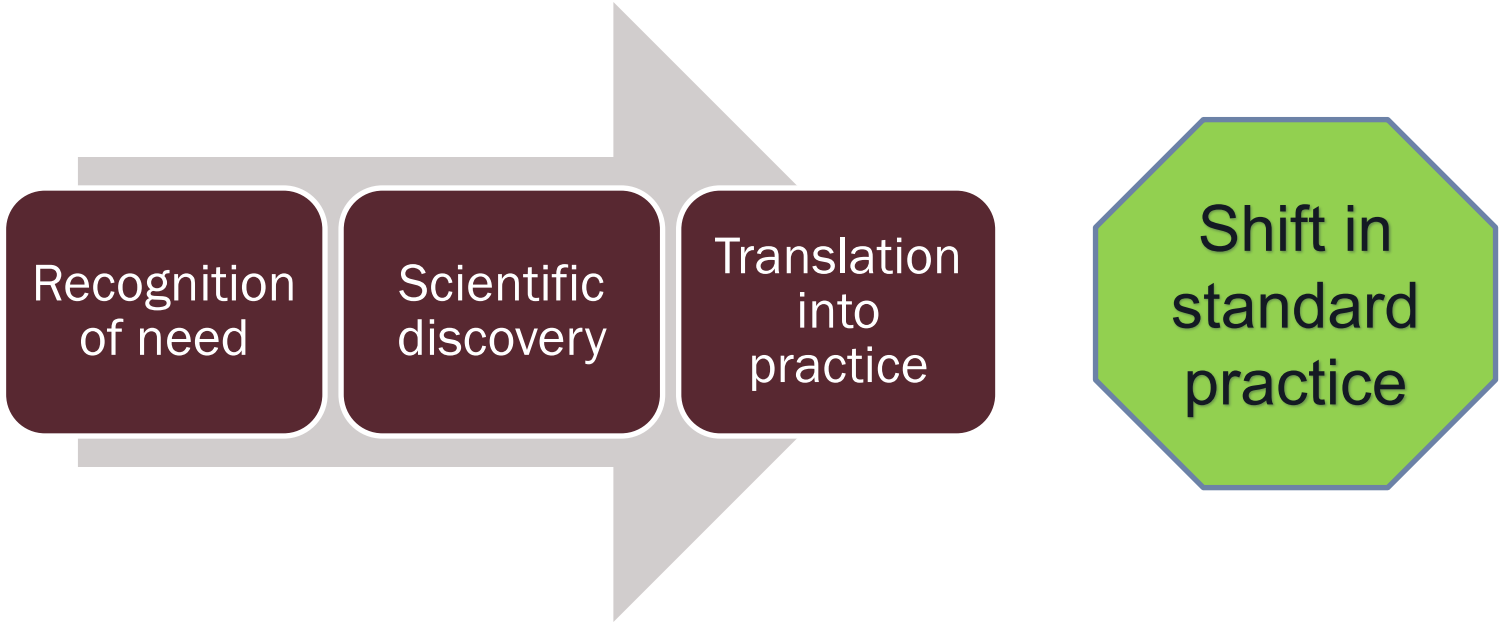
22	6	7	8	8	17	28	28	388	<.001
23	69	61	78	79	80	87	92	32	<.001
24	145	135	136	137	134	134	134	−8	.07
25	166	156	150	160	148	144	158	−5	.01
26	175	175	180	170	178	173	164	−6	.11
27	186	213	207	202	201	200	199	7	.77
28	253	253	241	244	242	234	225	−11	<.001

(Rysavy et al., 2024)

Rise of the 22-week Question

1. Outcomes of 22-weekers over time – from Japan in 1990s to Iowa in the 2010s
2. 2015 American Academy of Pediatrics (AAP) Clinical Report
3. 2015 National Institute for Child Health and Development (NICHD) outcome data in New England Journal of Medicine (NEJM)
   - Continued work of Matt Rysavy
   - Teamwork in Iowa
4. Shifting practices, narratives of survivors and their parents



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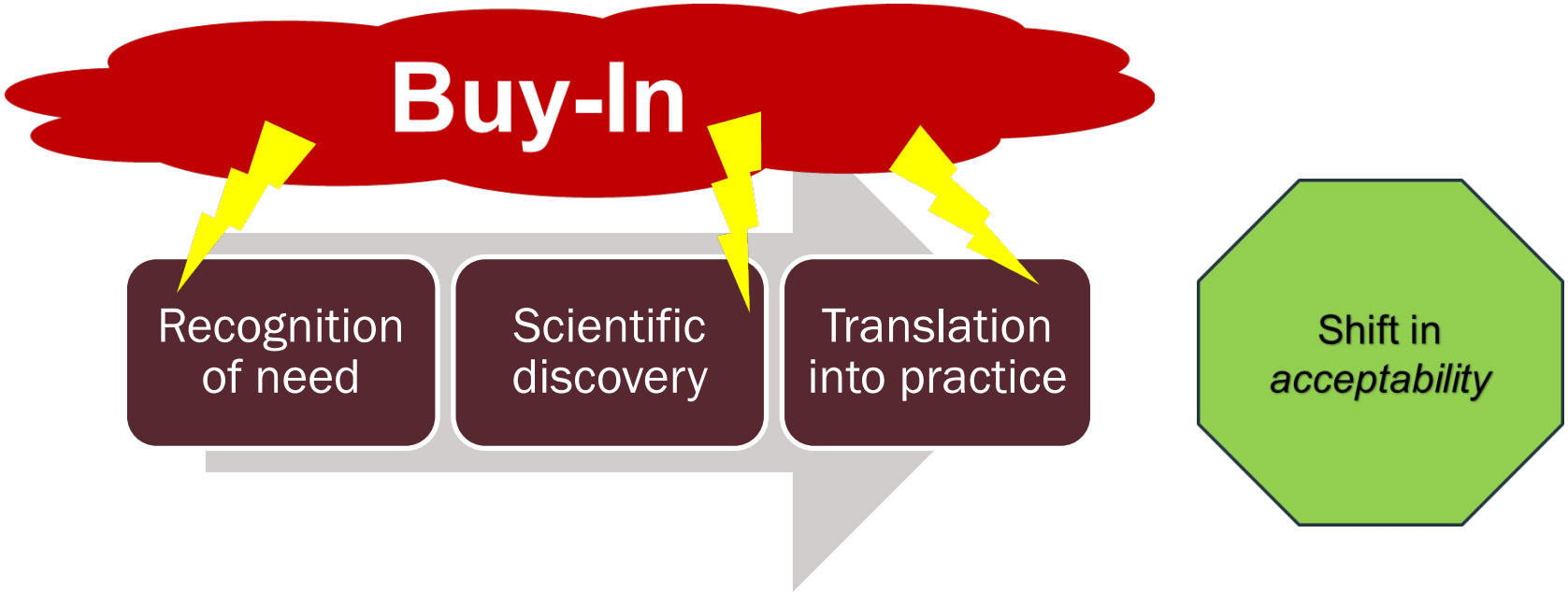

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What goes into buy-in?

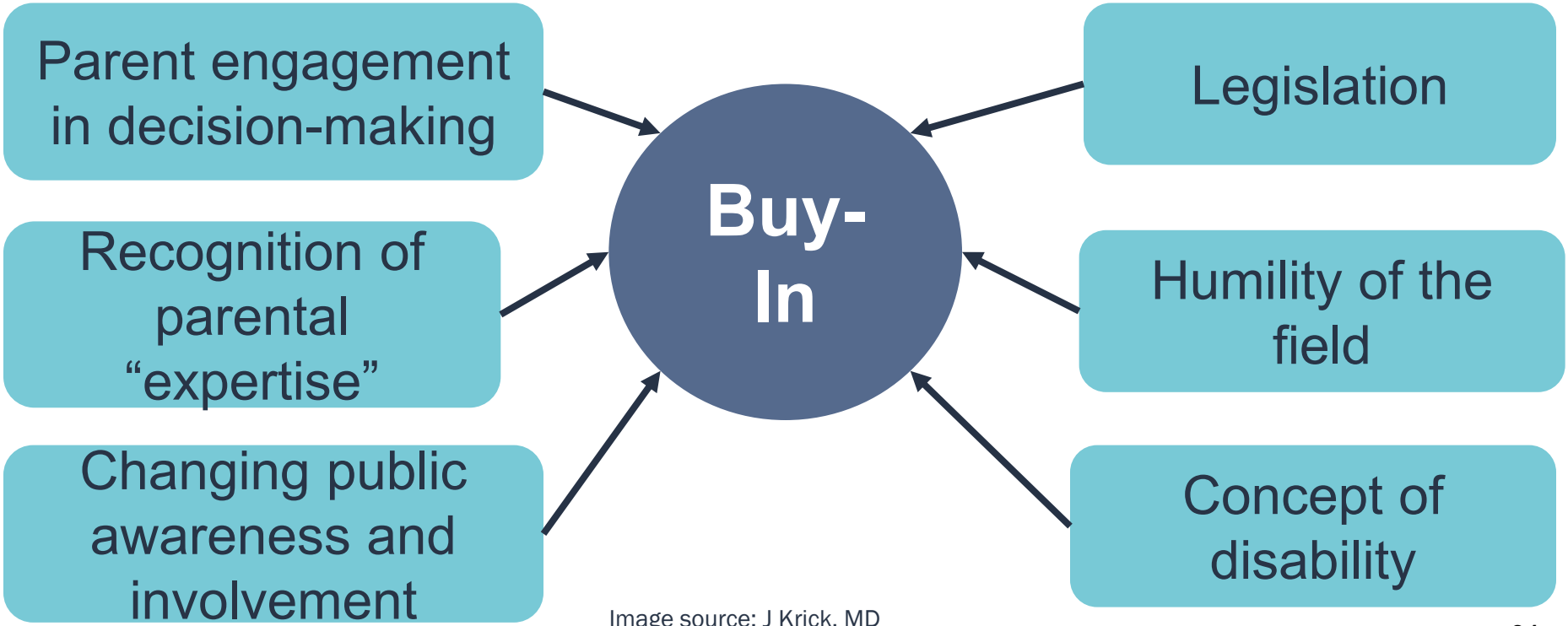
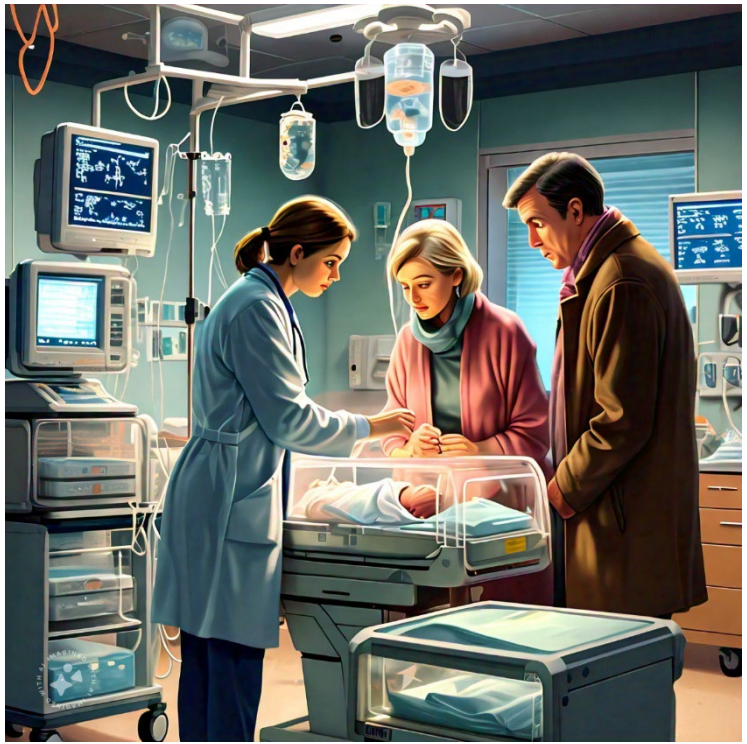


Image source: J Krick, MD

Look Towards the Future

- Role of Neonatologists
  - Gatekeepers or partners
- Advocacy
- Shared Decision Making (SDM) on a policy scale
- Parental involvement in setting priorities
  - Research
  - Treatment
- A contemporary breakthrough



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asked a question .

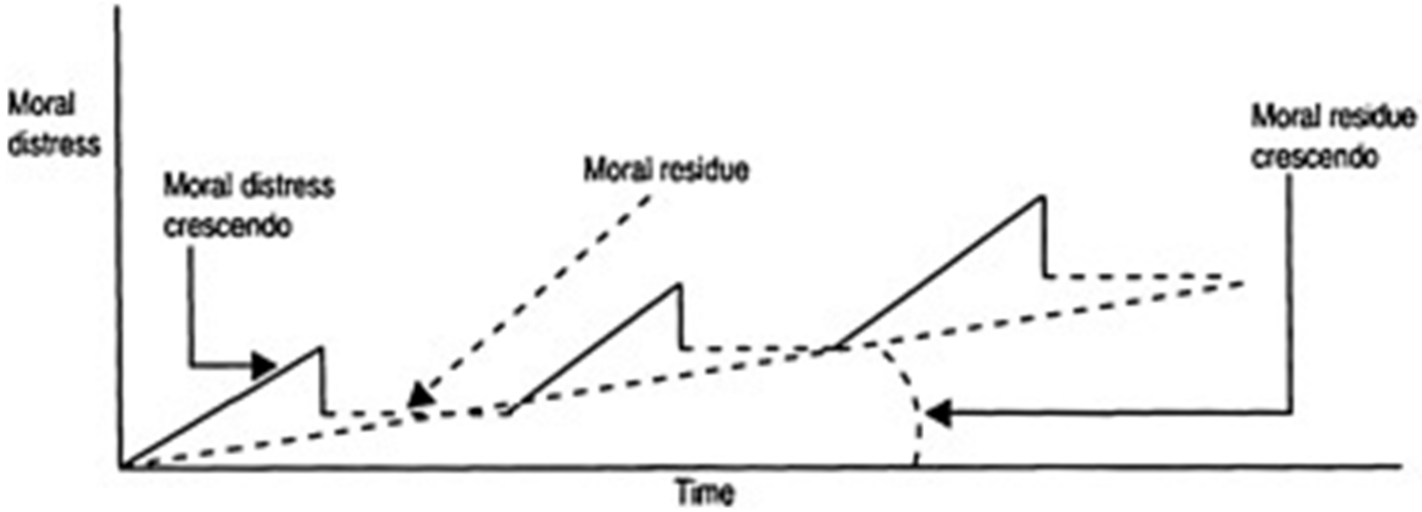
arch 25 at 8:42 PM ·

Anonymous post:

I am really struggling with our hospital's new move to resuscitating 22 weekers. I know we can, but I see no end to this and feel like we just keep pushing boundaries aka people. I totally get it's not my child or my decision but then I just feel like an empty vessel not allowed to have thoughts on this and expected to perform whatever tasks others need me to do. I don't understand historically why Japan opened the store and now it does a great job and now it's become the standard to strive for. I know this sounds harsh and awful. Believe me, I'm one of you and in awe of what we do, but this is really pushing my buttons. Tell me honestly, is it time for me to think about exiting neonatology? Is there a place for people who feel like me?

8

8 Answers



(Epstein & Hamric, 2009)

Physiologic futility: There is no reasonable expectation in deliberative clinical judgment that the usually expected physiologic outcomes of an intervention will occur. The outcome should be specified precisely, e.g., restoration of spontaneous circulation from cardiopulmonary resuscitation.

Imminent-demise futility: The patient is expected to die during current admission and not recover interactive capacity beforehand.

Overall futility: The patient is reliably expected to survive but has irreversibly lost interactive capacity.

Quality-of-life futility: The patient's reliably expected functional status will not support engagement in life tasks valued by the patient or enough satisfaction from engaging in valued life tasks.

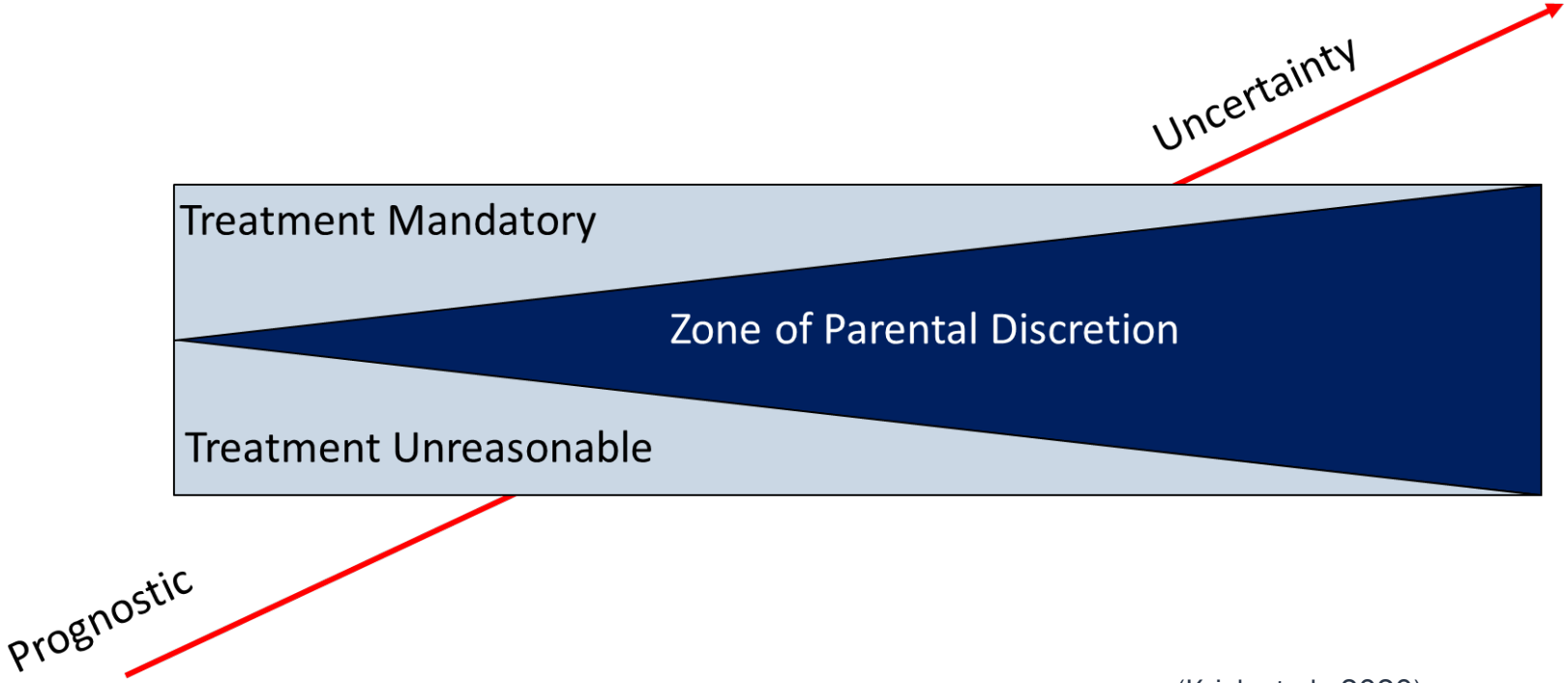
The Danaides (1903), a Pre-Raphaelite interpretation by John William Waterhouse

(Chervenak & McCullough, 2013)

Table 2. Survival of Infants Born at 22-28 Weeks' Gestational Age in 2013-2018 for All Infants and Infants Actively Treated at Birth

	No./total (%), by gestational age, in weeks									
	2013-2018								2008-2012[a]	Adjusted difference (95% CI)[b]
Survival	22	23	24	25	26	27	28	22-28	22-28	
All infants										
No.	550	1083	1398	1604	1836	1987	2419	10 877	8877	
Survived >12 h	159 (28.9)	856 (79.0)	1298 (92.8)	1546 (96.4)	1788 (97.4)	1943 (97.8)	2376 (98.2)	9966 (91.6)	8034 (90.5)	0.1 (−0.3 to 0.6)
Survived to discharge or 1 y[c]	60/549 (10.9)	535/1083 (49.4)	972/1391 (69.9)	1266/1599 (79.2)	1608/1835 (87.6)	1787/1979 (90.3)	2267/2412 (94.0)	8495/10 848 (78.3)	6746/8877 (76.0)	2.0 (1.0 to 2.9)
Discharged home	56/549 (10.2)	520/1083 (48.0)	948/1391 (68.2)	1245/1599 (77.9)	1582/1835 (86.2)	1772/1979 (89.5)	2259/2412 (93.7)	8382/10 848 (77.3)		
Remained in hospital at 1 y	4/549 (0.7)	15/1083 (1.4)	24/1391 (1.7)	21/1599 (1.3)	26/1835 (1.4)	15/1979 (0.8)	8/2412 (0.3)	113/10 848 (1.0)		
Infants actively treated at birth[d]										
No.	201	958	1369	1589	1827	1976	2400	10 320		
Survived >12 h	159 (79.1)	856 (89.4)	1298 (94.8)	1546 (97.3)	1788 (97.9)	1943 (98.3)	2375 (99.0)	9965 (96.6)		
Survived to discharge or 1 y[c]	60/200 (30.0)	535/958 (55.8)	972/1362 (71.4)	1266/1584 (79.9)	1608/1826 (88.1)	1787/1968 (90.8)	2266/2393 (94.7)	8494/10 291 (82.5)		
Discharged home	56/200 (28.0)	520/958 (54.3)	948/1362 (69.6)	1245/1584 (78.6)	1582/1826 (86.6)	1772/1968 (90.0)	2258/2393 (94.4)	8381/10 291 (81.4)		
Remained in hospital at 1 y	4/200 (2.0)	15/958 (1.6)	24/1362 (1.8)	21/1584 (1.3)	26/1826 (1.4)	15/1968 (0.8)	8/2393 (0.3)	113/10 291 (1.1)		

(Bell et al., 2022)



(Krick et al., 2020)

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ARTICLE

Values Parents Apply to Decision-Making Regarding Delivery Room Resuscitation for High-Risk Newborns

Renee D. Boss, MD[a], Nancy Hutton, MD[a], Leslie J. Sulpar, MSN[a], Anna M. West, MHS[b], Pamela K. Donohue, ScD, PA-C[a,c]

[a]Department of Pediatrics, School of Medicine, and
Health, Johns Hopkins University, Baltimore, Maryla

The authors have indicated they have no financial relationships

What's Known on This Subject

Many parents of high-risk newborns desire to collabor
making regarding resuscitation. Physicians emphasiz
counseling families in such situations. What informatior
during decision-making is not clear.

ABSTRACT

OBJECTIVE. The aim of this study was t
delivery room resuscitation for inf
tially lethal congenital anomalies.

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ORIGINAL ARTICLES

Antenatal Consultations at Extreme Prematurity: A Systematic Review of Parent Communication Needs

Ashraf Kharrat, MD, BSc, FRCPC[1], Gregory P. Moore, MD, FRCPC[1], Stéphanie Beckett, BSc[2], Stuart G. Nicholls, PhD, MRes, MSc, BSc(Hons)[2], Margaret Sampson, MLIS, PhD, AHIP[3], and Thierry Daboval, MD, MSc, FRCPC[1]

Objective To synthesize and describe parental expectations on how healthcare professionals should interact with them during a peripartum, antenatal consultation for extremely preterm infants.

Study design For this systematic literature review with textual narrative synthesis, we included studies that explored parental perspectives regarding the antenatal consultation for an extremely preterm infant. Electronic searches of Medline, CINAHL, PsycInfo, and Embase were conducted, along with a search of the grey literature. Quality appraisal was conducted using the guide by Walsh and Downe. Two independent reviewers reviewed 783 titles, of which 130 abstracts then 40 full-text articles were reviewed. Final data abstraction includes 19 studies. We predetermined 6 topics of interest (setting, timing, preferred healthcare professional, information, resources, and parents–physician interaction) to facilitate thematic analysis.

Antenatal Counseling and Shared Decision-making

Recommendations for Providers

Define the required decision

Avoid artificially dichotomization options

Determine parents' desired role in decision-making

Focus on building a partnership

Provide balanced and individualized information

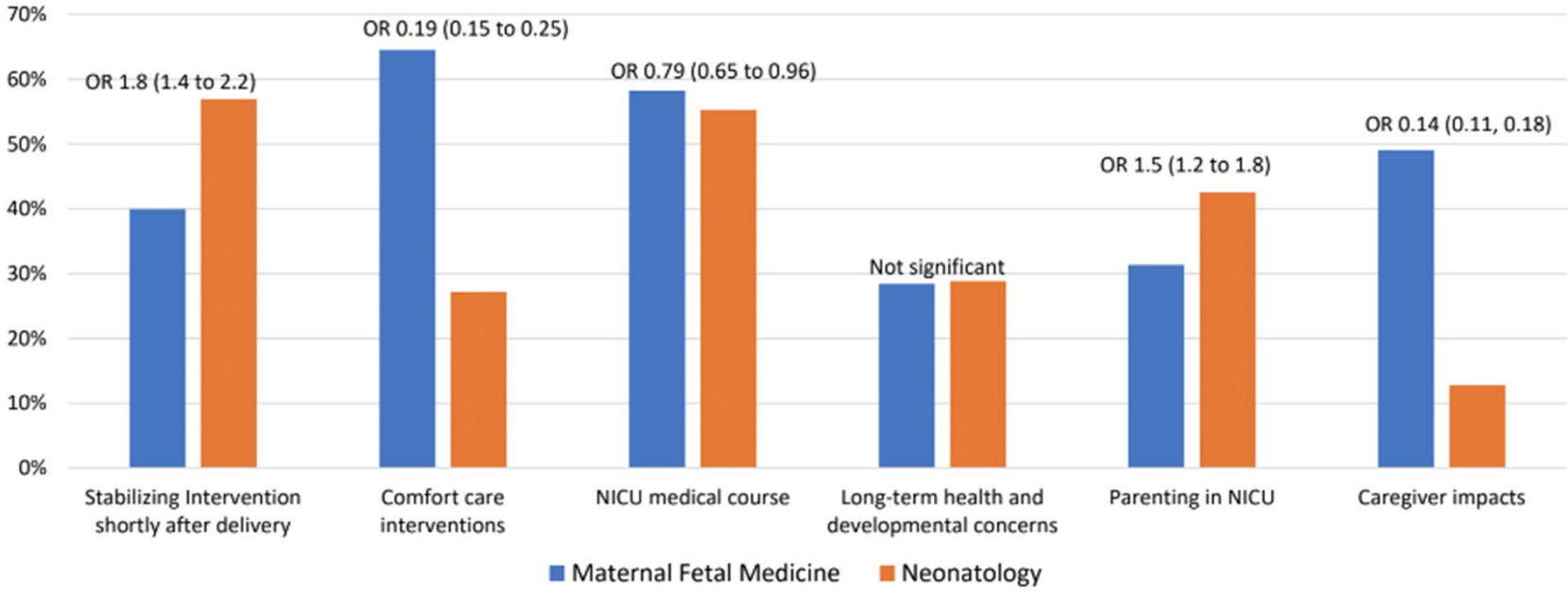
Support parents' decision-making

THE JOURNAL OF PEDIATRICS • www.jpeds.com REFLECTIONS ON ETHICS AND ADVOCACY IN CHILD HEALTH

Decision-making for extremely preterm infants: A qualitative systematic review

Jeanne A. Krick, MD, MA[1], Dalia M. Feltman, MD, MA[2,3], and Marin Arnolds, MD[4]

Information Topics Reported as "Usually" Discussed, by Specialty



(Kim et al., 2021)

Implicit or Unconscious Bias in Counseling

BIAS	EXPLANATION	EXAMPLE	COUNTER[a]
Framing effect	Decision based on information presented with positive or negative connotations	Presentation of only survival or mortality statistics during prenatal consultation	Offer balanced data (positives/negatives)
Availability bias	Decision based on most easily recalled and/or available information	Parental declination of a standard treatment (vaccine, vitamin K) based on recent story in media about isolated poor outcome related to treatment	Provide evidence-based research and guidelines
Anchoring bias	Decision that relies too heavily on one value or initial piece of information	Physician recommendation to withdraw life-sustaining technology based on intraventricular hemorrhage	Seek second opinion from relevant stakeholders (eg, family, colleagues, institution, ethics committee)
Optimism bias	Tendency to believe one is less likely to experience a negative outcome	Parental belief that their child will not develop cerebral palsy despite significant parenchymal hemorrhage	Provide facts while acknowledging uncertainty and nurturing hope
Implicit bias	Unconscious attribution of particular quality to certain social/ethnic/racial group	Offering or withholding a specific management/treatment option (eg, resuscitation at extreme prematurity, surfactant)	Use consensus-driven and evidence-based guidelines

(Sullivan & Cummings, 2020)

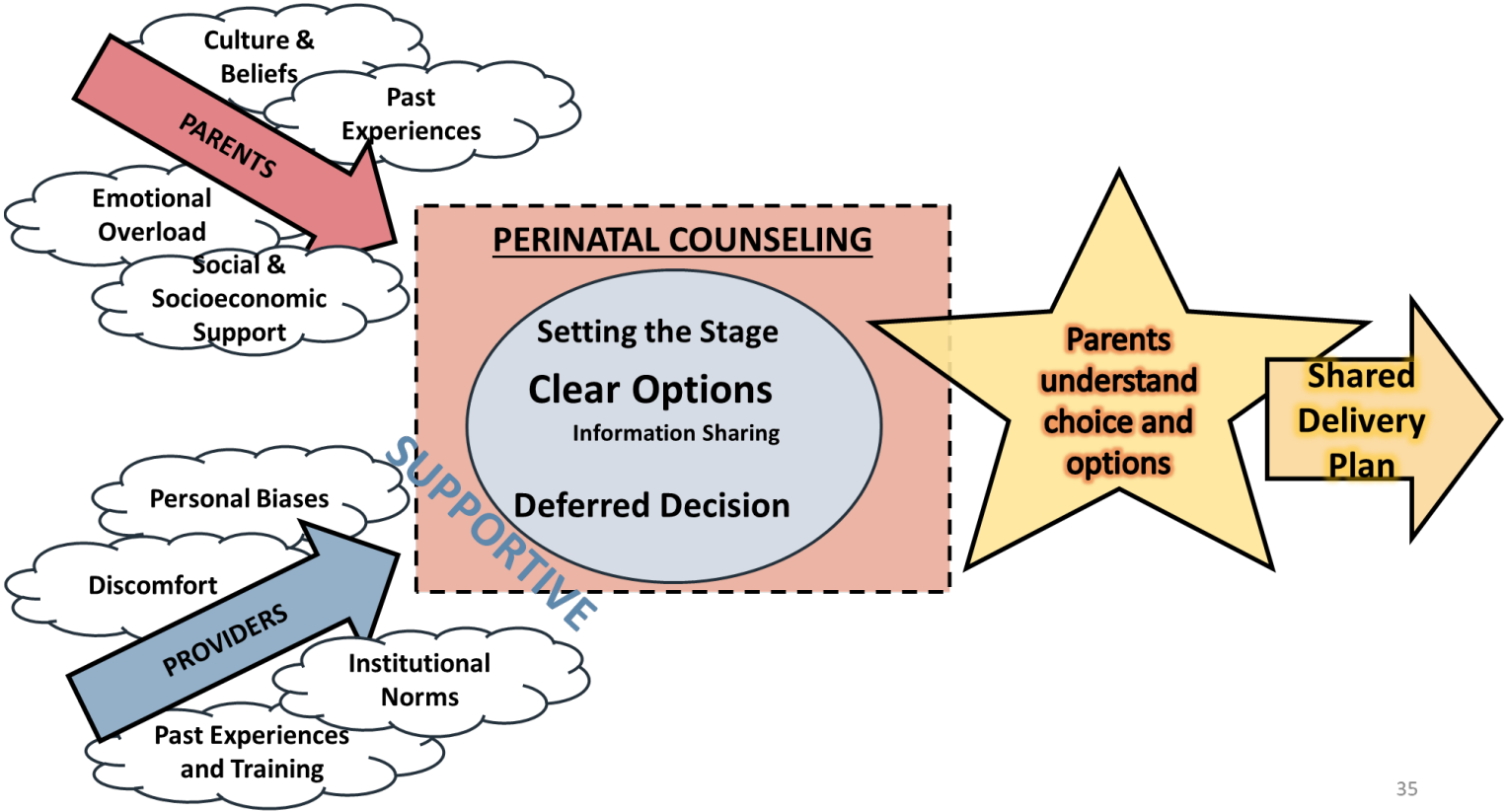


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Image source: J Krick, MD

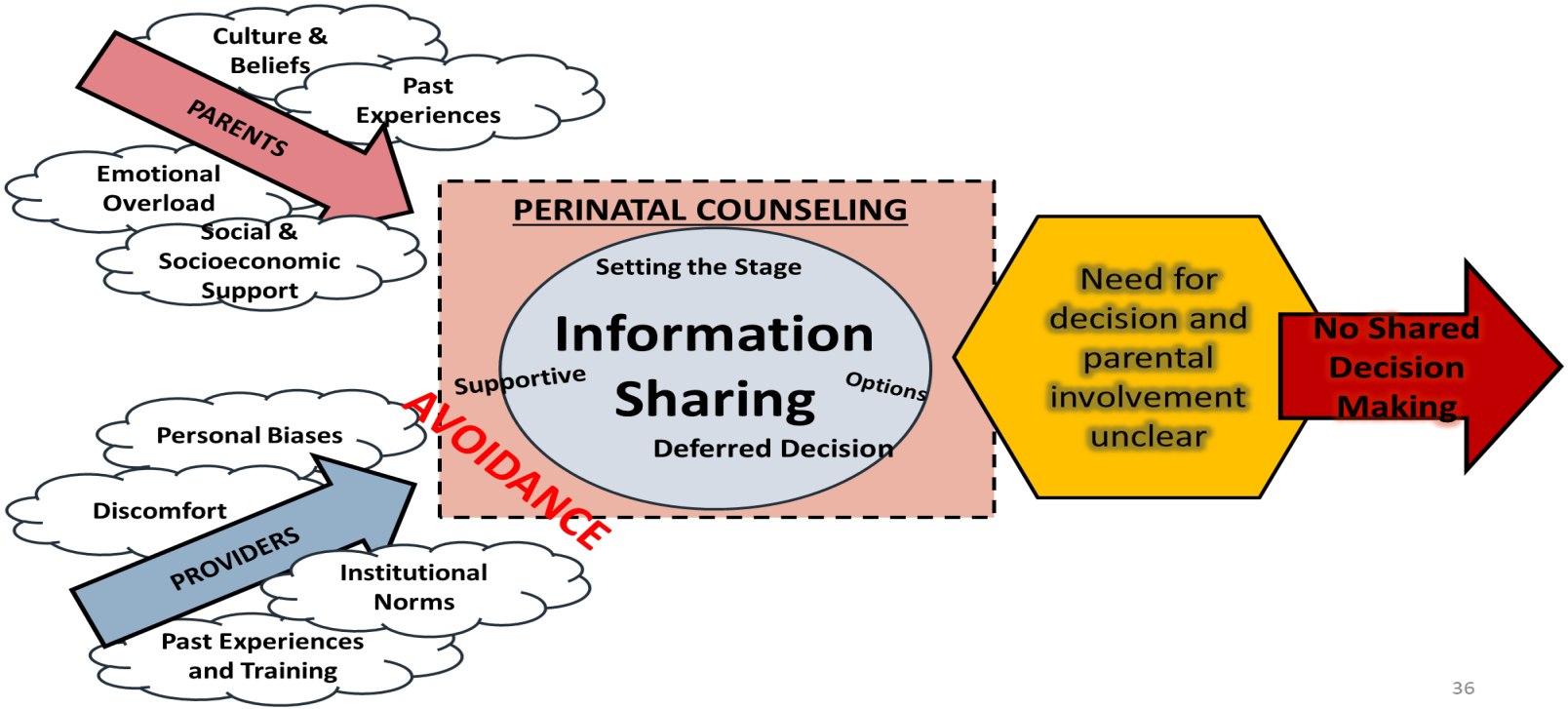

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Image source: J Krick, MD

Key Takeaways

- Know current outcomes, institutional policies/guidelines
- Acknowledge uncertainty
- Be mindful about our role in shaping the future
- Acknowledge moral distress, work to mitigate
- Shared decision-making
  - Be mindful of language, preferences
  - Elicit/construct parental values and perspectives
  - Recognize biases & mitigate
- Recognize physician/medical limitations

Thank you

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