

Communiquer en pédiatrie et en périnatalité

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CHU Sainte-Justine
*Le centre hospitalier
universitaire mère-enfant*

Pour l'amour des enfants

Faculté de médecine
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Défis multiples

- Place des parents
 - Aptitude croissante de l'enfant
 - Place de l'enfant dans le processus décisionnel
 - Protection de l'enfant
-
- → en général: une relation tripartite où la place de l'enfant est celle donnée par les parents
 - Beaucoup de situations complexes, enfant incapable de s'exprimer → « Meilleur intérêt »

Quelques défis en clinique

- Les parents qui ont des orientations qui semblent contraire au meilleur intérêt de l'enfant
- L'adolescent qui « suit » le désir de ses parents
- Le jeune enfant très mature avec une expérience de la maladie chronique
- Le nouveau-né
- Le fœtus...
- Aborder une situation humaine complexe

Décisions autour de la
naissance et en période
néonatale

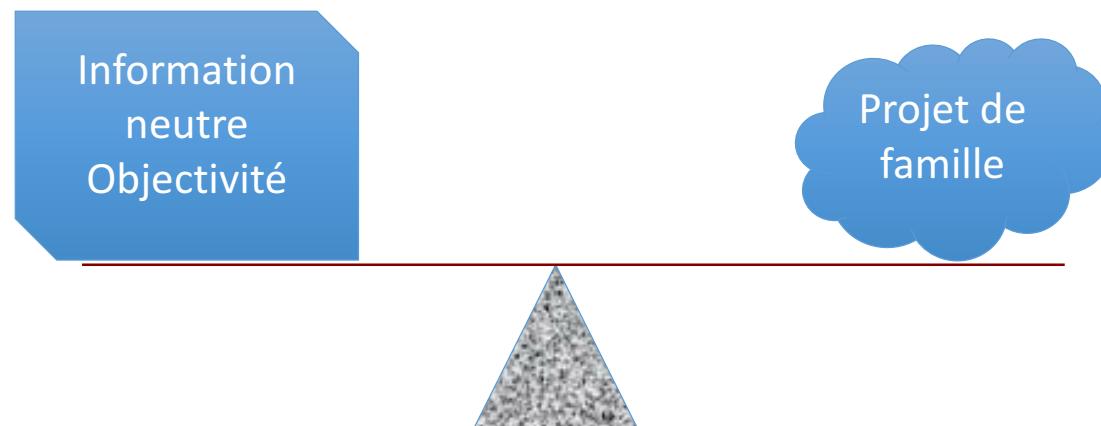
Le processus décisionnel complexe

- Années 1980-2000
 - Accent mis sur l'autonomie
 - Réaction au “paternalisme médical”
 - Vue sous la forme individualiste (autonomie libérale)
- Années 2000-2010
 - Limites de "l'autonomie libérale"
 - Elan vers le “Shared Decision Making”
 - Accent mis sur l'information
- Années 2010-...
 - Reconnaissance de l'asymétrie
 - Importance de la relation de soin

Analytical stages		Paternalistic model	Intermediate approaches	Shared model	Intermediate approaches	Informed model
Information exchange	Flow	One way (largely)		Two way		One way (largely)
	Direction	Doctor ↓ patient		Doctor ↓↑ patient		Doctor ↓ patient
	Type	Medical		Medical and personal		Medical
	Minimum amount	Legal requirement		Anything relevant for decision making		Anything relevant for decision making
Deliberation		Doctor alone or with other doctors		Doctor and patient (plus potential others)		Patient (plus potential others)
Who decides what treatment to implement?		Doctors		Doctor and patient		Patient

Comment traduire cette ambivalence dans la relation ?

Équilibre

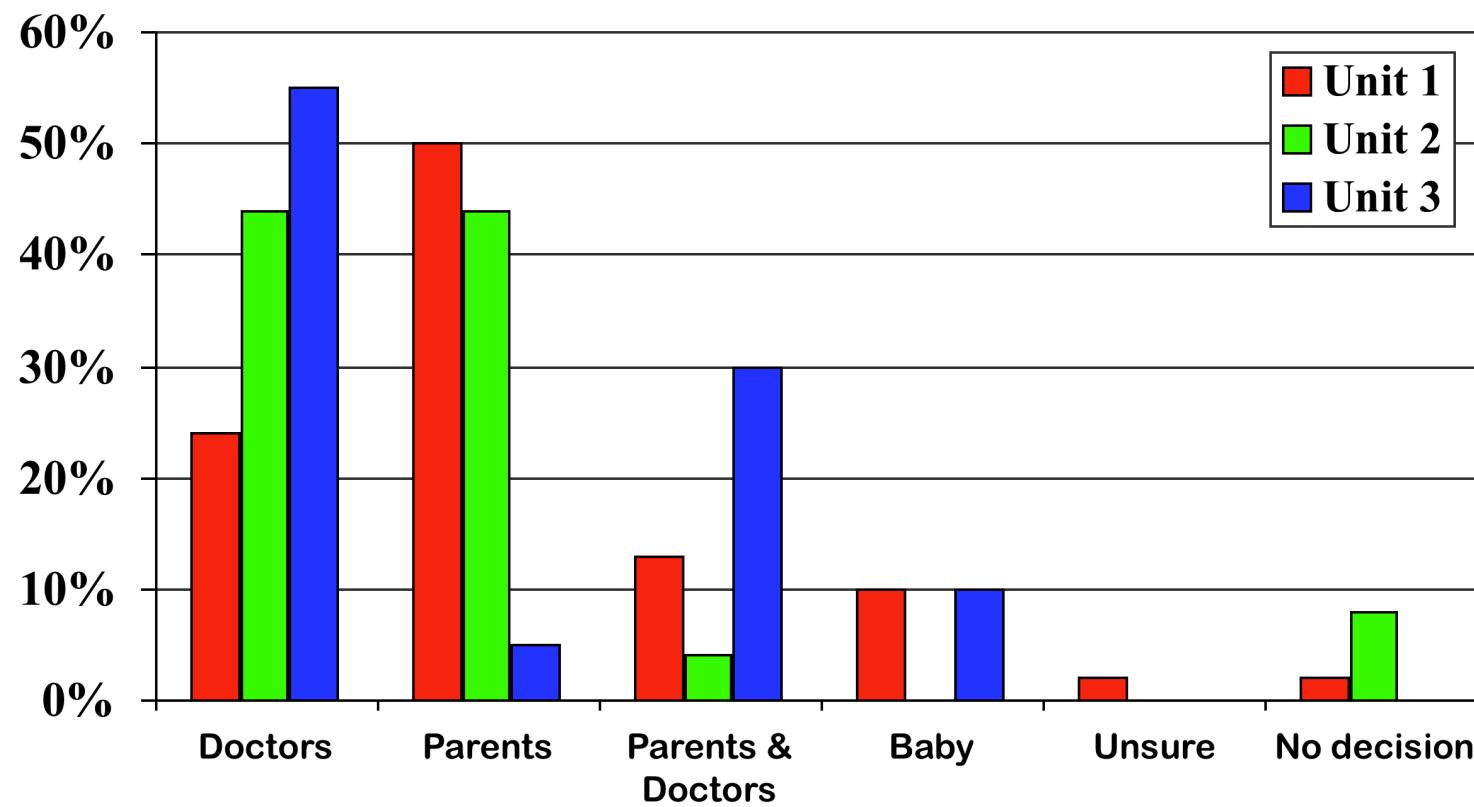


Expérience des Parents



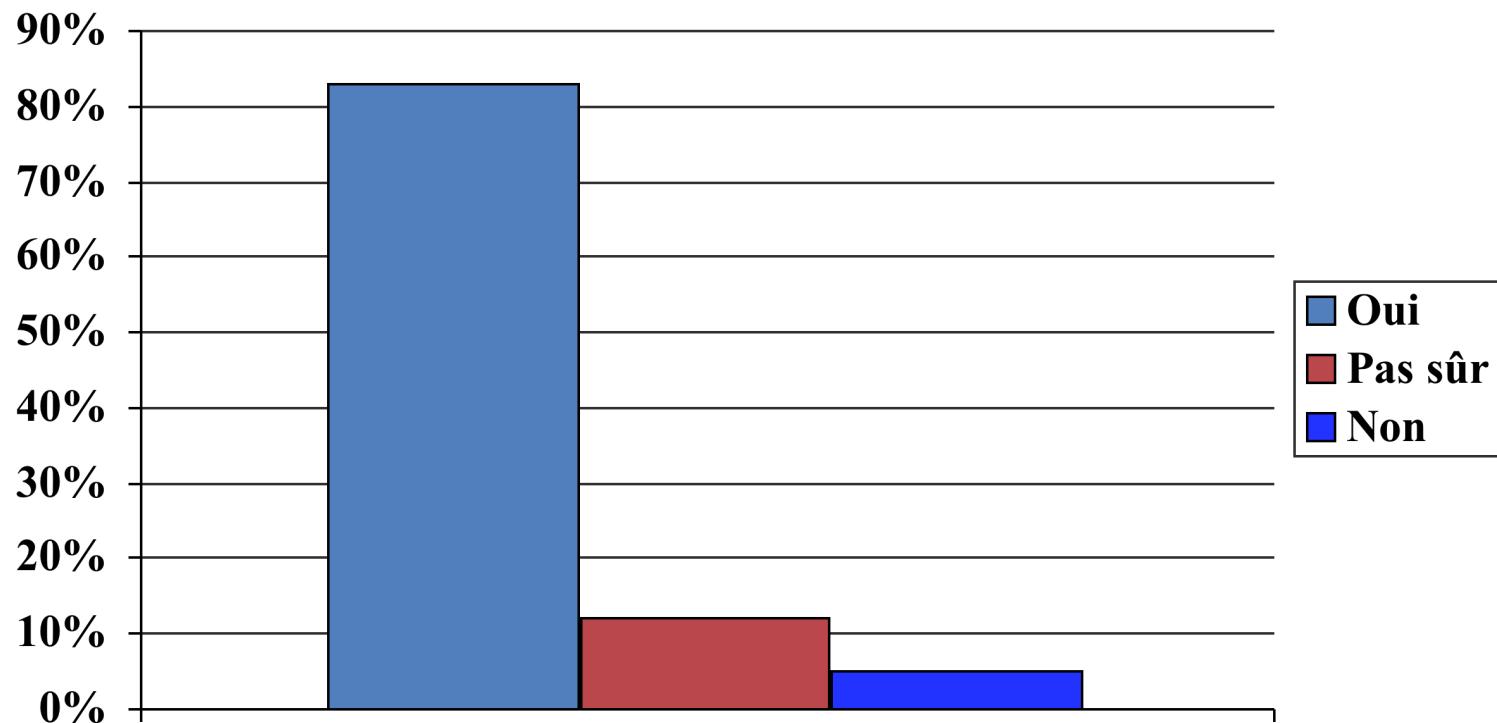
Qui décide ?	Les parents	Les parents
Alternative ?	Oui	Non
«Empowerment»	Non	Non
Responsabilité	Les parents Dilution	La nature Inéluctabilité
Suivi ψ	++ culpabilité	Deuil

Qui a décidé ? (perception des parents)



McHaffie HE, Lyon AJ, Hume R. Eur J Pediatr 2001;160(6):339-44.

Did the right people decide ?



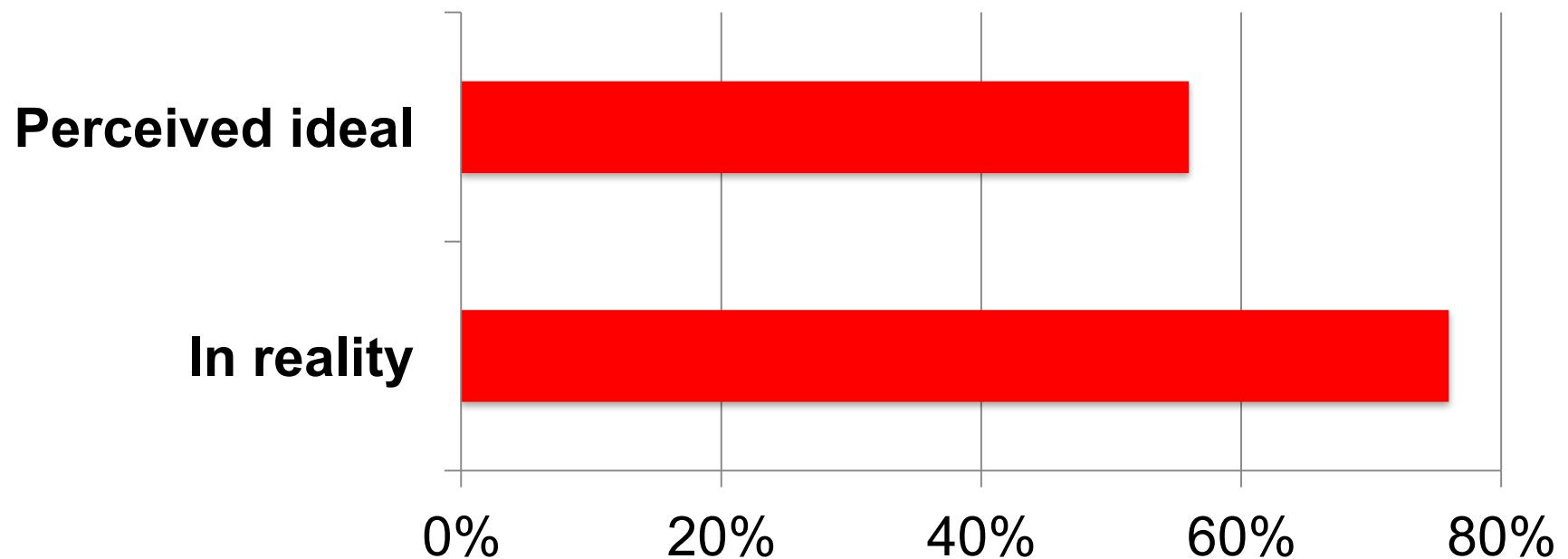
McHaffie HE, Lyon AJ, Hume R. Eur J Pediatr 2001;160(6):339-44.

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Autonomie ? (au Canada...)

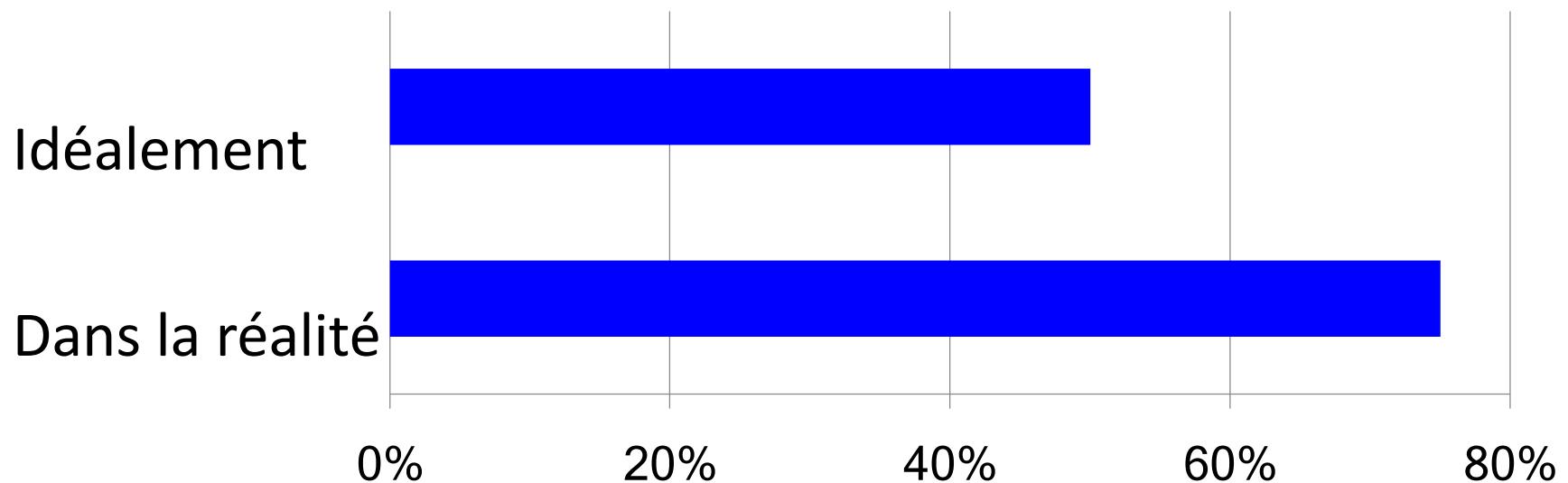
DANS QUELLE PROPORTION VOS **PROPRES CONVICTIONS INFLUENCENT-ELLES**
LA PRISE DE DÉCISION D'UN COUPLE D'EFFECTUER UNE IMG



Payot A & al, Canadian Paediatric Society, 2006

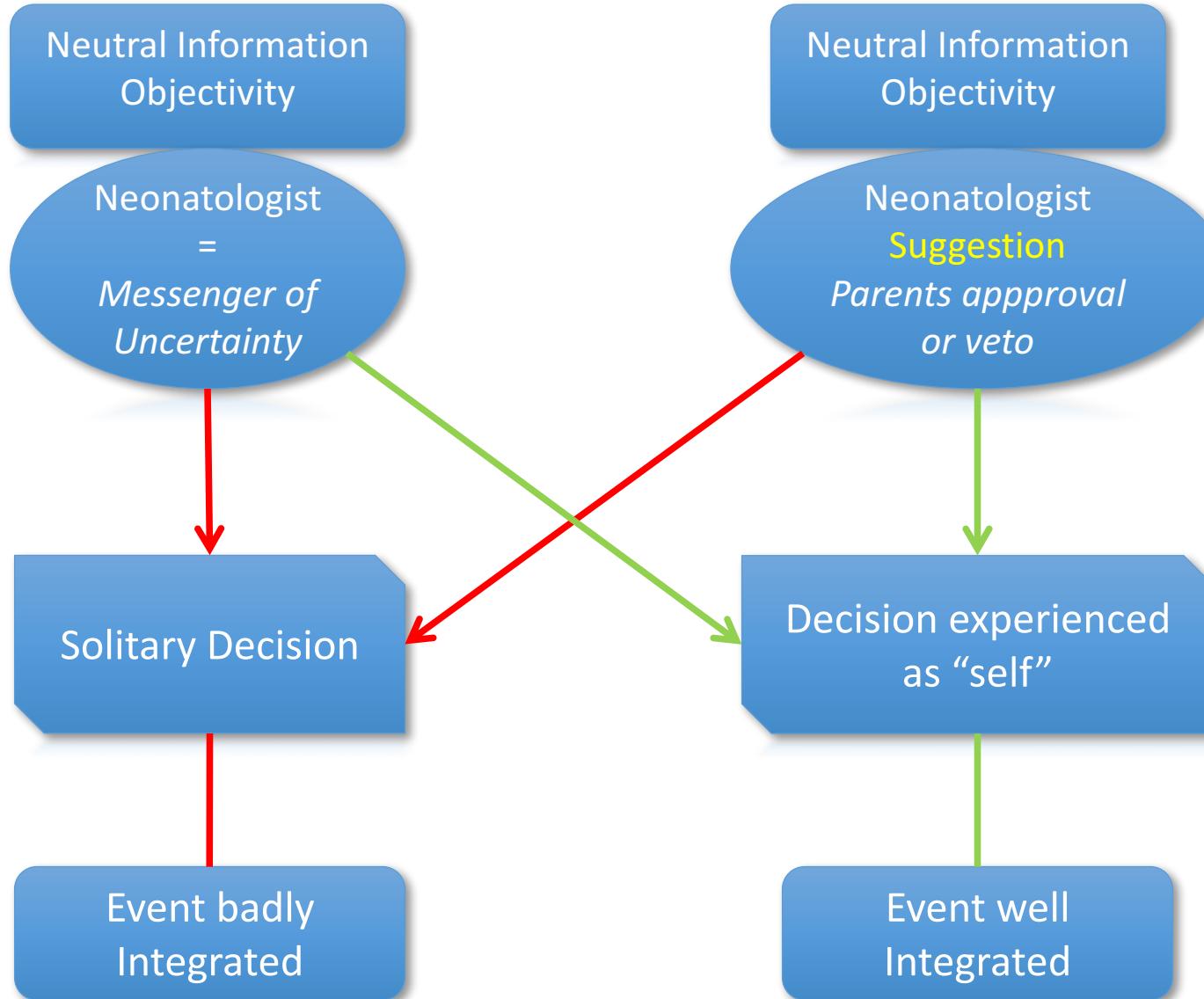
Autonomie ? (En France...)

**INFLUENCE DES CONVICTIONS DES MEDECINS DANS LA DECISION
D'UN COUPLE D'INTERROMPRE LA GROSSESSE POUR ANOMALIE**



Gorincour, G., Tassy, S., Payot, A., Philip, N., Malzac, P., Harlé, J.-R., Mattei, J.-F., et al. (2011). Décision d'interruption médicale de grossesse : le point de vue des soignants français. Gynecologie Obstetrique et Fertilité

Liberal Autonomy Model



Assent Model

Payot A et al. Deciding to resuscitate extremely premature babies: How do parents and neonatologists engage in the decision? *Social Science & Medicine* 2007.

Prenatal Consultation
Parents Experience of the Decision Making
Parents After 6 months

Overview

- Listened to parents' understanding of situation
- Discussed survival odds / Morbidity & mortality
- Discussed uncertainty of dates / Prognosis
- Explained NICU team presence / Role at delivery

Immediate morbidities/treatments

- Risk of RDS / Intubation / Surfactant
- Risk factors for infection / Need for antibiotics
- Access / Verbal consent obtained for UAC / UVC
- Blood conservation / Anemia / Possible transfusion

Long-term morbidities

- Risk of chronic lung disease
- Risk of intraventricular hemorrhage
- Risk of mental disability / Cerebral palsy
- Risk of blindness and deafness

Other

- Benefits of Breast Milk / Nutrition
- Location of NICU / Visiting policy
- Approximate length of stay
- Parental questions and concerns addressed

Griswold, K. J., & Fanaroff, J. M. (2010). An **Evidence-Based Overview** of Prenatal Consultation With a Focus on Infants Born at the Limits of Viability. *PEDIATRICS*, 125(4), e931–e937. doi:10.1542/peds.2009-1473

Evidence based = Basé sur l'évidence du point de vue des médecins et d'un modèle d'autonomie libérale

Focusing on information: What do women **recall** after prenatal consult ?

Table 2. After counseling, percentage of participants aware of postnatal risks for their unborn premature infant. N=49^a

Problems	Gestational age (weeks)			P-value ^b
	23–25 (n = 11)	26–30 (n = 24)	31–33 (n = 14)	
<i>Short-term</i>				
Respiratory distress syndrome	100	100	93	96
Intra-ventricular hemorrhage (IVH)	91	83	37 ^c	77 ^c
Infections	100	92	86	93
Feeding problems	100	92	93	94
Retinopathy of prematurity (ROP)	100	67	—	77 ^d
Total short-term knowledge	98	87	77	87
<i>Long-term</i>				
Chronic lung disease	91	62	21	57
Cerebral palsy without IVH	82	37	29	45
Visual impairment	82	58	14	51
Hearing impairment	82	54	21	51
Behavior problems	73	62	29	55
Learning problems	82	58	29	55
Total long-term knowledge	82	55	24	52

Abbreviation: NS, not significant.

^an for IVH and ROP are 43 and 35, respectively.

^bLogistic regression (with increasing gestational age less women are aware of the problem).

^c≤32 weeks for IVH.

^d≤30 weeks for ROP.

What do mothers expect of the prenatal consultation ?

- La littérature se concentre sur ce que **les médecins** considèrent être important:
 - “Informer les parents de la prématureté”
 - Eléments d'importance immédiate:
 - Décrire les soins du nouveau-né,
 - Morbidités après la naissance (respiratory distress syndrome, intraventricular hemorrhage, sepsis)
 - Risque de séquelles neurologiques à long terme

Halamek, J Perinat 2001

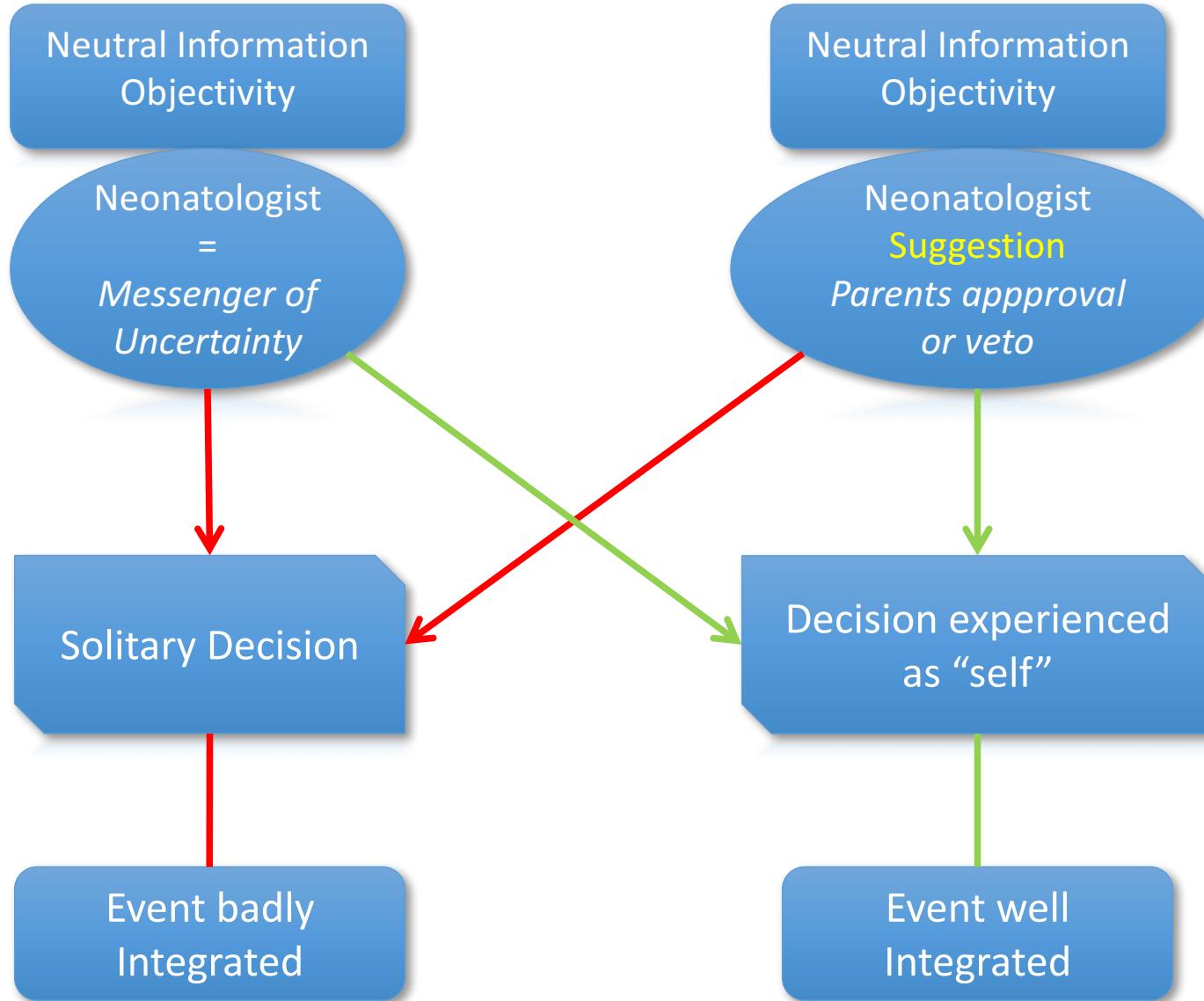
- Néonatalogistes se considèrent comme “**pourvoyeurs d'information**”

Bastek & al, Pediatrics 2005

Où est le patient dans le choix du mode de communication et de l'information ?

Savons-nous ce que les parents attendent d'une consultation prénatale ?

Liberal Autonomy Model



Assent Model

Payot A et al. Deciding to resuscitate extremely premature babies: How do parents and neonatologists engage in the decision? *Social Science & Medicine* 2007.

Prenatal Consultation
Parents Experience of the Decision Making
Parents After 6 months

MOTHERS' PERSPECTIVES	%
<u>Important to discuss*</u>	
-Prematurity's complications	96%
-Feeding strategies	91.4%
-Care they can provide their baby	83.4%
-Role as mother of premature baby	82.2%
-How to feel close to baby	81.7%
-Visiting schedules for family	58.3%
<u>Wanted to visit NICU*</u>	68.5%
<u>Wanted spouse present*</u>	71.4%
<u>Want written information about</u>	
-Services offered by the NICU	91.7%
-Prematurity's complications	87.3%
-How the NICU functions	86.9%
<u>Worried about their own health*</u>	27.2%

Gaucher N, Payot A et al; Personalized Antenatal Consultations for Preterm Labor: Responding to Mothers' Expectations. *J Pediatr.* 2016;178(C):130-134.e137.

	HIGHLIGHTS	OPPORTUNITIES FOR IMPROVEMENTS
INFORMATION IMPORTANT TO MOTHERS	<p>Very well <u>informed about prematurity</u> (4.4/5)</p> <p>Just enough information about prematurity (53.9%)</p>	<p>Less well <u>prepared for their role as mother of a premature baby</u> (3.65/5, p<0.001)</p> <p><u>Too much information about prematurity</u> (39.3%)</p> <p><u>Mothers' decision-making role</u> not explained (75.2%)</p>
SETTING	<p><u>Longer consultations</u> associated with feeling:</p> <ul style="list-style-type: none"> - Informed about prematurity (p<0.001) - Prepared as mother o premature baby (p<0.001) - Reassured (p<0.001) 	<p><u>Spouse</u> absent (51.1%)</p> <p><u>NICU visits</u> not offered (65.6%)</p> <p><u>Not warned</u> about consultation (19.2%)</p>
PHYSICIAN- PATIENT RELATIONSHIP	<p><u>What a trusting relationship means to women:</u></p> <ul style="list-style-type: none"> - Good bond with neonatologist (87.3%) - At ease to ask questions (96.0%) - At ease to discuss issues important to <u>them</u> (87.7%) - Information relevant to their situation (88.5%) 	<p><u>Clinicians' roles</u> not explained (18.9%)</p> <p>Not informed about <u>available support resources</u> (84.7%)</p>

Gaucher N, Payot A et al; Personalized Antenatal Consultations for Preterm Labor: Responding to Mothers' Expectations. *J Pediatr.* 2016;178(C):130-134.e137.

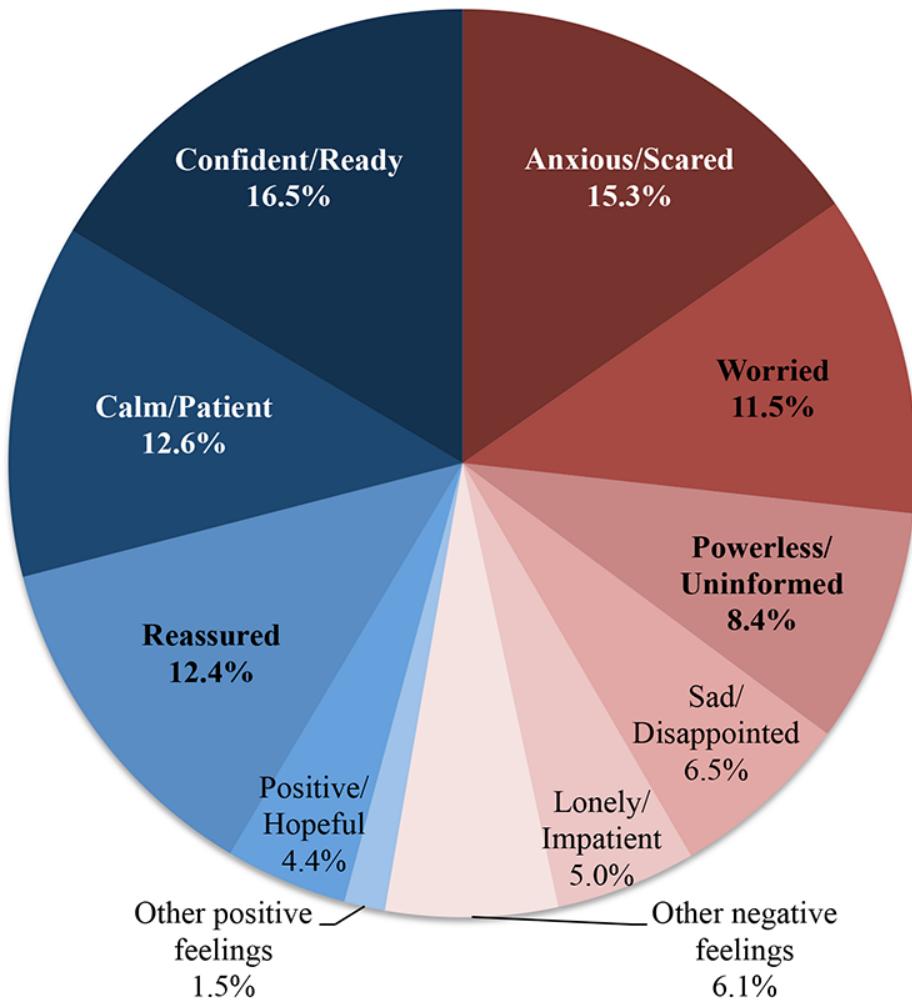


Figure 1 Feelings reported by women after the antenatal consultation for preterm labour (n=620).

Gaucher, Nadeau, Barbier, Payot, (2017).
Archives of Disease in Childhood Fetal and Neonatal Edition

Autonomie Relationnelle

Table 1 Relational autonomy in antenatal consultations for late preterm labour

Relational autonomy	Relational autonomy in practice	Relational autonomy in antenatal consultations for late preterm labour
Self-determination	Relational moral agents	<ul style="list-style-type: none">• Women want more than information about prematurity• Women want to discuss issues important to them• Tailor information to each woman's needs and situation• Women seek a trusting relationship with neonatologists
	Development of self-determination	<ul style="list-style-type: none">• Women can be empowered to discuss issues important to them• Choices can be made available to women
	Each person's lived experience	<ul style="list-style-type: none">• Consultations should seek to identify individual patients' stressors (financial, familial, social, etc.)• Multidisciplinary teams may be helpful
Situational awareness	Addressing power imbalances	<ul style="list-style-type: none">• Women hospitalised for preterm labour feel powerless• Power differentials exist within the physician–patient relationship• Neonatologists should foster empowering environments for women (sitting down, explaining their role, etc.)
	Contextual issues	<ul style="list-style-type: none">• Neonatologists should be advocates to improve antenatal consultation practices within their institutions• Research programmes and funding agencies should encourage more research into patients' experiences• Professional organisations' policy statements should be inclusive of patients' perspectives

Gaucher N, Payot A. Focusing on relationships, not information, respects autonomy during antenatal consultations. *Acta Paediatr*. October 2016;1-7. doi:10.1111/apa.13590.

Autonomie relationnelle

- Interdépendance
- Identité se construit à travers les relations sociales
- Autodétermination ≠ Autosuffisance
- Importance du contexte dans lequel s'exerce l'autonomie
- Décisions ne sont pas seulement rationnelles et se prennent dans un univers émotionnel et symbolique

Mackenzie, C., & Stoljar, N. (2000). Autonomy refigured. Oxford University Press

Autonomie relationnelle:

Vers un nouveau modèle de relation médecin-patient

- Zones grises – Situations humaines complexes
- Information qui doit **faire sens** pour le patient
- Dans le cadre d'une engagement à reconnaître ce qui est important pour l'autre
- Processus relationnel / humilité / ouverture d'esprit
- Partenariat et Engagement
- « *Empowerment* » du patient (adulte ou enfant) pour lui permettre de développer son autonomie

Haward, Gaucher, Payot, Janvier; Personalized Decision Making.
Clinics in Perinatology. 2017;44(2):429-445.

Que feriez vous si vous étiez à ma place ?

- Demande un engagement de “connaître” l’autre pour être en mesure de le conseiller à travers les valeurs qui lui sont importantes.
- Requiert la capacité de prendre des distances par rapport à ses propres valeurs pour prendre conscience qu’elles teintent nos « recommendations »
 - Du partage de l’information vers un partage de valeurs ?

The 'ouR-HOPE' approach for ethics and communication about neonatal neurological injury

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- ouR-HOPE
 - Reflection
 - Humility
 - Open-mindedness
 - Partnership
 - Engagement

Developmental medicine and child neurology. 2016;59(2):125-135.



<http://www.redmphoto.ca/les-premas/>