

ENJEUX ETHIQUES ET COMMUNICATIONNELS EN (PERI)NÉONATOLOGIE

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Espace Ethique
PACA - Corse

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hm

Il était une fois...

Case 1

A neonatologist went to speak to the teenage parents of a premature baby, Gabriel, who had been born at a gestational age of 27 weeks.⁵⁹ The parents were married and had two other children. Neither parent had finished high school.

By day 3 of life, Gabriel had pulmonary and intraventricular hemorrhages. After reviewing these findings, the doctor spoke with the parents about their baby's condition and poor prognosis. She was going to recommend discontinuation of life support. Instead, she asked if they had any questions. The father asked, "Will I be able to love him, even if he is handicapped?" The doctor reassured the father that Gabriel would be very lovable. The mother asked, "Will he be able to love us?" The doctor replied, "He will love you as much as any other child, probably more."

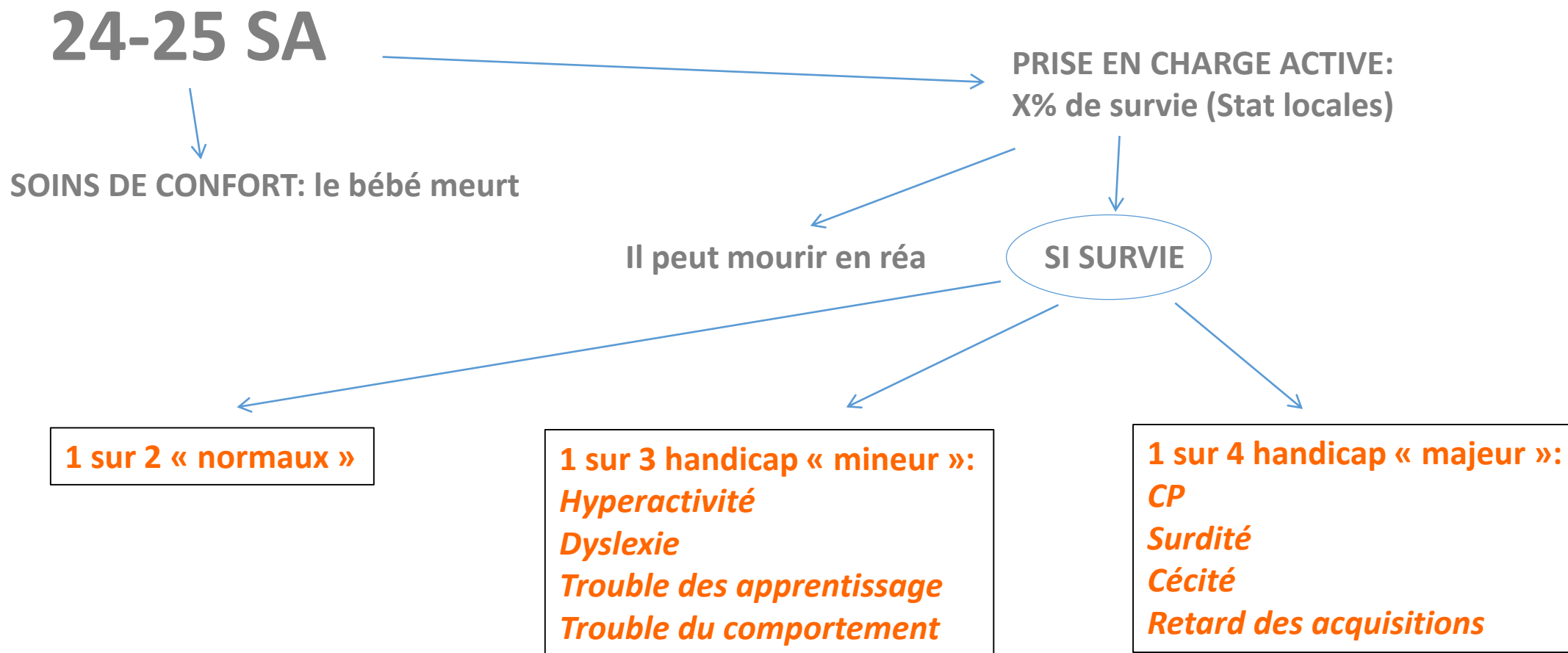
The father told the doctor that they had a nephew with Down's syndrome whom they adored. He asked if Gabriel would be like that nephew. The doctor told them that it was too early to predict the long-term effects of Gabriel's brain hemorrhage. She promised to meet with the parents every morning and update them on his condition and prognosis. The discussion never explicitly addressed questions about whether to discontinue life support. But the doctor got a good sense of the parents' values, and the discussion built a basis for trust.

Case 2

A neonatologist was called for a prenatal consultation concerning a woman with premature rupture of membranes who was in labor at 25 weeks of gestation. The obstetricians said that she would deliver within the next few hours. The pregnancy was complicated by a prenatal diagnosis of a large omphalocele on an ultrasound examination performed at 18 weeks of gestation. The parents said they wanted everything done to save the baby. The neonatologist was tempted to simply tell the parents that treatment would be futile and that the only option was comfort care. Instead, he asked them what it was like when they first heard the diagnosis of omphalocele. He asked what they were hoping for and what they feared most. The mother expressed her shock, confusion, and grief. She wondered whether she had done something wrong to cause the baby's problems. The doctor assured her that she had not. The father wondered whether treatment in the NICU would cause pain. The doctor said that they do their best to control pain but that it would depend on how sick the baby was and what interventions were needed. Together, the parents and doctor agreed not to make any decision until the baby was born.

At birth, the baby had a heart rate of 50 beats per minute, a large omphalocele, and physical findings consistent with a gestational age of 25 weeks. The doctor told the parents that their baby could not be saved. The mother asked to hold her baby. The neonatologist wrapped the motionless and apneic baby in a warm blanket. A few minutes later, the infant was pronounced dead. The neonatologist's focus on the parents' emotional state, rather than on the futility of treatment, helped build the trust that enabled a shared decision to be made in the delivery room.⁶⁰

Les néonatalogistes aiment les chiffres!





NICHD Neonatal Research Network (NRN): Extremely Preterm Birth Outcome Data

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PLEASE NOTE: The information on this website is intended to better inform health care providers and families about possible infant outcomes based on standardized assessments. *It is not intended to be the only information that care decisions are based on, nor is it intended to be a definitive means of predicting infant outcomes.* Users should keep in mind that every infant is an individual, and that factors beyond those used to formulate these standardized assessments may influence an infant's outcomes.

Based on the following characteristics:

Gestational Age (*Best Obstetric Estimate in Completed Weeks*):23 weeks
 Birth Weight:600 grams
 Sex:Male
 Singleton Birth:Yes
 Antenatal Corticosteroids:No

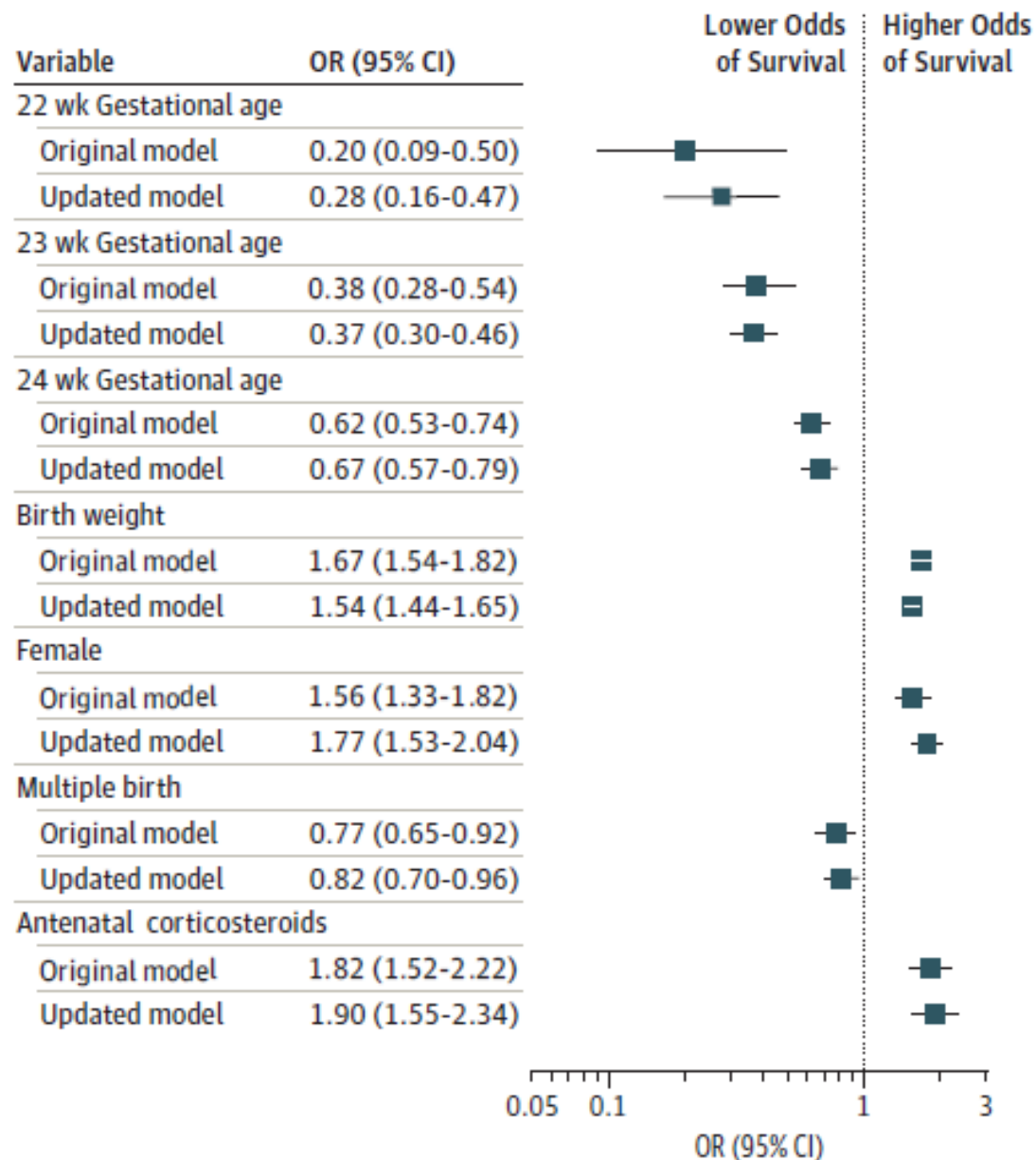
Estimated outcomes* for infants in the NRN sample are as follows:

Outcomes	Outcomes for All Infants	Outcomes for Mechanically Ventilated Infants
Survival	17%	26%
Survival Without Profound Neurodevelopmental Impairment	9%	14%
Survival Without Moderate to Severe Neurodevelopmental Impairment	4%	7%
Death	83%	74%
Death or Profound Neurodevelopmental Impairment	91%	86%
Death or Moderate to Severe Neurodevelopmental Impairment	96%	93%

Janvier A, Semin Perinatol, 2016

Einarsdottir J, Medical Anthropol Q, 2009

Figure 1. Odds Ratios for Survival in the Original and Updated Models



Research Network Model in the Vermont Oxford Network

PhD; Lucy T. Greenberg, MS;
E. Younge, MD, MHS;
C. Walsh, MD, MS;
Kennedy Shriver National
and Vermont Oxford Network

JAMA Pediatr. 2020;174(5):e196294.

Table 3. Relative Contribution of Variables to the Multivariable Model^a

Variable	Decrease in Log Likelihood	Relative Contribution, %
Birth weight	79.4	36
Infant sex	31.3	14
Antenatal corticosteroids	18.9	9
Plurality	3.2	1
Gestational age	45.0	20
Hospital of birth	43.7	20

SPECIAL FEATURE

Shared decision making for infants born at the threshold of viability: a prognosis-based guideline

B Lemyre¹, T Daboval¹, S Dunn^{2,3}, M Kekewich⁴, G Jones¹, D Wang¹, M Mason-Ward⁵ and GP Moore¹

<i>Risk estimation of anticipated mortality and long-term major or possibly major NDD</i>	<i>Suggested level of care</i>
<i>Extremely high likelihood</i> Mortality \geq 90% or Major NDD \geq 90%	Palliative care is the standard of care
<i>Moderate to very high likelihood</i> Mortality 25–89% or Major or possibly major NDD 25–89%	Intensive care or palliative care acceptable
<i>Low likelihood</i> Mortality <25% or Major or possibly major NDD <25%	Intensive care is the standard of care

Abbreviation: NDD, neurodevelopmental disability.

**Les estimations de la survie
changent-elles les décisions prises ?**

RESEARCH ARTICLE

Open Access

Effect of written outcome information on
attitude of perinatal healthcare
professionals
randomized



ARTICLE IN PRESS

THE JOURNAL OF PEDIATRICS • www.jpeds.com

ORIGINAL
ARTICLES

**Effect of Presenting Survival Information as Text or Pictograph During
Periviable Birth Counseling: A Randomized, Controlled Trial**

Siobhan M. McDonnell, MS¹, Mir A. Basir, MD, MS¹, Ke Yan, PhD², Melodee Nugent Liegl, MA², and Paul D. Windschitl, PhD³

V. Papadimitriou¹, B. Tose

ORIGINAL
ARTICLES

www.jpeds.com • THE JOURNAL OF PEDIATRICS



**Evaluating the Use of a Decision Aid for Parents Facing
Extremely Premature Delivery: A Randomized Trial**

Úrsula Guillén, MD¹, Amy Mackley, RN¹, Naomi Laventhal, MD², Stephanie Kukora, MD², Lori Christ, MD³,
Matthew Derrick, MD⁴, Jennifer Batza, LCSW⁴, Sarvin Ghavam, MD⁵, and Haresh Kirpalani, BM, MSc³

2019

Et les (futurs) parents?

Original Investigation | CARING FOR THE CRITICALLY ILL PATIENT

Prevalence of and Factors Related to Discordance About Prognosis Between Physicians and Surrogate Decision Makers of Critically Ill Patients

Douglas B. White, MD, MAS; Natalie Ernecoff, MPH; Praewpannaral Buddadhumaruk, RN, MS;
Seoyeon Hong, PhD; Lisa Weissfeld, PhD; J. Randall Curtis, MD, MPH; John M. Luce, MD; Bernard Lo, MD

Parental decision-making preferences in the pediatric intensive care unit*

Vanessa N. Madrigal, MD; Karen W. Carroll, BS; Kari R. Hexem, MPH; Jennifer A. Faerber, PhD; Wynne E. Morrison, MD, MBE; Chris Feudtner, MD, PhD, MPH

2012

- 40% de décisions partagées;
- 40% prise de décision seul;
- 20% le médecin seul prend cette décision ou après avoir recueilli leur avis.

Besoins des familles dans la relation ?

- Sécurité
- Légitimité
- Réassurance
- Soutien
- De comprendre, de se préparer
- De temps

*Bonnot Fazio S, Dany L, Dahan S, Tosello B.
Communication, information, and the parent-caregiver relationship in neonatal intensive care units:
A review of the literature.
Arch Pediatr. 2022 Jul;29(5):331-339.*

Ethics and Etiquette in Neonatal Intensive Care

Annie Janvier, MD, PhD; John Lantos, MD; for the POST Investigators

- Here are 10 essentials of etiquette-based neonatal care from the parents' perspective:
- 1. Say my baby's name,
- 2. Don't label my baby. My baby is not a diagnosis. She is not the "T-18," the "23-weeker," the "tiny critter," or the "horrible BPDer in room 8."
- 3. Say your name.
- 4. Listen to me.
- 5. Speak my language. Every parent is different. Some of us want numbers, predictions, and statistics. Others don't.

A PIECE OF MY MIND

Katharine P. Callahan, MD, MSME
Division of Neonatology, The Children's Hospital of Philadelphia, Philadelphia, Pennsylvania; and Department of Medical Ethics and Health Policy, Perelman School of Medicine at the University of Pennsylvania, Philadelphia.

Discarding Information

We draw a retina with vessels tracking from the optic disk to the periphery. Their child, if she survives, may have trouble with vision. We draw 3 stick figures of equal size and color one in. About one-third of children with hypoxic ischemic encephalopathy and no clear clinical sequelae will still have problems with development. The images emerge, black lines on white paper. If we communicate clearly, they will understand. If they understand, this information will be important to them. They will take it with them and make good decisions.

Yet here I am, sitting in a hospital meeting room, when a father poses the question "What are we supposed to do with this information?" The room is crowded with geneticists, neonatologists, and 2 parents; all are here to discuss the results of a DNA microarray test. This father's child

families. When parents can recall information just as we give it to them, we count it as a success.¹ If they make the choices we expect based on the information provided, we count it as an even bigger success. When they recount things differently or make unexpected decisions, we say "they don't get it." But what if information is uncertain or ends up being wrong? What if families understand information and it still is not important to them? What if they intentionally work to forget our information? My own family's experience with medicine, over generations, leaves me wondering what constitutes success.

In 1992, my mother was diagnosed with likely toxoplasmosis early in her second pregnancy. Toxoplasmosis serologies had recently been added to the routine prenatal panel at her obstetrician's practice. The positive

INFORMATION / COMMUNICATION

Définition conceptuelle

- L'information est la mise en forme d'un matériau préexistant,
Aristote 384-322 avant JC

Code de Déontologie Article 35 (article R.4127-35 du code de la santé publique)

Le médecin doit à la personne qu'il examine, qu'il soigne ou qu'il conseille une information loyale, claire et appropriée sur son état, les investigations et les soins qu'il lui propose.

MENTIR??

Définition

- *Est menteur celui qui pense quelque chose en son esprit, et qui exprime autre chose dans ses paroles, ou dans tout autre signe»*

(Saint Augustin)

Principes

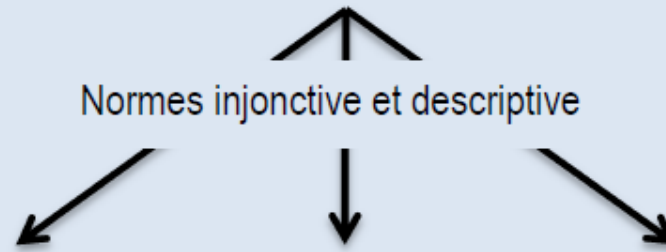
- « Tu n'étais pas obligé de me le dire »
- « Il y a une petite tumeur, on va s'en débarrasser »; « vous êtes jeunes, en ferez d'autres (enfants) »
- Mentir stratégiquement; très politique
- **Mentir pour des raisons éthiques**

Mentir pour des raisons éthiques

- Principe d'autonomie du patient

Contexte social

(Système de référence commun, Représentations de la maladie, de la médecine, du soin)

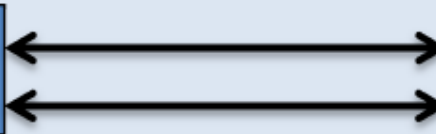


« Proches »

« Proches »

« Société »

Malade



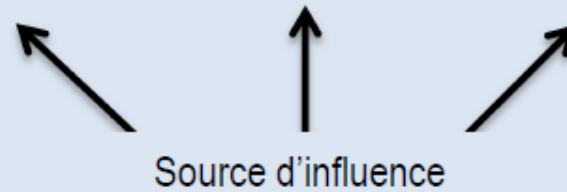
Médecin

« Société »

Malades

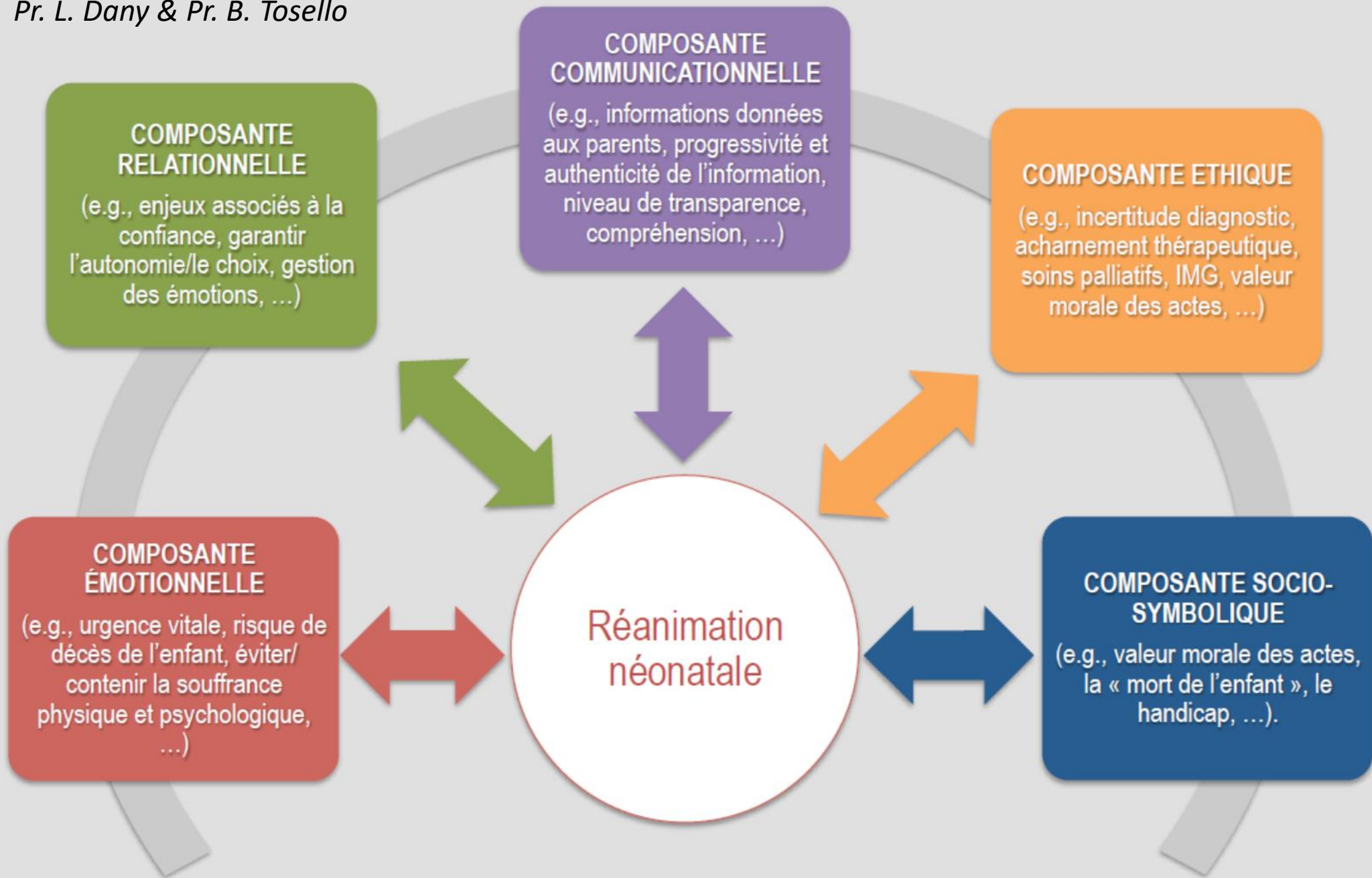
Validation / Confirmation

Malades



Trajectoire de la maladie

(Cours et durée de la maladie, évènements de santé)



RESEARCH ARTICLE

Open Access

REGULAR ARTICLE

ACTA PÆDIATRICA
NURTURING THE CHILD

How do
intensiv

RESEARCH

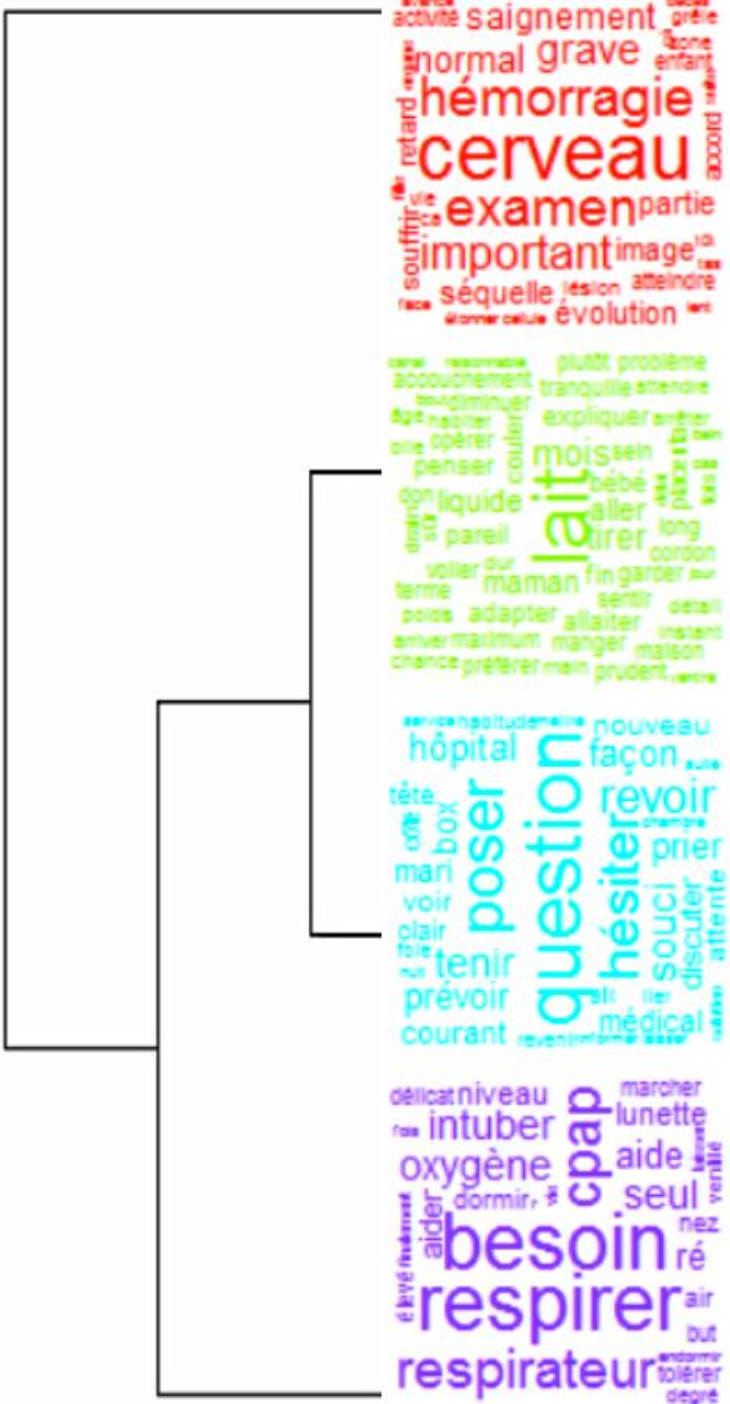
Open Access

Gaelle Sorin
Sophie Has

Analysis of communication and logistic processes in neonatal intensive care unit



J. Pirrello^{1,2}, G. Sorin², S. Dahan¹, F. Michel^{1,3}, L. Dany^{4,5} and B. Tosello^{1,2*}



activité saignement
normal grave
hémorragie
cerveau
examen
important
séquelle
évolution

Entretien en chambre ($\chi^2 = 10.73^{**}$)
 PCS faible ($\chi^2 = 9.08^{**}$)
 Première rencontre avec les parents ($\chi^2 = 6.32^*$)
 Enfant instable ($\chi^2 = 5.65^*$)
 Enfant à terme ($\chi^2 = 4.05^*$)

PENSER - VIE

« Lieu » de l'inaction / de l'attente

plutôt problème
tranquille attende
expliquer
mois
lait
bébé
aller
tirer
long
maman
fin
garder
sentir
ceci
manger
instant

Enfant vivant ($\chi^2 = 40.66^{***}$)
 Enfant stable ($\chi^2 = 23.23^{***}$)
 Entretien en bureau ($\chi^2 = 12.08^{***}$)
 Père présent ($\chi^2 = 10.44^{**}$)
 PCS faible ($\chi^2 = 6.49^*$)
 Mère présente ($\chi^2 = 4.77^*$)

MANGER

Les « lieux » de l'action médicale

hôpital
nouveau
façon
revoir
question
hésiter
prier
souti
discuter
attente
discuter
médical

Mère absente ($\chi^2 = 4.71^*$)

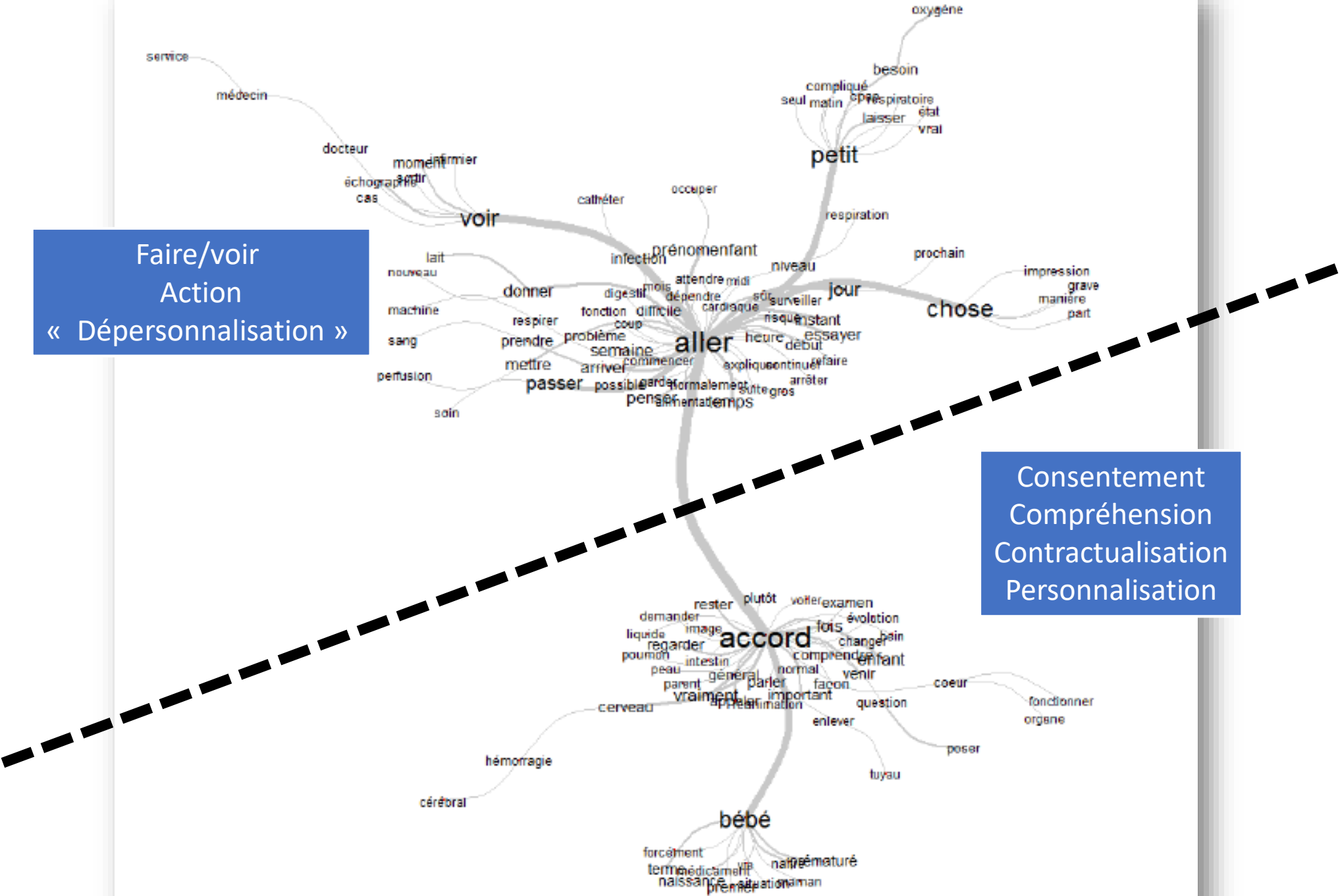
COMMUNIQUER

niveau
marcher
lunette
aide
seul
besoin
respirer
respirateur

Enfant décédé ($\chi^2 = 28.26^{***}$)
 Entretien en box ($\chi^2 = 22.96^{***}$)
 Père absent ($\chi^2 = 15.19^{***}$)
 Parents déjà rencontrés ($\chi^2 = 12^{***}$)
 Enfant prématuré ($\chi^2 = 6.4^*$)
 Enfant instable ($\chi^2 = 6.31^*$)

RESPIRER

Faire/voir
Action
« Dépersonnalisation »



Consentement
Compréhension
Contractualisation
Personnalisation

LA RÉALITÉ

An approach focused on the process of shared decision making

Start with open-ended invitations: Is now a good time to talk? Tell me how you're feeling today. How does your child look to you? Tell me more.

Let parents tell you what they know and how they feel:

What have other doctors and nurses told you about your child?

What do you fear?

What do you hope for?

Stop talking.

Let parents speak.

Listen actively.

Make eye contact, nod head, and focus on person speaking.

Circle back: "What I'm hearing you say is.... Did I get that right?"

Find common ground; use "we":

"We are both hoping for that goal!"

"Here are some of the options and the decisions that we have to make."

Madrigal et al, Pediatrics 2018; 142: Suppl 3: S170-S177.

An approach focused on giving parents information and asking for a decision

For each gestational age, provide parents with data in an "outcome-by-gestational-age" format for babies born at 22, 23, and 24 weeks.

Short-term outcomes

Percent of babies who survive

Percent of babies who leave the NICU with respiratory problems

Percent of babies with abnormal findings on ultrasonography of the head

Percent of babies with jaundice requiring phototherapy

Average number of days in hospital

Long-term outcomes

Percent of babies who need tracheostomy

Percent of babies who need gastrostomy tube

Percent of babies with cerebral palsy

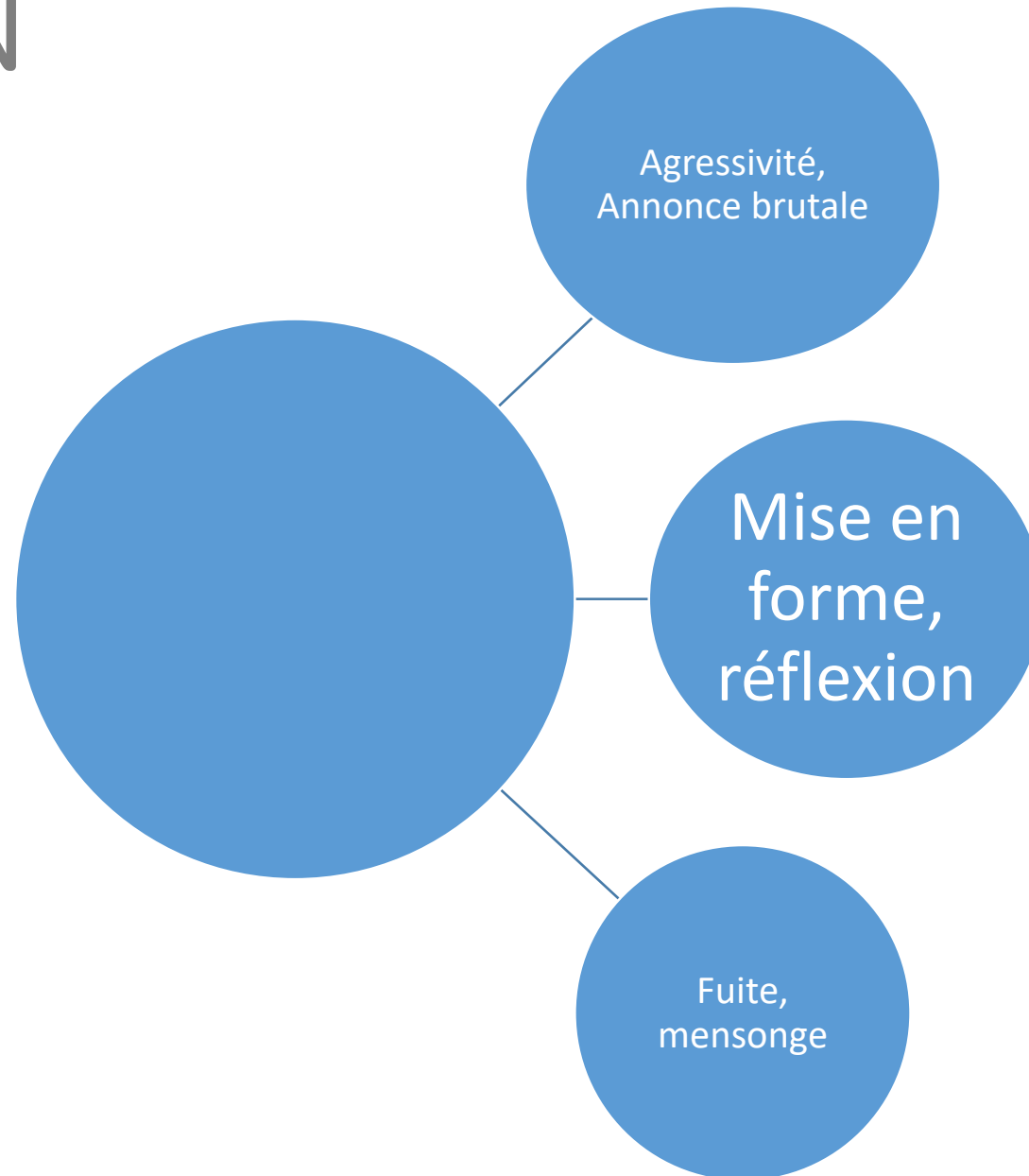
Percent of babies with cognitive impairment

Percent of babies with visual impairment

Ask the parents whether, given the information provided, they want to choose life-sustaining treatment or comfort care only.

Koh et al, J Perinatol 2000; 20:504-8.

L'INFORMATION



Baile WF, The Oncologist, 2000

S

Setting

Choose a private, comfortable, non-threatening setting



P

Perception

Uncover what patient & family think is happening



I

Invitation

Ask patient what they would like to know



K

Knowledge

Explain disease and care options in plain language



E

Emotion

Respect feelings, respond with empathy

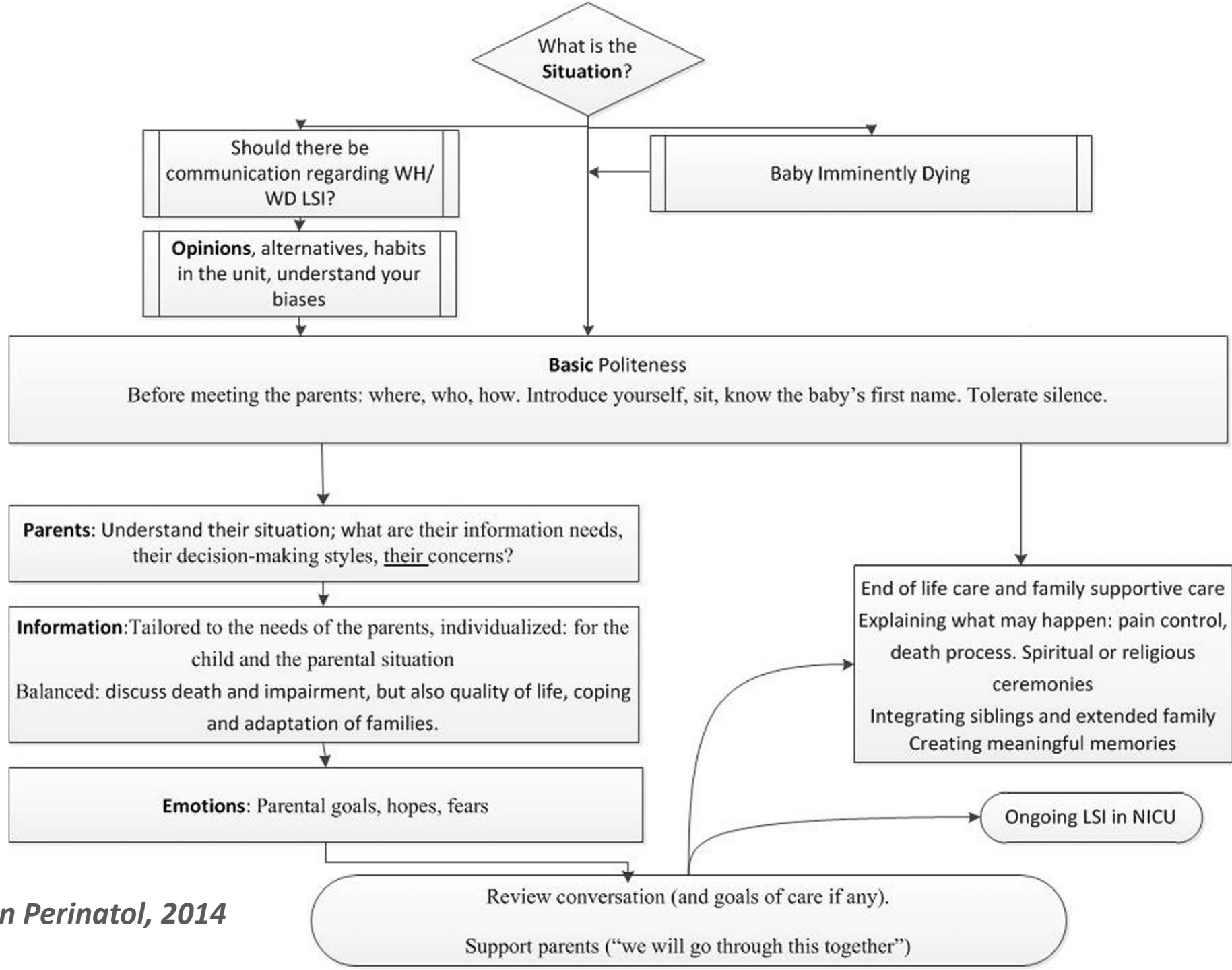


S

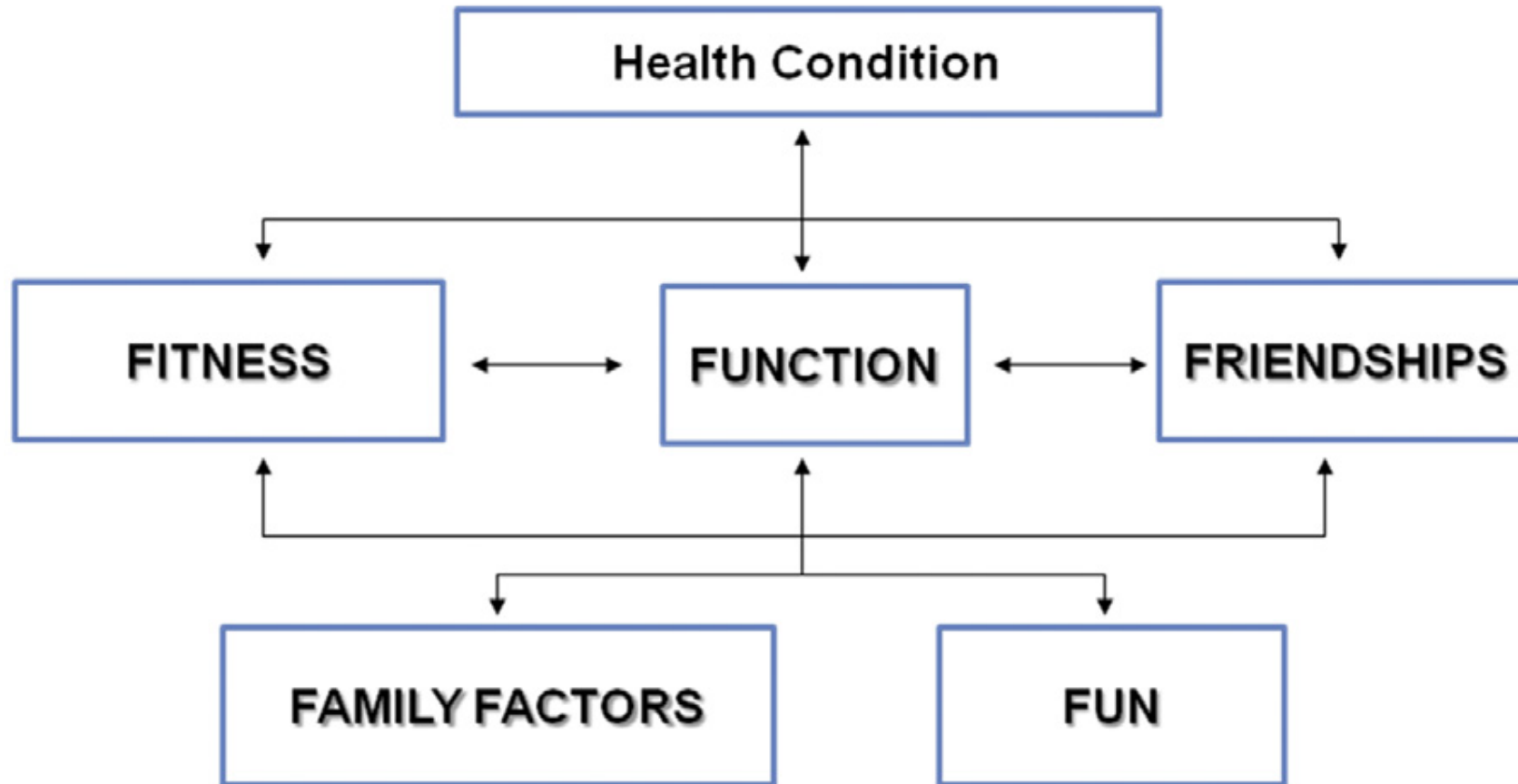
Summarize

Recap and decide what's next





The International Classification of Functioning, Health and Disability (ICF) 2001



PERSPECTIVES

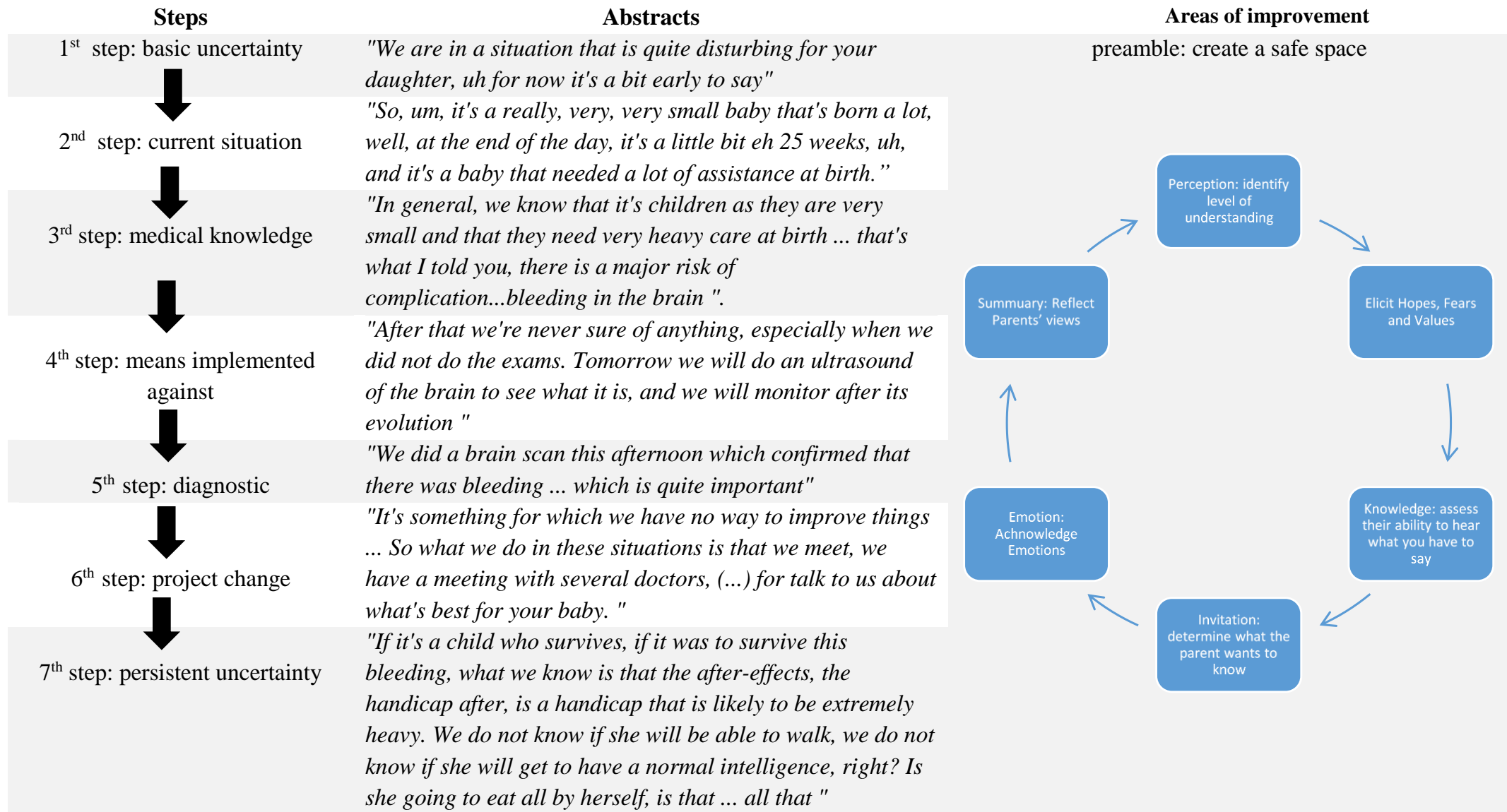


Figure 1: Example of the construction of information progressivity

(Background: birth at 25SA + 4days, 625g, premature rupture of membranes, diagnosis of intraventricular and parenchymal haemorrhage stage 4)