Long-term care of patients in UWS/MCS in the Netherlands

Is it that simple?

Radboud umc

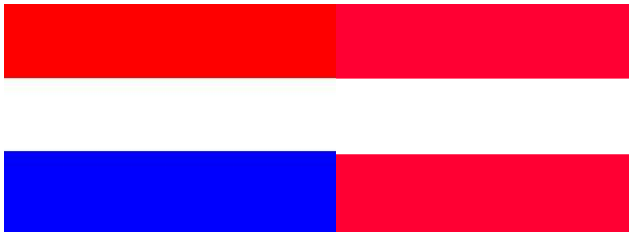
Vienna, 18-10-2013
Dr. Jan Lavrijsen, MD, PhD
Senior researcher
Radboud University Medical Centre
Nijmegen

Ist es so einfach?

Nein

Outline

- Nursing Home Medicine or Elderly Care Medicine
- Kontext UWS/MCS
- Long-term care in nursing homes
- Decision-making (Entscheidungen)
- Keys to solutions (Lösungen)
- Challenges (Herausforderungen)



To cross bridges

Brücken zu überqueren

Nursing Home Medicine (Dutch: verpleeghuisarts)
= Elderly Care Medicine (> 2009)

- 1980: erster professor Nursing Home Medicine (Nijmegen)
- 1990: Offiziell anerkannt
- Einzigartig in der Welt
- > 60.000 betten in > 350 nursing homes
- 3 jahre Ausbildung nach 6 jahre basis (Arzt)
- Rehabilitation + palliativmedizin + long-term care
- Outpatient care
- Decision-making at the end-of-life (Entscheidungsfindung)
- Wissenschaftliche Forschung, research programme

JAMDA

Long Term Care:
Management, Applied Research and Clinical Issues

ARTICLE IN PRESS

JAMDA xxx (2013) 1–3

JAMDA

journal homepage: www.jamda.com

Editorial

Concrete Steps Toward Academic Medicine in Long Term Care

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A nursing home physician specialty with a three-year training program

Establishment of academic networks of nursing homes providing an infrastructure for teaching, research, and best practices

Working in a nursing home in 80s

- Ärzte ohne Spezialität
- Patienten ohne Anzeichen von Bewusstsein
- Familien ohne Hoffnung

For team exercise in dealing with powerlessness

That is not simple!

Why?

- Feelings of powerlessness and hopelessness in long-term care
- Lack of knowledge of long-term care
- To shed light on hidden dramas

Coma patients Jan Lavrijsen at TEDxRadboudU 2013
http://www.youtube.com/watch?v=BrRTFUp7NLU

TEDx RadboudU
x = independently organized TED event

Patients in a vegetative state

Diagnosis, prevalence and long-term care in Dutch nursing homes

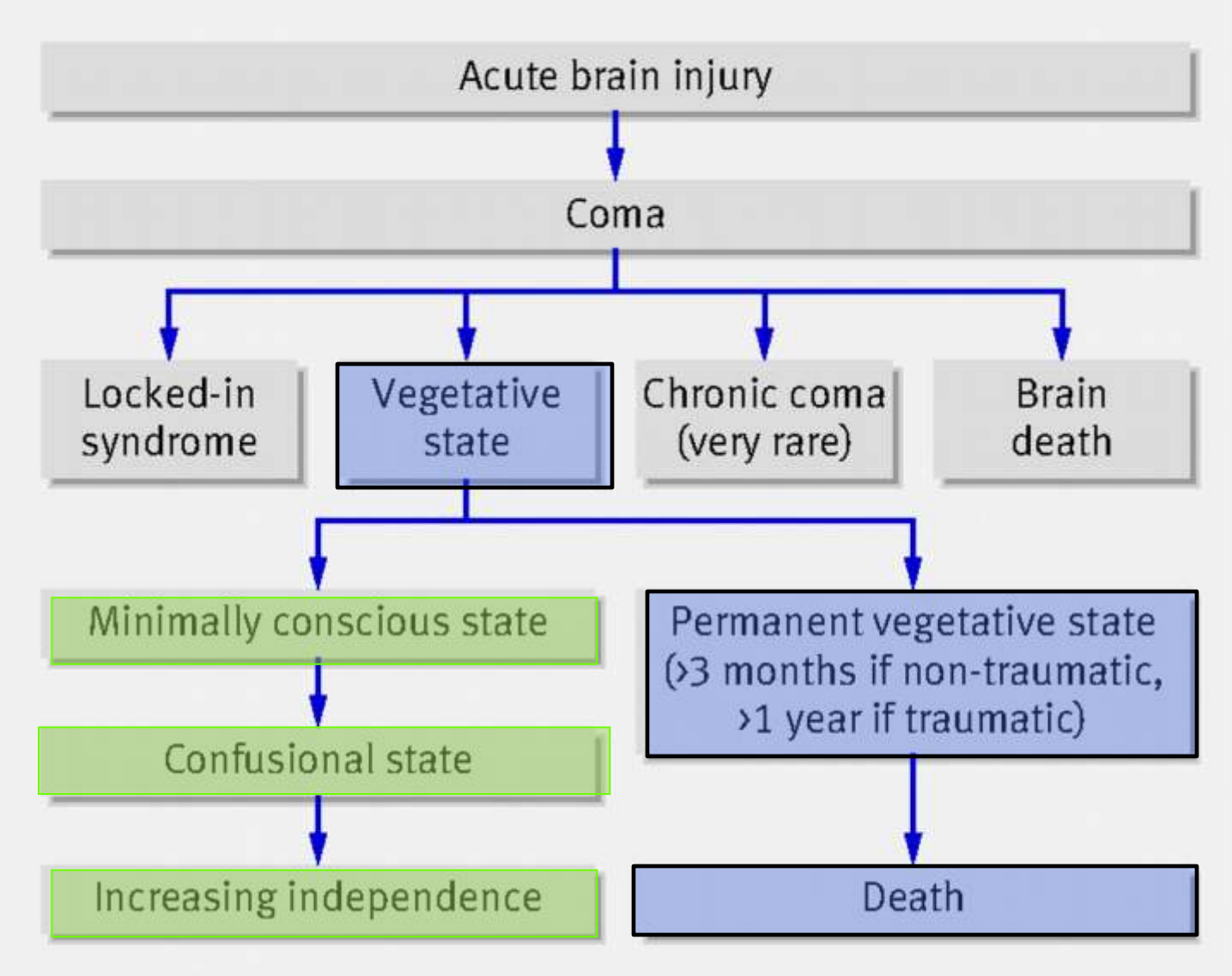
Jan Lavrijsen

Liebevolle Pflege

Die Frage, ob etwas davon erlebt wird

Und am Ende in Liebe loszulassen

Flow chart of cerebral insult and coma. Adapted from Laureys et al, Lancet Neurology 2004



Monti, M, Laureys S., Owen, M. BMJ 2010;341:c3765

Minimally Conscious State

- Prävalenz unbekannt in den Niederlande
- Prognose, Vorhersage Verlauf unbekannt
- Ander Verlauf MCS vs UWS
- Weitere Erholung möglich > Jahre
- Ander contact VS/UWS vs MCS
- Schmerztherapie (Boly et al. Lancet Neurol. 2008;7:1013-20)

- Andere medizinische -ethischen dilemmata
- Mangel an Möglichkeiten für Rehabilitation

Overbeek, Lavrijsen, Eilander. Ned Tijdschr Geneeskd 2010;154:1-5

'HET IS DROEVIG, MAAR HET IS NIET ANDERS. HET DRAAIT

Ouder dan 25? Helaas, geen coma-revalidatie

TILBURG/NIJMEGEN • Tientallen volwassen patiënten die in vegetatieve of laagbewuste toestand verkeren, worden in Nederland aan hun lot overgelaten. Zij liggen zonder behandeling thuis en in verpleeghuizen. Het AD volgde de afgelopen maanden een gezin in een vergelijkbare situatie als prins Friso's gezin en sprak met deskundigen die pleiten voor betere zorg. Vandaag deel 1 in een tweeluik over een groep patiënten die tussen wal en schip valt.

TONNY VAN DER MEE

Revalidatiecentrum Leijpark in Tilburg moet soms 'nee' verkopen aan patiënten met zwaar hersenletsel en ernstig bewustzijnsverlies. Niet omdat een behandeling bij voorbaat kansloos is, maar simpelweg omdat hij of zij te 'oud' is.

Door het zorgaanbod voor deze patiënten loopt een strikte leeftijdsgrens. Ben je 26 jaar dan word je geholpen, vanaf 25 jaar, zoals prins Friso, niet. „Dat leidt tot schrijnende situaties," zegt revalidatiearts en medisch manager Evert Schouten.

„Het komt geregeld voor dat we aanvragen moeten afwijzen. We hebben er geen toestemming voor."

Leijpark biedt als enige in Nederland een speciaal behandelprogramma (Vroege Intensieve Neurorevalidatie) voor patiënten in een vegetatieve of laagbewuste toestand (zie kader hieronder). Ze hebben door een ongeluk, beroerte of hersenschudding in coma gelegen en verrunnen na het ontwaken geen of minimale tekenen van bewustzijn.

Bij de behandeling in Leijpark worden de zintuigen geprikkeld om het bewustzijn terug te brengen. Daarna worden lichamelijke en cognitieve functies getraind. Uit eerder onderzoek blijkt dat dit bij twee derde - van de twintig tot dertig patiënten per jaar - in meer of mindere mate lukt.

Deskundigen en revalidatieartsen pleiten er al jaren voor om het behandelprogramma ook toe te passen op andere patiënten. Maar voorstellen van Leijpark zijn door het College voor Zorgverzekeringen (CVZ) en het ministerie van VWS geweigerd, omdat wetenschappelijk onderzoek naar het effect bij 25-plussers ontbreekt.

Schouten: „Ons aanbod om een prospectief onderzoek te doen, geldt nog steeds. Wij zijn erg gemotiveerd om de behandeling ook aan patiënten vanaf 25 jaar aan te bieden. De bal ligt bij het ministerie."

VWS vroeg in augustus 2012 bij Revalidatie Nederland informatie op over deze patiënten. Het was een half jaar na het skiongeluk van prins Friso, die sinds november in een toestand van minimaal bewustzijn verkeert. De branchevereniging stuurde een document op. Sindsdien is het stil.

„De aandacht voor niet aangeboren hersenletsel is politiek altijd onderbelicht geweest," zegt Pauline Hoendenlaal, voorheen revalidatiearts en bestuurslid van lotgenotenvereniging Cerebraal. „Droevig, maar het is niet anders. Het gaat al-

Jan Lavrijsen

'Familie moet erop kunnen vertrouwen dat artsen een goede beslissing nemen'

Revalidatie in bijzondere gevallen toch vergoed

UTRECHT/DIEMEN • Bij patiënten vanaf 25 jaar, die in Nederland niet in aanmerking komen voor coma-revalidatie, kunnen verzekeraars in bijzondere gevallen die behandeling in het buitenland toch vergoeden. Dat zegt Zorgverzekeraars Nederland.

„Een verzekeraar kan uit coulance de hand over het hart strijken," zegt een woordvoerder. „Dat is een individuele afweging als het gaat om specialistische zorg in een specialistisch geval. De arts maakt die inschatting."

Verzekeraar Agis vergoedde om die reden de kosten van de 32-jarige Tülay. Zij raakte 2 jaar geleden in coma door een ernstig auto-ongeluk, ontwaakte daaruit, maar ligt sindsdien in een toestand van minimaal bewustzijn. Agis vergoedde de 180.000 euro die de behandeling in België kostte.

„Gezien de leeftijd kwam zij niet in aanmerking voor opname in Leijpark," zegt een woordvoerster. „Echter juist gezien die leeftijd was opname in een verpleeghuis niet adequaat omdat daar niet de juiste zorg zou worden gegeven. In het belang van de verzekerde is toen gekozen voor een multidisciplinair revalidatietraject in Overpelt."

Andere zorgverzekeraars zijn niet eenduidig. VGZ zegt een dergelijke behandeling wel te vergoeden, mits er perspectief is op succes. „Ook als dat in België is."

Menzis vergoedt de kosten in het buitenland alleen als die zorg ook in Nederland zou worden vergoed. CZ laat weten coma-revalidatie in het buitenland niet te vergoeden. „Voor een Nederlandse verzekerde geldt nog steeds de Nederlandse Zorgverzekeringswet."

Het College voor Zorgverzekeringen (CVZ) blijft op het standpunt uit 2009. Toen wees het een voorstel om ook de behandeling voor patiënten vanaf 25 jaar te vergoeden af.

Volgens het college is er weinig onderzoek gedaan naar het effect bij deze categorie patiënten en zijn de bestaande onderzoeken 'matig' van kwaliteit. Het voldoet dus niet aan 'de stand van wetenschap en praktijk'.

Steven Laureys

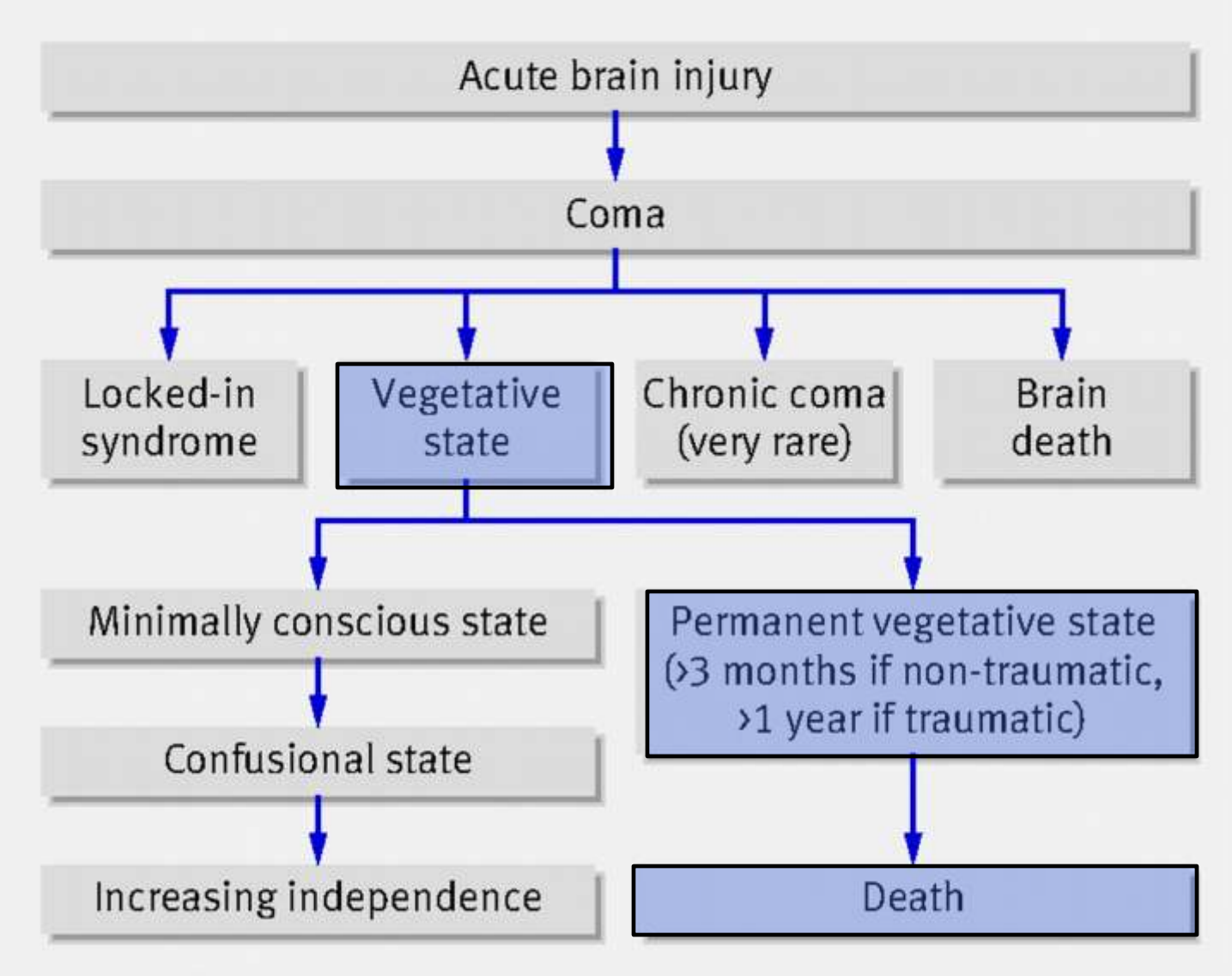
'De leeftijdgrens is arbitrair en niet wetenschappelijk onderbouwd'

Dies ist nicht einfach: *research started*

- MCS in long-term care
- 2013-2014: Diagnose- Koncept
- 2014/2015: Prävalenz MCS
- Kohortenstudie
- Ethische dilemmata
- Lebensqualität
- Qualität der Versorgung

Berno Overbeek
Specialist Elderly Care

Flow chart of cerebral insult and coma. Adapted from Laureys et al, Lancet Neurology 2004



Monti, M, Laureys S., Owen, M. BMJ 2010;341:c3765

A new name

Debate

Highly accessed | Open Access

Unresponsive wakefulness syndrome: a new name for the vegetative state or apallic syndrome

Steven Laureys, Gastone G Celesia, Francois Cohadon, Jan Lavrijsen, Jose Leon-Carrrion, Walter G Sannita, Leon Sazbon, Erich Schmutzhard, Klaus R von Wild, Adam Zeman, Giuliano Dolce and the European Task Force on Disorders of Consciousness

BMC Medicine 2010, **8**:68 doi:10.1186/1741-7015-8-68

Published: 1 November 2010

DESCRIPTIVE

NEUTRAL

BESSER KONNOTATION

WENIGER FATALISTISCH

VS/UWS

Das Leben auf den Kopf

- ‘Awake but not aware’
- Lange Überleben möglich
- Die andere, dunklere Seite von erfolgreiche Medicin
- Müssen wir alles tun was wir tun können?

Impact on society

USA 1990-2005: Terri Schiavo

Italy 1992-2009: Eluana Englaro

The Netherlands ’74-’90: Ineke Stinissen

Eheman im Fernsehen: “ Die medizinische Welt ist verantwortlich für eine Lösung“

How many people?

What is the prognosis?

Do they suffer?

Is this living in dignity?

What to do?

When to decide?

Who decides?

Is this dying in dignity?

Research questions

- How, by whom and at which moment, can the **diagnosis** VS be made as accurate as possible?

→

- What is the **prevalence** of VS in Dutch nursing homes?

→

- What is the **long-term course and care**?

Finding the key

How can

a hopeless VS/UWS

be prevented?

Prävalenz in Niederlande

- In September 2003
- VS/UWS > 1 Monat
- Definition Multi Society Task Force on PVS
- Dutch nursing homes (n=380; 62,331 betten)
- Per Brief, Antwordformular, interview Telefon
- Fragen zu Konsensus artzen-team-familien
- Im Zweifel: assessment Western Neuro Sensory Stimulation Profile (WNSSP)

32 patients > 1 Monat in VS/UWS

Ergebnisse

- Jung (mean age 53 years)
- Mehr Frauen (73%)

- Stroke 14 (46.7%)
- Trauma 8 (26.7%)
- Anoxia 7 (23.3%)

- Other 1 (3.3%)

- Main period uncounsciousness:

  6 Jahre (2 Monaten-20 Jahren)

Lange Überlebenszeit

- zwischen 5 und 10 Jahre: 8 patienten
- über 10 Jahre: 5 patienten

Conclusion

- Prävalenz VS/UWS in Niederlande (2 PPM) niedriger als in der Literatur gefunden (5-140 PPM)
- Bestätigt in Aktuelle Studie, alle patienten Coma Recovery Scale-revised (CRS-r) (Van Erp, Lavrijsen et al. *in progress)*
- Österreich 19 PPM (Stepan 2001), 17 PPM (Stepan 2003), 33,6 PPM (Donis, 2007-2009)
- Auch in Niederlande relative stabilität
- Trotz der möglichkeit beendigung der Behandlung

End-of-life decisions in Nursing Homes

43 VS/UWS-patienten verstorben
2000-Sept 2003:

- **24** von Komplikationen nach Nichtbehandlung Entscheidung
- **10** von Komplikationen trotz behandlung
- **9** nach beendigung Behandlung incl. artificial nutrition and hydration (ANH)

Nutrition and Hydration

1. Nutrition and hydration as a general human need
2. Nutrition and hydration as part of the normal nursing and care
3. **Nutrition and hydration as a form of medical treatment**

Artificial Nutrition and Hydration =
medizinischen Behandlung patienten
in a VS/UWS

Auch in Rechtsprechung

Dutch Health Council 1994

- If patient is unconsciousness and chance of recovery is negligible
- It is **allowed to withdraw ANH**
- As part of decision to withheld/withdraw life-sustaining treatment
- For patient a dying process in dignity

Royal Dutch Medical Association (KNMG), 1997

Committee on the Acceptability of the termination of life (CAL)

- Continuing treatment is **contrary to human dignity**
- Continuing treatment is **futile**
- One would expect from physician that he **withdraws medical treatment** on a certain time
- Medical treatment that is **no longer legitimized**, should **not be continued**

And the family…?

- If relatives insist on continuing treatment, the physician has **to give information and guide** them…
- .. to bring them to **other thoughts**
- .. to **withdraw medical treatment** within some time **in agreement** with the relatives

That is not simple!

The long-term care

Course, care and decision-making

5 patients described in depth

Age	Sex	Cause	Start	Survival	End point
17	M	Trauma	1978	11½ y	Sepsis
43	F	Trauma + anoxia by bleeding spleen	1983	6y 5m	Withdrawal ANH
44	M	Anoxia after cardiac arrest	1989	1y 3m	Withdrawal ANH
15	M	Trauma	1991	8y 4½m	Pneumonia
18	M	Trauma	1987	16 (now 25y)	Still alive

Lavrijsen et al. *Brain Injury* 2005;19:67-75

Characteristics long-term care

- ***'Intensive care'*****:** complex, multidisciplinary & intensive
- Washing, changing incontinence materials, supplying ANH, frequent turning, fixing splints, providing mouth care, supplying laxatives, medicines, changing urinary catheters, cleaning tracheal tube
- Under direction of a Nursing Home Physician/Elderly Care Physician
- Multidisciplinary meetings about **care plan: goals, actions, evaluations, family meetings**

Lavrijsen et al,.*Brain Injury* 2005;19:67-75

And..

- Only incidental bed sores (> 60.000 turns!)
- Chronic medication
- Several medical specialists involved

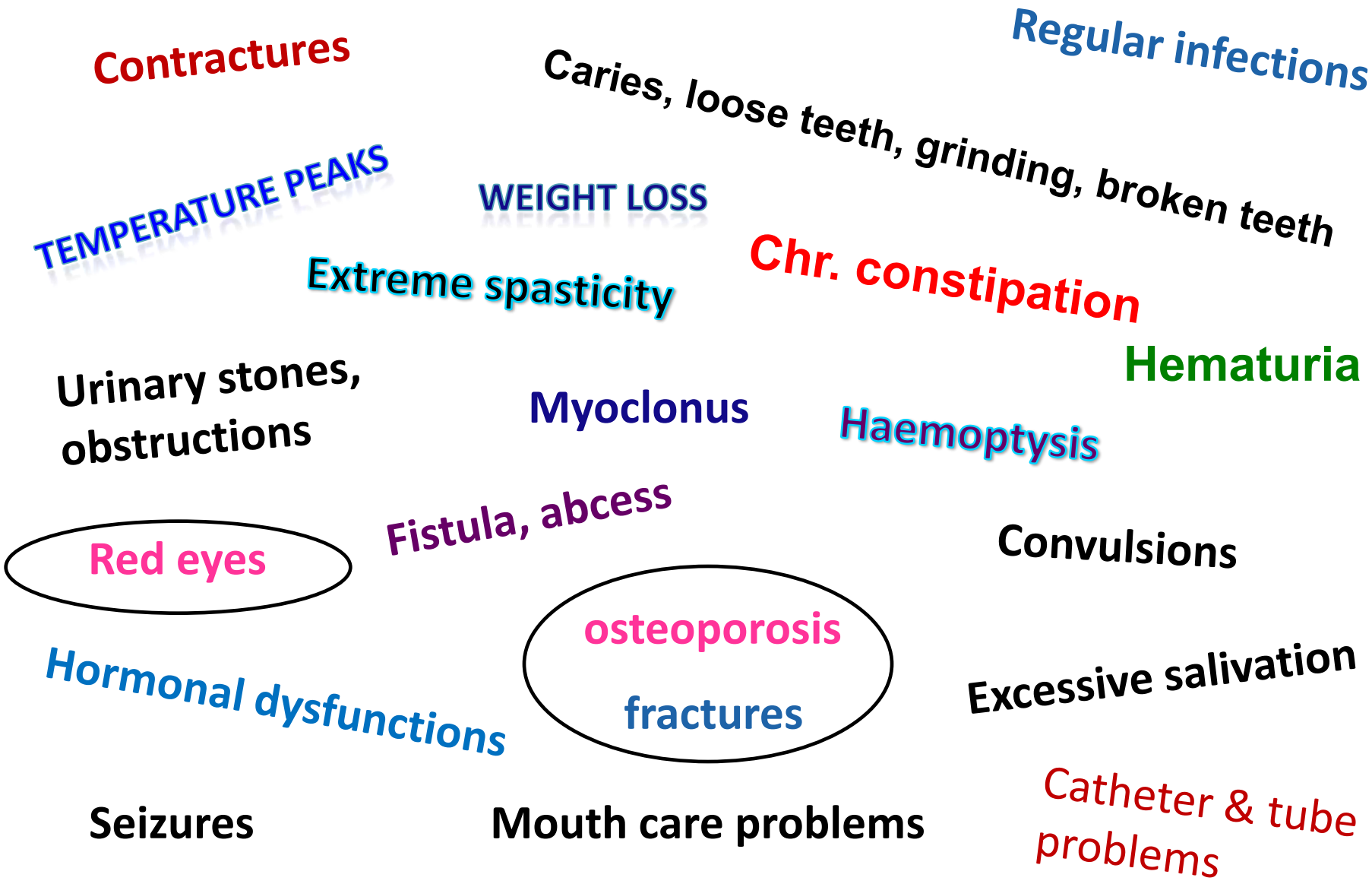
That is not simple!

Where others stop….

…we begin

That is Intensive Care too

Considerable medical & nursing problems



Lavrijsen et al.*Brain Injury* 2005;19:67-75

A remarkable finding: red eyes

Filamentary Keratitis

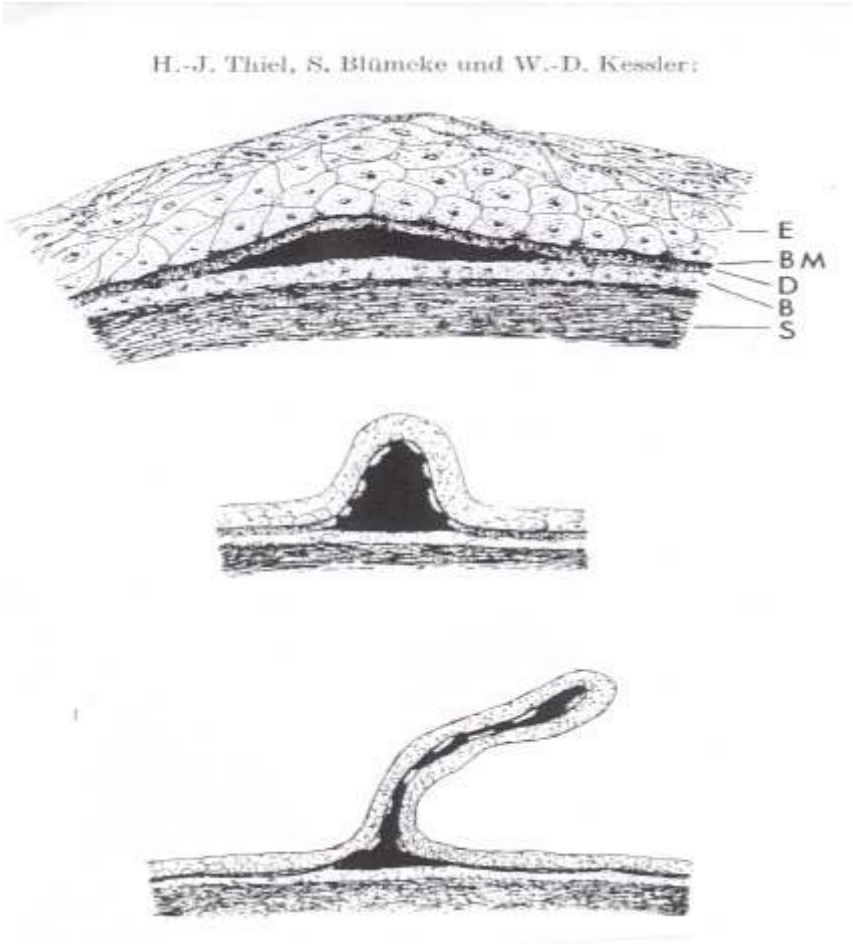
- Einwachsen von Blutgefäßen & filamenten Cornea in 2 Patienten
- Keine Literatur Zusammenhang UWS
- Chronisches Problem

- 15 Jahre Behandlung

- Jetzt: nichts tun, nur regelmäßig die Augen zu öffnen

- Effektive in letzten 10 Jahren

Filaments on cornea



Brain Injury, August 2007; 21(9): 993–996

informa
healthcare

CASE STUDY

Beine brechen

Bone fractures in the long-term care of a patient in a vegetative state: A risk to conflicts

JAN LAVRIJSEN[1], HANS VAN DEN BOSCH[2], & JOOST VEGTER[3]

[1]*Nursing Home Medicine, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands,* [2]*Nursing Homes, De Zorgboog, Bakel, The Netherlands, and* [3]*Orthopaedic Surgery, Elkerliek Hospital, Helmond, The Netherlands*

(Received 10 January 2007; revised 1 June 2007; accepted 21 June 2007)

Nach 19 Jahre UWS:
Radiologist: *'extrem niedrigen Knochendichte'*

Weiche Materialien
Optimale Transfers
Risikommunikation

Entscheidungs-prozess

Wer, wenn, wie?

5 scenarios

Withholding antibiotics † 11½

Waiting for a fatal complication † 8,5

Reactive approach to withdrawing ANH † 6,5

Continuing treatment > 16

(now 25)

Proactive approach to withdrawing ANH † 1,3

Lavrijsen et al. Brain Inj 2005;19:67-75

Scenario case 1, ♂ 17 y

Not treating complications

Withholding antibiotics — **† 11½ years**

After 7 years a life-threatening urine stoppage was treated

Young people survive infections without antibiotics

Risk of chronic infections

Lavrijsen et al. Brain Inj 2005;19:67-75

Key statement made at family meetings

- ‘The parents told me that, should they be confronted with a recurrence of the life-threatening urine stoppage, they would probably insist on medical treatment’

… but…

- ‘if the physicians were to say that treatment is not the most sensible choice, they would understand’

Conclusion case 1

- This scenario did not lead to expected death, resulted in a chronic infectious state and turned out to be an inappropriate way to let the patient die in dignity
- Infections not lethal
- '*This never again*'

Lesson case 1

- Instead of only withholding therapy for incidental complications,
- regular evaluation of the **total treatment** is necessary

Scenario casus 2, ♀ 43 y

Reactive approach

Withdrawing ANH at the moment of complications

† 6,5 years

Consultations about decision

- Colleagues NHP
- Multidisciplinary team
- General Practitioner
- Professor in ethics
-
- Lawyer, jurist (no jurisprudence)

‘Medical treatment for patients in a VS

‘a contribution of nursing home medicine’

- First case withdrawing ANH
- As futile medical treatment
- Positive experience for all
- No sign of suffering or discomfort
- ‘Meaningful final phase’
- In contrast with other descriptions about ‘starvation’ in lay press
- Positive publicity, reactions

Lavrijsen, van den Bosch. Ned Tijdschr Geneeskd 1990

Preliminary judicial investigation

- “The decision to withdraw ANH was made with due care from a medical and ethical point of view”

Lavrijsen et al. Ned Tijdschr Geneeskd 1991;135:1097. Brain Inj 2005;19:67-75

Key statement case 2

- ‘ The husband explained that he was afraid to decide himself whether or not complications should be treated’

- ‘He requested not to involve him in the decision making, but only to explain to him what has been decided’.

A quiet and dignified dying process

- No signs of discomfort
- The same experience in psychogeriatric wards
- Normal palliative approach *'to ensure dignity'*
- Adequate information and guidance of family
- Death usually within 1-2 weeks

Confirmed in case study 2011

Lesson case 2

- ANH can be regarded as **futile medical treatment**
- Withdrawing ANH can be an **acceptable scenario**
- **Earlier evaluation** of total treatment could possibly prevent a long-term VS

Scenario casus 3: ♂ 44 y

Proactive approach

Direct after admission working towards the moment of withdrawing ANH

† 1,3 year

Making clear that the doctor decides

Key statement in case 3

Doctor:

‘I have told her that I think the time has come that I should decide to withdraw ANH…

… No one raised any serious objections’

Lessons case 3

- Long-term VS/UWS can be prevented by a **proactive approach** from the beginning in which evaluation of the total treatment, including ANH, is the starting point
- Informing them that the decision to withdraw treatment would be **entirely up to the physician**
- Letting family **grow towards decision** to withdraw ANH

Scenario casus 4: ♂ 15 y

Waiting for a fatal complication

Parents did not agree with withdrawal medical treatment, ANH

No other option than to wait for a fatal complication

† 8,5 years

Key statement in case 4

Parents:

‘We recognize that our son would never have wanted this situation to continue like this: who would? With hindsight, it would have been better for him if he had died in the hospital. We hope that he doesn’t realize in which situation he is’

Scenario casus 5: ♂ 18 y

Continuing treatment

Parents do not agree to withdrawal medical treatment

now > 25 years

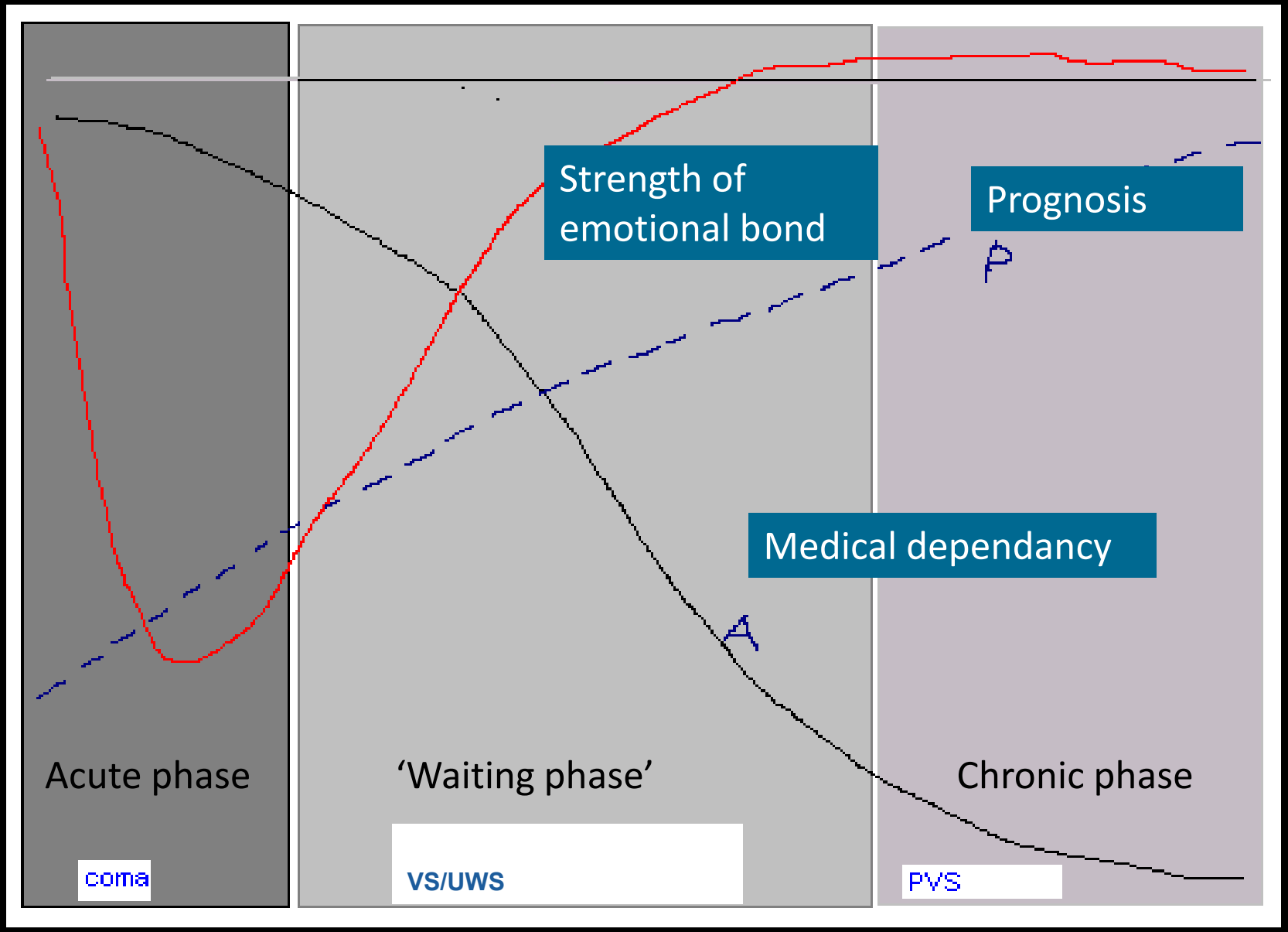
‘This is a fate worse than death, but we don’t want to lose him’

Lavrijsen Brain Inj 2005; Quoted in NEJM, 9.6.2005

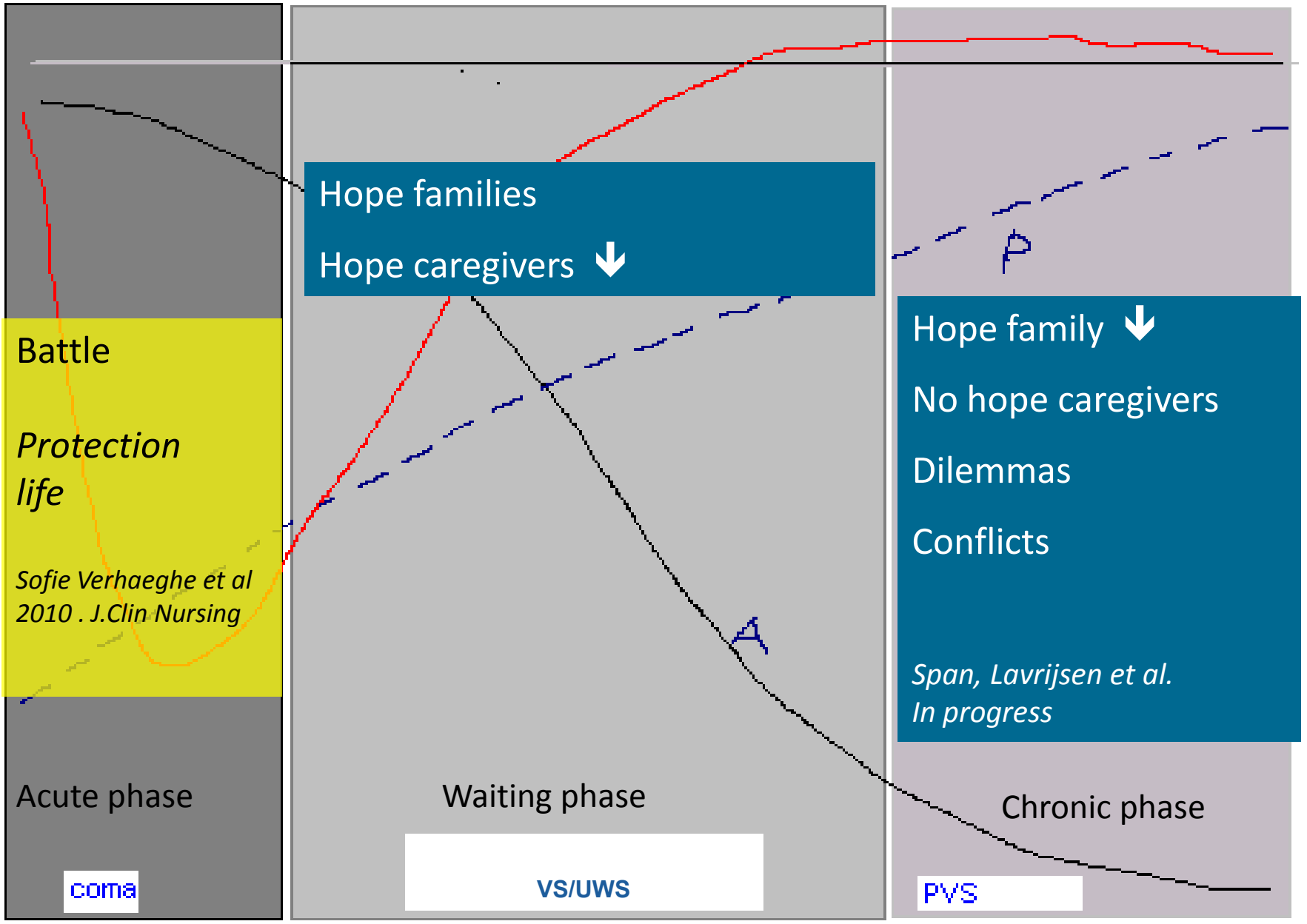
Lessons of case 4 + 5

- **Attitudes of families are crucial** in ultimate decisions of physicians
- **Intensive guidance** towards the key decisions is necessary
- Accepting consequences remains **difficult**
- Particularly for parents who have found **new balance** in the stable phase

When?



JM Minderhoud. In: Traumatische hersenletsels, 2003


Hope families
Hope caregivers
Battle
Protection
life
Sofie Verhaeghe et al
2010 . J.Clin Nursing
Hope family
No hope caregivers
Dilemmas
Conflicts
Span, Lavrijsen et al.
In progress
Acute phase
Waiting phase
Chronic phase
coma
VS/UWS
PVS

The ‘window of opportunity’

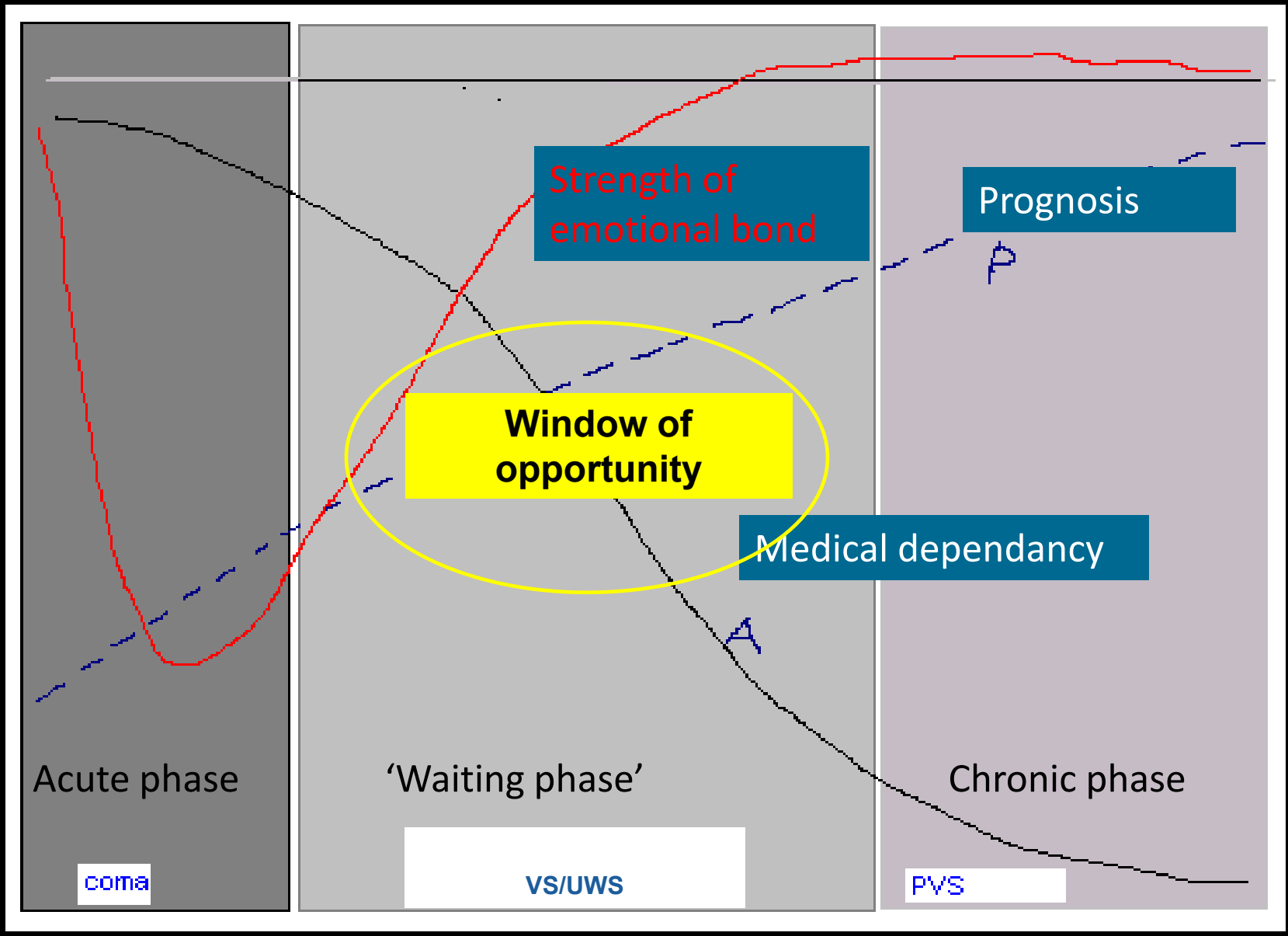
through the lens of family experience

Experiences of 26 family members (14 families)

“First they say it was too soon, now they say it is too late”

‘’We show that some people believe that **their relatives are being kept alive against their wishes**
and this seems to be partly because the **‘window of opportunity’** for allowing death has closed
and there seems to them to be no legal or human way of releasing them”

When?



JM Minderhoud 2003; Lavrijsen et al Ned Tijdschr Geneeskd 2005; Kitzinger 2012

Who has to decide?

.. and to bear the burden of a decision

- The physician
- After intensive guidance of the family
- After a state-of-the-art diagnosis & prognosis
- With a proactive attitude
- Individual solutions

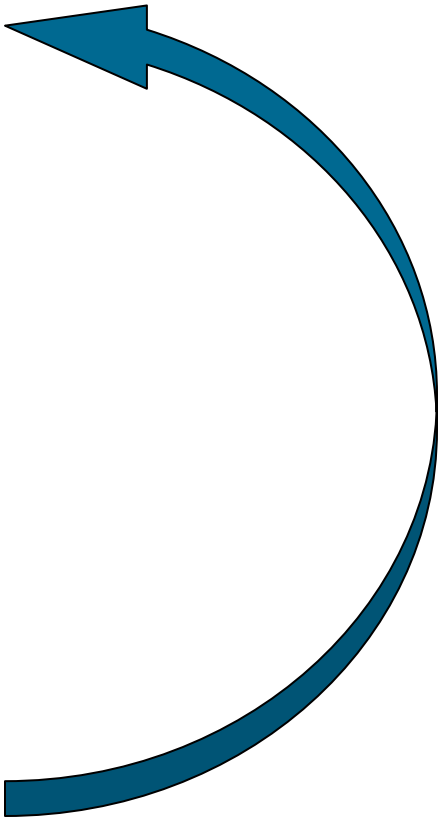
Keys of prevention hopeless VS/UWS

- The best diagnosis & prognosis
- Formulate prevention permanent UWS as a collective point of departure
- The best treatment to recover (Austria and Netherlands: ~ 50% without rehabilitation)
- Regular evaluation of the total treatment
- From the beginning intensive guidance of family towards medical decisions
- Communicate that physician is responsible
- **Educate and support them**
- Co-operate ‘through the walls’ of institutions

Lavrijsen J. Thesis 2005, Radboud University

Challenges

- Engage people, society for long-term care
- Connect experts
- Build teams of expertise
- Technical support diagnosis, prognosis
- Specialized rehabilitation facilities
- ‘Transmural’ care plans
- Stimulate Advanced Directives
- Support ethical dilemmas, moral debates
- Linked with research and education



Tell and write the stories

‘Niemand tussen Wal en Schip’
Acquired brain injury

Development

Centre of Research & Expertise

Development expertise & research about

- Locked-in syndrome (LIS)
- Minimally Conscious State (MCS)
- Unresponsive Wakefulness Syndrome (UWS)
- Ethical dilemmas, end-of-life decisions UWS
- Severe Acquired Brain Injury in Nursing Homes
- Follow-up Early Intensive Neurorehabilitation
- Coping families

Learning from families

How to cope with this?

- 60% > 3 hours/day visit
- 65% no time for friends
- 59% signs depression
- 40% financial problems

- Support
- More research, started 2013

M. Leonardi et al. Brain Inj, febr 2012

Quote of a mother

‘My son died at the side of the road and the funeral was 6 years later’

In: Bryan Jennett . *The vegetative state* 2002

Learning from (ex)-patients

Unexpected recovery of consciousness…. and then?

Learning from you

- Support nursing staff
- By moral debates
- About their dilemmas

Span, Lavrijsen et al. In progress

Nursing care: it's not that easy

Compassion

Conflicts

Fear

Powerlessness

Burnout

Span, Lavrijsen et al. In progress

Learning from other countries
Comparison of values and ethics

The Netherlands

- ‘VS patients are in a blocked dying process’
- Cases in media
- Debate in society
- Jurisprudence
- Guidelines KNMG, Health Council

Austria, Vienna

- ‘VS patients are not dying’
- No cases in media
- No debate in society
- No jurisprudence
- No guidelines about discontinuation medical treatment

Beljaars, Valckx, Stepan, Donis, Lavrijsen. In review

Quotes of families

The Netherlands

Austria, Vienna

‘I told the neurologist that if something like VS would be the prospect, treatment should be stopped’

Died by pneumonia after being in VS for 13 years

‘Stopping treatment is unthinkable here’

Beljaars, Valckx, Stepan, Donis, Lavrijsen. In review

Quotes of families

The Netherlands

- ‘Her wish has been fulfilled. She is at peace now’.

  ANH withdrawn after 12 years. She had expressed that here wish was not to live in VS after seeing Stinissen case

Austria, Vienna

‘I decide for him, the way I do for myself’

13 years in VS after a car accident at 24 years

Beljaars, Valckx, Stepan, Donis, Lavrijsen. In review

Co-operation with our hands, mind and heart!

in Respekt für Ihre wunderbare Arbeit

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