SYLLABUS

TC48: Breaking Bad News

Wednesday, November 16, 2011 09:00 - 12:30 Hall I

Marrakesh, Morocco, November 12-17, 2011

XXth WORLD CONGRESS OF NEUROLOGY

XXth WCN 2011 MARRAKESH World Congress of Neurology

WFN

SMN SOCIETE MAROCAINE DE NEUROLOGIE

WCN Education Program

Wednesday, 16 November, 2011

09:00-12:30

BREAKING BAD NEWS

Chairperson: **Charles J. Vecht**, *The Netherlands*

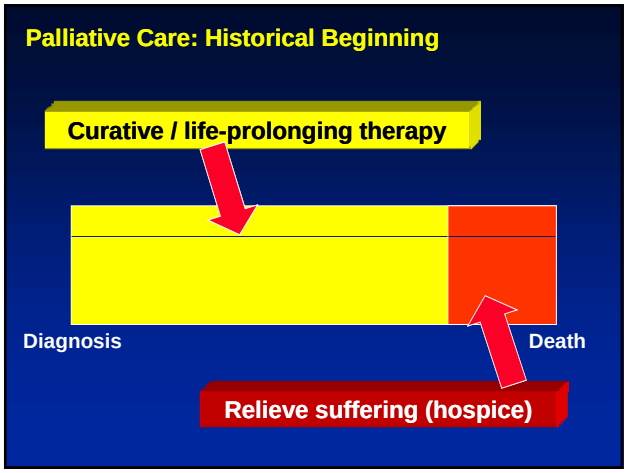
BREAKING THE NEWS IN ALS: LESSONS LEARNED FROM PATIENTS
Gian Domenico Borasio, *Germany*

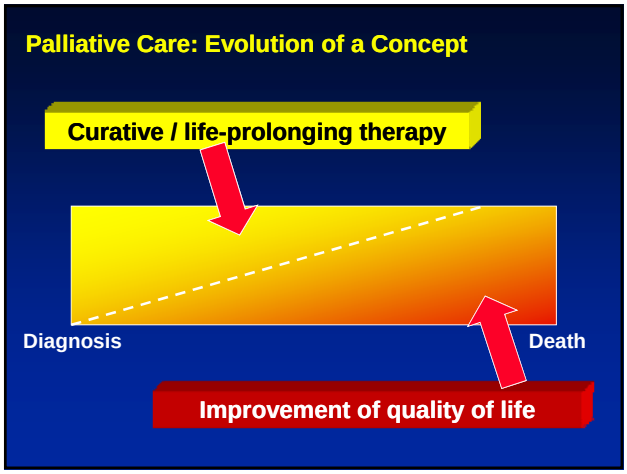
GENETIC COUNSELING OF FAMILY-MEMBERS: CONFRONTED WITH MYOTONIC DYSTROFIA AND HUNTINGTON'S DISEASE
Marianne de Visser,*The Netherlands*

BRAIN TUMORS: A JOURNEY THROUGH BAD AND GOOD NEWS
Charles J. Vecht, *The Netherlands*

10:30-11:00 *Coffee Break*


Breaking the news in ALS: Lessons learned from patients
Prof. Gian Domenico Borasio
Université de Lausanne
CHUV


Palliative Care: Historical Beginning
Curative / life-prolonging therapy
Diagnosis
Death
Relieve suffering (hospice)


Palliative Care: Evolution of a Concept
Curative / life-prolonging therapy
Diagnosis
Death
Improvement of quality of life

Palliative Care
is care for the end of life,
not just at the end of life.

Amyotrophic Lateral Sclerosis

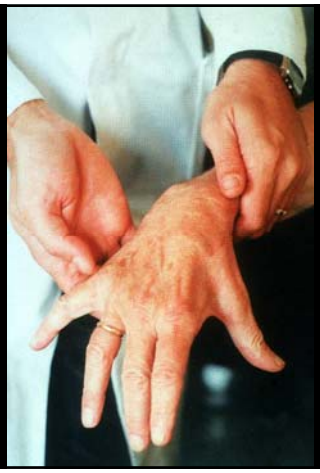
- degenerative disease of the first (central) and the second (peripheral) motor neuron
- progressive paralysis of all voluntary muscles
- no major deficits in sensation
- mostly mild cognitive changes of the frontotemporal type

Epidemiology of ALS

incidence	1.5-2 / 100,000 / year
prevalence	6-8 / 100,000 (increasing tendency)
gender distribution	m : f 1.5 : 1
average age at onset	58 years

Clinical Course of ALS

- constant progression, different speeds
- rarely phases of stabilisation
- virtually no remissions
- no abrupt deteriorations
- median life expectancy: 3 years (10% >10yrs)
- death through respiratory insufficiency



Amyotrophic Lateral Sclerosis: a chronic illness?

- Loss of ambulation
- Loss of manual dexterity
- Loss of writing
- Loss of driving ability
- Loss of working ability
- Loss of self-care ability
- Loss of ability to swallow
- Loss of speech
- Loss of breathing ability
- Loss of all communication (locked-in)
- Loss of emotional control
- Loss of independence
- Loss of social role
- Loss of family role
- Loss of intimacy
- Loss of dignity
- Loss of hope
- Loss of faith
- Loss of meaning in life

"When you think that you've lost everything, you find out you can always lose a little more."

Bob Dylan, *Trying To Get To Heaven*

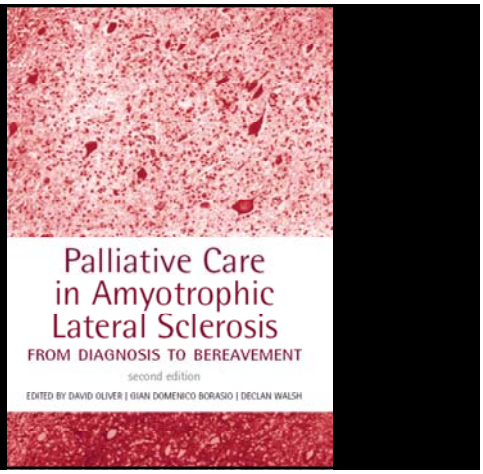
Symptoms of ALS

Direct

- weakness and atrophy
- fasciculations and muscle cramps
- spasticity
- dysarthria
- dysphagia
- dyspnea
- pathol. laughing/crying

Indirect

- psychological problems
- sleep disorders
- constipation
- drooling
- thick mucous secretions
- symptoms of chronic hypoventilation
- pain



Role play

Palliative Care in ALS

breaking the news → psychological support →

sympt. treatments → PEG, noninv. ventilation →

end-of-life decisions → terminal phase and death

→ bereavement counselling

Survey on breaking the news

(Borasio et al, J Neurol Sci 1998)

- >50% of ALS patients were unsatisfied with the way the diagnosis was told
- Reasons for dissatisfaction:
  - unclear explanation of the diagnosis
  - no open discussion of course and prognosis
  - no information on where to find help
  - lack of empathy

Breaking the news in ALS

- integral part of palliative therapy
- not standardisable
- early, frank and open
- with relatives
- stepwise
- repeated

Goals

- telling the diagnosis (probable/definite ALS)
- preventing fears and anxiety
- providing information for life planning
- discussion of forthcoming palliative measures
- establishment of a mutual trust relationship

Standards of palliative care for patients with ALS: results of a European survey

(Borasio et al., ALS & Other MND 2001)

Telling the diagnosis

- 15% do not inform in the presence of a relative
- 24% do not inform on existing ALS associations
- 31% do not tell the diagnosis of ALS to all patients
- 37% take <30 min (4% <10 min)
- 12% have a counsellor available

Why breaking bad news is difficult for doctors

(after Buckman, 1996)

- Fear of the messenger getting blamed for bad news
- Perceived lack of time
- Lack of training
- Fear of causing distress
- Fear of being asked difficult questions
- Fear of not having all the answers
- Invoking fears of one's own mortality

Three basic rules

(after Maguire et al., 1986)

- do not withhold information if the patient wants it
- do not impose information if the patient does not want it
- gauge and respond to the patient's reaction to the news

The stages in breaking bad news

(after Maguire et al., 1986)

- Setting
- Finding out what the patient already knows or suspects
- Finding out how much more they want to know
- Firing the warning shot
- Hierarchy of euphemisms
- Observing and responding to the patient's reactions at each step
- Contract for the future

Initial information

- usually after an inpatient workup
- stepwise offering of information over several days
- final discussion with:
  - relatives
  - social worker
  - ALS clinic physician

Minimal information

- name of the disease
- progressive disease of the motor nerves
- emphasis on positive aspects and palliative measures
- discussion of ongoing research and drug studies
- discussion of available drug options

Additional information

- beginning of the disease: long before onset of symptoms
- no sudden worsening to be expected
- patient organisations (ALSA, MNDA…)
- second opinion
- prognosis: no reliable prediction possible

Therapies

- approved therapies
  - realistic expectations
  - known side effects
- "alternative" therapies
  - no concerns regarding e.g. homeopathy or acupuncture
  - warning about health and financial risks

Possible or suspected ALS

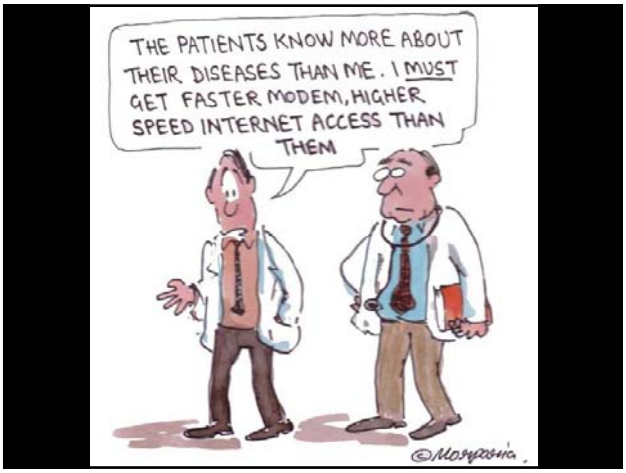
- careful approach, depending on the degree of clinical certainty
- discussion of possible differential diagnoses and planned diagnostic workup
- if ALS is strongly suspected: information about palliative therapy and available medication

„**If we want to help somebody, we must first find out where he stands.** This is the secret of all caring. Those who cannot do this, are stuck with an illusion if they think they can help others. In order to really be able to help somebody, I must understand more than he does – but first and foremost I must understand what he understands. If I do not, then my greater understanding won't help him at all."

(cont.)

„If I still want to assert my greater understanding, then it is because of my vanity, or my pride, so that my goal actually, instead of helping him, is to be admired by him. But: **Every real act of help starts with an act of humility**; the helper must understand that helping does not mean ruling, but serving, and that helping also implies the willingness to accept that one may be wrong, that one may not understand what the other understands.“

Søren Kierkegaard



When should communication about end–of–life issues be initiated in ALS?

Information on respiratory failure, ventilation and terminal phase

- at the onset of
  - dyspneic symptoms
  - symptoms of chronic nocturnal hypoventilation
  - rapid decrease of vital capacity
- description of hypercapnic coma
- discussion of ventilatory options
- advance care planning

Movie „Death on request“

(Holland, 1994)

- Documentary on the euthanasia of an ALS patient
- >10 untreated symptoms (incl. pain, dyspnea, depression and anxiety)
- Two physician state that, without euthanasia, he will „choke to death“
- Patient asks for, and receives, euthanasia

➢ **The information was wrong!**

The terminal phase in ALS

(Neudert et al, J Neurol 2001)

- 171 patients (Munich 121, Rochester 50)
- causes of death: respiratory insufficiency 86%, cardiac failure 6%, pneumonia 5%
- 91% peaceful deaths (USA: 90.4%)
- **no patient choked to death**

Triggers for end of life discussions in ALS

- The patient or family asks – or “opens the door”
- Severe psychosocial and/or spiritual distress
- Pain requiring high doses of analgesics
- Dysphagia requiring feeding tube
- Dyspnea, symptoms of hypoventilation, FVC <50%
- Loss of function in two body regions

Mitsumoto et al., RWJ report 2003

End-of-Life decisions in ALS

- Patients‘ QoL priorities and EoL preferences change over a 6-month period
  (Silverstein et al. 1991; Neudert et al. 2001)
- Religiousness and spirituality influence EoL decisions (Murphy et al. 2000; Robbins et al. 2001)

BREAKING THE NEWS IN HUNTINGTON'S DISEASE AND MYOTONIC DYSTROPHY

Including Genetic Counseling

Marianne de Visser
Dept of Neurology
Academic Medical Center
Amsterdam
The Netherlands

The diseases: Huntington's disease

Huntington's disease is

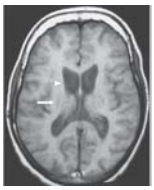
- a progressive, fatal, neurodegenerative disorder leading to death 15 to 20 years after its onset
- caused by an expanded CAG repeat in the huntingtin gene, which encodes an abnormally long polyglutamine repeat in the huntingtin protein
- inherited in an autosomal dominant manner with age-dependent penetrance, and repeat CAG lengths of 40 or more are associated with nearly full penetrance by age 65 years

Huntington's disease

- Prevalence ~ 10 per 100 000
- Mean age of onset is 40 years (1-85)
- Characterized by progressive motor dysfunction, cognitive decline, and psychiatric disturbance, caused by both neuronal dysfunction and neuronal cell death
- Many patients have substantial cognitive or behavioural disturbances before onset of diagnostic motor signs
- Up to now, no drug has proven efficacious in a randomised placebo-controlled trial of disease-modifying therapy

Diagnosis

- Huntington disease is distinguished by the triad of autosomal dominant inheritance, chorea and dystonia and dementia.
- Magnetic resonance imaging reveals atrophy of the caudate nucleus (arrowhead) and putamen (arrow), with enlarged ventricles, which is suggestive of Huntington's chorea. Can also be found at an early stage.
- Diagnosis is confirmed by DNA analysis



Suicide and suicide attempt in HD

- Depression is typical and suicide is estimated to be about 5-10 times that of the general population (about 5–10%).
- Suicidal ideation is frequent finding in Huntington's disease. In a cross-sectional study, ~ 9% of asymptomatic at-risk individuals contemplated suicide at least occasionally.
- In prediagnostic phase, the proportion rose to 22% but in patients who had been recently diagnosed, suicidal ideation was lower. The frequency increased again in later stages of the illness

Presymptomatic screening

- Since 1986, presymptomatic DNA testing using genetic linkage analysis has made it possible for risk carriers to have their risk modified to approximately 98% or 2%.
- Identification of the HD gene mutation in 1993, CAG repeat size analysis of the huntingtin gene allowed complete certainty of either having or not having HD.
- Presymptomatic testing is not without risk. Suicide can follow a positive result.
- There are protocols to exclude testing for children or those with suicidal ideation, inform patients of the implications of test results for relatives

Review of studies addressing psychological and psychiatric adjustment of people at risk for HD

Not related to presymptomatic testing

- Children of HD patients had high rate of psychiatric disorder (25% conduct disorder or antisocial personality disorder, 18% major depression).
- Most conditions (anxiety and depression) were mild or occurred only in adolescence (conduct disorder).

Duisterhof et al. J Med Genet 2001;38: 852–861.

Review of studies on psychological and psychiatric adjustment of people at risk for HD

Psychological well-being of test applicants before disclosure of test result

- Mean scores of psychological well-being and Huntington specific distress before disclosure of test result (baseline level) within normal range.
- Approximately 20% of the risk carriers scored at mild levels of depression and hopelessness, whereas very few scored at the level of moderate or severe depression.

Course of psychological well-being after the test result

- Identified gene carriers showed at 7 days post-test more depression, hopelessness, and a decrease in general well-being (in the mild range).
- A return to baseline levels of anxiety and depression occurred in the first month. Hopelessness, depression, and general well-being returned to baseline level within six months and remained there 1 and 3 years post-test.
- The relief non-carriers expressed in the first weeks disappeared afterwards; they experienced most distress at six months. Some have survivors guilt.

Percentage of those at risk asking for testing

- The percentage of those at risk who requested testing when approached by registries or testing centres varied from 9% in Wales, 10% in Indiana, 16% in the Manchester area, to 20% in the Vancouver area.
- In The Netherlands, 24% of the subjects at risk registered in the Leiden Roster for HD applied for presymptomatic testing in the period 1987 to 1997.

Management of HD

- In the northern part of the Netherlands coordinated multidisciplinary care is offered to HD patients.
- A team of a neurologist, psychologist, occupational therapist, speech and language therapist, social worker and nursing home doctor monitors the patient and companion on a half-year basis and provide them with a plan of care.
- A case manager coordinates the plan of care in the dwelling place of the patient.

R.B. Veenhuizen, A. Tibben - Brain Research Bulletin 2009;80:192

Beware of genetic discrimination

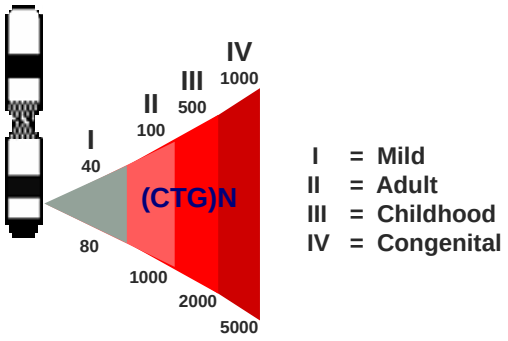
- In the Netherlands, clinical geneticists discuss employment and insurance with the client in the pretest counselling sessions, but only a few clients are concerned that genetic information may be used by insurers to deny, limit, or cancel health insurance, and by employers to discriminate in the workplace.

Tibben A. BMJ 2009; 338:b1281

The diseases: Myotonic dystrophy

- Myotonic dystrophy (DM1): prevalence of 1 in 8000 among Western Europeans
- Marked inter- and intrafamilial variability caused by dynamic mutation of DM protein kinase (DMPK) gene on chromosome 19q: expansion of a CTG repeat (n 5-37, affecteds 50-several 1000s)
- CTG repeat is unstable and increases in length when transmitted from generation to generation
- Anticipation: clinical picture becomes more severe in successive generations

Myotonic dystrophy type 1



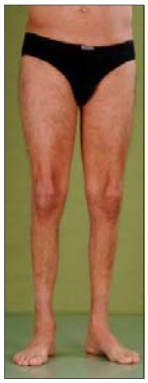
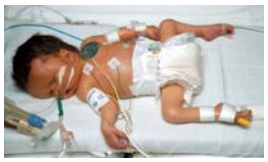
I = Mild
II = Adult
III = Childhood
IV = Congenital

Myotonic dystrophy

Type	Age (years)	Features
Mild	> 50	Cataract, mild weakness
Adult	10-50	Myotonia, muscle weakness, cataract, fatigue
Childhood	1-10	Hypotonia, learning disabilities, limited motor skills
Congenital	Prenatal-birth	Swallowing- and breathing diffficulty, hypotonia, contractures, psychomotor retardation

Various phenotypes



Myotonic dystrophy

Multi-organ disorder

- myotonia
- muscle weakness
- cataract
- cardiac abnormalities
- mental retardation
- excessive sleepiness
- other abnormalities, e.g., endocrine, gastro-intestinal, etc.

Often easily recognisable

Sometimes more difficult

Myotonia is a characteristic feature

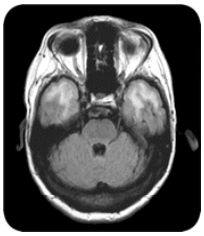
Four pictures of the same patient:
From normal looking toddler to severely affected adult

DMPK

- DMPK is produced in substantial amounts only in human heart and skeletal muscle
- In the central nervous system, DMPK is synaptically localized in the cerebellum, midbrain, hippocampus, and medulla, at the apical membrane of the ependyma and choroid plexus

Cognitive disturbances

- The congenital form is associated with mental retardation.
- From 10% to 24% of DM1 patients show mental retardation.
- IQ steadly declines as: (1) the age of onset decreases and (2) the CTG expan-sion increases. Lower IQs correlate with longer expansions, mainly related to maternal inheritance
- IQ apparently does not correlate with the neuromuscular impairment and the severity of disease



Personality and behavioral disturbances were noted in the first clinical descriptions by Steinert in 1909; several descriptions of suspicious attitude, egocentricity, disagreeableness, or indifference were subsequently published

Prognosis and course of the disease

Age at death:

- Adult type, median 56 years
- Congenital type, median 35 years

Cause of death (adult type):

• Arrhythmias	31%
• Pneumonia	29%
• Post operative	6%
• Fracture	7%
• Malignancy	10%

(de Die-Smulders et al., Brain 121;1998)

Breaking the bad news: diagnosis

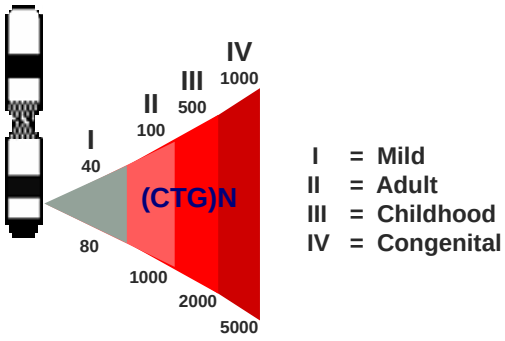
This lady was examined when her daughter gave birth to a floppy child

Myotonic dystrophy and pregnancy

Neuromuscular diseases and pregnancy

- Anticipating pregnancy: preconceptional counseling
- During pregnancy:
  - prenatal counseling and monitoring of pregnancy
  - diagnosis and treatment of neuromuscular complications
- After delivery: monitoring of mother and neonate

Myotonic dystrophy type 1



I = Mild
II = Adult
III = Childhood
IV = Congenital

Preconceptional counseling of DM1
Genetic aspects

- Marked inter- and intrafamilial variability caused by dynamic mutation of DM protein kinase (DMPK) gene on chromosome 19q: expansion of a CTG repeat (n 5-37, affecteds 50-several 1000s)
- CTG repeat is unstable and increases in length when transmitted from generation to generation
- Anticipation: clinical picture becomes more severe in successive generations

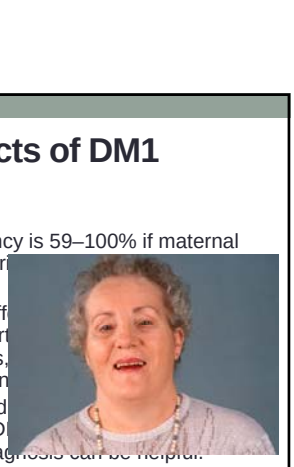
Question

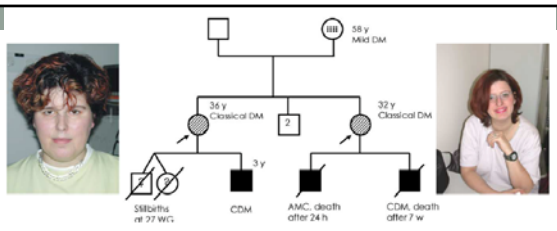
Congenital myotonic dystrophy occurs if

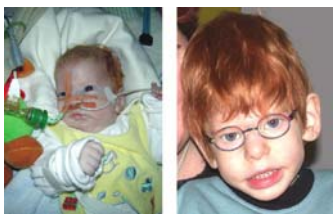
1. The mother has myotonic dystrophy with a CTG expansion of 1-4 kb
2. The mother is subclinically affected (CTG expansion < 1kb)
3. Both answers are correct

Genetic aspects of DM1

- A priori risk of a CDM pregnancy is 59–100% if maternal CTG expansion is 1-4 kb, the ri
expansion is <1 kb.
- However, even subclinically aff
sizes as low as 75 can give birt
more than one third of families,
brought the mother to the atten
- Recurrence risk to further child
mother has given birth to a CD
or pre-implantation genetic diag







Anticipation

Obstetric risks of DM1

Obstetric risks associated with DM (summary of 157 reported gestations completed to at least 6 months[a])

Complication	Frequency (%)		
	This series ($n = 64$)	Literature ($n = 93$)	Reference population (%)[b]
Miscarriage	12	13[c]	12–15
Ectopic pregnancy	4	n.a.	0.3–1.4
Pre-eclampsia	9	9[c]	5–7
Placenta previa	9	4	0.3–0.5
Polyhydramnios	17	10–15	0.5–0.7
Preterm birth (≤36 WG)	34	30–35	7
Operative delivery	13	11	9–12
Cesarean section	36	31	10–15
Perinatal mortality	15	10–20	0.5–1

Rudnik-Schöneborn S, Zerres K. Eur J Obst Gynec Reprod Biol 2004;114: 44

Complications and Management

- Hazards of anesthesia in case of surgery
  - Severe myotonic spasms due to administration of depolarizing relaxants
  - Marked respiratory depression due to barbiturates.
  - Hypersensitivity to anesthetic drugs (prolonged apnoea after administration of thiopentone or opiates)
  - Chest infections, delayed gastric emptying and cardiovascular problems in later p.o. period

Recommendations:
- Obstetric monitoring
- Delivery should take place in centres with perinatal facilities
- Patients in labor should not receive heavy sedation
- Local/regional anesthetics preferable to general anesthesia.

My precious healthy baby

“ BREAKING BAD NEWS "

- Lessons learned from ALS Patients
  Professor Gian Domenico Borasio
- Huntington's Diseae and Myotonic Dystrophy: Consequences for Family Members
  Professor Marianne de Vissser
- Brain Tumours: a Journey through Bad and Good News
  Dr Charles J. Vecht

Option 1

“ Hello,Mr. Jones.

You have a brain tumor and may only have a year to live.

We suggest you begin some type of therapy right away.

You probably want to get some referrals for radiation and chemotherapy.

Best of luck. ”

Option 2

“Hello, Mr. Jones.

You have a brain tumor and it is malignant.

Some might tell you that you have less than 2 years to live because, historically, this tumor has been pretty nasty, but there are exceptions to every trend, and there is no reason you can’t be one of them.

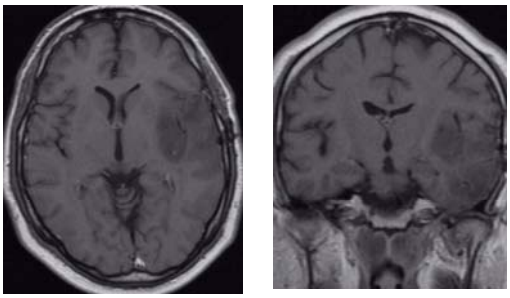
In fact, I just returned from speaking at a conference where I met many other survivors who are more than 5 years out from diagnosis.

One fellow has had this for 13 years!

You’ll need to pursue some fairly aggressive therapy, but you can do it. Odds are meant to be beaten, and there are people and organizations across the country that can and will help you. Here is an information kit at www. …. ”

Issues on Bad News in Oncology

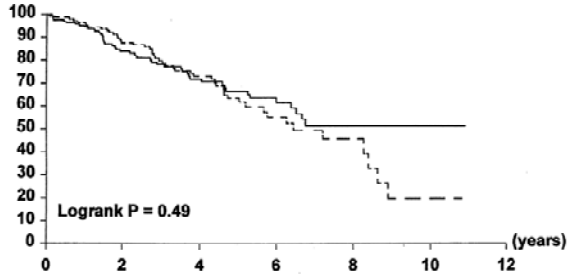
- Own Background
- Background on Gliomas: Two Cases
- Wait-and-See Policy
- Cultural Background
- Patients' Preferences
- How to inform the patient
- Informed Consent
- Anticipation on Action
- How to maintain Hope



M 36 yrs
Single Seizure in February 2002

41005

Initial Wait-and-See Policy in Low-Grade Glioma



EORTC study 22845; Karim et al, 2002

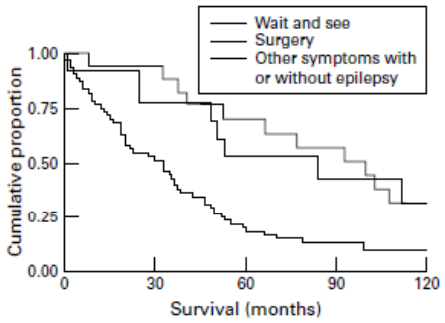


Figure 2 The "wait and see" and surgery groups had epilepsy only at referral. The group with other symptoms presented with or without epilepsy.

Van Veelen, 1998

Prognosis in Low-Grade Glioma in adults

- older age (> 40 years)
- astrocytoma histology (oligo/mixed vs. astrocytoma)
- neurologic deficits before surgery
- largest tumor diameter
- tumor crossing the midline

EORTC Karim, Pignatti J Clin Oncol 2002

Wait-and-See Approach in Low-Grade Glioma

Method: Semi-structured interview with 24 patients with imaging evidence of LGG without prior intervention;F-U>1yr

- Initial devastation followed by acceptance and low anxiety
- Absence of symptoms mitigates anxiety concerning the possibility of progression
- Patients prefer to defer surgery until progression or change in quality of life;
- Anxiety reduced by trust in physician
- QoL not affected by diagnosis, as fear of morbidity from intervention is greater than fear of uncertainty
- CONCLUSIONS: Wait-and-see approach does not enhance anxiety or reduce QoL in LGG

Hayhurst, 2011

Proper information during Surgical Decision-Making Process lowers Anxiety in High-grade Glioma

- Study on 26 patients with High-Grade Glioma
  Measurement of Comprehension and Satisfaction of Information about treatment options during surgical decision-making process, together with Hospital Anxiety and Depression Scale (HADS)
- Less Anxiety:
  - if desire to receive information regarding their illness
  - if higher degree of comprehension
  - higher level of satisfaction with information provided
- Improvement in Communication contributes to:
  - decrease in anxiety
  - enhancement of well-being

Díaz et al 2009

Influence of Cultural Background

Anglo-Saxon background:
Prefer disclosure

Other Backgrounds:
Vary, with tendency to favour non-disclosure

Asian cultures:
In favour of non-disclosure
Patients unaware of diagnosis and prognosis

Family :
In some cultures: Highly involved, i.e family be informed first of diagnosis and prognosis
Patients be told gradually or not at all

Hagerty, 2005

Highest Ratings of Patients' Preferences Regarding Bad News Delivery

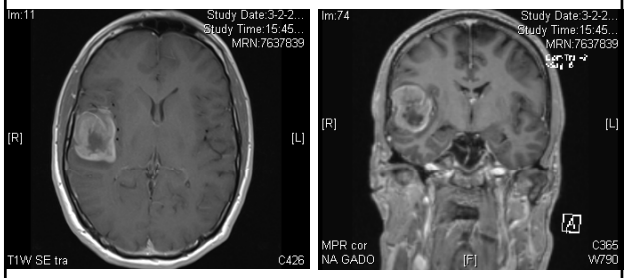
• Doctor up-to-date on research on my type of ca	4.72	.49
• Doctor telling me best treatment option	4.70	.57
• Doctor takes time to answer all my questions	4.66	.56
• Doctor honest about severity of my condition	4.61	.64
• Feeling confident about my doctor's skill	4.59	.55
• Given enough time to ask all of my questions	4.57	.63
• Giving information in simple, clear language	4.56	.70
• Doctor giving me full attention	4.53	.68

Parker 2001

Lowest Ratings of Patients' Preferences Regarding Bad News Delivery

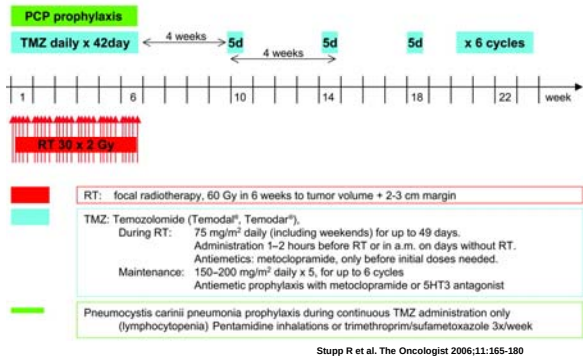
- Encouraging me to talk about my feelings about the news 3.42
- Telling me it's ok if I become upset 3.40
- Having doctor inform my family about my Diagnosis 3.38
- Being told by a doctor who knows me well 3.33
- Comforting me if I become emotional 3.30
- Doctor warning me there will be unfavorable news 3.01
- Doctor helps me how to tell others about my Cancer 2.62
- Doctor holding my hand/my arm when giving news 2.23

Parker 2001



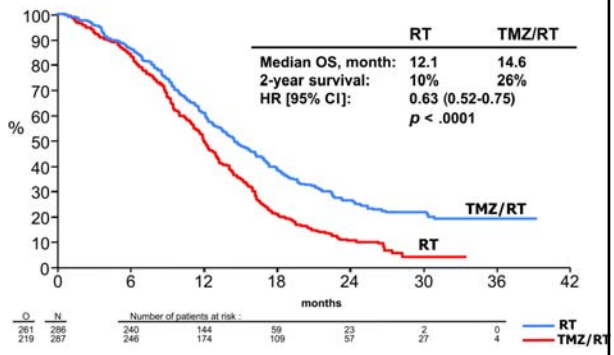
030202010 7637839

EORTC/NCIC Treatment Scheme for Glioblastoma



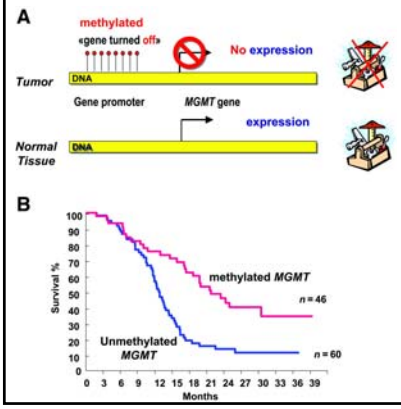
Stupp R et al. The Oncologist 2006;11:165-180

Survival in EORTC/NCIC trial
Temozolomide plus Radiotherapy vs. Radiotherapy alone



Stupp R et al. The Oncologist 2006;11:165-180

Inactivation of Methylguanine-methyltransferase (MGMT) gene and Benefit from Temozolomide



Stupp R et al. The Oncologist 2006;11:165-180

- Identify the spectrum of treatments that are indicated for the patient's condition
- Understand patient preferences and goals in order to inform the patient about options
- Advise the patient concerning choice of cancer care

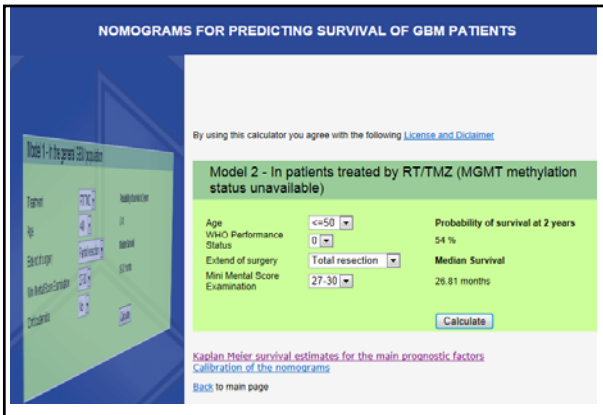
CHECKLIST:
Take Care of the Whole Picture

- - HEADACHE, NAUSEA / VOMITING
- - SEIZURES
- - QUESTIONS ON COGNITION
- - DEPRESSION : “VITAL SIGNS “
- - MEDICATION
- - EXAMINE THE PATIENT
- - PERFORMING A COGNITIVE EXAM

SPIKES

- S - SETTING UP the Interview
- P - ASSESSING THE PATIENT’S PERCEPTION
- I - OBTAINING THE PATIENT’S INVITATION
- K - GIVING KNOWLEDGE AND INFORMATION
- E - ADDRESSING THE PATIENT’S EMOTIONS WITH EMPATHIC RESPONSES
- S - STRATEGY AND SUMMARY

Baile 2005



www.eortc.be/tools/gbmcalculator

Table 2 Capacity outcomes for controls and patients with malignant glioma on CCTI consent standards

Standard	Capable	Marginal	Incapable
S1: expressing choice			
Controls	22 (100)	0 (0)	0 (0)
MG	25 (96.2)	0 (0)	1 (3.8)
S3: appreciation			
Controls	20 (90.9)	0 (0)	2 (9.1)
MG	20 (76.9)	2 (7.7)	4 (15.4)
S4: reasoning			
Controls	20 (90.9)	2 (9.1)	0 (0)
MG	17 (65.4)	6 (23.1)	3 (11.5)
S5: understanding			
Controls	20 (90.9)	2 (9.1)	0 (0)
MG	12 (46.2)	8 (30.8)	6 (23.1)

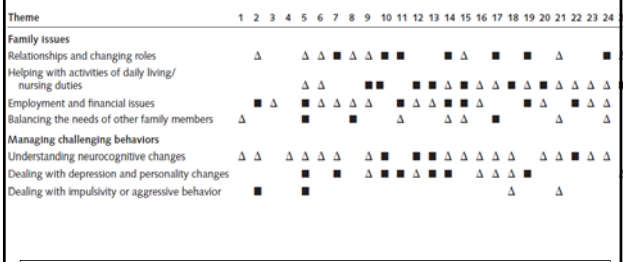
Triebel 2009

Informed Consent Procedure

- MG group perform below control group on - Appreciation, - Reasoning, - Understanding
- Patients with MG perform equivalently to controls in evidencing a simple research participation choice
- 1/3 of patients with MG show compromised impairment (mild/moderate or severe) on the 3 consent abilities.
- Cognitive measures of phonemic/semantic word-fluency predict performance on consent standards
- Steroid treatment and anticonvulsant use are related to poorer CCRI performance

Marson 2010

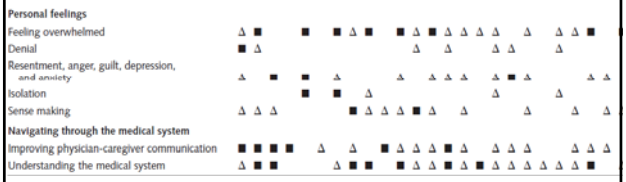
Caring for the Brain Tumor Patient : Family Caregiver Burden



Black square : Very strong theme (mentioned 3 or more times by caregiver, or topic dominates interview).
White triangle ; Moderately strong theme (mentioned at least 2 by caregiver).

Schubart, 2008

`Caring for the Brain Tumor Patient : Family Caregiver Burden



Black square : Very strong theme (mentioned 3 or more times by caregiver, or topic dominates interview).
White triangle; Moderately strong theme (mentioned at least 2 by caregiver).

Schubart, 2008

GOAL OF TREATMENT AND HOW TO FACE REALITY

- CONFRONT WITH REALITY:
  - " OTHER SIDE OF THE MIRROR "
- KEEPING-UP THE SPIRITS
  - TREAT DEPRESSION
  - ENCOURAGE PHYSICAL ACTIVITY
  - ENCOURAGE WORKING

ANTICIPATION

- BAD NEWS : TELL WHAT YOU ARE GOING TO DO IN CASE OF…..: ANTICIPATE ON ACTION
- UNCERTAINTY
- UNEXPECTED TURNS
- YOU ARE YOUR OWN PERSONALITY: DIFFERENT WAYS
- MULTIDISCIPLINARY TEAM
  (Median survival 18.7 vs. 11.9 months)

Back, 2007

HONESTY

- WITH YOURSELF:
- WHAT YOU CAN AND WHAT YOU CANNOT
- YOU LIKE TO BE A PROFESIONAL
- TACKLE THE PROBLEM

HOW TO LEARN OF YOURSELF

- PERSONAL EXPERIENCE:
  - INCREASING WITH YEARS
  - INCREASING WITH EXPERIENCE
- RECOGNIZE (SMALL) MISTAKES:
  - WHAT COULD I HAVE BEEN DOING BETTER
  - WHAT TO DO IN THE NEXT CASE

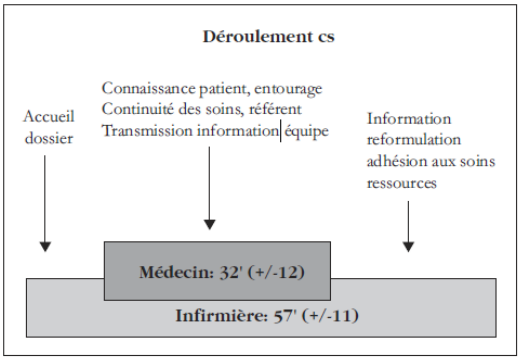
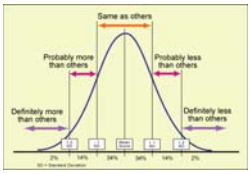


Figure 2. Déroulement de la consultation d'annonce.

Tivoli 2005

How to Foster Hope …



- ANTICIPATION ON ACTION
- EMPHASIZE NEGATIVE AND POSITIVE PROGNOSTIC FACTORS
- GAUSS (CURVE) DISTRIBUTION
- TRY TO BE A GOOD PROFESSIONAL

Specifics aside, the second example does two things that the first does not. It identifies a real living person as an example of someone who is making it—not just a laboratory theory. This gives the patient living proof that he or she can make it; it gives that person a goal to work toward and a reason to believe they can achieve it. The second example also ends with a tangible tool and a note of hope. The bare facts must be told, but the key to this delivery is that those facts are simultaneously presented with a tangible cause for hope, and the last word is one of hope and specific action.

D. Bailey , 2000