

The Good...

The Bad.....

The Ugly

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DEFINITIONS

- *The Good* - THOSE CASES IN WHICH THE CHOICE FOR WITHHOLDING WAS MADE APPROPRIATELY AND EXECUTION WAS WELL CARRIED OUT
- *The Bad* - THOSE CASES IN WHICH THE OPTION TO WITHHOLD WAS INAPPROPRIATE OR POORLY MADE
- *The Ugly* - CASES IN WHICH THE CHOICE WAS POORLY MADE AND EXECUTION WAS INEXPERT LEADING TO INCREASED SUFFERING



WAHN = WITHHOLDING ARTIFICIAL HYDRATION / NUTRITION



THE CONTEXT

- MOST CASES INVOLVE NEUROLOGICALLY DEVASTATED CHILDREN WHO ARE MINIMALLY CONSCIOUS
- WAHN IN PATIENTS WITH ANY DEGREE OF CONSCIOUSNESS IS COMPLICATED, E.G. ALS
- WAHN IS CONSIDERED WHEN THERE IS NO OTHER ARTIFICIAL SUPPORT TO WITHHOLD



WAHN = WITHHOLDING ARTIFICIAL HYDRATION / NUTRITION



A Case of the Good

- PREVIOUSLY HEALTHY 3-YO FEMALE
 - TWO WEEK HX OF NEW ONSET SEIZURES → RAPID PROGRESSION TO APHASIA, R HEMIPARESIS, CONTINUOUS EEG SEIZURE ACTIVITY → PROGRESSING TO OPPOSITE CORTEX
 - PROGRESSIVE ENCEPHALOPATHY → UNRESPONSIVE TO ALL STIMULI INCLUDING PAIN
 - BRAIN BIOPSY → ENCEPHALITIS BOTH HEMISPHERES
 - NO RESPONSE TO AGGRESSIVE MEDICAL TREATMENT



More of the Good

- HEMISPHERECTOMY STANDARD TREATMENT
 - USUALLY UNILATERAL DISEASE
- SUPPORTIVE CARE INSTITUTED
 - G-TUBE, HOSPITALIZATIONS AS NEED
- NEUROLOGIST ASKED FAMILY ABOUT LIMITING LIFE-PROLONGING THERAPIES AND WAHN → PALLIATIVE CARE CONSULT
- PARENTS DECLINED HOME HOSPICE AND REQUESTED ADMISSION FOR WAHN



More of the Good

- ADMITTED TO NEUROLOGY WARD ♣
- PALLIATIVE CARE TEAM INVOLVEMENT
- FLOOR STAFF PREPARED FOR ROLE IN CARE ♣
- IV FOR PRN ANTICONVULSANTS
- GT FEEDINGS HELD
- REGIMEN OF SCHEDULED OPIATE AND BENZODIAZEPINE GIVEN FOR COMFORT ♣
- CLINICAL COURSE
 - SOME TEMPERATURE LABILITY
 - DIED COMFORTABLY AFTER 5 DAYS

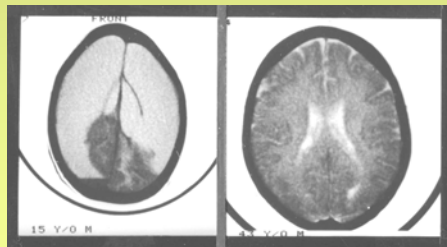


DISCUSSION



One of the Bad (ca. 1995)

- 15-YO PREVIOUSLY HEALTHY MALE → ADMITTED TO PICU FOLLOWING ASPHYXIA FROM GLUE-SNIFFING ACCIDENT
- DIFFUSE, GLOBAL HIE WITH PVS
- EXTUBATED, FREQUENT 'THALAMIC STORMS'



MRI 4 MONTHS FOLLOWING INJURY
(L) PATIENT (R) NORMAL ADULT



More of the Bad

- FOLLOWING DISCUSSIONS WITH ICU ATTENDING, PARENTS REQUESTED LIMITATION OF ARTIFICIAL, LIFE-SUSTAINING TREATMENTS
- HOSPITAL ATTORNEY FELT THERE WAS NO PRECEDENT FOR THIS COURSE → SOUGHT COURT OPINION FOR MEDICAL DECISION ♣
- COURT APPOINTED GUARDIAN AD LITEM
 - MID-40'S SINGLE WOMAN ATTORNEY → HAD OVERCOME PREVIOUS MEDICAL DISABILITY ♣



More of the Bad

- COURT BATTLE DRAGGED ON FOR ALMOST TWO MONTHS
- GUARDIAN WAS INSTRUCTED BY COURT TO VISIT PATIENT IN HOSPITAL BUT THAT DID NOT CHANGE HER POINT OF VIEW
- SEVERE WRITHING EPISODES WITH NON-SPECIFIC PHONATION → SWEATING THROUGH MULTIPLE BED CHANGES DAILY, ABRADING HEELS, ELBOWS, KNEES



More of the Bad

- DEVELOPED ASPIRATION PNEUMONIA AND DIED IN THE PICU WITHOUT BEING INTUBATED
- COURT RULED THE POINT IN QUESTION MOOT AND REFUSED TO RENDER AN OPINION IN THE MATTER



DISCUSSION



One of the Very Ugly

- FULL-TERM MALE BORN VIA VACUUM-ASSISTED EXTRACTION; APGARS 4₁ & 7₅
- DEVELOPED SEIZURES / APNEA → INTUBATED
- SUBSEQUENT CT/MRI c/w DIFFUSE HIE
 - MULTIPLE AREAS OF INFARCTION AND BLEEDING
- PROGNOSIS ASSESSED AS VERY POOR



More of the Very Ugly

- WEANED TO ROOM AIR AND EXTUBATED
- TOLERATING NG FEEDINGS FOR 2 WEEKS
- PARENTS REQUESTED REMOVAL OF NG ♣
- MINIMAL PREPARATION OF PARENTS AND NURSING STAFF PRIOR TO NG REMOVAL ♣
- COMFORT MEASURES PROVIDED
 - MOISTENED LIPS, ORAL MORPHINE P.R.N.
- SLOW PATH TO DEATH AFTER 24 DAYS ♣
 - SIGNIFICANT STAFF AND FAMILY DISTRESS



DISCUSSION



Conclusion

- WAHN ELICITS SERIOUS DISTRESS IN MANY
- THE COURTS HAVE LITTLE ROLE TO PLAY
- CAREFUL PLANNING AND SELECTION OF CASES IS CRITICAL
 - I.E. WE CAN'T MAKE ALL PROBLEMS GO AWAY
- WAHN IS A COMPLEX TREATMENT OPTION
 - SIGNIFICANT THOUGHT AS TO HOW, WHERE AND WHO SHOULD BE INVOLVED IS CRITICAL
 - STAFF PREPARATION IS VITAL



Conclusion

- WAHN SHOULD INVOLVE MATURE, EXPERIENCED CLINICIANS AS WELL AS CONSULTATION AMONGST PEERS
- WAHN IS AN IMPORTANT AND VALUABLE END-OF-LIFE OPTION FOR SOME PATIENT
- WE MUST PROTECT WAHN FROM BAD PUBLICITY AND LEGAL RESTRICTIONS THROUGH ITS RESPONSIBLE AND COMPASSIONATE UTILIZATION

