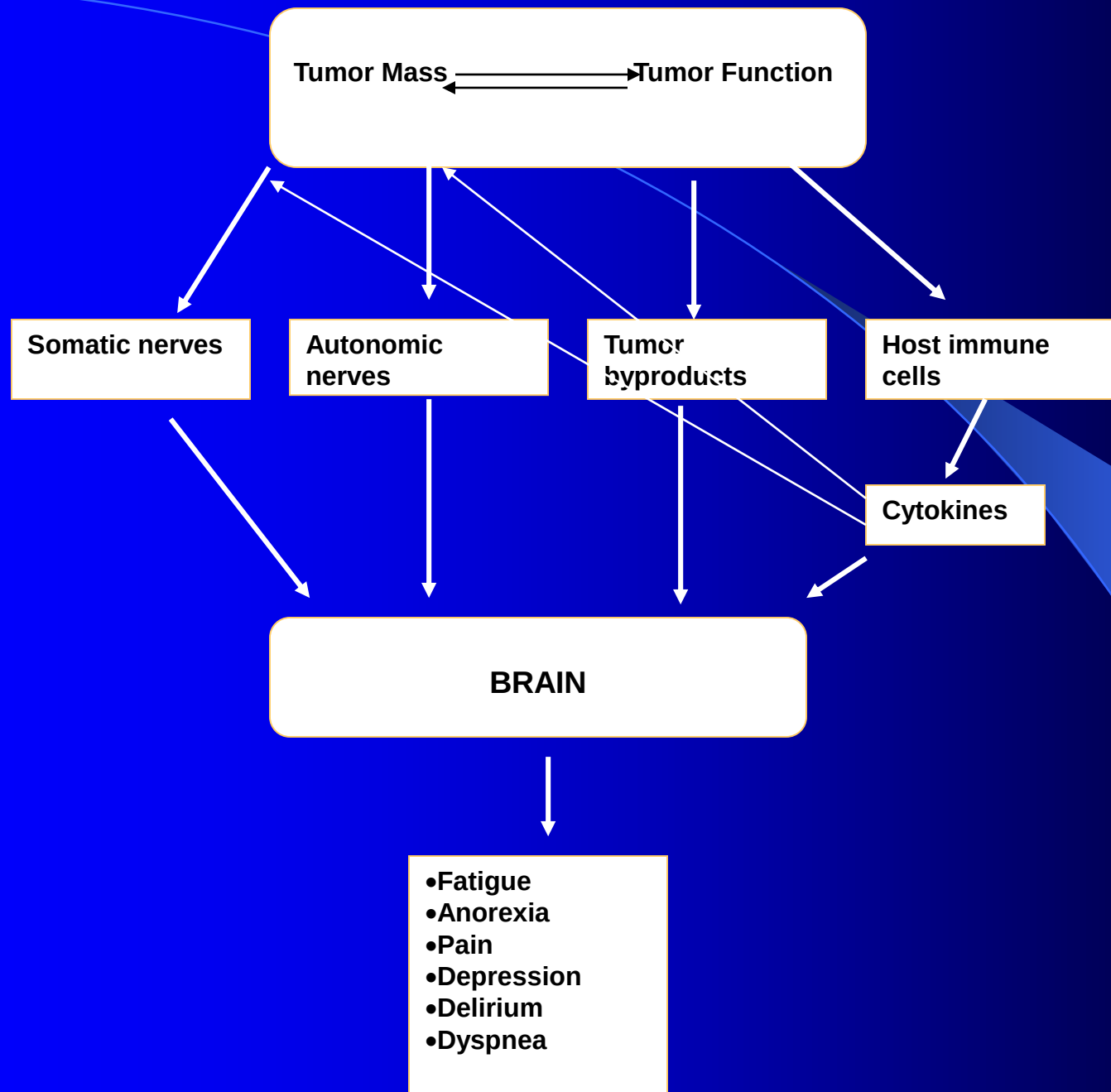


Patient's Problems

- Pain (80%)
- Fatigue (90%)
- Weight Loss (80%)
- Lack of Appetite (80%)
- Nausea, Vomiting (90%)
- Anxiety (25%)
- Shortness of Breath (50%)
- Confusion-Agitation (80%)



42 y.o. Woman, advanced NSCC Lung

Admitted to hospital

cc: pain, nausea, confusion

Measurements:

RN

- vitals twice/shift
- neuro vitals q/shift
- ins & outs

LAB

Liver function test

Peripheral -- by hematologist

Coagulation tests

Respiratory test

X-RAY

Bone scan –

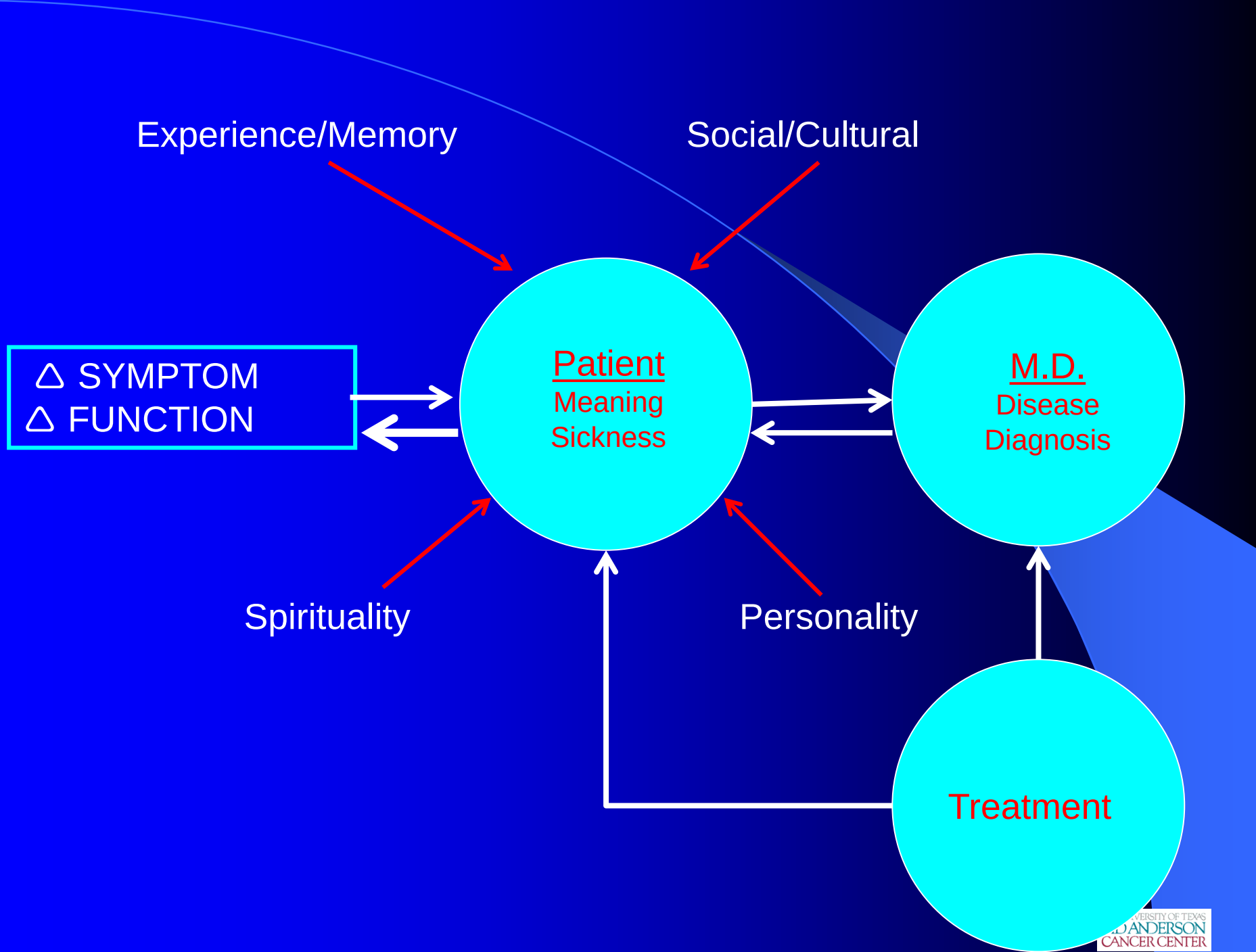
Liver u/sound -

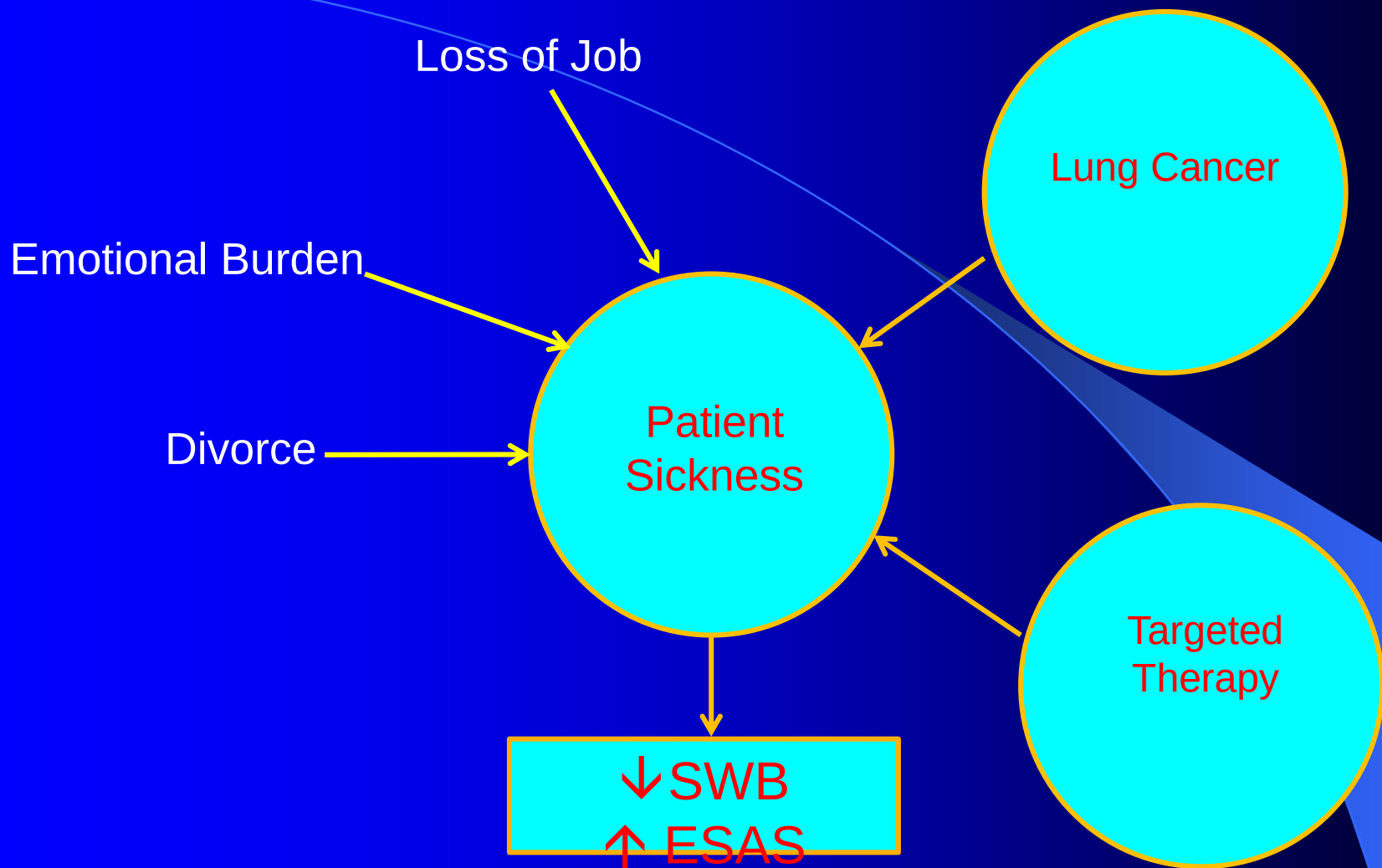
PURPOSE OF ADMISSION

Symptom control; no antineoplastic treatment
Pall. Care Consult: Day 12

NO

- Pain intensity monitoring (6 $\neq$ analgesic changes)
- Nausea vomiting (3 $\neq$ antiemetics)
- Cognitive monitoring (“confusion worse”)





- Utilization, satisfaction
- Invasive procedures
- ER visits, admissions, ICU

WHAT DO WE NEED TO ASSESS?

- Symptom Intensity
- Cognition
- Mood
- Knowledge
- Communication Preference
- Family structure and function

THE UNIVERSITY OF TEXAS
MD ANDERSON
CANCER CENTER

Patient Name: _____
MDACC #: _____
Date: _____

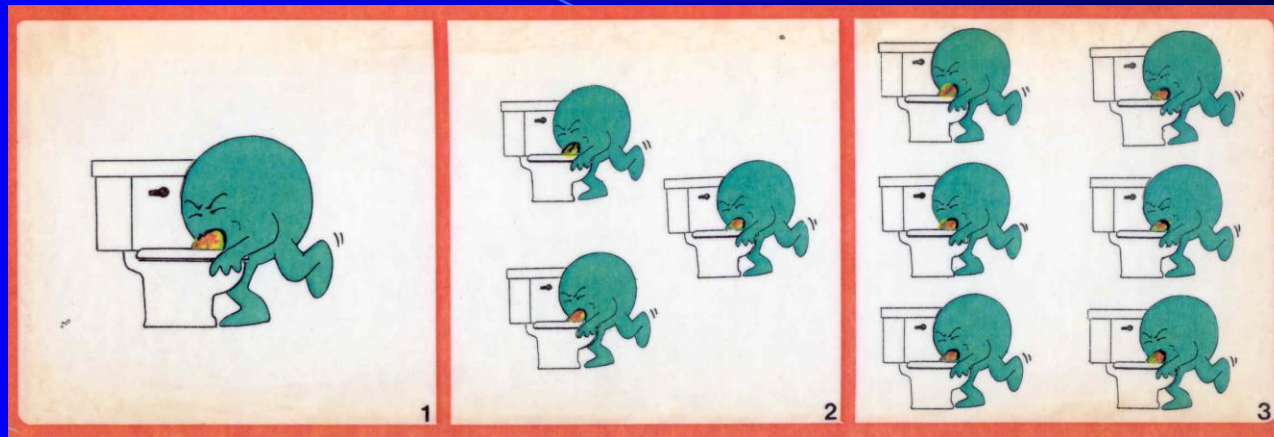
SYMPTOM CONTROL & PALLIATIVE CARE
SYMPTOM ASSESSMENT

No Pain	0 1 2 3 4 5 6 7 8 9 10	Worst Pain Imaginable
No Fatigue	0 1 2 3 4 5 6 7 8 9 10	Worst Fatigue Imaginable
No Nausea	0 1 2 3 4 5 6 7 8 9 10	Worst Nausea Imaginable
No Depression	0 1 2 3 4 5 6 7 8 9 10	Worst Depression Imaginable
No Anxiety	0 1 2 3 4 5 6 7 8 9 10	Worst Anxiety Imaginable
No Drowsiness	0 1 2 3 4 5 6 7 8 9 10	Worst Drowsiness Imaginable
No Shortness Of Breath	0 1 2 3 4 5 6 7 8 9 10	Worst Shortness of Breath Imaginable
Best Appetite	0 1 2 3 4 5 6 7 8 9 10	Worst Appetite Imaginable
Best Sleep	0 1 2 3 4 5 6 7 8 9 10	Worst Sleep Imaginable
Best Feeling Of Wellbeing	0 1 2 3 4 5 6 7 8 9 10	Worst Feeling of Wellbeing Imaginable

Assessed by: _____



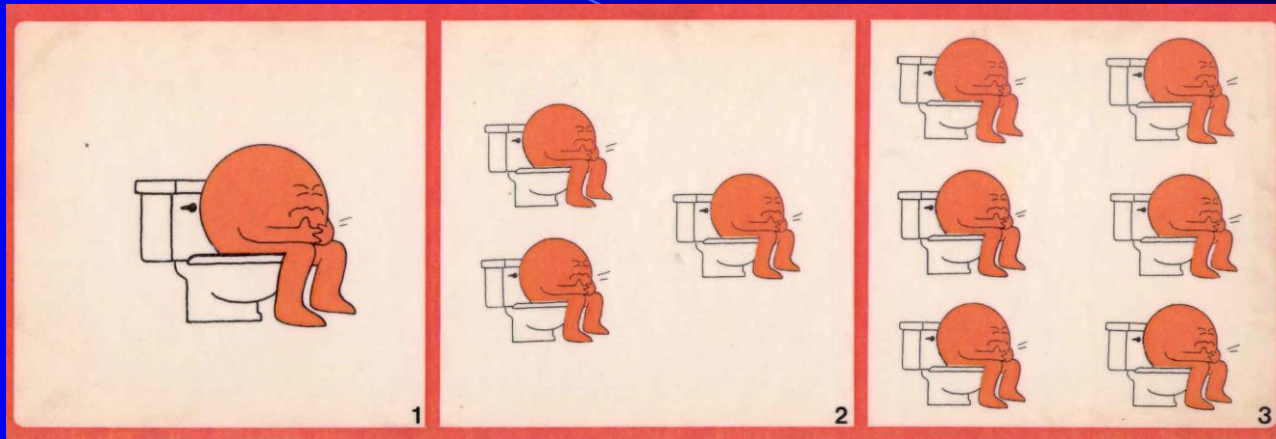
PC Assessment



Physical Assessment

Card No. 9 - Vomit

To the Patient: "Which of these situations best represents your present condition?"



Physical Assessment

Card No. 4 - Diarrhea

To the Patient: "Which of these situations best represents
your present condition?"

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CANCER CENTER

FOLLOW-UP AND PROGRESS NOTES

PATIENT IDENTIFICATION

DATE

Symptom Control & Palliative Care Symptom Assessment Scale

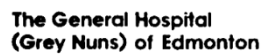
		↑ Morphine					↓ PE → Heparin						
Date: April		4	5	6	7	8	9	10	11	12	13	14	15
Pain	(0-10)*												
Fatigue	(0-10)*												
Nausea	(0-10)*												
Depression	(0-10)*												
Anxiety	(0-10)*												
Drowsiness	(0-10)*												
Shortness of Breath	(0-10)*												
Appetite	(0-10)*												
Sleep	(0-10)*												
Feeling of Wellbeing	(0-10)*												
Mini Mental State Score (0 - 30)		30		28		30		29		30		27	
Assessment from: Pt/SO/HCP (If SO or HCP - use red ink)													
Total Opioid MEDD: _____ mg/day													
Staff Initials (Signature & Title Below)													

* 0 = No Symptom/Best

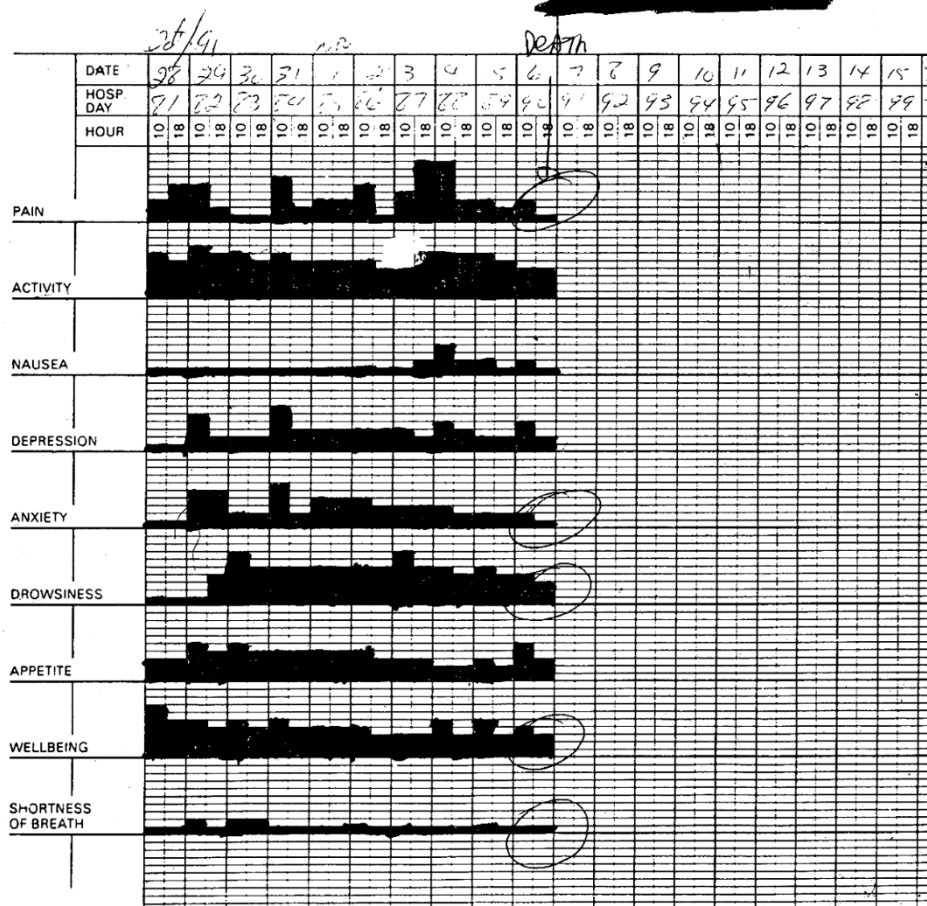
10 = Worst Imaginable

Why should we use tools?

1. We find more symptoms (median of 9 Vs 2)
2. We are able to follow up over time
3. We are able to conduct quality control



SYMPTOM ASSESSMENT GRAPH



ASSESSED BY

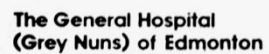
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 61 62 63 64 65 66 67 68 69 70 71 72 73 74 75 76 77 78 79 80 81 82 83 84 85 86 87 88 89 90 91 92 93 94 95 96 97 98 99 100

Code P - Patient N - Nurse NA - Nurse Assisted F - Family

Mini-Mental State Score

	24									2
--	----	--	--	--	--	--	--	--	--	---

990



ESAS:

- “Multiple symptoms
- Patient self assessment if possible
- Graphic display of data
- Simple – repeated assessments

ESAS: No copyright!

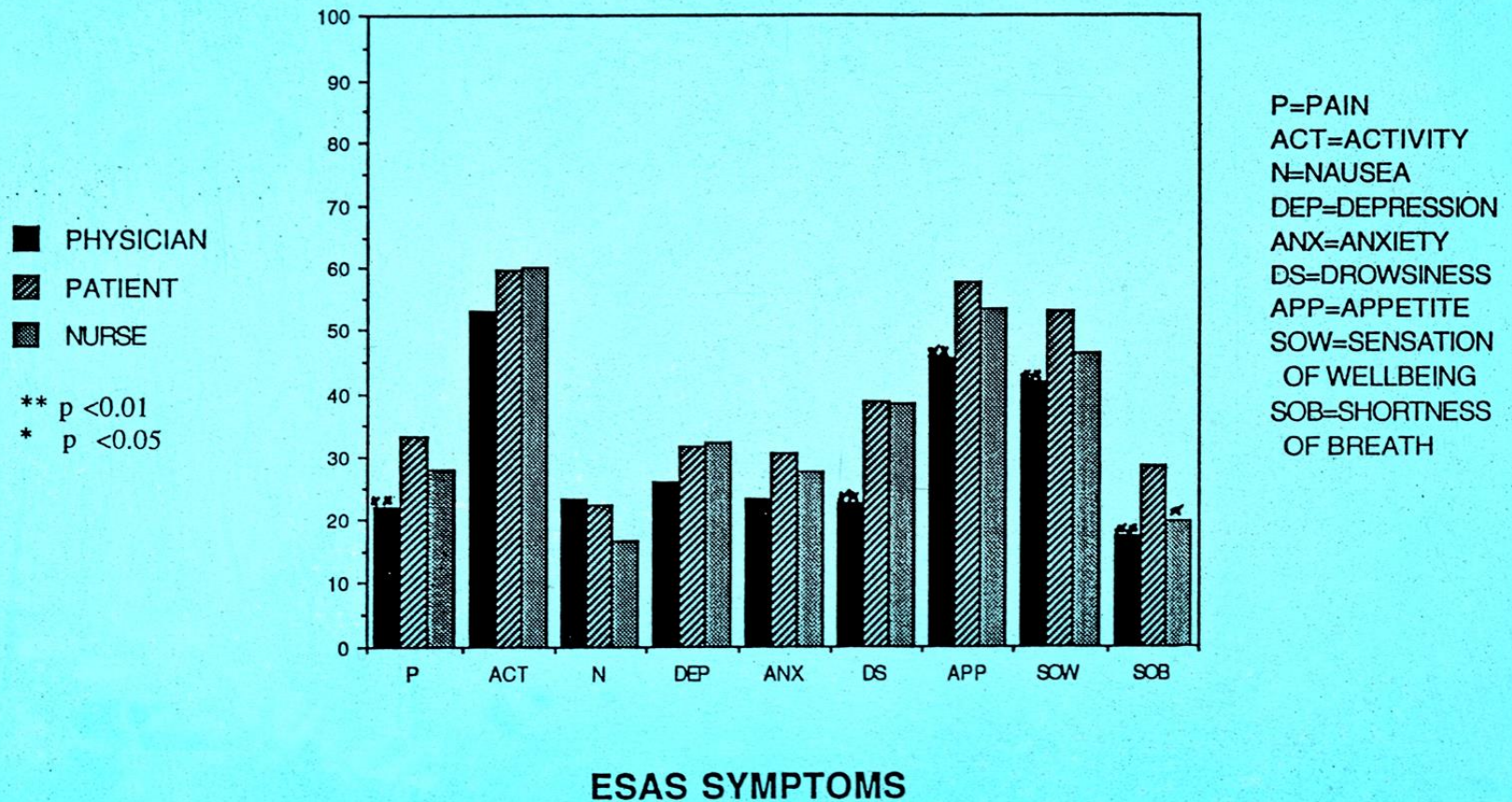
- MMSE: after >100 studies by our team, Folstein lawyers want 1 \$ per assessment !!
- Computer software deals for symptom tools!
- All “Edmonton” tools: ESAS, EFAT, ESS, HDAT, etc. had no copyright- For all to use!
- Most common tool in cancer and Pall Care

Lessons from ESAS development

- Clinically actionable items (worse, average, least, interferences- ?). No action: delete
- Extremely short and free
- No need for computer or patient training
- RNs and MDs need to see how this will help clinically to adopt.
- Instrument development cartels: not validated yet in tall people, or soccer fans

Why patient reported outcomes (PROs)?

SYMPTOM INTENSITY AS ASSESSED BY THE PHYSICIAN, PATIENT, AND NURSE DAY 1-4

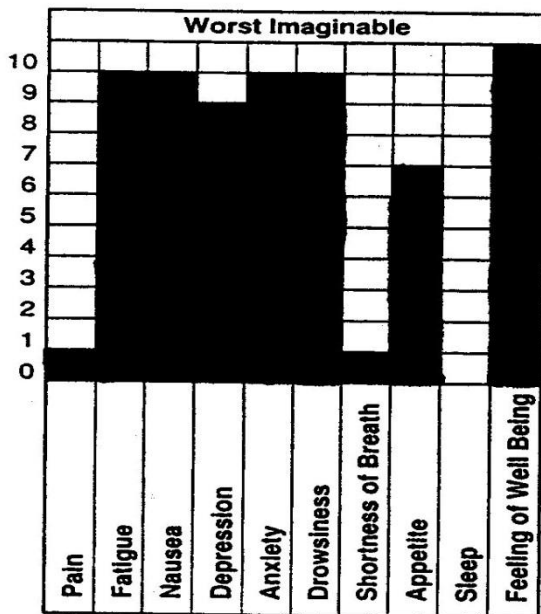


SYMPTOM CONTROL
&
PALLIATIVE CARE CENTER

PATIENT IDENTIFICATION

Interdisciplinary Assessment & Plan of Care

SYMPTOM ASSESSMENT



Mini Mental Status Score	<u>29</u> 30
Number of years of schooling?	
Mini Mental Status Score Normal for age and education	<u>24</u>
Cage Questionnaire Score (2/4 = a positive Cage)	<u>0</u> 4

Information obtain from: Patient _____

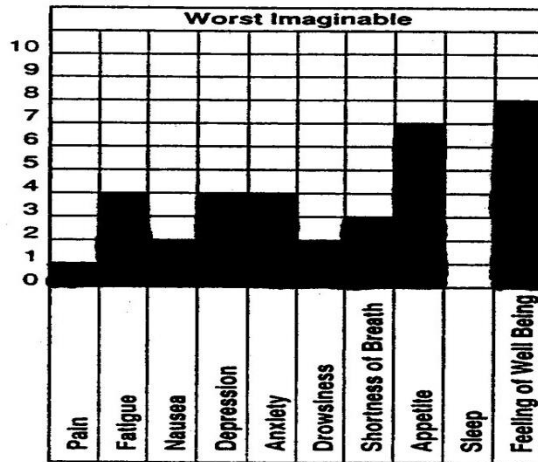
Other (specify) _____

SYMPTOM CONTROL
&
PALLIATIVE CARE CENTER

PATIENT IDENTIFICATION

Interdisciplinary Assessment & Plan of Care

SYMPTOM ASSESSMENT



Mini Mental Status Score	<u>29</u> 30
Number of years of schooling?	
Mini Mental Status Score Normal for age and education	<u>24</u>
Cage Questionnaire Score (2/4 = a positive Cage)	<u>0</u> 4

Information obtain from: Patient _____

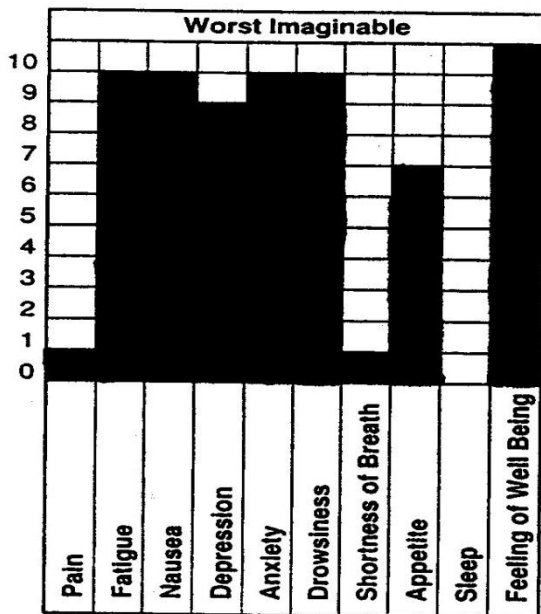
Other (specify) _____

SYMPTOM CONTROL
&
PALLIATIVE CARE CENTER

PATIENT IDENTIFICATION

Interdisciplinary Assessment & Plan of Care

SYMPTOM ASSESSMENT

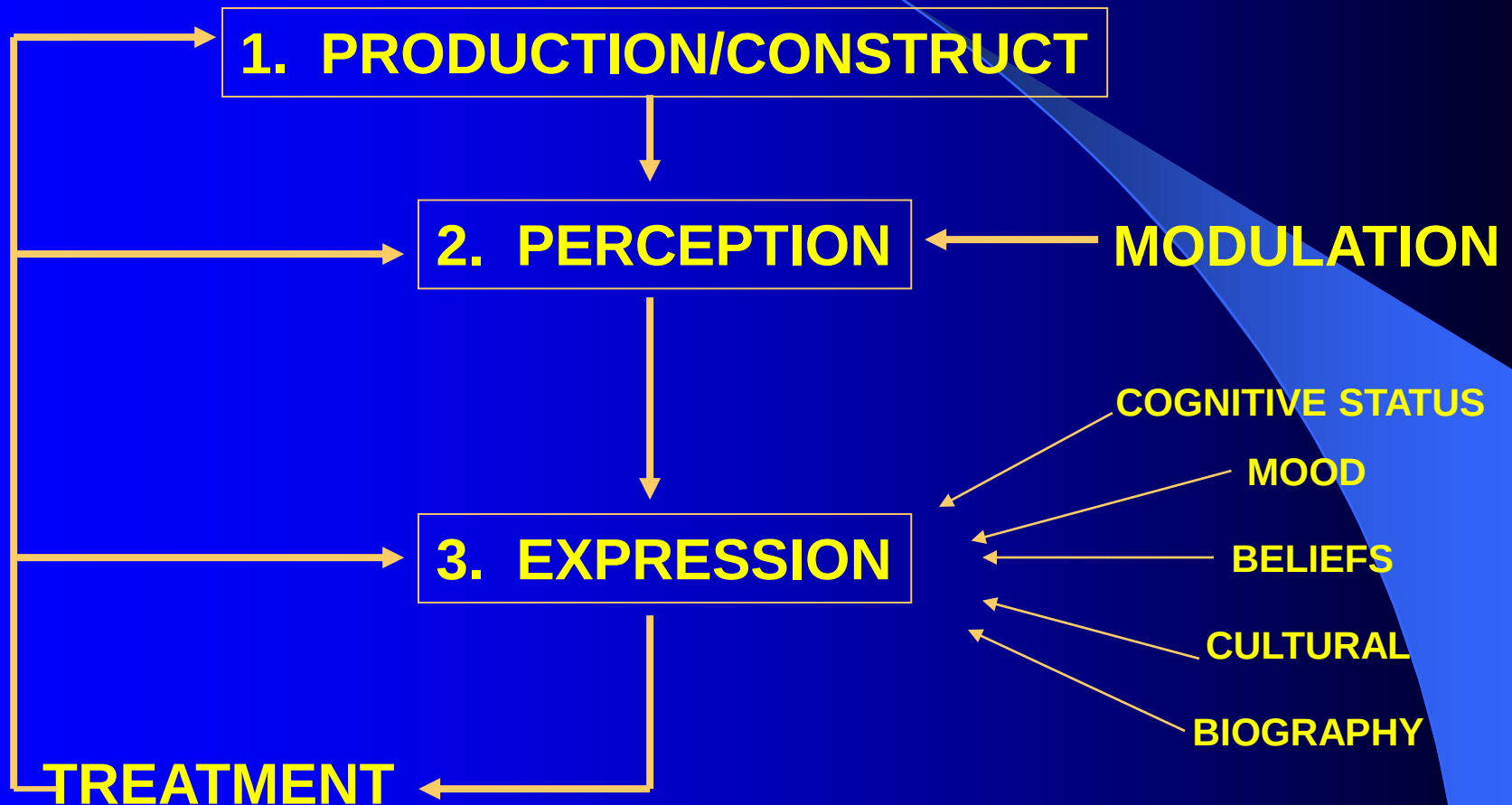


Mini Mental Status Score	<u>29</u> 30
Number of years of schooling?	
Mini Mental Status Score Normal for age and education	<u>24</u>
Cage Questionnaire Score (2/4 = a positive Cage)	<u>0</u> 4

Information obtain from: Patient _____

Other (specify) _____

Schema of Symptom Construct



Pain is a multidimensional construct

- What's in a name? PAIN
- What's in a number? 0-10

Pain Intensity 8/10

	Patient #1	Patient #2
Nociception	85%	30%
Somatization	5%	20%
Coping Chemically	5%	30%
Tolerance	5%	0%
Incidental Pain	<u>0%</u>	<u>20%</u>
	100%	100%

Fatigue 8/10

	<u>Patient 1</u>	<u>Patient 2</u>
Depression	● 60%	● 10%
Cachexia	● 10%	● 50%
Anemia	● 10%	● 30%
Opioids	● 20%	● 0%
Autonomic	● 0%	● 10%

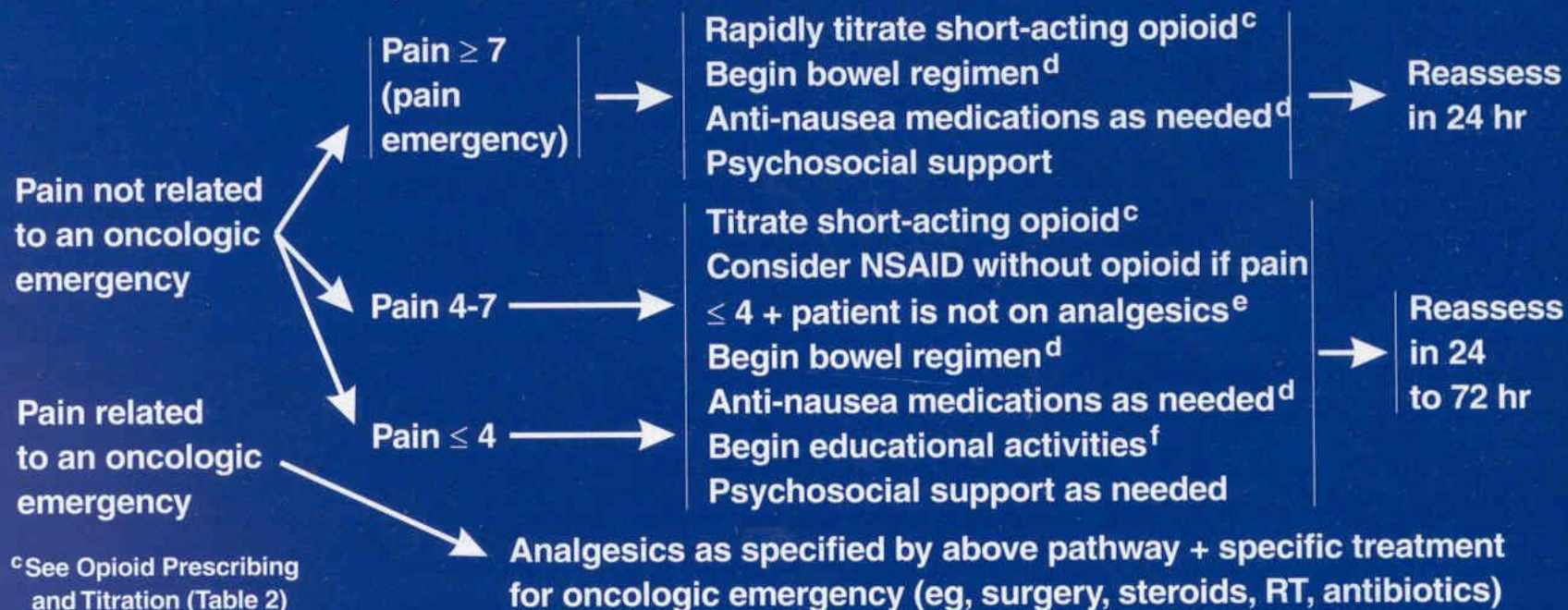
WHAT IMPACTS PAIN INTENSITY

0-10?

1. Afferent Nociception
2. Meaning (Cancer, Osteoporosis?)
3. Personality (Stoic, Histrionic?)
4. Experience/Memory (Father died in pain)
5. Alcoholism/Drugs (Chemical coping)
6. Intelligence/Education (Understands pain & treatment)
7. Culture (Pain expression OK?)
8. Spirituality (Pain Good? Punishment?)
9. Secondary Gain (Attention from family)
10. Depression/Anxiety (Somatization)
11. Delirium (Disinhibition)
12. Trust In Doctors (Adherence, Placebo!)

Cancer Pain

TREATMENT #1



^cSee Opioid Prescribing and Titration (Table 2)

^dSee Management of Opioid Toxicities (Table 3) ^eSee NSAID Prescribing (Table 6) ^fSee Patient and Family Education (Table 5)

Cancer Related

Tumor Growth

Infection

Ischemia

Fracture

**↑ Pain
Intensity**

**Chemical
Coping**

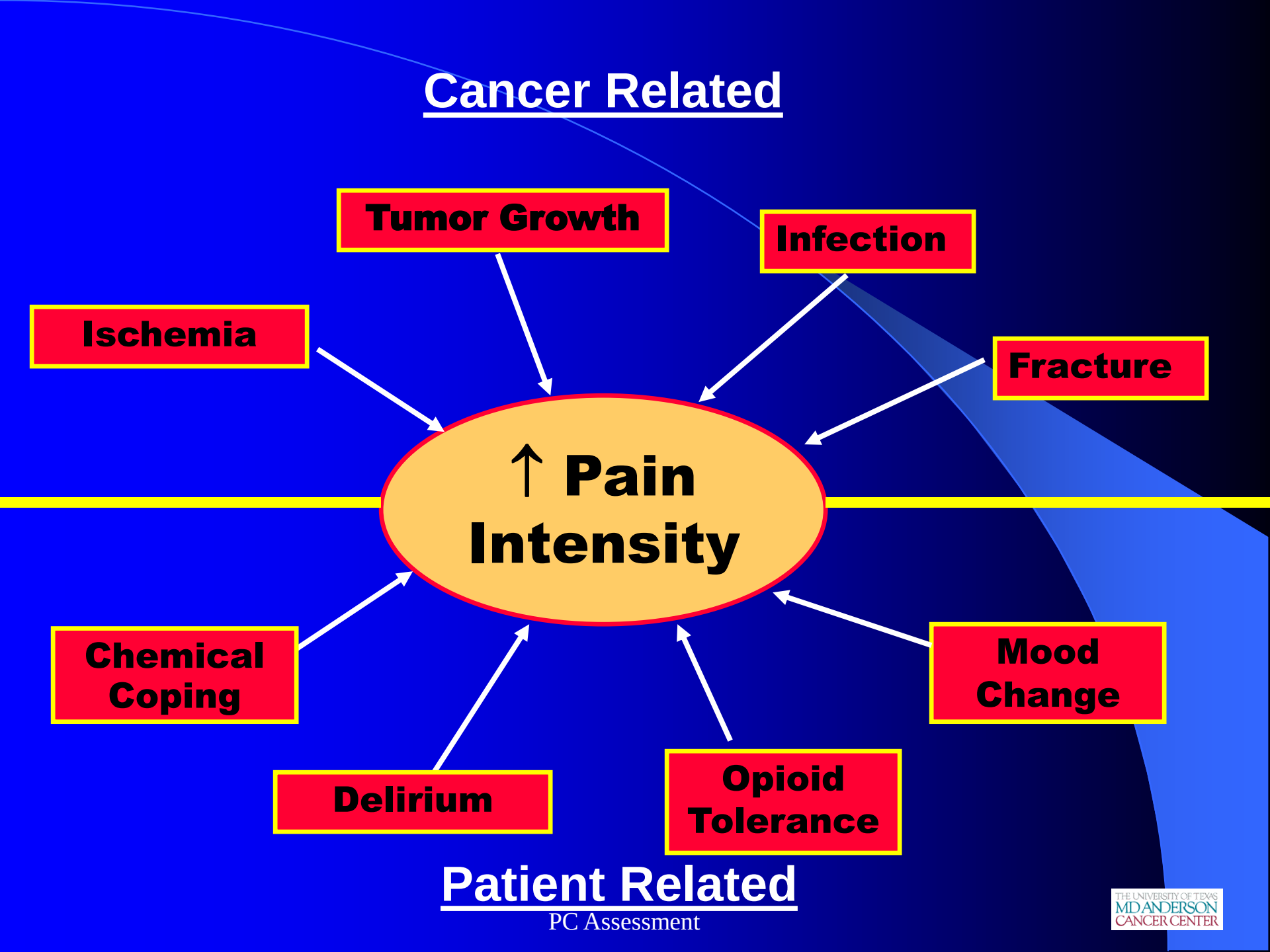
**Mood
Change**

Delirium

**Opioid
Tolerance**

Patient Related

PC Assessment



Prognostic factors

- Incident pain
- Neuropathic pain
- Alcohol/drugs
- Somatization
- Tolerance
- Previous dose- not independent
- Cognitive failure- not independent

Minimal Clinically Important Differences in the Edmonton Symptom Assessment Scale in Cancer Patients: A Prospective, Multicenter Study

David Hui, MD, MSc¹; Omar Shamieh, MD, MBA²; Carlos Eduardo Paiva, MD, PhD³; Pedro Emilio Perez-Cruz, MD⁴; Jung Hye Kwon, MD, PhD⁵; Mary Ann Muckaden, MD⁶; Minjeong Park, MS⁷; Sriram Yennu, MD¹; Jung Hun Kang, MD, PhD⁸; and Eduardo Bruera, MD¹

Cancer 2015

Methods

- Compared ESAS symptom intensity between 1st and 2nd visit
- Asked pts their perception of overall improvement (better, same, worse) for each symptom

TABLE 2. Changes in ESAS

	ESAS, Average (SD)			% Change From First Visit ^a	<i>P</i> ^b	Patient's Global Impression, No. (%)		
	First Clinic Visit	Second Clinic Visit	Change ^a			Better	Same	Worse
Pain	4.55 (3)	3.79 (3)	0.76 (3.01)	17	<.0001	377 (47)	251 (32)	167 (21)
Fatigue	4.93 (2.82)	4.47 (2.92)	0.46 (2.95)	9	<.0001	293 (37)	297 (37)	206 (26)
Nausea	1.72 (2.68)	1.59 (2.53)	0.14 (2.91)	8	.10	209 (26)	460 (58)	125 (16)
Depression	2.55 (2.87)	2.38 (2.83)	0.18 (2.58)	7	.02	169 (21)	494 (62)	132 (17)
Anxiety	3.18 (3.11)	2.82 (2.9)	0.36 (2.78)	11	.0002	191 (24)	472 (59)	131 (16)
Drowsiness	3.31 (2.99)	3.26 (2.88)	0.05 (3.08)	2	.31	217 (27)	410 (52)	169 (21)
Poor appetite	4.01 (3.03)	3.85 (3.06)	0.15 (3.16)	4	.09	267 (34)	353 (44)	176 (22)
Poor well-being	4.41 (2.76)	4.12 (2.74)	0.29 (2.92)	7	.002	293 (37)	328 (41)	174 (22)
Dyspnea	2.51 (2.89)	2.23 (2.81)	0.27 (2.42)	11	.0008	155 (19)	533 (67)	108 (14)
Poor sleep	4.08 (3.06)	3.46 (2.85)	0.62 (3.13)	15	<.0001	258 (32)	410 (52)	128 (16)

Abbreviations: ESAS, Edmonton Symptom Assessment Scale; SD, standard deviation.

^aImprovement is indicated by a positive value

^bA paired *t* test was used to determine the differences in the ESAS scores between the first and second study visits.

TABLE 4. Minimal Clinically Important Differences Based on Other Anchor- and Distribution-Based Approaches

Symptom	Within-Patient Changes ^a		SD of Baseline ESAS ^b		SEM ^c
	Improvement, Average (SD)	Deterioration, Average (SD)	0.3 SDs	0.5 SDs	
Pain	1.4 (2.4)	−1 (2.1)	0.90	1.51	1.35
Fatigue	1.5 (2.5)	−1.5 (2.4)	0.89	1.48	1.36
Nausea	1.6 (3.2)	−2.3 (2.6)	0.87	1.46	1.32
Depression	1 (2.5)	−1.8 (2.2)	0.77	1.29	1.27
Anxiety	1.7 (2.5)	−1.4 (2.6)	0.83	1.39	1.56
Drowsiness	0.8 (2.4)	−2 (2.4)	0.92	1.54	1.75
Poor appetite	1.2 (2.3)	−2.1 (2.4)	0.95	1.58	1.50
Poor well-being	1.2 (2.5)	−0.8 (2.5)	0.88	1.46	1.67
Dyspnea	1.2 (2.1)	−1.3 (2.2)	0.73	1.21	1.38
Poor sleep	2.2 (2.8)	−1.2 (2.3)	0.94	1.57	1.66

Abbreviations: ESAS, Edmonton Symptom Assessment Scale; SD, standard deviation; SEM, standard error of measurement.

^a Within-patient changes were calculated through the computation of the average ESAS changes among patients who reported that their symptoms were “a little better” (for improvement) or “a little worse” (for deterioration) on the Patient’s Global Impression questionnaire.

^b As estimates of minimal clinically important differences, 0.2, 0.3, and 0.5 SDs are often used.

^c SEM was calculated as $SD \times (1 - \text{reliability})^{1/2}$. One SEM is often considered a measure of a minimal clinically important difference.

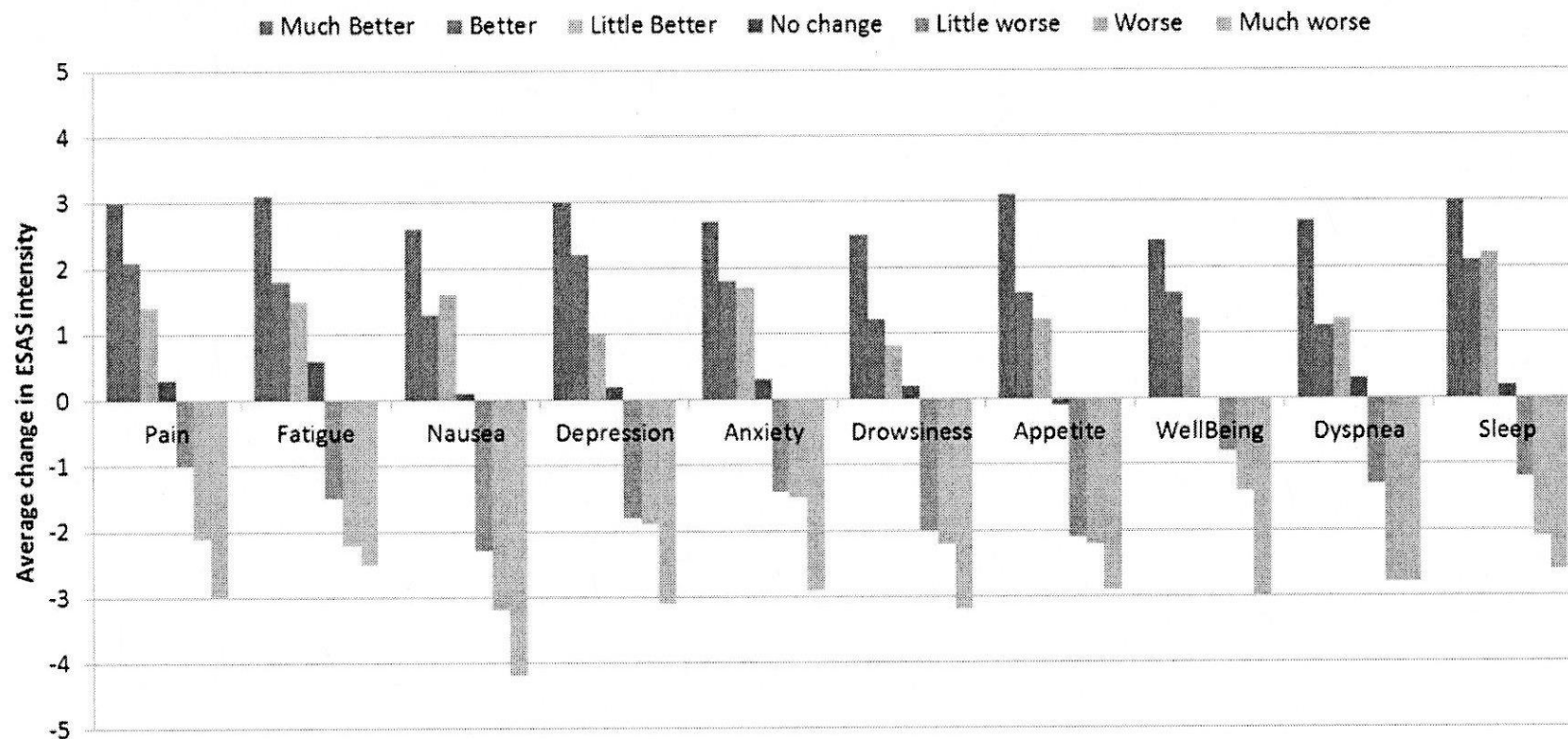


Figure 2. Average changes in ESAS intensity between the first and second study visits by Patient's Global Impression categories (n = 796). ESAS indicates Edmonton Symptom Assessment Scale.

TABLE 5. Proportion of Patients With Improvement or Deterioration at Visit 2 According to the Sensitivity-Specificity Minimal Clinically Important Difference Cutoffs

Symptom	Improved ($\geq +1$), No. (%)	No Change (0), No. (%)	Deteriorated (≤ -1), No. (%)
Pain	384 (48)	195 (24)	217 (27)
Fatigue	367 (46)	163 (20)	266 (33)
Nausea	217 (27)	371 (47)	208 (26)
Depression	259 (33)	308 (39)	229 (29)
Anxiety	305 (38)	283 (36)	208 (26)
Drowsiness	285 (36)	220 (28)	291 (37)
Poor appetite	304 (38)	207 (26)	285 (36)
Poor well-being	350 (44)	174 (22)	272 (34)
Dyspnea	267 (34)	342 (43)	187 (23)
Poor sleep	352 (44)	200 (25)	244 (31)

Discussion

- MCID is 1 for improvement or deterioration for ALL symptoms
- More than one visit needed to control symptoms
- Some pts deteriorate by the 2nd visit
- MCID is not the Personalized symptom goal

Original Article

Achievement of Personalized Pain Goal in Cancer Patients Referred to a Supportive Care Clinic at a Comprehensive Cancer Center. *CANCER 2012*

Shalini Dalal, MD; David Hui, MD, MSc; Linh Nguyen, MD; Ray Chacko, BBA; Cheryl Scott, RN; Lynn Roberts, RN; and Eduardo Bruera, MD

- Pain Relief: $\geq 2/10$ or $\geq 33\%$
- Relief: 9 – 7?
- What is the patient's goal?

- 465 Patients seen at Supportive Care Center by a Palliative Medicine Specialist with follow-up in 1 – 6 weeks
- ESAS
- CAGE
- MDAS

Objetivo personalizado de dolor

- 445 cancer patients at Supportive Care Center
- Median followup 14 days

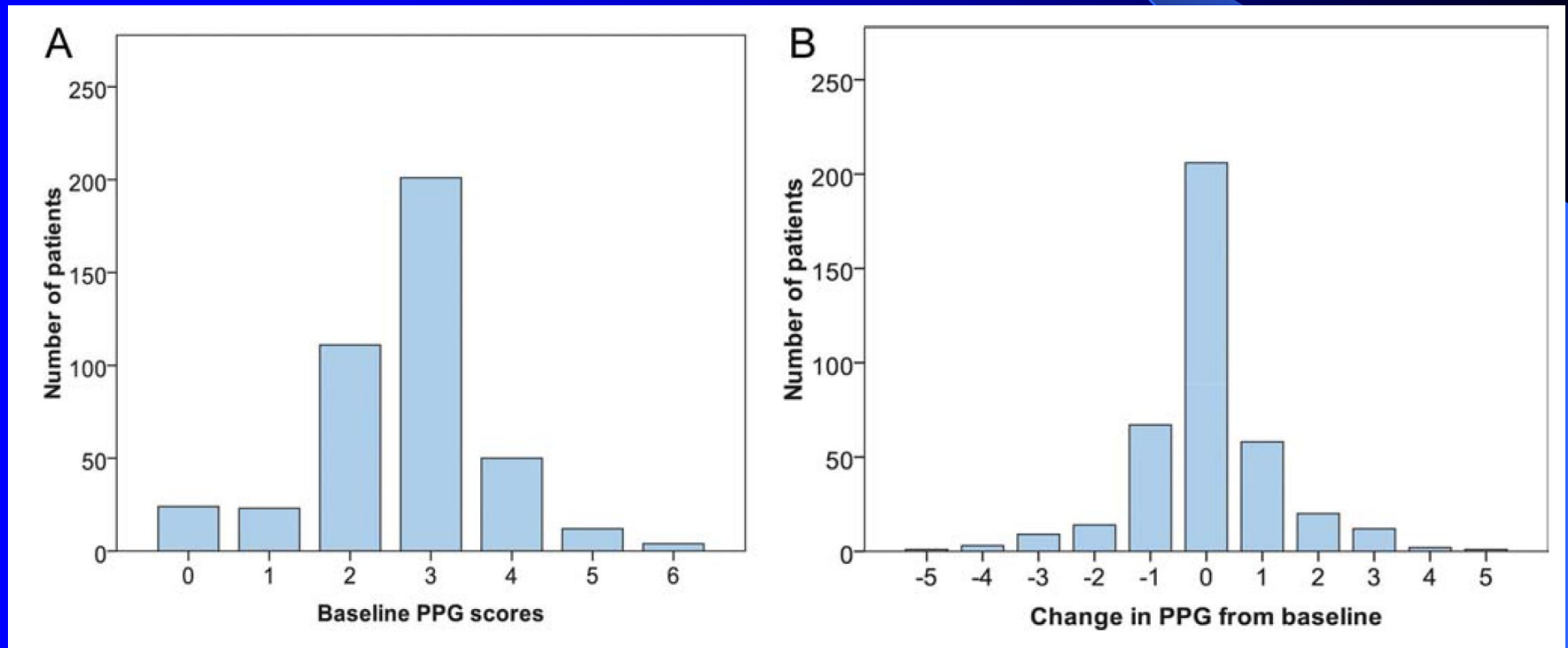


Table 1. Selected Baseline and Follow-up Characteristics for all Patients and by Baseline Pain Category

Characteristic	Baseline Pain Category				P	All Patients
	No Pain	Mild	Moderate	Severe		
Patients, No. (%)	35 (8)	152 (34)	95 (21)	163 (37)	—	445
Age, y, median [range]	64 [27-83]	59 [20-85]	61 [30-85]	57 [16-89]	.010	59 [16-89]
Time to follow-up visit, d [range]	16 [10-28]	21 [13-28]	16 [14-27]	14 [8-21]	.014	14 [10-25]
Zubrod, median {IQR}	1 {1-2}	1 {1-2}	1 {1-2}	2 {1-2}	.001	1 {1-2}
Zubrod status ≥ 3 , No. (%)	8 (23)	16 (11)	14 (15)	26 (16)	.241	68 (15)
CAGE ≥ 2 , No. (%)	9 (25)	13 (9)	10 (10)	19 (11)	.034	50 (11)
MDAS ≥ 7 , No. (%)	1	2	2	4	.941	9 (2)
MEDD, mg {IQR}	0 {0-24}	15 {0-90}	15 {0-100}	55 {0-120}	<.001	30 {0-92}
Median survival, d {IQR}	128 {84-266}	139 {80-265}	128 {84-237}	118 {66-238}	.476	128 {76-248}
Baseline PPG, median {IQR}	2 {0-3}	3 {2-3}	3 {2-3}	3 {3-3}	<.001	3 {2-3}
Baseline symptoms,^a median {IQR}						
Pain	0 {0-0}	3 {2-3}	5 {5-6}	8 {7-9}	<.001	5 {3-8}
Fatigue	6 {3-8}	5 {3-7}	6 {4-8}	7 {4-8}	<.001	6 {4-8}
Nausea	0 {0-2}	0 {0-3}	1 {0-4}	1 {0-4}	.001	1 {0-4}
Depression	0 {0-4}	2 {0-4}	2 {0-5}	3 {0-6}	.011	2 {0-5}
Anxiety	1 {0-4}	2 {0-5}	3 {0-5}	4 {0-7}	<.001	3 {0-6}
Drowsiness	3 {0-5}	3 {1-5}	4 {0-5}	5 {1-7}	.001	4 {1-7}
Appetite	5 {1-7}	5 {2-7}	5 {3-8}	5 {3-8}	.484	5 {3-8}
Well-being	5 {2-7}	5 {3-6}	5 {3-7}	6 {4-8}	<.001	5 {3-7}
Shortness of breath	5 {2-7}	1 {0-4}	3 {0-5}	3 {0-6}	.137	2 {0-5}
Sleep	4 {1-6}	5 {2-7}	5 {3-7}	6 {4-8}	<.001	5 {3-7}
ESAS-SDS	28 {16-39}	33 {25-44}	39 {31-48}	48 {37-62}	<.001	39 {29-50}
Follow-up PPG, median {IQR}	2 {0-2}	3 {2-3}	3 {2-3}	3 {3-3}	<.001	3 {2-3}
Follow-up symptoms, median {IQR}						
Pain	0 {0-3}	3 {1-5}	5 {3-6}	6 {4-8}	<.001	4 {2-7}
ESAS-SDS	24 {16-38}	32 {21-43}	35 {26-47}	38 {25-53}	<.001	34 {23-49}

Abbreviations: CAGE, cut down, annoy, guilt, eye-opener; ESAS, Edmonton Symptom Assessment Scale; ESAS-SDS, sum of individual ESAS scores; IQR, interquartile range; MDAS, Memorial Delirium Assessment Scale; MEDD, morphine equivalent daily dose; PPG, personalized pain goal.

^a ESAS.

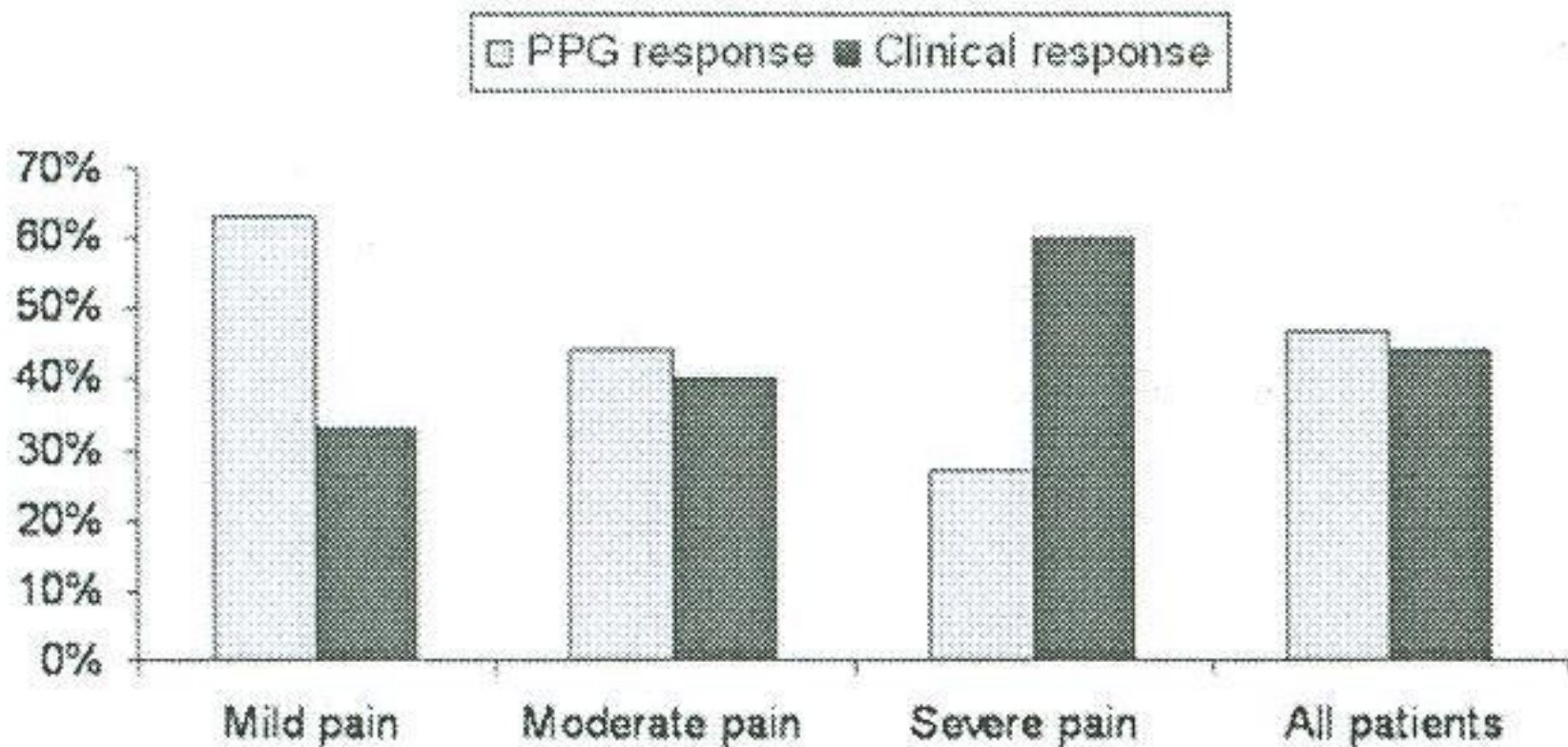
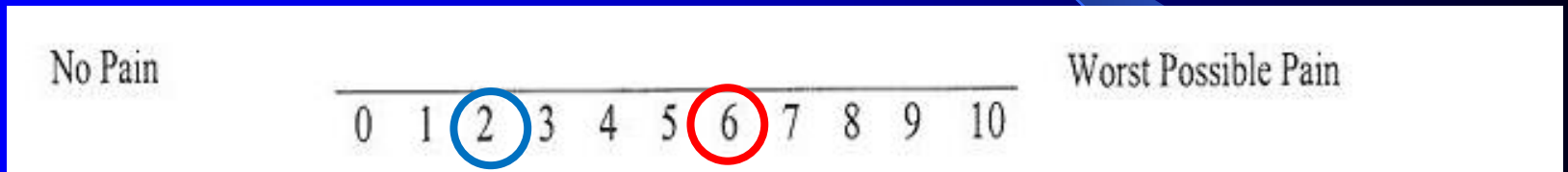


Figure 3. The proportion of patients who achieved clinical response and personalized pain goal (PPG) response is shown for all patients and by baseline pain category (mild, moderate, and severe).

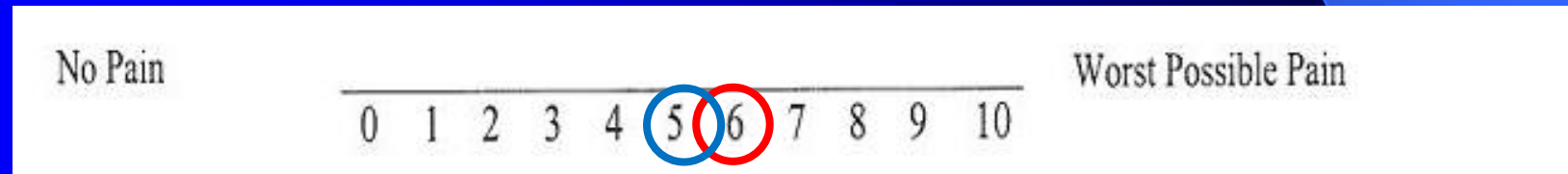
Personalized Pain Goal

A Tale of Two Patients

Patient 1

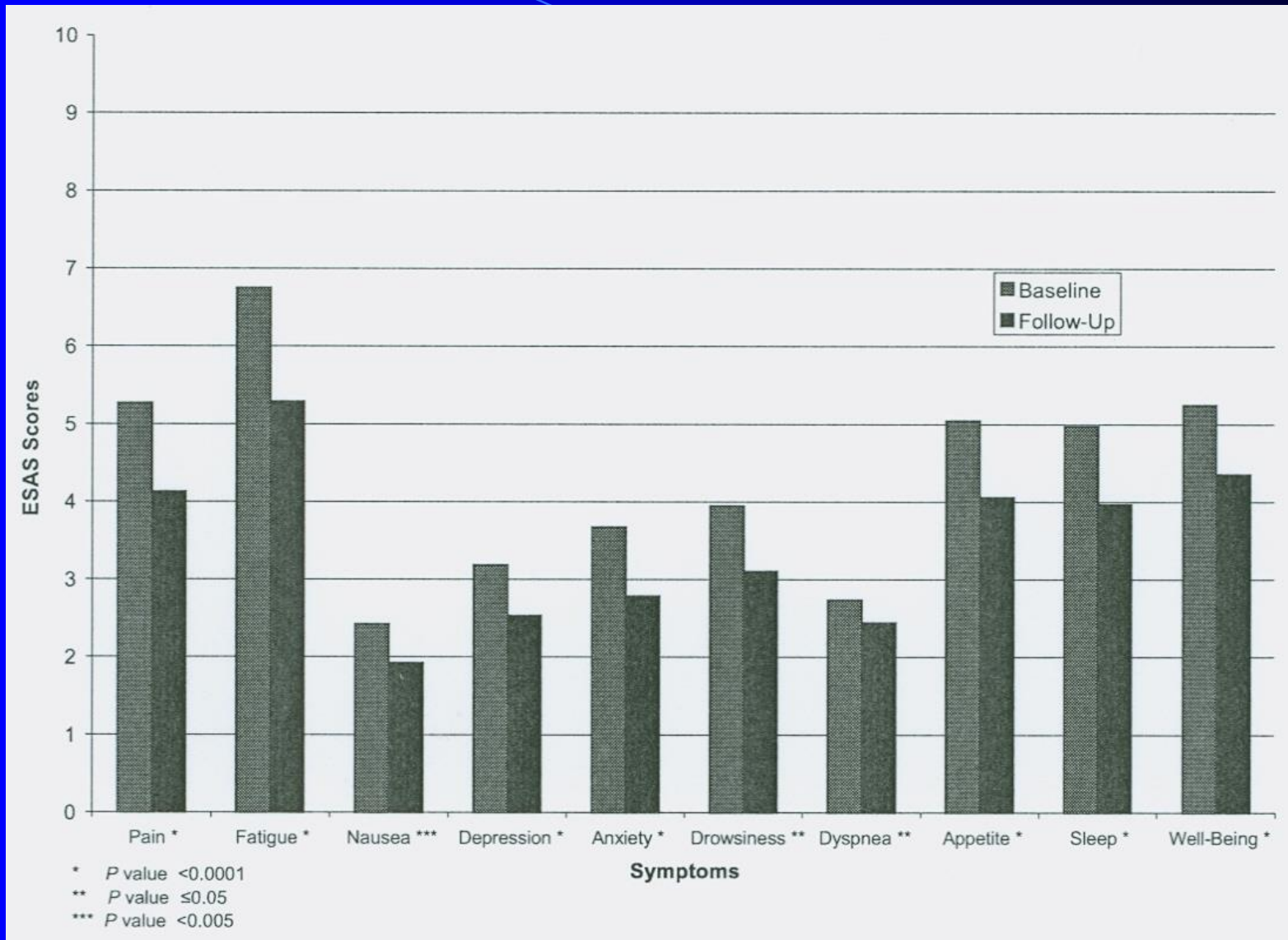


Patient 2



At what level of pain would YOU feel comfortable?

ESAS Scores at Baseline & Follow Up Visits



Impact of Palliative Care Consultation – Yennurajalingam S, et al JPSM 2010

Comparison of ESAS Scores Between Cohort with Follow-Up Visit and Cohort with Only One Visit

ESAS	Eligible Patients ^a		Noneligible Patients		<i>P</i> value
	Mean (SD)	Median (Min–Max)	Mean (SD)	Median (Min–Max)	
Pain	5.11 (2.96)	5 (0–10)	3.09 (2.67)	3 (0–10)	<0.001
Fatigue	5.69 (2.62)	6 (0–10)	1.73 (1.31)	2 (0–3)	<0.001
Nausea	1.94 (2.71)	0 (0–10)	0.76 (1.67)	0 (0–8)	<0.001
Depression	2.7 (2.76)	2 (0–10)	1.04 (1.76)	0 (0–9)	<0.001
Anxiety	3.17 (2.95)	3 (0–10)	1.43 (2.18)	0 (0–10)	<0.001
Drowsiness	3.42 (2.95)	3 (0–10)	1.24 (2.03)	0 (0–10)	<0.001
Appetite	4.63 (3.03)	5 (0–10)	2.2 (2.59)	1 (0–10)	<0.001
Feeling of well-being	4.84 (2.55)	5 (0–10)	1.96 (2.06)	2 (0–9)	<0.001
Shortness of breath	2.49 (2.83)	1 (0–10)	1.28 (1.97)	0 (0–8)	<0.001
Sleep	4.59 (2.8)	5 (0–10)	2.29 (2.61)	2 (0–10)	<0.001
SDS	33.74 (14.81)	32 (3–80)	15.06 (10.56)	14 (0–57)	<0.001

Personalized symptom goal in ESAS

- 728 patients with advanced cancer
- 5 centers worldwide
- ESAS + “ at what level would you feel comfortable with **this** symptom ?”
- Follow up response in symptom and stability of PSG

Personalized Symptom Goals and Response in Patients With Advanced Cancer *cancer 2016*

David Hui, MD, MSc¹; Minjeong Park, PhD²; Omar Shamieh, MD³; Carlos Eduardo Paiva, MD, PhD⁴;
Pedro Emilio Perez-Cruz, MD, MPH⁵; Mary Ann Muckaden, MD⁶; and Eduardo Bruera, MD¹

TABLE 1. Patient Characteristics (N = 728)

Variables	No. (%) ^a
Average age (range), y	57 (19–85)
Female sex	361 (50)
Race	
White	229 (31)
Black	37 (5)
Hispanic	224 (31)
Asian	55 (8)
Other	183 (25)
Marital status	
Single	98 (13)
Married	502 (69)
Divorced	126 (17)
Education	
Illiterate	6 (1)
≤High school	355 (49)
Some college up to Bachelor's degree	299 (41)
Advanced degree	68 (9)
Cancer	
Breast	131 (18)
Gastrointestinal	157 (22)
Genitourinary	77 (11)
Gynecological	64 (9)
Head and neck	70 (10)
Hematological	31 (4)
Other	84 (12)
Respiratory	114 (16)
Stage	
Advanced, nonmetastatic	96 (13)
Metastatic	632 (87)
CAGE positive ^b	100 (14)
Median Memorial Delirium Assessment Scale (Q1–Q3)	2 (1–3)
Average Karnofsky performance status (SD) ^c	69 (13)
Median duration between visits (Q1–Q3)	21 (18–28)
Median Edmonton Symptom Assessment Scale (Q1–Q3)	
Pain	3 (1–4)
Fatigue	3 (1–4)
Nausea	1 (0–3)
Depression	2 (0–3)
Anxiety	2 (0–3)
Drowsiness	2 (1–4)
Appetite	3 (1–4)
Well-being	2 (1–3.5)
Dyspnea	2 (0–3)
Sleep	2 (1–4)

TABLE 2. Achievement of Personalized Symptom Goal

Symptom	No.	Median PSG Intensity (Q1-Q3)	Percentage of Patients With PSG ≤ 3 No. (%)	Percentage of Patients Who Achieved PSG at First Visit No. (%) ^a	Percentage of Patients Who Achieved PSG at Second Visit No. (%) ^a	Difference, %	<i>P</i> ^b
Pain	722	3 (1–4)	548 (76)	215 (30)	301 (42)	12	<.0001
Fatigue	722	3 (1–4)	541 (75)	182 (25)	235 (33)	8	<.0001
Nausea	721	1 (0–3)	645 (89)	485 (67)	526 (73)	6	.007
Depression	722	2 (0–3)	603 (84)	395 (55)	425 (59)	4	.03
Anxiety	723	2 (0–3)	593 (82)	333 (46)	392 (54)	8	<.0001
Drowsiness	722	2 (1–4)	564 (78)	342 (47)	354 (49)	2	.41
Appetite	722	3 (1–4)	505 (70)	279 (39)	334 (46)	7	.0002
Well-being	721	2 (1–3.5)	569 (79)	211 (29)	246 (34)	5	.009
Dyspnea	722	2 (0–3)	626 (87)	403 (56)	460 (64)	8	<.0001
Sleep	723	2 (1–4)	552 (76)	255 (35)	333 (46)	11	<.0001

Abbreviations: PSG, personalized symptom goal; Q1-Q3, interquartile range.

^a Achievement of PSG was defined as symptom intensity less than or equal to the PSG for that symptom.

^b The percentage of patients who achieved PSG was compared between visit 1 and visit 2 using the McNemar test.

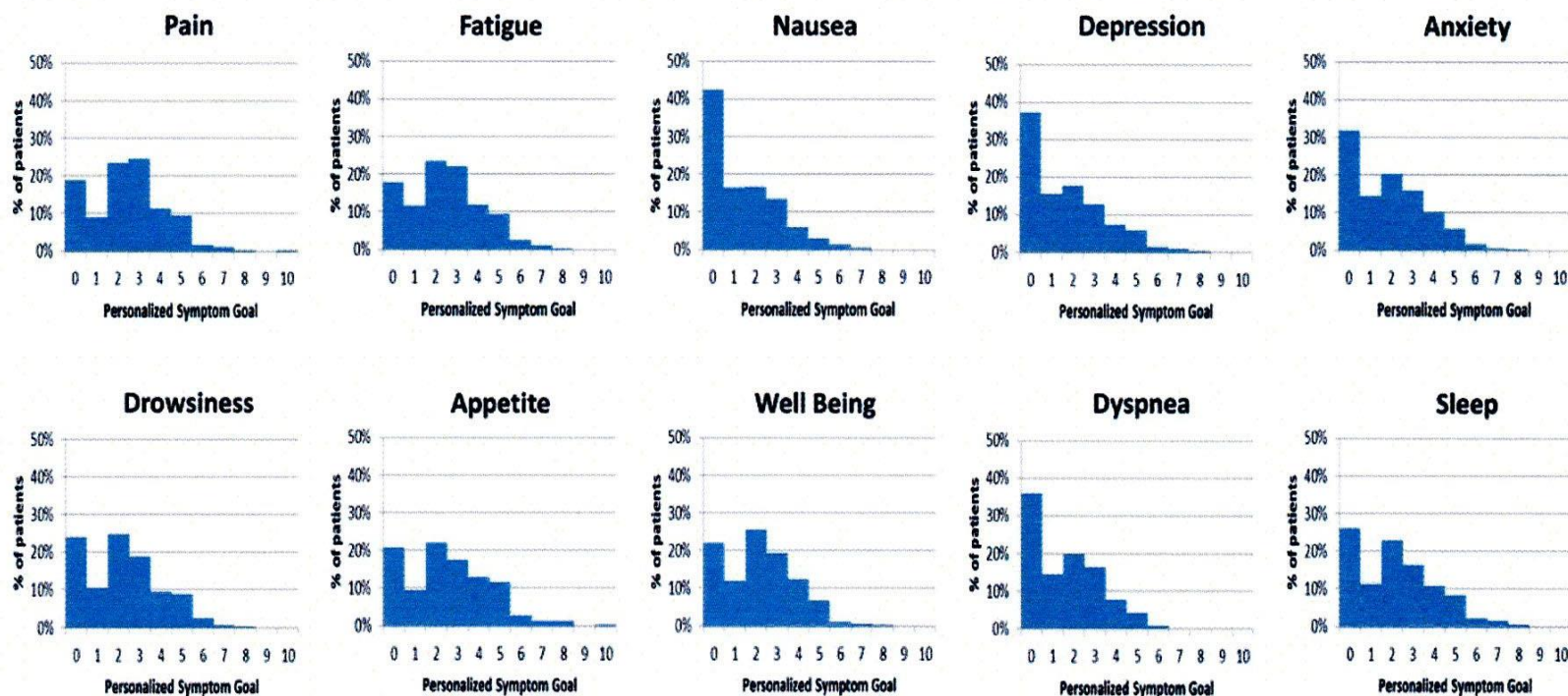


Figure 1. Distribution of personalized symptom goals for 10 symptoms. A majority of patients reported a personalized symptom goal of ≤ 3 .

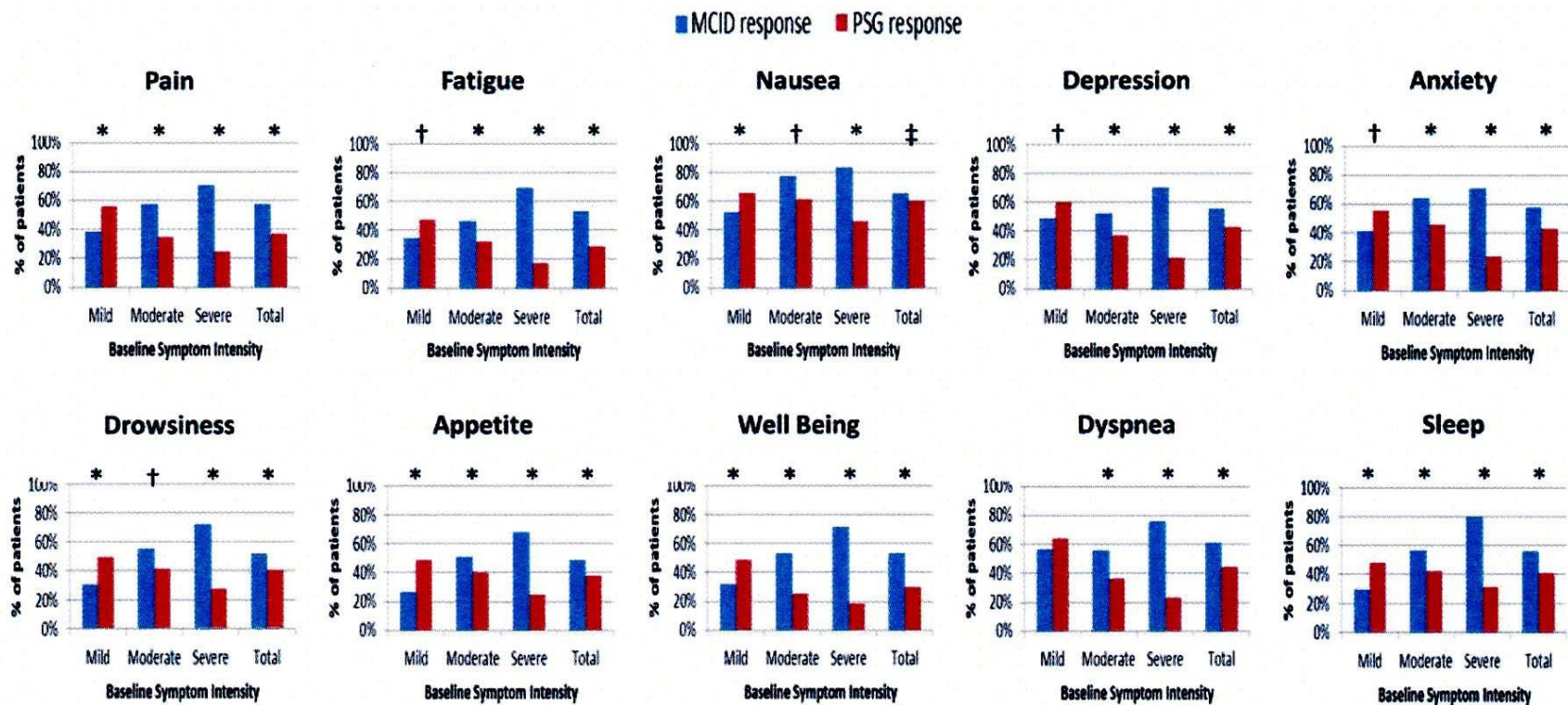
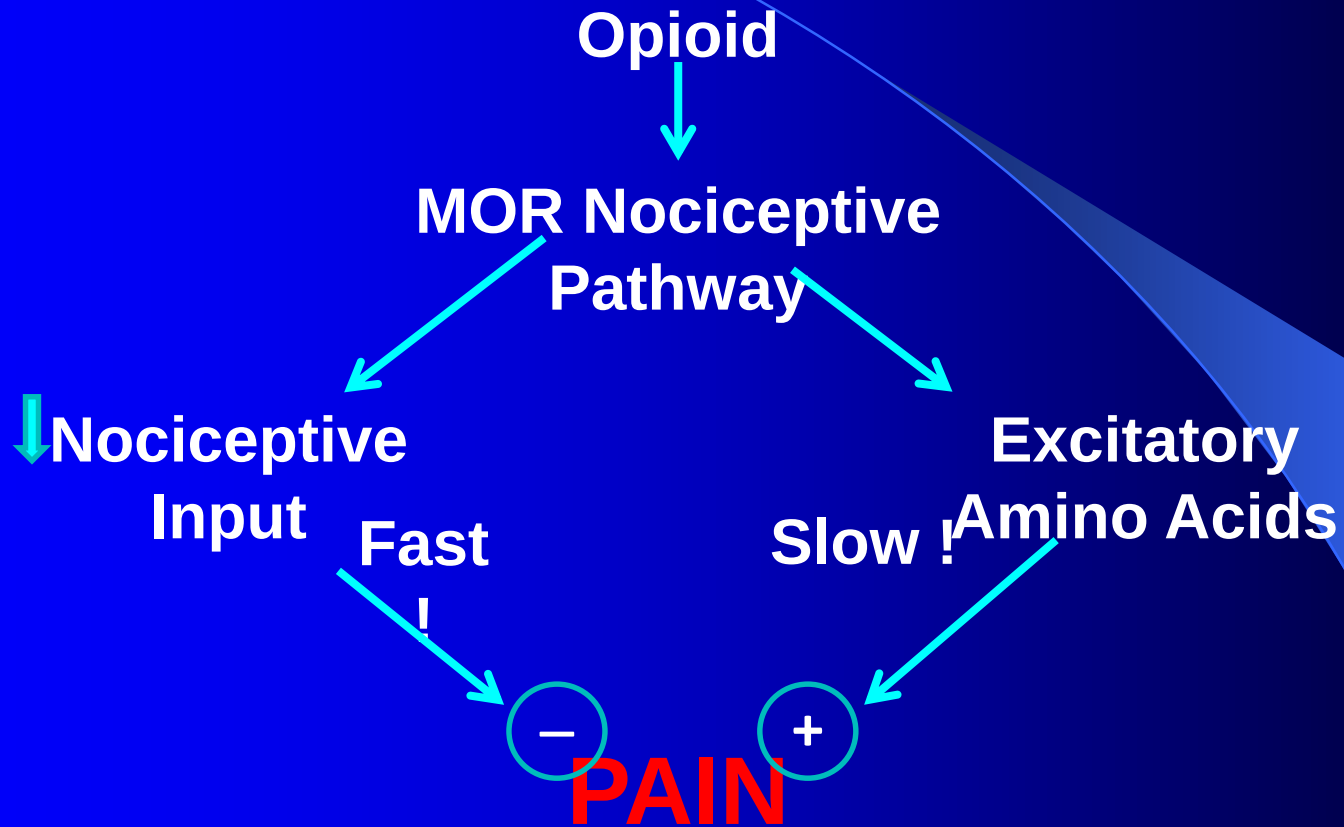


Figure 2. Differences in response rates by baseline symptom intensity and response criteria. The response rates were plotted using 2 criteria-minimal clinically important difference (MCID) and personalized symptom goal (PSG)-according to baseline symptom intensity (ie, mild: 1-3; moderate: 4-6; and severe: 7-10). Using the MCID criteria, patients with higher baseline symptom intensity were more likely to achieve a response and vice versa. In contrast, the personalized symptom response criteria resulted in the opposite conclusion. *P* values were computed based on the McNemer test. * indicates $P < .0001$; †, $P < .001$; ‡, $P < .05$.

Patient understanding

- Addiction
- Pain escalation in the future
- Opioids as the cause of death
- Fear of side effects
- Regular Vs prn





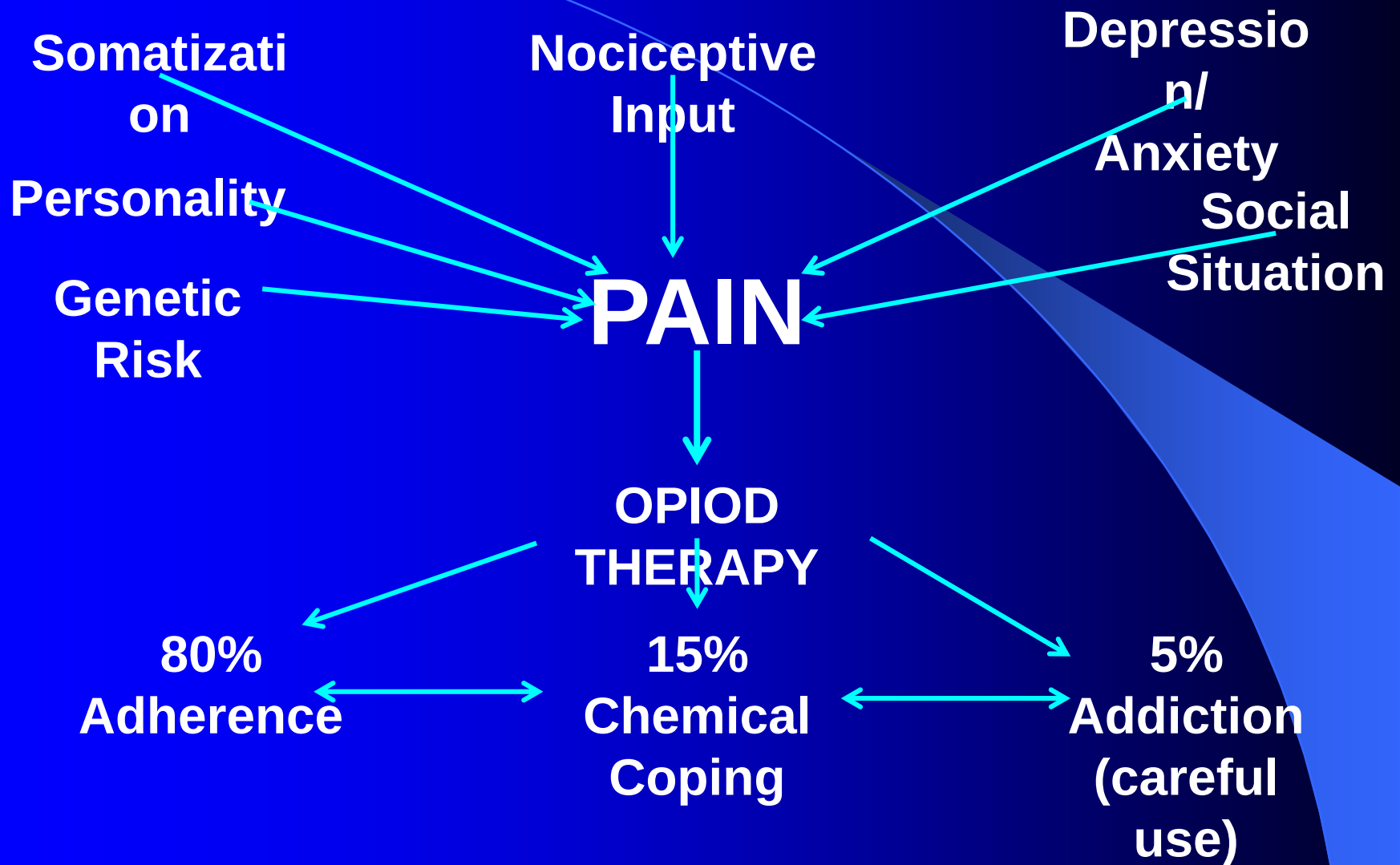
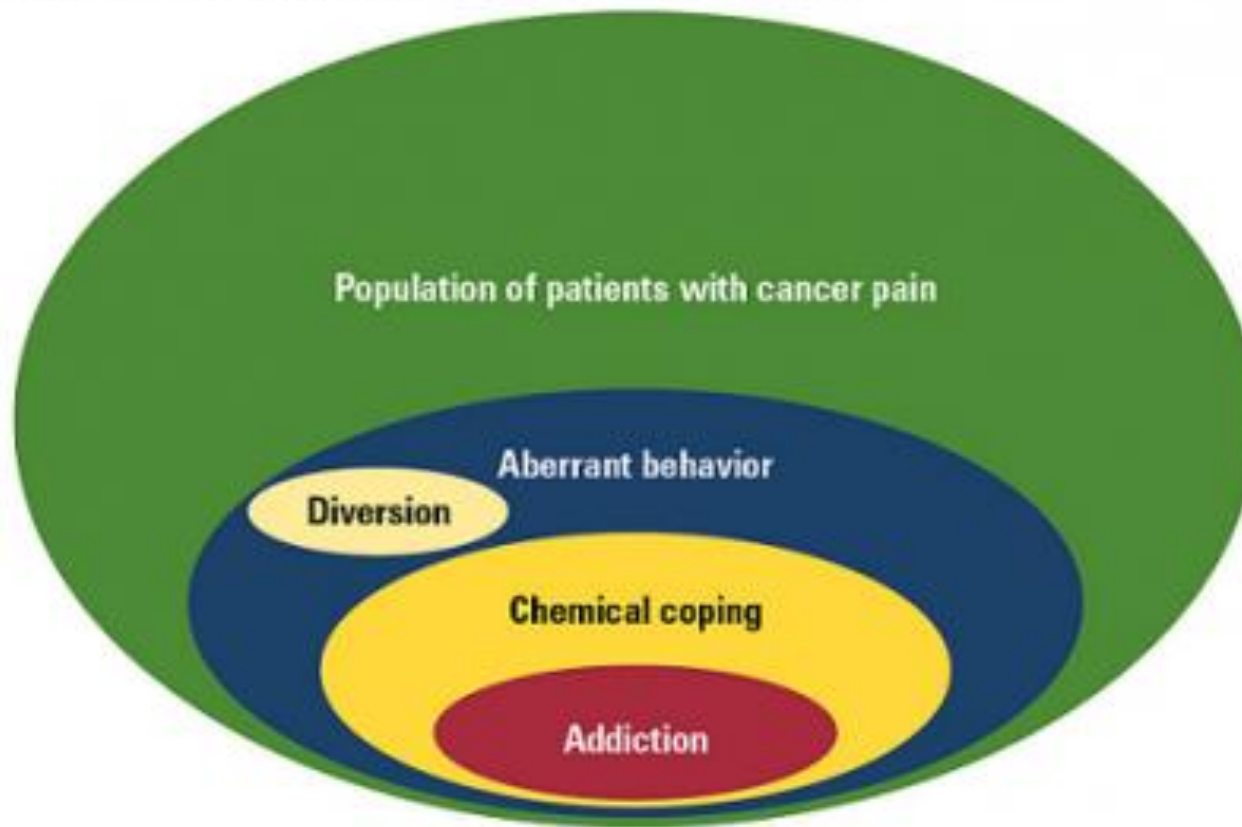


Fig. 1. Spectrum of Aberrant Opioid-Related Behavior



Coping chemically

- 75% of individuals regular alcohol intake
- 7-9% alcoholics (CAGE questionnaire, etc)
- 20% CAGE + hospitalized
- Advanced head and neck CA: 47% +
- Breast 18% CAGE +
- Endorphin mediation of ETOH reward

CAGE (AID) Questionnaire

- Have you ever felt that you should cut down on your drinking (or drugs)?
- Have you ever been annoyed by people criticizing your drinking (or drugs)?
- Have you ever felt bad or guilty about your drinking (or drugs)?
- Have you ever had a drink first thing in the morning or a drink (or drugs) to get rid of a hangover (eye-opener)?

Frequency of Diagnosis of Alcoholism

	1989 (%)	1992 (%)	“p” Value
# Patients	100	100	
Evaluable for assessment	100 (100)	66 (66)	
Diagnosis of alcoholism	28 (28)	18 (27)	0.9

Results...5: Addiction History (Aa, Ao, Ax)

	Aa	Ao	Ax
Tel-Av Hos	0	100	0
Auck-Hos	2.7	89.3	8
Calg-PCU	9.3	84.5	6.2
Edm-Acu	10	86.3	3.8
Auck-Acu	10.1	72.2	17.7
Hou-OuPt	11.1	79.8	9.1
Melb-Acu	12	66.3	21.7
Hou-InPt	12.9	76.5	10.6
Dub-Hos	15.9	74.4	9.8
Edm-TPCU	18.6	78.4	3.1
Dub-Acu	20.3	59.5	20.3

Fainsinger et al.
Eur J Cancer 2010

Dev R et al, Oncologist 2012

- 100/ 598 pts were CAGE+ (17%).
- CAGE+ patients > males and younger .
- Male patients and patients with lung tumors were significantly more likely to have a history of tobacco use.
- CAGE + patients > smoke history !!

Table 1. Patient Demographic and Clinical Characteristics by CAGE- versus CAGE+ groups

	CAGE+ (N=100)	CAGE- (N=100)
Male Gender	68 (68%)^a	51 (51%)
Race		
White	74 (74%)	76 (76%)
African American	17 (17%)	9 (9%)
Hispanic	8 (8%)	11 (11%)
Asian	1 (1%)	2 (2%)
Other	0 (0%)	2 (2%)
Median Age (range)	58.6 (51.2-64.7)^b	61.3 (52.3-71.2)
Type of Cancer		
Lung	19 (19%)	18 (18%)
Gastrointestinal	23 (23%)	24 (24%)
Urologic	8 (8%)	7 (7%)
Breast	5 (5%)	6 (6%)
Gynecologic	6 (6%)	7 (7%)
Head/Neck	24 (%)	17 (17%)
Hematologic	3 (3%)	4 (4%)
Other	12 (12%)	17 (17%)
History of Tobacco Use	86 (86%)^c	48 (48%)
Active Tobacco Use	33 (33%)^d	9 (9%)
History of Illegal Drug Use	17 (17%)^c	1 (1%)
On Strong Opioids Prior to Palliative Care Consultation	47 (47%)^a	29 (29%)
Median MEDD at consultation (range)	100 (50-150)	60 (47.5-200)
Use of ≥ 1 Sedatives, Hypnotics, Anxiolytics	42 (42%)	34 (34%)

^ap<0.05; ^bp=0.07; ^cp<0.001; ^dp=.02

Table 2. Documentation of Alcoholism prior to Palliative Care Consult among CAGE+ patients (n=100)

Primary Oncology Team	7 (7%)
Oncology Fellow Trained in Palliative Care	2 (2%)
Consulting Psychiatry Team	4 (4%)
Total	13 (13%)

Table 3. Patient Demographic and Clinical Characteristics by History of Tobacco Use Status

	History of Tobacco Use N=134 (%)	No Tobacco Use N=66 (%)
Male Gender	94 (67%)^a	25 (38%)
Race		
White	103 (77%)	47 (71%)
African American	19 (14%)	7 (11%)
Hispanic	9 (7%)	10 (15%)
Asian	2 (1%)	1 (1%)
Other	1 (1%)	1 (1%)
Median Age (Range)	59.8 (51.8-69.4)	58.9 (50.6-68.4)
Type of Cancer		
Lung	36 (27%)^a	1 (1%)
Gastrointestinal	29 (22%)	18 (27%)
Urologic	9 (7%)	6 (9%)
Breast	6 (4%)	5 (8%)
Gynecologic	5 (4%)	8 (12%)
Head and Neck	28 (21%)	13 (20%)
Hematological	7 (5%)	0 (0%)
Other	14 (10%)	15 (23%)
On Strong Opioids Prior to Palliative Care Consultation	59 (44%)^b	17 (26%)
Median MEDD (Range)	90 (50-150)	100 (50-400)
CAGE+ Status	86 (64%)^a	14 (21%)
Use of ≥1 Sedative, Hypnotics, Anxiolytics	53 (40%)	23 (35%)

^ap<0.001, ^bp=0.01

Table 2
Characteristics of Advanced Cancer Patients According to Smoking Status

Characteristics, N = 300	Current Smokers, N = 33 (%)	Former Smokers, N = 148 (%)	Never Smokers, N = 119 (%)	Pvalue
Age, mean $\pm$ SD (yrs)	56 $\pm$ 13	63 $\pm$ 12	57 $\pm$ 13	<0.001
Gender				
Female	14 (42)	59 (40)	84 (71)	<0.001
Race				
White	22 (67)	111 (75)	81 (68)	0.35
Black	6 (18)	12 (8)	11 (9)	
Hispanic	4 (12)	16 (11)	17 (14)	
Asian/other	1 (3)	9 (6)	10 (8)	
Marital status				
Single	11 (33)	13 (9)	17 (14)	<0.01
Married	13 (39)	102 (69)	80 (67)	
Divorced/separated	4 (12)	23 (16)	11 (9)	
Widowed	5 (15)	7 (5)	11 (9)	
Other	0 (0)	3 (2)	0 (0)	
Primary cancer type				
Gastrointestinal	9 (27)	50 (34)	26 (22)	
Lung	7 (21)	42 (28)	11 (9)	
Breast	3 (9)	12 (8)	24 (20)	
Gynecologic	4 (12)	11 (7)	22 (18)	
Genitourinary	4 (12)	15 (10)	8 (7)	
Head and neck	2 (6)	3 (2)	5 (4)	
Hematologic	1 (3)	4 (3)	2 (2)	
Other	3 (9)	11 (8)	21 (17)	
Head and neck or lung Cancer				
Yes	9 (27)	45 (30)	16 (13)	<0.01
CAGE positive (≥ 2)				
Yes	14 (42)	31 (21)	4 (3)	<0.001
Illicit drug use history				
Yes	11 (33)	24 (16)	4 (3)	<0.001
MEDD (mg/day), median (IQR)	45 (25–100)	45 (3.4–112.5)	30 (0–95)	0.34
MEDD ≥ 30 mg/day				
Yes (initial consultation)	23 (70)	83 (56)	62 (52)	0.20
Medications including ≥ 1 sedative, hypnotic, or anxiolytic				
Yes	6 (18)	34 (23)	27 (23)	0.83
ESAS, median (IQR)				
Pain	7 (4–9)	5.5 (2–8)	5 (3–8)	0.02
Fatigue	5 (4–8)	6 (3.5–8)	5 (4–7)	0.59
Nausea	2 (0–4)	1 (0–4)	1 (0–3)	0.42
Depression	1 (0–5)	2 (0–5)	2 (0–5)	0.79
Anxiety	2 (0–7)	3 (1–5.5)	3 (0–6)	0.83
Drowsiness	4 (2–5)	4 (1–7)	4 (1–6)	0.60
Dyspnea	2 (0–6)	2.5 (0–5.5)	2 (0–5)	0.63
Anorexia	4 (3–8)	5 (3–8)	5 (2–7)	0.32
Feeling of well-being	5 (4–7)	5 (3–8)	5 (3–7)	0.76
Sleep	7 (3–7)	5 (2–7)	5 (2–8)	0.48
Symptom distress score	36 (22–50)	37 (25–47)	32 (24–48)	0.65

CAGE, Cut down/Annoyed/Guilty/Eye opener; MEDD, morphine equivalent daily dosing; IQR, interquartile range; ESAS, Edmonton Symptom Assessment Scale.

Pain during primary treatment

- Cancer related (65%)
- Surgery
- Radiation/ chemotherapy mucositis
- Chemotherapy induced neuropathy
- Pre- existing conditions (15%)

Head and neck curative RT

- 70 patients referred to supp care center
- . 3 months disease free
- No treatment after completion of RT

Opioid discontinuation after treatment

- 44/70 (63%) on opioids >3 months
- 23/70 (33%) on opioids > 6 months
- 18/44 non stoppers CAGE + (41%)
- 3/26 stoppers CAGE + (12%) $p=0.014$
- Median opioid days 261 CAGE+ Vs 93 CAGE – ($p=0.008$)

Conclusions on opioids for survivors

- Regular assessment of CAGE/ addiction history
- Meticulous follow up and avoid refilling medication without assessment.

Fig. 2. Approach to Treating Patients With Cancer With Opioid Therapy

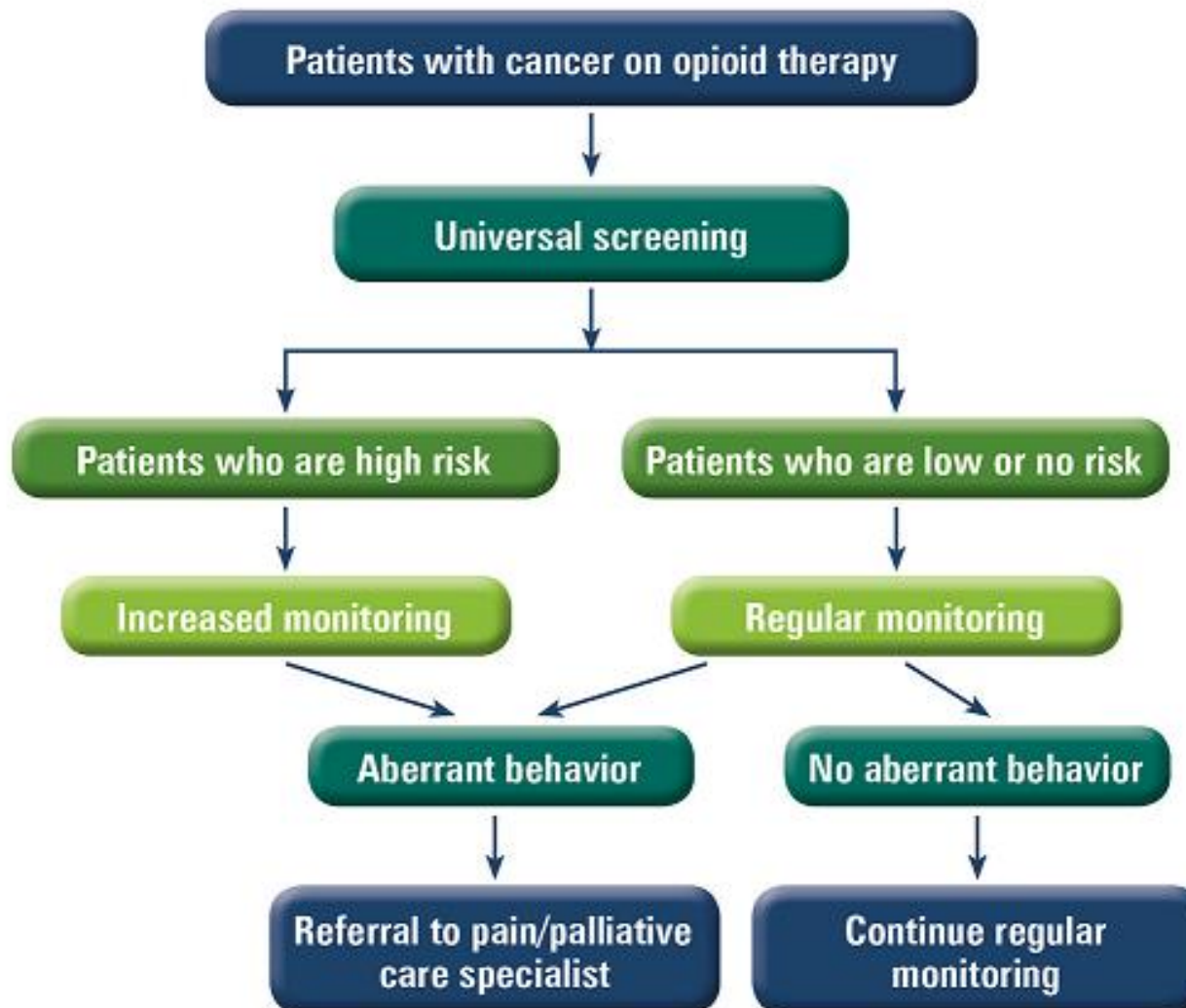


Table. Behaviors Suggestive of Aberrant Opioid Use^{10,21}

Frequent unscheduled clinic appointments or telephone calls for early opioid refills
Self-escalation or request for excessive increase in the opioid dosage not consistent with patient's pain syndrome
Reports of lost or stolen opioid prescription/medication
Frequent emergency room visits for opioids
Seeking opioids from multiple providers ("doctor shopping")
Requests for a specific opioid
Resistance to changes in the opioid regimen even when clinically indicated
Use of non-prescribed restricted medications or illicit drugs
Requesting opioids for their euphoric effect or for symptoms such as anxiety or insomnia
Reports of impaired functioning in daily activities due to opioid use
Family members expressing concern over patient's use of opioids
Reports of hoarding drugs
Reports of stealing or selling prescription drugs
Obtaining opioids from non-medical sources
Reports of stealing, tampering with, or forging opioid prescriptions
Discrepancy in pill counts without good explanation

What does this mean to your practice?

- Approximately 20% of cancer pts screen positive for alcohol (Vs 8% for population)
- We miss 80% of patients!!
- Alcohol predicts opioid chemical coping!
- The profile of smoking has changed (due to decrease from 40% to 22%)
- Always screen with CAGE. Alcohol questions do not work

What do we do with the information?

- Alcohol makes us feel good. 90% drink, 8% maladaptive (20% in cancer)
- CAGE +: opioids reduce suffering. Difference with pain

Somatization

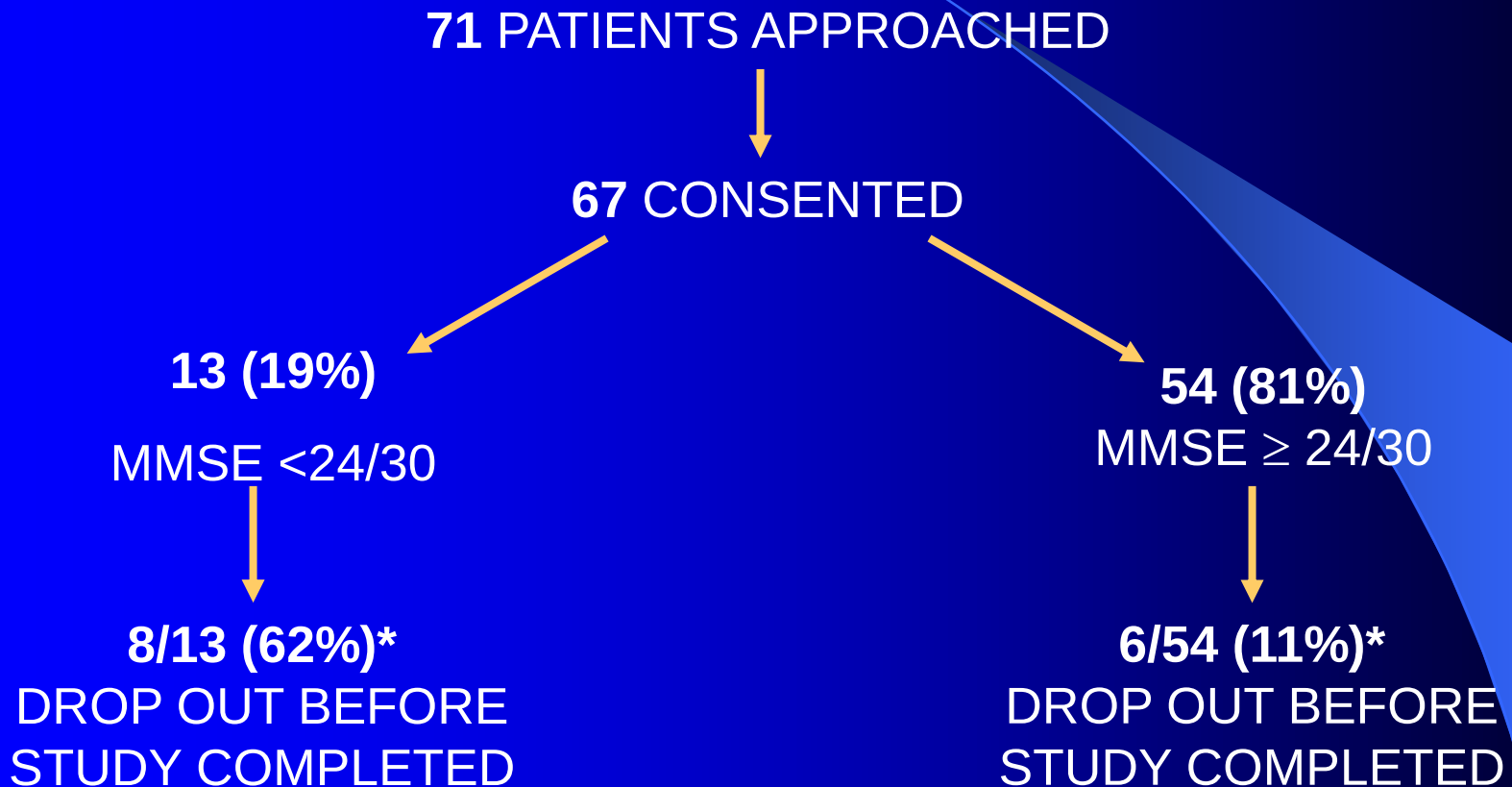
- “total pain”, “total suffering”.
- Diagnostic criterion for affective disorders
- Meaning of pain for the patient
- Aggravated by stressors
- High intensity expression (10/10)
- Multiple symptoms (“all black graph”)

Causes of somatization

- Personality (functional disorders!!!)
- Depression/ anxiety
- Spiritual pain (Delgado-Guay JPSM)
- Cultura! “pain in the neck” (or somewhere else), “ad nauseam”
- Physical Sign of somatization? Mass on the flank
- Patients at high risk of medical attack

**Function better than intensity expression-
complain can be adaptive**

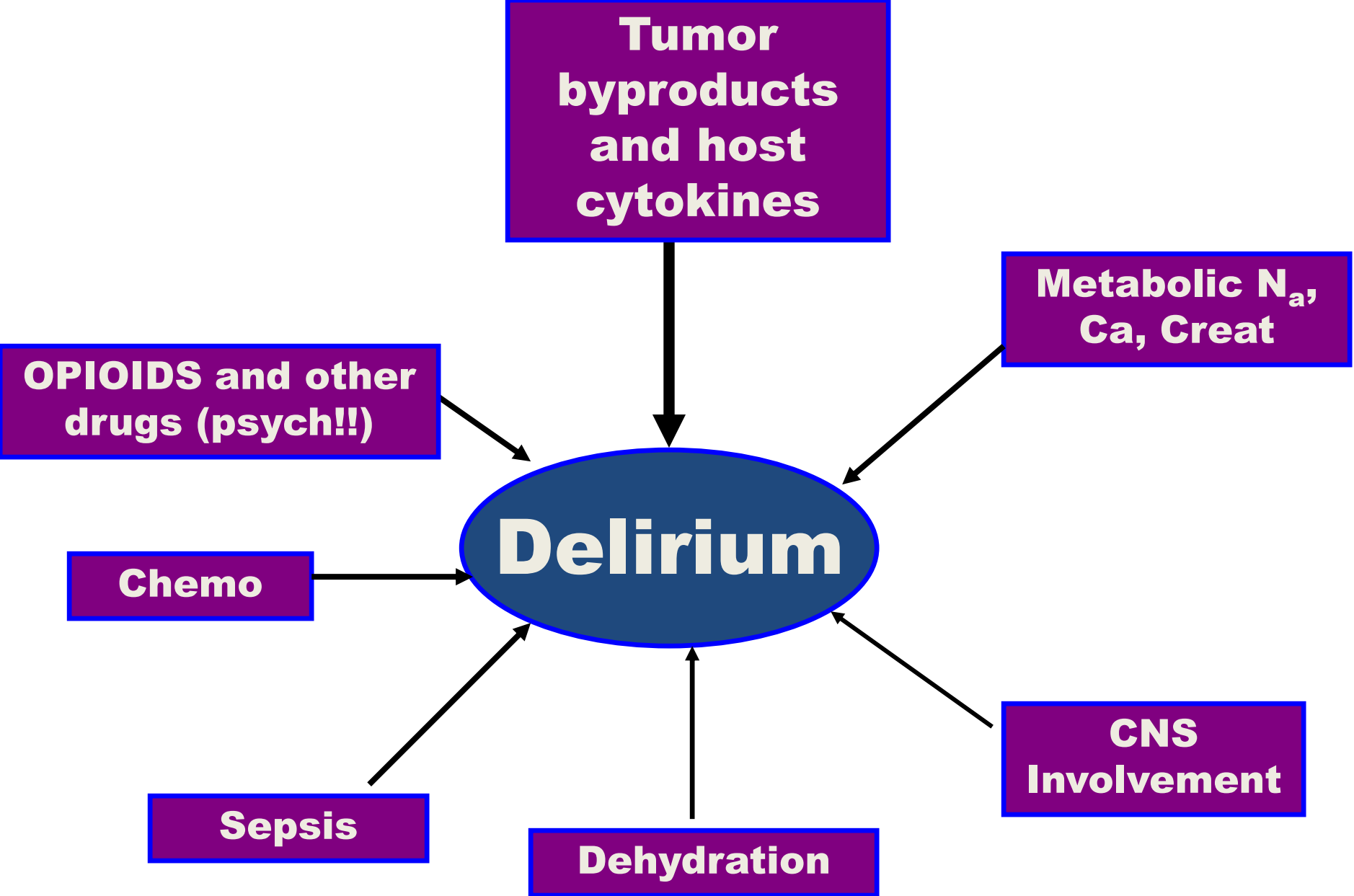
COGNITIVE FAILURE IN CANCER PATIENTS



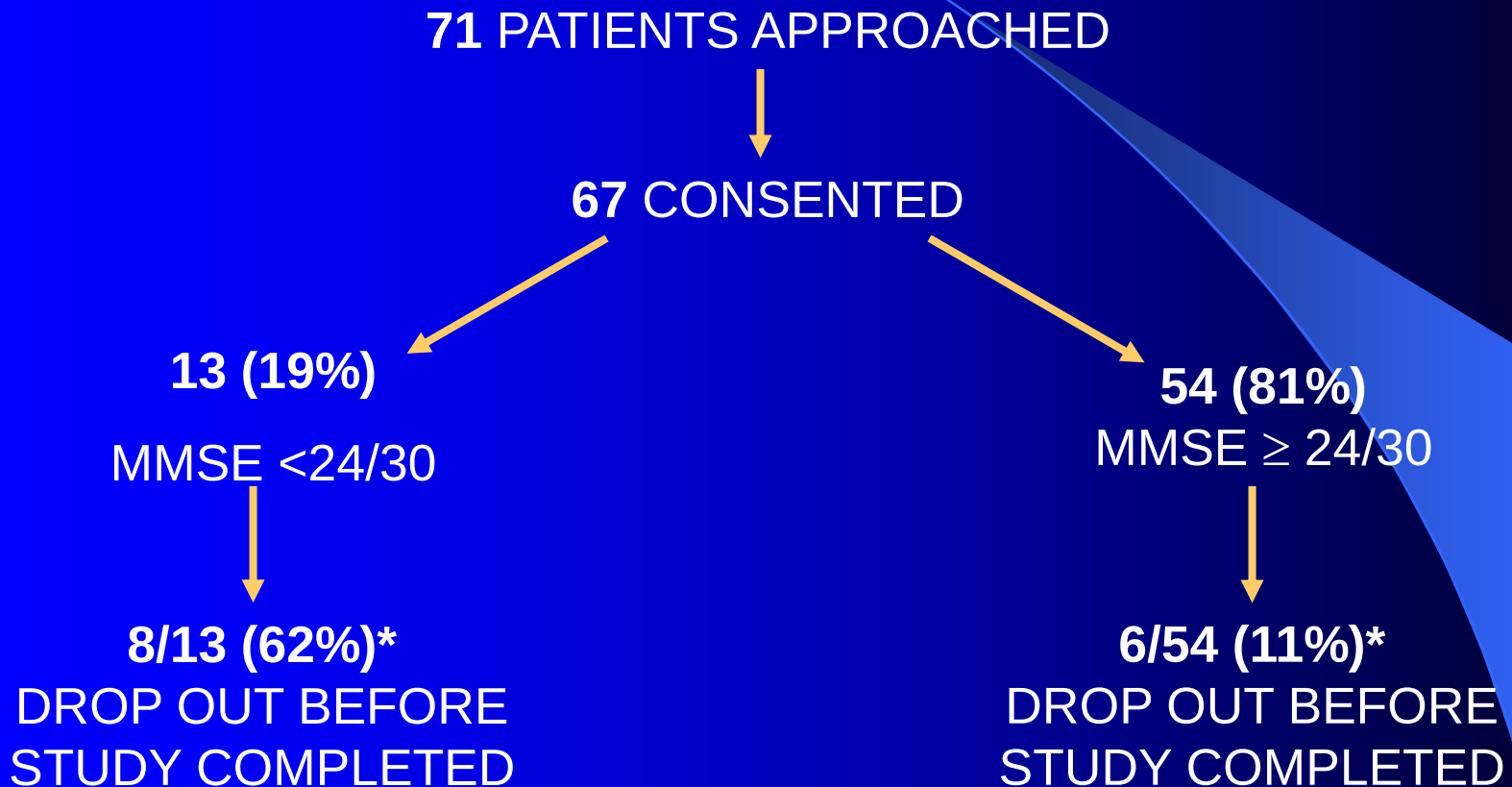
* p,0.01, χ^2 Test

Delirium

- 85% cancer pts before death
- Multicausal
- 80% of brain is GABA
- Disinhibition: expression of symptoms and emotions



COGNITIVE FAILURE IN CANCER PATIENTS



* p,0.01, χ^2 Test

Delirium

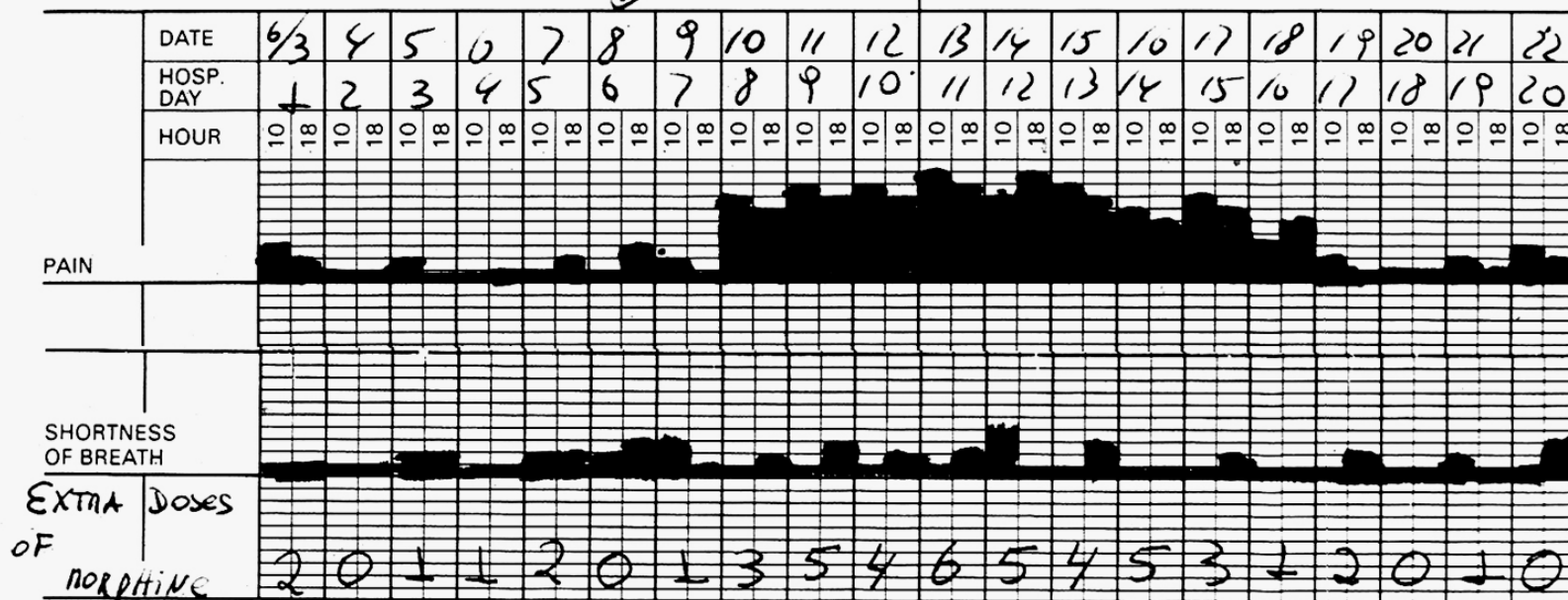
- Opioids can cause- dose escalation!!
- Increased pain: hyperalgesia /delirium
- Screening!! MMSE, hallucinations, agitation



The General Hospital
(Grey Nuns) of Edmonton

SYMPTOM ASSESSMENT GRAPH

C. FAILURE
CHANGE OPINTE.
HALOPERIDOL



ASSESSED BY

PPPPPPPPPPPPPPPPPPNNNNNNNNNNFNNFNNNNPPPPNPPPPPP

Code P - Patient N - Nurse NA - Nurse Assisted F - Family

Mini-Mental State Score

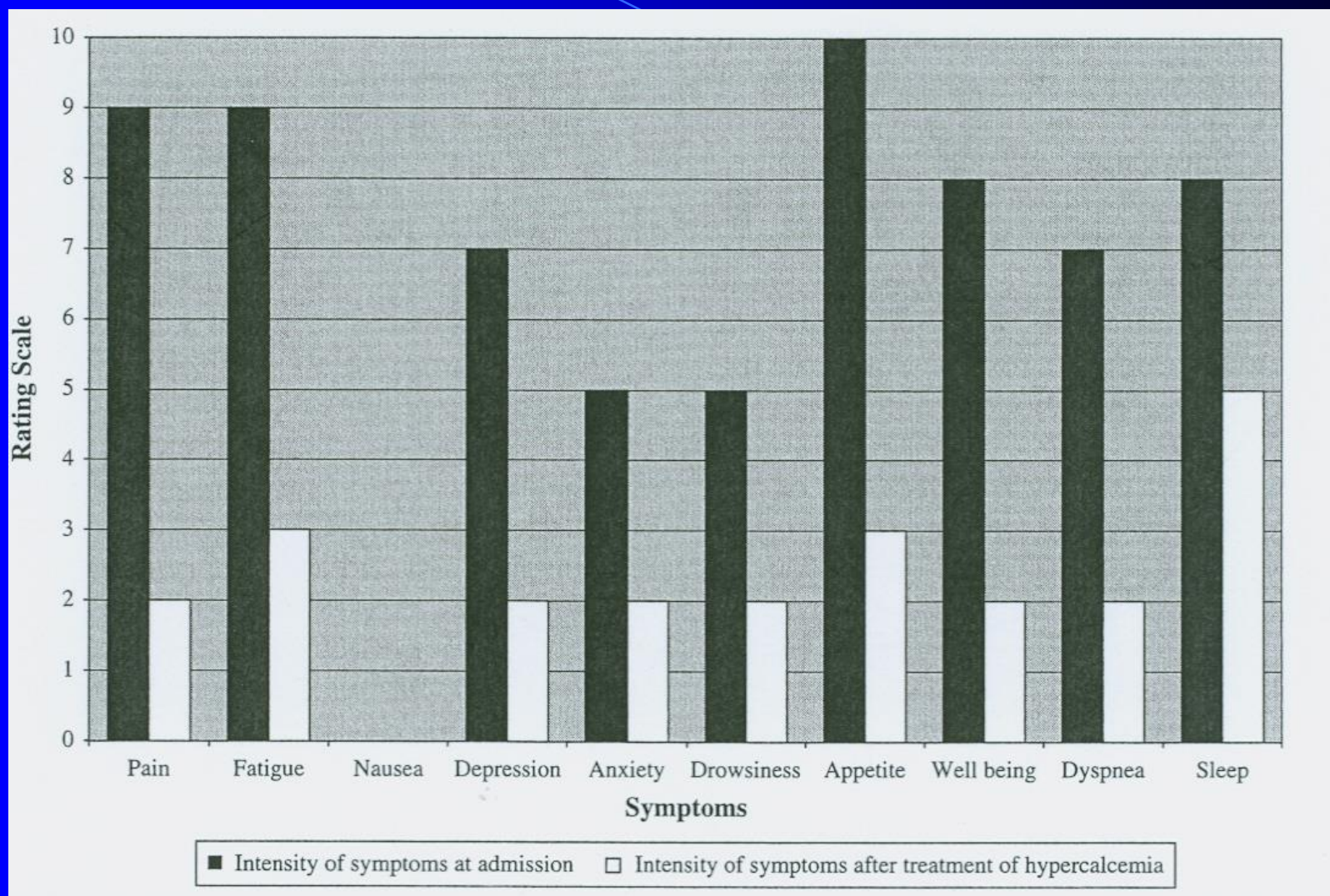
30 28 27 19 5 0 16 24 28 27

PSYCHOMOTOR 0 0 0 1 3 3 2 1 0 9 9 9

Delirium and symptom expression (Delgado- Guay)

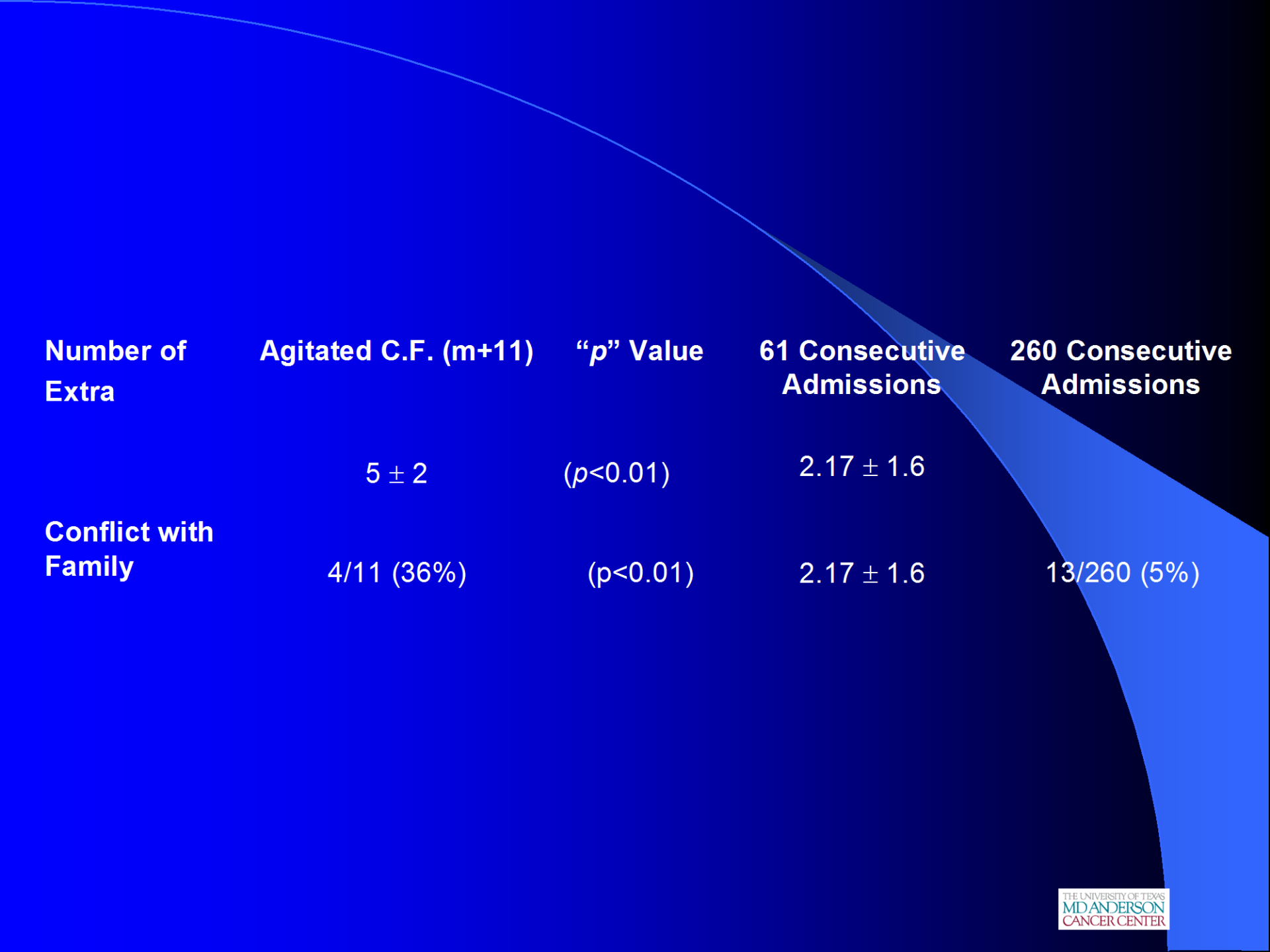
- 60 yo man, advanced small cell prostate ca, lumbar adenopathies and bone mts
- Chemo + lumbar RT
- Referred stat due to severe pain
- Admission: Ca 12.44, creat 1.6
- Pain 9, MDAS 14
- Bedridden

ESAS Findings at Admission



Delgado-Guay MO, Yennu S, Bruera E JPSM 2008; 36(4):442-449

PC Assessment



Number of Extra	Agitated C.F. (m+11)	“p” Value	61 Consecutive Admissions	260 Consecutive Admissions
	5 ± 2	($p < 0.01$)	2.17 ± 1.6	
Conflict with Family	4/11 (36%)	($p < 0.01$)	2.17 ± 1.6	13/260 (5%)

Delirium recall study

- Adult inpatients with advanced cancer
- Diagnosis of delirium and complete < 3 days before study entry

99 Patients

Caregivers

Bedside
nurses

Palliative care
specialists

Delirium recall



Data collection



Symp frequency

- Disorientation
- Hallucinations
- Delusions
- Agitation

Self reported distress

- Disorientation
- Hallucinations
- Delusions
- Agitation



Average daily **neuroleptic dose** used during delirium

Patient & Family Caregiver Characteristics

	Patient	Family Caregiver
Mean age (SD), y	60 (12)	55 (12)
Female (%)	46 (46)	72 (73)
Ethnicity (%)		
White	76 (77)	76 (77)
African American	15 (15)	15 (15)
Hispanic	7 (7)	6 (7)
Asian	1 (1)	2 (2)
Total	99 (100)	99 (100)
Primary cancer diagnosis (%)		NA
Lung	30 (30)	
GI	20 (20)	
GU	13 (13)	
Breast	8 (8)	
GYN	8 (8)	
Leukemia	5 (5)	
Melanoma	5 (5)	
Other	10 (10)	
Total	99 (100)	
Median duration of acute episode of delirium (25th to 75th quartile), d	3 (2-5)	NA
Median MDAS score (25th to 75th quartile)*	3 (2-5)	NA
Median MMSE score (25th to 75th quartile)*	28 (26-29)	NA
Educational level (%)		
<6 y	1 (1)	0
6-9 y	4 (4)	1 (1)
9-12 y	37 (37)	28 (28)
College	41 (41)	54 (54)
Graduate school	15 (15)	13 (13)
Total	98 (99)	96 (97)
Relationship to patient (%)		
Spouse/significant others	—	61 (62)
Adult child	—	21 (21)
Sibling	—	8 (8)
Friend	—	4 (4)
Parent	—	5 (5)
Total		99 (100)

Bruera E, Bush SH, et al Cancer 2009;115:2004-12

Patient Distress Level (0-5)

		No. (%)	No. of Evaluable Reports (%)	Median Distress Level (Q1-Q3)	P*
Remember	No	26 (26)	25 (96)	2 (0-4)	.03
	Yes	73 (74)	69 (94)	3 (1-4)	
Delirium subtype	Hypoactive	20 (20)	19 (95)	2 (0-3)	.32
	Hyperactive	13 (13)	13 (100)	2 (2-4)	
	Mixed delirium	66 (67)	62 (94)	3 (1-4)	
Gender	Male	53 (54)	49 (92)	3 (1-4)	.67
	Female	46 (46)	45 (98)	3 (1-4)	
Race	White	76 (77)	74 (97)	2.5 (1-4)	.40
	Nonwhite	23 (23)	20 (86)	3 (2-4)	

The source of conflict!

Symptoms	Patient/ Family Caregiver		Patient/ Nurse		Patient/ PCS		Family Caregiver/ Nurse		Family Caregiver/ PCS		Nurse/ PCS	
	n	WK (P)	n	WK (P)	n	WK (P)	n	WK (P)	n	WK (P)	n	WK (P)
Auditory hallucinations	93	0.38 (<.01)	79	0.19 (<.01)	92	0.2 (.02)	78	0.03 (.52)	93	0.18 (.01)	80	0.26 (<.01)
Delusional thoughts	95	0.29 (<.01)	80	0.15 (.09)	93	0.1 (.26)	79	0.08 (.3)	94	0.07 (.36)	80	0.04 (.63)
Time orientation	91	0.28 (<.01)	74	-0.08 (.4)	87	-0.02 (.79)	79	-0.03 (.73)	94	0.01 (.97)	78	0.19 (.03)
Place orientation	91	0.26 (<.01)	74	-0.01 (.93)	87	0.06 (.43)	80	0.09 (.26)	94	0.01 (.93)	79	0.18 (.03)
Psychomotor agitation	94	0.25 (<.01)	79	0.13 (.12)	90	0.09 (.26)	80	0.13 (.06)	95	0.06 (.4)	80	0.08 (.33)
Tactile hallucinations	93	0.18 (.02)	79	0.09 (.37)	91	-0.003 (.97)	79	0.13 (.12)	94	0.07 (.34)	80	0.13 (.18)
Visual hallucinations	96	0.45 (<.01)	78	0.14 (.01)	91	0.21 (.01)	80	0.18 (<.01)	94	0.24 (<.01)	79	0.05 (.38)

Delirium recall and management lessons

- Patient and caregiver reported outcomes useful!
- MD/ RNs frequently overestimate their ability to assess
- Management is more MD/RN based and less patient/ family based

MDAS

Memorial Delirium Assessment Scale

ITEM 1 – REDUCED LEVEL OF CONSCIOUSNESS (AWARENESS):

- ☐ 0: none
- ☐ 1: mild
- ☐ 2: moderate
- ☐ 3: severe

ITEM 2 – DISORIENTATION:

- ☐ 0: none
- ☐ 1: mild
- ☐ 2: moderate
- ☐ 3: severe

ITEM 3 – SHORT-TERM MEMORY IMPAIRMENT:

- ☐ 0: none
- ☐ 1: mild
- ☐ 2: moderate
- ☐ 3: severe

ITEM 4 – IMPAIRED DIGIT SPAN:

- ☐ 0: none
- ☐ 1: mild
- ☐ 2: moderate
- ☐ 3: severe

ITEM 5 – REDUCED ABILITY TO MAINTAIN AND SHIFT ATTENTION

- ☐ 0: none
- ☐ 1: mild
- ☐ 2: moderate
- ☐ 3: severe

MDAS

Memorial Delirium Assessment Scale

ITEM 6 – DISORGANIZED THINKING

- ☐ 0: none
- ☐ 1: mild
- ☐ 2: moderate
- ☐ 3: severe

ITEM 7 – PERCEPTUAL DISTURBANCE:

- ☐ 0: none
- ☐ 1: mild
- ☐ 2: moderate
- ☐ 3: severe

ITEM 8 – DELUSIONS:

- ☐ 0: none
- ☐ 1: mild
- ☐ 2: moderate
- ☐ 3: severe

ITEM 9 – DECREASED OR INCREASED PSYCHOMOTOR ACTIVITY:

- ☐ 0: none
- ☐ 1: mild
- ☐ 2: moderate
- ☐ 3: severe

ITEM 10 – SLEEP-WAKE CYCLE DISTURBANCE (DISORDER OR AROUSAL):

- ☐ 0: none
- ☐ 1: mild
- ☐ 2: moderate
- ☐ 3: severe

TOTAL _____

MEMORIAL DELIRIUM ASSESSMENT SCALE (MDAS)

INSTRUCTIONS: Rate the severity of the following symptoms of delirium based on current interaction with subject or assessment of his/her behavior or experience over past several hours (as indicated in each time.)

ITEM 1-REDUCED LEVEL OF CONSCIOUSNESS (AWARENESS): Rate the patient's current awareness of and interaction with the environment (interviewer, other people/objects in the room; for example; ask patients to describe their surroundings).

- ☐ 0: none (patient spontaneously fully aware of environment and interacts appropriately)
- ☐ 1: mild (patient is unaware of some elements in the environment, or not spontaneously interacting appropriately with the interviewer; becomes fully aware and appropriately interactive when prodded strongly; interview is prolonged but not seriously disrupted)
- ☐ 2: moderate (patient is unaware of some or all elements in the environment, or not spontaneously interacting with the interviewer; becomes completely unaware and inappropriately interactive when prodded strongly; interview is prolonged but not seriously disrupted)
- ☐ 3: severe (patient is unaware of all elements in the environment with no spontaneous interaction of awareness of the interviewer, so that the interview is difficult-to-impossible even with maximal prodding)

ITEM 2-DISORIENTATION: Rate current state by asking the following 10 orientation items: date, month day, year, season, floor, name of hospital, city, state, and country.

- ☐ 0: none (patient knows 9-10 items)
- ☐ 1: mild (patient knows 7-8 items)
- ☐ 2: moderate (patient knows 5-6 items)
- ☐ 3: severe (patient knows no more than 1 item)

ITEM 3-SHORT-TERM MEMORY IMPAIRMENT: Rate current state by using repetition and delayed recall of 3 words [patient must immediately repeat and recall words 5 min later after an intervening task. Use alternate sets of 3 words for successive evaluations (for example, apple, table, tomorrow, sky, cigar, justice)].

- ☐ 0: none (all 3 words repeated and recalled)
- ☐ 1: mild (all 3 words repeated, patient fails to recall 1 of 3)
- ☐ 2: moderate (all 3 words repeated, patient fails to recall 2 of 3)
- ☐ 3: severe (patient fails to repeat 1 or more words)

Number & Percentage of Correct Diagnosis for Each Patient

<i>Case</i>	<i>True MDAS score</i>	<i>Median participant score (range)</i>	<i>No. of correct participant diagnoses (%)</i>
Patient 1 (no delirium)	5	5 (2-15)	30/31 (96.8%)
Patient 2 (severe delirium)	20	18 (10-26)	28/31 (90.3%)
Patient 3 (mild delirium)	14	19 (13-25)	31/31 (100%)

Number & Percentages of Correct Diagnosis According to Health Care Professional

<i>Case</i>	<i>Physicians (n = 11)</i>	<i>Nurses (n = 12)</i>	<i>Other (n = 8)</i>	<i>All raters (n = 31)</i>	<i>p Value</i>
Patient 1 (no delirium)	10 (91%)	12 (100%)	8 (100%)	30 (97%)	0.61
Patient 2 (severe delirium)	11 (100%)	10 (83%)	7 (88%)	28 (90%)	0.46
Patient 3 (mild delirium)	11 (100%)	12 (100%)	8 (100%)	31 (100%)	>0.99
All cases	32 (97%)	34 (94%)	23 (96%)	89 (96%)	>0.99

Relatives and Nurses Perceptions of Discomfort in Unresponsive Terminally Ill Cancer Patients

- 60 unresponsive, actively dying patients
- One relative and one nurse for each patient evaluated:
 - patient's discomfort level 0-10 scale,
 - frequencies of 6 observed behaviors 0 – 4 scale

Results

- 20/60 (33%) relatives rated discomfort (DL) as moderate or severe $\geq 3/10$
- 20/60 (33%) hospice nurses rated DL as moderate or severe $\geq 3/10$
- Correlation in rating of DL poor (0.25)
- Relatives rated frequency of observed behaviors (OB) higher than nurses ($p < 0.0001$).

Correlation between behaviors observed by relatives and nurses

Variable	Frequency relatives (%)	Frequency nurse (%)	Kappa
Overall discomfort $\geq 3/10$	20 (33)	20 (33)	0.25
Grimacing $\geq 1/4$	40 (67)	29 (48)	0.34
Groaning $\geq 1/4$	34 (57)	23 (38)	0.10
Shouting $\geq 1/4$	8 (13)	1 (2)	0.20
Touch rubbing an area $\geq 1/4$	22 (36)	7 (12)	0.11
Purposeless movement $\geq 1/4$	27 (45)	20 (33)	0.26

Results

- 20/60 (33%) relatives rated discomfort (DL) as moderate or severe $\geq 3/10$
- 20/60 (33%) nurses rated DL as moderate or severe $\geq 3/10$
- Correlation in rating of DL poor (0.25)
- Relatives rated frequency of observed behaviors (OB) higher than nurses ($p < 0.0001$)
- Rating of at least one OB $\geq 3/4$ by nurse significantly associated with rating DL $\geq 3/10$ ($p < 0.05$). Not for relatives.

What to look for?

1. Somatization: pain and expression of suffering
history of headache – back pain –
frequent somatic complaints
2. Addiction or
alcoholism: MOST patients go undetected
after admission
3. Psychiatric
illness: affective disorders

ASSESSMENT TOOLS

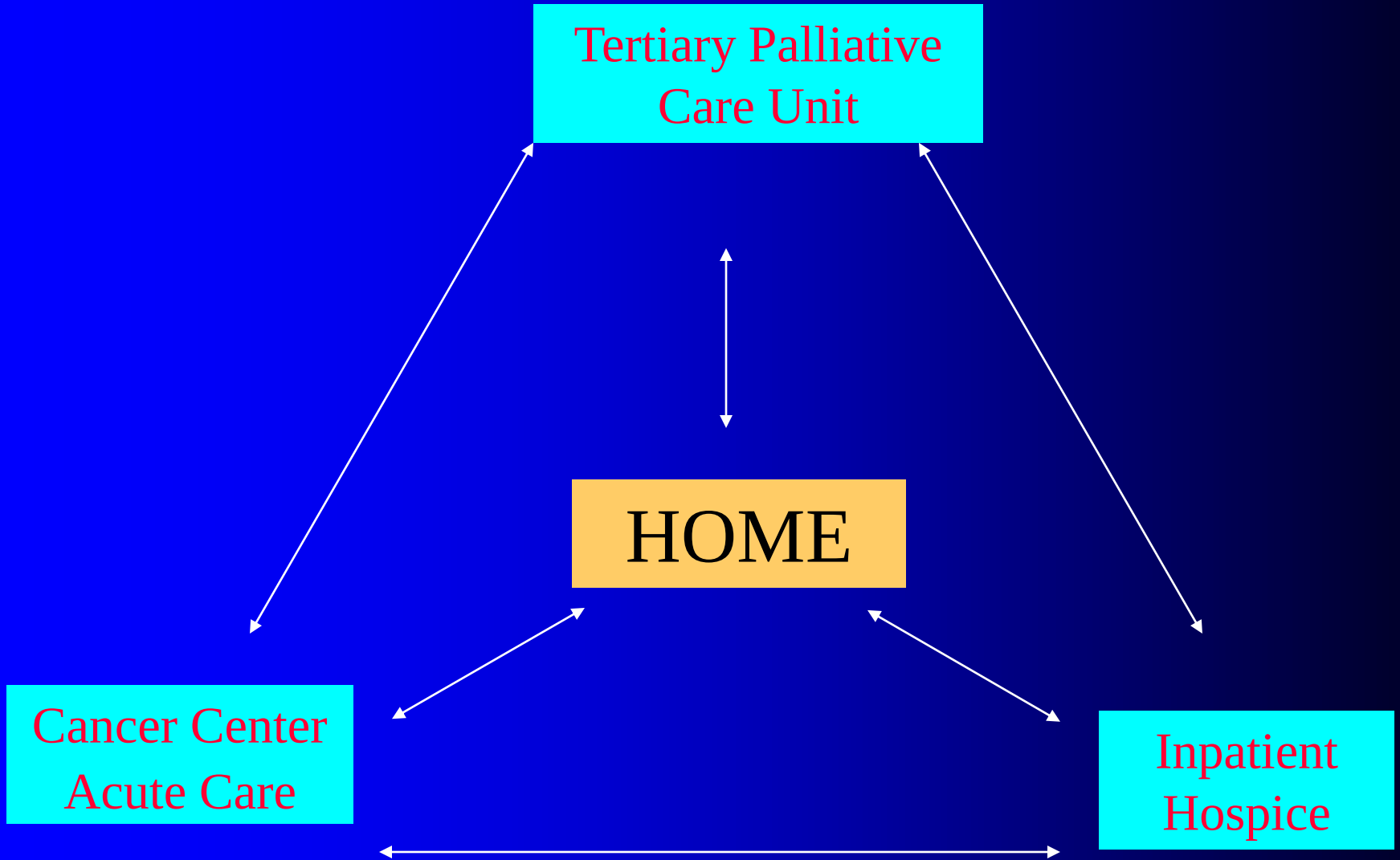
- ESAS
- CAGE
- MDAS
- Constipation

Tertiary Palliative
Care Unit

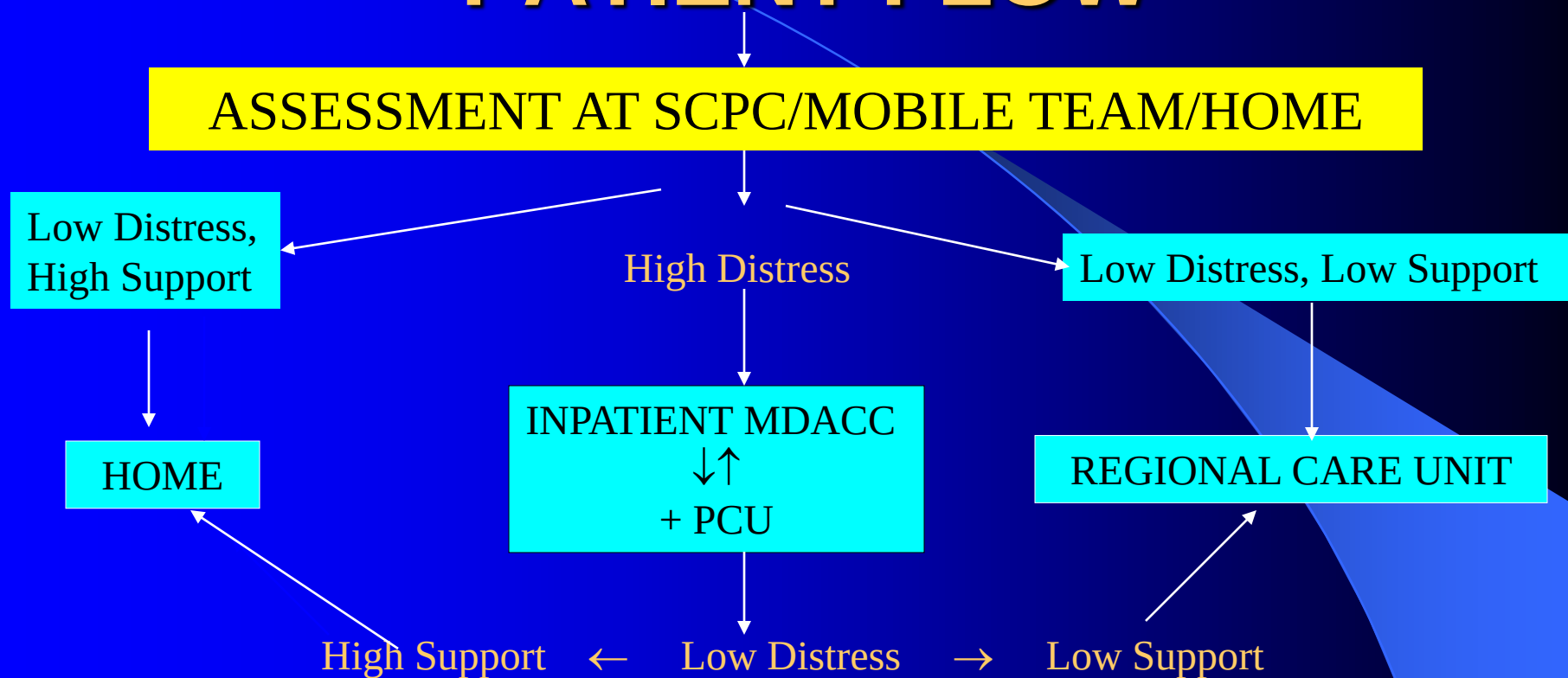
HOME

Cancer Center
Acute Care

Inpatient
Hospice



PATIENT FLOW



Main Difference with Hospice: 1) All patients will remain in contact with their primary oncologist and will qualify for phase I and Research treatments; 2) Patients will remain as UT MDACC patients.

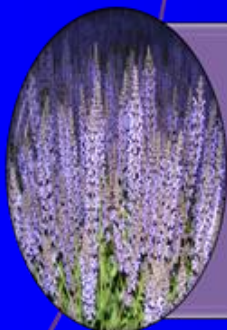


100 patients. Median age (IQR range): 56 (27-83) years. 60% were female. 68% were White, 17% Hispanic, and 9% African-American. 62% were married. Age, marital status, religion, education and cancer diagnosis were not significant different among the 4 groups.



All patients were able to complete the GWG. 43/50 (88%) agreed that the instructions of GWG were clear. 45/50 (92%) agreed that GWG was easy to understand.

31/50 (63%) patients exposed to both tools, preferred GWG.



39/50(80%) expressed that GWG did not increased their anxiety.

31/50 (63%) expressed that having conversations about priorities near EOL is beneficial to them (p=NS for all items).

STAI median (IQR) score after GWG was 48(39-59) v. 47(27-63) for LOS, p=0.2952.

10 most Common Very Important Wishes at First and Second Test

	Items	1 st Test	2 nd Test	Correlation**	
		N=100	N=100		
		N* (%)	N* (%)	r	p-value
1	To be at peace with God	74(74%)	71(71%)	0.73	<0.0001
2	To pray.	62(62%)	61(61%)	0.57	<0.0001
3	To have my family with me.	57(57%)	61(61%)	0.23	0.0280
4	To be free from pain	54(54%)	60(60%)	0.31	0.0019
5	Not being a burden to my family.	48(48%)	49(49%)	0.23	0.0241
6	To trust my doctor.	44(44%)	45(45%)	0.49	<0.0001
7	To keep my sense of humor.	41(41%)	45(45%)	0.53	<0.0001
8	To say goodbye to important people in my life.	41(41%)	37(37%)	0.46	<0.0001
9	To have my family prepared for my death.	40(40%)	49(49%)	0.48	<0.0001
10	To be able to help others.	36(36%)	31(31%)	0.52	<0.0001

Physical findings ≤ 3 days of life

(Cancer, Oncologist 2015)

- 357 consecutive pts admitted to PCU
- Twice a day exams until d/c or death
- 38 % deaths ≤ 3 days

Signs of Impending Death

Likelihood Ratio for Death in 3 Days

Sign	Prevalence N (%)	Sensitivity (95% CI)	Specificity (95% CI)	Negative LR (95% CI)	Positive LR (95% CI)
Inability to close eye lids	93 (46)	21.4 (20.9-21.8)	97.9 (97.7-98.1)	0.8 (0.8-0.81)	13.6 (11.7-15.5)
Grunting of vocal cords	86 (43)	19.5 (19-19.9)	97.9 (97.7-98.1)	0.82 (0.82-0.83)	11.8 (10.3-13.4)
Resp. w. mand. movement	92 (46)	22 (21.5-22.4)	97.5 (97.3-97.6)	0.8 (0.8-0.81)	10 (9.1-10.9)
Death rattle	110 (54)	22.4 (21.8-22.9)	97.1 (96.9-97.3)	0.8 (0.79-0.81)	9 (8.1-9.8)
Drooping of nasolabial fold	137 (68)	33.7 (33.2-34.3)	95.5 (95.3-95.8)	0.69 (0.69-0.7)	8.3 (7.7-8.9)
Hyperextension of neck	73 (36)	21.2 (20.6-21.7)	96.7 (96.5-96.9)	0.82 (0.81-0.82)	7.3 (6.7-8)
Palliative PS $\leq 20\%$	176 (87)	64 (63.4-64.7)	81.3 (80.9-81.7)	0.44 (0.43-0.45)	3.5 (3.4-3.6)
Inability to clear secretions	155 (77)	46.1 (45.6-46.7)	84.9 (84.5-85.3)	0.64 (0.63-0.64)	3.1 (3-3.2)
Non-reactive pupils	53 (26)	15.3 (14.9-15.7)	99 (98.8-99.1)	0.86 (0.85-0.86)	16.7 (14.9-18.6)
Cheyne Stokes breathing	61 (30)	14.1 (13.6-14.5)	98.5 (98.4-98.7)	0.9 (0.9-0.9)	12.4 (10.8-13.9)
↓ response to verbal stimuli	118 (58)	30 (29.4-30.5)	96 (95.8-96.3)	0.73 (0.72-0.74)	8.3 (7.7-9)
↓ response to visual stimuli	121 (60)	31.9 (31.4-32.4)	94.9 (94.6-95.1)	0.72 (0.71-0.72)	6.7 (6.3-7.1)
Apnea periods	71 (35)	17.6 (17.1-18)	95.3 (95.1-95.6)	0.86 (0.86-0.87)	4.5 (3.7-5.2)
Speech abnormalities	143 (70)	42.6 (42-43.2)	90.2 (89.8-90.5)	0.64 (0.63-0.64)	4.4 (4.3-4.6)
Withdrawal	72 (35)	10.6 (10.2-11)	96.8 (96.5-97)	0.92 (0.92-0.93)	3.9 (3.3-4.5)
Pulselessness of radial artery	57 (28)	11.3 (10.9-11.8)	99.3 (99.2-99.5)	0.89 (0.89-0.9)	15.6 (13.7-17.4)
Urine output <200cc/d	48 (49)	24.2 (23.2-25.1)	98.2 (98-98.5)	0.77 (0.76-0.78)	15.2 (13.4-17.1)
Peripheral cyanosis	99 (49)	26.7 (26.1-27.3)	94.9 (94.7-95.2)	0.77 (0.77-0.78)	5.7 (5.4-6.1)
Cool skin temperature	59 (29)	13.6 (13.2-14)	96.8 (96.6-97)	0.89 (0.89-0.9)	4.9 (4.4-5.3)
Mottling	71 (35)	17.1 (16.6-17.6)	95.8 (95.5-96)	0.87 (0.86-0.87)	4.4 (4.1-4.6)

Cardiovascular signs

Neurological signs

Neuromuscular signs

Signs of actively dying

1. Non reactive pupils
2. Decreased resp visual stimuli
3. Inability to close eyelids
4. Hyperextension of the neck
5. Mandibular breathing
6. Decreased nasolabial fold
7. Decreased verbal response
8. Death rattle
9. Grunting of vocal cords
10. Cheyne Stokes respirations

Signs of actively dying

- Very specific: admission + grunting= 88% death <3 days
- Not sensitive! Absence does not rule out

The background is a dark blue gradient. A thin, light blue curved line starts from the top left and arcs towards the bottom right. A larger, semi-transparent blue shape, resembling a spotlight or a fan, originates from the bottom right and points towards the center of the slide.

**“The perfect is the enemy of
the good”**

Voltaire