"There is a general rule, and I have seen great physicians acting on it, that the physician should NOT treat the DISEASE but the PATIENT who is suffering from it"

Maimonides (1135-1204)

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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%)

The Fringe!!

- 1967- St Cristopher's hospice
- Houses and home care. Emphasis on assessement and management of symptoms, family care, counseling, planning end of life, bereavement support

Main stream medicine

- Critical care medicine
- Emergency medicine
- Multiple other subspecialties
- About 10 years older, but within the system

1987 problem : Many symptoms, no time, no clinical tools

- Questions: "Brief tools"; Pain: 10 – 28 ; depression: 12- 25, anxiety: 6- 12, fatigue: 12- 20, dyspnea: 3- 12, QoL: 30- 80
- " comprehensive": 122 questions- police interrogation techniques?

1987-ESAS (Edmonton symptom assessment system)

- 2 minutes by patient in the waiting room or bedside
- Graphic display of multiple symptoms(faster to read and compare)

Appendix C Symptom Assessment System

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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: _____

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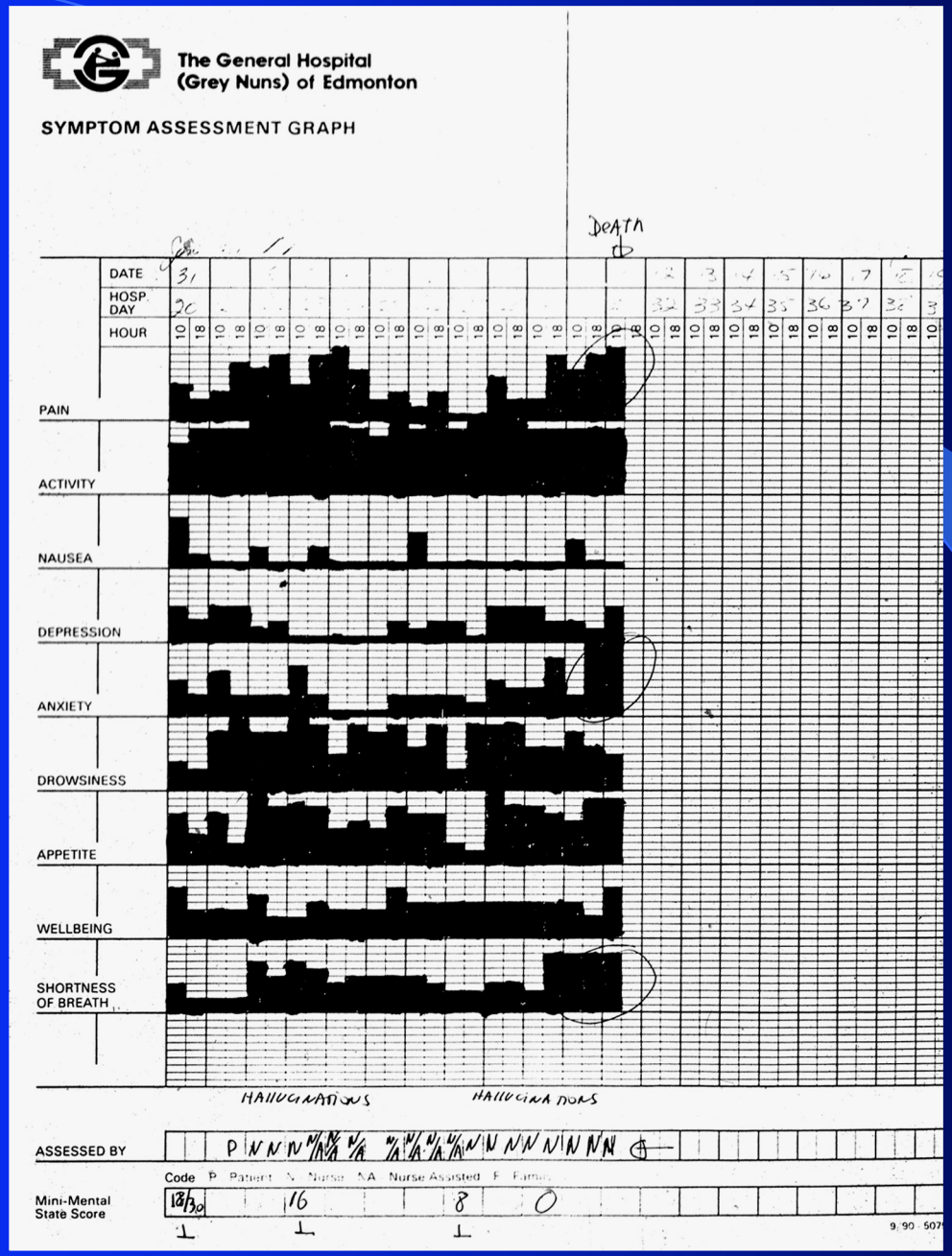

The General Hospital
(Grey Nuns) of Edmonton
SYMPTOM ASSESSMENT GRAPH
DEATH
DATE
HOSP. DAY
HOUR
PAIN
ACTIVITY
NAUSEA
DEPRESSION
ANXIETY
DROWSINESS
APPETITE
WELLBEING
SHORTNESS OF BREATH
HALLUCINATIONS
HALLUCINATIONS
ASSESSED BY
Code P Patient N Nurse NA Nurse Assisted F Family
Mini-Mental State Score
18/30
16
8
0

ESAS

- 101 Patients
- 85 Completed assessment alone or with nurse

Day 1 of hospitalization:

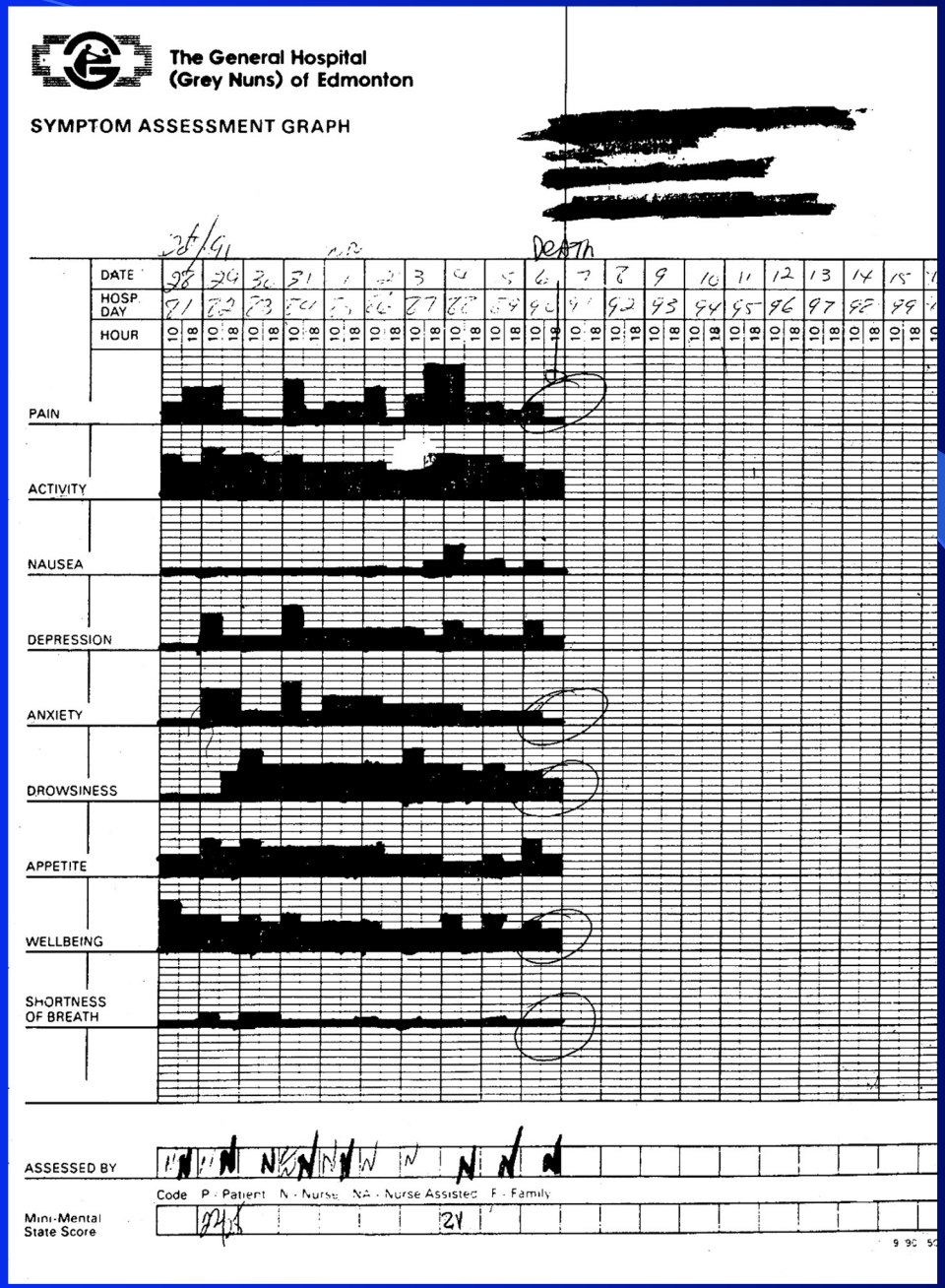
Mean Symptom Distress – 410 ± 95*

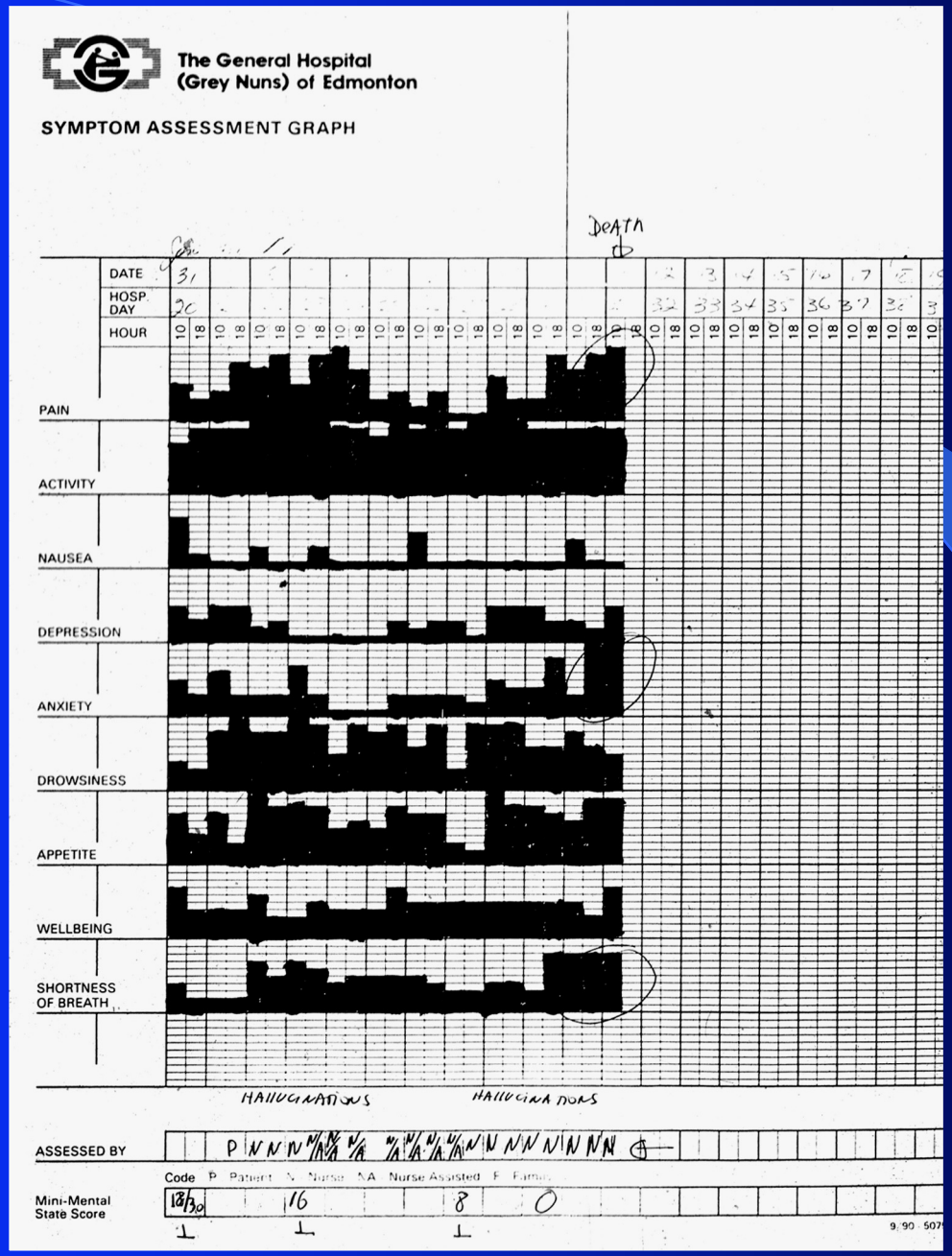
Day 5 of hospitalization:

Mean Symptom Distress – 362 ± 83*

* $P < 0.01$

Bruera et al. J Palliative Care; 1991

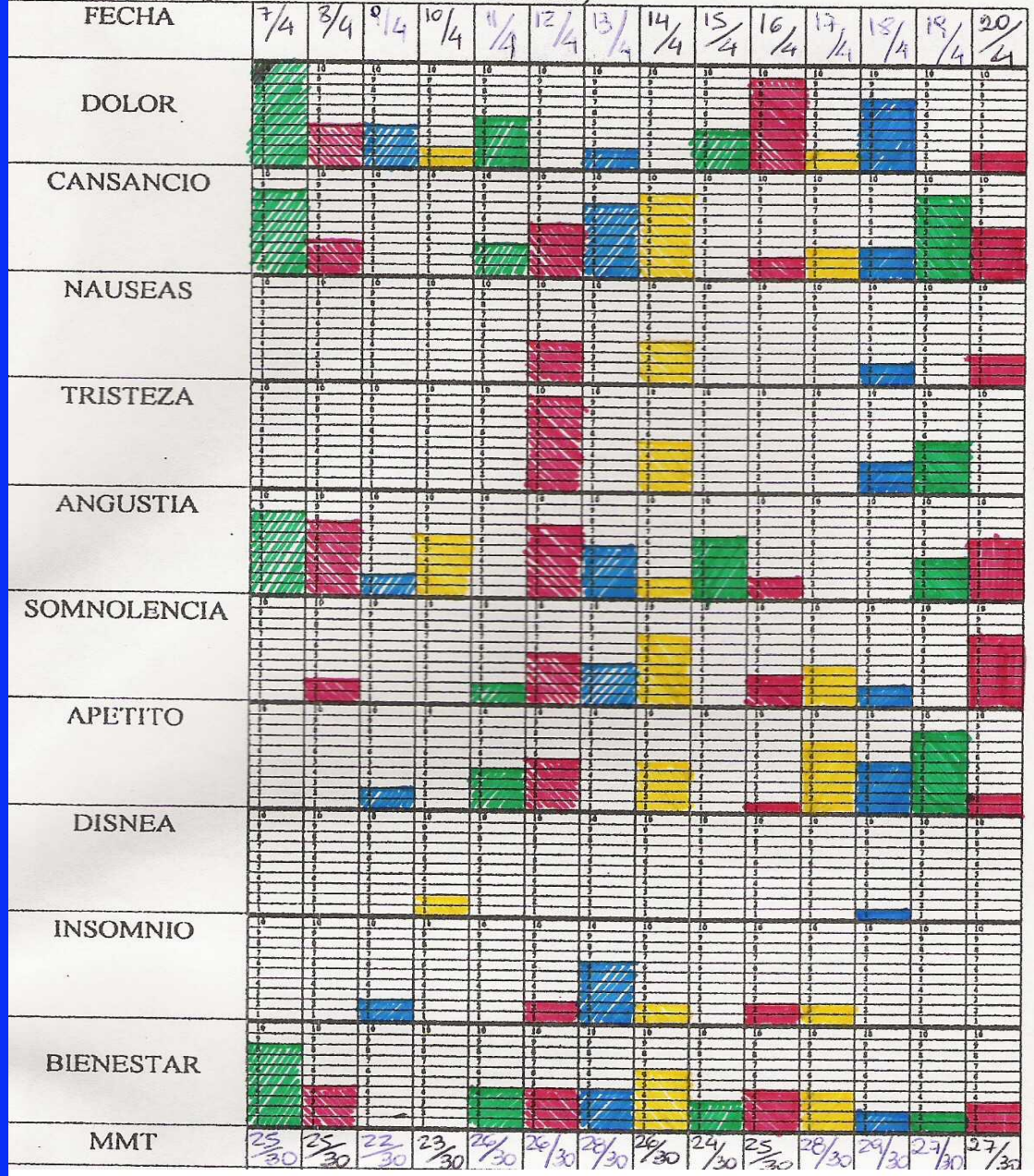



The General Hospital
(Grey Nuns) of Edmonton
SYMPTOM ASSESSMENT GRAPH
DEATH
DATE
HOSP. DAY
HOUR
PAIN
ACTIVITY
NAUSEA
DEPRESSION
ANXIETY
DROWSINESS
APPETITE
WELLBEING
SHORTNESS OF BREATH
HALLUCINATIONS
HALLUCINATIONS
ASSESSED BY
Code P Patient N Nurse NA Nurse Assisted F Family
Mini-Mental State Score
18/30
16
8
0

Unidad de Cuidados Paliativos. Hospital Tornú- Fund FEMEBA.

PACIENTE..... Cama ..203....

Grilla síntomas (promedio de las últimas 24 horas).



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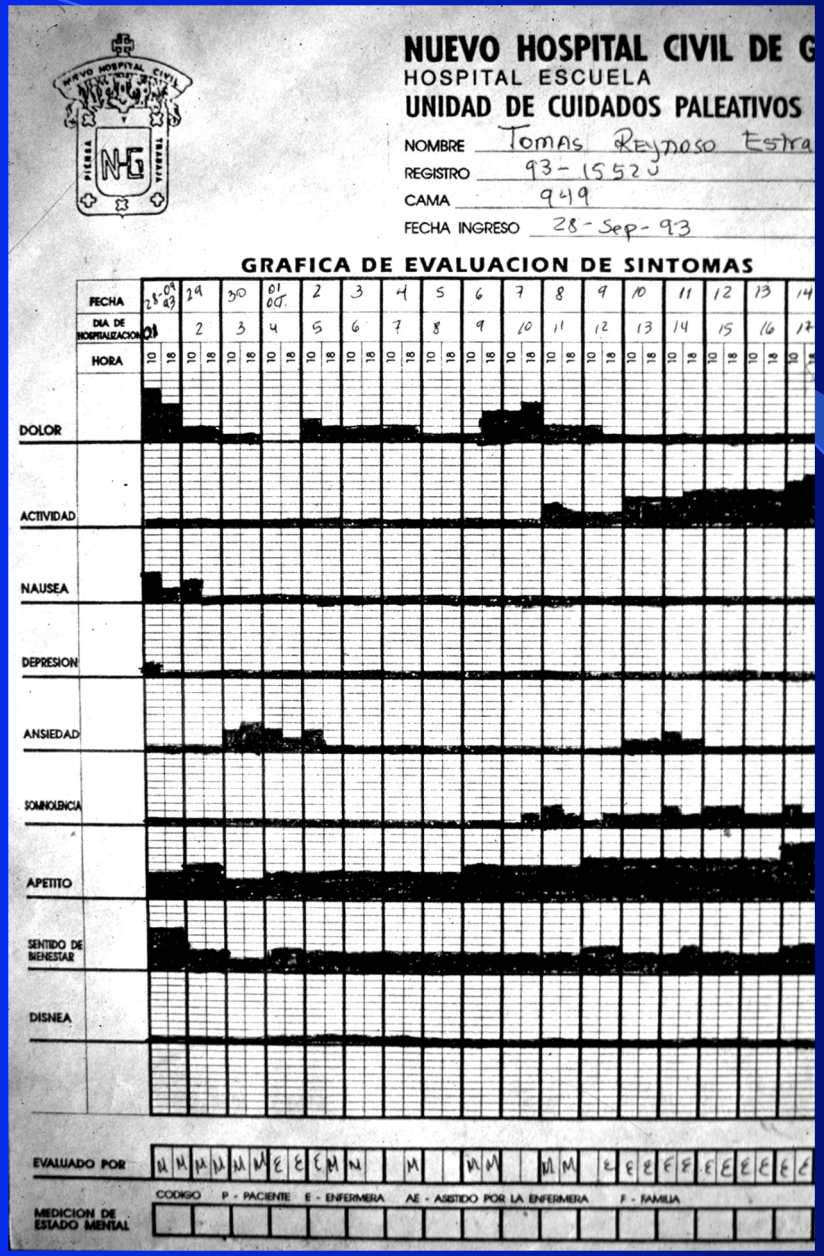

NUEVO HOSPITAL CIVIL DE G
HOSPITAL ESCUELA
UNIDAD DE CUIDADOS PALEATIVOS

NOMBRE Tomas Reynoso Estra
REGISTRO 93-1552
CAMA 949
FECHA INGRESO 28-Sep-93

GRAFICA DE EVALUACION DE SINTOMAS

FECHA: 28-09-93 | 29 | 30 | 01 OCT. | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14
DIA DE HOSPITALIZACION: 01 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17
HORA: 10 18 ...

DOLOR
ACTIVIDAD
NAUSEA
DEPRESION
ANSIEDAD
SOMNOLENCIA
APETITO
SENTIDO DE BIENESTAR
DISNEA

EVALUADO POR: M M M M M M E E E M N M M M M E E E E E E E E E E

MEDICION DE ESTADO MENTAL
CODIGO P - PACIENTE E - ENFERMERA AE - ASISTIDO POR LA ENFERMERA F - FAMILIA

PC Assessment

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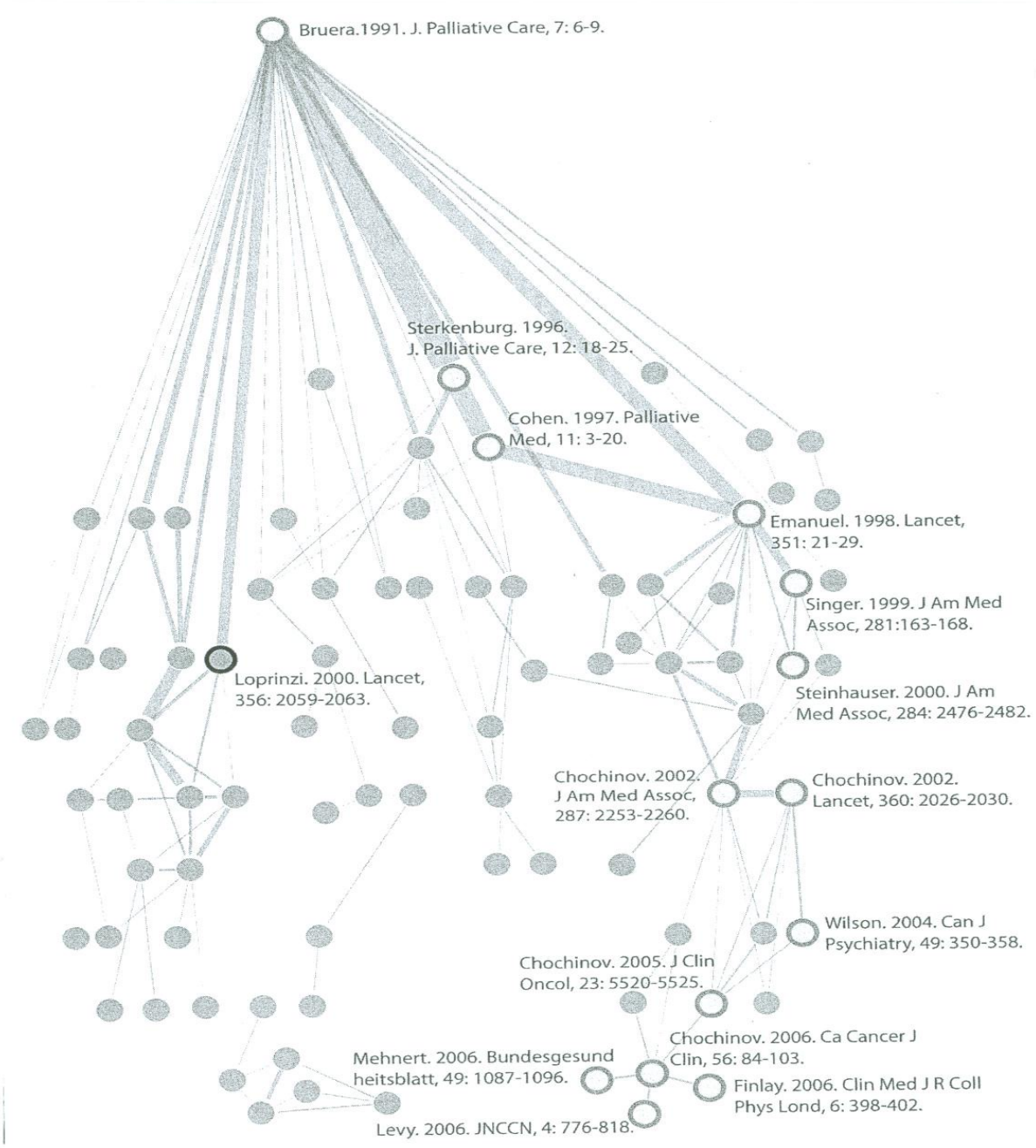

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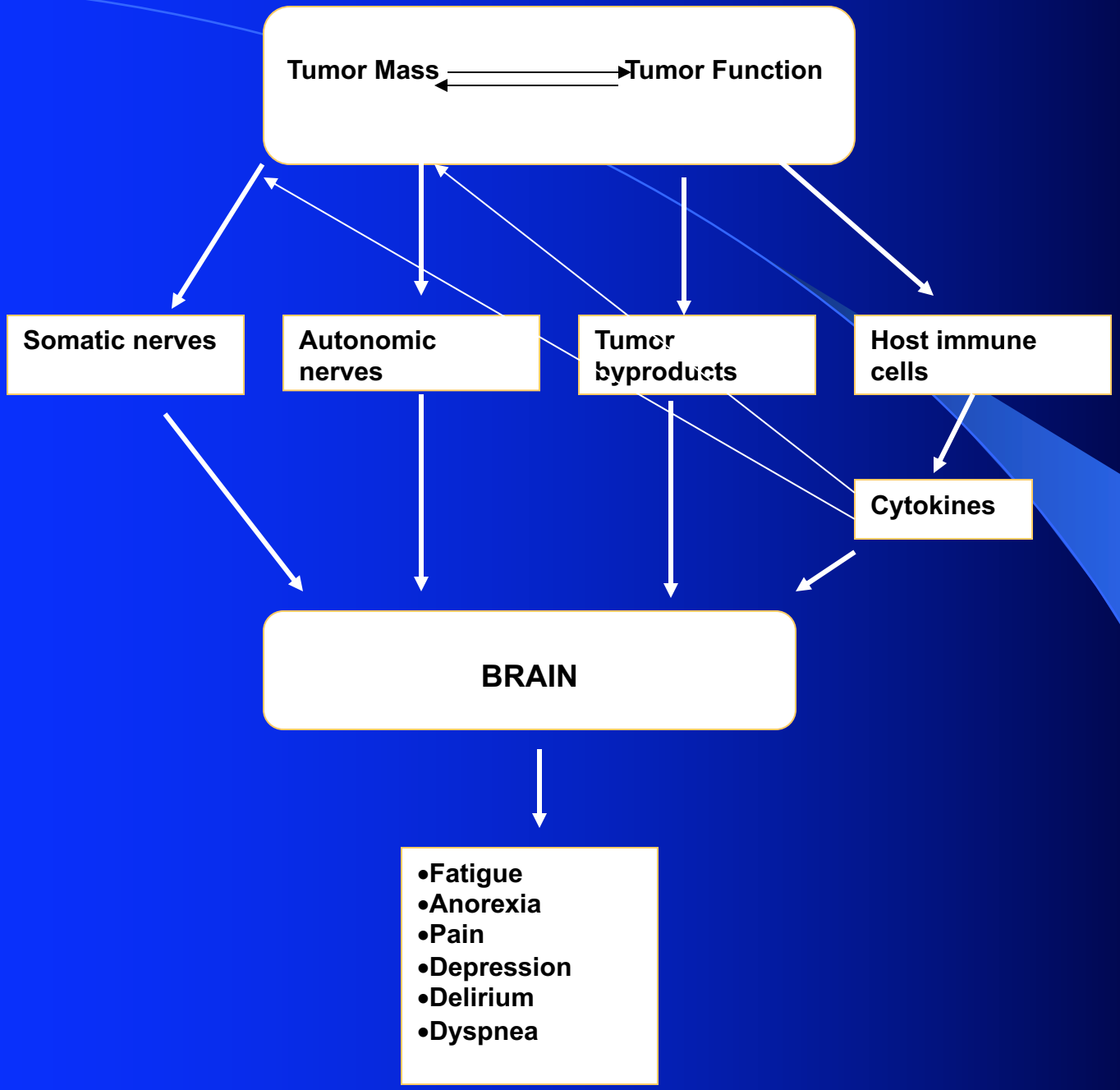
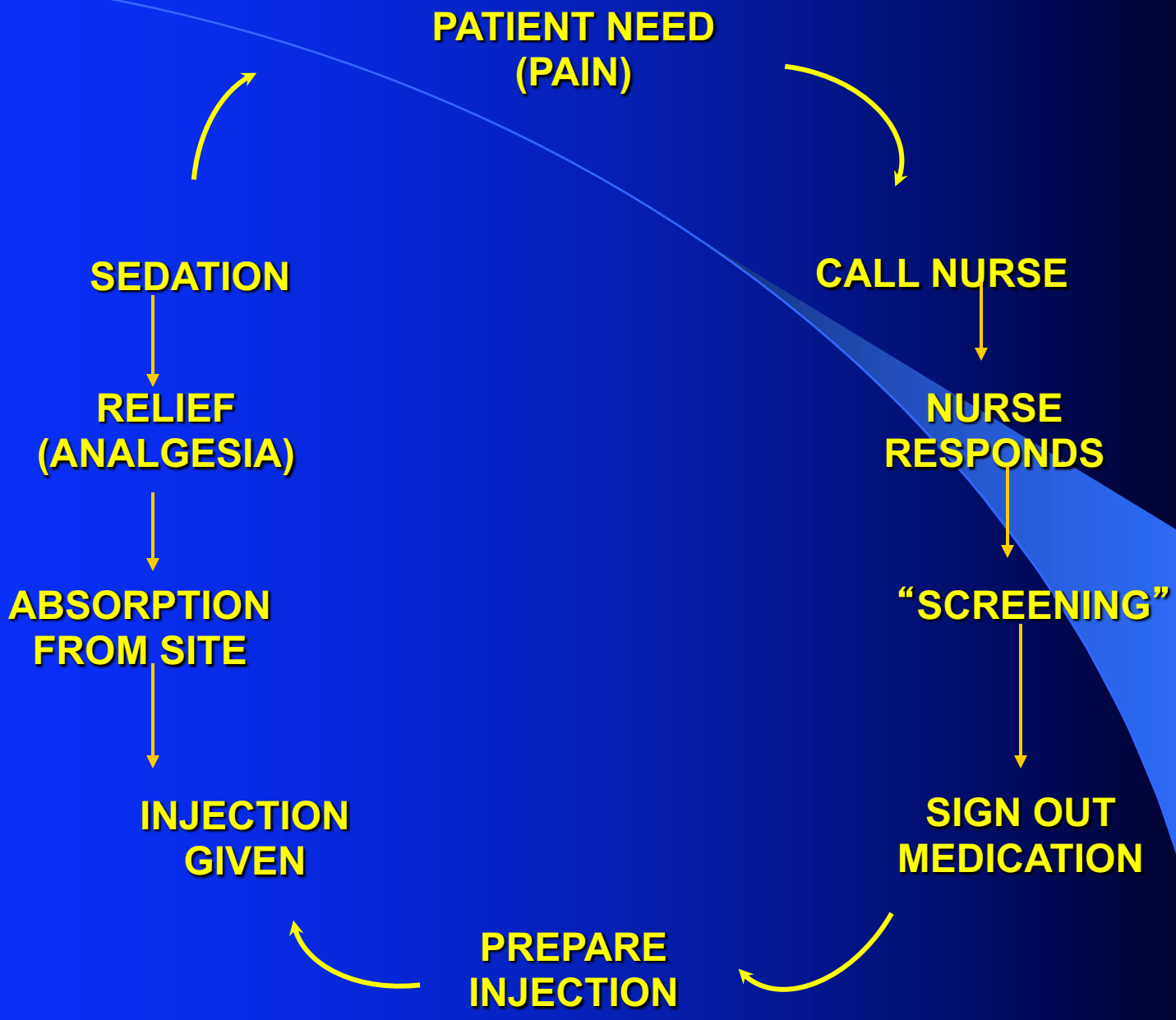
Lessons from ESAS develoment

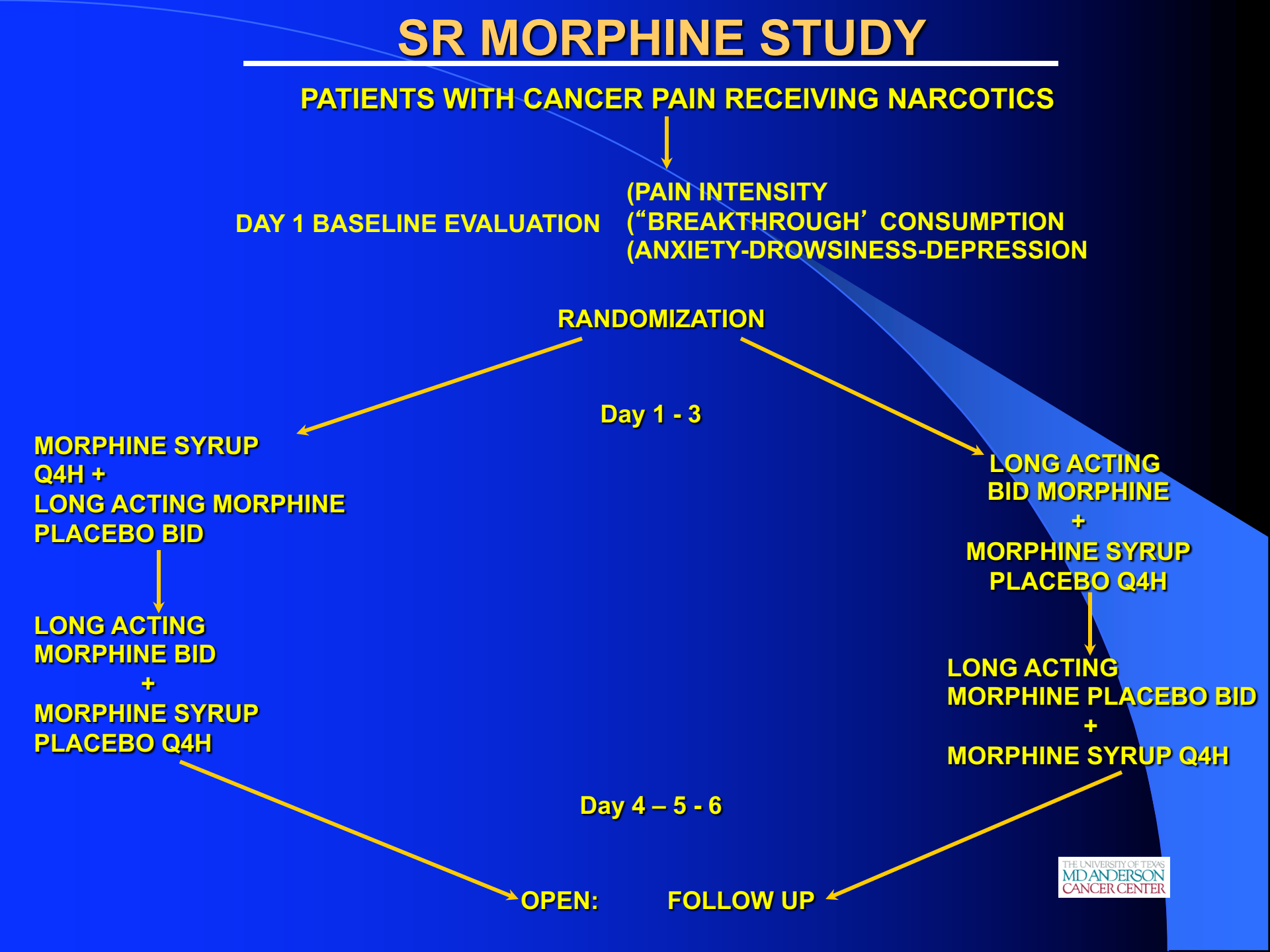
- Clinically actionable items (worse, average, least, interferences- ?). No action: delete
- Extremely short and free
- No need for computer or patient training
- RNs and MDs need to see how this will help clinically to adopt.
- Instrument development cartels: not validated yet in tall people, or soccer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





The cyclic character of conventional analgesic therapy

SR MORPHINE STUDY



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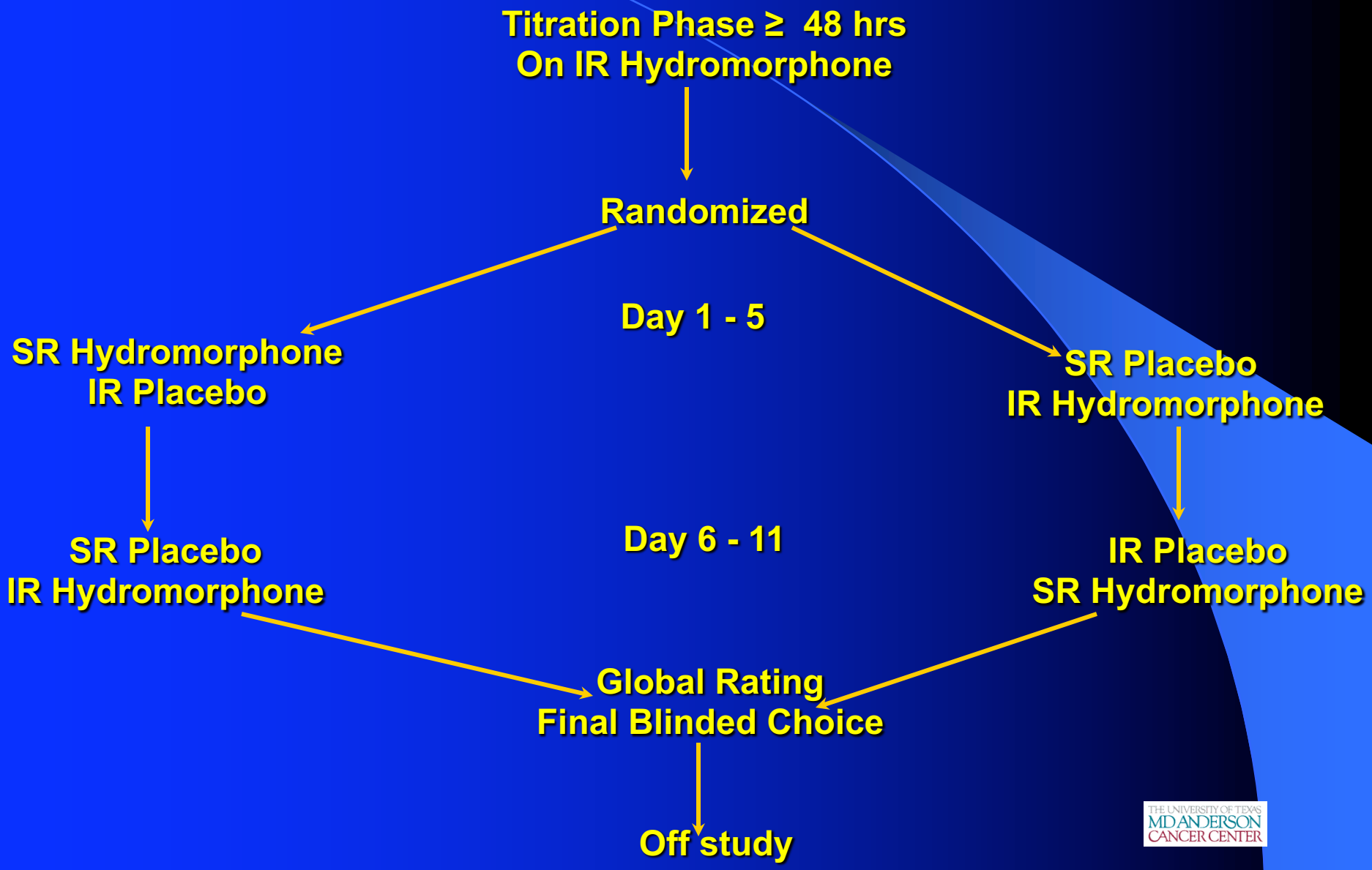
SR HYDROMORPHONE STUDY



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RESULTS AFTER THE COMPLETION OF THE DOUBLE-BLIND STUDY*

	IRH	'p' Value	SRH
Pain intensity VAS average from the patient's diary (0-100)	27 ± 21	0.14	29 ± 21
Pain intensity VAS during day 6 or day 11 (0 = 100)	30 ± 22	>0.2	34 ± 21
Pain intensity rating average from patient's dairy (0 – 3)	1.3 ± 0.6	>0.2	1.3 ± 0.6
Pain intensity rating during visit day 0 or day 11 (0-3)	1.47 ± 0.6	>0.2	1.6 ± 0.6
Total number of analgesic rescue doses per phase	10 ± 8	>0.2	9 ± 7
Mean daily mg of rescue analgesics per phase	20 ± 33	>0.2	16 ± 21

* DATA EXPRESSED AS MEAN ± STANDARD DEVIATION

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GLOBAL RATING OF BOTH DRUGS BY PATIENTS & INVESTIGATORS (cross-over!)

Overall Rating	Patients (%)		Investigators (%)	
	IRH	SRH	IRH	SRH
Excellent	2 (3)	3 (4)	3 (4)	3 (4)
Very Good	20 (27)	18 (23)	32 (41)	33 (41)
Good	38 (51)	37 (47)	36 (46)	36 (45)
Fair	13 (17)	18 (23)	6 (8)	8 (10)
Poor	2 93)	3 (4)	1 (1)	0
Not Reported	9	7	6	7
Total*	84	86	84	87

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Lessons: why were those studies possible ?

- Investigator, NOT drug company design. Higher risk studies. Good synergy!
- Cross-over! Before the FDA / industrial complex
- NOW: Mucosal/ nasal/ buccal fentanyl "enrichment"!. Only include in RCT those who responded to Fentanyl !!!. Drug company design, FDA blessing, professor adds patients and smile !

SLOW RELEASE OPIOIDS

- No better analgesia
- No reduced side effects
- Increased convenience
- 5 Times more expensive, 80% market

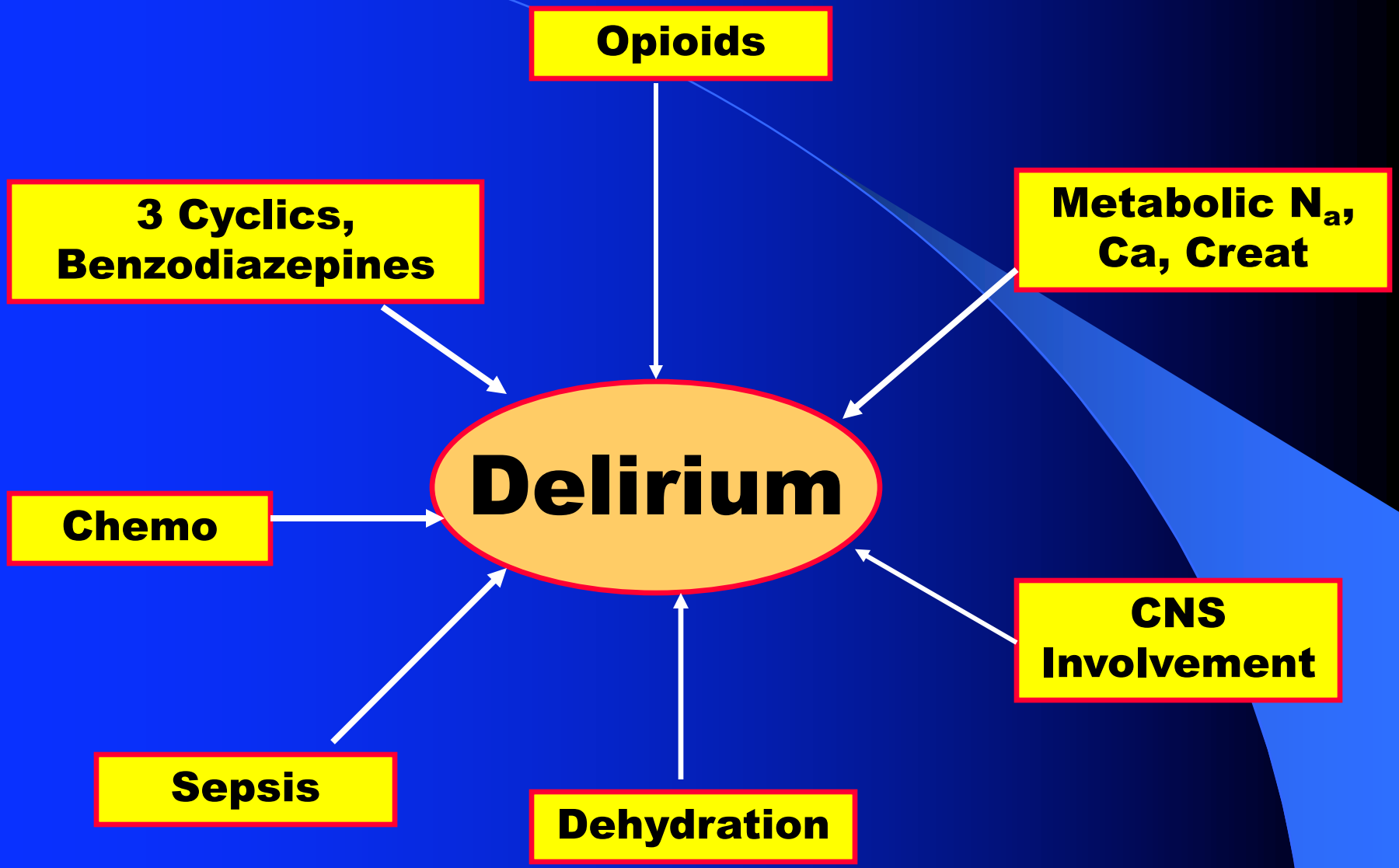
SR opioids among 200 med onc US & Canada, 2003

- 60% believed better analgesia
- 80 % believed lower side effects
- 75% believed same cost

Marketing does work!

Lesson: how did SR opioids change things?

- Good: Regular use instead of prn
- Good: Increase in opioid use globally
- Opioid use for non- cancer pain (toxicity- addiction)
- Increase in cost of pain treatment



Occurrence and Reversibility of Delirium

- Prospective study, admissions to PCU
- 44/104 (42%) delirium on admission
- 71/104 (68%) delirium at some stage
- 46 of 52 who died (88%) had terminal delirium
- 46 of 94 episodes, (49%) reversible
- Reversibility associated with psychoactive medication
- Patients with delirium had poorer survival than controls

Lawlor et al. Arch Intern Med, 2000

ALGORHYTHM

1. MMSQ → No delirium / Delirium

2. Hyperactive (MIXED)80%
   - Holoperidol
   - Methotrmeprazine
   - Midazolam

   Hypoactive 20%

3. Assess for reversible cause (50%!!)
   a) Laboratory
   b) CNS
   c) Sepsis
   d) Opioid rotation – drug review
   e) Hydration

4. Counseling and education
   - Patient
   - Family
   - Staff

5. Reassess

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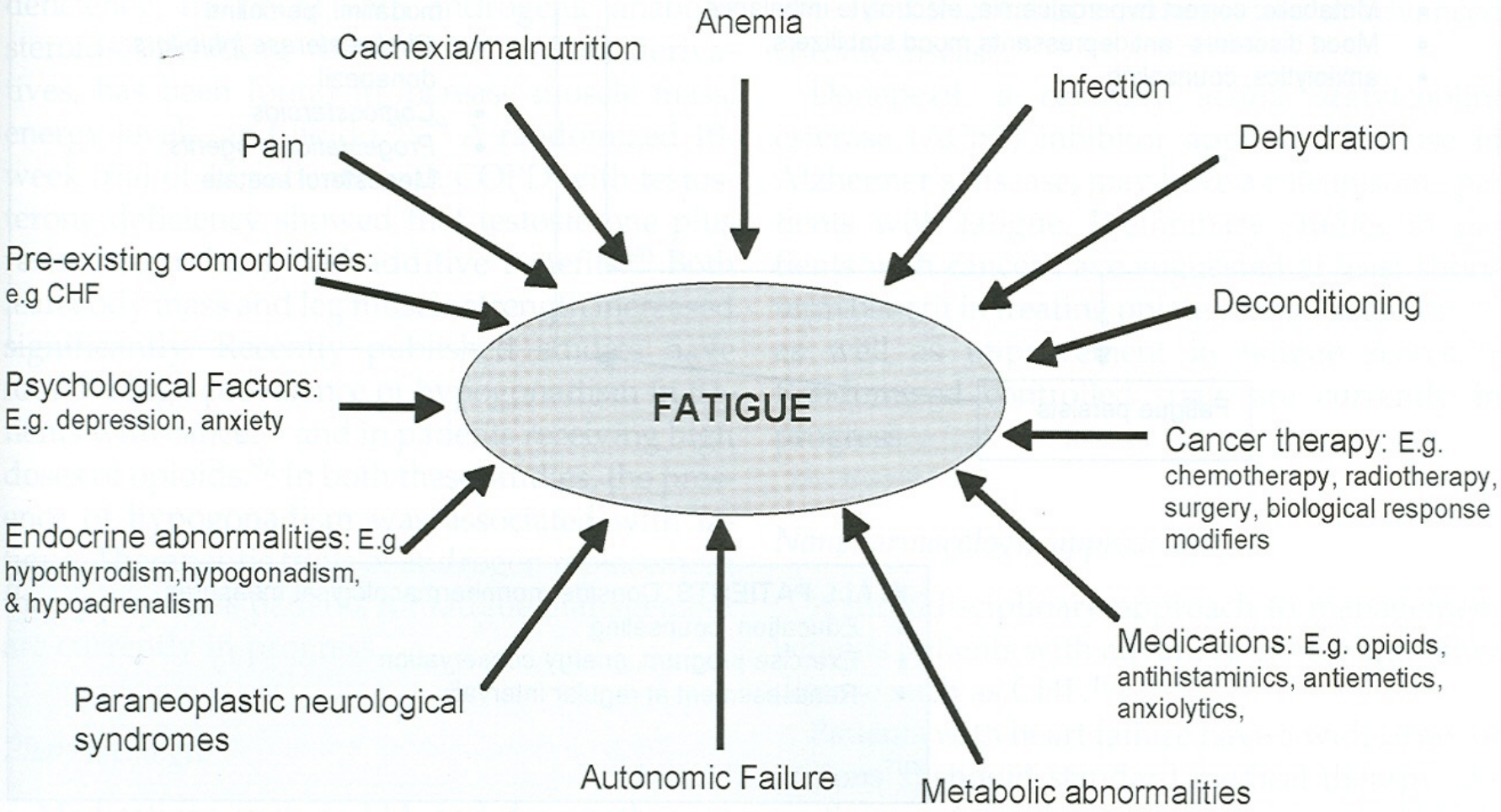

FATIGUE

Specific treatment of underlying causes

- Cachexia
- Anemia
- Electrolyte disorders
- Infection
- Hypoxia
- Hypogonadism
- Depression
- Others

Symptomatic Treatment

Pharmacological

- Corticosteroids
- psychostimulants
- Megestrol-acetate
- L- carnitine
- donepezil

Non-pharmacological

- Counseling
- Exercise
- Oxygen
- O.T/ PT

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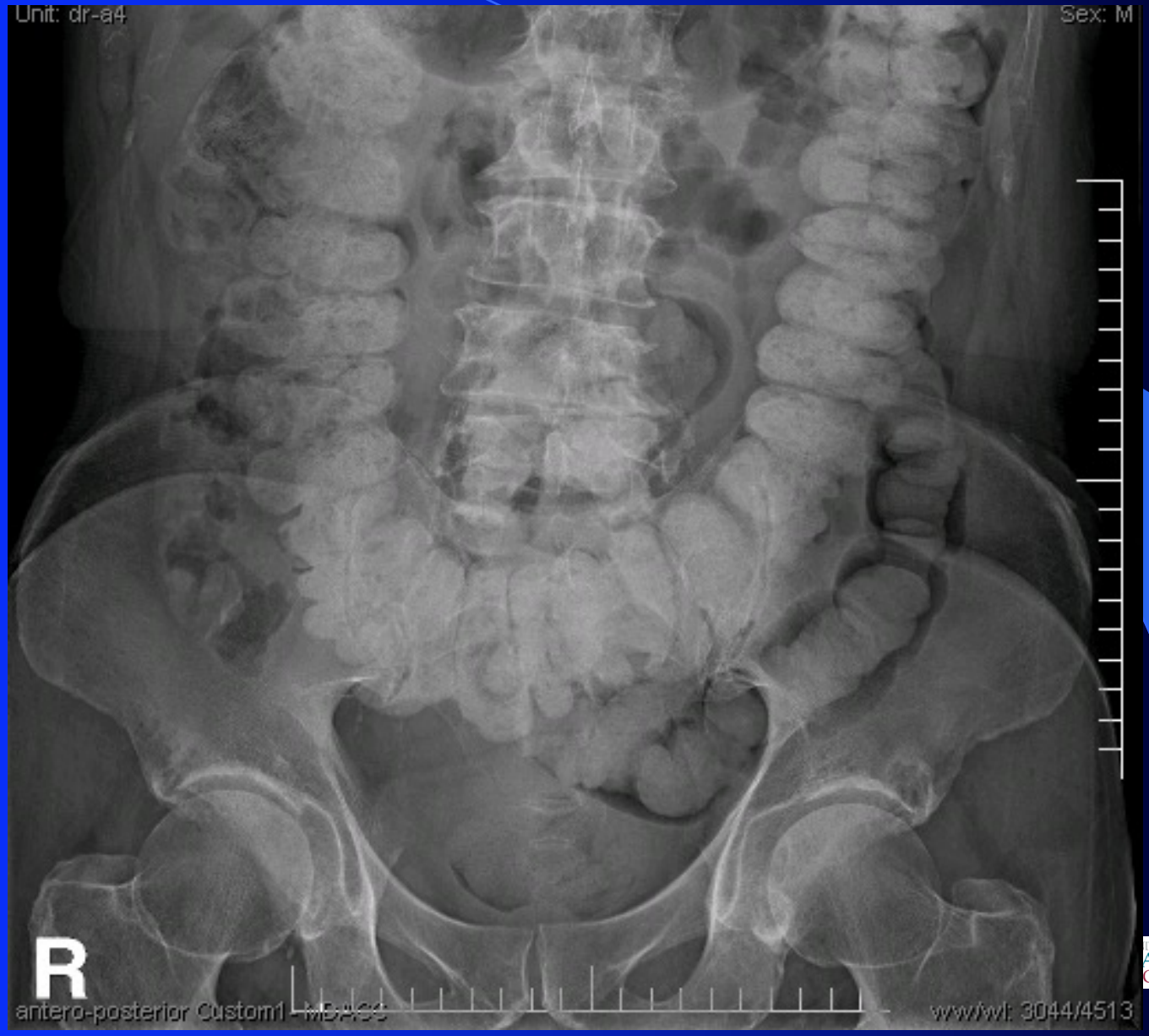
Assessment- Dame Cicely

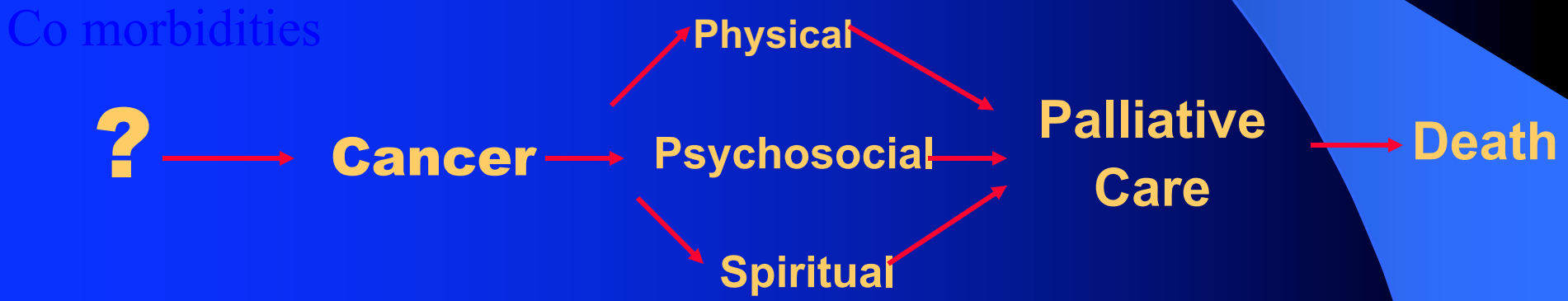


ASSESSMENT TOOLS

- ESAS
- CAGE
- MDAS
- Constipation

Assessment – Patient Characteristics

Traditional Model



Assessment – Patient Characteristics

Emerging Model

- AFFECTIVE
- ALCOHOLISM
- PERSONALITY
- SOMATIC FUNCTIONAL DISORDERS

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Rules of evidence

- Systematic reviews/ meta- analyses useless unless they consider who paid for the study!
- **Some of our most useful research for the patients was retrospective** (ESAS, opioid rotation, SC route, delirium)
- Funding is NOT the purpose of a research career. Mafias frequently control funding but they cannot kill research ideas and hard work. **Our best studies were unfunded**

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A. ,Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H. ,Vicki A Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

n engl j med 363;8 nejm.org august 19, 2010

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Methods

- June 2006 – July 2009
- Massachusetts General Hospital
- Ambulatory patients with newly diagnosed metastatic NSCLC
- Nonblinded RCT of early Palliative care integrated with standard oncologic care vs. standard oncologic care alone
- Enrolled within 8 weeks of diagnosis
- Palliative care team visit within 3 weeks of enrollment and at least monthly thereafter

Palliative care

- Physicians and advanced-practice nurses
  - Physical symptoms
  - Psychosocial symptoms
  - Establish goals of care
  - Assistance with decision making regarding treatment
  - Coordinating care

Table 2. Bivariate Analyses of Quality-of-Life Outcomes at 12 Weeks.*

Variable	Standard Care (N=47)	Early Palliative Care (N=60)	Difference between Early Care and Standard Care (95% CI)	P Value†	Effect Size‡
FACT-L score	91.5±15.8	98.0±15.1	6.5 (0.5–12.4)	0.03	0.42
LCS score	19.3±4.2	21.0±3.9	1.7 (0.1–3.2)	0.04	0.41
TOI score	53.0±11.5	59.0±11.6	6.0 (1.5–10.4)	0.009	0.52

Patients in the palliative care group had significantly higher scores when compared to the standard care group with effect sizes in the medium range

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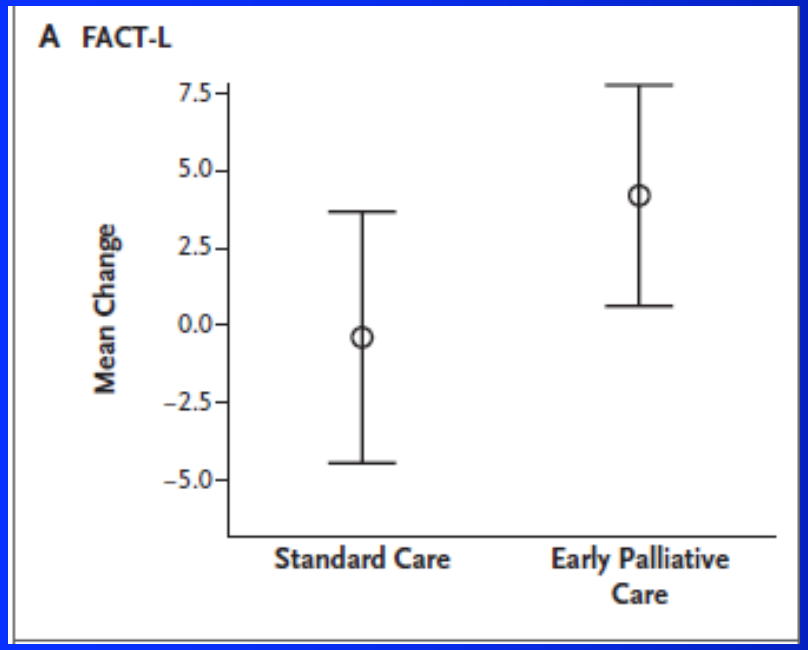
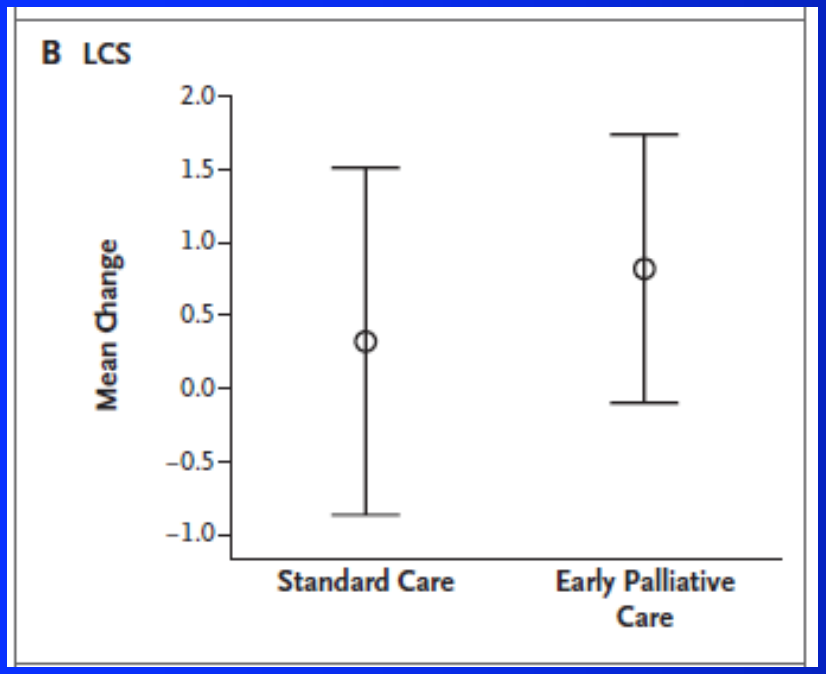
Mean Change in Quality-of-Life Scores from Baseline to 12 Weeks in the 2 Study Groups



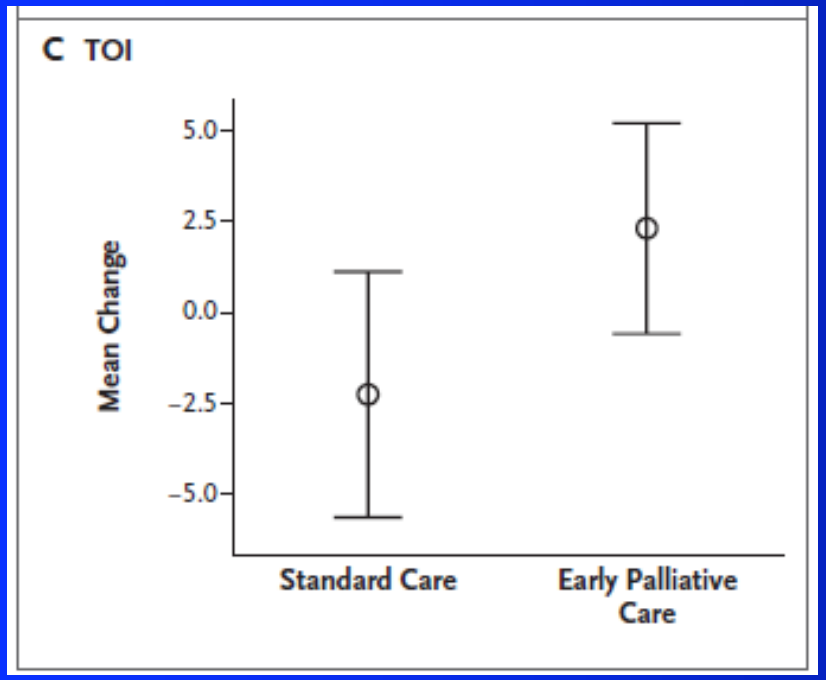
- A trend toward a sig between-group difference in the mean (+—SD) change in scores from baseline to week 12 on the FACT-L scale (−0.4+—13.8 in the standard care group vs. 4.2+—13.8 in the palliative care group)
- Difference between groups, 4.6; 95% confidence interval [CI], −0.8 to 9.9
- P = 0.09

Mean Change in Quality-of-Life Scores from Baseline to 12 Weeks in the 2 Study Groups



- No sig between-group difference in the mean change in scores on the LCS (0.3+—4.0 and 0.8+—3.6)in the two groups
- Difference between groups, 0.5; 95% CI, −1.0 to 2.0
- P = 0.50

Mean Change in Quality-of-Life Scores from Baseline to 12 Weeks in the 2 Study Groups*



- A sig between-group difference in the mean change in scores on the TOI (−2.3+—11.4 vs. 2.3+—11.2)
- Difference between groups, 4.6; 95% CI, 0.2 to 8.9
- P = **0.04**

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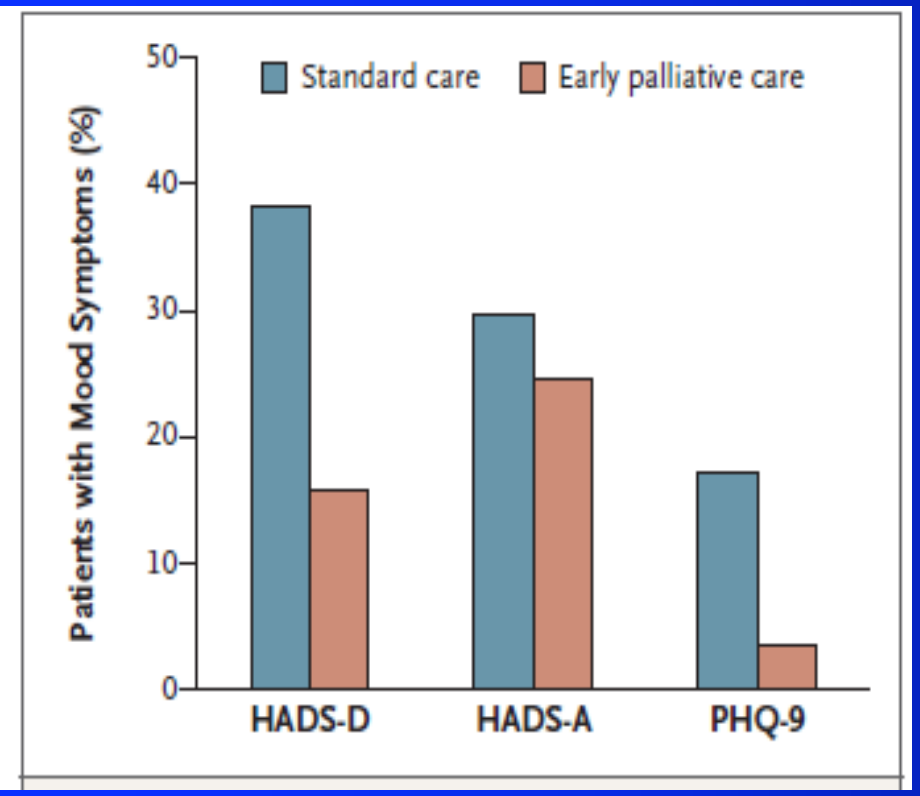
Twelve week outcomes of mood assessment



- HADS-D, 38% (18 of 47 standard care patients) versus 16% (9 of 57 palliative care patients),
  P = 0.01
- HADS-A, 30% (14 of 47 SC patients) and 25% (14 of 57 PC patients),
  P = 0.66
- PHQ-9, 17% (8 of 47 SC patients) versus 4% (2 of 57 PC patients),
  P = 0.04

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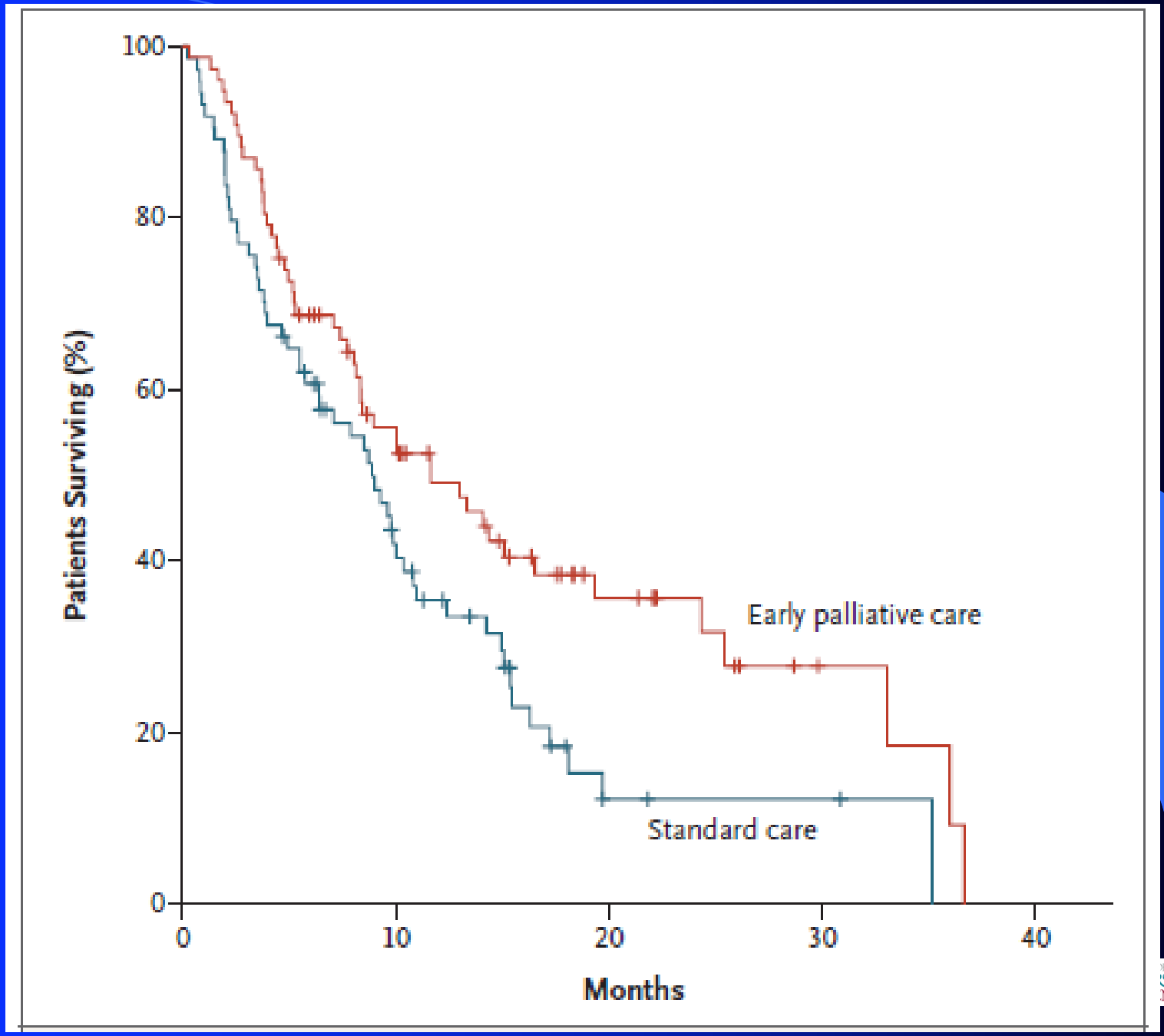

100
80
60
40
20
0
Patients Surviving (%)
0
10
20
30
40
Months
Early palliative care
Standard care

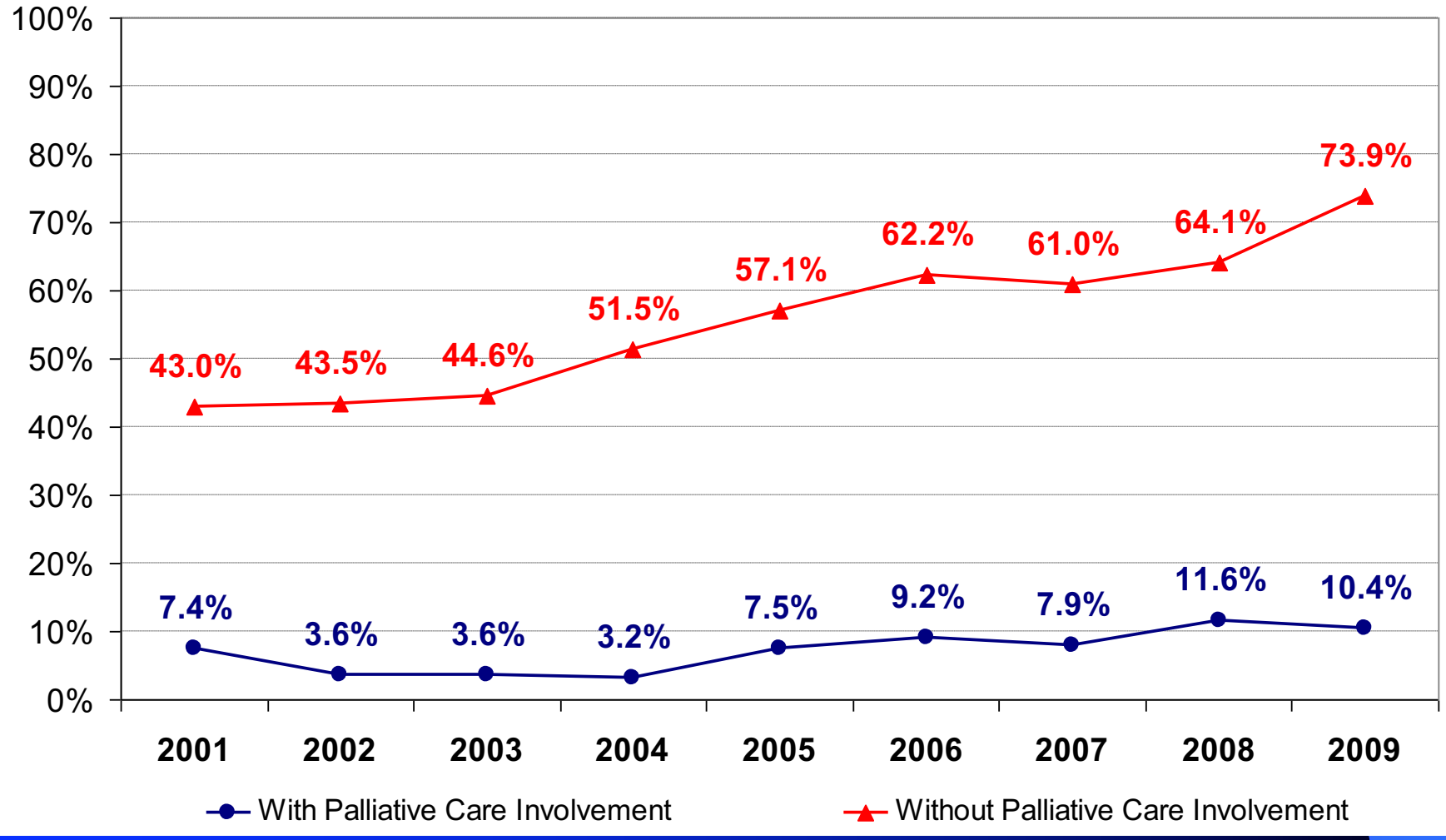
Why do patients feel better and perhaps live longer with early palliative care access?

- 1. Improved symptoms and function increase adherence to more cancer treatments
- 2. Poorly managed symptoms and distress shorten life
- 3. PC spares patients toxic and expensive treatments that could shorten life

Response Rate to the PC When Baseline ESAS Symptom Score Was ≥4

ESAS Symptoms	*n*	Response Rates % (95% CI)
Pain	275	52 (46–58)
Fatigue	317	45 (39–50)
Nausea	98	71 (61–80)
Depression	148	57 (49–66)
Anxiety	174	59 (52–67)
Drowsiness	182	56 (48–63)
Shortness of breath	126	52 (43–61)
Appetite	242	54 (48–61)
Sleeplessness	256	50 (44–57)
Feeling of well-being	285	47 (41–53)

Percent of Inpatient Deaths Occuring in the MICU CY2001-2009



2001-2009 Total 7.6%

2001-2009 Total 50.5%

Palliative care programs

- Mobile teams in acute care hospitals
- Palliative care units
- Outpatient centers
- Home care specialist programs

Mobile team

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Table 2. Location of Hospital Deaths ELSAYEM, JPM 2006

	1999	2000	2001	2002	2003	2004	Significance level
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	
Medical intensive Care unit	226 (39)	234 (36)	252 (38)	194 (30)	185 (27)	213 (28)	< 0.0001
Surgical intensive Care unit	54(9)	49 (7)	34 (5)	52 (8)	46 (7)	45 (6)	0.06
Palliative care unit	N/A	N/A	N/A	54 (9)	123 (18)	169 (22)	< 0.0001
Medical oncology Nursing unit	258 (44)	321 (49)	344 (51)	305 (46)	276 (40)	290 (38)	< 0.0001
Surgical oncology Nursing unit	38 (7)	43 (7)	30 (4)	35 (5)	42 (6)	38 (5)	0.28
Pediatrics	7 (1)	10 (2)	11 (2)	17 (3)	17 (2)	9 (1)	0.51
TOTAL	583 (100)	657(100)	671 (100)	657 (100)	689 (100)	764 (100)	

Are we getting to the cancer/ non cancer patients at the right time?

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Interval Between 1st Palliative Care Consult and Death

- 3142 consecutive patients referred to palliative care
- April 2003 – Sept. 2005
- Measured interval between 1st palliative care consult and death [BC1 – T]
- Annual growth of program 10- 20%

Patient Characteristics

Characteristic	*No. of patients*	*%*
Median age in years (range)	60 (2–96)	
Ethnicity		
White	2004	70
Black	373	13
Hispanic	369	13
Other	122	4
Total	2868	100
Primary tumor		
Solid tumor	2563	89
Head, neck, and thoracic	1045	36
Breast	161	6
Gastrointestinal	432	15
Genitourinary	313	11
Gynecological	311	11
Other	301	10
Liquid Tumor	305	11
Total	2868	100
Patients		
Confirmed dead	2645	92
Censored	223	8
Still alive	159	5
Lost follow-up	64	3
Total	2868	100

CANCER CENTER

El Osta B et al J Palliat Medicine 2008

Intervals between CA-D, aCA-D, aCA=-PC1, PC1-D (*n = 2868*)

Interval	*Median in days (95% CI)*
CA to death	570 (529–596)
aCA to death	250 (235–265)
aCA to PC1	147 (134–161)
PC1 to death	42 (38–46)

CI, confidence interval.

El Osta B et al J Palliat Medicine 2008

Changes in the PC1-D, aCA-D, PC1-D/aCA-D Over Time *(n=2868)*

6-month interval starting on (n)[a]	*PC1-D interval*[b]	*ACA-D interval*[b]	*PC1-D/ACA-D ratio*[b]
April 03 (544)	46 (38–53)	222 (189–249)	0.30 (0.25–0.38)
October 03 (485)	56 (47–68)	264 (225–302)	0.36 (0.31–0.45)
April 04 (594)	42 (35–48)	236 (194–267)	0.29 (0.25–0.34)
October 04 (591)	41 (33–51)	283 (246–310)	0.22 (0.19–0.25)
April 05 (654)	34 (28–38)	255 (211–295)	0.26 (0.21–0.32)
p	0.02	0.08	0.0004

[a](n) represents the number of patients.
[b]Data expressed as median days (95% CI).
CI, confidence interval.

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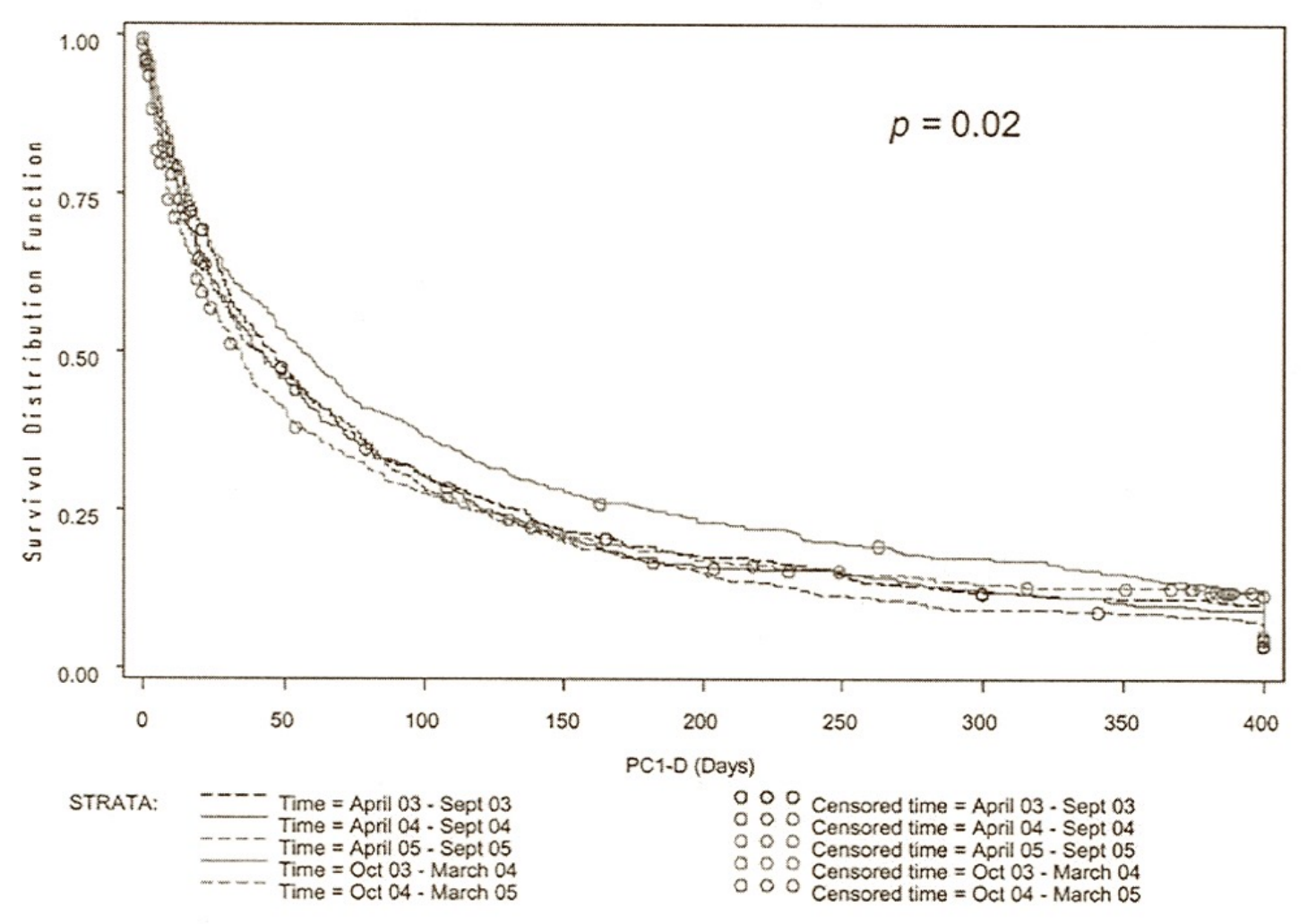
Days between 1st PC Consult & Death for each of the 6-month Periods



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Difference in Time Intervals Between Solid Tumors & Hematological Malignancies in Days

Interval[a]	*Solid tumors (n = 2563)*	*Liquid tumors (n = 305)*	p
CA to death	685 (556–807)	561 (522–586)	0.051
aCA to death	169 (145–204)	259 (242–277)	0.0001
aCA to PC1	143 (116–172)	147 (132–165)	0.74
PC1 to death	48 (45–53)	14 (10–17)	< 0.0001

[a]Data expressed as median days (95% CI).
PC1, first palliative care consult; aCA, advanced cancer diagnosis; CA, cancer diagnosis.
CI, confidence interval.

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Palliative Vs supportive: What's in a name?

- Does name and understanding of program impact on referral timing ?
- Random survey of 100 med oncologists and 100 mid level providers (response rate 66%)

Characteristics of Participants

Characteristic	***Mid Level Providers*** *74*	***Medical Oncologists*** *66*	***All Participants*** 140
Median **Age** (quartiles)	42 (32-51)	43 (38-50)	43 (34.5-50)
Female **Gender**(%)	64 (86 %)	19 (29 %)	83 (59%)
Race			
Asian	15	20	35
Black/African American	10	1	11
Hispanic	6	4	10
Other	1	1	2
White	42	40	82
Median **Years in Oncology** (quartiles)	9 (4-16)	9.5 (5-18)	9 (4-16.5)
Service Area (%)			
Solid	44 (59%)	48 (73%)	92 (66%)
Liquid	30 (41%)	18 (27 %)	48 (34 %)
Training in Palliative Care (PC)			
Previous training	46 (62%)	31 (47%)	77 (55%)
No Training	28 (38 %)	35 (53 %)	63 (45%)
# Patients who died of cancer in the past year under participant's care			
0-20	42 (56.76%)	36 (54.55%)	78 (55.71%)
>20	32 (43.24%)	36 (45.45%)	62 (44.29%)

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Likelihood of referral for patients at different stages of cancer

Question	Midlevel Providers*			Medical Oncologists*			All Participants*		
I would use this service for a patient with symptoms and	PC	SC	P-Value	PC	SC	P-Value	PC	SC	P Value
is newly diagnosed with cancer	24 (34%)	52 (70%)	<0.0001	41 (62%)	24 (37%)	0.0039	48 (35%)	93 (66%)	<0.0001
is undergoing active primary treatment for cancer	32 (45%)	61 (84%)	<0.0001	50 (76%)	29 (43%)	0.0002	61 (45%)	111 (80%)	<0.0001
Has no evidence of active cancer (remission)	24 (35%)	47 (64%)	0.0004	45 (68%)	24 (36%)	0.0003	48 (36%)	92 (66%)	<0.0001
Is receiving active treatment for advanced cancer	53 (72%)	69 (93%)	0.0005	56 (85%)	43 (65%)	0.0090	96 (69%)	125 (89%)	<0.0001
Is no longer receiving treatment advanced cancer or is in transition to end of life	63 (87%)	67 (93%)	0.2605	59 (89)%	64 (97%)	0.0842	127 (92%)	126 (91%)	<0.8296

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General perceptions of the two terms – Palliative Care / Supportive Care

	Midlevel Providers*			Medical Oncologists*			All Participants*		
	PC	SC	P-Value	PC	SC	P-Value	PC	SC	P-Value
Service Name is a Barrier for me to refer Patients	20 (27%)	5 (7%)	0.0014	12 (18%)	4 (6%)	0.0327	32 (23%)	9 (7%)	0.0001
Service Name is synonymous with hospice and end of life	42 (58%)	17 (23%)	<0.0001	36 (56%)	4 (6%)	<0.0001	78 (57%)	21 (15%)	<0.0001
Service Name can decrease hope in patient and families	30 (41%)	10 (14%)	0.0002	31 (48%)	5 (8%)	<0.0001	61 (44%)	15 (11%)	<0.0001
Service name is associated with treatment of chemotherapy side effects	13 (18%)	41 (55%)	<0.0001	7 (11%)	44 (67%)	<0.0001	20 (15%)	85 (61%)	<0.0001

PC= Palliative Care; SC= Supportive Care. * Agree and strongly agree

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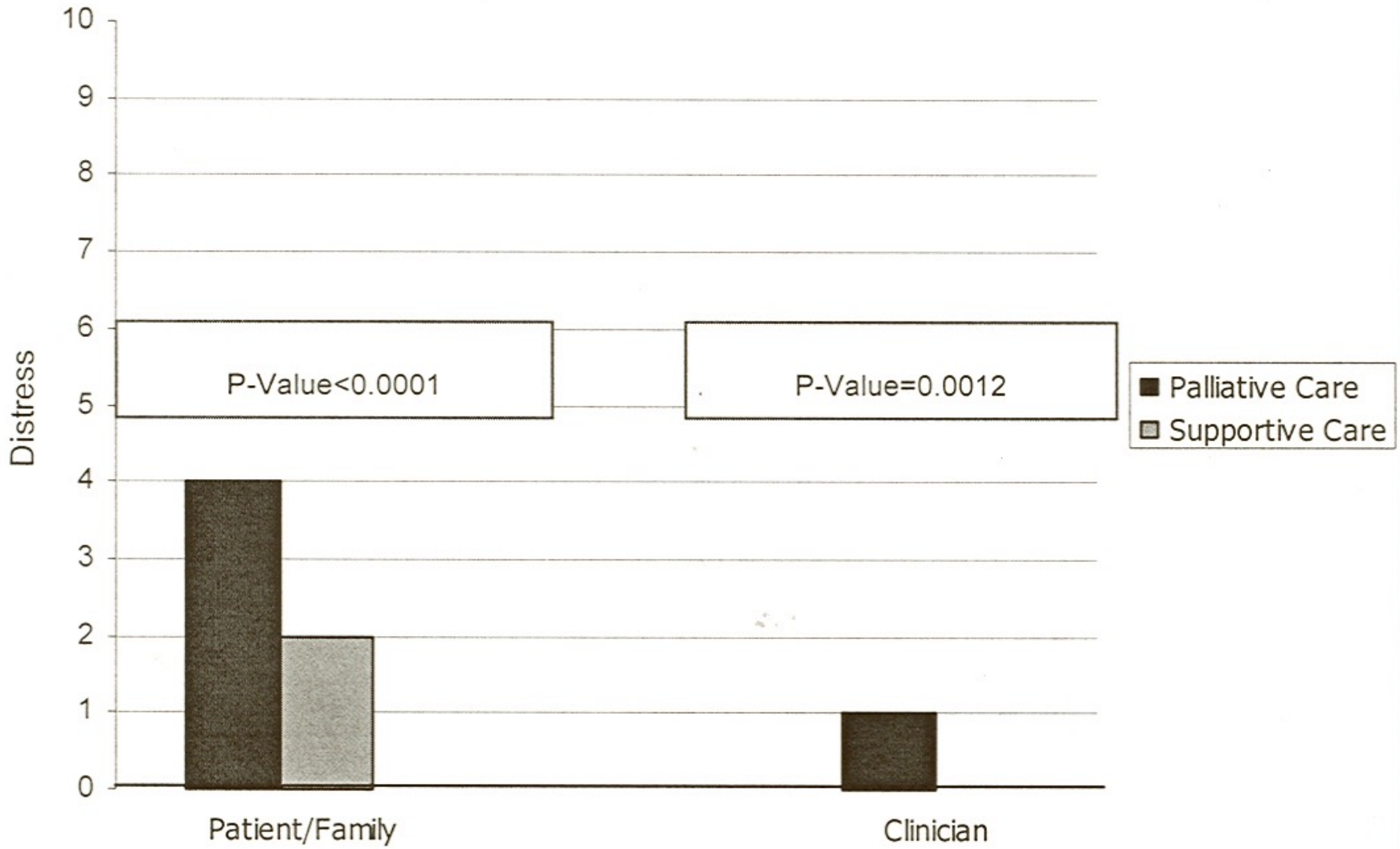
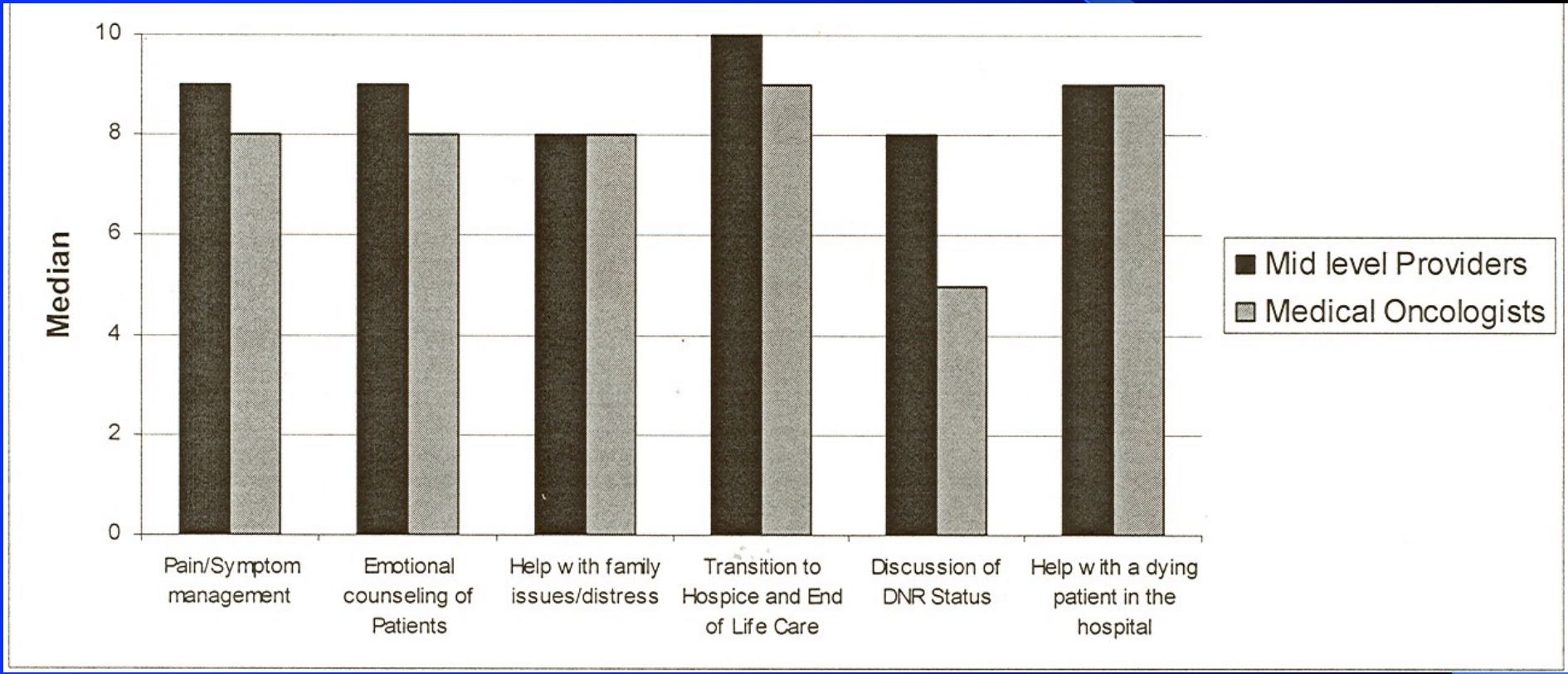
Median Distress Level Associated with the Names Palliative and Supportive Care



Perceived Usefulness of the current Palliative Care Service at M. D. Anderson Cancer Center



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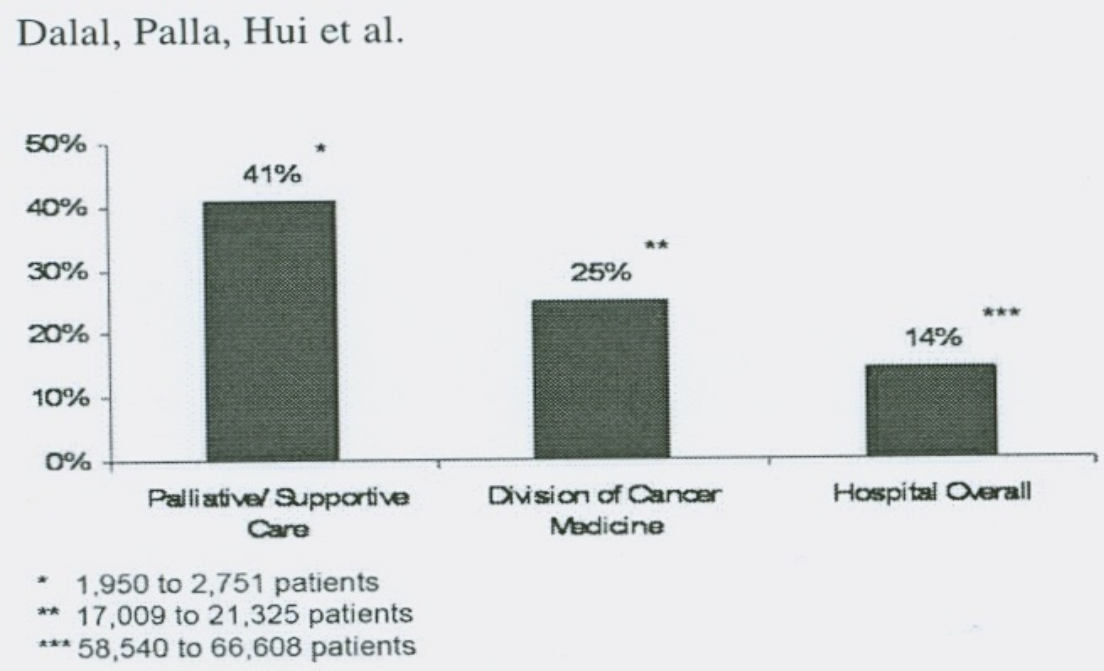
	Before SC Name	After SC Name	OR, "p"
Median Time from SC Consult to Death	4.7 months	6.2 months	1.21. p <0.001
Median Time from Advanced Cancer Dx to SC Consult	6.9 months	5.2 months	0.82, p <0.001
Median Time from Anderson Registration to SC Consult	13.2 months	9.2 months	0.85, p <0.001

The change in name for our center from Palliative Care to Supportive Care has allowed for earlier access to our palliative care program.



Percentage growth in new patient activity for palliative/supportive care, the Division of Cancer Medicine, and the hospital after the name change.

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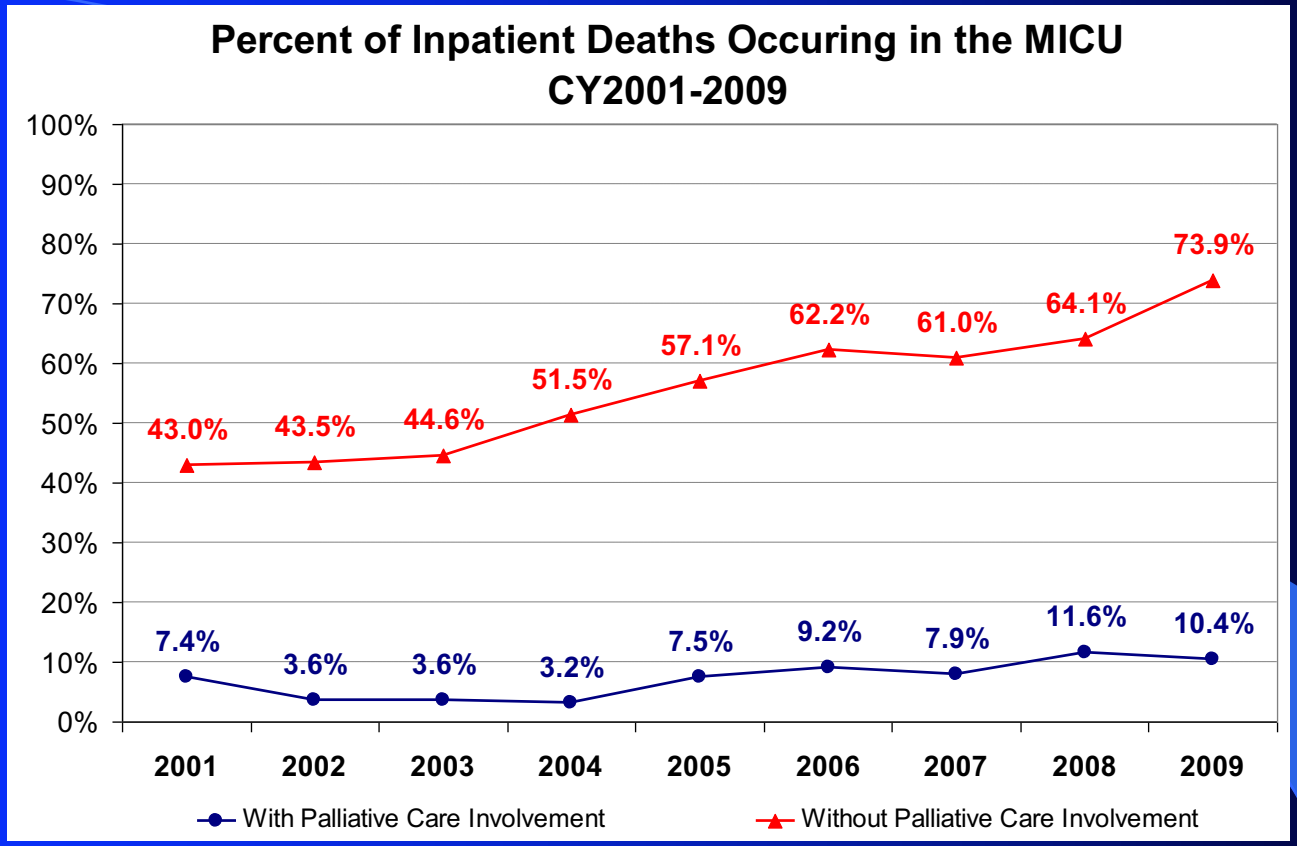

2001-2009 Total 7.6%

2001-2009 Total 50.5%

The number of inpatient and intensive care unit deaths have increased. On the contrary, patients referred to palliative care have maintained a very low percentage of ICU deaths.

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- MDs and APNs are worried about the HOPE stuff.

In America:

- Palliative = hospice
- Hospice= no treatment, dementia, death

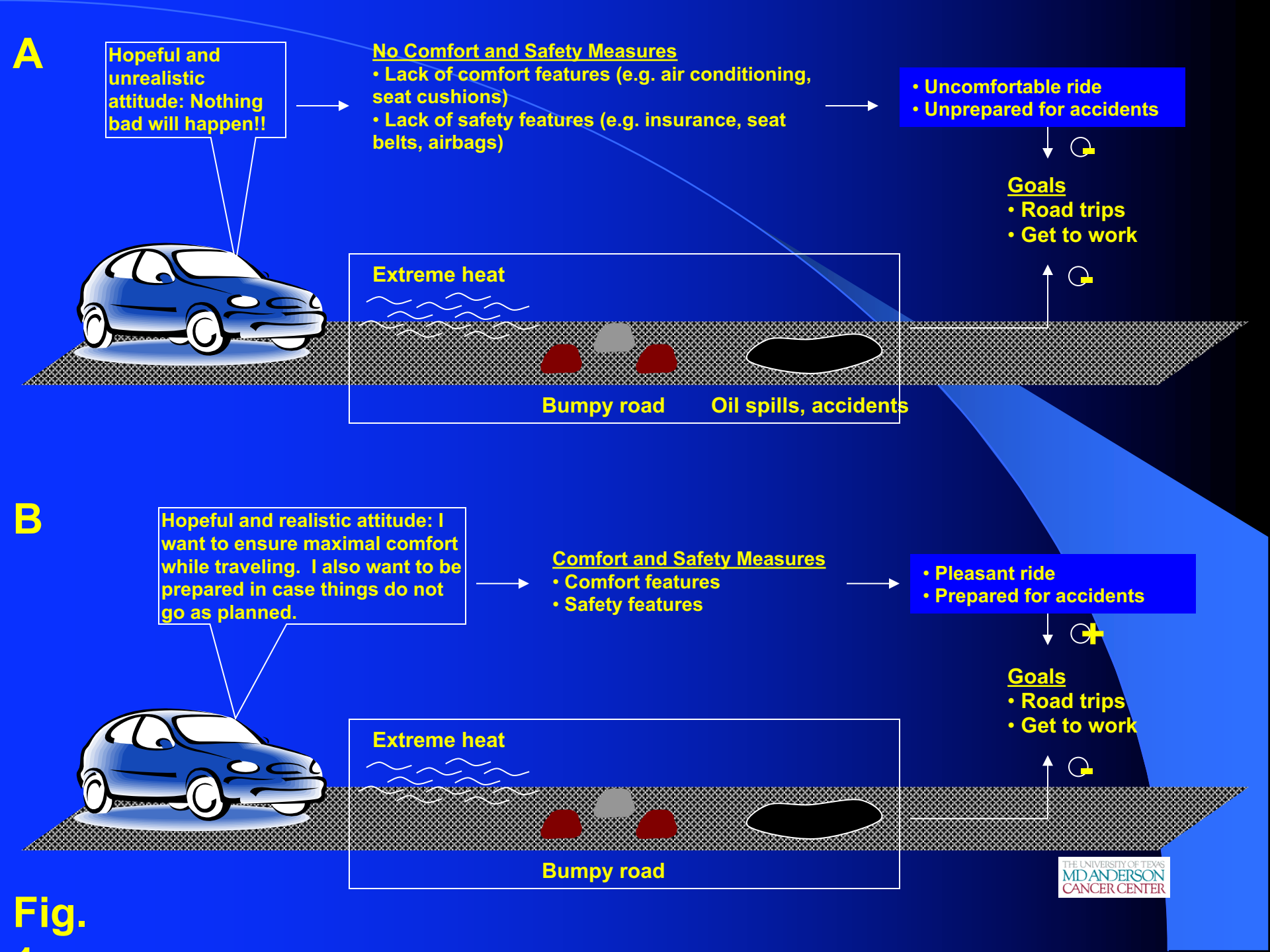
A
Hopeful and unrealistic attitude: Nothing bad will happen!!
No Comfort and Safety Measures
• Lack of comfort features (e.g. air conditioning, seat cushions)
• Lack of safety features (e.g. insurance, seat belts, airbags)
• Uncomfortable ride
• Unprepared for accidents
Goals
• Road trips
• Get to work
Extreme heat
Bumpy road
Oil spills, accidents
B
Hopeful and realistic attitude: I want to ensure maximal comfort while traveling. I also want to be prepared in case things do not go as planned.
Comfort and Safety Measures
• Comfort features
• Safety features
• Pleasant ride
• Prepared for accidents
Goals
• Road trips
• Get to work
Extreme heat
Bumpy road
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Fig. 1

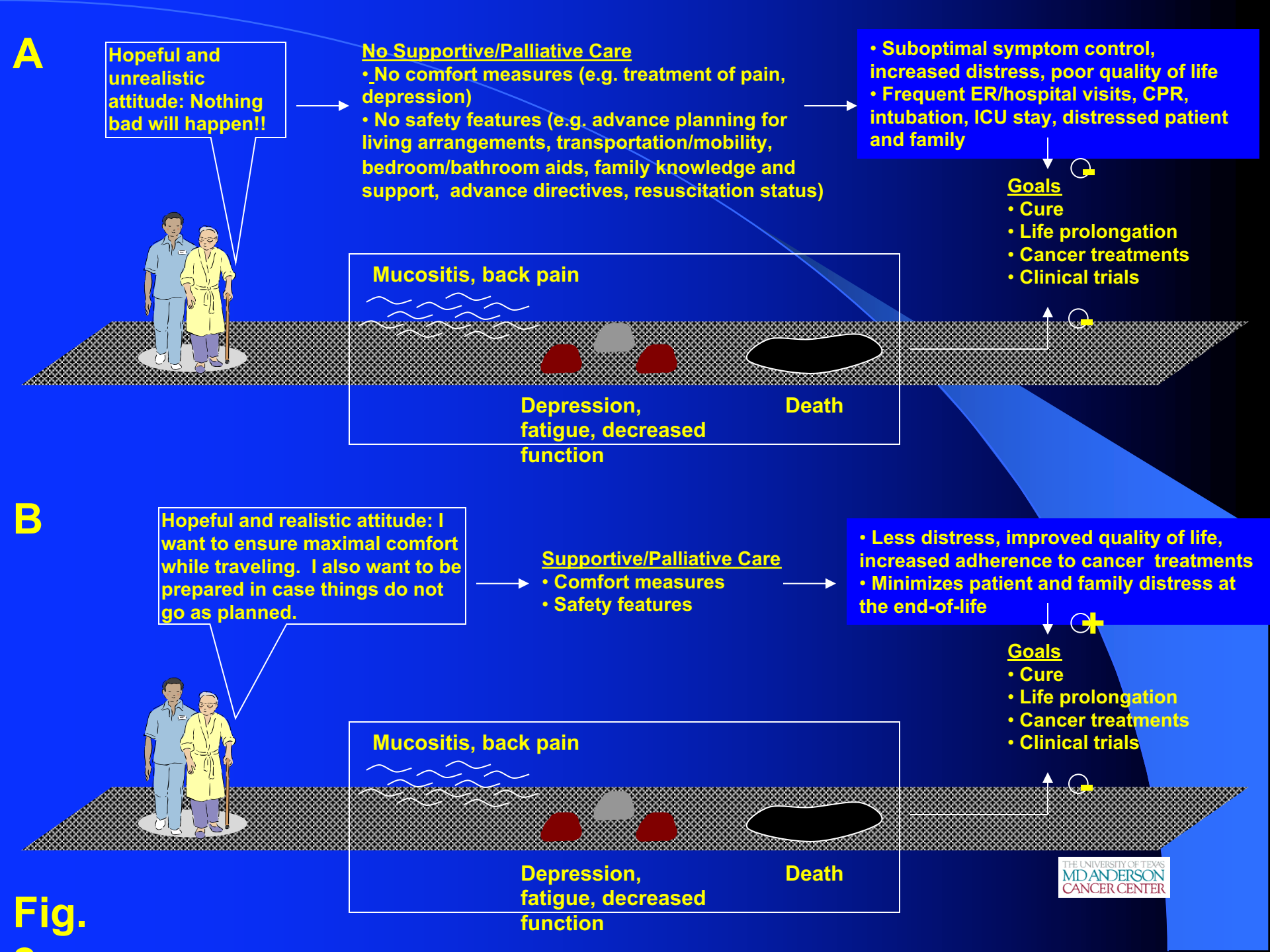
A
Hopeful and unrealistic attitude: Nothing bad will happen!!
No Supportive/Palliative Care
• No comfort measures (e.g. treatment of pain, depression)
• No safety features (e.g. advance planning for living arrangements, transportation/mobility, bedroom/bathroom aids, family knowledge and support, advance directives, resuscitation status)
• Suboptimal symptom control, increased distress, poor quality of life
• Frequent ER/hospital visits, CPR, intubation, ICU stay, distressed patient and family
Goals
• Cure
• Life prolongation
• Cancer treatments
• Clinical trials
Mucositis, back pain
Depression, fatigue, decreased function
Death
B
Hopeful and realistic attitude: I want to ensure maximal comfort while traveling. I also want to be prepared in case things do not go as planned.
Supportive/Palliative Care
• Comfort measures
• Safety features
• Less distress, improved quality of life, increased adherence to cancer treatments
• Minimizes patient and family distress at the end-of-life
Goals
• Cure
• Life prolongation
• Cancer treatments
• Clinical trials
Mucositis, back pain
Depression, fatigue, decreased function
Death
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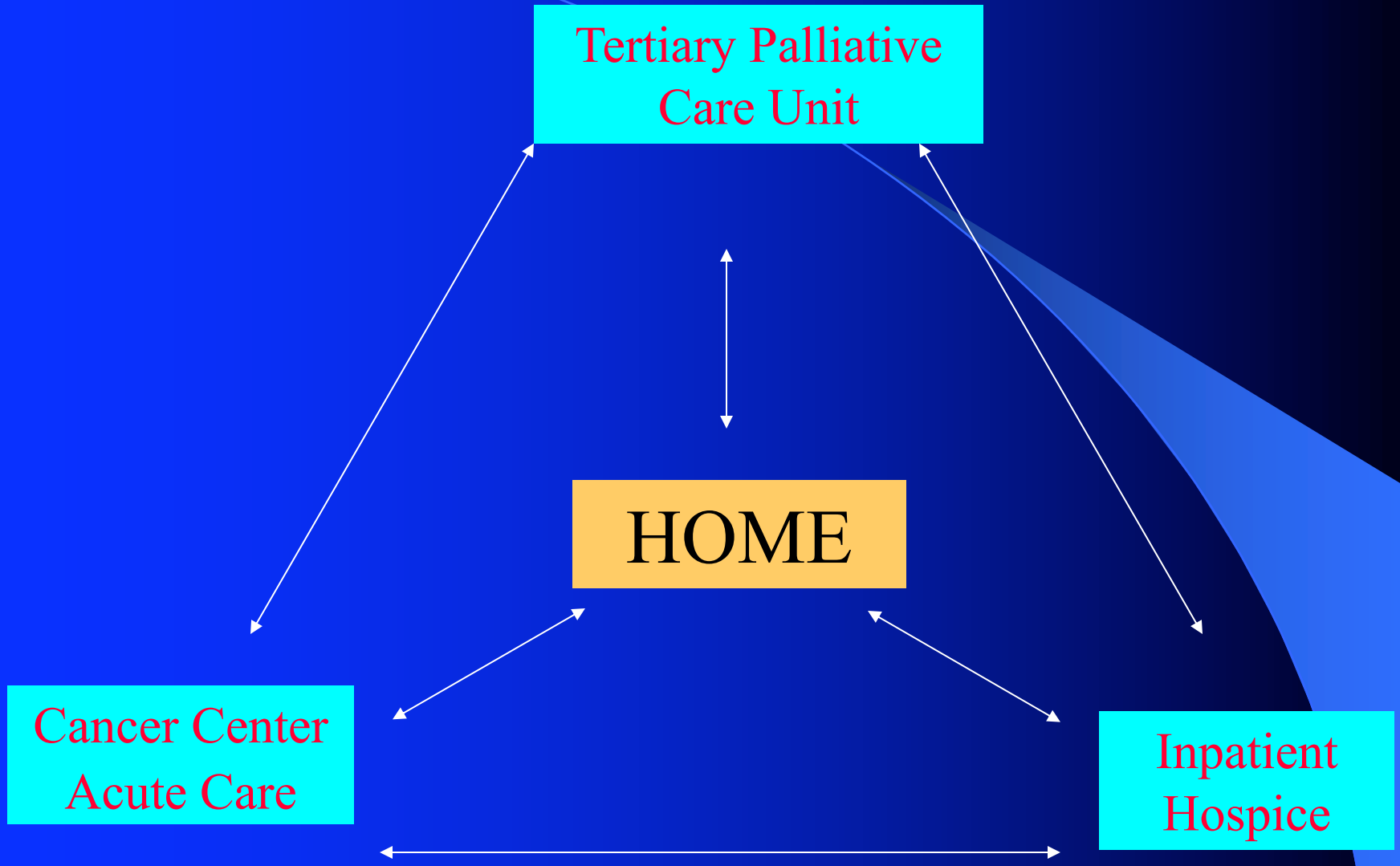
Fig.



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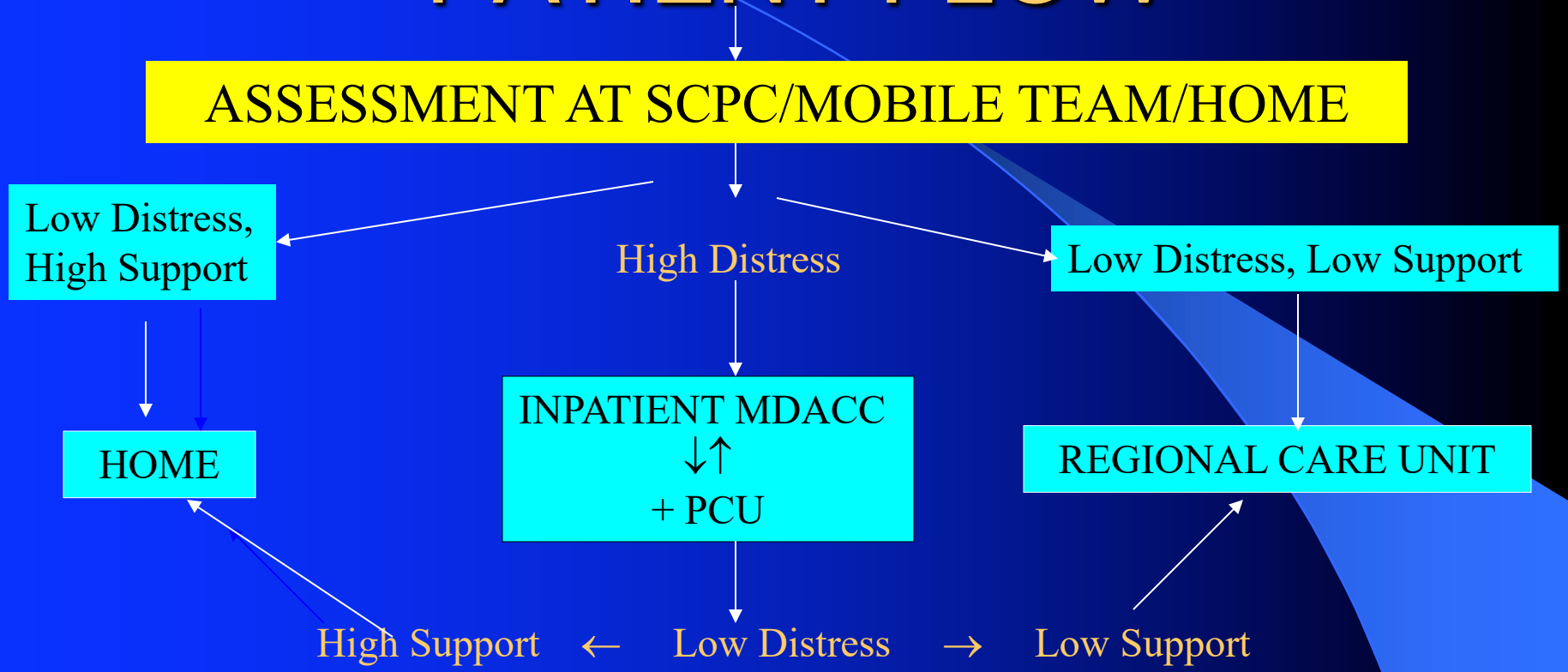
PATIENT FLOW



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.

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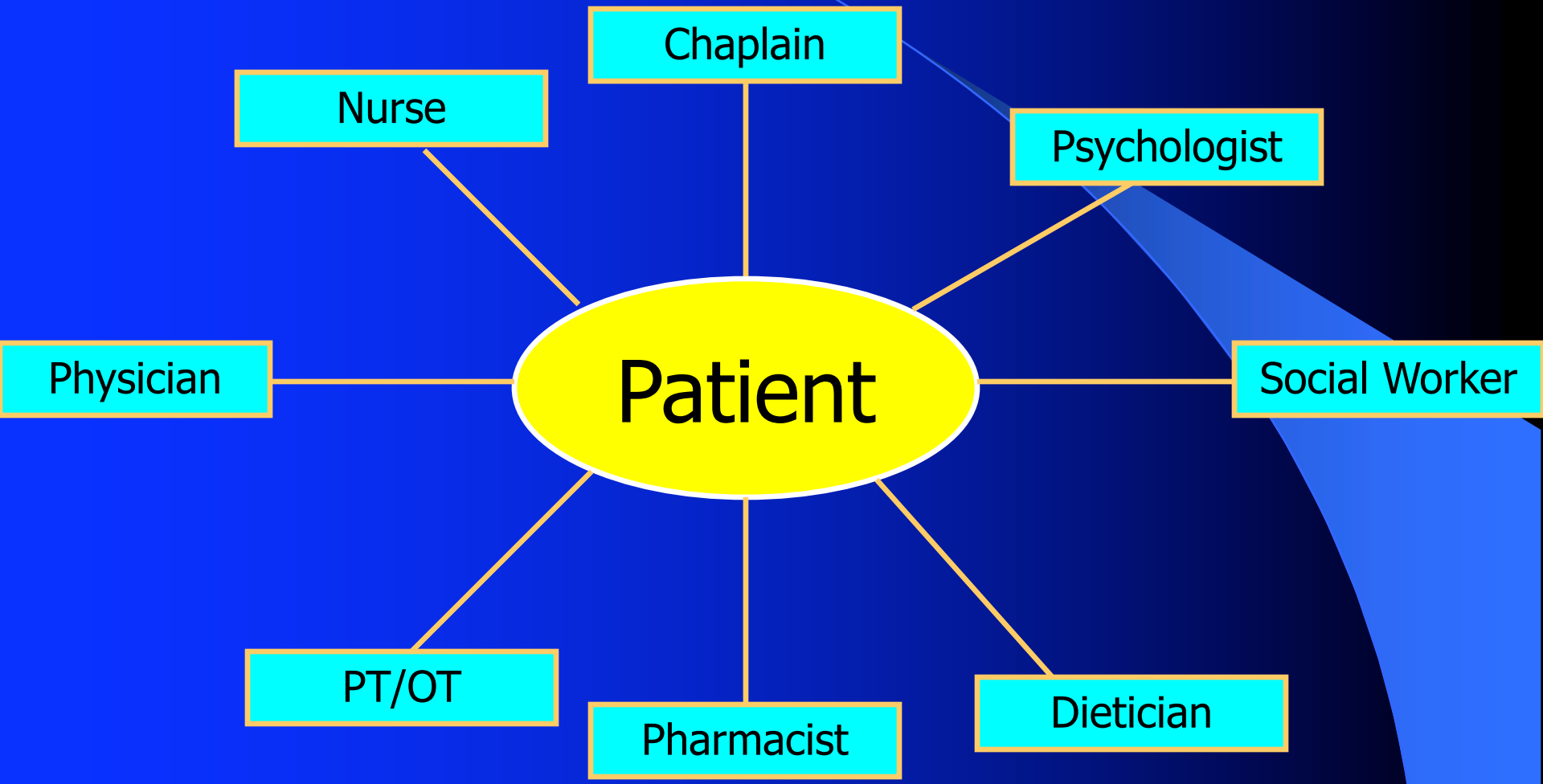
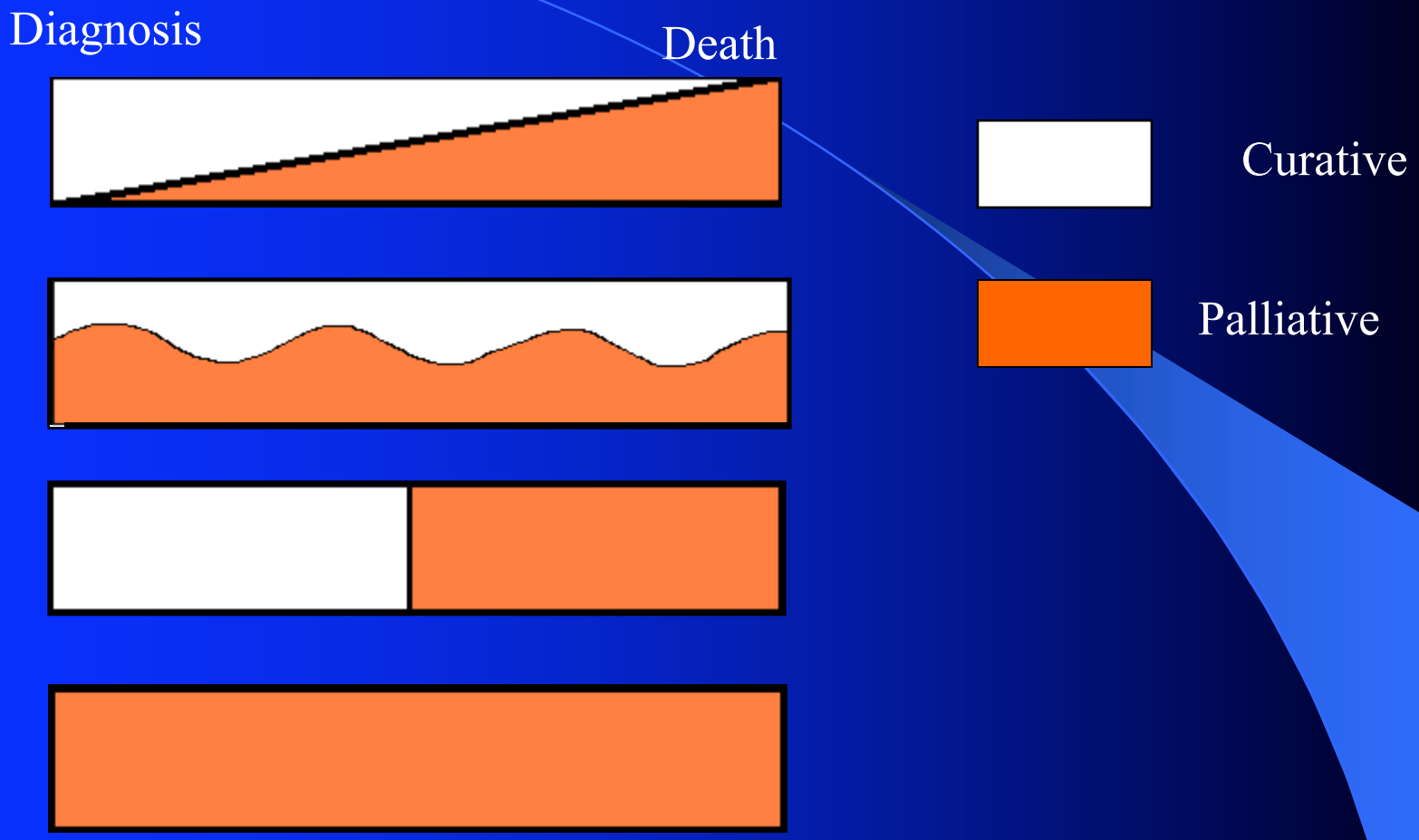
Multidisciplinary Consultation





We Address Suffering

- **Mount BM.**
-
- The problem of caring for the dying in a general hospital; the palliative care unit as a possible solution.
- Can Med Assoc J. 1976 Jul 17;115(2):119-21.

The palliative care unit

- Sophisticated interdisciplinary assessment and management of patient and family suffering
- Management of most difficult problems
- Attention to physical plant and team
- Education and research

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THE PALLIATIVE CARE TEAM
FACULTY
NURSING
INTER-DISCIPLINARY
FELLOWS
ISC'S
APNS
CLINICAL PHARMACISTS
CNA'S
PSYCHO-SOCIAL

Bal Mount on teams

- “if you think you’ve been on a team show me your scars” (Susan Block)

Work, sacrifice of positions, compromise, respect = better patient and family care, prevention of burn out

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Outcomes?

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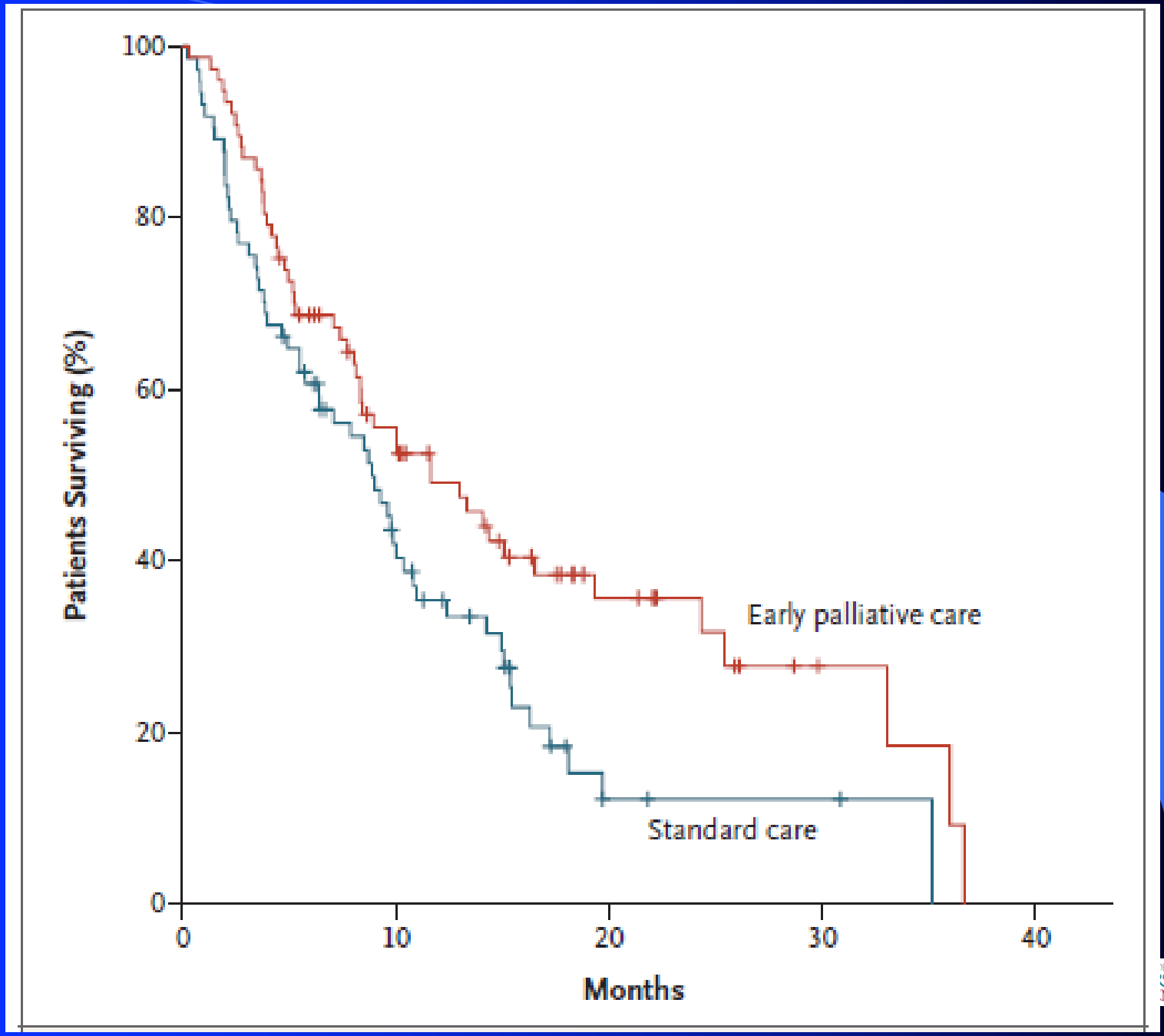
100
80
60
40
20
0
Patients Surviving (%)
0
10
20
30
40
Months
Early palliative care
Standard care

Availability of Palliative Care Programs According to Cancer Center Executives

Characteristics	NCI Cancer Centers (n = 51)	Non-NCI Cancer Centers (n = 50)	*P* Value
Type of cancer center			
NCI-designated comprehensive	31 (61) [46-74]	0	
NCI-designated clinical	11 (21) [11-35]	0	
NCI-designated community	9 (18) [8-31]	0	
Non–NCI-designated	0	50 (100) [93-100]	
Unknown or not answered	0	0	
No. of outpatients in 2008 (IQR)	10 000 (2500-55 000)	3002 (800-8400)	.01
Unknown or not answered	12	16	
Inpatient beds available	41 (87) [74-95]	30 (67) [51-80]	.02
Unknown or not answered	4	5	
No. of inpatient beds (IQR)[b]	80 (44-400)	52 (20-300)	.22
Unknown or not answered	13	23	
Palliative care program			
Available any time over the last 10 y	50 (98) [90-100]	39 (78) [64-88]	.002
Unknown or not answered	0	0	
Currently active	50 (98) [90-100]	39 (78) [64-88]	.002
Unknown or not answered	0	0	
Palliative care physician present	46 (92) [79-97]	28 (74) [57-87]	.04
Unknown or not answered	1	12	
Palliative care infrastructure			
Inpatient consultation team	47 (92) [81-98]	28 (56) [41-70]	<.001
Unknown or not answered	0	0	
Outpatient clinic	30 (59) [44-72]	11 (22) [12-36]	<.001
Unknown or not answered	0	0	
Dedicated acute care beds	13 (26) [14-40]	10 (20) [10-34]	.64
Unknown or not answered	0	0	
Institution-operated hospice	16 (31) [19-46]	21 (42) [28-57]	.31
Unknown or not answered	0	0	

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Structure & Processes of Palliative Care Education & Research in Cancer Centers According to Palliative Care Program Leaders

	No. of Respondents (%) [95% CI]		
	NCI Cancer Centers (n = 61)	Non-NCI Cancer Centers (n = 35)	*P* Value
Palliative care education			
Palliative care fellowship program	23 (38) [26-51]	6 (17) [7-34]	.04
Unknown or not answered	0	0	
≥5 Fellows in the program	4 (18) [5-40]	1 (17) [0-64]	>.99
Unknown or not answered	1	0	
Training for physician assistants	23 (43) [30-58]	11 (42) [23-63]	>.99
Unknown or not answered	8	9	
Mandatory rotation for medical oncology	14 (27) [16-42]	4 (22) [6-48]	.76
Unknown or not answered	10	17	
Mandatory rotation for radiation oncology	1 (2) [0-10]	0	>.99
Unknown or not answered	10	19	
Mandatory rotation for pediatric oncology	3 (6) [1-17]	0	.57
Unknown or not answered	12	19	
Mandatory rotation for medical students	6 (12) [4-23]	2 (13) [2-38]	>.99
Unknown or not answered	9	19	
Palliative care research			
Research programs	28 (46) [33-59]	6 (17) [7-34]	.007
Unknown or not answered	0	0	
Receives research funding	19 (70) [50-86]	4 (80) [28-99]	>.99
Unknown or not answered	1	1	
Peer-reviewed grants	13 (68) [43-87]	3 (75) [19-99]	>.99
Unknown or not answered	0	0	
Private foundations/philanthropy	12 (63) [38-84]	3 (75) [19-99]	>.99
Unknown or not answered	0	0	
Funding source private industry	9 (47) [24-71]	2 (50) [7-93]	>.99
Unknown or not answered	0	0	
Funding source institutional sources	8 (42) [20-67]	3 (75) [19-99]	.32
Unknown or not answered	0	0	

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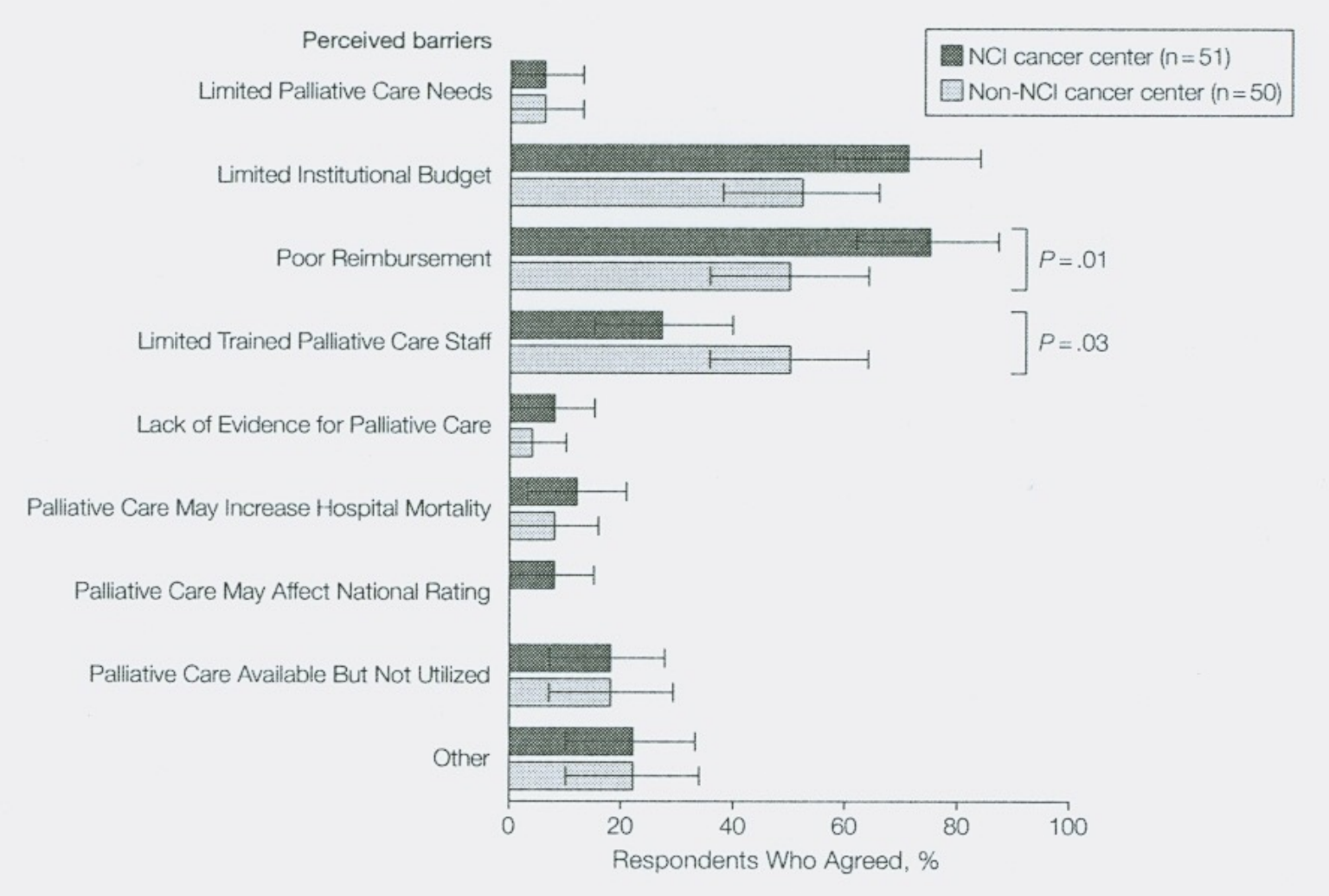
Perceived Barriers to Palliative Care Access According to Cancer Center Executives



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What does this mean?

- "Palliative care" much more available!!
- About 1in 3 outpatient center
- Less than 1 in 4 PCU
- About 1/3 24/7
- Barriers are financial. Limited growth expectations

The outpatient center

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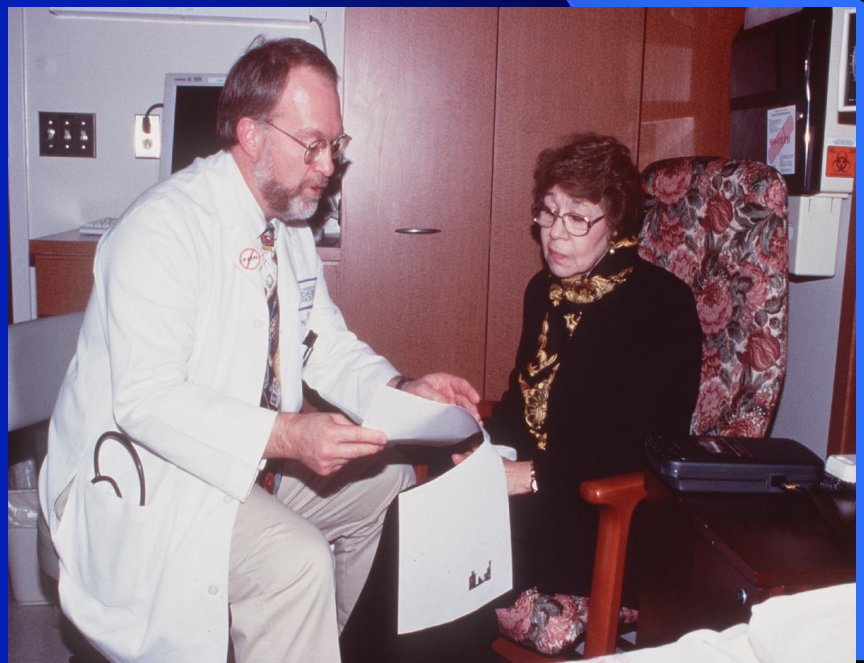
RED HOT
HAPPY VALENTINE'S DAY

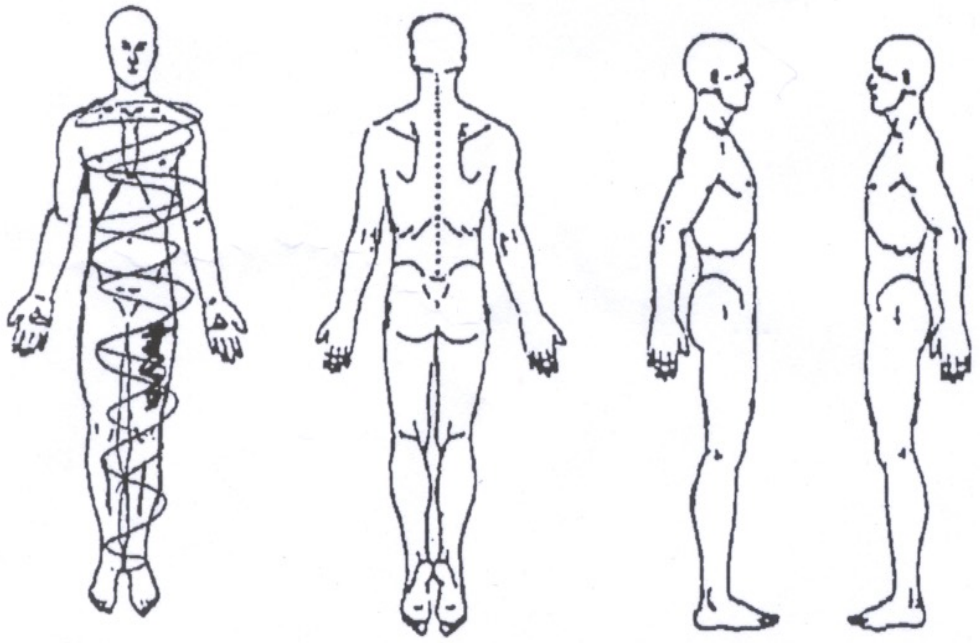

PALLIATIVE CARE
&
REHABILITATION
MEDICINE
CENTER
REGISTRATION



Symptom Assessment (Day 1)

SYMPTOM ASSESSMENT

Where is your pain located? Shade in the diagram and mark the worst spots with an X. 5 of 6 sessions of chemo carbo + ?



Check if N/A

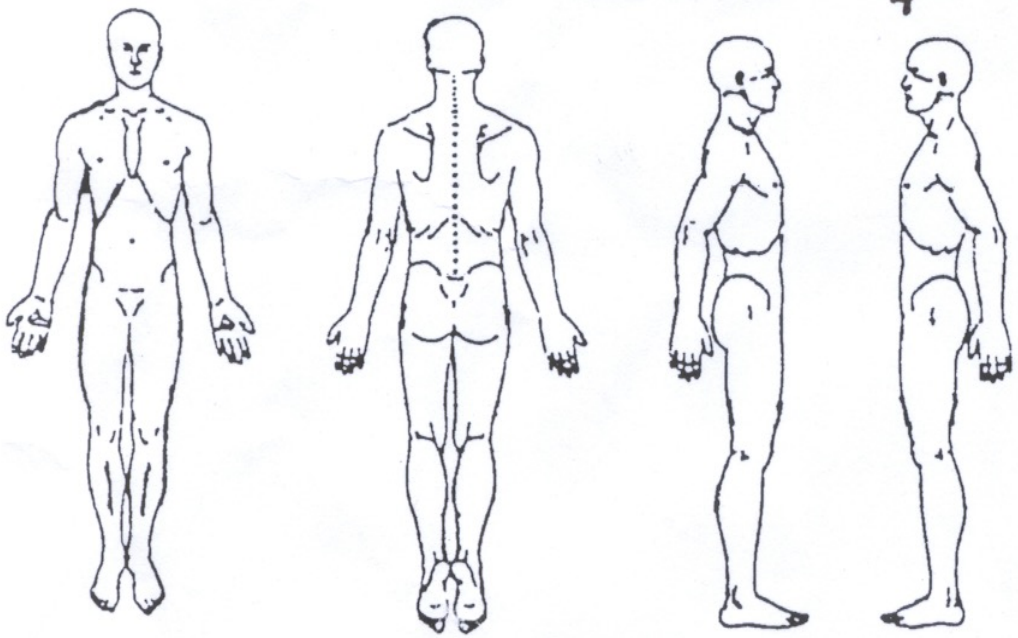
61 - NSCLC Worst Imaginable DAY 1

	Pain	Fatigue	Nausea	Depression	Anxiety	Drowsiness	Shortness of Breath	Appetite	Sleep	Feeling of Well Being
10										
9										
8										
7										
6										
5										
4										
3										
2										
1										
0	5	7	0	7	7	5	7	0	6	6

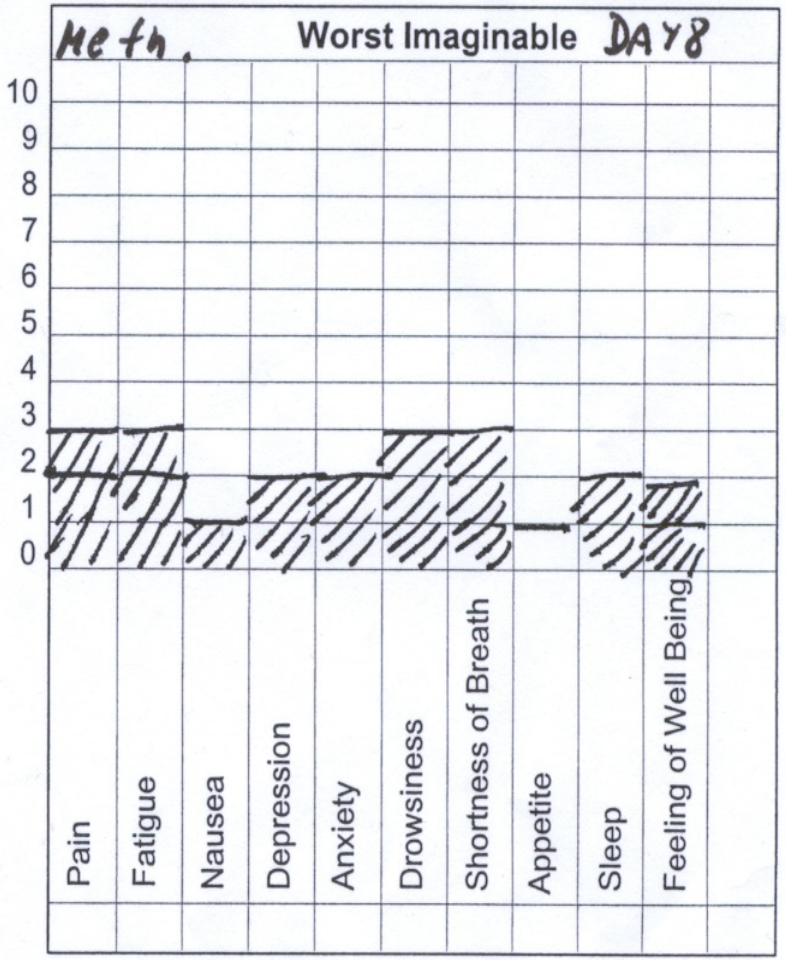
Symptom Assessment (Day 8)

SYMPTOM ASSESSMENT

Where is your pain located? Shade in the diagram and mark the worst spots with an X. Methadone 2.5 q8. Donepezil 5 q am.



Check if N/A




Hill-Rom


Edmonton Limousine
LIMOUSINE


11821


01

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Palliative care interventions

- Radiotherapy, chemotherapy, transfusions, hydration, colostomy, antibiotics, dyalisis, opioids, antiemetics, laxatives.
- No inherent negative or positive value
- Decision making process important!!

Elements for palliative care decision making

- Discomfort associated with the application (stretcher downstairs, IV)
- Need to leave home (IV antibiotics, Xrays)
- Importance of clear sensorium (wedding, dyalisis plus methylphenidate)
- Family participation (conference)

Why are no PCUs in all hospitals?

- Patients die and families grieve in all hospitals
- PC teams improve suffering
- PCUs would allow better care and save money!!

Cultural issues

- National identity, race, religion, gender
- Discipline: oncology, pain, supportive care, hospice, nursing
- Hospital/ institution: mission- “making cancer history”; “we do not hydrate”; “we do not use assessment tools”
- University: curriculum wars

Developmental stages of a palliative culture

- Individuals, and groups (hospitals, governments and universities) usually progress slowly but regression can happen at any time.
- Frequent coexistence of signs of different stages in the same person/ group

1. Denial

- "We don't have those problems here"
- "Our symptom control is very good; our patients and families are happy!!"
- "Hospice takes care of all our problems"
- "Research on problems that do not exist"

2. Palliphobia

- Panic episodes when the “P” word is mentined.

  Most common among oncologists, pain specialists and deans of medical school

  “we will lose patients”; “it is covert euthanasia”; “there is no science”; “medicare fraud”

3. Pallilallia

- Repetitive nonsense talking about Palliative care without any accompanying actions
- Collective pallilalia: affects organizations and governments
- “Do a study to document/demonstrate”; “consensus group”; “this is VERY important”

4. Palliactive

- Appoint MDs/ RNs
- Physical space: Unit/clinic
- Administrative space: Division – Department
- $$$$$$$$$!!!

Who needs education?

- Medicare administrator: Break the acute/ long term interests, get the $$$ moving. In our country (sadly) insurance owners.
- Deans of Medical Schools- Importance of PC education and research.
- Directors of cancer centers- cancer treatment Vs patient treatment (“personalized : reality or joke?”)
- Hospital CEOs- patients dying in hospital with no palliative care

Mary Vachon- burnout

- Low responsibility, high autonomy- NO
- Low responsibility, low autonomy- NO
- High responsibility, high autonomy- NO
- High responsibility, low autonomy- YES!

The Granger Collection, New York City

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Knowledge Vs Wisdom

- Opioid dose escalation, survivors
- Epidural/ intrathecal opioids
- Nerve blocks
- Vertebro/ kyphoplasty
- Adjuvant drugs

Wisdom not possible with bad knowledge

- Poor trial design (patient characteristics, outcomes, measurement)
- Trivial questions (“the value of a smile”)- difficult for granting agencies AND journals (500 pt RCT of “me too” intervention Vs 40 pt pilot open of new intervention)

Wisdom not possible with bad knowledge

- Corruption of clinical academics (company funding, company design and analysis, ghost writers, speaking tours, multicenter studies). The makings of the Dean?
- Corruption of translational research (patent oriented research, company driven research and confidential data). The makings of the Dean?
- Corruption of the regulatory process for multiple drugs and devices (FDA irrelevant)

Some reading

- Can a doctor be a humanist? Robertson Davies (The Merry Heart, Penguin, 1996)
- Man's search for meaning (Viktor Frankl)
- Eric Cassell, Daniel Sulmasy

Nurturing your personhood. B Mount to Medical graduates 1986 (Can Med Assoc J 86)

- Good brings good
- One person can make a difference
- The most unlikely people (you) can be the one who makes a difference

Caring for ourselves- Professional

- Knowledge about palliative care assessment and management, physical and psychosocial
- Wisdom for assessment, management and counseling
- Realistic goals for patient/ family care
- Team work (among MDs and with interdisciplinary team)
- Palliative care unit
- Academic scope (teaching, research)

Caring for ourselves- personal

- Social network (family, friends, community)- communication
- Activities other than work (hobbies, music, sports, spirituality)- distraction
- Take time off- respite
- Exercise regularly- fatigue, depression, sleep, self-esteem
- WET (wisdom enhancement techniques!!) (reading, arts, spiritual and personal growth)
-

Matrix corporate model

- Hygiene: Salary, safety (physical and emotional), supervision, office, parking

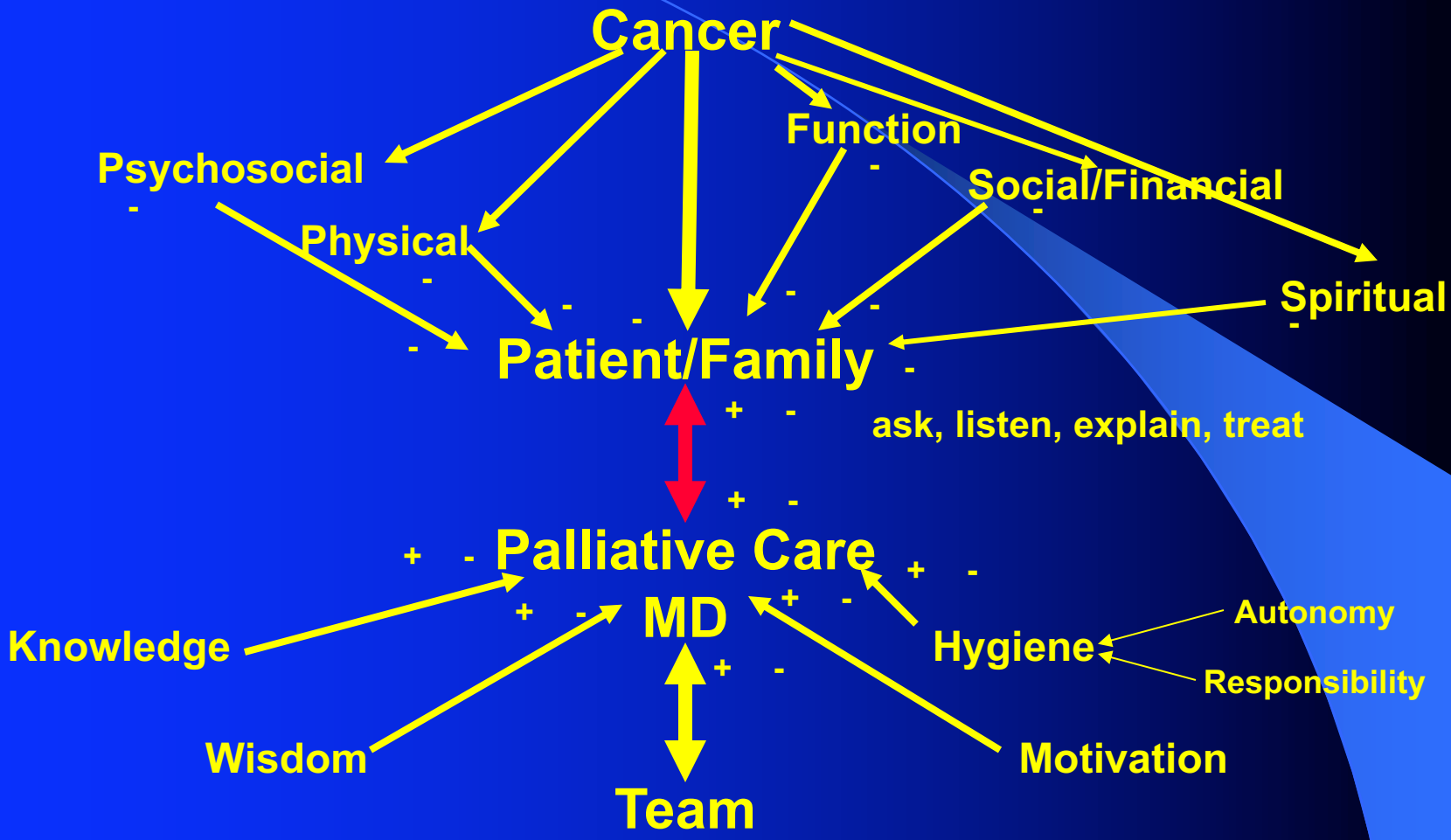
Related to the structure of the job

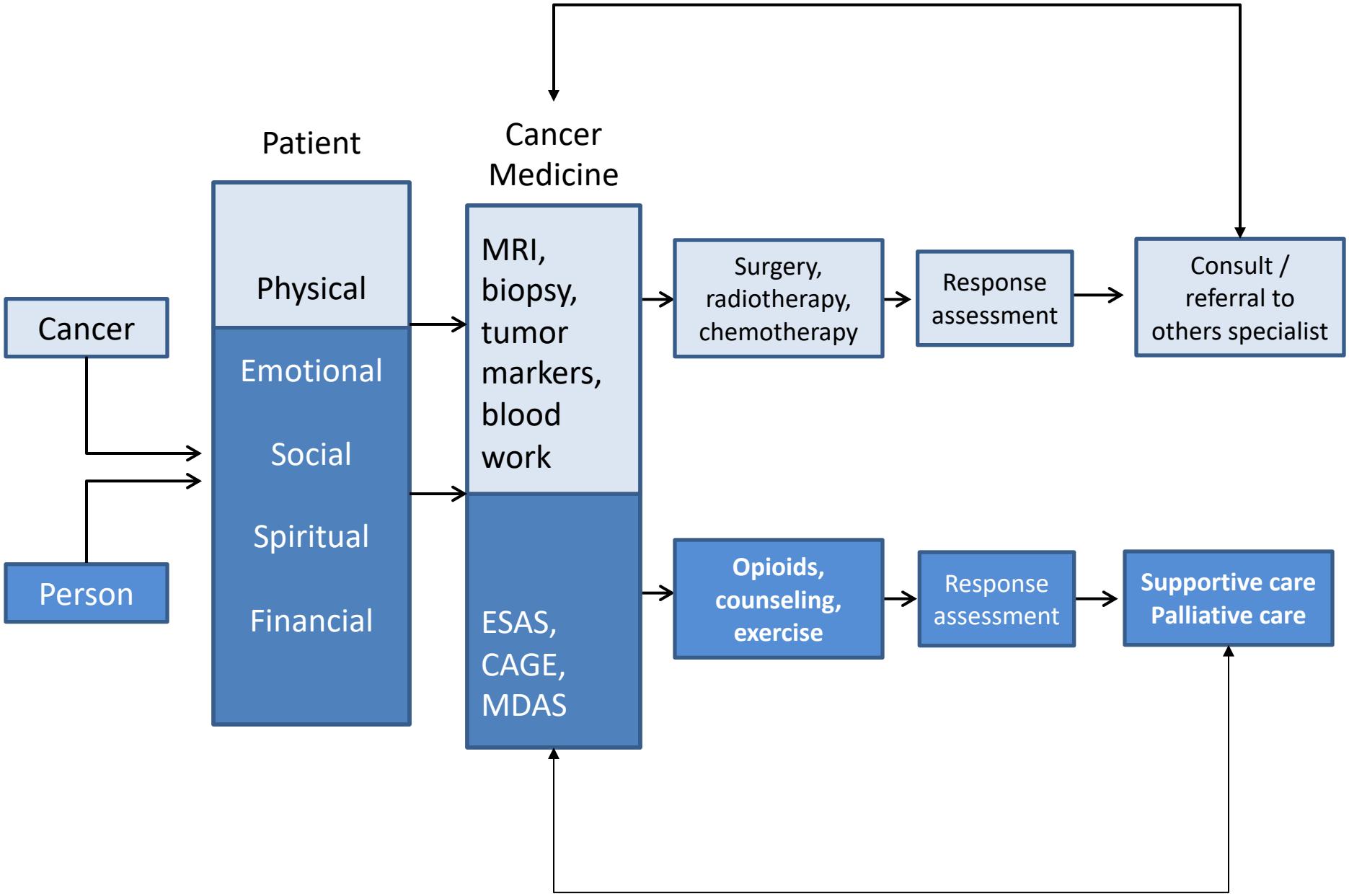
- Motivation: Achievement, recognition, promotion, mentorship

Related to leader and team

- > hygiene > motivation: ideal
- < hygiene > motivation: erratic output, lots of complaints
- > hygiene < motivation: low output, conflict
- < hygiene < motivation: low output, burnout, turnover

The Palliative Encounter




Patient
Cancer Medicine
Cancer
Person
Physical
Emotional
Social
Spiritual
Financial
MRI, biopsy, tumor markers, blood work
ESAS, CAGE, MDAS
Surgery, radiotherapy, chemotherapy
Response assessment
Consult / referral to others specialist
Opioids, counseling, exercise
Response assessment
Supportive care Palliative care