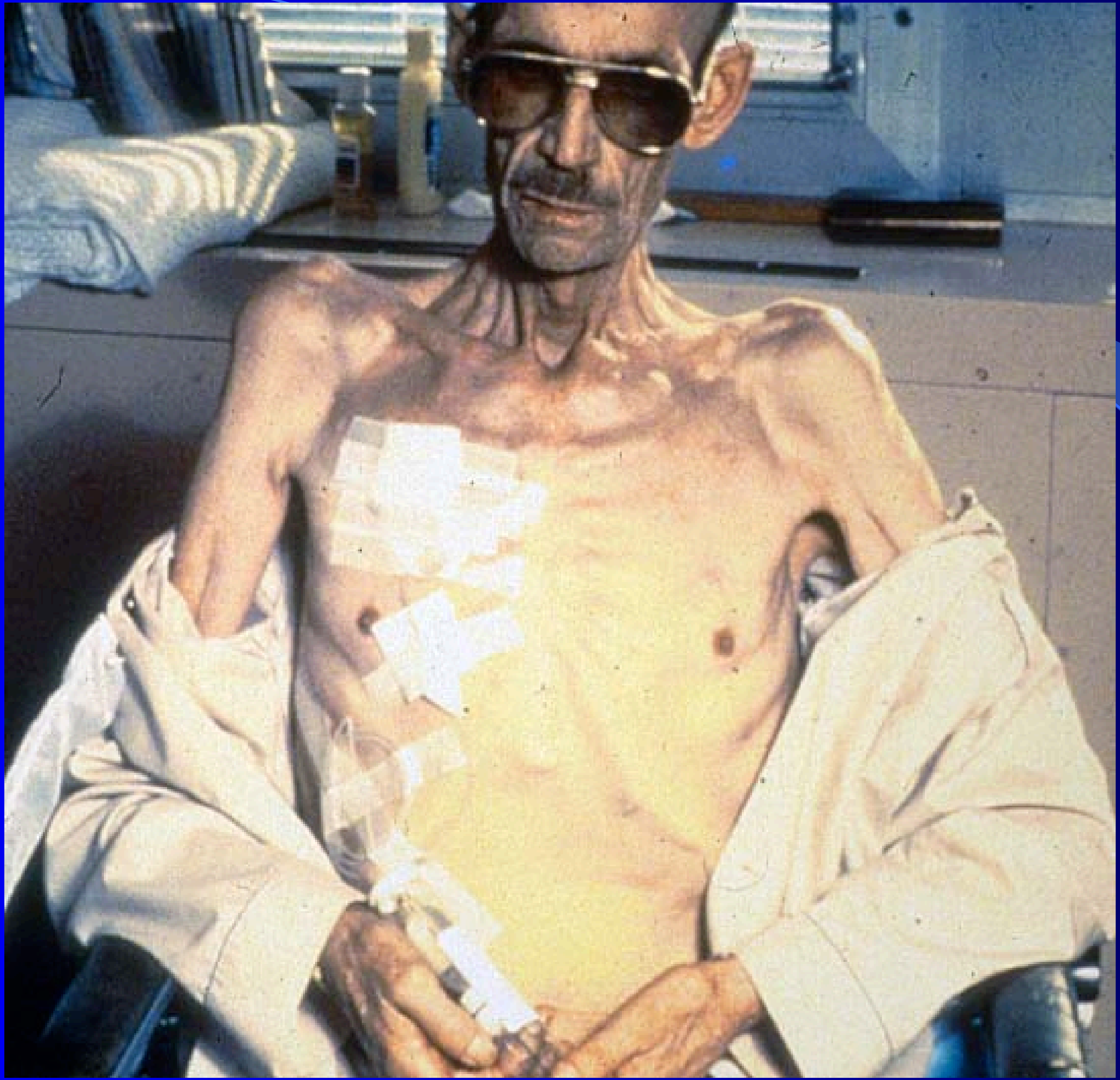


Problemi del paziente

- Dolore (80%)
- Fatica (90%)
- Perdita di peso (80%)
- Mancanza di appetito (80%)
- Nausea, Vomito (90%)
- Ansia (25%)
- Mancanza di respiro (50%)
- Confusione-agitazione (80%)

“C'è una regola generale, e ho visto grandi medici agire su di essa, che il medico NON dovrebbe curare la MALATTIA ma il PAZIENTE che ne soffre.”

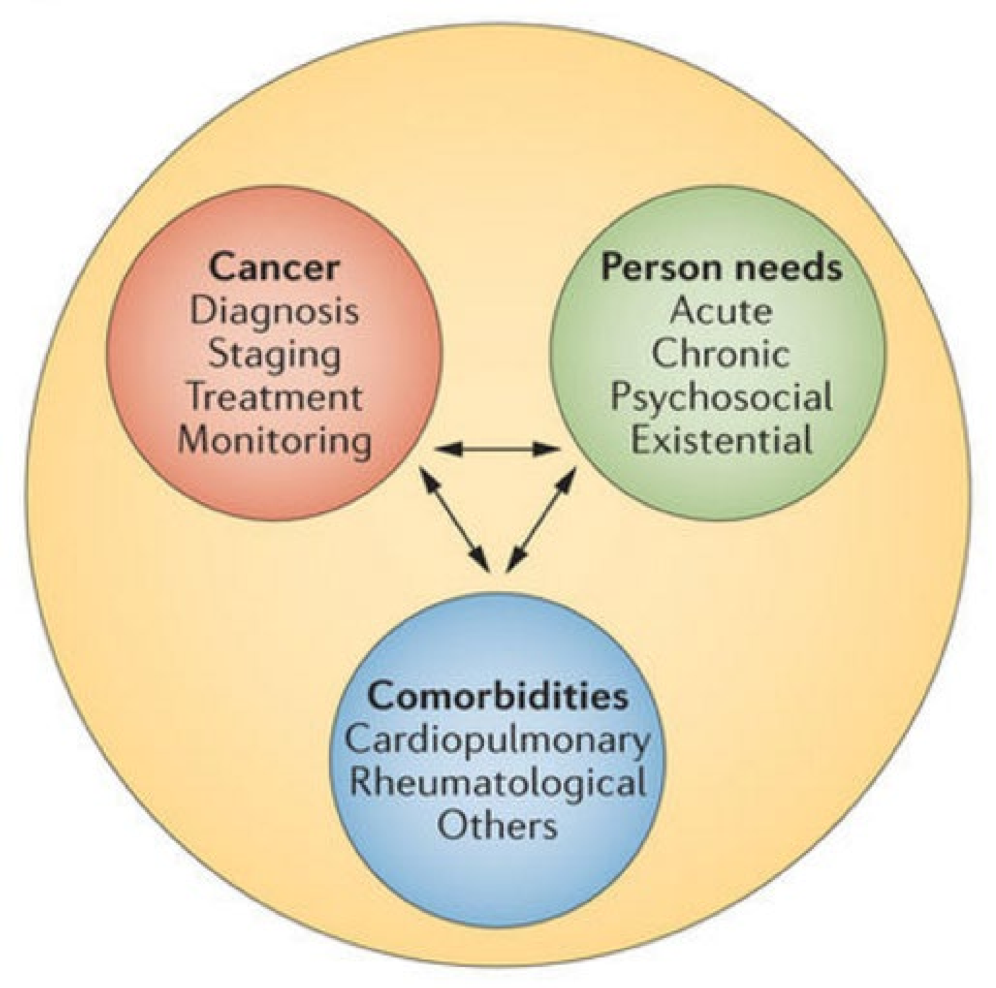
Maimonides (1135-1204)

La Frangia!!

- 1967- St Cristopher’s hospice
- Case e assistenza domiciliare. Enfasi sulla valutazione e la gestione dei sintomi, assistenza familiare, consulenza, pianificazione della fine della vita, supporto al lutto

Medicina principale in Nord America

- Medicina di terapia intensiva
- Medicina d'urgenza
- Oncologia e molte altre sottospecialità
- Tutto > 10 anni più giovane, ma all'interno del sistema!!



Cancer
Diagnosis
Staging
Treatment
Monitoring

Person needs
Acute
Chronic
Psychosocial
Existential

Comorbidities
Cardiopulmonary
Rheumatological
Others

Crescita e adozione della conoscenza - Cancro - Biomedico

Few Blood Markers

Biopsy

Nuclear Medicine Scan - CT

Chemotherapy

25 Years Ago

Some Hormones

Molecular Profile

Re-Biopsy

Multiple Blood Markers

MRI

Today

PET – CT

Immunotherapy

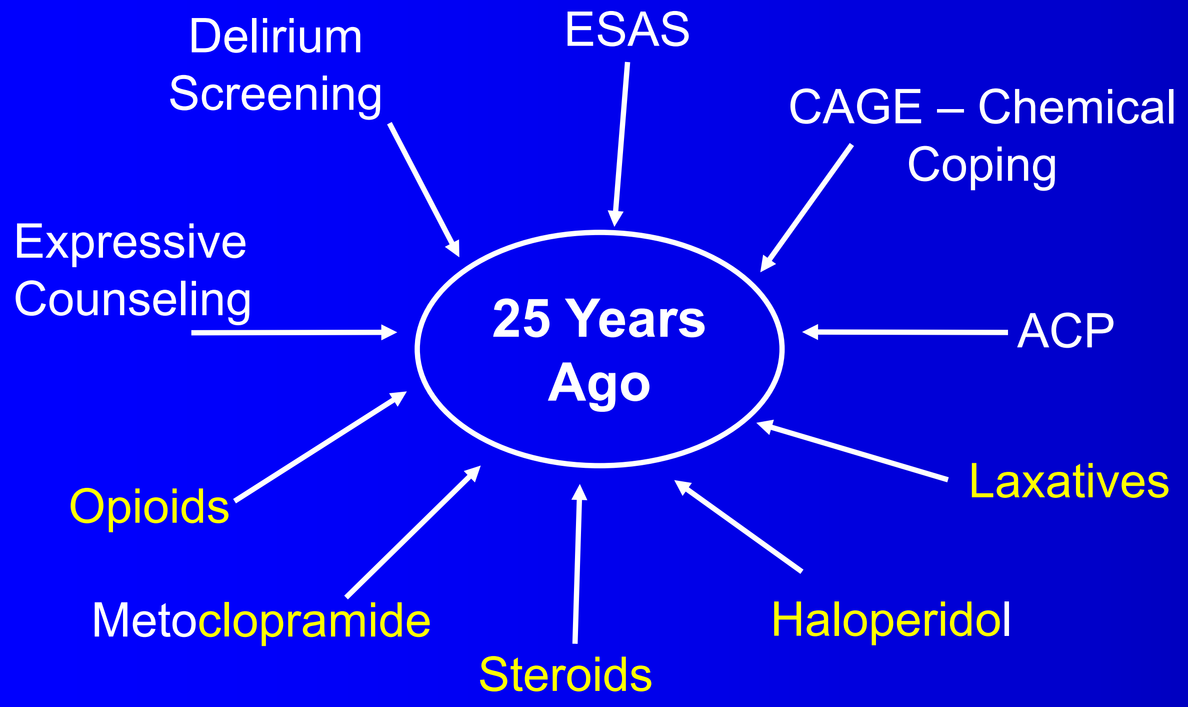
Better Chemotherapy

Better Hormones

Targeted Therapy

ADOZIONE RAPIDA UNIVERSALE

Crescita e adozione della conoscenza - Centrato sul cancro - Persona



25 Years Ago

Delirium Screening

ESAS

CAGE – Chemical Coping

Expressive Counseling

ACP

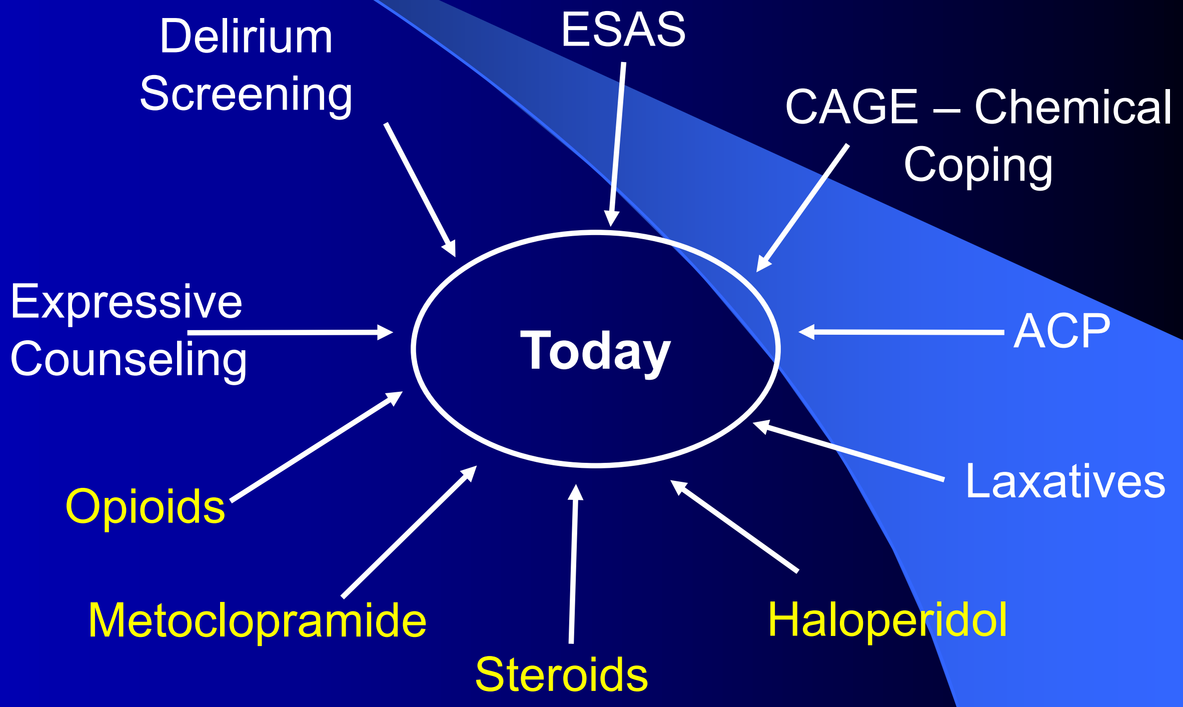
Opioids

Laxatives

Metoclopramide

Steroids

Haloperidol



Today

Delirium Screening

ESAS

CAGE – Chemical Coping

Expressive Counseling

ACP

Opioids

Laxatives

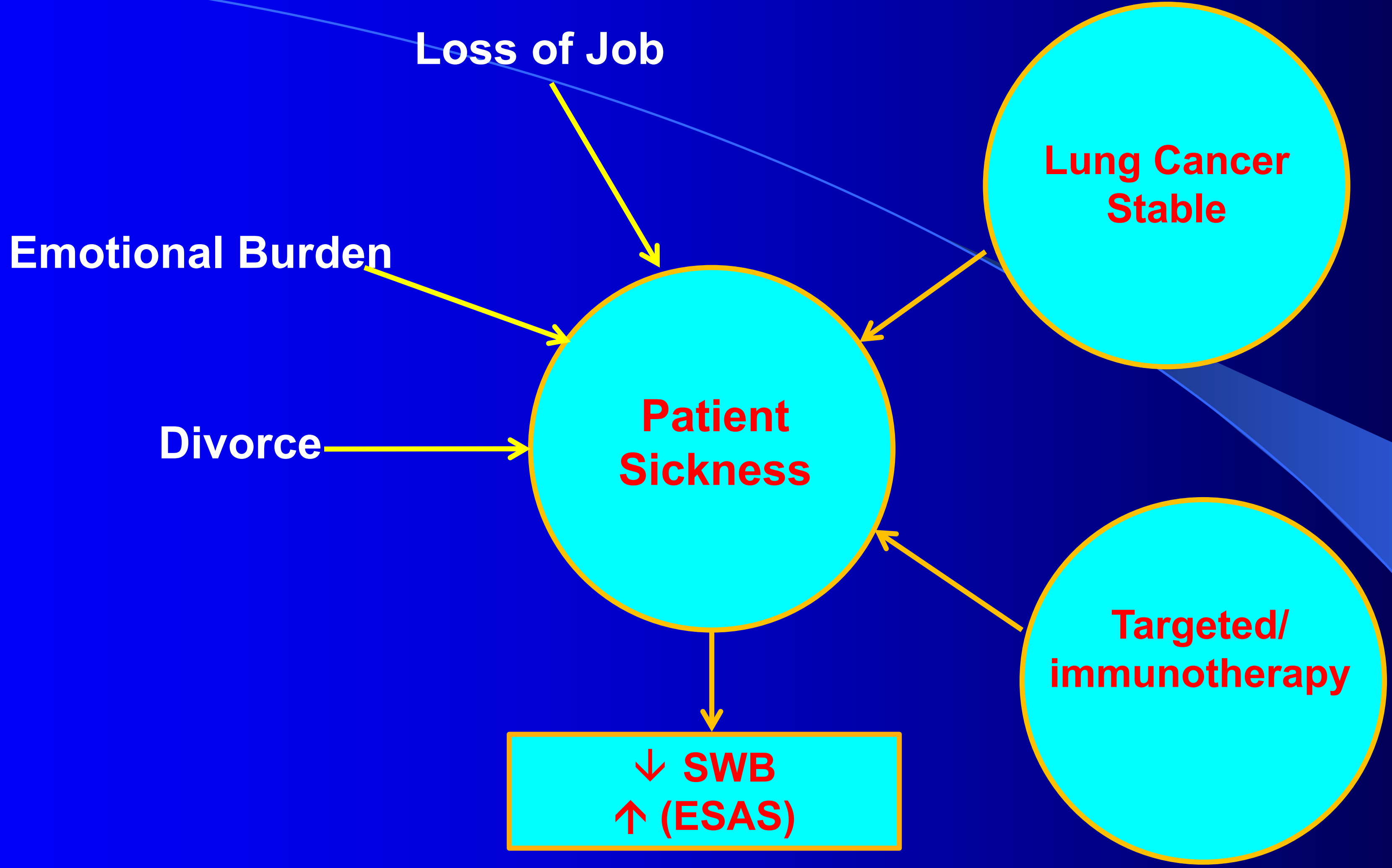
Metoclopramide

Steroids

Haloperidol

ADOZIONE ANCORA PARZIALE!!

Affrontiamo la sofferenza



Loss of Job

Emotional Burden

Divorce

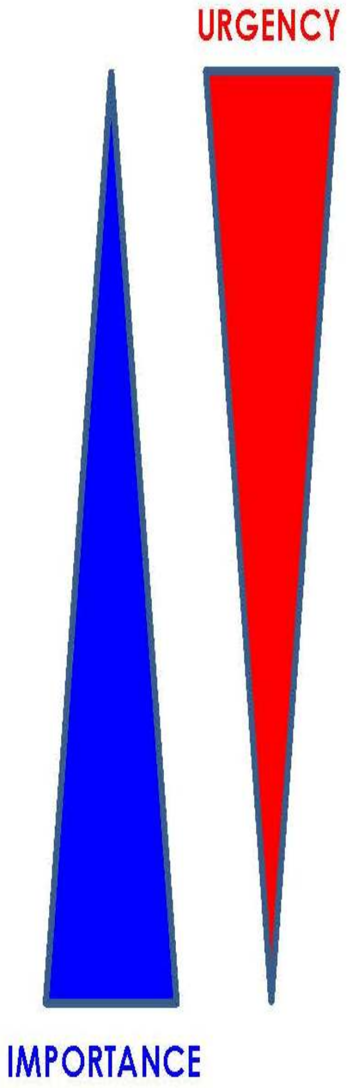
Patient Sickness

Lung Cancer Stable

Targeted/ immunotherapy

↓ SWB
↑ (ESAS)

- Cambiamenti farmacologici
- Procedura diagnostica invasiva
- Esprimere preoccupazione per la crescita del cancro



RED -

Physical Symptoms: Pain, Dyspnea, Nausea, Other
Delirium
Depression (Suicide Risk)

ORANGE -

Constipation
Physical Symptoms: Insomnia, Anorexia, Fatigue, Sedation
Emotional: Anxiety, Depression
Nutrition

GREEN -

Physical – Social Function
Family structure & function
Financial
Spiritual

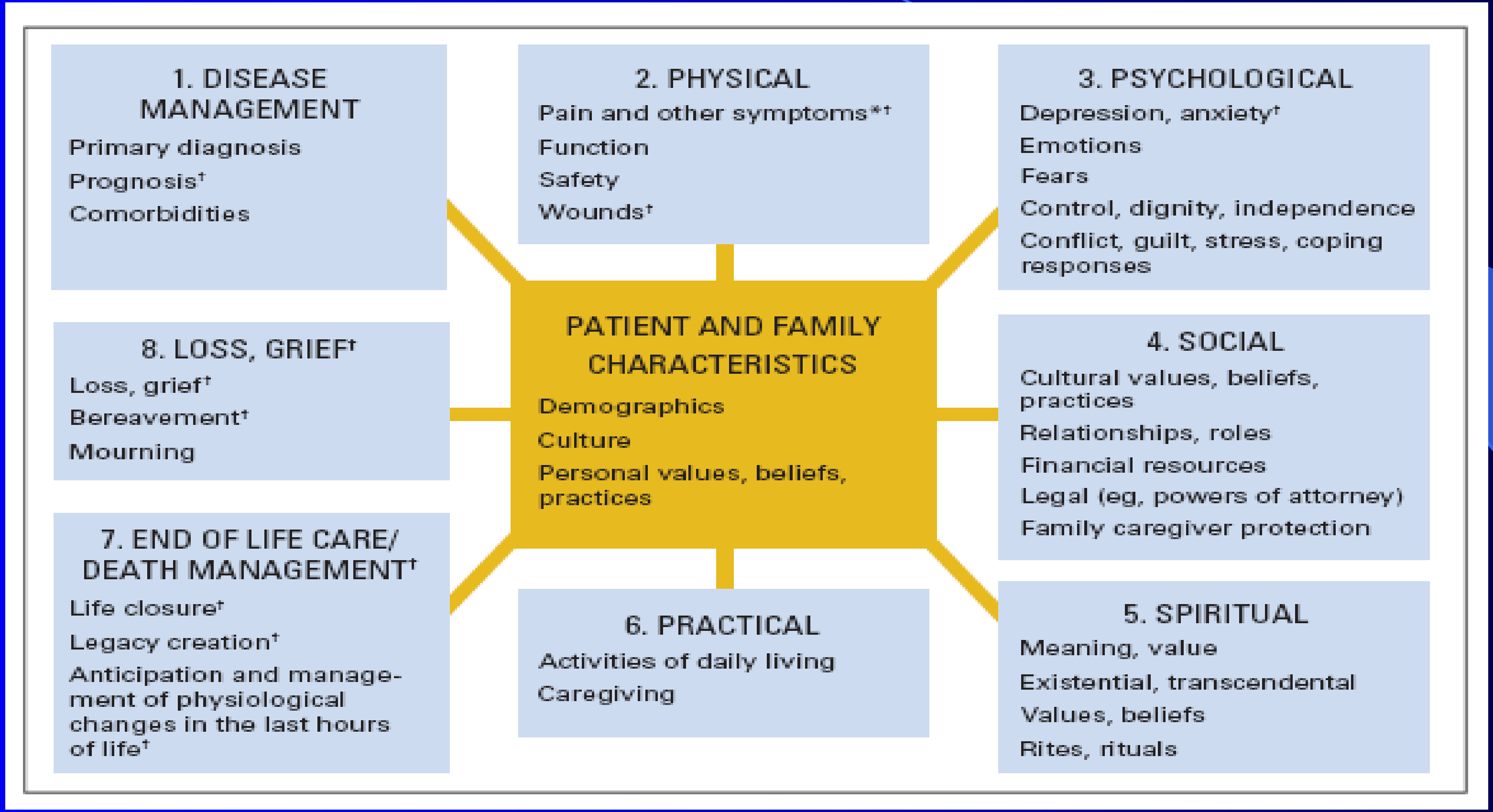
Advanced Care Planning

BLUE -

LEGACY – Dignity Therapy
Meaning – Logotherapy
Symbolic Immortality
Well-being
Sources of Joy

Le cure palliative sono complesse: L'oncologo, l'internista, il medico di famiglia non sono riusciti ad alleviare la sofferenza prima del rinvio

Cure Palliative: Domini Chiave



1. DISEASE MANAGEMENT
Primary diagnosis
Prognosis[†]
Comorbidities

2. PHYSICAL
Pain and other symptoms[*†]
Function
Safety
Wounds[†]

3. PSYCHOLOGICAL
Depression, anxiety[†]
Emotions
Fears
Control, dignity, independence
Conflict, guilt, stress, coping responses

8. LOSS, GRIEF[†]
Loss, grief[†]
Bereavement[†]
Mourning

PATIENT AND FAMILY CHARACTERISTICS
Demographics
Culture
Personal values, beliefs, practices

4. SOCIAL
Cultural values, beliefs, practices
Relationships, roles
Financial resources
Legal (eg, powers of attorney)
Family caregiver protection

7. END OF LIFE CARE/ DEATH MANAGEMENT[†]
Life closure[†]
Legacy creation[†]
Anticipation and management of physiological changes in the last hours of life[†]

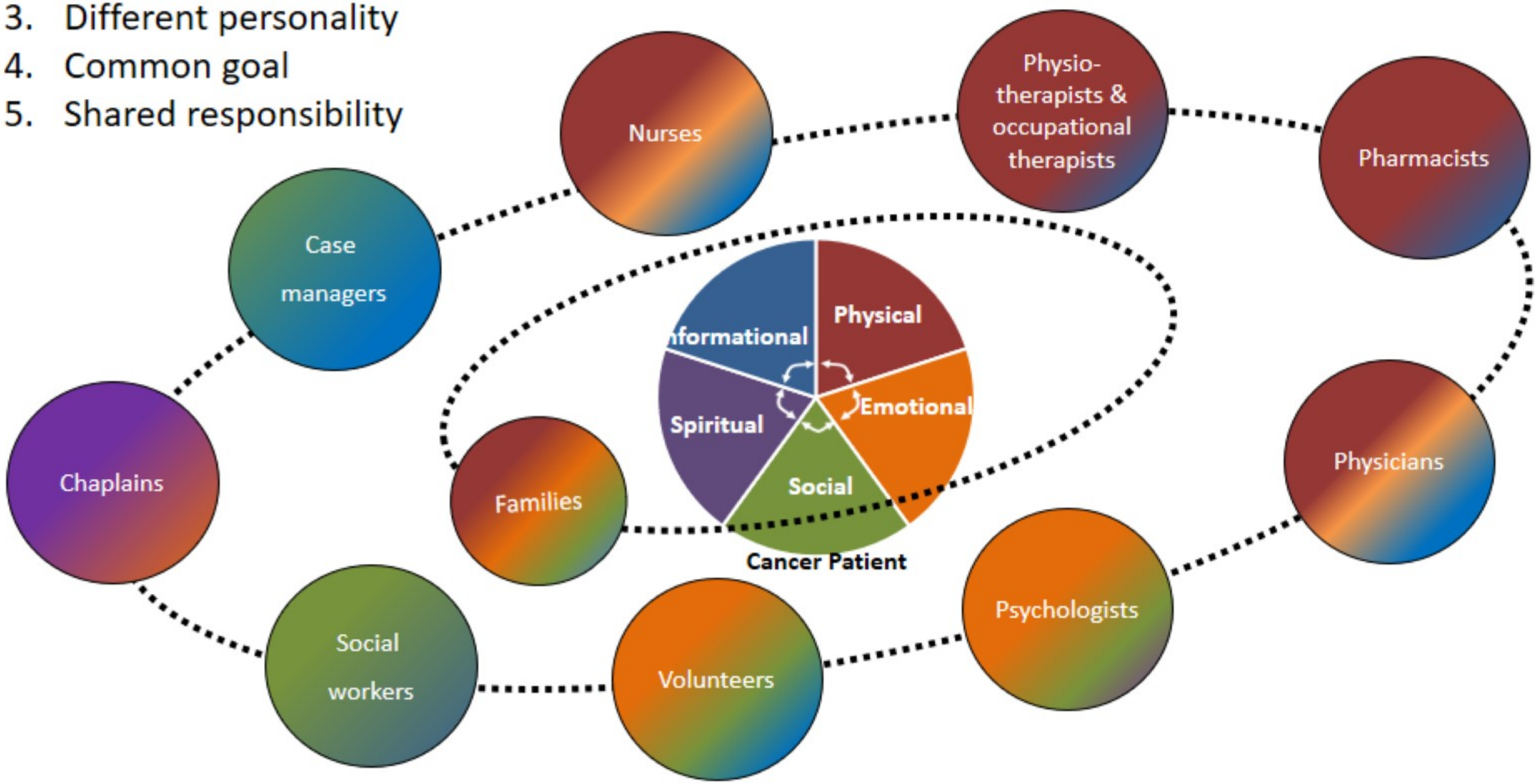
6. PRACTICAL
Activities of daily living
Caregiving

5. SPIRITUAL
Meaning, value
Existential, transcendental
Values, beliefs
Rites, rituals

Ferris et al. J Clin Onc 2009

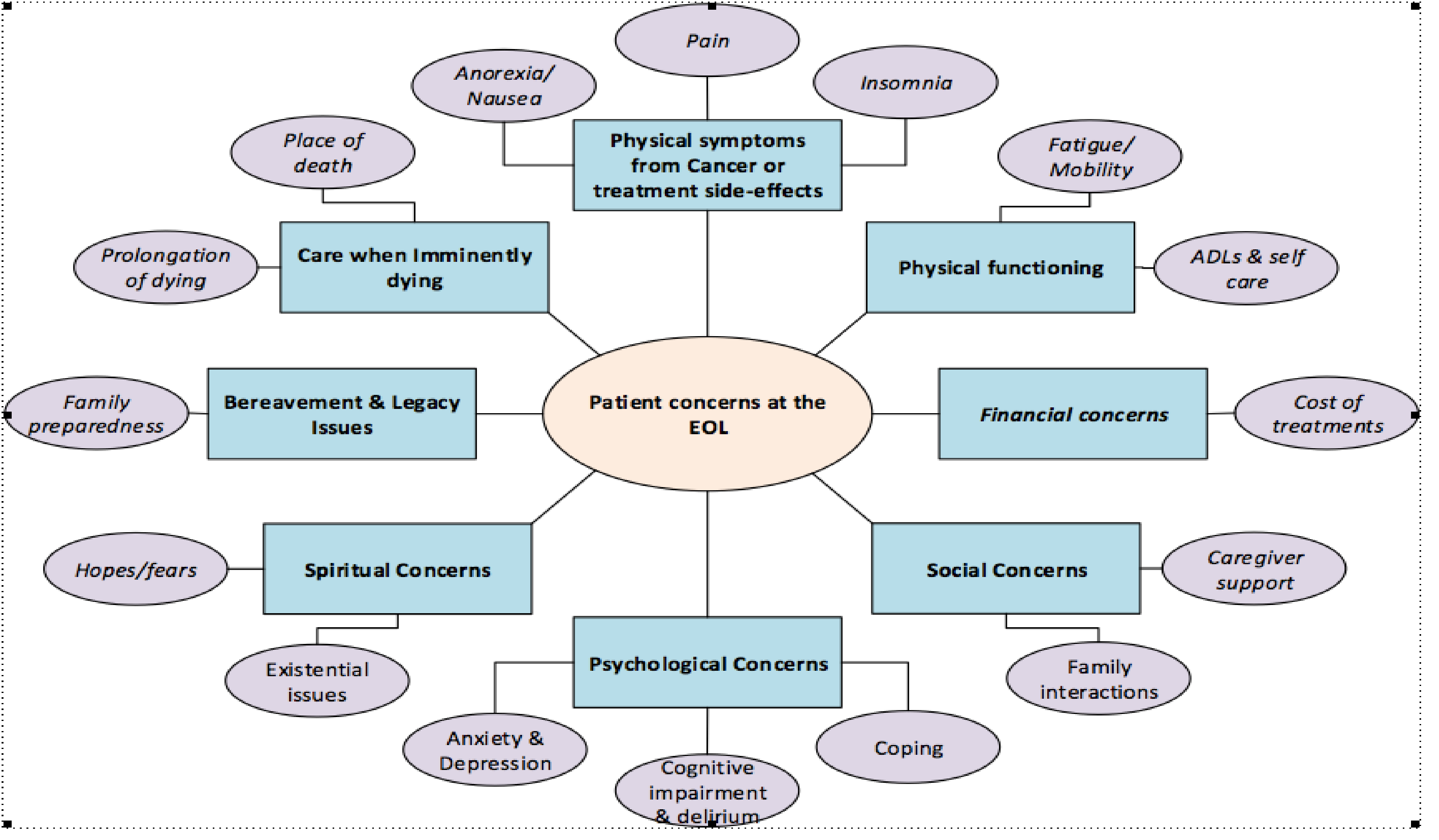
Interprofessional Team

1. Situational leadership
2. Unified message
3. Different personality
4. Common goal
5. Shared responsibility


Nurses
Physio-therapists & occupational therapists
Pharmacists
Case managers
Physical
nformational
Emotional
Spiritual
Social
Cancer Patient
Chaplains
Families
Physicians
Psychologists
Social workers
Volunteers

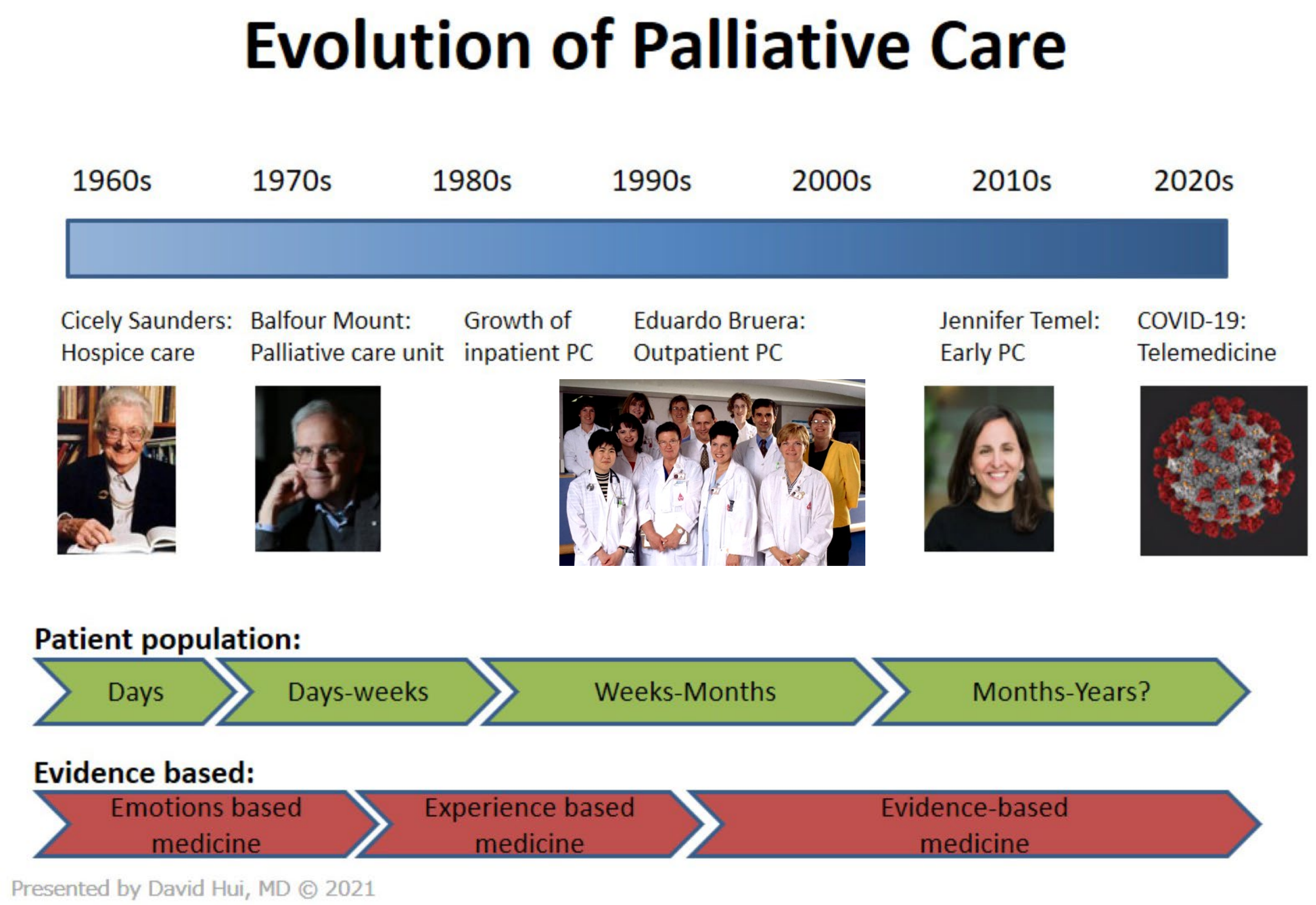
Presented by David Hui, MD © 2021

Hui et al. *CA: Cancer J Clin* 2018



Patient concerns at the EOL

- **Physical symptoms from Cancer or treatment side-effects**
  - *Pain*
  - *Anorexia/ Nausea*
  - *Insomnia*
- **Physical functioning**
  - *Fatigue/ Mobility*
  - *ADLs & self care*
- ***Financial concerns***
  - *Cost of treatments*
- **Social Concerns**
  - *Caregiver support*
  - Family interactions
- **Psychological Concerns**
  - Coping
  - Cognitive impairment & delirium
  - Anxiety & Depression
- **Spiritual Concerns**
  - *Hopes/fears*
  - Existential issues
- **Bereavement & Legacy Issues**
  - *Family preparedness*
- **Care when Imminently dying**
  - *Place of death*
  - *Prolongation of dying*



Evolution of Palliative Care

1960s	1970s	1980s	1990s	2000s	2010s	2020s
Cicely Saunders: Hospice care	Balfour Mount: Palliative care unit	Growth of inpatient PC	Eduardo Bruera: Outpatient PC		Jennifer Temel: Early PC	COVID-19: Telemedicine

Patient population:

Days → Days-weeks → Weeks-Months → Months-Years?

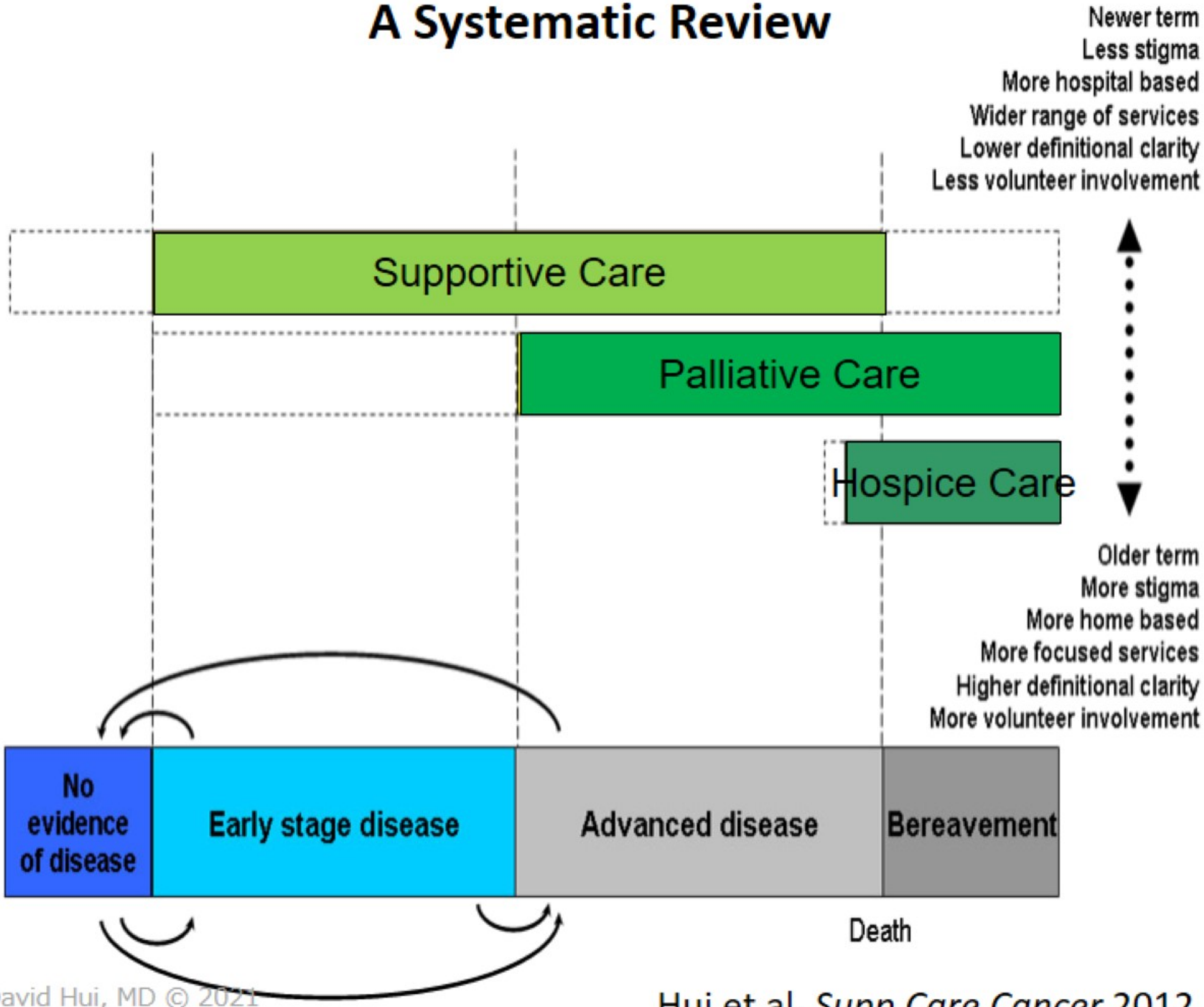
Evidence based:

Emotions based medicine → Experience based medicine → Evidence-based medicine

Presented by David Hui, MD © 2021

Definition of Palliative Care

A Systematic Review



Newer term
Less stigma
More hospital based
Wider range of services
Lower definitional clarity
Less volunteer involvement
Supportive Care
Palliative Care
Hospice Care
Older term
More stigma
More home based
More focused services
Higher definitional clarity
More volunteer involvement
No evidence of disease
Early stage disease
Advanced disease
Bereavement
Death

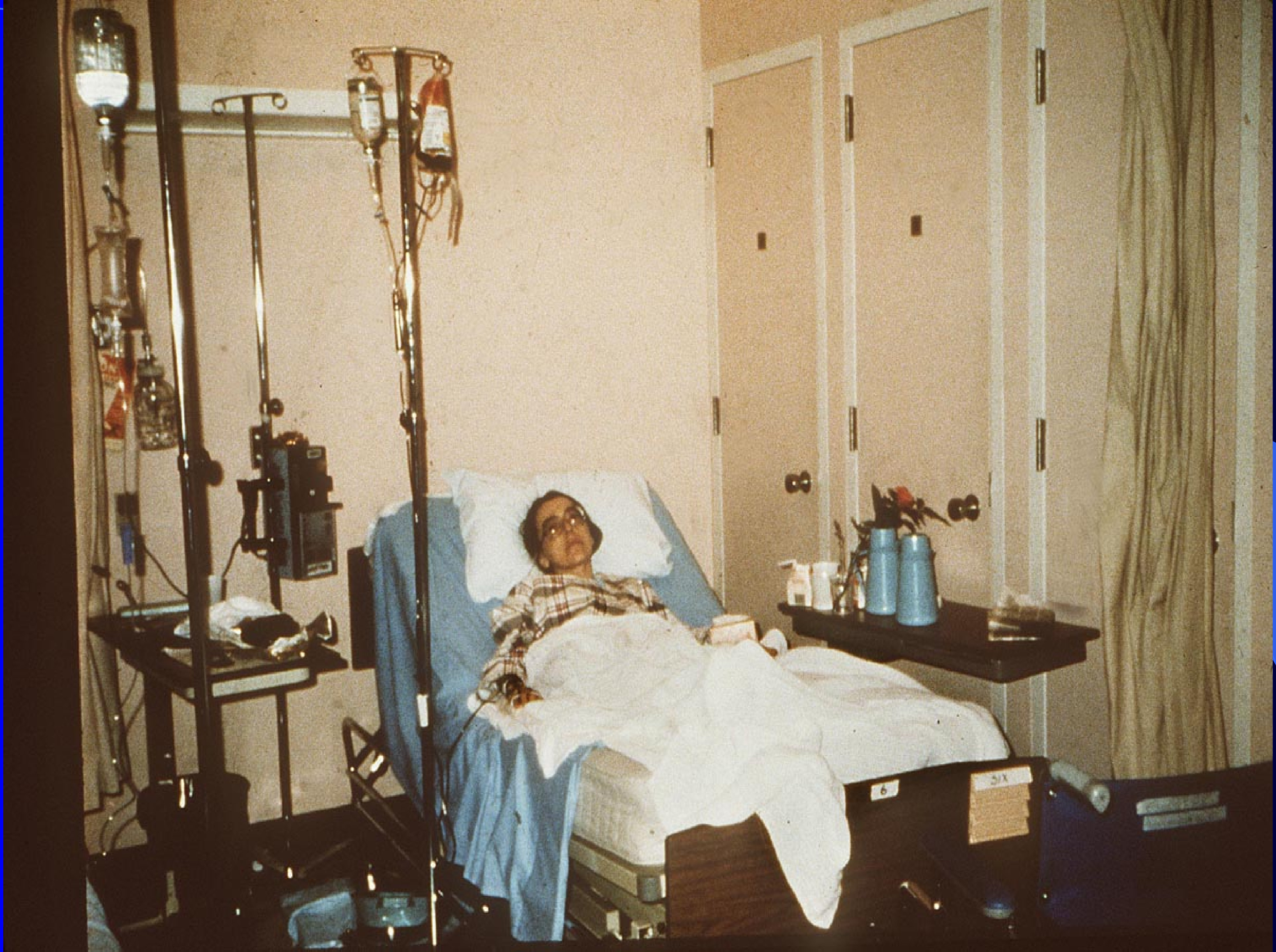
Presented by David Hui, MD © 2021

Hui et al. *Supp Care Cancer* 2012

Pain &
Symptom
Control Clinic

Assistenza orientata alla persona

- Diverse strutture, processi e risultati dell'assistenza orientata alla malattia
- Le differenze sono sempre frustranti per gli amministratori!


6
SIX

ERONG
ERONG

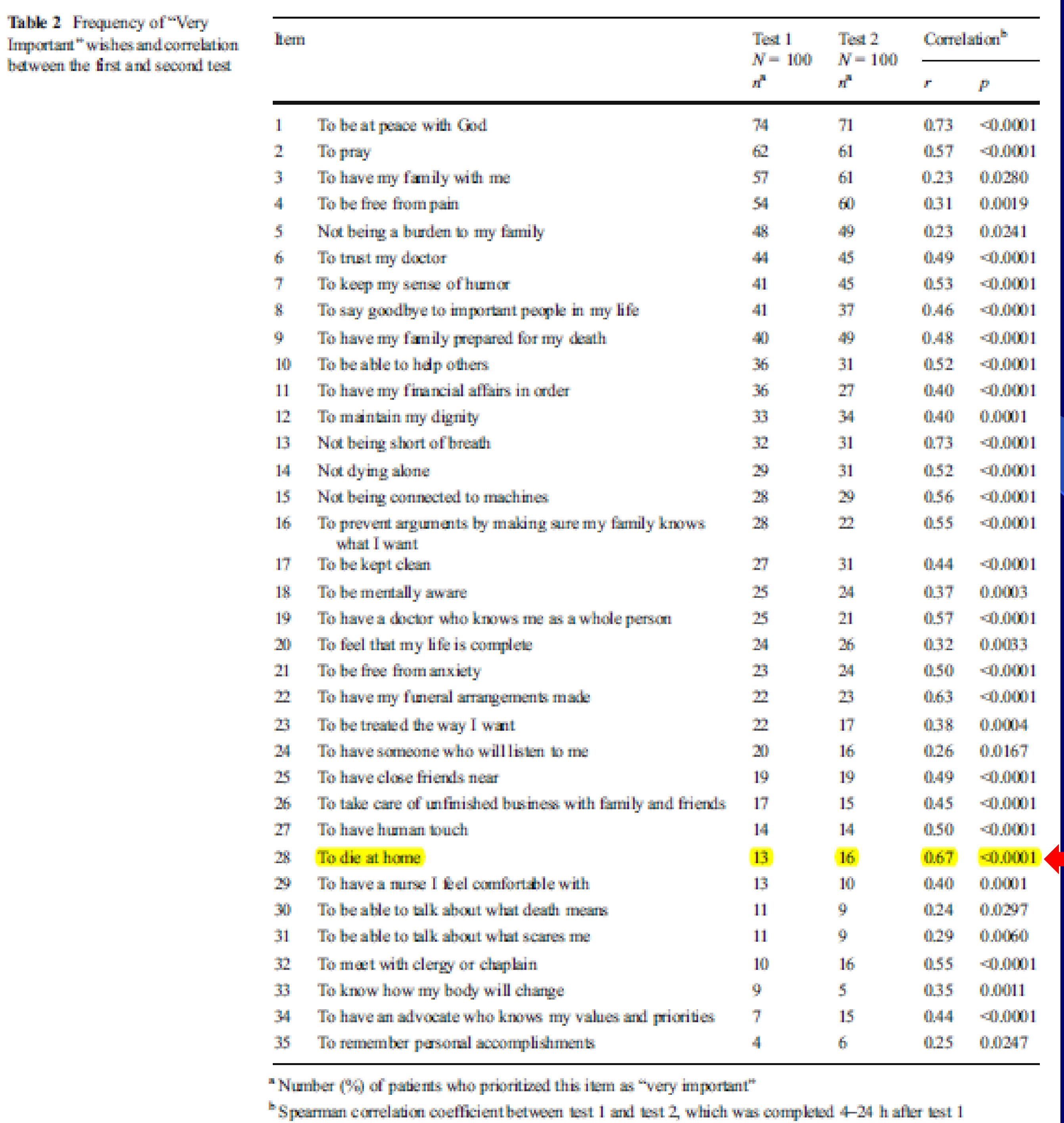


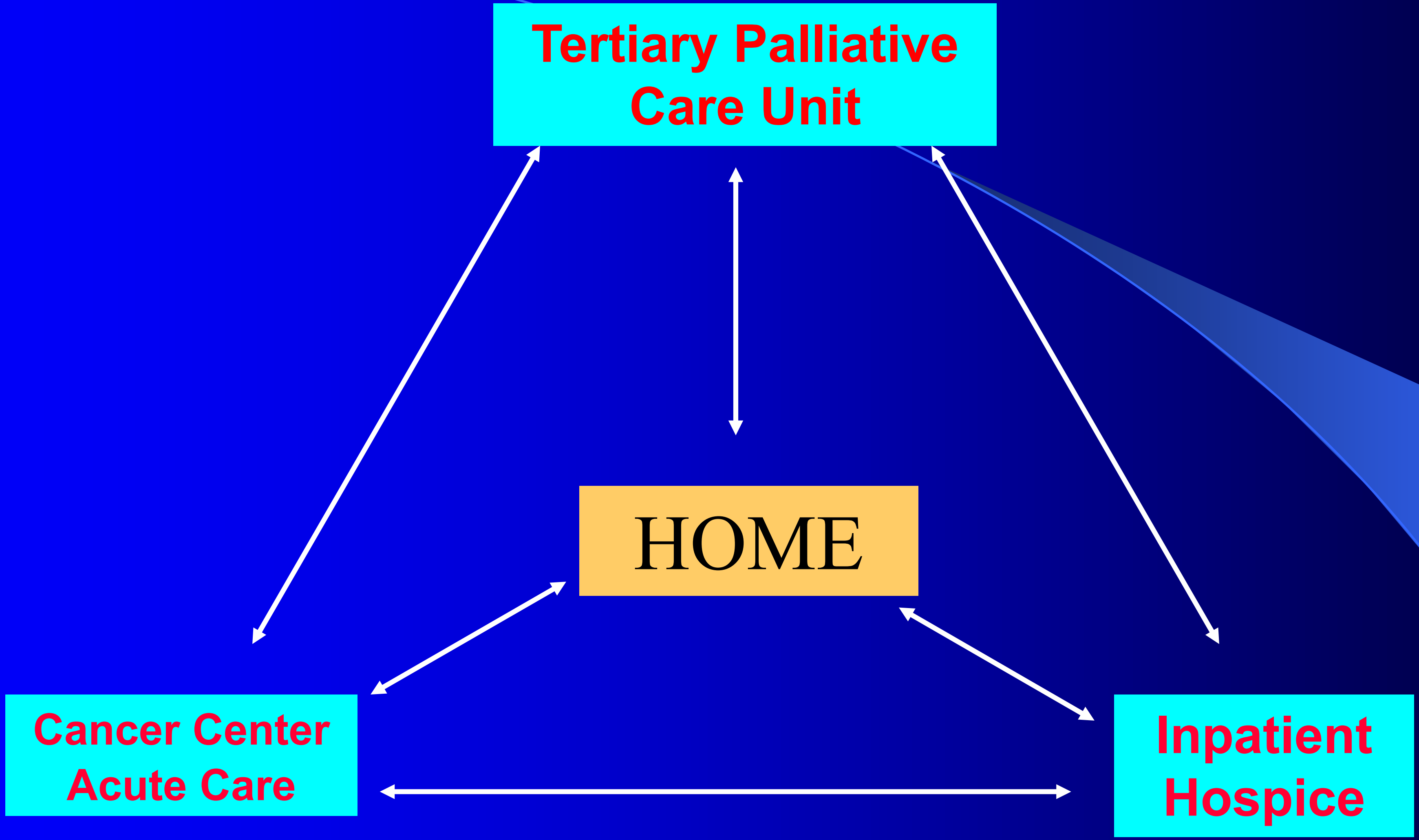
Table 2 Frequency of "Very Important" wishes and correlation between the first and second test

Item		Test 1 $N = 100$ n^a	Test 2 $N = 100$ n^a	Correlation[b]	
				r	p
1	To be at peace with God	74	71	0.73	<0.0001
2	To pray	62	61	0.57	<0.0001
3	To have my family with me	57	61	0.23	0.0280
4	To be free from pain	54	60	0.31	0.0019
5	Not being a burden to my family	48	49	0.23	0.0241
6	To trust my doctor	44	45	0.49	<0.0001
7	To keep my sense of humor	41	45	0.53	<0.0001
8	To say goodbye to important people in my life	41	37	0.46	<0.0001
9	To have my family prepared for my death	40	49	0.48	<0.0001
10	To be able to help others	36	31	0.52	<0.0001
11	To have my financial affairs in order	36	27	0.40	<0.0001
12	To maintain my dignity	33	34	0.40	0.0001
13	Not being short of breath	32	31	0.73	<0.0001
14	Not dying alone	29	31	0.52	<0.0001
15	Not being connected to machines	28	29	0.56	<0.0001
16	To prevent arguments by making sure my family knows what I want	28	22	0.55	<0.0001
17	To be kept clean	27	31	0.44	<0.0001
18	To be mentally aware	25	24	0.37	0.0003
19	To have a doctor who knows me as a whole person	25	21	0.57	<0.0001
20	To feel that my life is complete	24	26	0.32	0.0033
21	To be free from anxiety	23	24	0.50	<0.0001
22	To have my funeral arrangements made	22	23	0.63	<0.0001
23	To be treated the way I want	22	17	0.38	0.0004
24	To have someone who will listen to me	20	16	0.26	0.0167
25	To have close friends near	19	19	0.49	<0.0001
26	To take care of unfinished business with family and friends	17	15	0.45	<0.0001
27	To have human touch	14	14	0.50	<0.0001
28	To die at home	13	16	0.67	<0.0001
29	To have a nurse I feel comfortable with	13	10	0.40	0.0001
30	To be able to talk about what death means	11	9	0.24	0.0297
31	To be able to talk about what scares me	11	9	0.29	0.0060
32	To meet with clergy or chaplain	10	16	0.55	<0.0001
33	To know how my body will change	9	5	0.35	0.0011
34	To have an advocate who knows my values and priorities	7	15	0.44	<0.0001
35	To remember personal accomplishments	4	6	0.25	0.0247

[a] Number (%) of patients who prioritized this item as "very important"

[b] Spearman correlation coefficient between test 1 and test 2, which was completed 4–24 h after test 1

ALBERGUE MANO AMIG
235



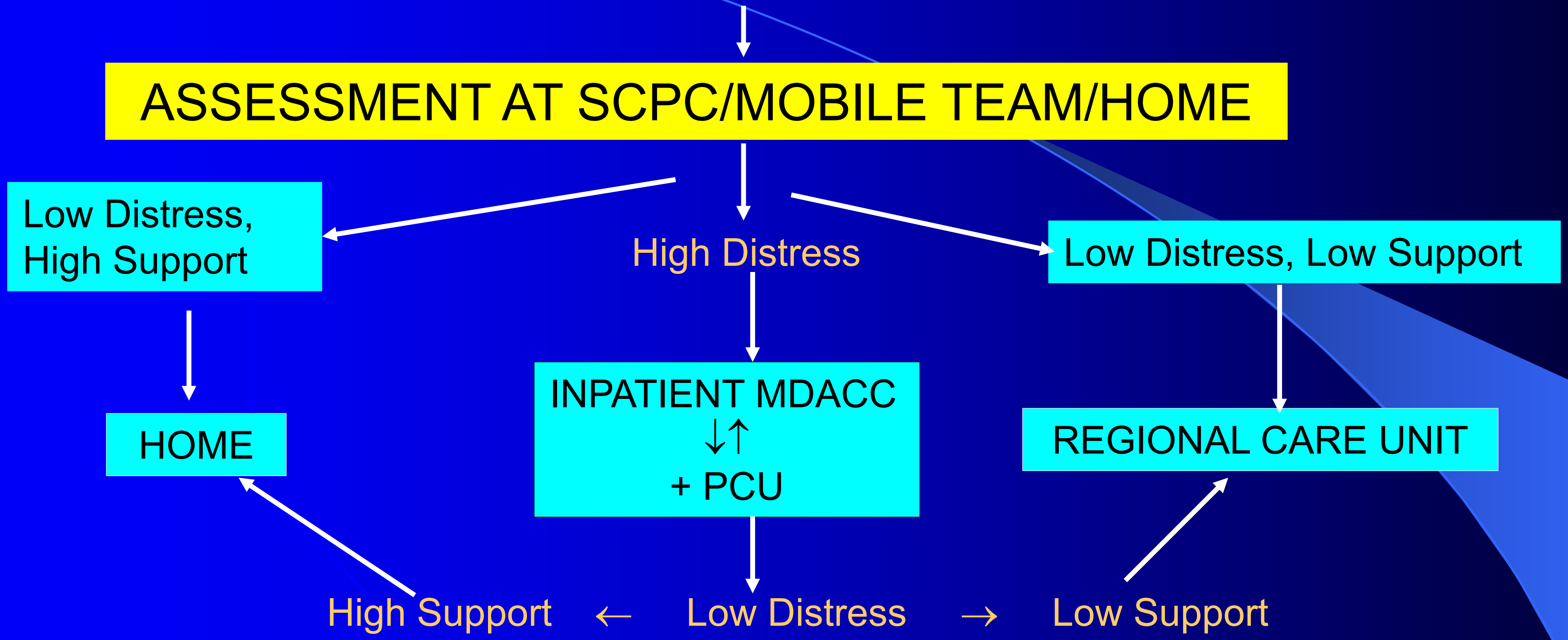
Tertiary Palliative Care Unit

HOME

Cancer Center Acute Care

Inpatient Hospice

FLUSSO DEI PAZIENTI



ASSESSMENT AT SCPC/MOBILE TEAM/HOME

Low Distress,
High Support

High Distress

Low Distress, Low Support

HOME

INPATIENT MDACC
↓↑
+ PCU

REGIONAL CARE UNIT

High Support ← Low Distress → Low Support

Principale differenza con l'Hospice: 1) Tutti i pazienti rimarranno in contatto con il loro oncologo primario e si qualificheranno per i trattamenti di fase I e di ricerca; 2) I pazienti rimarranno come pazienti UT MDACC.

L'unità di cure palliative

- Sofisticata valutazione interdisciplinare e gestione della sofferenza del paziente e della famiglia
- Gestione dei problemi più difficili
- Attenzione all’ambiente e al team
- Istruzione e ricerca

- **Mount BM.**
- Il problema della cura dei morenti in un ospedale generale; L'unità di cure palliative come possibile soluzione.
- Can Med Assoc J. 1976 Jul 17;115(2):119-21.

Affrontiamo la sofferenza

Pain &
Symptom
Control Clinic

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

Father of the Bride

Father of the Bride

Risultati?

Edmonton Limousine
ICC-MC-23715
Edmonton Limousine
LIMOUSINE
11821

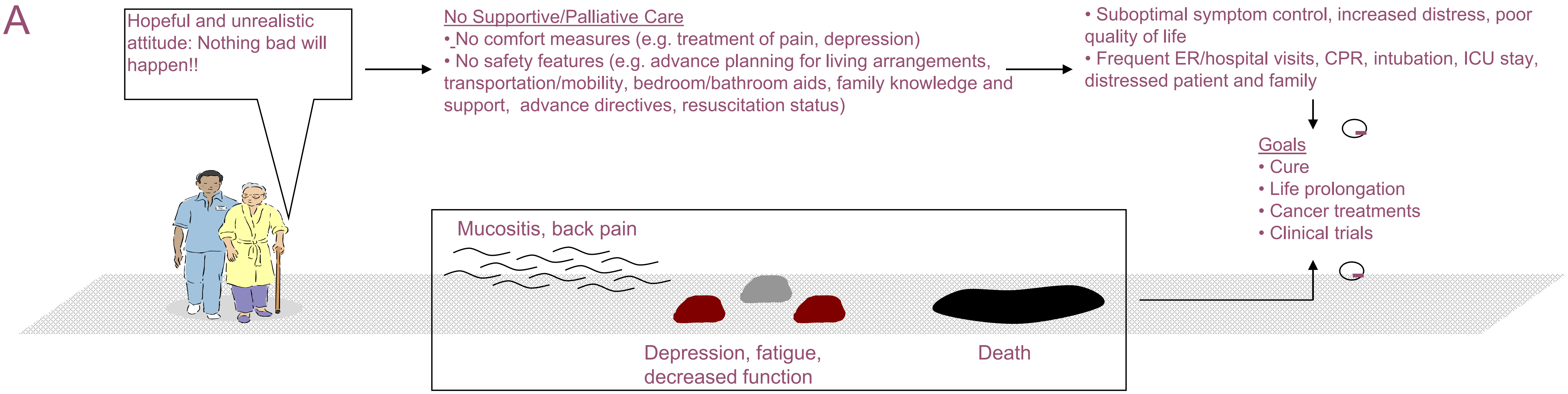
01

Come possiamo aumentare le aspettative di miglioramento?

1. Comunicare (telefonare al paziente)
2. Preparare e dare un foglio di istruzioni
3. Siediti quando visiti il paziente
4. Esaminare sempre il paziente
5. Offri la registrazione audio della visita o raccomandazioni
6. Chiedi come il paziente preferisce prendere decisioni
7. Riproduci un po' di musica
8. Nessuna sala d'attesa, impiegato sorridente, nessuna sala d'esame, luce rosa, segno sul soffitto, benvenuti animali domestici e matrimoni

Come possiamo aumentare le aspettative di miglioramento?

1. Comunicare (telefonare al paziente) - Prospettiva aperta
2. Preparare e dare un prompt-sheet - RCT
3. Siediti quando visiti il paziente - RCT
4. Esaminare sempre il paziente - Prospettiva aperta
5. Offri la registrazione audio della visita o delle raccomandazioni - RCT
6. Chiedi come il paziente preferisce prendere decisioni – Prospettiva aperta
7. Riproduci un po' di musica - Prospettiva aperta
8. Nessuna sala d'attesa, nessun uso del computer EPIC, illuminazione rosa, cartelli sul soffitto, introduzione di consulente, oppioidi e costipazione: ricerca attuale



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

↓ ⊖

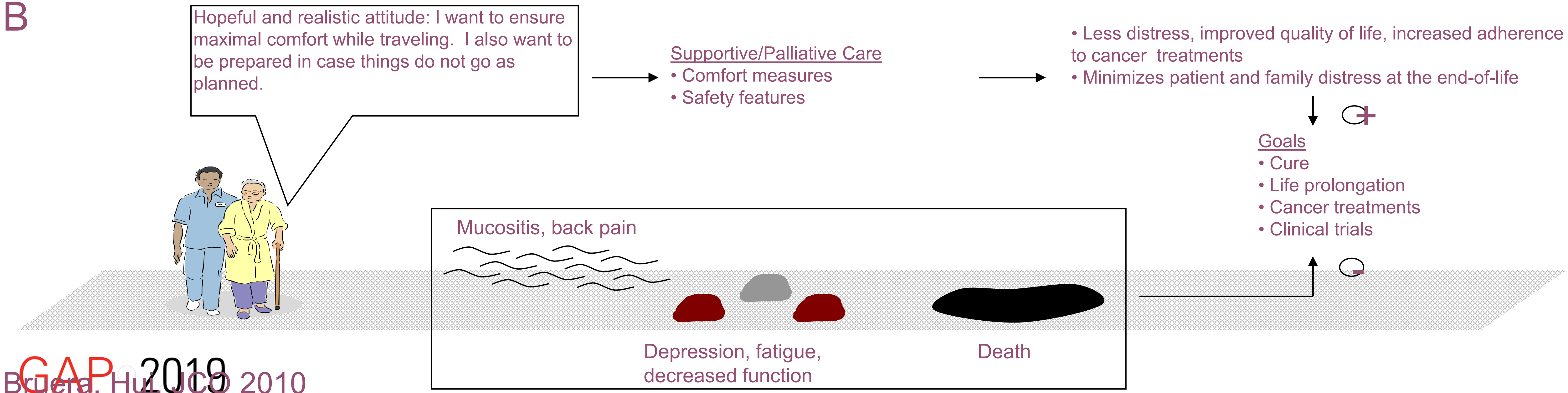
Goals
- Cure
- Life prolongation
- Cancer treatments
- Clinical trials

↑ ⊖

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

Bruera, Hui, JCO 2010

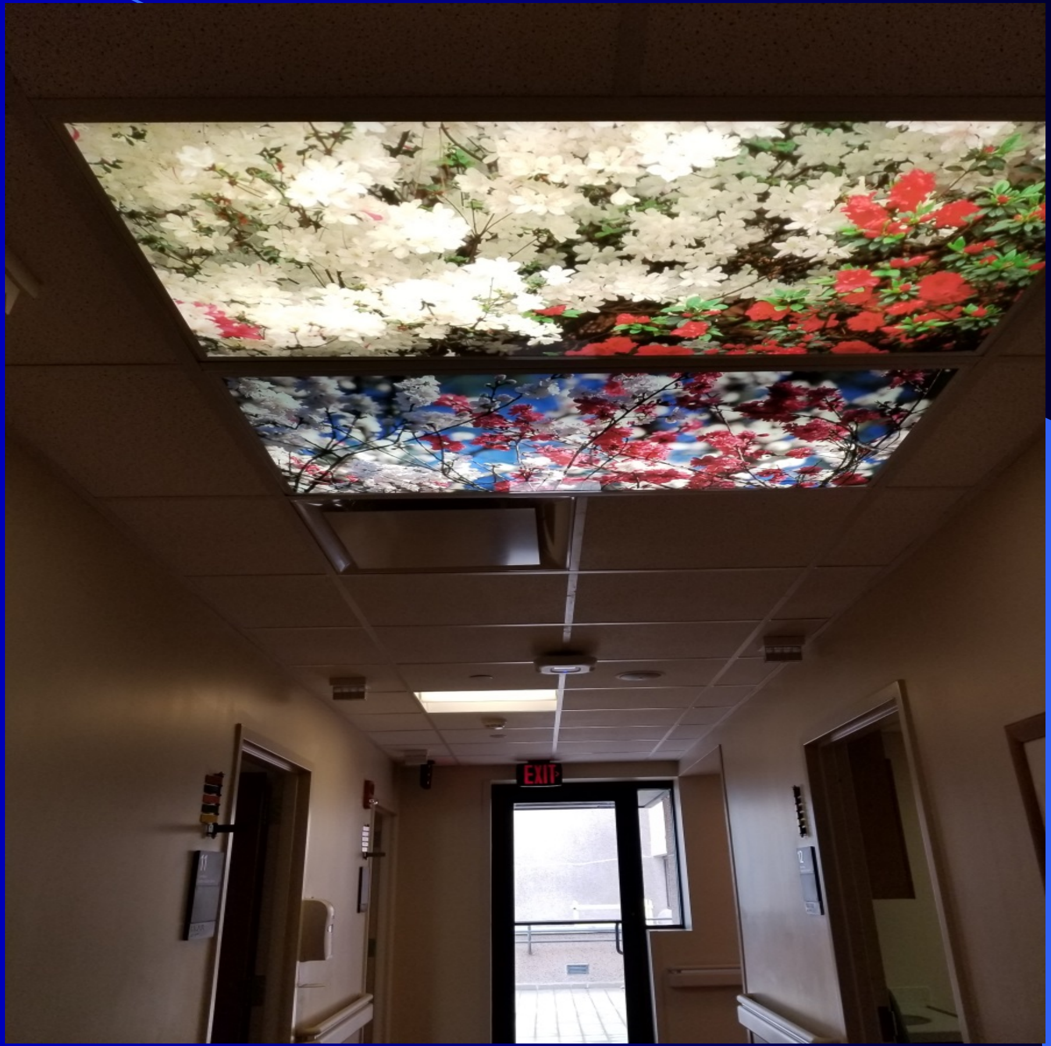
Supportive Care Center
me to
enter

Messenger
REAL SIMPLE

Esperienza di assistenza di supporto

Thank you for visiting our Center

Esperienza di assistenza di supporto



quiet/shhh
EXIT
MD Anderson Cancer Center
WATCH

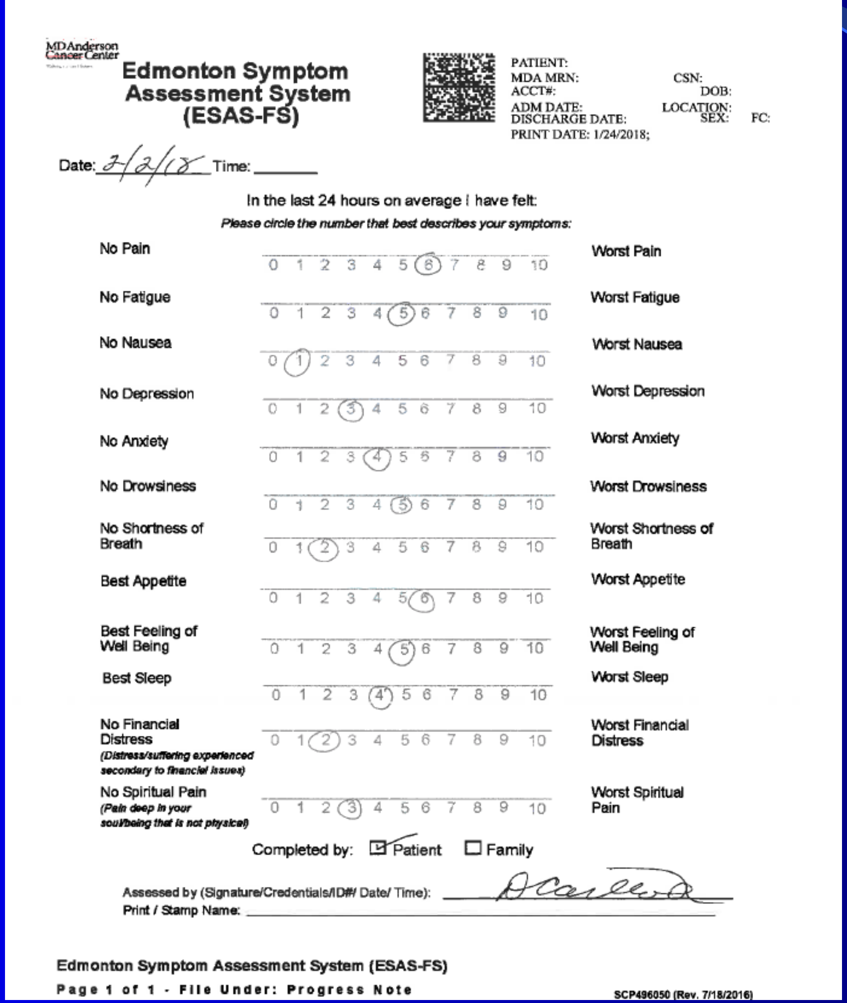
ATTENTION
Cover Your Cough
PALLIATIVE CARE & REHABILITATION MEDICINE CENTER
REGISTRATION
4
RS.2161

Pain &
Symptom
Control Clinic

Valutazioni infermieristiche - Team dedicato!

- Storia completa
- ESAS
- MDAS
- CAGE-AID
- SOAPP

Sistema di valutazione dei sintomi di Edmonton (ESAS)



MDAnderson Cancer Center

Edmonton Symptom Assessment System (ESAS-FS)

PATIENT:
MDA MRN: CSN:
ACCT#: DOB:
ADM DATE: LOCATION:
DISCHARGE DATE: SEX: FC:
PRINT DATE: 1/24/2018;

Date: 2/2/18 Time: ______

In the last 24 hours on average I have felt:

Please circle the number that best describes your symptoms:

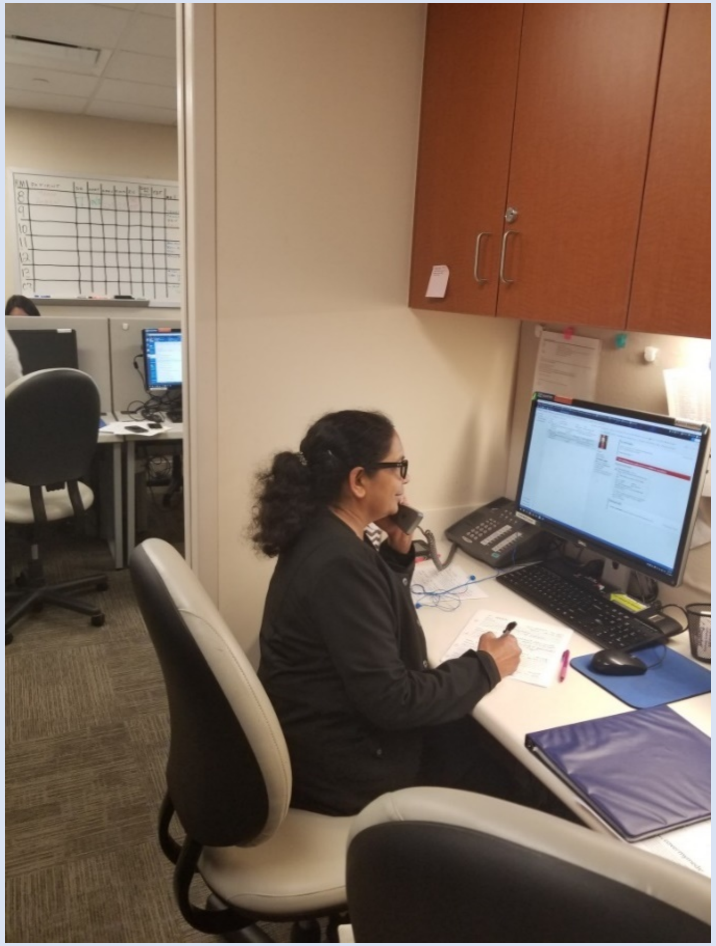
No Pain	0 1 2 3 4 5 [✓ 6] 7 8 9 10	Worst Pain
No Fatigue	0 1 2 3 4 [✓ 5] 6 7 8 9 10	Worst Fatigue
No Nausea	0 [✓ 1] 2 3 4 5 6 7 8 9 10	Worst Nausea
No Depression	0 1 2 [✓ 3] 4 5 6 7 8 9 10	Worst Depression
No Anxiety	0 1 2 3 [✓ 4] 5 6 7 8 9 10	Worst Anxiety
No Drowsiness	0 1 2 3 4 [✓ 5] 6 7 8 9 10	Worst Drowsiness
No Shortness of Breath	0 1 [✓ 2] 3 4 5 6 7 8 9 10	Worst Shortness of Breath
Best Appetite	0 1 2 3 4 5 [✓ 6] 7 8 9 10	Worst Appetite
Best Feeling of Well Being	0 1 2 3 4 [✓ 5] 6 7 8 9 10	Worst Feeling of Well Being
Best Sleep	0 1 2 3 [✓ 4] 5 6 7 8 9 10	Worst Sleep
No Financial Distress *(Distress/suffering experienced secondary to financial issues)*	0 1 [✓ 2] 3 4 5 6 7 8 9 10	Worst Financial Distress
No Spiritual Pain *(Pain deep in your soul/being that is not physical)*	0 1 2 [✓ 3] 4 5 6 7 8 9 10	Worst Spiritual Pain

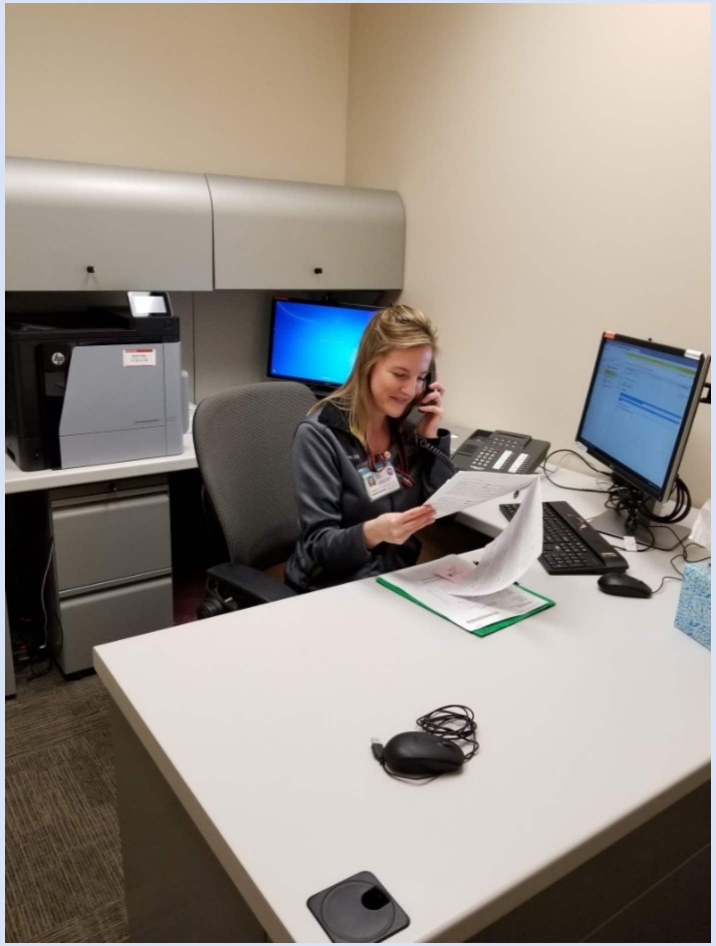
Completed by: ☑ Patient ☐ Family

Assessed by (Signature/Credentials/ID#/ Date/ Time): ______
Print / Stamp Name: ______

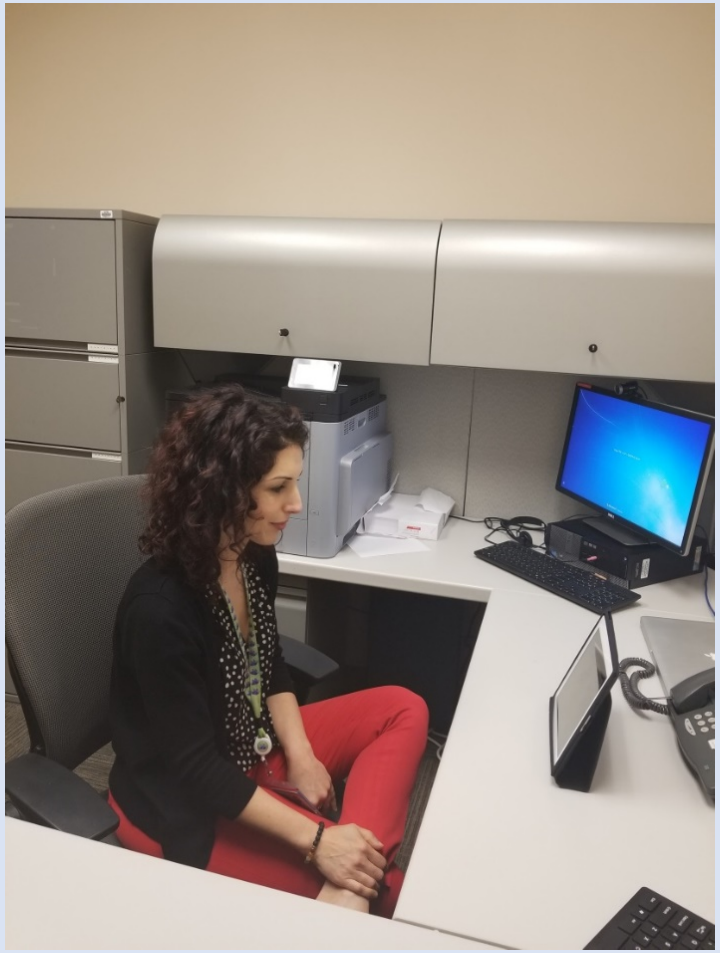
Edmonton Symptom Assessment System (ESAS-FS)
Page 1 of 1 - File Under: Progress Note
SCP496050 (Rev. 7/18/2016)

Infermieri Telefonici Dedicati





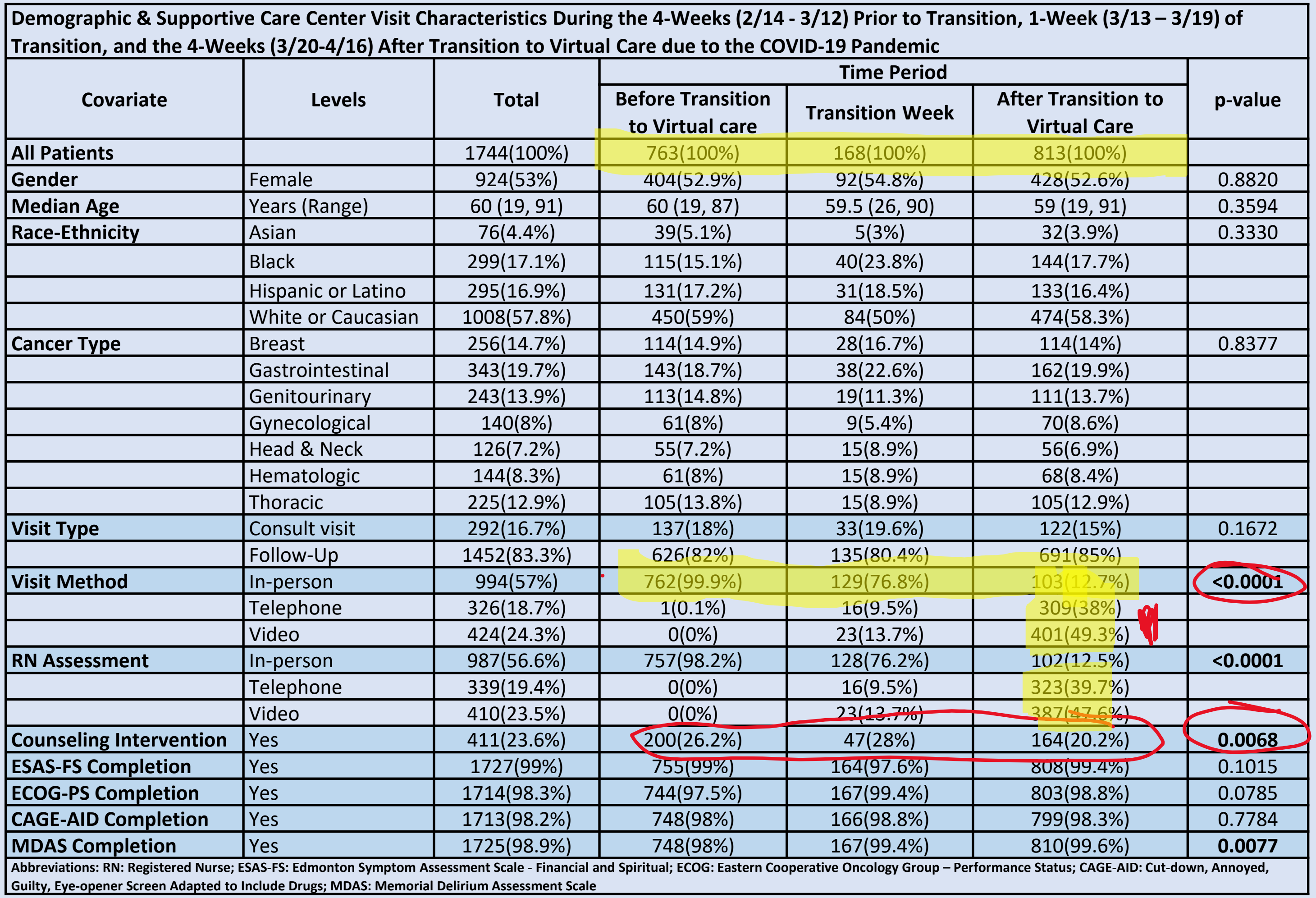
I nostri couselors



Il Covid è iniziato improvvisamente ad Anderson

- Chiusura di tutti gli interventi chirurgici non urgenti, RT e della maggior parte dei nuovi pazienti.
- Dimissione dei pazienti ricoverati, in particolare in terapia intensiva
- Chiusura della maggior parte dei servizi ambulatoriali
- NESSUN accesso a parenti/visitatori
- Riallocazione degli spazi per creare il "fossato"

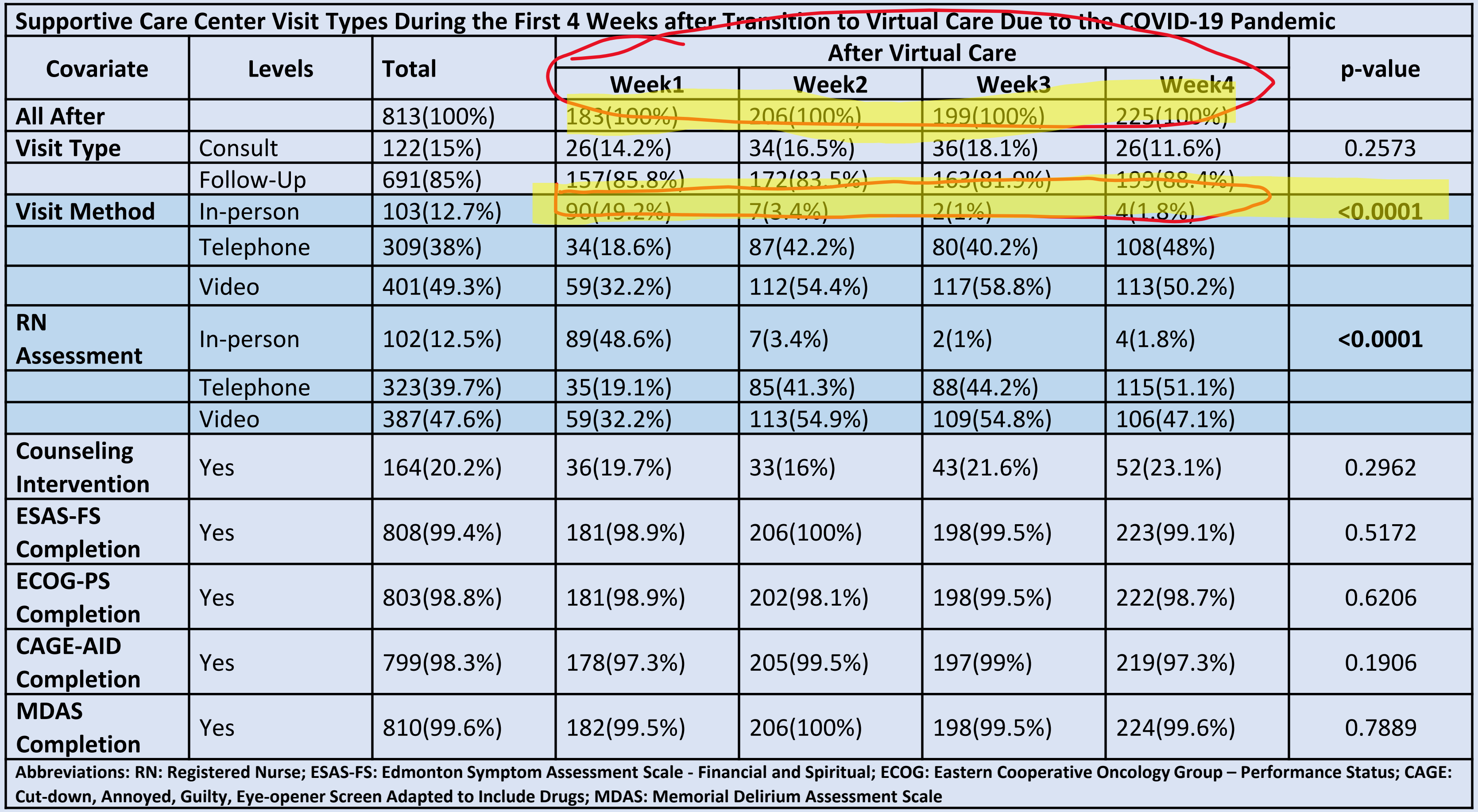
I vantaggi degli uragani



Demographic & Supportive Care Center Visit Characteristics During the 4-Weeks (2/14 - 3/12) Prior to Transition, 1-Week (3/13 – 3/19) of Transition, and the 4-Weeks (3/20-4/16) After Transition to Virtual Care due to the COVID-19 Pandemic

Covariate	Levels	Total	Time Period			p-value
			Before Transition to Virtual care	Transition Week	After Transition to Virtual Care	
All Patients		1744(100%)	763(100%)	168(100%)	813(100%)	
Gender	Female	924(53%)	404(52.9%)	92(54.8%)	428(52.6%)	0.8820
Median Age	Years (Range)	60 (19, 91)	60 (19, 87)	59.5 (26, 90)	59 (19, 91)	0.3594
Race-Ethnicity	Asian	76(4.4%)	39(5.1%)	5(3%)	32(3.9%)	0.3330
	Black	299(17.1%)	115(15.1%)	40(23.8%)	144(17.7%)	
	Hispanic or Latino	295(16.9%)	131(17.2%)	31(18.5%)	133(16.4%)	
	White or Caucasian	1008(57.8%)	450(59%)	84(50%)	474(58.3%)	
Cancer Type	Breast	256(14.7%)	114(14.9%)	28(16.7%)	114(14%)	0.8377
	Gastrointestinal	343(19.7%)	143(18.7%)	38(22.6%)	162(19.9%)	
	Genitourinary	243(13.9%)	113(14.8%)	19(11.3%)	111(13.7%)	
	Gynecological	140(8%)	61(8%)	9(5.4%)	70(8.6%)	
	Head & Neck	126(7.2%)	55(7.2%)	15(8.9%)	56(6.9%)	
	Hematologic	144(8.3%)	61(8%)	15(8.9%)	68(8.4%)	
	Thoracic	225(12.9%)	105(13.8%)	15(8.9%)	105(12.9%)	
Visit Type	Consult visit	292(16.7%)	137(18%)	33(19.6%)	122(15%)	0.1672
	Follow-Up	1452(83.3%)	626(82%)	135(80.4%)	691(85%)	
Visit Method	In-person	994(57%)	762(99.9%)	129(76.8%)	103(12.7%)	**<0.0001**
	Telephone	326(18.7%)	1(0.1%)	16(9.5%)	309(38%)	
	Video	424(24.3%)	0(0%)	23(13.7%)	401(49.3%)	
RN Assessment	In-person	987(56.6%)	757(98.2%)	128(76.2%)	102(12.5%)	**<0.0001**
	Telephone	339(19.4%)	0(0%)	16(9.5%)	323(39.7%)	
	Video	410(23.5%)	0(0%)	23(13.7%)	387(47.6%)	
Counseling Intervention	Yes	411(23.6%)	200(26.2%)	47(28%)	164(20.2%)	**0.0068**
ESAS-FS Completion	Yes	1727(99%)	755(99%)	164(97.6%)	808(99.4%)	0.1015
ECOG-PS Completion	Yes	1714(98.3%)	744(97.5%)	167(99.4%)	803(98.8%)	0.0785
CAGE-AID Completion	Yes	1713(98.2%)	748(98%)	166(98.8%)	799(98.3%)	0.7784
MDAS Completion	Yes	1725(98.9%)	748(98%)	167(99.4%)	810(99.6%)	**0.0077**

Abbreviations: RN: Registered Nurse; ESAS-FS: Edmonton Symptom Assessment Scale - Financial and Spiritual; ECOG: Eastern Cooperative Oncology Group – Performance Status; CAGE-AID: Cut-down, Annoyed, Guilty, Eye-opener Screen Adapted to Include Drugs; MDAS: Memorial Delirium Assessment Scale



Supportive Care Center Visit Types During the First 4 Weeks after Transition to Virtual Care Due to the COVID-19 Pandemic

Covariate	Levels	Total	After Virtual Care				p-value
			Week1	Week2	Week3	Week4	
All After		813(100%)	183(100%)	206(100%)	199(100%)	225(100%)	
Visit Type	Consult	122(15%)	26(14.2%)	34(16.5%)	36(18.1%)	26(11.6%)	0.2573
	Follow-Up	691(85%)	157(85.8%)	172(83.5%)	163(81.9%)	199(88.4%)	
Visit Method	In-person	103(12.7%)	90(49.2%)	7(3.4%)	2(1%)	4(1.8%)	**<0.0001**
	Telephone	309(38%)	34(18.6%)	87(42.2%)	80(40.2%)	108(48%)	
	Video	401(49.3%)	59(32.2%)	112(54.4%)	117(58.8%)	113(50.2%)	
RN Assessment	In-person	102(12.5%)	89(48.6%)	7(3.4%)	2(1%)	4(1.8%)	**<0.0001**
	Telephone	323(39.7%)	35(19.1%)	85(41.3%)	88(44.2%)	115(51.1%)	
	Video	387(47.6%)	59(32.2%)	113(54.9%)	109(54.8%)	106(47.1%)	
Counseling Intervention	Yes	164(20.2%)	36(19.7%)	33(16%)	43(21.6%)	52(23.1%)	0.2962
ESAS-FS Completion	Yes	808(99.4%)	181(98.9%)	206(100%)	198(99.5%)	223(99.1%)	0.5172
ECOG-PS Completion	Yes	803(98.8%)	181(98.9%)	202(98.1%)	198(99.5%)	222(98.7%)	0.6206
CAGE-AID Completion	Yes	799(98.3%)	178(97.3%)	205(99.5%)	197(99%)	219(97.3%)	0.1906
MDAS Completion	Yes	810(99.6%)	182(99.5%)	206(100%)	198(99.5%)	224(99.6%)	0.7889

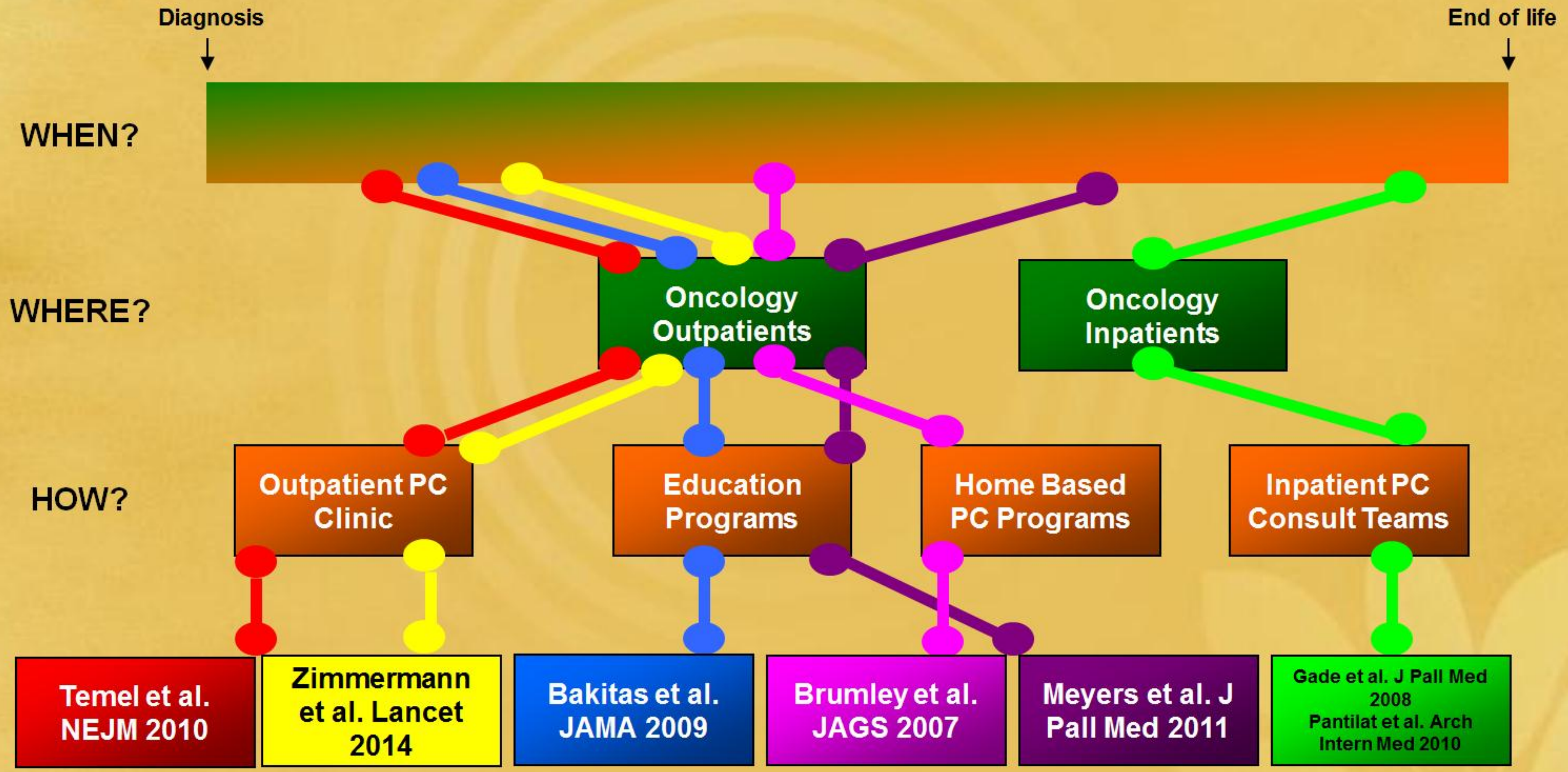
Abbreviations: RN: Registered Nurse; ESAS-FS: Edmonton Symptom Assessment Scale - Financial and Spiritual; ECOG: Eastern Cooperative Oncology Group – Performance Status; CAGE: Cut-down, Annoyed, Guilty, Eye-opener Screen Adapted to Include Drugs; MDAS: Memorial Delirium Assessment Scale

La telemedicina deve rimanere

- È tempo **che tutte le parti interessate collaborino** per rendere la telemedicina disponibile per i pazienti anche dopo la pandemia (conformità, convenienza, migliore accesso alle cure, prevenzione, QOL, coinvolgimento del caregiver, ecc.)
- È tempo di sostenere una **licenza nazionale** per praticare attraverso i confini statali?
- Telemedicina per **tirocinanti**
- **Regolamenti** – oppioidi, consultazioni, linee statali, ecc.
- **Tecnologia** - Come possiamo renderlo più facile?
- **Rimborso**

Comprehensive Cancer Care

Randomized Controlled Trials



Diagnosis

End of life

WHEN?

WHERE?

Oncology Outpatients

Oncology Inpatients

HOW?

Outpatient PC Clinic

Education Programs

Home Based PC Programs

Inpatient PC Consult Teams

Temel et al. NEJM 2010	Zimmermann et al. Lancet 2014	Bakitas et al. JAMA 2009	Brumley et al. JAGS 2007	Meyers et al. J Pall Med 2011	Gade et al. J Pall Med 2008 Pantilat et al. Arch Intern Med 2010
Symptoms ($P=0.04$) Mood ($P=0.01$) Quality of life ($P=0.03$) Quality of care ($P=0.05$) Advance care ($P=0.05$) Survival ($P=0.02$)	Quality of life ($P=0.008$) Symptoms ($P=0.05$) Satisfaction ($P=0.001$)	Symptoms ($P=0.06$) Mood ($P=0.02$) Quality of life ($P=0.02$)	Satisfaction ($P<0.05$) Cost ($P=0.03$) Quality of care ($P=0.02$)	Caregiver decline ($P=0.02$)	Satisfaction ($P=0.02$) Cost ($P=0.03$) Advance care planning ($P<0.001$)

RCTs since 2009

- Bakitas et al. *JAMA* 2009
- Temel et al. *NEJM* 2010
- Zimmermann et al. *Lancet* 2014
- Tattersall et al. *Palliat Care Med* 2014
- Bakitas et al. *J Clin Oncol* 2015
- Grudzen et al. *JAMA Oncol* 2016
- Maltoni et al. *Eur J Cancer* 2016
- Temel et al. *J Clin Oncol* 2016
- El-Jawahri et al. *JAMA* 2016
- Groenvold et al. *Palliat Med* 2017
- Monteiro do Carmo et al. *BMC Cancer* 2017
- Vanbutsele et al. *Lancet Oncol* 2018
- Scarpi et al. *Supp Care Cancer* 2018
- Franciosi et al. *Ann Palliat Care* 2019
- Temel et al. *J Palliat Med* 2020
- El-Jawahri et al. *JAMA Oncol* 2020

Outpatient Models

What Does the Literature Say?

	Interdisciplinary					MD only		APN-led		RN-led		Primary PC: APN-led	
	Temel 2010	Zimmermann 2015	Temel 2016	Groenvold 2017	Monteiro do Carmo 2018	Maltoni 2016	Scarpi 2018	Bakitas 2009	Bakitas 2015	Tattersall 2014	Vanbutsele 2018	Dyar 2012	McCorkle 2015
Quality of life	PC > UC	PC > UC for some	PC > UC for some	No difference	No difference	PC > UC	No difference	PC > UC	No difference	No difference	PC > UC	No difference	No difference
Symptom	-	PC > UC for some	-	No difference	No difference	-	-	No difference	No difference	UC > PC for some	No difference	-	No difference
Depression	PC > UC	-	PC > UC for some	-	No difference	No difference	No difference	PC> UC	No difference	No difference	No difference	PC > UC for some	No difference
Patient satisfaction	-	PC > UC	-	-	-	-	-	-	-	-	-	-	-
Communication	PC > UC	No difference	PC > UC for some	-	-	-	-	-	-	-	No difference	-	UC > PC
End-of-life care	PC > UC for some	-	-	-	-	PC > UC for some	No difference	No difference	No difference	No difference	-	No difference	-
Survival	PC > UC	-	-	No difference	-	No difference	No difference	No difference	PC > UC at 1 yr	UC > PC	No difference	-	-
Caregiver outcomes	-	-	-	-	-	No difference	No difference	-	PC > UC for some	-	-	-	-

Take Home Messages: Interdisciplinary, Timely, Personalized care

Hui & Bruera *J Clin Oncol* 2020

COSA SAPPIAMO FINORA?

- Il PC precoce del team guidato da specialisti MD riduce il carico di sintomi
- Il primo PC del team guidato da specialisti MD migliora Qo L
- Early PC migliora o non riduce la sopravvivenza
- I primi PC consentono di risparmiare denaro

Perché non ci sono PCU in tutti gli ospedali?

- I pazienti muoiono e le famiglie piangono in tutti gli ospedali
- I team PC migliorano la sofferenza
- Le PCU consentirebbero una migliore assistenza e risparmierebbero denaro !!

Questioni culturali

- Identità nazionale, razza, religione, genere
- Disciplina: oncologia, dolore, terapia di supporto, hospice, infermieristica
- Ospedale/istituzione: missione- "fare la storia del cancro"; "non ci idratiamo"; "Non utilizziamo strumenti di valutazione"
- Università: guerre curricolari

Fasi di sviluppo di una cultura palliativa

- Gli individui e i gruppi (ospedali, governi e università) di solito progrediscono lentamente, ma la regressione può avvenire in qualsiasi momento.
- Frequente coesistenza di segni di stadi diversi nella stessa persona / gruppo

1. Negazione

- "Non abbiamo questi problemi qui"
- "Il nostro controllo dei sintomi è molto buono; I nostri pazienti e le nostre famiglie sono felici!!"
- "L'Hospice si prende cura di tutti i nostri problemi"
- "Ricerca su problemi che non esistono"

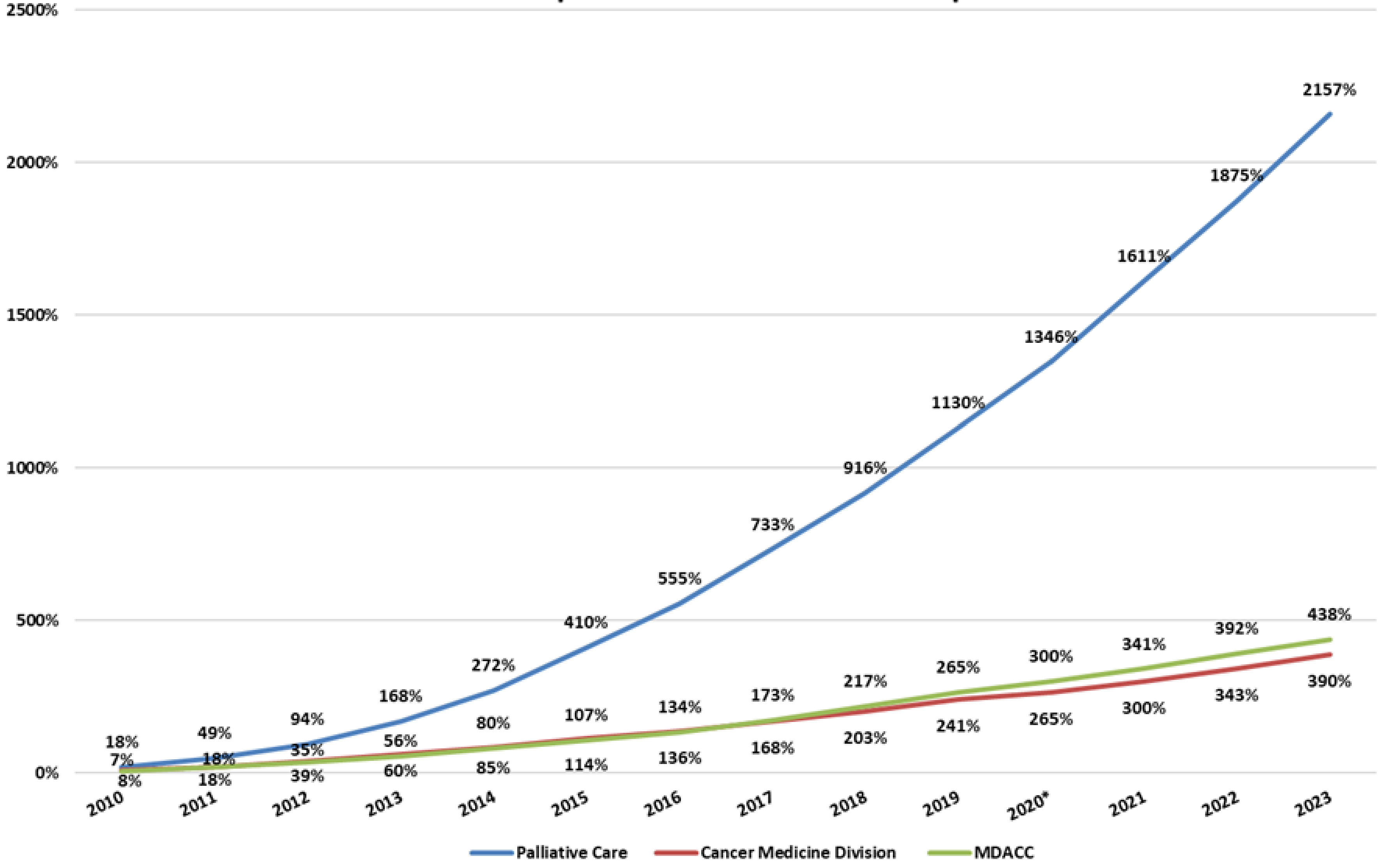
2. Pallifobia

- Episodi di panico quando viene menzionata la parola "P". Più comune tra oncologi, specialisti del dolore e presidi della scuola di medicina "perderemo pazienti"; "è eutanasia nascosta"; "non c'è scienza"; "Frode Medicare"

3. Pallilallia

- Sciocchezze ripetitive parlare di cure palliative senza alcuna azione di accompagnamento
- Palilalia collettiva: colpisce organizzazioni e governi
- "Fare uno studio per documentare/dimostrare"; "gruppo di consenso"; "questo è MOLTO importante"

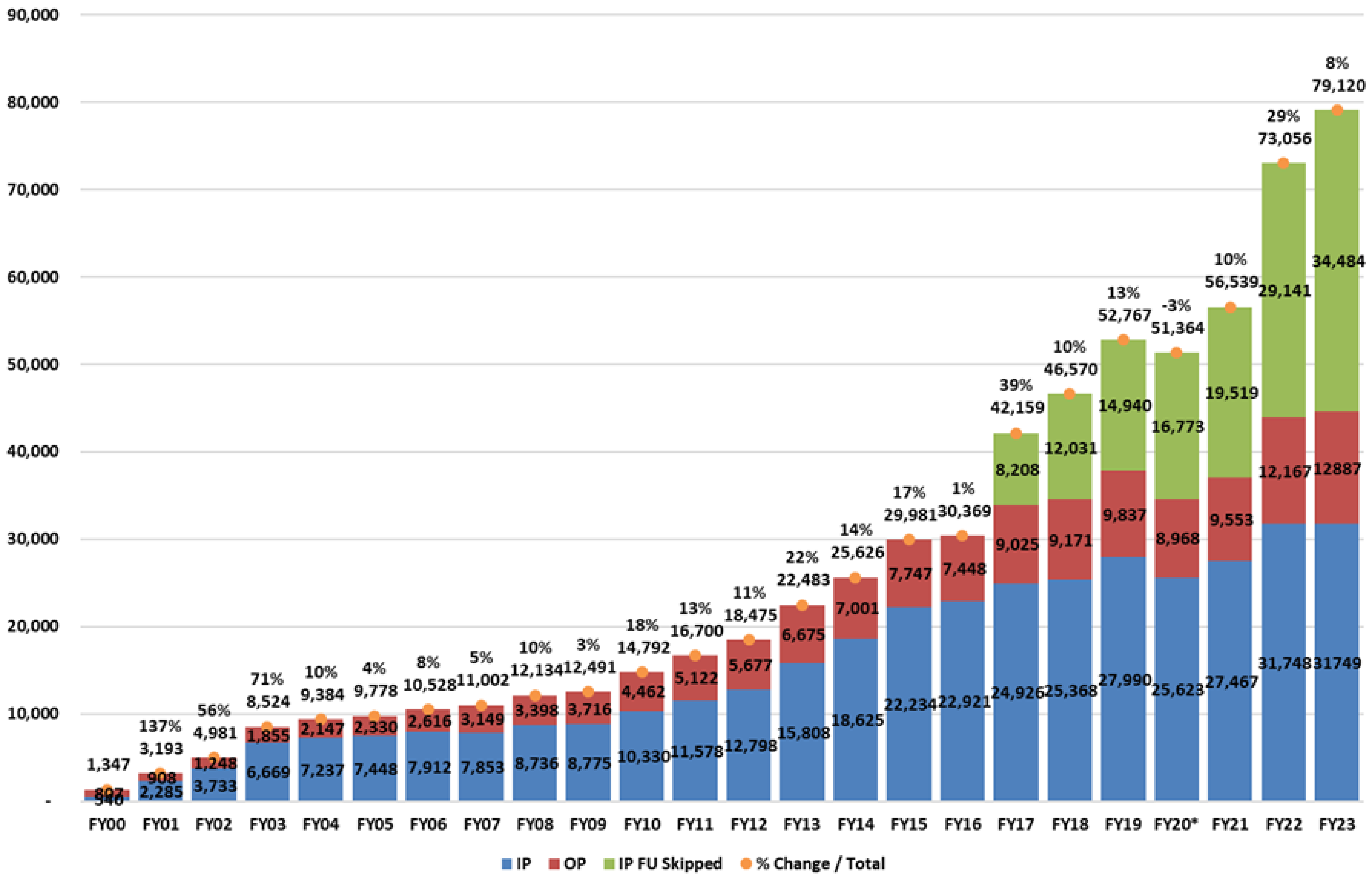
Palliative Care Total Professional Activity Growth
Current Year Compared to FY09 Baseline[1] Compounded



[1] Baseline is representative of Palliative Care's commencement with Cancer Medicine Division.

*Decrease due to the decline in number of billed encounters; however, unbilled encounters reamined steady.

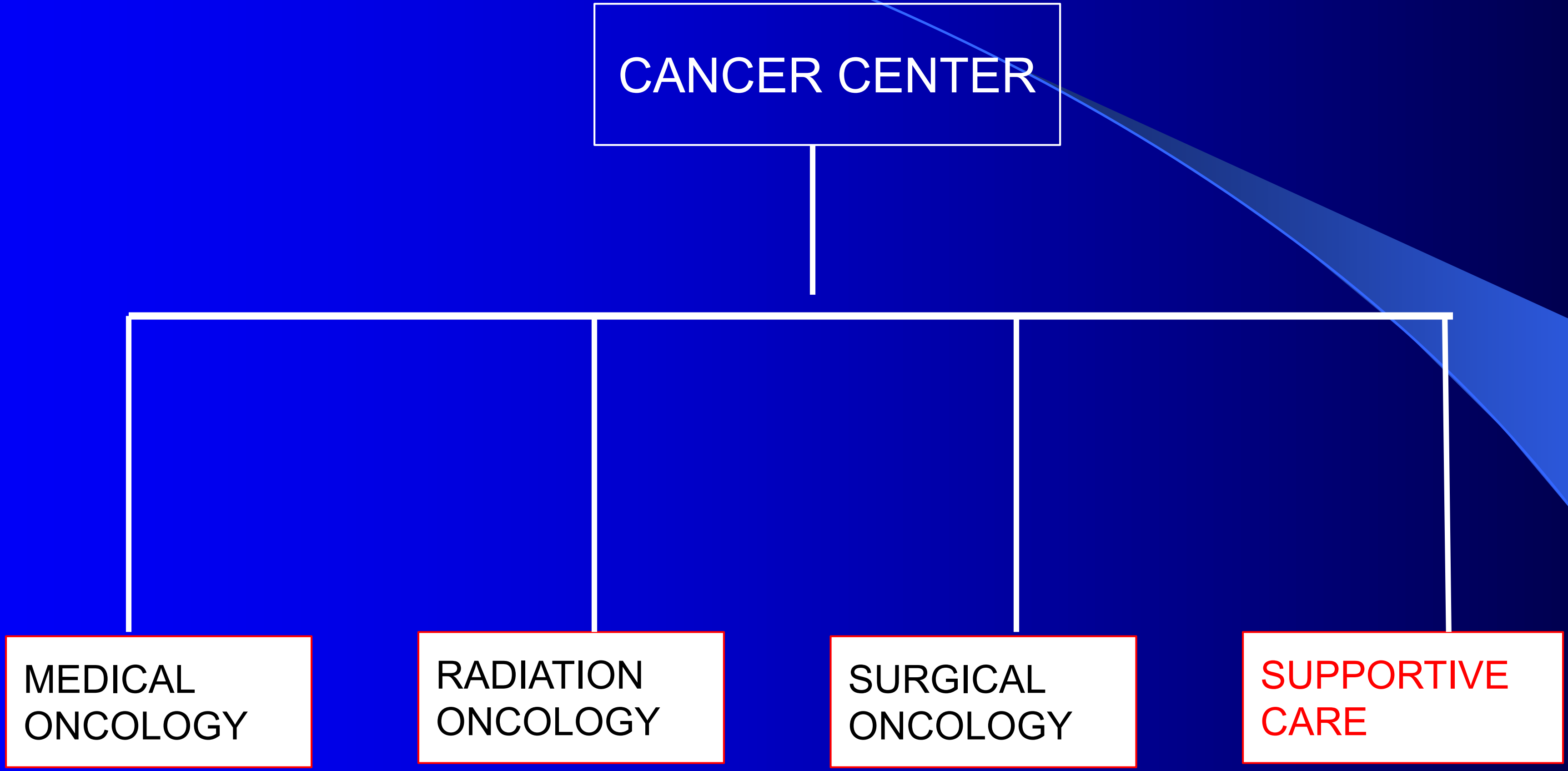
Palliative Care Professional Patient Volumes | FY00 - FY23
(All Providers Excluding Procedures & Other Categories)



*Decrease due to the decline in number of billed encounters; however, unbilled encounters reamined steady.

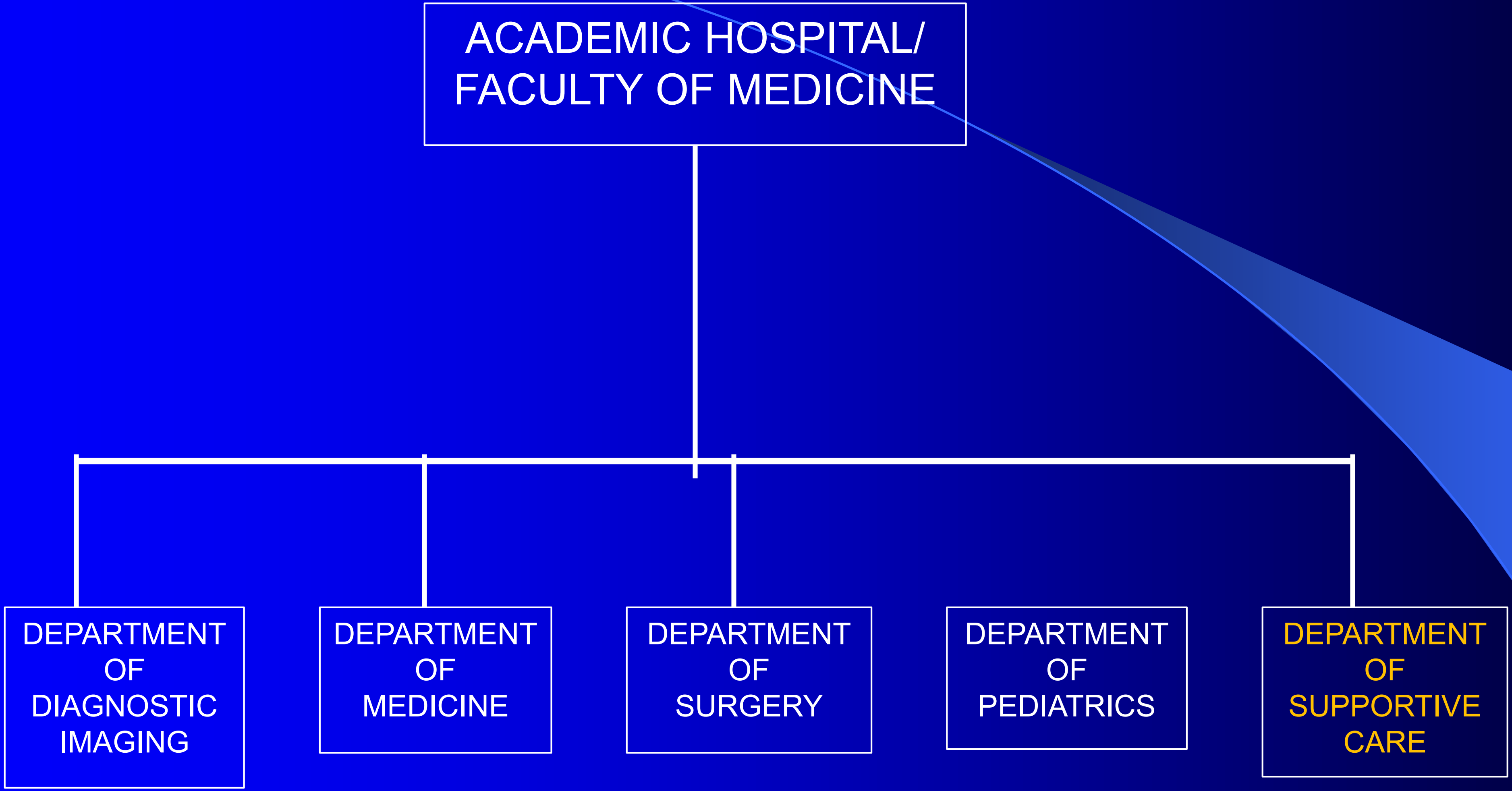
4. Palliactive

- Nominare MD / RN
- Spazio fisico: Unità/clinica
- Spazio amministrativo: Divisione – Dipartimento
- $$$$$$$$$!!!



CANCER CENTER

- MEDICAL ONCOLOGY
- RADIATION ONCOLOGY
- SURGICAL ONCOLOGY
- SUPPORTIVE CARE



ACADEMIC HOSPITAL/
FACULTY OF MEDICINE

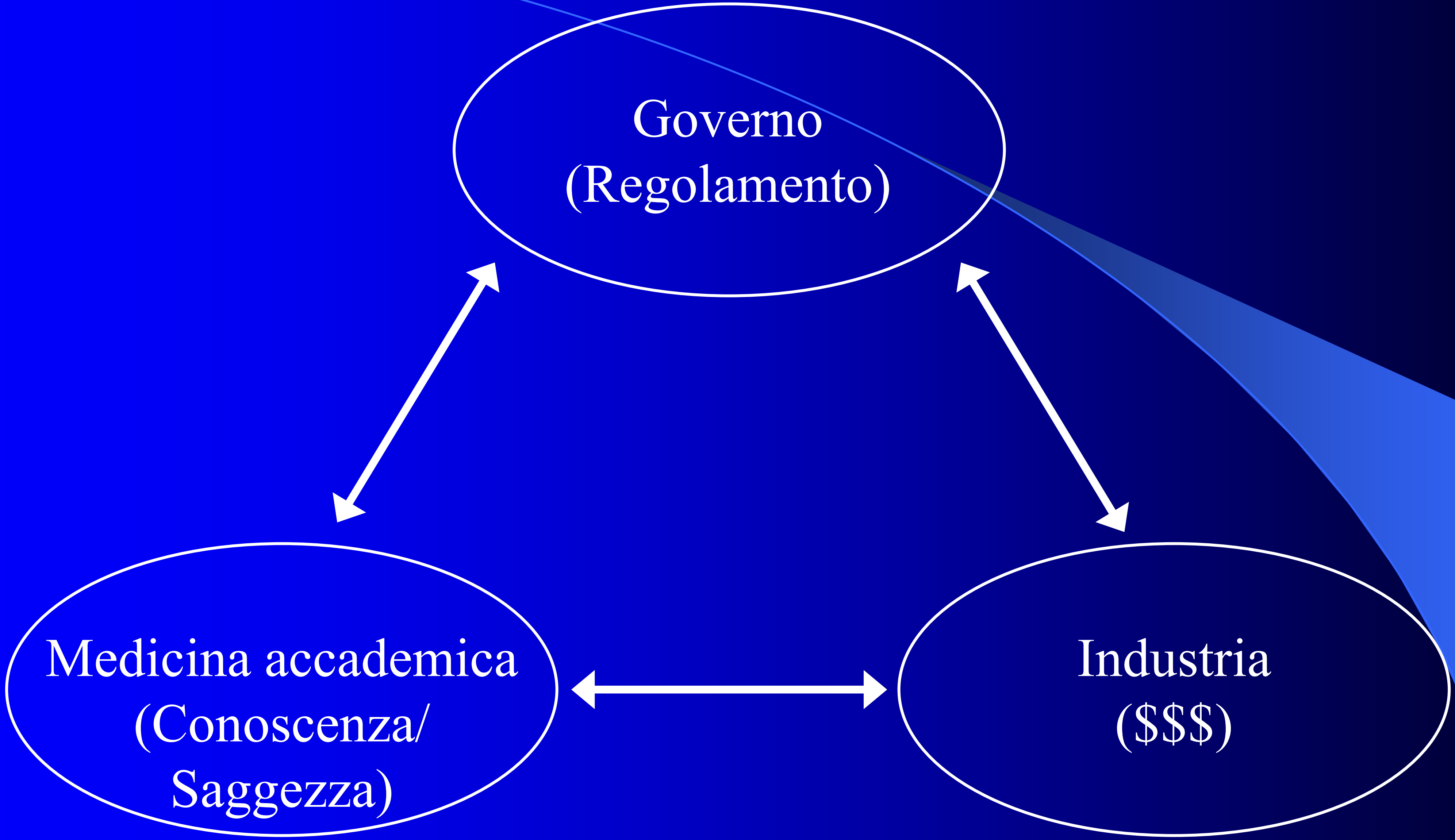
- DEPARTMENT OF DIAGNOSTIC IMAGING
- DEPARTMENT OF MEDICINE
- DEPARTMENT OF SURGERY
- DEPARTMENT OF PEDIATRICS
- DEPARTMENT OF SUPPORTIVE CARE

Chi ha bisogno di istruzione?

- Amministratore di Medicare: rompere gli interessi acuti / a lungo termine, ottenere il $$$ in movimento. Nel nostro paese (purtroppo) proprietari di assicurazioni.
- Presidi delle scuole di medicina - Importanza dell'educazione e della ricerca del PC.
- Direttori di centri oncologici - trattamento del cancro Vs trattamento del paziente ("personalizzato: realtà o scherzo?")
- Amministratori delegati degli ospedali - pazienti che muoiono in ospedale senza cure palliative

Assistenza orientata alla persona

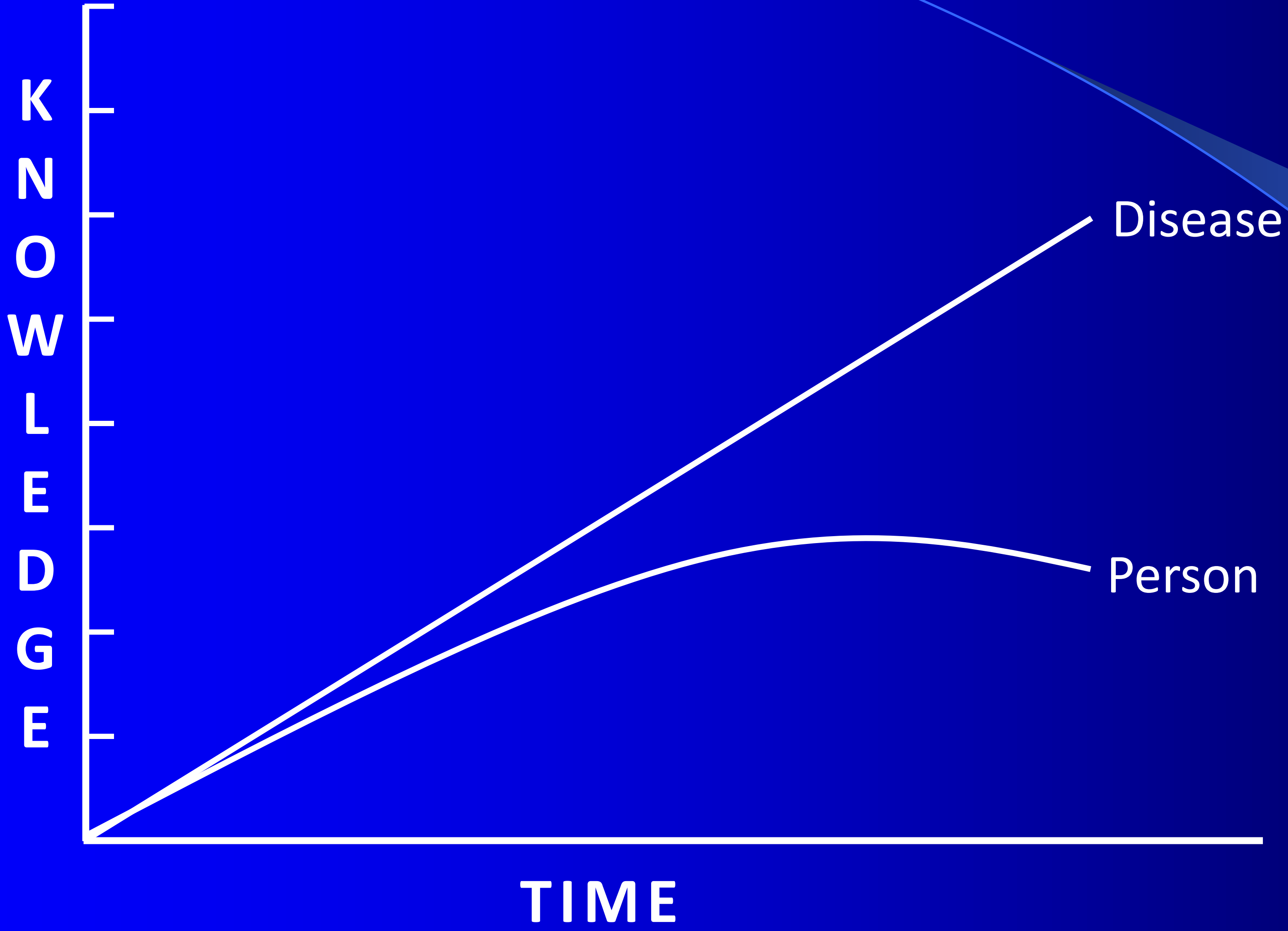
- Non interessante per i potenti in medicina: industria farmaceutica, assicurazioni, leader ospedalieri / universitari
- Ostacoli alla cura della persona: Decano della Facoltà di Medicina, Direttore dell'Ospedale, Ministro della Salute. Sono quelli che dovremmo educare

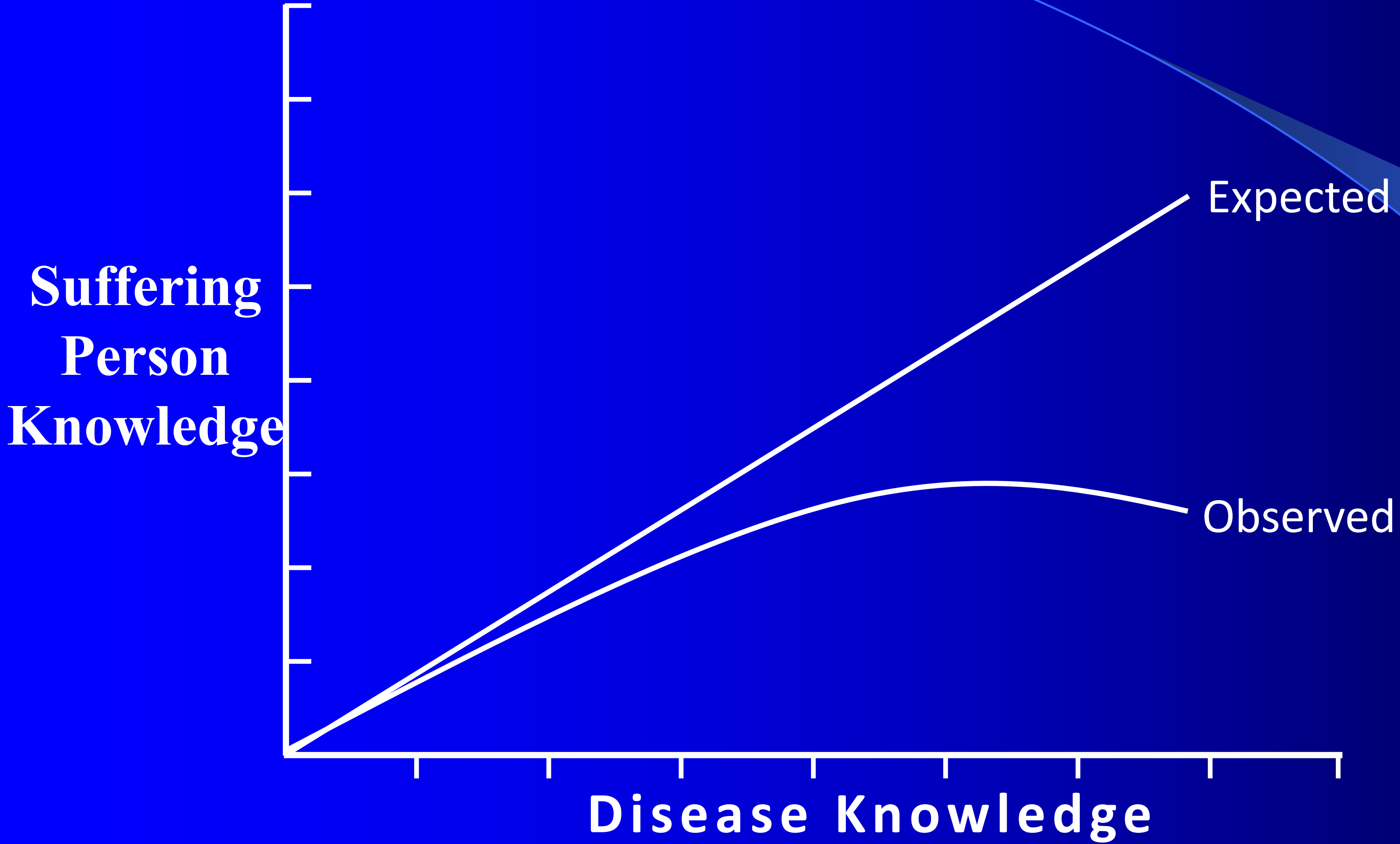


Governo
(Regolamento)

Medicina accademica
(Conoscenza/
Saggezza)

Industria
($$$)


KNOWLEDGE
Disease
Person
TIME


Suffering Person Knowledge
Expected
Observed
Disease Knowledge

Perché questo GAP? *(Donabedian)*

- Strutture (Persone + Dipartimenti)

↓

- Processi (Ricerca / Istruzione)

↓

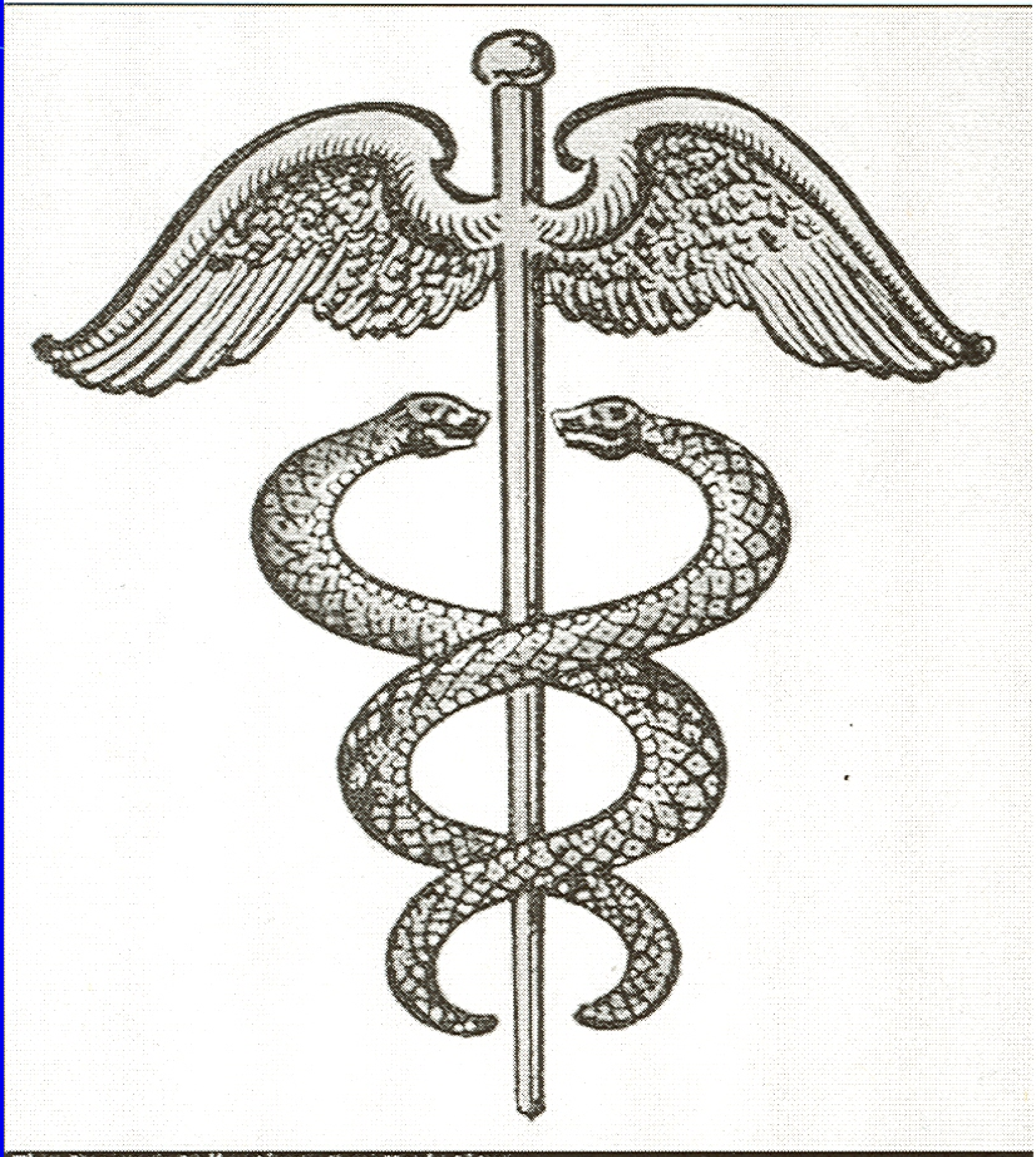
- Risultati (miglioramento delle conoscenze)

Chi sceglie cosa è "nuovo ed eccitante"?

- La leadership medica e accademica consolidata
- Quelli ai margini non sono visibili e spesso trattati con indifferenza o disprezzo

Cosa riempie il GAP nella leadership medica accademica?

- L'epidemia di oppioidi da prescrizione (dolore Vs sofferenza)
- Marihuana "medica" (eroina)
- Droghe psichedeliche
- Terapie integrative/alternative
- Assistenza "medica" nella morte (medici della morte)
- Suicidio assistito dal medico



The Granger Collection, New York City

Conoscenza Vs Saggezza

- Aumento della dose di oppioidi, sopravvissuti
- Oppioidi epidurali/intratecali
- Blocchi nervosi
- Vertebro/ cifoplastica
- Farmaci adiuvanti

Alcune letture

- Può un medico essere un umanista? Robertson Davies (The Merry Heart, Penguin, 1996)
- La ricerca di senso da parte dell'uomo (Viktor Frankl) Eric Cassell, Daniel Sulmasy

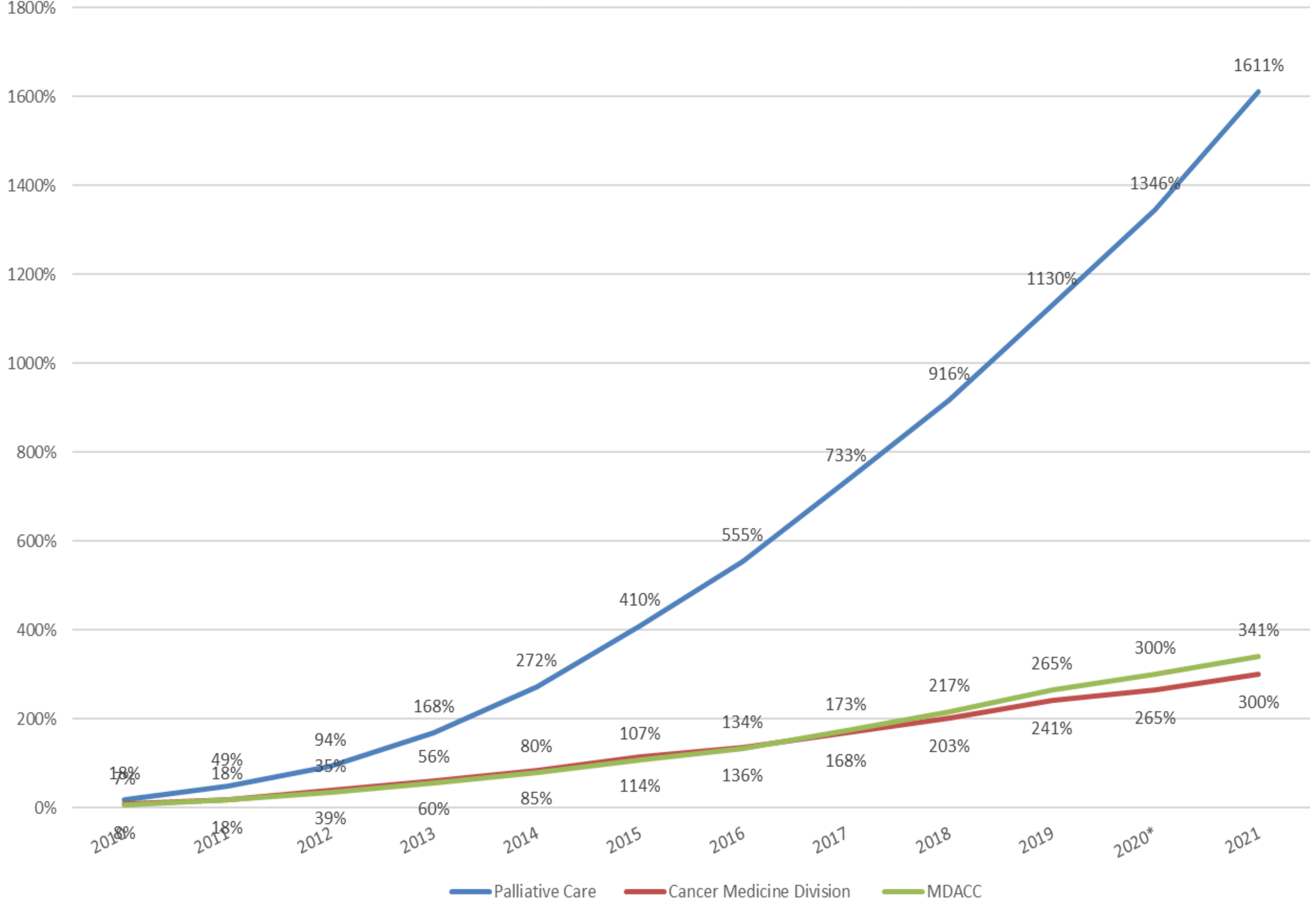
Rev Dr Martin Luther King:

"Una società segregata dà al segregatore un falso senso di superiorità e al segregato un falso senso di inferiorità"

Come ci comportiamo nei sistemi segregati?

1. Copiare il linguaggio biomedico e il comportamento del segregatore (biomedicalizzare la sofferenza e la morte)
2. Separati dai segregati, lascia il campo alle spalle il prima possibile!

Palliative Care Total Professional Activity Growth
Current Year Compared to FY09 Baseline[1] Compounded



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Prendersi cura di noi stessi - Professionale

- Conoscenze sulla valutazione e gestione delle cure palliative, fisiche e psicosociali
- Saggezza per la valutazione, la gestione e la consulenza
- Obiettivi realistici per l'assistenza al paziente / alla famiglia
- Lavoro di squadra (tra MD e con team interdisciplinari)
- Unità di cure palliative
- Ambito accademico (insegnamento, ricerca)

Alleviare la sofferenza è > Arte e < Scienza

Hai bisogno di tutti e 3:

1. Un grande mentore clinico
2. Un Boss sicuro
3. Un datore di lavoro sicuro

Prendersi cura di noi stessi - personale

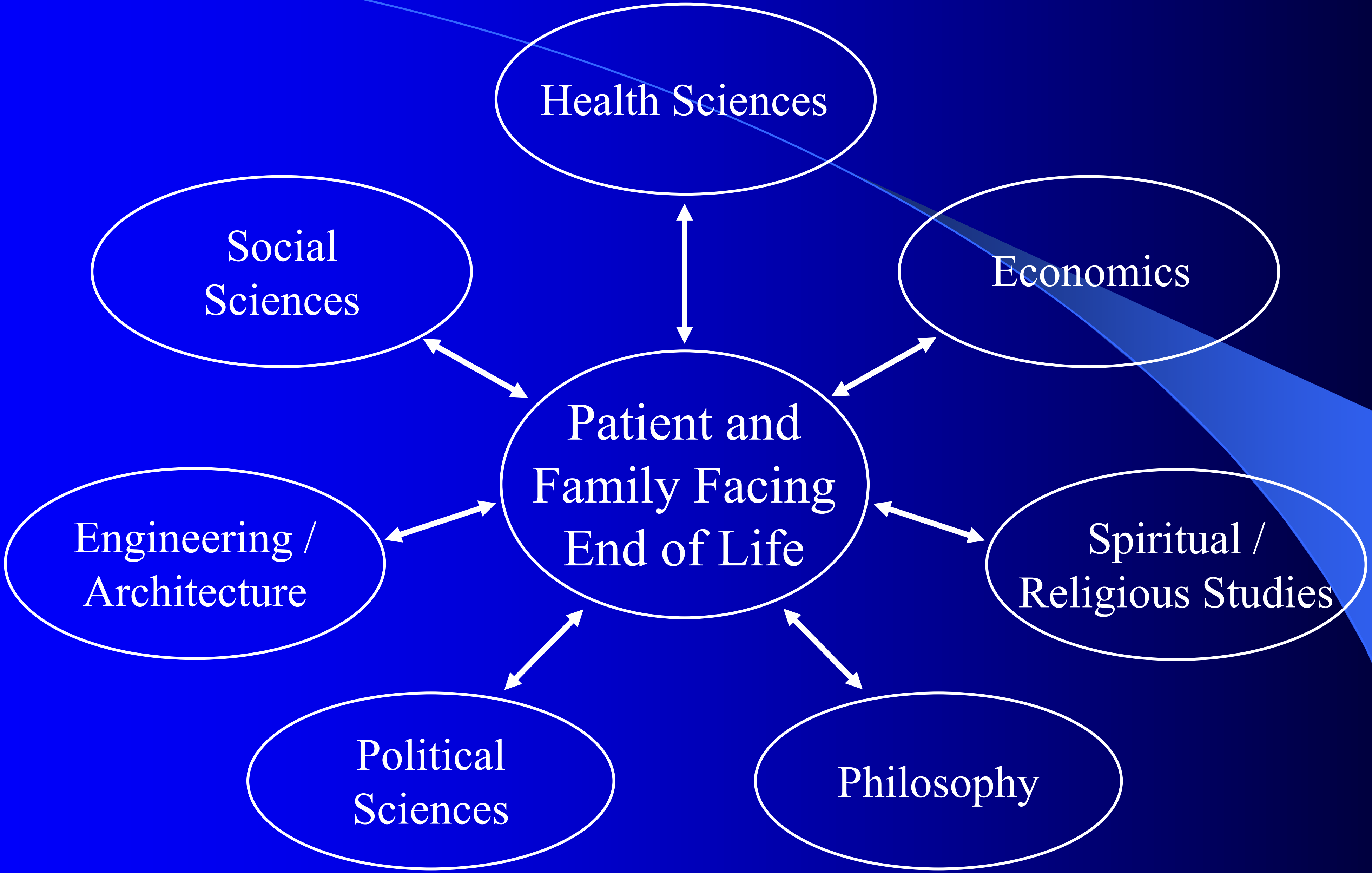
- Social network (famiglia, amici, comunità) - comunicazione
- Attività diverse dal lavoro (hobby, musica, sport, spiritualità) - distrazione
- Prenditi del tempo libero - tregua
- Esercizio fisico regolare - affaticamento, depressione, sonno, autostima
- WET (wisdom enhancement techniques!!) (lettura, arte, crescita spirituale e personale)

Assistenza orientata alla persona

- Diverse strutture, processi e risultati dell'assistenza orientata alla malattia
- Le differenze sono sempre frustranti per i dirigenti!

Cosa possiamo fare?

1. Creare strutture di supporto / cure palliative all'interno della medicina accademica
2. I leader esecutivi devono fornire sicurezza a questo team di assistenza centrato sulla persona dissonante
3. Ristabilisci i confini etici nella tua squadra. Pensare globalmente ma agire localmente; Gandhi: "Sii il cambiamento che vuoi"



Health Sciences

Social Sciences

Economics

Patient and Family Facing End of Life

Engineering / Architecture

Spiritual / Religious Studies

Political Sciences

Philosophy

- Siamo tutti parte di una lunga catena di conoscenze
- Le università hanno strutture e processi per la creazione etica e l'insegnamento della conoscenza
  (rispetto all'industria o al governo)
- La cura della personalità deve essere abbracciata dalle università