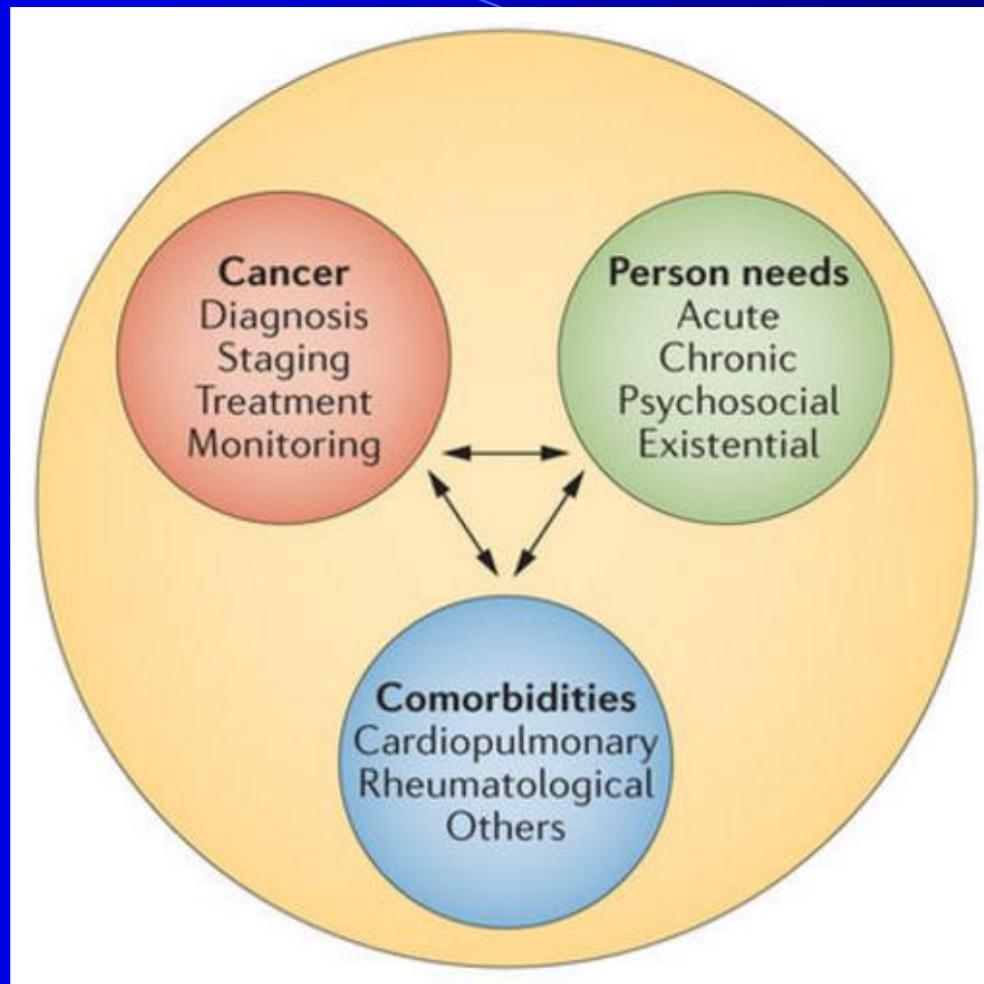




“There is a general rule, and I have seen great physicians acting on it, that the physician should NOT treat the DISEASE but the PATIENT who is suffering from it”

Maimonides (1135-1204)



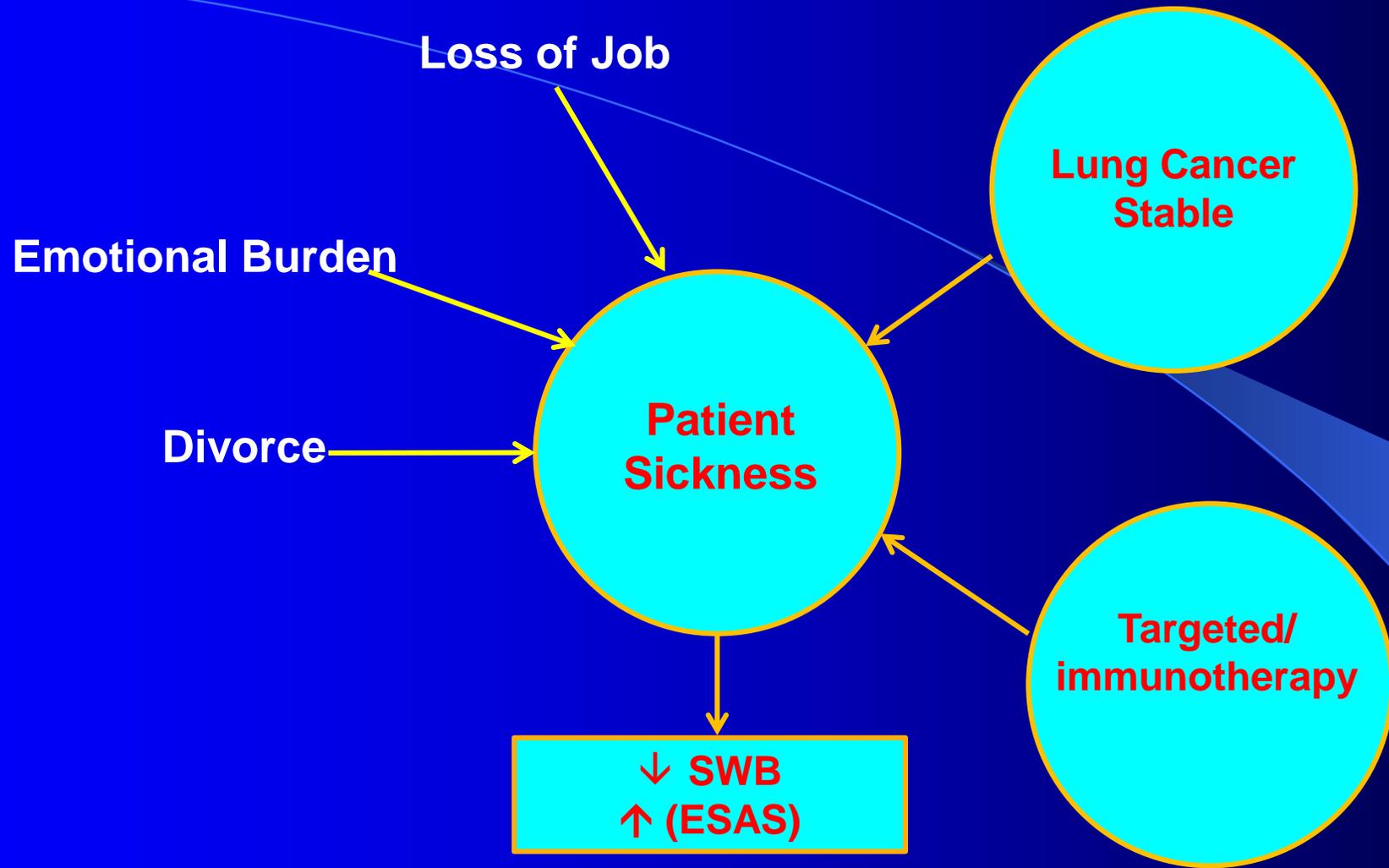
We Address Suffering



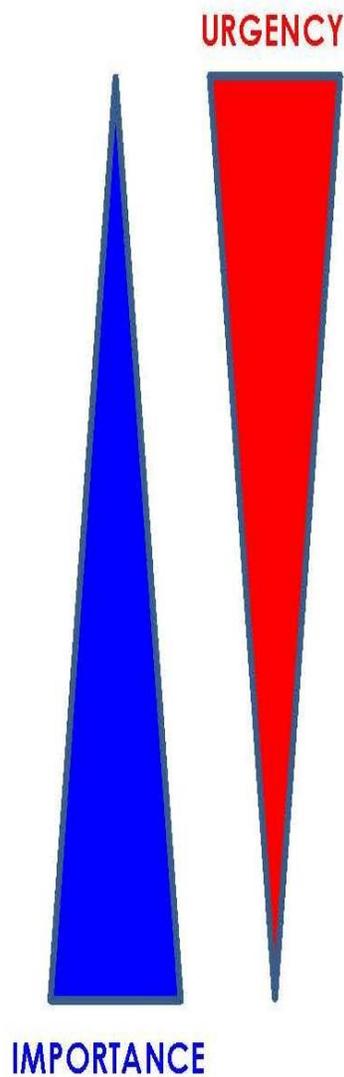
Patient's Problems

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





- Drug Changes
- Invasive diagnostic procedure
- Express concern of cancer growth



- 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

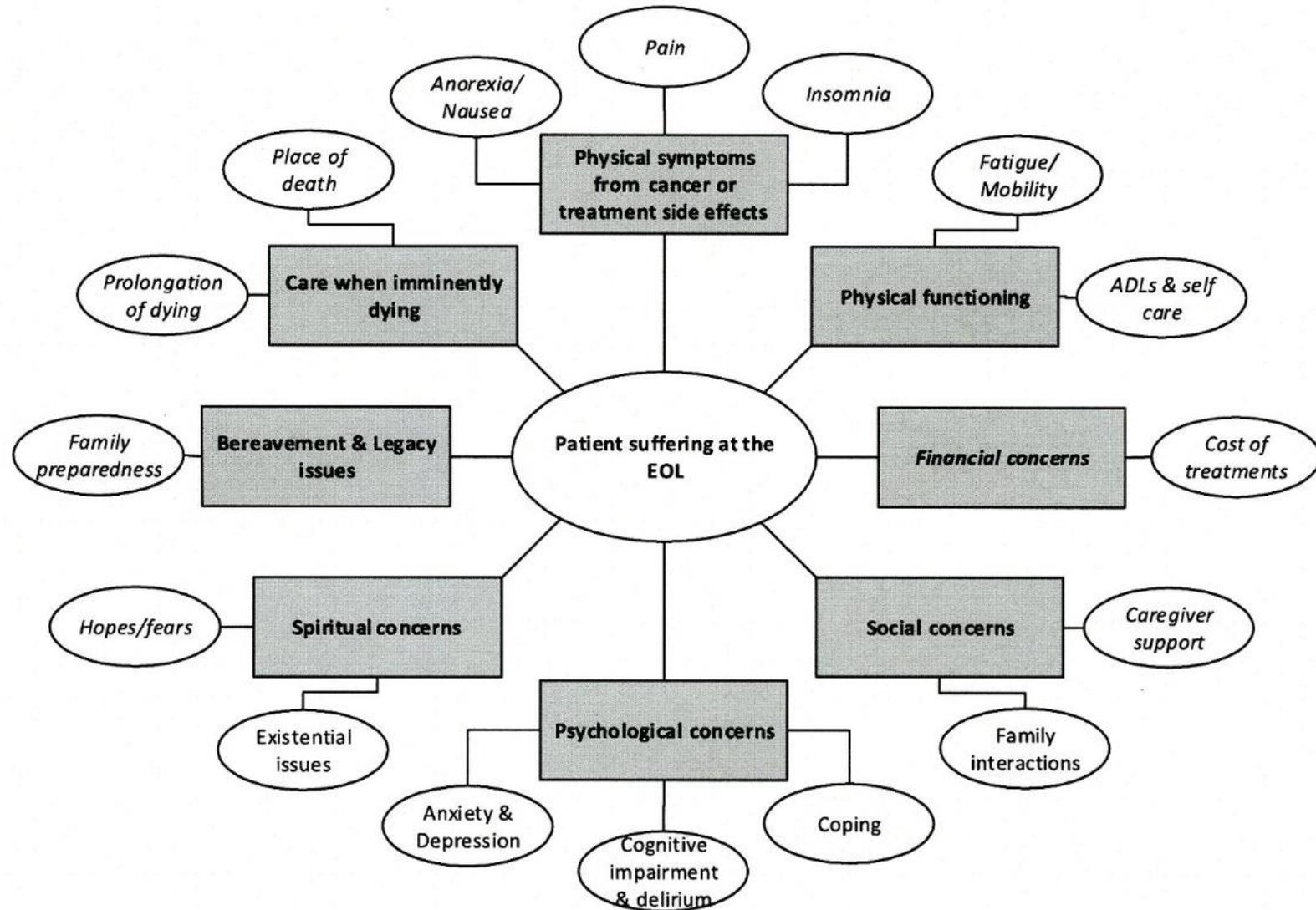


Figure 1. Multidimensional causes of patient suffering at the EOL.
 Abbreviations: ADL, activities of daily living; EOL, end of life.

The Fringe!!

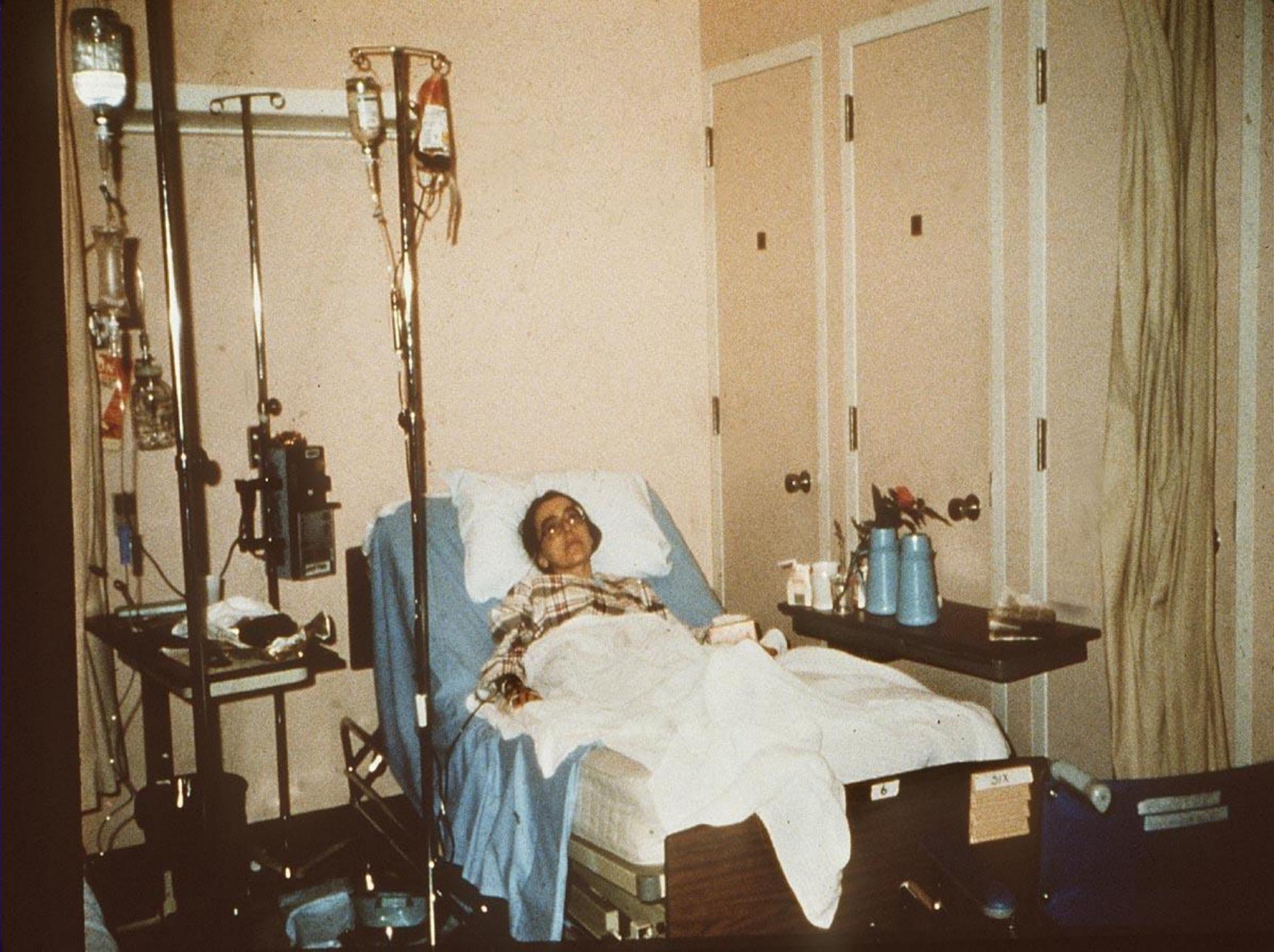
- 1967- St Christopher's hospice
- Houses and home care. Emphasis on assessment and management of symptoms, family care, counseling, planning end of life, bereavement support

Main stream medicine in North America

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

Person Oriented Care

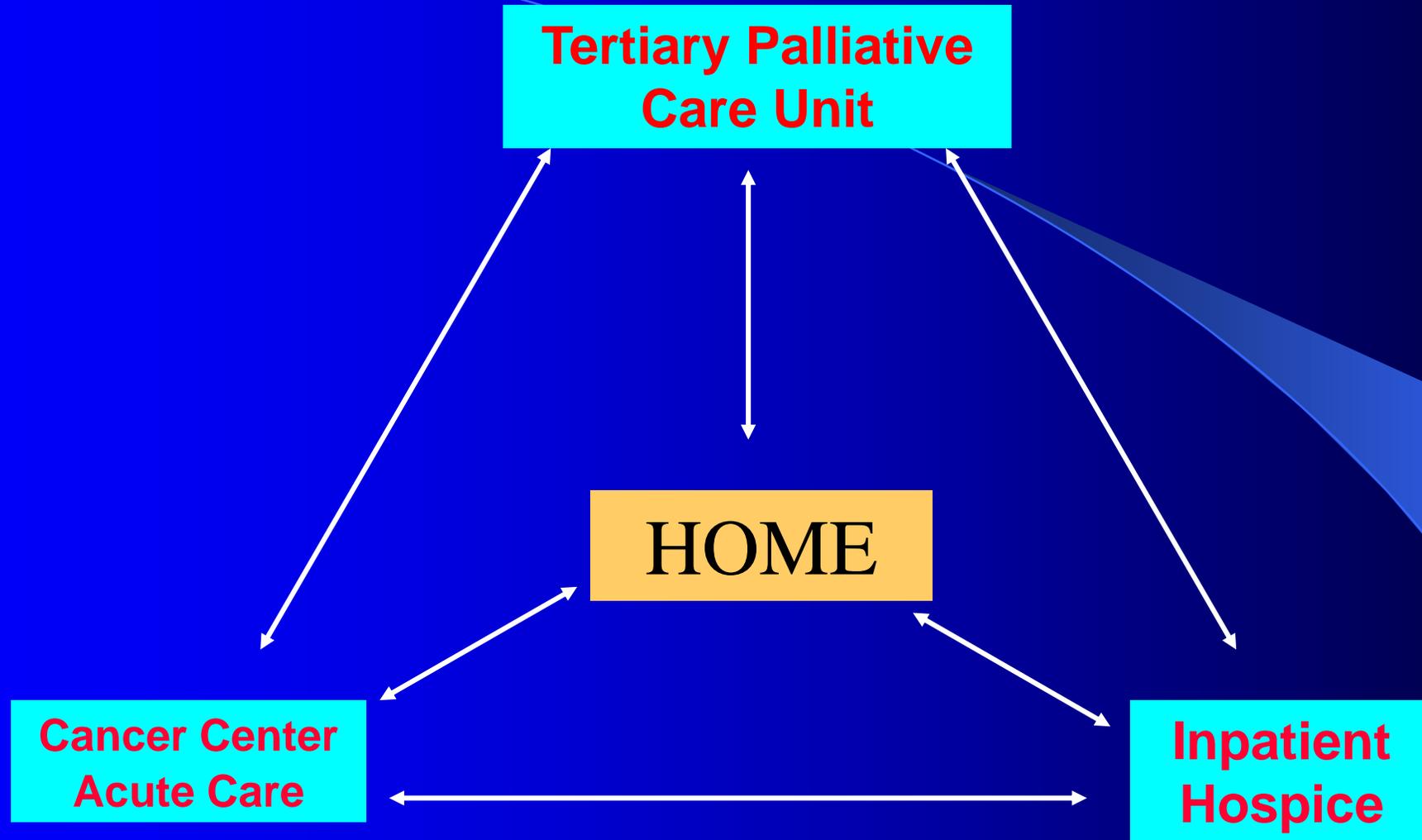
- Different structures, processes and outcomes from disease oriented care
- Differences are always frustrating to administrators!



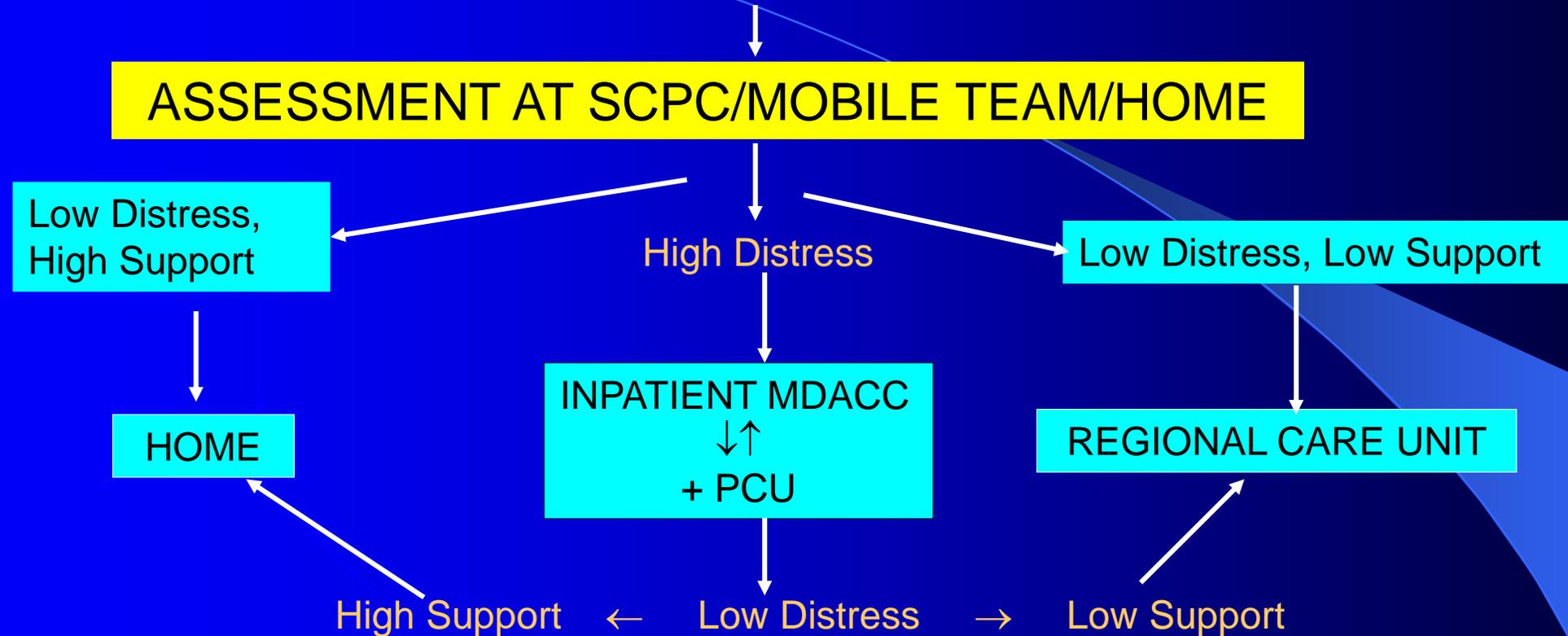








PATIENT FLOW



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.

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

- **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.

We Address Suffering







THE PALLIATIVE CARE TEAM

FACULTY



NURSING



INTER-DISCIPLINARY



FELLOWS



ISC'S



CNA'S



APNS



CLINICAL PHARMACISTS



PSYCHO-SOCIAL

















Outcomes?















How can we increase expectation of improvement?

1. Communicate (phone the patient)
2. Prepare and give a prompt- sheet
3. Sit when you visit the patient
4. Always examine the patient
5. Offer audio recording of the visit or recommendations
6. Ask how the patient prefers to make decisions
7. Play some music
8. No waiting room, smiling clerk, no exam room, pink light, sign on the ceiling, wellcome pets and weddings

How can we increase expectation of improvement?

1. Communicate (phone the patient) - **Prospective open**
2. Prepare and give a prompt- sheet - **RCT**
3. Sit when you visit the patient - **RCT**
4. Always examine the patient - **Prospective open**
5. Offer audio recording of the visit or recommendations - **RCT**
6. Ask how the patient prefers to make decisions – **Prospective open**
7. Play some music - **Prospective open**
8. No waiting room, no EPIC computer use, pink lighting, signs on the ceiling, introducing counselor, opioid and constipation education: **current research**



Supportive Care Center

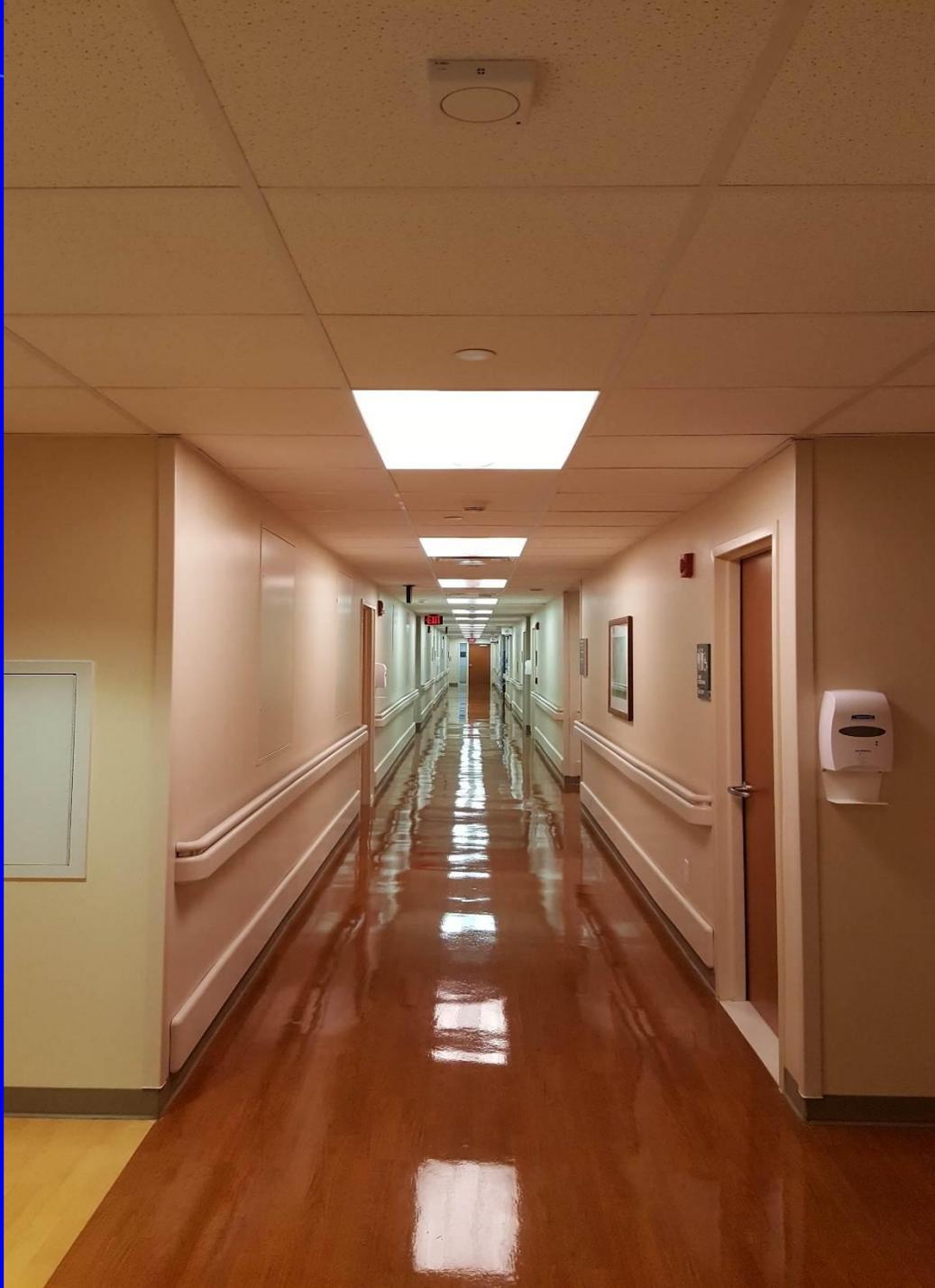
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Thank you for visiting our Center







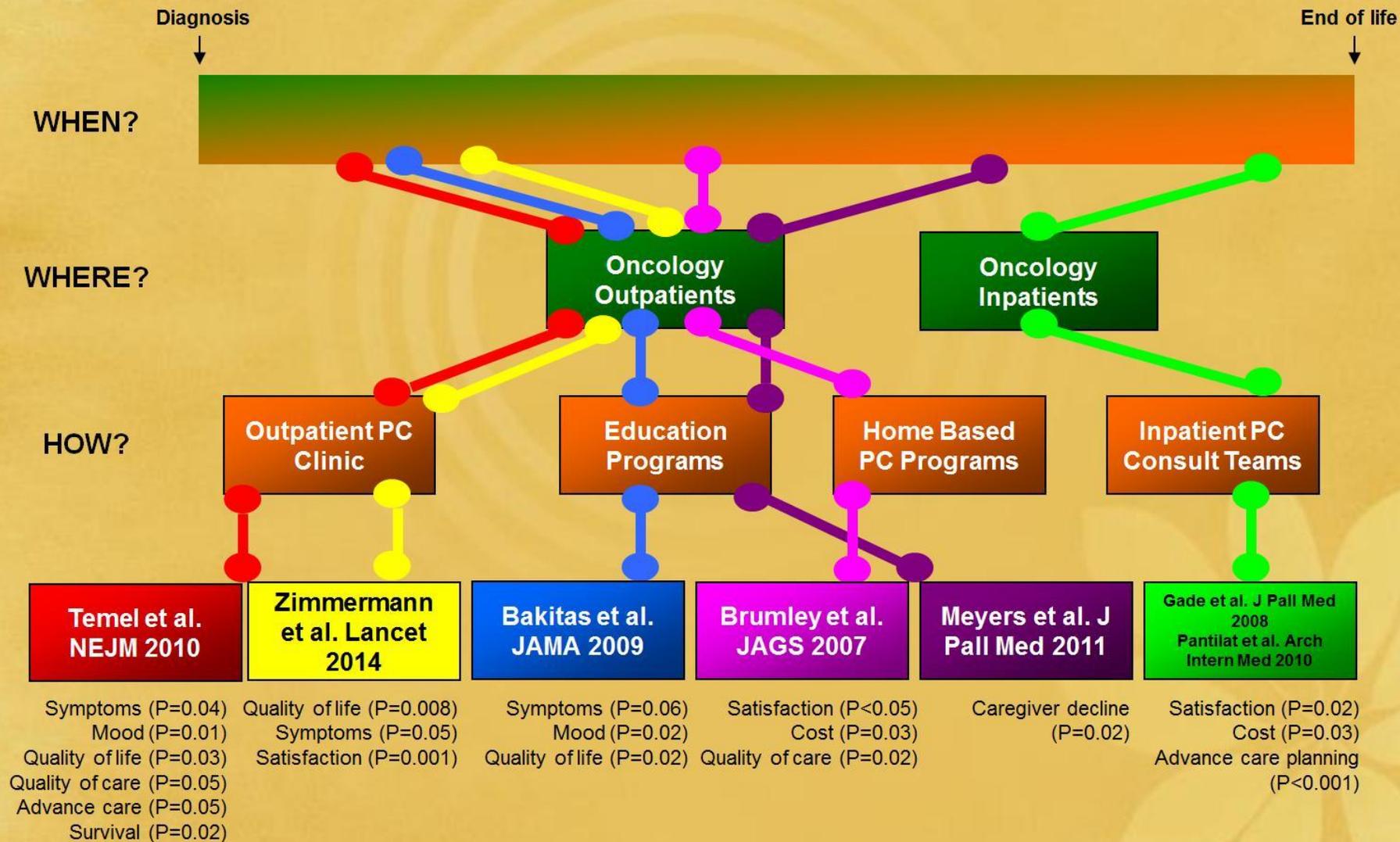






Comprehensive Cancer Care

Randomized Controlled Trials



Results	Frequency (0 vs. 1-10)	Median intensity (interquartile range)
Do you consider yourself a spiritual person?	97 (98%)	9 (7-10)*
Do you consider yourself a religious person?	94 (98%)	9 (5-10)*
Is spirituality/religiosity a source of strength and comfort to you?	99 (100%)	10 (8-10)*
Does spirituality/religiosity help you cope with your illness?	98 (99%)	10 (8-10)*
Does spirituality/religiosity help your family member/caregiver cope with your illness?	89 (99%)	9 (6-10)*

* [0 to 10 (max) scale]

10 MOST COMMON VERY IMPORTANT WISHES AT FIRST AND SECOND TEST

	Items	1 st Test	2 nd Test	Correlation**	
		N=100	N=100	r	p-value
		N* (%)	N* (%)		
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

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

Item	Test 1 <i>N</i> = 100 <i>n</i> ^a	Test 2 <i>N</i> = 100 <i>n</i> ^a	Correlation ^b	
			<i>r</i>	<i>p</i>
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

^aNumber (%) of patients who prioritized this item as “very important”

^bSpearman correlation coefficient between test 1 and test 2, which was completed 4–24 h after test 1



WHAT DO WE KNOW SO FAR?

- Early PC by MD specialist led team reduces symptom burden
- Early PC by MD specialist led team improves Qo L
- Early PC improves or does not reduce survival
- Early PC saves money

The
Oncologist®

Value in Cancer Care



End-of-Life Care Matters: Palliative Cancer Care Results in Better Care and Lower Costs

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Department of Palliative Care and Rehabilitation Medicine, The University of Texas MD Anderson Cancer Center, Houston, Texas, USA

Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. End of life · Palliative care · Cancer costs · Value in EOL care

Table 1. Selected Quality Oncology Practice Initiative's end-of-life quality outcome performance measures

Description	Measure
Pain	Plan for pain Pain assessed before death Pain intensity quantified before death Pain assessed appropriately before death
Dyspnea	Dyspnea assessed before death Dyspnea addressed before death Dyspnea addressed appropriately before death
Hospice	Hospice or palliative care used Enrolled in hospice Hospice within 3 days of death
Chemotherapy	Chemotherapy administered within the last 2 weeks of life
Emergency room visit	Any emergency room visit within the last month of life Two or more emergency room visits within the last month of life
Hospital admission	Any hospital admission within the last month of life Two or more hospital admission within the last month of life More than 14 days of hospitalization within the last month of life Hospital death
ICU admission	Any hospital admission within the last month of life ICU death

Abbreviations: ICU, intensive care unit.

Table 2. Studies demonstrating cost savings associated with PC consultations in the inpatient setting

Author (Year)	Study design/objective	Findings: PC versus SC
Greer (2016) [3]	Randomized controlled, single center; secondary analysis. Advanced lung cancer; $n = 151$	As compared with SC, early PC was not associated with higher overall medical care expenses. There was a statistical trend for PC patients towards lower mean total cost per day (\$117; $p = .13$). In the last 30 days of life, PC patients had lower chemotherapy expenses (mean difference = \$757; $p = .03$) and higher hospice care costs in last 30 days (mean difference = \$1,053; $p = .07$). Other costs (emergency visits, hospitalizations) not significant over study period.
May (2016) [81]	Prospective observational, multi-site. Advanced cancer patients; $n = 906$	PC consult ≤ 2 days of admission associated with lower costs. Cost savings were proportional to patient comorbidity scores: 22% lower for scores of 2–3 and 32% lower for ≥ 4 .
May (2015) [87]	Prospective observational, multi-site. Advanced cancer patients; $n = 969$	PC consultation ≤ 2 days and ≤ 6 days of admission associated with cost reductions of 24% and 14%, respectively.
Whitford (2014) [79]	Retrospective case–control, single-center. Advanced illness including cancer; $n = 5,908$	Among patients discharged alive, overall hospitalization costs were lower, and higher numbers (31% versus 1%) were discharged to hospice care. Among patients who died in hospital, costs of PC patients were significantly lower.
Morrison (2011) [76]	Retrospective case control, multi-site. Medicaid patients with advanced illness	Hospital cost savings of \$4,098 and \$7,563 for patients who were discharged alive and when death happened during hospitalization, respectively.
Penrod (2010) [73]	Prospective observational, multi-site. Advanced illness; $n = 3,321$	PC patients were approx. 44% less likely to be admitted to ICU, and daily total direct hospital costs were lower than SC patients.
Zhang (2009) [88]	Prospective observational, single center. Advanced cancer; $n = 603$	Patients who had EOL conversations were less likely to undergo aggressive care (e.g., resuscitation/ventilation, ICU) and more likely to receive hospice care with longer LOS. Cost of care was about 36% lower in the final week of life. Higher costs associated with worse quality of death.

Table 2. (Cont.)

Gade (2008) [59]	Randomized controlled, multi-center. Advanced illness; <i>n</i> = 517	Six months post hospital discharge, PC patients had fewer ICU admissions on readmission, longer hospice LOS and about 32% reduction in total health care.
Morrison (2008) [75]	Retrospective case controlled, multi-site. Advanced illness including cancer; <i>n</i> = 4,402	As compared with SC, PC patients who were discharged alive had significant savings in daily and overall admission costs, including lower laboratory and ICU costs. For PC patients who died in hospital, the net savings in daily and overall admission costs were higher than for patients who were discharged.
Penrod (2006) [72]	Retrospective, observational, multi-site. 40% cancer diagnosis; <i>n</i> = 314	Cost analysis of hospital deaths at two Veterans Affairs hospitals demonstrated PC involvement associated with 40% less likelihood of ICU admission.
Elsayem (2004) [64]	Retrospective, single center. Advanced cancer patients; <i>n</i> = 320	The mean daily PCU charges were 38% lower than the rest of the hospital.
Smith (2003) [82]	Retrospective with case control design, single center. Majority cancer diagnosis; <i>n</i> = 237	Study compared period before and after PCU transfer and found daily charges and costs after transfer to be lower by 66%. For patients who died in PCU versus outside PCU, direct and total costs were lower by 59% and 57%, respectively.
Bruera (2000) [86]	Retrospective, multi-center. Advanced cancer patients; <i>n</i> = 2,583	Study compared the period before and after PC program implementation and demonstrated significantly lower hospital LOS, hospital mortality, and acute care facility costs after PC program implementation.

Abbreviations: EOL, end of life; ICU, intensive care unit; LOS, length of stay; PC, palliative care; PCU, PC unit; SC, standard care.

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 mentioned.

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. Palliative

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

CANCER CENTER

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graph TD; CC[CANCER CENTER] --- MO[MEDICAL ONCOLOGY]; CC --- RO[RADIATION ONCOLOGY]; CC --- SO[SURGICAL ONCOLOGY]; CC --- SC[SUPPORTIVE CARE];
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MEDICAL
ONCOLOGY

RADIATION
ONCOLOGY

SURGICAL
ONCOLOGY

SUPPORTIVE
CARE

ACADEMIC HOSPITAL/
FACULTY OF MEDICINE

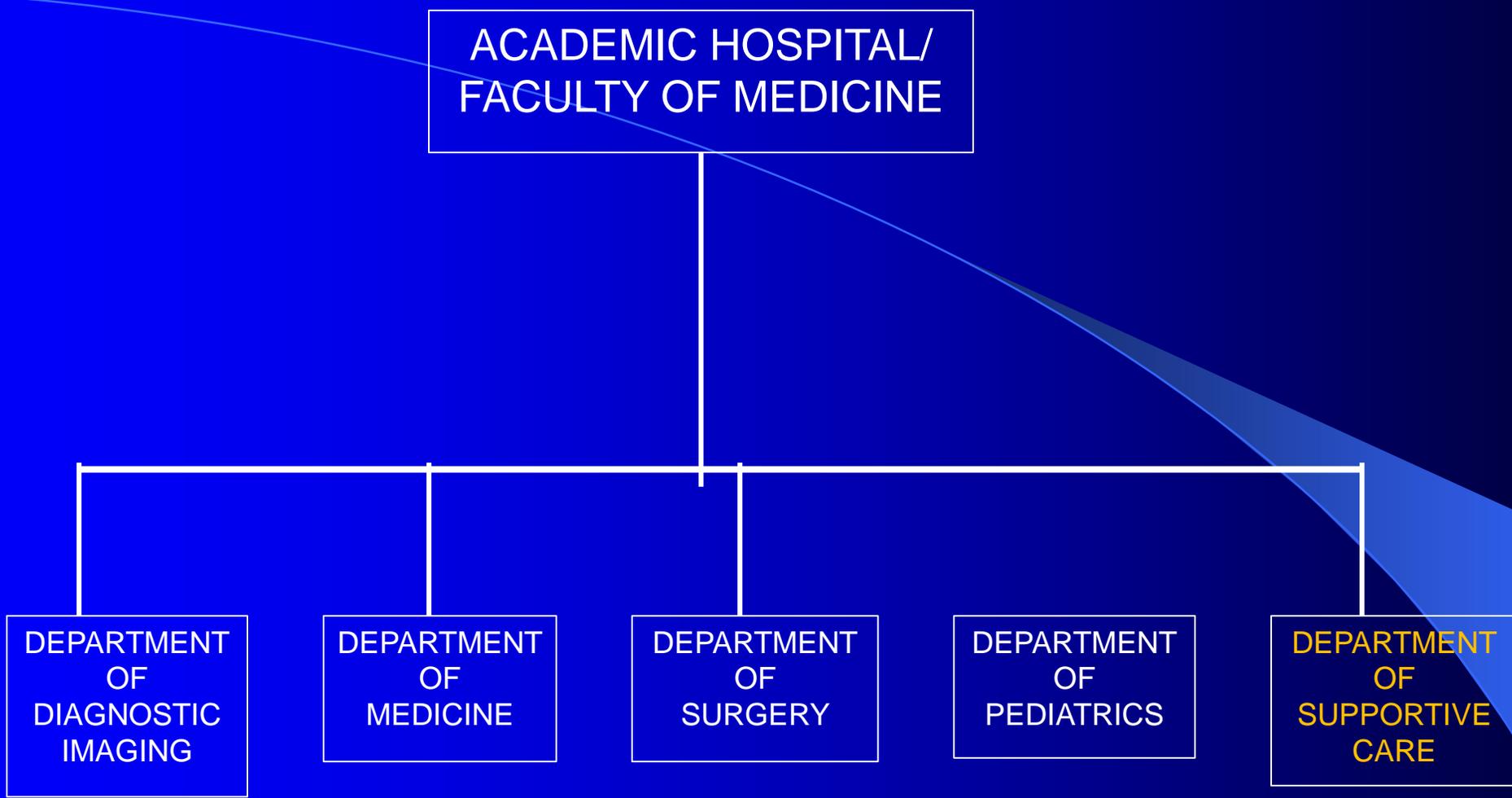
DEPARTMENT
OF
DIAGNOSTIC
IMAGING

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SURGERY

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PEDIATRICS

DEPARTMENT
OF
SUPPORTIVE
CARE



Who needs education?

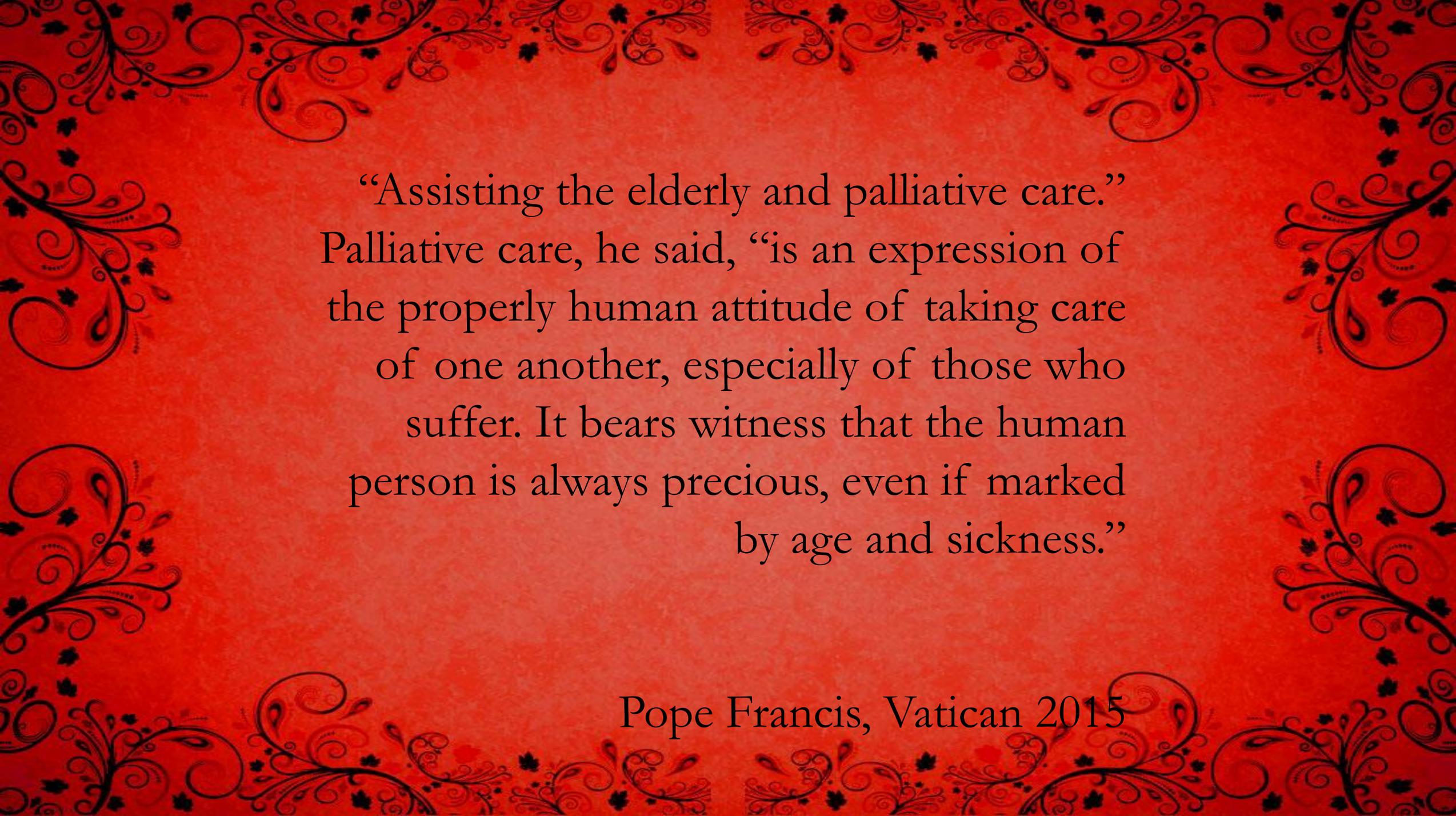
- Medicare administrator: Break the acute/ long term interests, get the \$\$\$ moving. In our country (sadly) insurance owners.
- Deans of Medical Schools- Importance of PC education and research.
- Directors of cancer centers- cancer treatment Vs patient treatment (“personalized : reality or joke?”)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

Person oriented care

- Not interesting to the powerful in medicine: Pharma industry, insurance, hospital/ university leaders
- Barriers to personhood care: Dean of Faculty of Medicine, Hospital Director, Minister of health. They are the ones we should educate

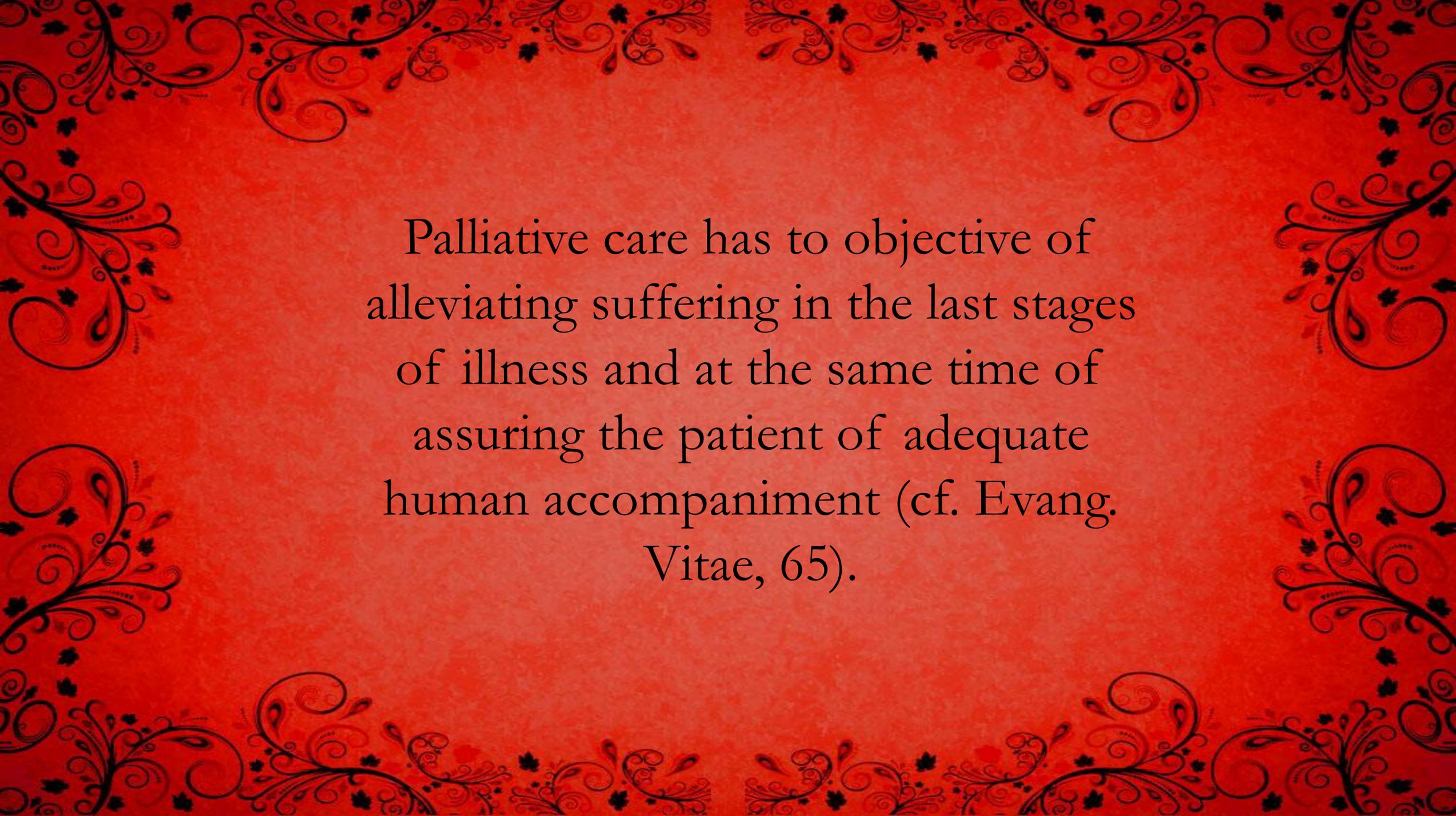




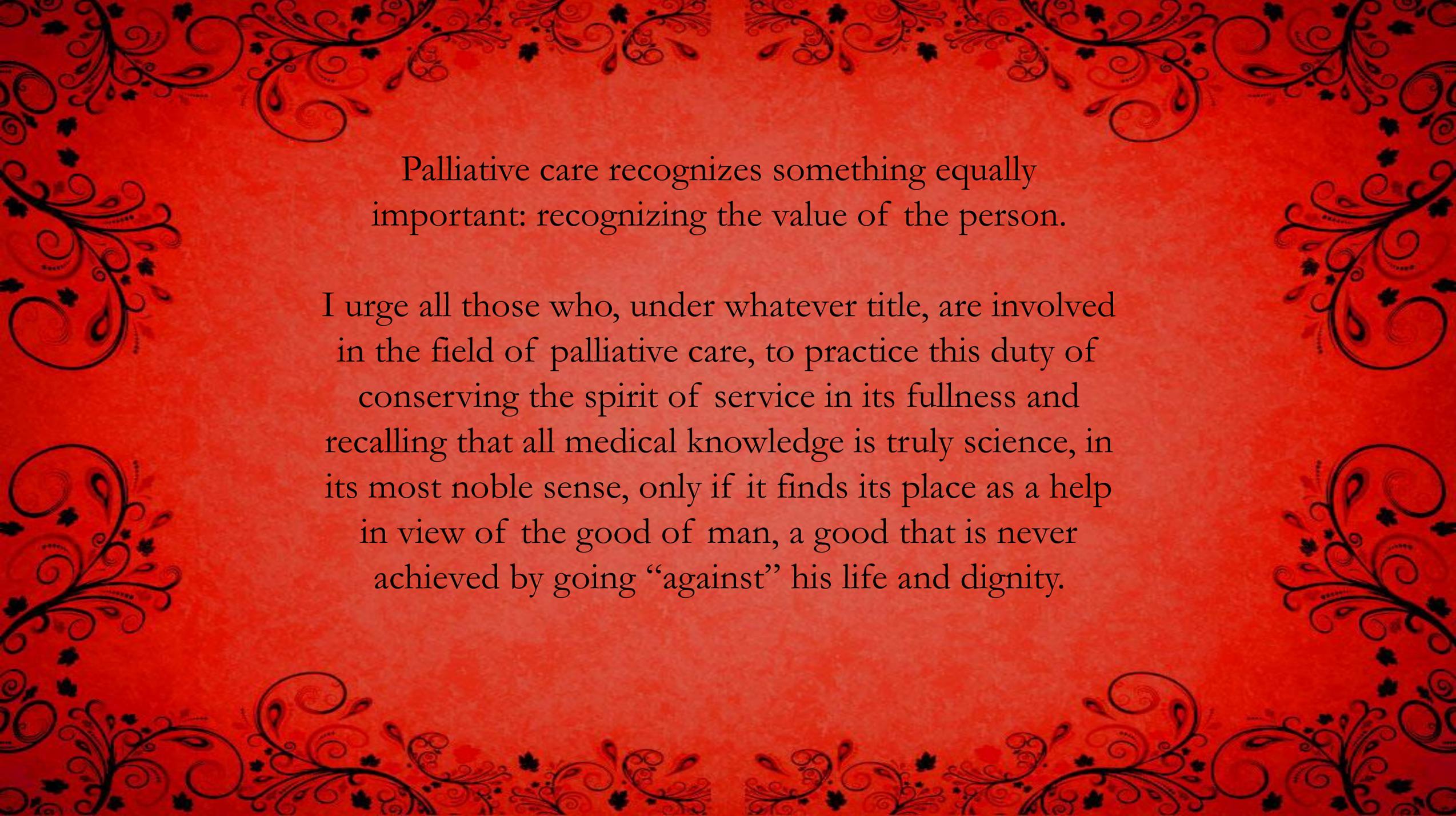


“Assisting the elderly and palliative care.”
Palliative care, he said, “is an expression of
the properly human attitude of taking care
of one another, especially of those who
suffer. It bears witness that the human
person is always precious, even if marked
by age and sickness.”

Pope Francis, Vatican 2015



Palliative care has to objective of
alleviating suffering in the last stages
of illness and at the same time of
assuring the patient of adequate
human accompaniment (cf. Evang.
Vitae, 65).



Palliative care recognizes something equally important: recognizing the value of the person.

I urge all those who, under whatever title, are involved in the field of palliative care, to practice this duty of conserving the spirit of service in its fullness and recalling that all medical knowledge is truly science, in its most noble sense, only if it finds its place as a help in view of the good of man, a good that is never achieved by going “against” his life and dignity.