
Research in Palliative Care

**Training Course in Sexual and Reproductive Health Research
Geneva, February 2009**

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Learning objectives

At the end of this session, participants should be able to:


- Define palliative care (PC)
- Defend the position that PC is an integral component of health care (and the care you provide)
- Describe the WHO ladder for pain control
- Defend the position that PC research constitutes an ethical imperative
- Defend the position that everyday practice lends itself to PC research
- List the domains relevant to PC research

Learning objectives

- Describe the ethical issues related to PC research
- Describe the methodological challenges related to PC research
- Describe some outcome measures used in PC
- Describe different research methods used in PC research

We will draw on examples and cases to illustrate the above

Plan

- Definition of PC (WHO)
 - Extent of the problem
 - Why is research important?
 - Challenges in conducting research in PC
 - Eg of research and methods
 - Conclusions
- 

Palliative care: WHO definition



Definition of palliative care (WHO)

- Hospice and Palliative Care is **the active care** of patients with advanced, progressive and incurable disease.
- Palliative Care is an approach that improves the **quality of life** of patients and their families facing the problem associated with life-threatening illness, through the **prevention and relief of suffering** by means of early identification **and impeccable assessment and treatment** of pain and other problems, physical, psychosocial and spiritual.

Definition of palliative care (WHO)

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;

Definition of palliative care (WHO)

- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;

Definition of palliative care (WHO)

- Will enhance quality of life, and may also positively influence the course of illness;
- Is **applicable early in the course of illness**, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

National Cancer Control Programmes:

Policies and Managerial Guidelines, 2nd Ed. Geneva: WHO, 2002

Definition of Hospice /Palliative care

- Involves broad spectrum of illnesses
 - Cancer
 - AIDS
 - COPD
 - End-stage heart diseases
 - End-stage lung diseases
 - End-stage neurological diseases (e.g. ALS)
 - Etc
- Paediatrics & adults

Palliative Care

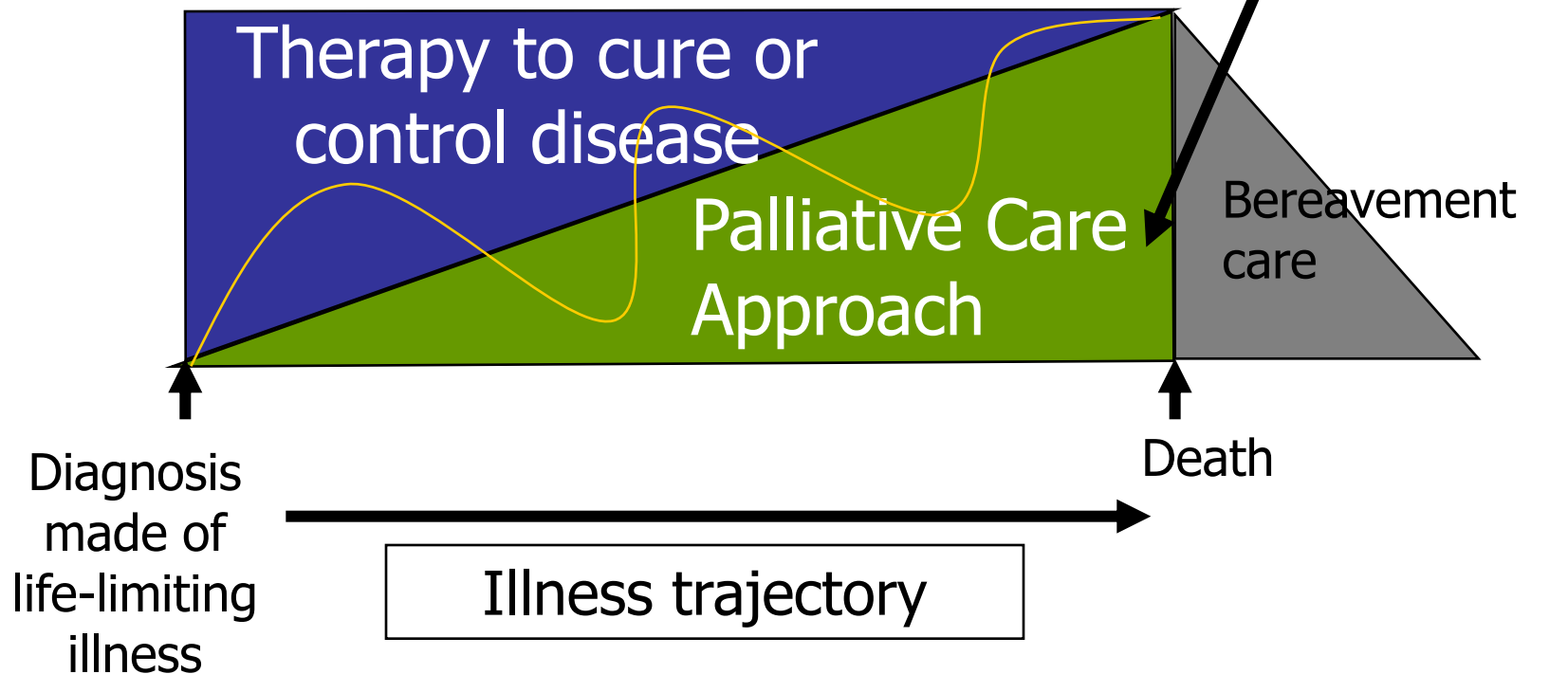
- Primary care
 - Palliative care as an approach: practiced by all
- Secondary & tertiary care
 - A specialization: in some countries
- Essential component of health care system at primary level
 - It is not merely a luxury
 - Patients suffer and die throughout the world
 - Additional infrastructure and support required

Hospice Palliative Care

Canadian Hospice and PC Model

Illness trajectory

- More predictable in cancer and ALS
- Less predictable in AIDS, lung & heart diseases



Extent of problem

Estimated number of people who would need palliative care (in millions)

Annual deaths globally	56 mil
Annual deaths in developing countries	44 mil
Annual deaths in developed countries	12 mil
Estimated numbers needing palliative care	33 mil

Approximately 60% of the dying need palliative care

In: Stjernswärd J, Clark D. Oxford Textbook of Pall. Med 2005

Extent of problem

- 50% of world's new cancer cases and deaths occur in developing nations
 - 80% already incurable at the time of diagnosis
- Adequate palliative care is still unavailable to 80-90% patients in these countries

Insufficient access to palliative care internationally

- The development of palliative care through effective and low cost approaches represents a priority

National Health Policy: WHO Public Health Model

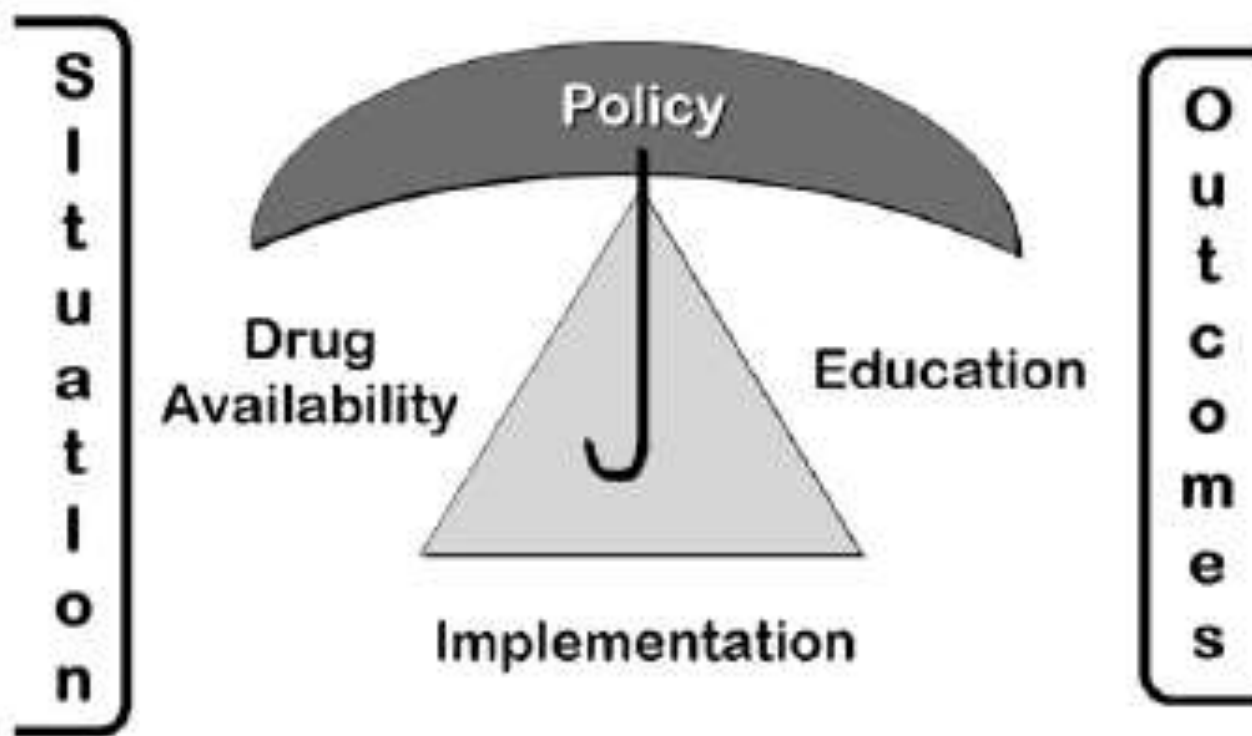


Fig. 1. WHO Public Health Model.

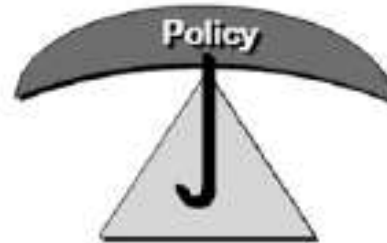
Stjernsward J, Foley K, Ferris F. The Public Health Strategy for Palliative Care. *J Pain Sympmt Manage* 2007;33(5):486-493

Policy

- Palliative care part of national health plan, policies, related regulations
 - Funding / service delivery models support palliative care delivery
 - Essential medicines
- (Policy makers, regulators, WHO, NGOs)

Drug Availability

- Opioids, essential medicines
 - Importation quota
 - Cost
 - Prescribing
 - Distribution
 - Dispensing
 - Administration
- (Pharmacists, drug regulators, law enforcement agents)



Implementation

- Opinion leaders
 - Trained manpower
 - Strategic & business plans – resources, infrastructure
 - Standards, guidelines measures
- (Community & clinical leaders, administrators)

Education

- Media & public advocacy
 - Curricula, courses – professionals, trainees
 - Expert training
 - Family caregiver training & support
- (Media & public, healthcare providers & trainees, palliative care experts, family caregivers)

Fig. 2. Detailed WHO Public Health Model.

Stjernsward J, Foley K, Ferris F. The Public Health Strategy for Palliative Care. J Pain Sympt Manage 2007;33(5):486-493

Domains of research

- Policy, service development and access
- Access to medications
- Symptom and problem profiles
- Patient needs
- Pain and symptom management
- Psychological needs & care
- Social needs & care
- Spiritual needs & care
- Quality of life
- Education

WHY IS RESEARCH IN PALLIATIVE CARE IMPORTANT?



Why is research in palliative care important?

- What problems do our patients (and their families, and our family members) who are dying face?
 - Pain and symptom management
 - Psychological
 - Social
 - Spiritual
- What are their needs?
- What are the sources of their suffering?
- Are their needs being addressed? If not, why not and how can we better address them?

Why is research in palliative care important?

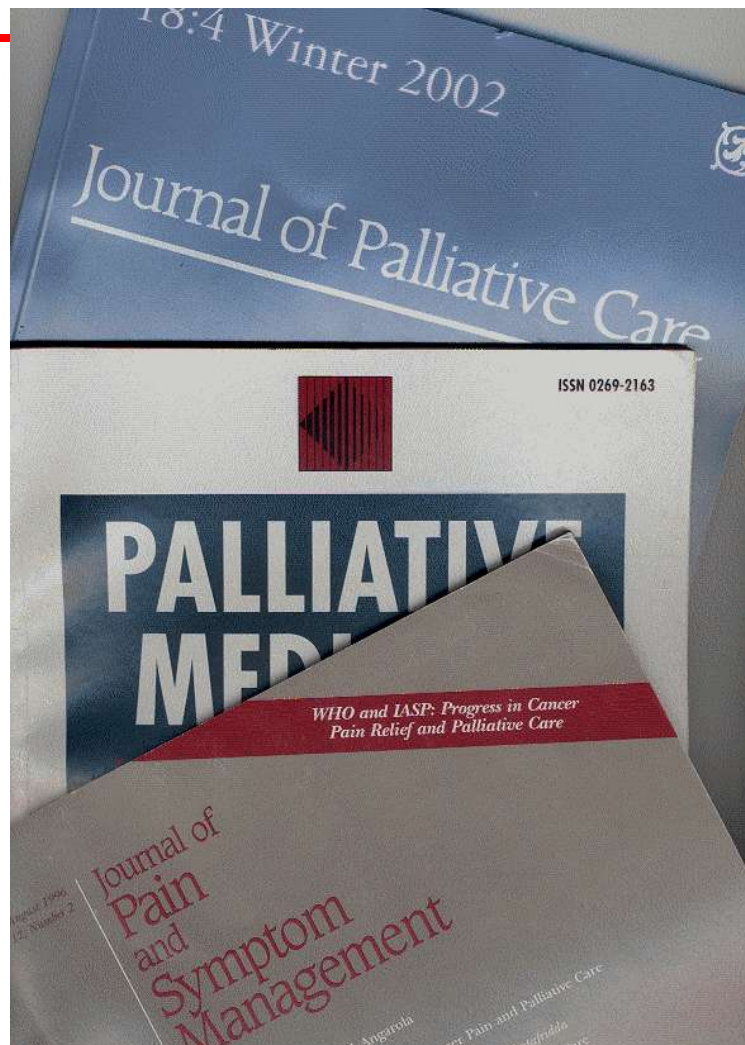
- What information do they want?
- How well are we providing this information?
- Are we providing appropriate clinical decision-making?
- How well are we and our colleagues trained to address their needs? What do we still need to learn and how can we ensure that all professionals learn about palliative care?
- Is there access to essential palliative care drugs (WHO essential drugs list for palliative care)
- What infrastructure does our health system provide for palliative care?
- Does the public know about palliative care?
- Do health professional know about palliative care?

Research in Palliative Care is an Ethical Imperative

- How are those who are dying in our societies cared for?
- Are we alleviating the burden of suffering?
- How effective are our treatments used to care for dying patients and their families?
- Are there better ways of caring for them?

Palliative care: an emerging scientific basis

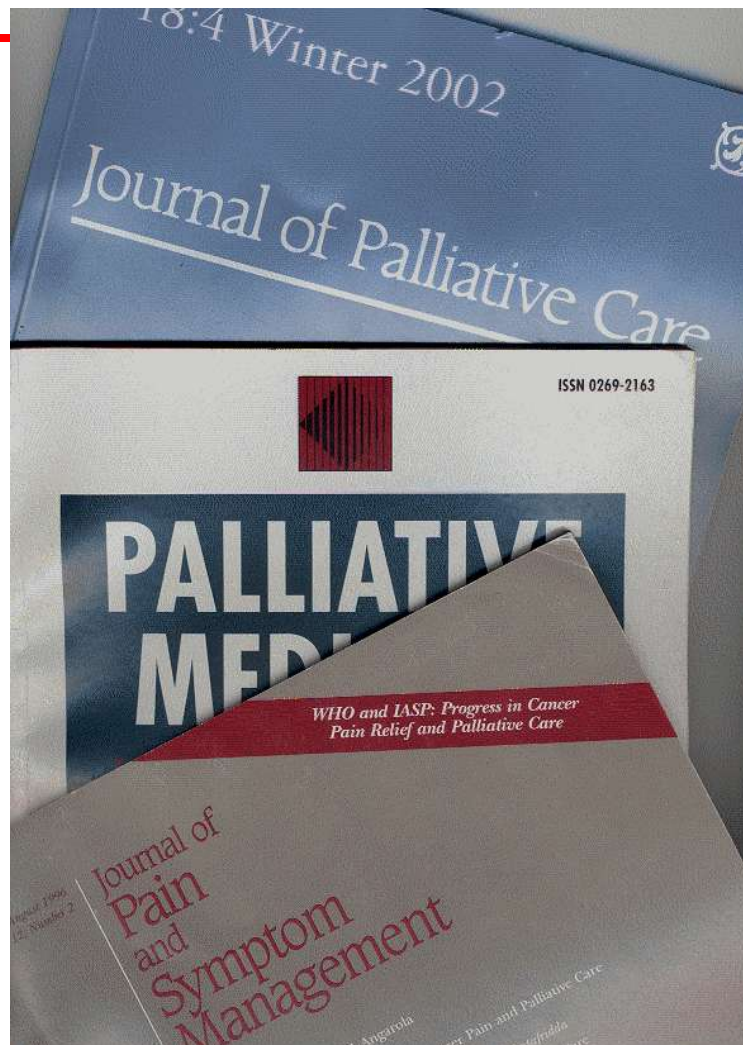
- Despite challenges, increasing research in the field
- Currently several international peer-reviewed journals dedicated to palliative care
- Increasing number of publications in general journals (e.g. NEJM, BMJ, Lancet)



Palliative care: an emerging scientific basis

But...

- Glaring lack of studies from developing countries
 - Needs of patients unknown
 - Treatments tailored to these communities
 - Outcomes measures specific to these communities



Ethics in palliative care research

- Is it ethical to conduct research in patients who are terminally ill?
- Are there special ethical considerations in this population compared to other populations?
- What do terminally ill patients think about participating in research?

Are there special ethical considerations for patients with terminal illnesses?

- Ethical concerns expressed:
 - Dying patients are especially vulnerable
 - Adequate informed consent may be difficult to obtain
 - Balancing research and clinical roles is particularly difficult
- Ethical issues raised by palliative care research are, for the most part, not unique to this field.
- PC researchers, like in other fields, must demonstrate that their research questions are important, their methods are appropriate to produce valid results, and that their findings will be generalizable

Casarett DJ, Karlawish J. *J. Pain Symptom Manage* 2000;20:130–139.

Ethics of Research in Palliative Care

- Research is possible in palliative care
- Studies show that terminally ill patients want to be involved in palliative-related research

Ross C, Cornbleet M. Palliative Medicine 2003;17(6):491-497
Olson T et al. Internal Medicine Journal 2006;36(7):406-13

Ethical considerations

- General ethical considerations apply
 - Declaration of Helsinki
- Use of placebos?
 - “every patient, including those of a control group, if any- should be assured of the best proven diagnostic and therapeutic method”
 - But in palliative care many therapies remain widely used but backed with few studies
 - Principle of equipoise
- Consent in patients lacking capacity

**WHAT ARE THE CHALLENGES
TO CONDUCTING RESEARCH
IN PALLIATIVE CARE?**



Challenges in conducting palliative care research

- Lack of awareness by health professionals, ethic committees, funding agents, of importance & need of PC research
- Frail patients ➔ need for low burden research
- Recruitment difficulties
 - Biases against conducting research in these patients
- Attrition
- Compliance
 - Jordhoy MS, et al. Challenges in palliative care research; recruitment, attrition, and compliance: experience from a randomized controlled trial. Pall Med 1999;13:299-310
 - Grande GE, Todd CJ. Why are trials in palliative care so difficult? Pall Med 2000;14:69-74

Challenges of assessing impact of palliative care interventions

- Multiple problems & many confounding factors
 - Concurrent symptom burden
 - Interplay between symptoms and domains
- Lack of appropriate outcome measures, with acceptable psychometric properties for palliative care
 - This is improving
 - Hopwood P, Stephens RJ. Br J Cancer. 1995 Mar;71(3):633-6.

Outcome measures developed for palliative care

- Many have been developed. Focus of ongoing research
- Symptom prevalence & intensity
 - Pain, dyspnea, delirium, cognitive status, nausea, etc
- Functional status
 - Palliative Performance Scale
- Psychological distress
 - Depression & anxiety
- Quality of life
- Sense of Dignity
- Etc
- Etc

Challenges can be overcome

- RCTs are possible
- Other methods are just as important:
- Retrospective
- Cohort studies
- Cohort, case control, audits, qualitative research

EXAMPLES OF RESEARCH ACROSS DOMAINS AND USING VARIOUS RESEARCH METHODS

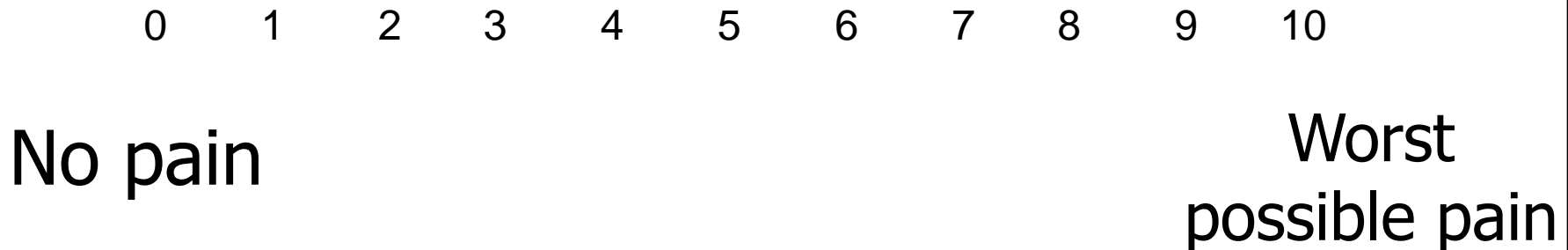


Types of Validated Pain Rating Scales

Visual Analogue Scale



Numerical Rating Scale



The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients

Bruera E et al. J Pall Care 1991 Summer;7(2):6-9

- Eight visual analog scales (VAS) 0-100 mm, completed by the patient alone or with assistance
- Indicate levels of pain, activity, nausea, depression, anxiety, drowsiness, appetite, and sensation of well-being
- Information then transferred to a graph that contains the assessments of up to 21 days on each page.
- Sum of the scores for all symptoms is defined as the symptom distress score

ESAS H&N ca

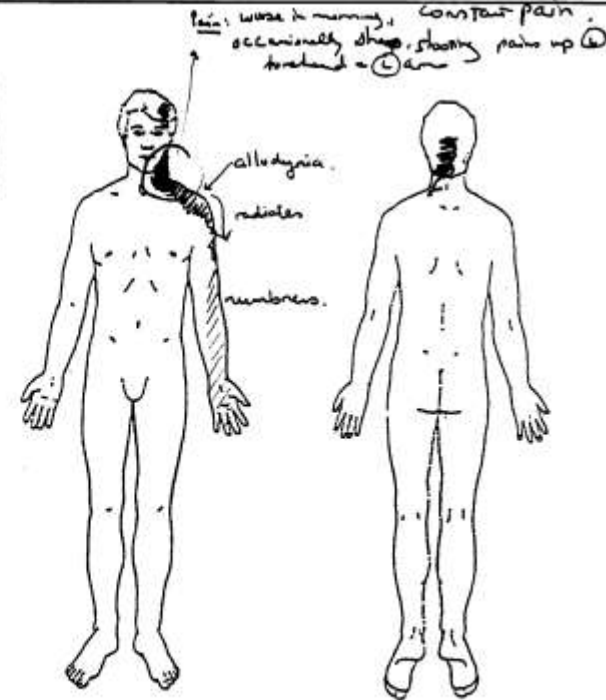
- 58y/o lady
- H&N ca
- Unable to swallow
- Pain

Please circle the number that best describes:

No Pain	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
Not Tired	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
Not Nauseated	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
Not Depressed	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
Not Anxious	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Not Drowsy	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
Best Appetite	1	2	3	4	5	6	7	8	9	10	Worst Possible Appetite
Best Feeling of Wellbeing	1	2	3	4	5	6	7	8	9	10	Worst Possible Feeling of Wellbeing
No Shortness of Breath	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
Other Problem	1	2	3	4	5	6	7	8	9	10	

dysphagia 9/10

Please mark on these pictures where it is you hurt.



Name: ~~_____~~ ~~_____~~
 Date: ~~_____~~ 9 May 96

Regional Palliative Care Program
 a: /forms/ESAS/

ESAS Hospice Morphine + Adjuvant

- 78y/o lady
- Ovarian Ca
- Hospice
- Neuropathic pain

	DATE	NOV 23	24	25	26	27	28	29	30	DEC 01	02	03	04	05	
	HOSP. DAY	ADM													
	HOUR	10	18	10	18	10	18	10	18	10	18	10	18	10	18
PAIN		█		█	█	█	█	█	█	█	█	█	█	█	█
ACTIVITY		█		█	█	█	█	█	█	█	█	█	█	█	█
NAUSEA		0		0	0	0	0	0	0	1	1				4
DEPRESSION		█		█	█	█	█	█	█	1	1	1			4
ANXIETY		█		█	█	█	█	█	█	█	█	█	█	█	█
DROWSINESS		█		█	█	█	█	█	█	1	1	1			█
APPETITE		█		█	█	█	█	█	█	1	1	1			█
WELLBEING		█		█	█	█	█	█	█	█	█	█	█	█	█
SHORTNESS OF BREATH		0		0	0	0	0	0	0	1	1	1			4

ASSESSED BY	P		P	P	P	U	P	P	NA	NA	NA	NA	NA	NA	NA
Code	P - Patient N - Nurse NA - Nurse Assisted F - Family														
Mini-Mental State Score	30														30

High burden of suffering on patients

<i>Symptom</i>	<i>TPCU (n=156)</i>	<i>Hospice (n=428)</i>
<i>Pain</i>	74%	57%
<i>Fatigue</i>	90%	83%
<i>Nausea</i>	36%	25%
<i>Depression</i>	59%	46%
<i>Anxiety</i>	67%	50%
<i>Drowsiness</i>	72%	74%
<i>Poor Appetite</i>	76%	73%
<i>Shortness of breath</i>	50%	38%
<i>Poor well-being</i>	80%	65%

E Bruera, K Neumann. Supp Care Cancer 1999

Portenoy et al. EJCO 1994; 30: 1326-1336

Figure 2 / ESAS SCORES DURING FIRST WEEK OF ADMISSION

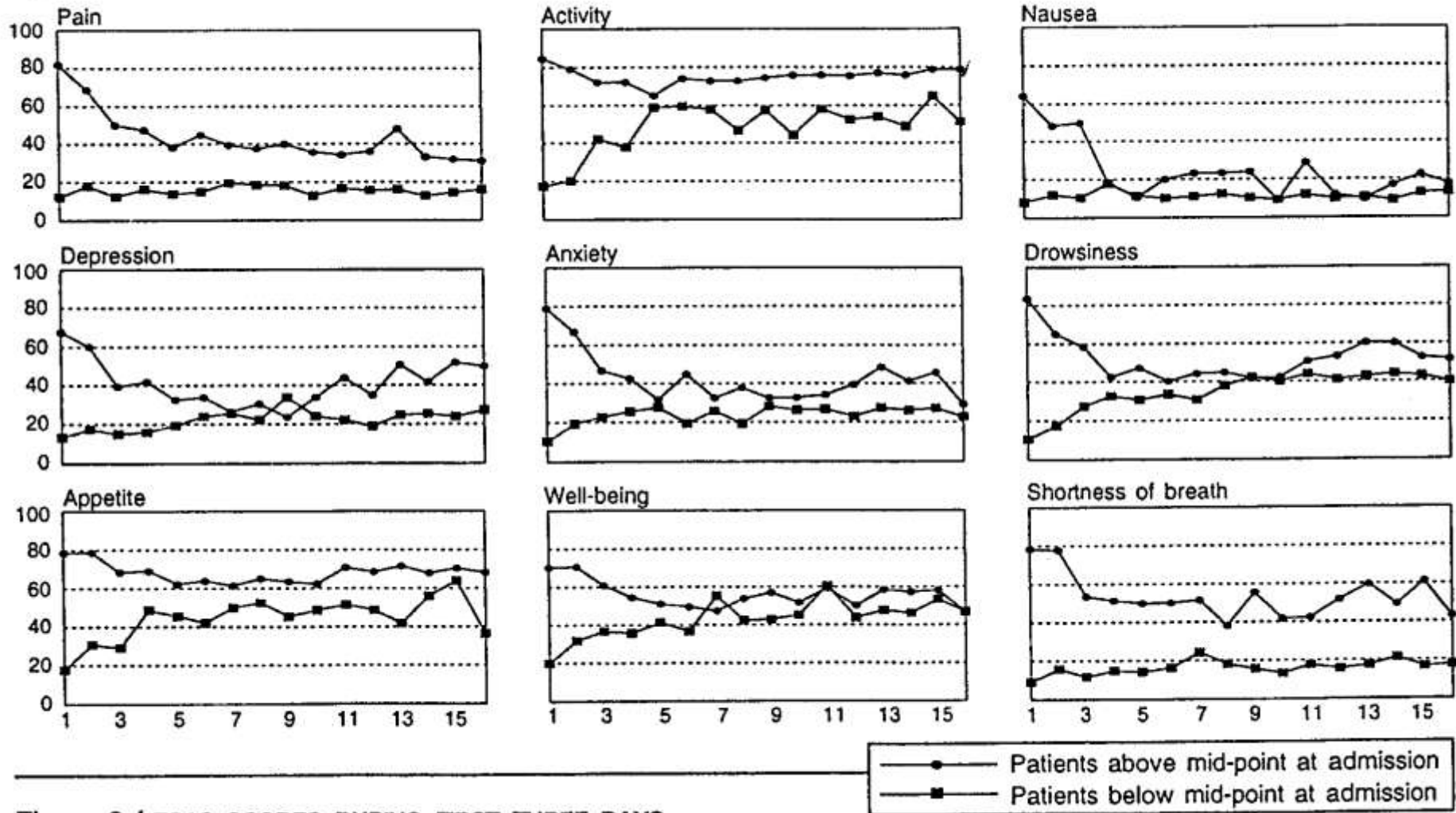
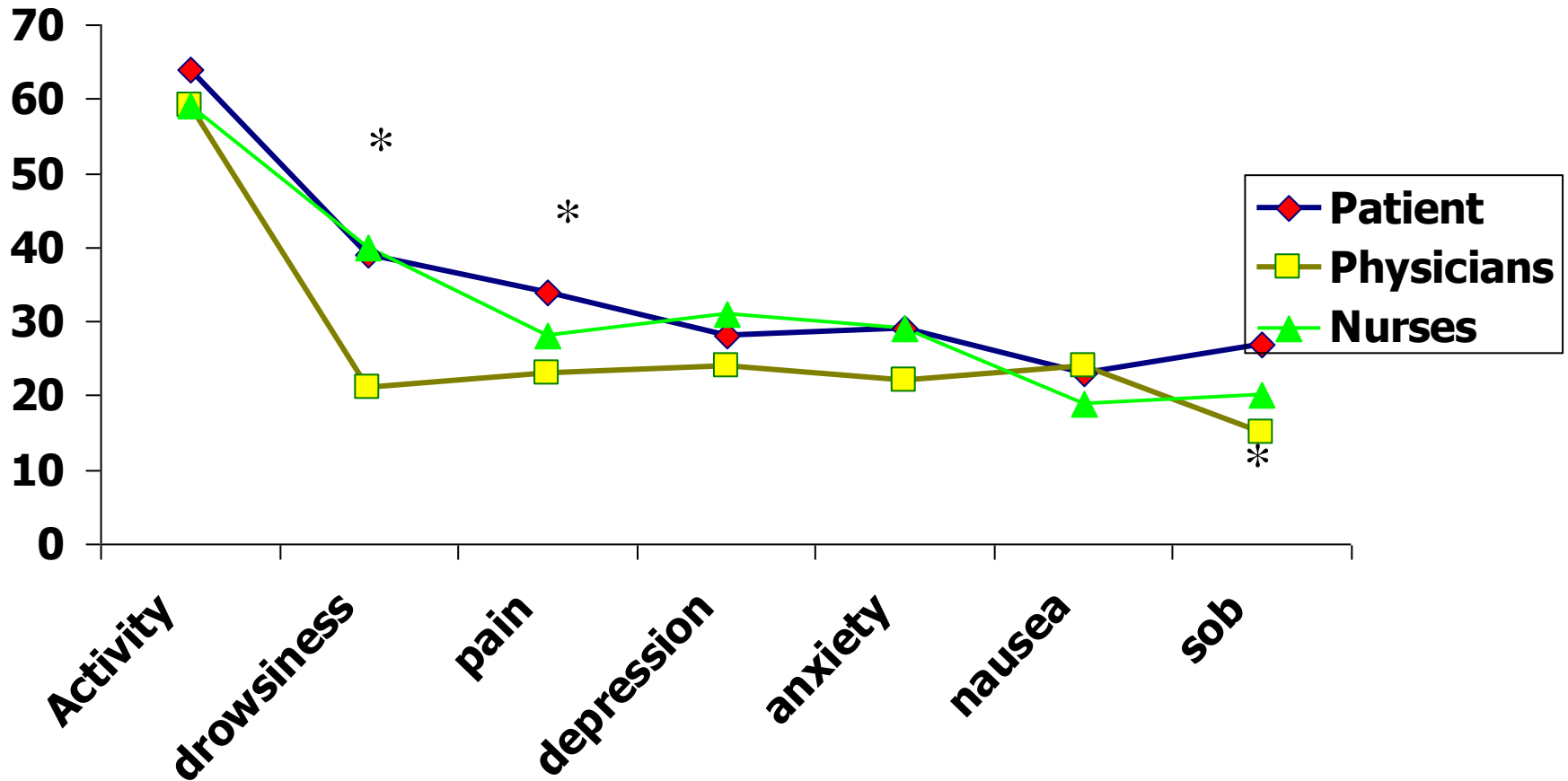


Figure 3 / ESAS SCORES DURING FIRST THREE DAYS

Patient vs Proxy Assessments

Nekolaichuk C et al Pall Med 1999

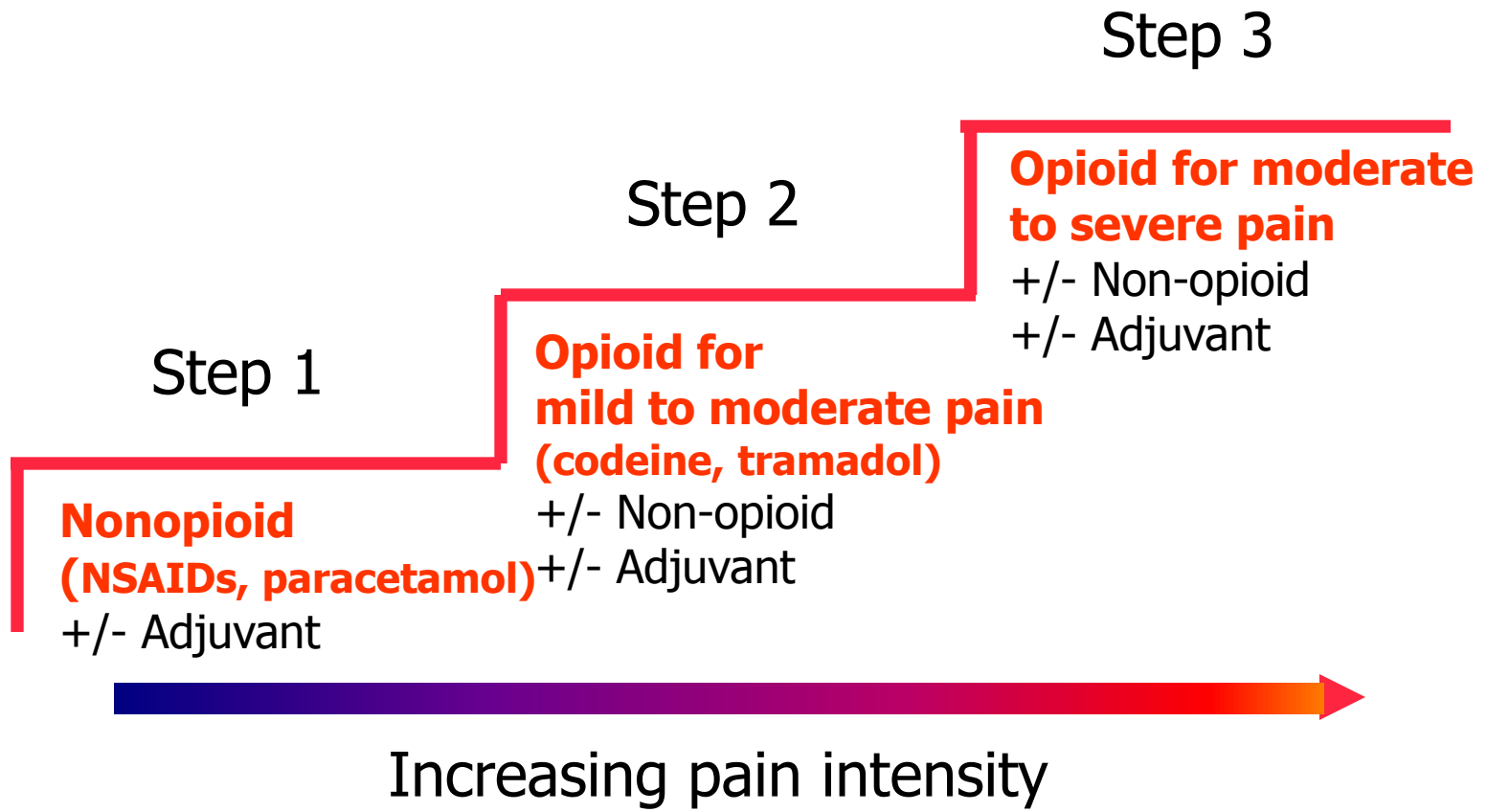


Multidisciplinary symptom control clinic in a cancer center.

Study to assess if patients seen in a cancer centre outpatients palliative care clinic actually were palliated.

Symptom	1 st visit	2 nd visit (n=110)	P	2-week phone call (n=64)	P
Pain	5.5 ± 2.7	5 ± 2.9	NS	3.7 ± 2.8	HS
Depression	3.3 ± 3	2.65 ± 2.7	HS	1.74 ± 2.5	HS
Anxiety	3.6 ± 3	3 ± 2.7	HS	1.8 ± 2.5	HS
Nausea	2.5 ± 2.9	2.1 ± 2.7	NS	1.84 ± 2.9	HS
Shortness of breath	2.8 ± 3	2.9 ± 2.8	NS	1.8 ± 2.6	HS
Overall sense of wellbeing	5.4 ± 2.9	4.5 ± 2.7	HS	3.25 ± 2.6	HS

WHO analgesic ladder



Non steroidal anti-inflammatory drugs (NSAIDs) for managing cancer pain

- NSAIDs are more effective than placebo and as effective as weak opioids or weak opioid/acetaminophen preparations for mild cancer pain
 - Caraceni A, et al. J Pain Symptom Manage 2001; 21(2):89-91.

Non steroidal anti-inflammatory drugs (NSAIDs)

- Evidence for a special role in bone pain is not strong
 - McNicol E, et al. J Clin Oncol 2004; 22(10):1975-1992.
 - Management of Cancer Pain. Evidence Report/Technology Assessment Number 35. Evidence Report/Technology Assessment Number 35. 2001. Rockville, MD., Agency for Healthcare Research and Quality.
 - Alkhenizan A, et al. European Journal of Palliative Care. 2004; 11[1], 121-125.

List of essential medicines in Palliative care

- **International Association for Hospice and Palliative Care list (IAHPC)**

Consensus on experts around the world

Criteria:

- ✓ Public health relevance
- ✓ evidence on efficacy
- ✓ safety
- ✓ effectiness

de Lima et al. Journal of Pain and Symptom management 2007

http://www.who.int/medicines/services/essmedicines_def/en/index.html

www.hospicecare.com

IAHPC list: essential opioids

- **Morphine: 1st choice for moderate to severe pain**

Optimal route: oral: immediate and sustained release

Preferred alternative route: subcutaneous

- **Alternative opioids:**

- oxycodone

- transdermal fentanyl

(stable opioid requirements) WITH a short acting opioid

- methadone (with special training)

de Lima et al. Journal of Pain and Symptom management 2007

http://www.who.int/medicines/services/essmedicines_def/en/index.html

www.hospicecare.com

Opioids for pain management

- Pain management, independently of life's prognosis
- Patients with progressive life-threatening illnesses (cancer and non-cancer)

Efficacy of WHO 3 step analgesic ladder

Reference	Cancer	Type of study	Nb pts	Results
Rappaport 1985	Various	Retrospective	63	97% appropriate control
Takeda 1986	Various	Prospective	156	87% total control
Ventafrida 1987	Various	Retrospective	1229	>70% appropriate control
Goisis 1989	Various	Prospective	45	93% total control or mild pain
Vijayaram 1988	Various	Prospective	88	88% satisfactory control
Walker 1988	Various	Prospective	20	100% good control
Schug 1990	Various	Prospective	174	>80% no or moderate pain
Grond 1991	Various	Retrospective	1070	70% no or mild pain
Grond 1991	Various	Prospective	401	76% pain free at the time of death
Mercadante 1992	Various	Prospective	98	> 70% good control
Radbruch 1992	Breast	Prospective	106	92% no or moderate pain
Vecht 1992	ENT	Prospective	25	72% good control
Grond 1993	ENT	Prospective	167	Good control; 5% severe pain

Could pain affect cancer prognosis?

□ Pain *Can Kill* John Liebeskind Pain 1991

☞ Pain and accompanying stress reaction could have deleterious effects on the evolution of certain cancers

□ K.Lillemoe Surg Oncol Clin North Am 1998

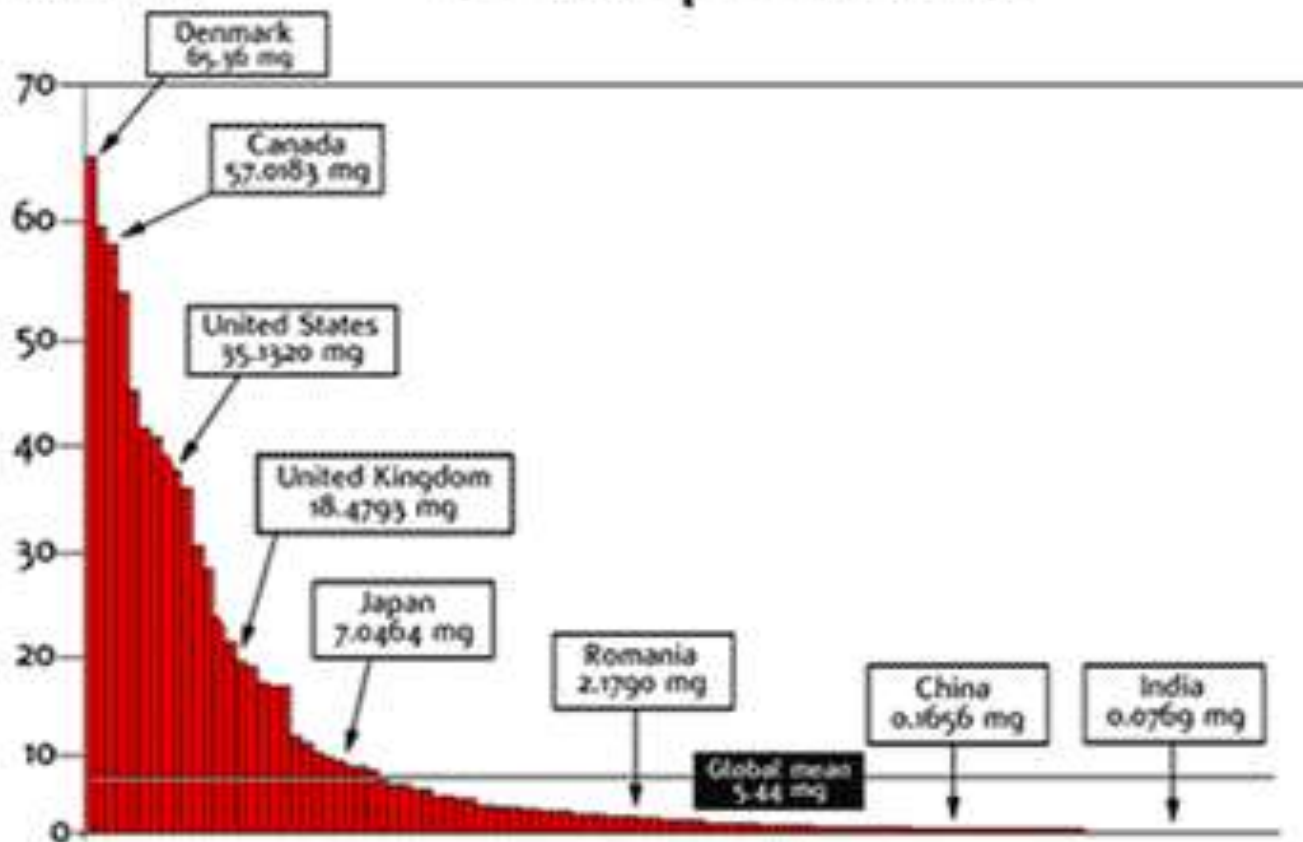
Pancreatic cancer patients undergoing laparotomy, randomization with coeliac plexus alcoholisation or normal saline.

Better pain control for patients having had coeliac plexus alcoholisation

☞ Patients who suffered from severe pain had a significantly increased survival after alcoholisation

Per Capita Global Consumption of Morphine 2001

mg/capita



Source: International Narcotics Control Board

Original Article

A Randomized, Double-Blind, Crossover Trial of the Effect of Oxygen on Dyspnea in Patients with Advanced Cancer

Jennifer Philip, MBBS, MMed, Dip Pall Med, FACHPM, Michelle Gold, MBBS, FRACP, FACHPM, Dip Pall Med, Alvin Milner, BSc, PhD, Juliana Di Iulio, BSc, PhD, Belinda Miller, MBBS, PhD, FRACP, and Odette Spruyt, MBChB, Dip Obs, FRACP, FRACHPM

Palliative Care Service (J.P., M.G.) and AIRMed (B.M.), The Alfred Hospital, Melbourne; and Center for Biostatistics & Clinical Trials (A.M., J.D.I.) and Department of Pain and Palliative Care (O.S.), Peter MacCallum Cancer Center, East Melbourne, Victoria, Australia

Open trial of olanzapine for treatment of delirium in hospitalized cancer patients.

Breitbart W, et al. Psychosomatics 2002;43:175-182

- N=79
- Delirium rated with MDAS
- 76% had complete resolution of delirium
- Mean olanzapine doses:
 - t0 = 3mg (2.5-10mg)
 - t2 = 4.6mg (2.5-10mg)
 - t3 = 6.3mg (2.5-20mg)

Open trial of olanzapine for treatment of delirium in hospitalized cancer patients.

Breitbart W, et al. Psychosomatics 2002;43:175-182

- Predictors of poor response
 - Age (>70yrs old) rr 42%
 - History of dementia (rr 46%)
 - Hypoactive delirium (rr 48%)
 - The more severe the delirium, the less likely the response
- Side effects
 - 30% experienced sedation
 - no EPS

Palliative radiotherapy

- Very useful- up to 75% of patients will have a response
- Pain relief lasts for many months
- Pain relief starts usually within 5-7 days, but response may be seen even up to 3-4 weeks after treatment
- Single dose (fraction) as effective as multiple doses.

Palliative Care Units improve QOL

Study to evaluate if care in a tertiary palliative care unit improves quality of life of terminally ill patients.

Montreal, Canada

Scale	Admission mean (SD)	7-8 days mean (SD)	Probability
MQOL-Total	4.6 (1.6)	6.3 (2.3)	<0.01
Physical symptoms	3.7 (2.6)	5.1 (2.4)	<0.01
Psychological	5.0 (2.5)	6.2 (2.8)	<0.01
Existential	6.0 (1.7)	6.5 (1.9)	0.02
Physical Well-being	3.6 (2.4)	5.6 (2.2)	<0.01

Decision-making

- Pts with advanced breast cancer interviewed:
 - 70 pts receiving first-line chemotherapy
 - 47 pts offered palliative second-line chemotherapy
- **Results**
 - Women offered second-line chemotherapy were more likely to undergo chemotherapy because of the “hope” it offers.
 - Compassionate and honest communication about prognosis and likelihood of benefit from treatment needed.

Grunfield E, et al. Journal of Clinical Oncology 2006; 24(7):1090-1098

Will to Live and Will to die

- Will to live fluctuates from day to day (and even hour to hour)
- Factors that correlate with decreased will to live
 - Depression
 - Loss of meaning
 - Feeling a burden
 - Loss of hope
 - Loss of sense of dignity
 - Chochinov et al. 1996, 1999, 2000, 2002
 - Chochinov H et al. Psychosomatics 2005; 46:7–10

Spiritual Unmet needs of Cancer Patients

n=248

- Overcoming fears - 51%
- Finding hope - 42%
- Finding meaning in life - 40%
- Finding peace of mind - 43%
- Finding spiritual resources - 39%

Higher rate of spiritual/existential needs in ethnic minorities, unmarried patients, more recent diagnosis

Do patients want physicians to inquire about their spiritual or religious beliefs when they become gravely ill?

- 51%: Identified themselves as religious
- 66%: Physicians should ask about religious/spiritual beliefs.
- 45%: Religious beliefs influence their medical decisions
- 16%: Do not want their beliefs explored.
- 15%: Recalled having been asked about their beliefs

Ehman JW, et al. *Arch Intern Med.* 1999;159:1803-1806.

How does we as health care professionals provide spiritual care

- Qualitative, ethnographic study
- Results
 - It is in the small things we do
 - The tenor of care
 - All members of a palliative care team contribute

Sinclair S, Raffin S, Pereira J, Guebert N. Collective Soul: The Spirituality Of An Interdisciplinary Palliative Care Team. Supportive and Palliative Care Cambridge University 2006;4(1):13-24.

Sexuality in palliative care

- How do palliative patients experience sexuality?
- How can we address their needs in this area
- Qualitative phenomenology approach
- Results
 - Intimacy rather than sexual intercourse as disease becomes very advanced
 - Privacy needed in hospital rooms just “to be close”

Lemieux L, Kaiser S, Pereira J, Meadows L.
Sexuality in Palliative Care: A Qualitative Study.
Palliative Medicine. 2004 18(7):630-7

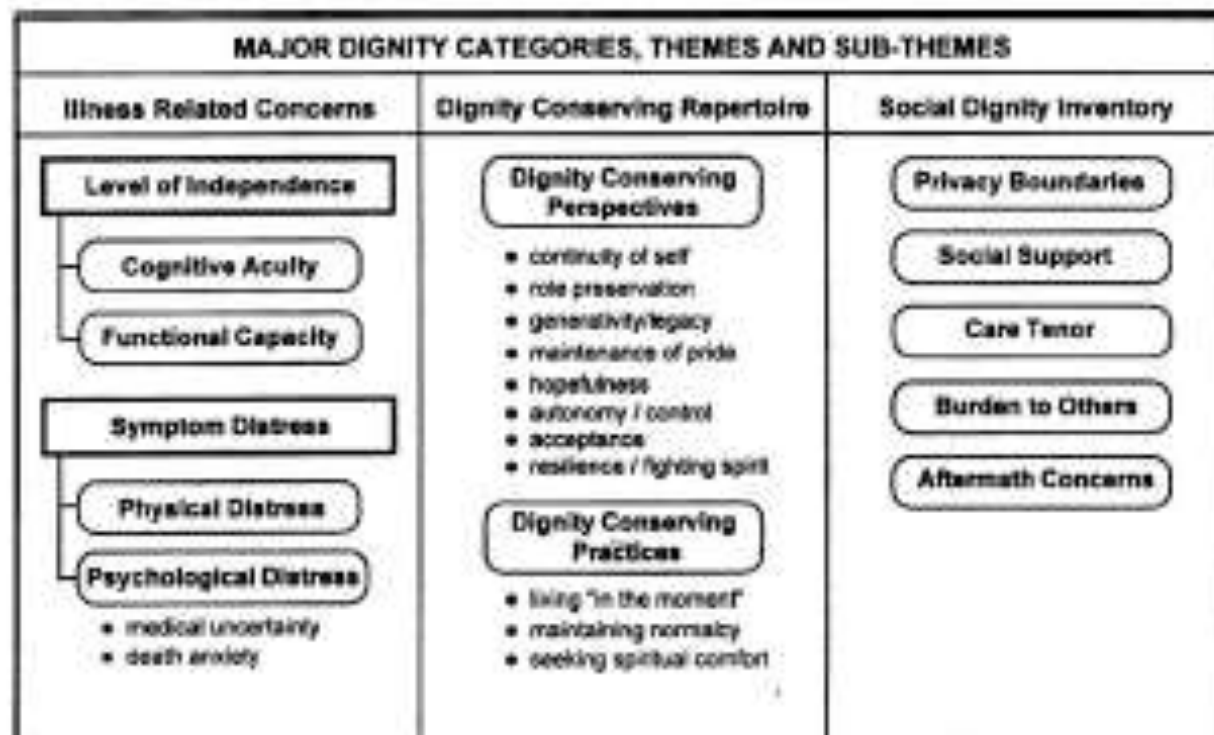


FIGURE 1 The Dignity Model. Reprinted from Chochinov et al.,⁴⁶ with permission from Elsevier.

Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life

Harvey Max Chochinov, Thomas Hack, Thomas Hassard, Linda J. Kristjanson, Susan McClement, and Mike Harlos

A B S T R A C T

Purpose

This study examined a novel intervention, dignity therapy, designed to address psychosocial and existential distress among terminally ill patients. Dignity therapy invites patients to discuss issues that matter most or that they would most want remembered. Sessions are transcribed and edited, with a returned final version that they can bequeath to a friend or family member. The objective of this study was to establish the feasibility of dignity therapy and determine its impact on various measures of psychosocial and existential distress.

Patients and Methods

Terminally ill inpatients and those receiving home-based palliative care services in Winnipeg, Canada, and Perth, Australia, were asked to complete pre- and postintervention measures of sense of dignity, depression, suffering, and hopelessness; sense of purpose, sense of meaning, desire for death, will to live, and suicidality; and a postintervention satisfaction survey.

Results

Ninety-one percent of participants reported being satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family. Postintervention measures of suffering showed significant improvement ($P = .023$) and reduced depressive symptoms ($P = .05$). Finding dignity therapy helpful to their family correlated with life feeling more meaningful ($r = 0.480$; $P = .000$) and having a sense of purpose ($r = 0.562$; $P = .000$), accompanied by a lessened sense of suffering ($r = 0.327$; $P = .001$) and increased will to live ($r = 0.387$; $P = .000$).

Conclusion

Dignity therapy shows promise as a novel therapeutic intervention for suffering and distress at the end of life.

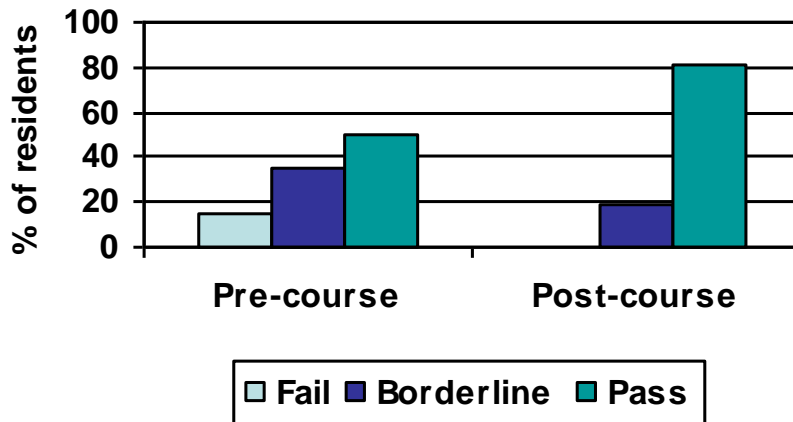
Dignity conserving care: Study results

- English-speaking Canadian & Australian patients
- 81/100 agreed to participate
- Mean age = 64 (range: 22-95)
- 64% married
- 91% satisfied w/ intervention
- 76% said it heightened sense of dignity
- 47% said it increased will to live
- Unchanged parameters (suicide ideation)

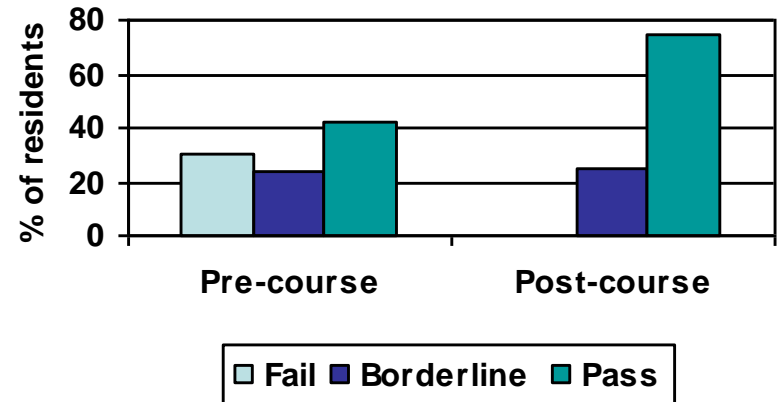
– Chochinov et al. JCO. 2005;23:5520-5525

Impact of education program

2005 OSCE 2



2005 OSCE 3



Pereira JL. The Development and Psychometric Assessment of an Instrument to Assess the Palliative Care Competencies. (Masters of Science in Medical Education Degree Thesis). Publisher: Ottawa: Library and Archives Canada; 2007. ISBN: 978049192566

Finding the balance

“Palliative Care in the 21st Century is rapidly developing into a scientifically based discipline, yet it needs to retain its humanely expressed clinical practice which has been its strength from its inception”

Bennet S, Ahmedzai S. Pall Med 2000

Where do deaths occur?

Period	% of deaths in hospitals
1949	50%
1958	61%
1980	74%
1992	74% (20% at home)

Emmanuel L, von Gunten C.
2000. Deaths in USA
institutions (1949-1992)

Period	% of deaths at home
1950	75%
1995	25%

Emmanuel L, von Gunten C.
2000. Deaths in France

Availability of various elements in regional palliative care programs

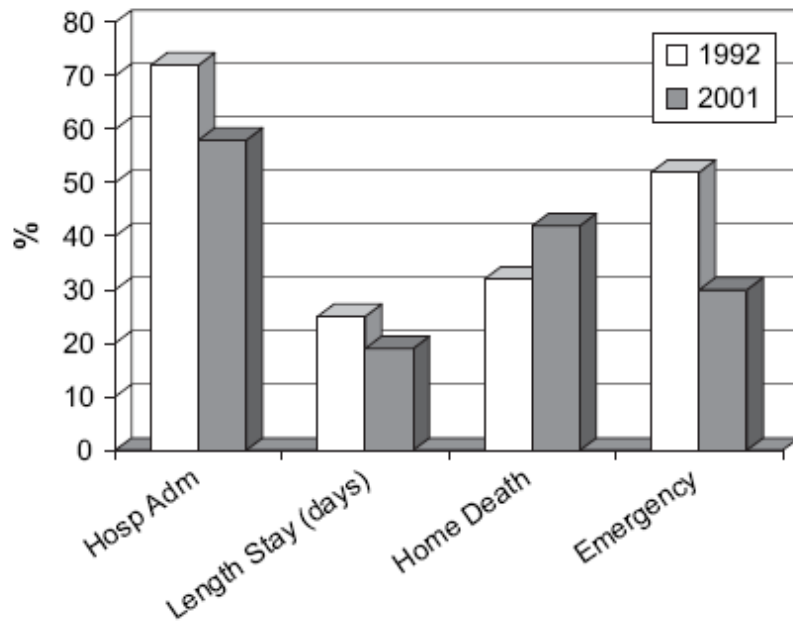


Fig. 2. Comparison of consumption of resources: 1992-2001. Hosp. Adm. = percentage of hospital

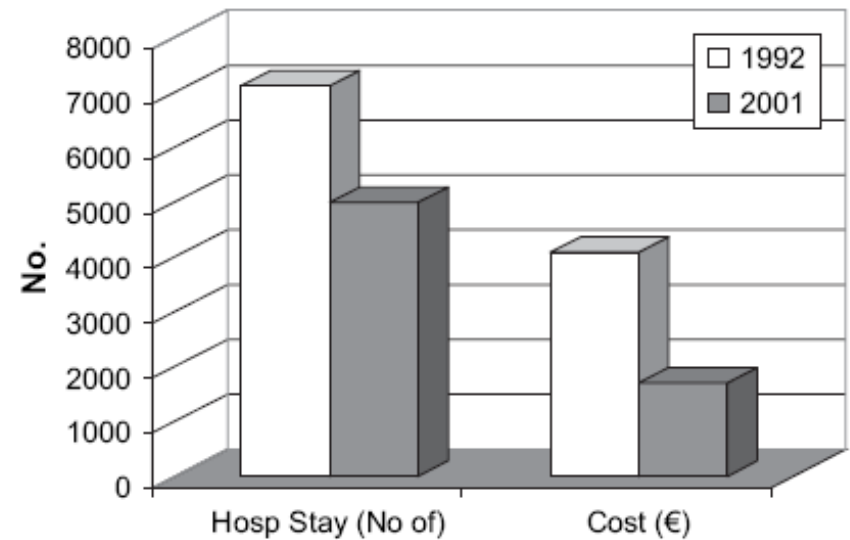


Fig. 3. Comparison of number of hospitalizations and cost: 1992-2001. Hosp. Stay = number of hospi-

Gomez-Batiste X, et al. Resource Consumption and Costs of Palliative Care Services in Spain: A Multicenter Prospective Study. *J Pain Symptom Manage* 2006;31:522--532.

Canadian National Norms & Standards

Square of Organization

***Principal
Activities***

**F
U
N
C
T
I
O
N
S**

Governance & Administration

Leadership - board, management
Organizational structure, accountability

Planning

Strategic planning
Business planning
Business development

Operations

Standards of practice, policies & procedures, data/documentation guidelines
Resource management
Safety, security, emergency systems

Quality Management

Performance improvement
Routine review
outcomes, resource utilization
risk management
compliance
satisfaction, needs
financial audit
accreditation
strategic & business plans
standards, policies & procedures, data/ documentation guidelines

Communications/ Marketing

Communication/marketing strategies
Materials
Media liaison

RESOURCES

Financial	Human	Informational	Physical	Community
Assets Liabilities	Formal caregivers Consultants Staff Volunteers	Records - health, financial, human resource, assets Resource materials, eg, books, journals, Internet, Intranet Resource directory	Environment Equipment Materials/supplies	Host Organization Healthcare System Partner healthcare providers Community organizations Stakeholders, public

Palliative Care Research in Developing Countries

- Infrastructure needed for palliative care research in developing countries
 - Expertise (design of studies, instrument development, data management, data analysis)
 - Research assistants
 - Capacity building
- Instruments specifically for developing countries and less privileged populations: Psychometric

Palliative care in Kerala (India)

A model for resource-poor settings

Bollini et al. Onkologie 2004

- Needs assessment: Information from government officials, health professionals involved in cancer care, patients and their families, sponsors, members of palliative care teams across Kerala and newly established palliative care clinics.
- Creation of a network of 33 PC clinics across Kerala, providing care free of charge. Supportive home care service: trained volunteers from the community assisted in providing care, empowerment of family members
- In 2002: network of clinics saw 6.000 new patients, about 25% of incident cancer cases.

Conclusions

- Palliative care begins earlier in the illness trajectory
- PC is an integral component of health care (and the care you provide)
- PC research constitutes an ethical imperative
- Everyday practice lends itself to PC research
- PC research involves many different domains

Conclusions

- Ethical issues should always be considered
 - Several methodological challenges exist to PC research
 - Outcome measures for PC exist
 - A variety of different research methods can be used in PC research
 - There have been many developments in the field as a result of research
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