

Symposium
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END-OF-LIFE QUESTIONS

BANGLADESH MEDICAL ASSOCIATION

PRESENTED BY

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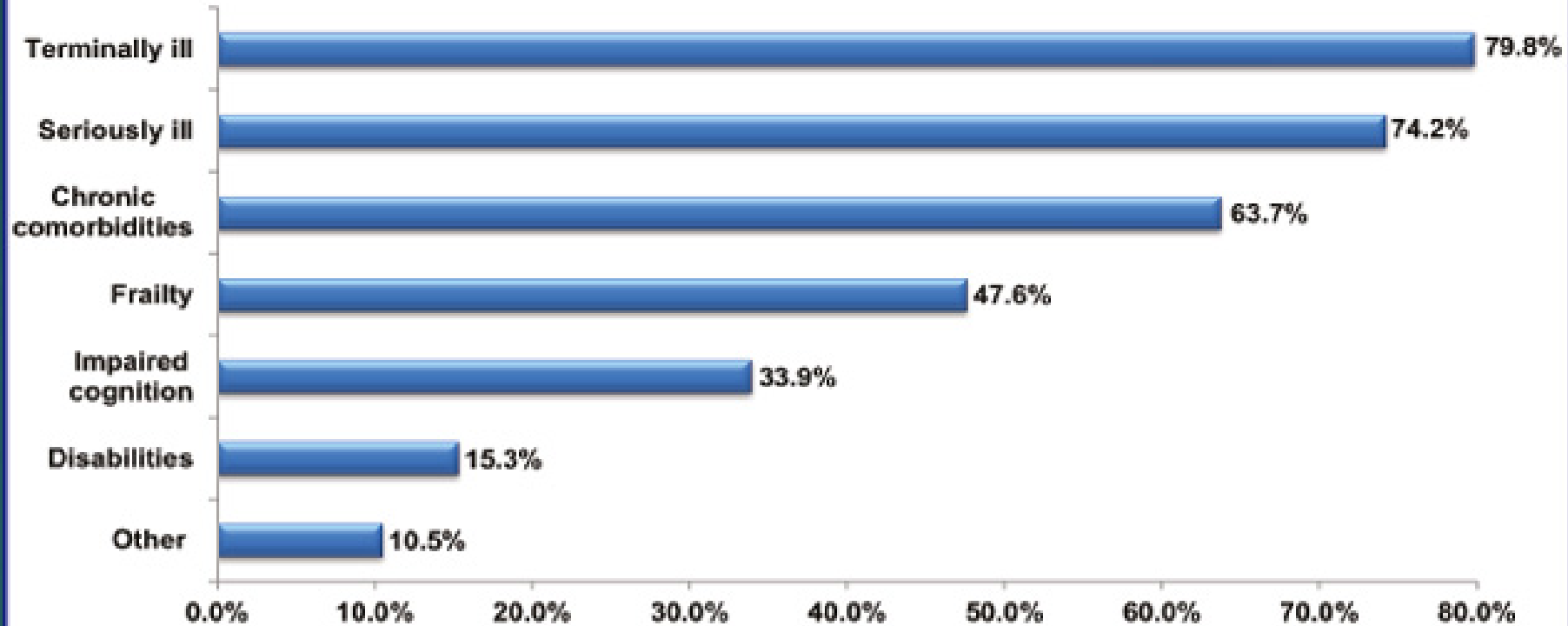
End-of-life questions

What does it mean

People are approaching the “End of Life” if they are likely to die within the next 12 months. It includes people with :

- ▶ advanced, progressive, incurable conditions
- ▶ general frailty and co-existing conditions
- ▶ existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- ▶ life threatening acute conditions caused by sudden catastrophic event
- ▶ People with dementia and similar conditions which affect capacity.

Key Characteristics of Palliative Care Patients

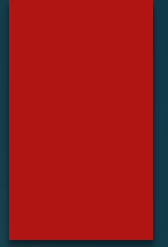


Source: 2014 Healthcare Performance Benchmarks: Palliative Care
February 2014

Various Aspects Of End-Of-Life Care



End-of-life Decisions



End of life care requires a range of decisions including :-

- a) questions of palliative care,
- b) patients' right to self-determination (of treatment, life),
- c) medical experimentation,
- d) the ethics and efficacy of extraordinary or hazardous medical interventions

In addition, end of life often touches upon rationing and the allocation of resources in hospitals and national medical systems.

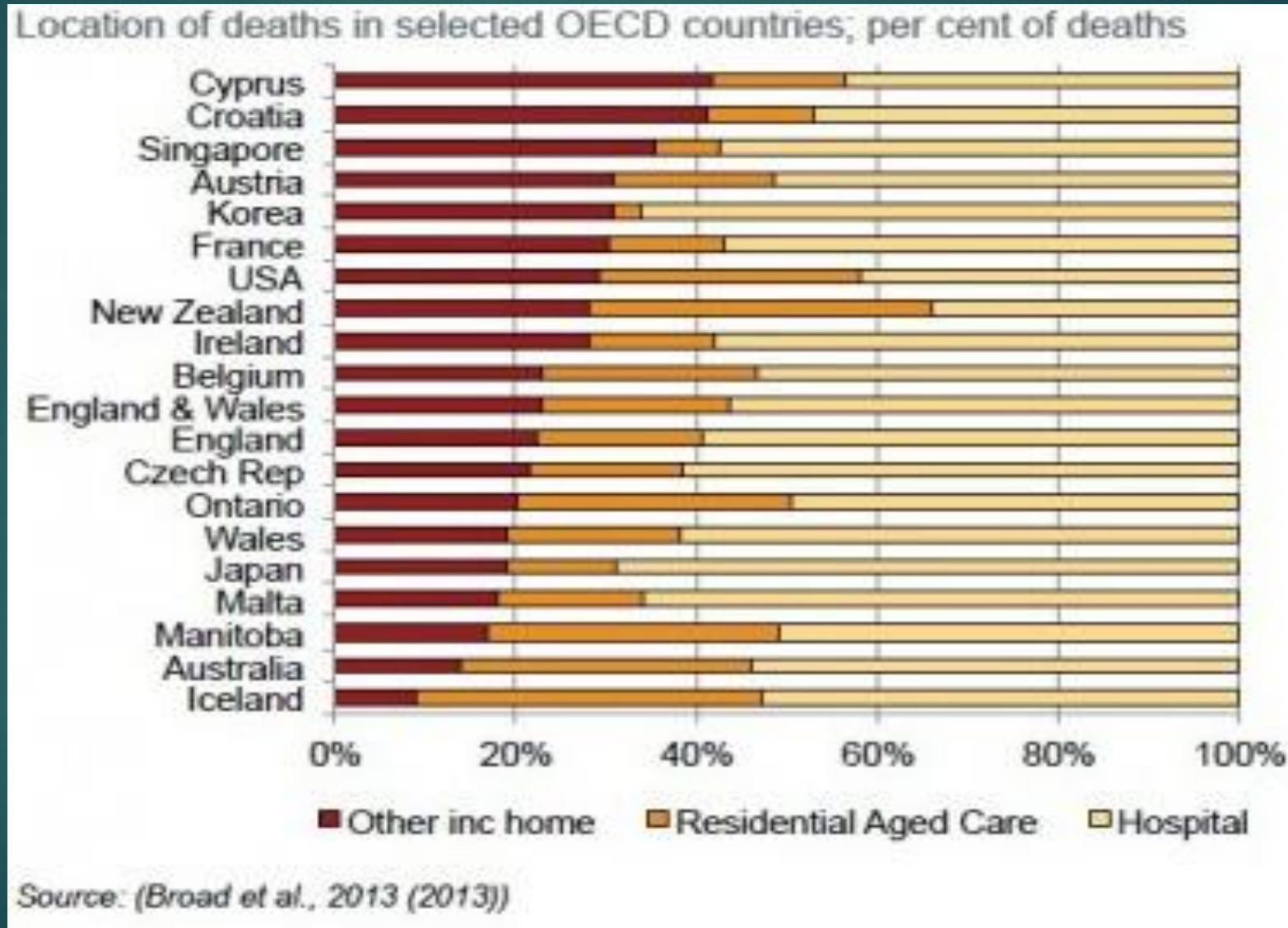
Present Scenario in end-of-life care

- ▶ A poll shows that almost one in four older Americans - approx. 25 million people experience excessive or unwanted medical treatment. This is especially true in the last year and very last days of life.
- ▶ There is an unspoken dark side of American medicine that is keeping patients alive at any price. Two-thirds of Americans die in healthcare institutions, tethered to machines and tubes at bankrupting costs, even though research shows that most prefer to die at home in comfort surrounded by loved ones.
- ▶ Cost burdens to individuals and families are matter of concern. A national study in the USA found that in 20% cases , a family member had to quit work ; 31% lost all or most savings (even though 96% had insurance) ; 20% reported loss of major source of income.
- ▶ A survey conducted by the California Healthcare Foundation found that 60% of respondents feel it is extremely important that their families not be burdened by tough decisions about their end of life care.

Present Scenario contd.

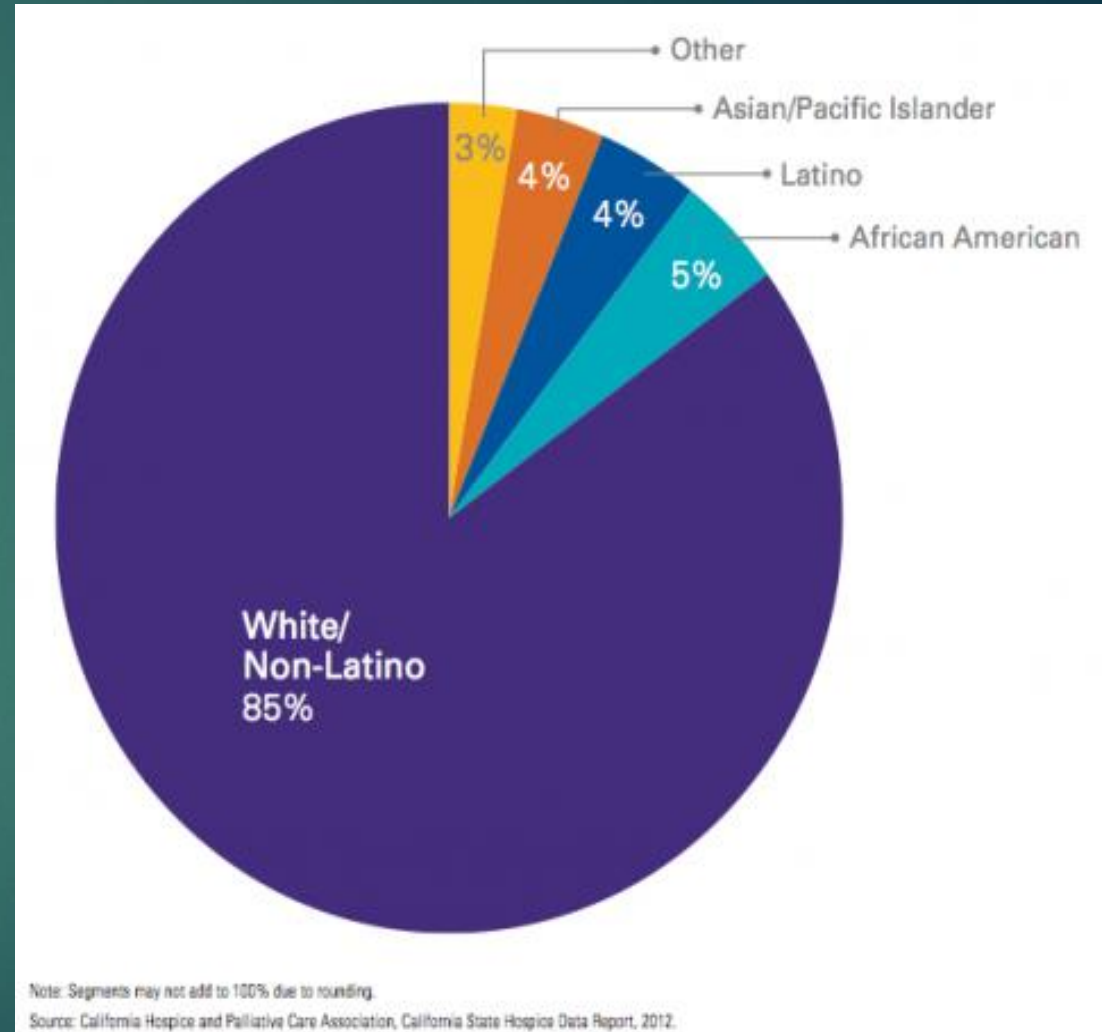
- ▶ In most advanced countries, medical spending on those in the last twelve months of life make up roughly 10% of total aggregate medical spending and spending on those in the last 3 years of life can account for upto 25%.
- ▶ Studies indicate that 70 - 95% of people would rather refuse aggressive medical treatment than have their lives medically prolonged in incompetent or other poor prognosis states.
- ▶ Over 60% of people (including those who were not facing life-threatening illness at the time) would prefer to die at home. In a population-based study involving 10000 adults across England, only 34% ranked dying in place as their top care-related priority.

Location And Percent Of Deaths in OECD Countries



Present Scenario contd.

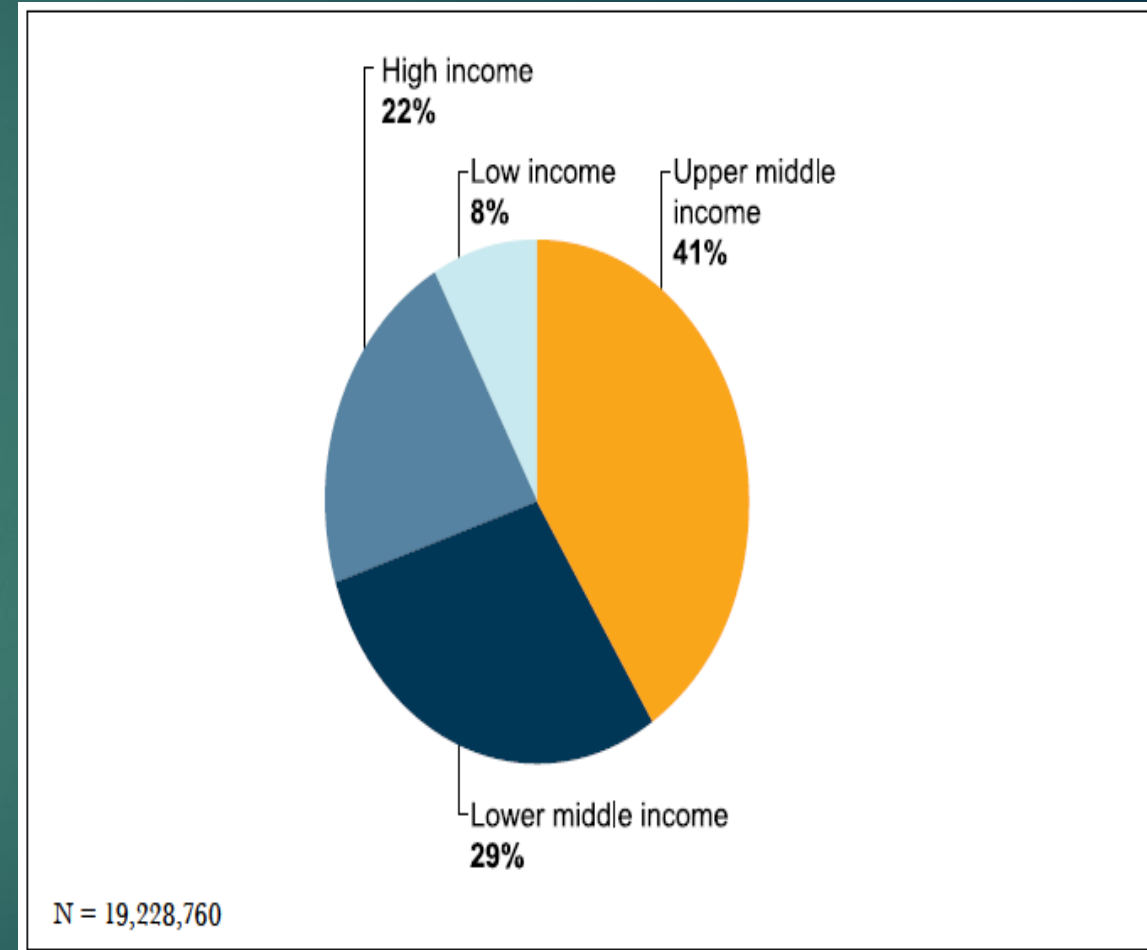
- ▶ Homeless people die at more than three times the rate of age-matched control in the general population ; their end of life care is almost non-existent.
- ▶ In case of black and minority ethnic population, there is a lower uptake of palliative and end of life care services compared to white/majority groups.
- ▶ People with learning difficulties are less likely to have access to specialist palliative care services, receive inadequate pain control in their final illness and are more likely to have their deaths described not being planned for, uncoordinated and poorly managed.
- ▶ Approx. one third of people aged 60 years will die with dementia, many with complex physical and psychological need. Many of them receive poor quality care towards the end of life.



Deaths in hospice care by ethnicity/ race

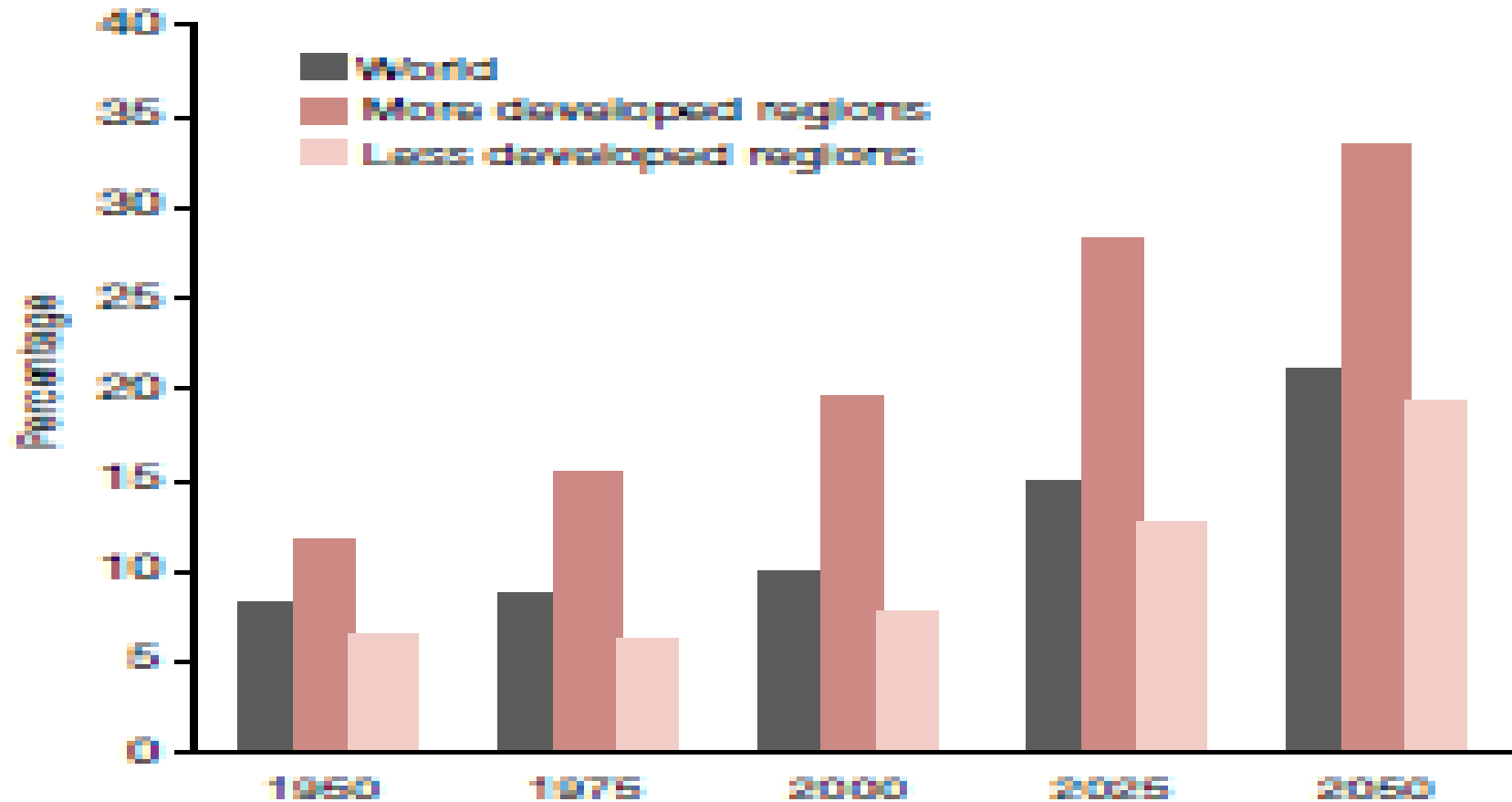
Present Scenario contd.

- ▶ One large scale study of cancer patients found that costs were about a third less for patients who had end of life discussions than for those who didn't.
- ▶ 37.4% of all deaths from all causes need palliative care. In higher income countries with aged population this percentage may exceed 60% of total mortality. While in low and middle-income countries the figure is much lower due to higher mortality from infections and injuries.
- ▶ Over 20 million people are estimated to require palliative care at the end of life every year. 69% are adults who are more than 65 years old and 6% are children. 78% of these adults live in low and middle-income countries.



Distribution of major causes of death worldwide by country income groups

World population ageing(1960-2060)



Source: World population ageing 1960–2060 (1).

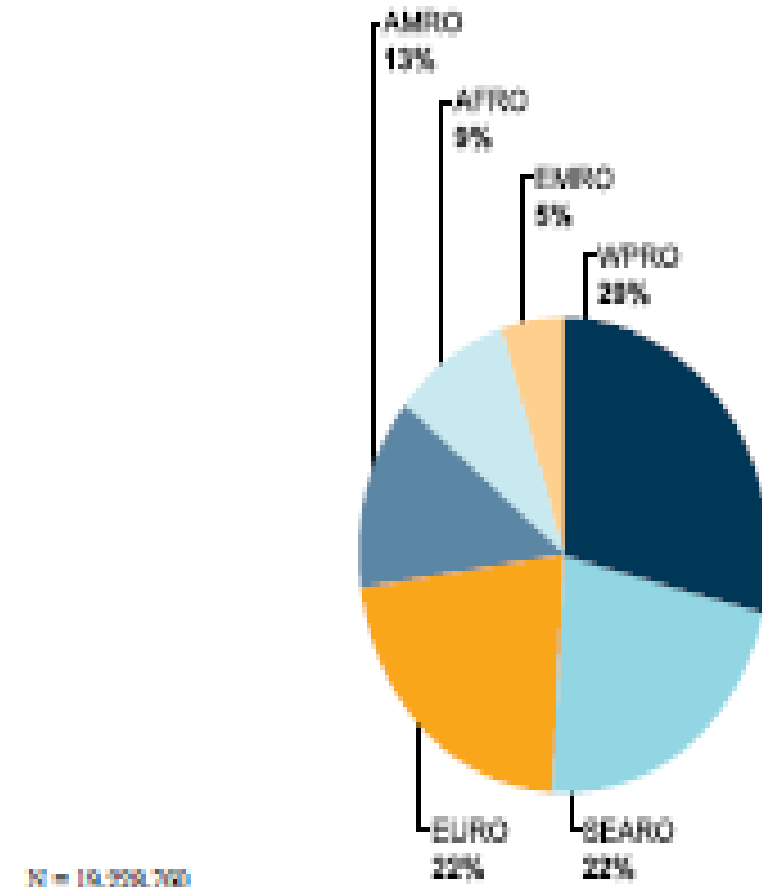
Fig. 1 – Population ageing: population aged 60 and over

Present scenario contd.

- ▶ Unfortunately, whatever development has taken place in palliative care provision, are mostly confined in the affluent part of the world with a few exceptions.
- ▶ With at least 2 family members involved in each patient's case a globally homogeneous development of palliative care could improve the quality of life of 100 million people worldwide.

Present Scenario contd.

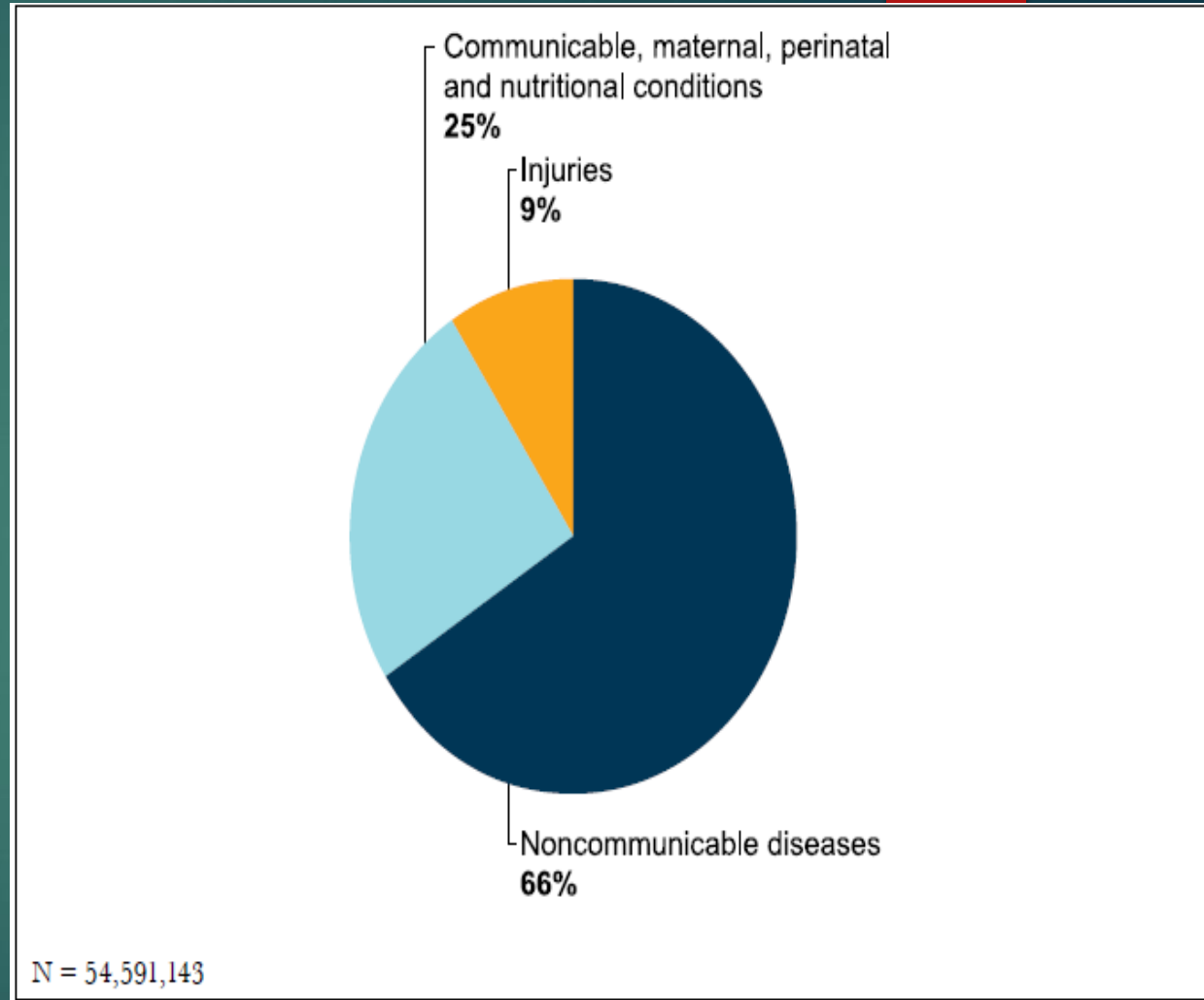
- ▶ According to World Palliative Care Alliance (WPCA), less than 8% of people in need of palliative care, have access to a palliative care service.
- ▶ With more than 85% of the world population living in developing countries, but only 6% of palliative care services that exist throughout the world being located in these regions.
- ▶ In 2011, 136 of the world's 234 countries had one or more hospice and palliative care services established.



Distribution of major causes of death worldwide by WHO regions

Present Scenario contd.

- ▶ Children in need of palliative care for progressive non-malignant disease represent by far the highest proportion of cases for all regions, whereas palliative care for cancer and HIV/AIDS represent a small percentage.
- ▶ WHO estimates that worldwide 5.5 million terminal cancer patients and 1 million end stage HIV/AIDS patients are suffering without adequate treatment for moderate to severe pain.



Distribution of major causes of death worldwide by disease groups

Options in End of Life Care decisions

- ▶ Dysthanasia
- ▶ Euthanasia
- ▶ Palliative care
- ▶ Hospice care

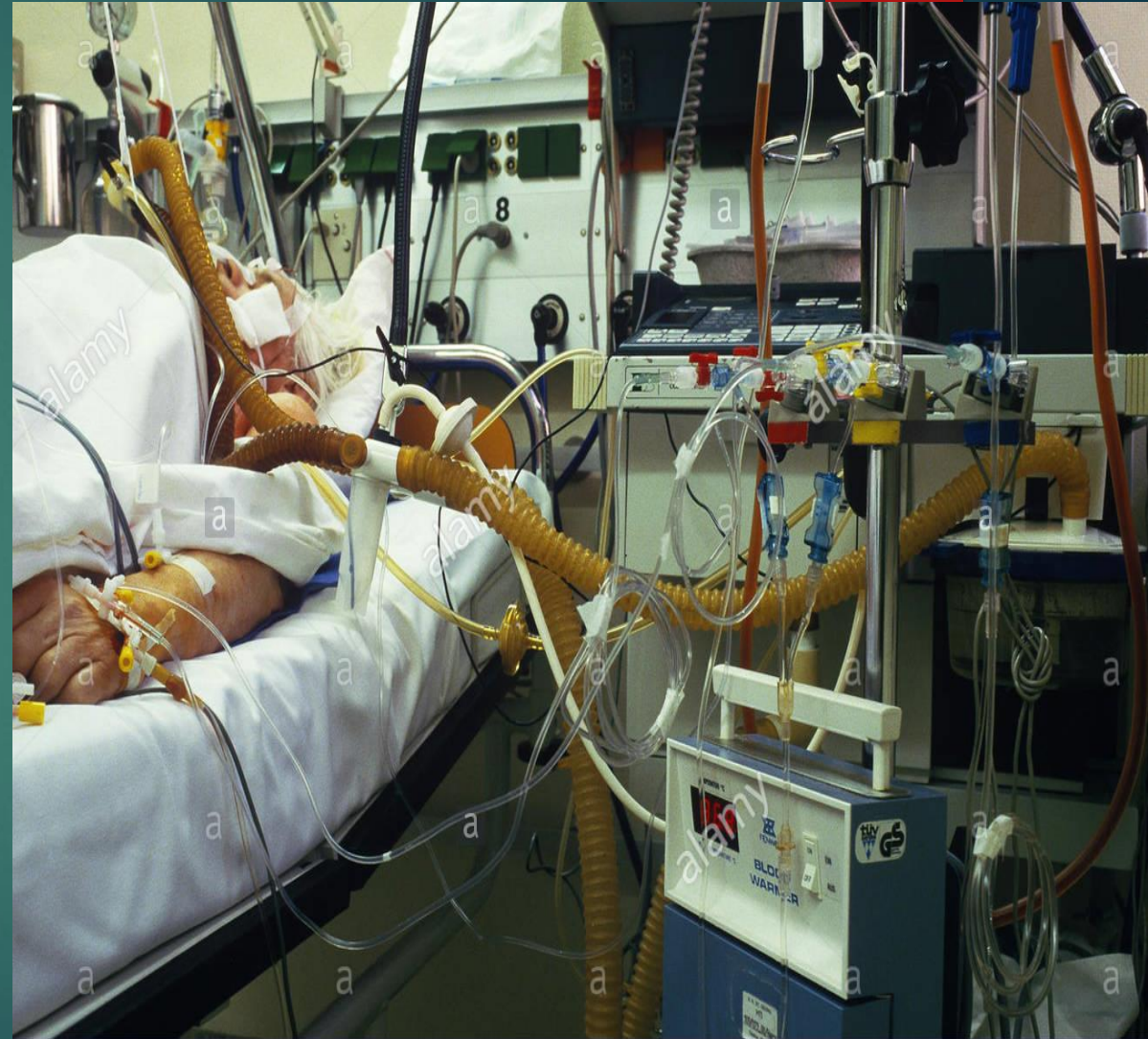
Dysthanasia



- ▶ The term is generally used when a person is seen to be kept alive artificially in a condition where, otherwise, they cannot survive, sometimes for some sort of ulterior motive.
- ▶ It occurs when a person who is dying has their biological life extended through technological means without regard to the person's quality of life. Technologies such as an implantable cardioverter defibrillator, artificial ventilation, ventricular assist devices and extracorporeal membrane oxygenation can extend the dying process.

What is happening around ICU

- ▶ 8% of all licensed hospital beds in the U.S. are in ICU. More than half a million deaths a year or 20-25% of all deaths in the U.S. occur in ICU.
- ▶ Mortality rates in patients admitted to ICU average 10 to 20% in most hospitals.
- ▶ Patients in ICU occupy between 5- 10 percent of in-patient beds in hospitals but account for 20 to 35 percent of total hospital costs.
- ▶ After a year on a mechanical ventilator, the mortality for patients in long-term acute care hospitals ranges from 48 to 69.1%.
- ▶ Patients older than 65 years now makeup more than half of all ICU admission.



Euthanasia

- ▶ It is a Greek word; means good death.
- ▶ It is the deliberate intervention undertaken with the express intention of ending a life to relieve intractable suffering.
- ▶ It is termed somewhere as assisted suicide and termination of life on request.
- ▶ It is legal in Switzerland and in some states of the U.S.
- ▶ It is illegal in Bangladesh.
- ❖ It is categorized in different ways, such as-
 - Voluntary, non-voluntary or involuntary.
- Voluntary :- It is conducted with the consent of the patient. It is legal in Belgium, Luxembourg, The Netherlands and the U.K.

Euthanasia contd.

- Non-voluntary:- It is conducted when the consent of the patient is unavailable. Examples include child euthanasia, which is illegal worldwide but decriminalized under certain specific circumstances in The Netherlands under the Groningen Protocol.
- Involuntary :- It is conducted against the will of the patient. It is considered as murder.
- ❖ Euthanasia may be categorized as active and passive also.
 - Active :- It entails the use of lethal substances or forces to kill.
 - Passive :- It entails the withholding of common treatments such as antibiotics necessary for continuance of life. In some cases, such as the administration of increasingly necessary but toxic doses of pain killers, there is a debate whether or not to regard the practice as active or passive. It is legal throughout the U.S.

Quality Standards For End Of Life Care

- ▶ Patients approaching the end of life are identified in a timely way.
- ▶ Their families and carers are communicated with and offered information in an accessible and sensitive way in response to their needs and preferences.
- ▶ Patients , their families and carers are offered comprehensive holistic assessments in response to their changing needs and preferences with the opportunity to discuss, develop and review a personalized care plan for current and future support and treatment.

Quality Standards For End Of Life Care contd.

- ▶ Patients have their physical and psychological needs safely, effectively and appropriately met at any time of day or night including access to medicines and equipment.
- ▶ Patients are offered personalized support for their social, practical and emotional needs, which is appropriate for their preferences and maximizes independence and social participation for as long as possible.
- ▶ Patients are offered spiritual support.

Quality Standards For End Of Life Care contd.

- ▶ Patients receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night and delivered by practitioners who are aware of the persons' current medical condition, care plan and preferences.
- ▶ Patients receive prompt, safe and effective urgent care appropriate to their needs and preferences.
- ▶ Generalist and specialist services providing care have a multidisciplinary workforce sufficient in number and skill mix to provide high quality care and support.

Quality Standards For End Of Life Care contd.

- ▶ The body of a person who died is cared for in a culturally sensitive and dignified manner.
- ▶ People closely affected by a death are communicated within a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
- ▶ Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high quality care and support for people approaching the end of life , their families and carers.

Questions for the person approaching end-of-life

Dr. Angelo Volandes (writer, physician, researcher, advocate) - author of **'The Conversation'**, has crafted six questions to be asked to the person approaching end-of-life :

1. What kind of things are important to you in your life?
2. If you were not able to do the activities you enjoy, are there any medical treatments that would be too much?
3. What fears do you have about getting sick or medical care.

Questions in end-of-life contd.

4. Do you have any spiritual, religious, philosophical or cultural beliefs that guide you when you make medical decisions.
5. If you had to chose between living longer or having a higher quality of life, which would you pick?
6. How important is it for you to be at home when you die.

Advance Healthcare Directives

- ▶ It is also known as ‘living will’, ‘personal directive’, ‘medical directive’, ‘advance decision’.
- ▶ It is a legal document in which a person specifies what actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity. In some countries, it has a legal status in itself, whereas in some it is legally persuasive without being a legal document.
- ▶ A living will is one form of advance directive leaving instructions for treatment. Another form is a specific type of power of attorney or health care proxy, in which the person authorizes someone to make decisions on their behalf when they are incapacitated.



When The Dying Patient Should Stop Treatment

Dr. Atul Gawande's "Being Mortal"

Dr. Atul Gawande

US Surgeon, writer & Public Health Researcher

file

to

at 12th

at 12th

at 12th

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Palliative Care

The word “Palliative” literally means to cloak or conceal. It is a multidisciplinary approach to specialized medical and nursing care for people with life-limiting illnesses. It focuses on providing people with relief from the symptoms, pain, physical stress and mental stress of the terminal diagnosis. The goal of such therapy is to improve quality of life for both the person and his family. As for example, tumour debulking can continue to reduce pain from mass effect even when it is no longer curative.



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- ▶ In 2002, WHO proposed a revised definition of palliative care for adults - “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through prevention and relief of sufferings by means of early identification and impeccable assessment and treatment of pain and other problems - physical, psychological and spiritual”.

Palliative Care : The Integrated Model



History of Palliative Medicine

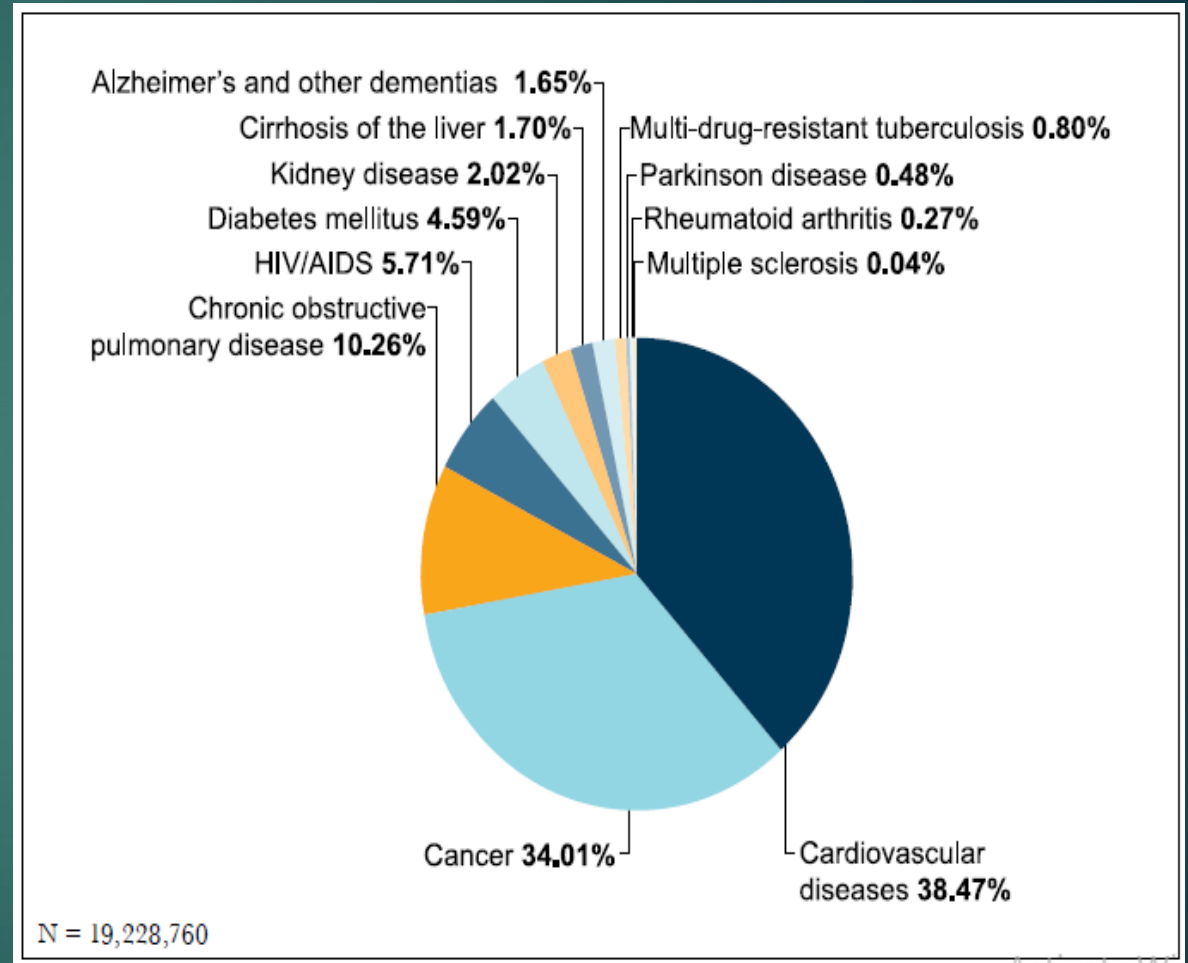
- ▶ Palliative medicine got recognition as a medical specialty in 1987, first in UK. So far it has gained specialty status in 26 countries.
- ▶ Modern palliative care movement is said to have begun with the pioneering work of Dr. Dame Cicely Saunders with the establishment of St. Christopher's hospice in East London in 1967.
- ▶ Dr. Dame Cicely Saunders - a physician, nurse, writer and social worker said “ You matter because you are you and you matter to the end of your life”.

Palliative care contd.

- ▶ The following items are indications named by the American Society of Clinical Oncology as characteristics of a person who should receive palliative care but not any cancer-directed therapy :
- ▶ People who have a limited ability to care for themselves.
- ▶ People who received no benefit from prior evidence based treatments.
- ▶ People who are ineligible to participate in any appropriate clinical trial.
- ▶ Physicians see no strong evidence that treatment would be effective.

Diseases requiring Palliative Care In adults

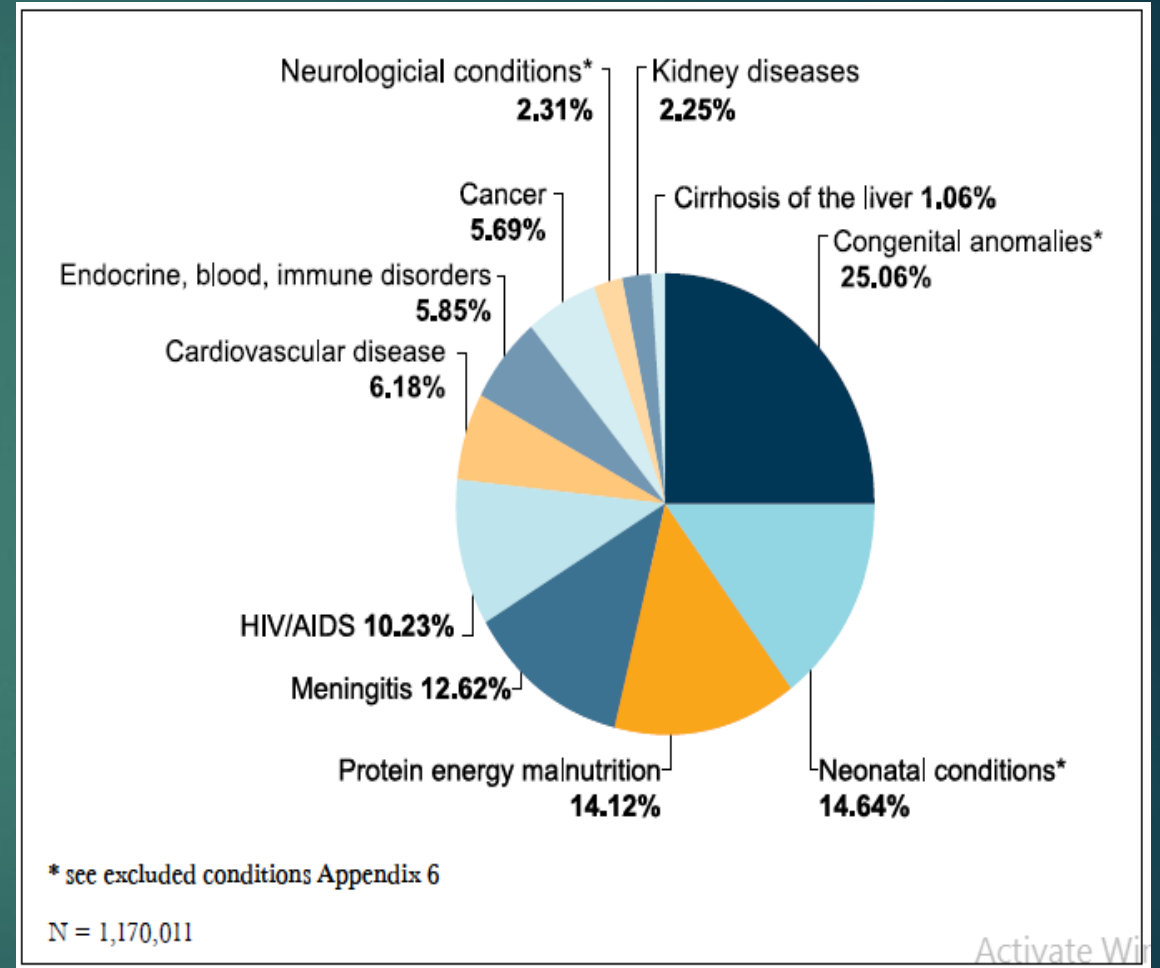
- ▶ Cancer
- ▶ Alzheimer's disease other dementias
- ▶ Chronic Cardiovascular diseases
- ▶ Cirrhosis of liver
- ▶ Chronic obstructive pulmonary diseases
- ▶ Diabetes
- ▶ HIV/AIDS
- ▶ Chronic kidney failure without kidney transplant option available
- ▶ Multiple sclerosis & motor neuron diseases
- ▶ Parkinson's disease
- ▶ Rheumatoid arthritis
- ▶ MDR TB



Distribution of adults in need of palliative care by disease groups

Diseases requiring Palliative care in children

- ▶ Cancer
- ▶ Chronic cardiovascular diseases
- ▶ Cirrhosis of liver
- ▶ Congenital anomalies(excluding heart abnormalities)
- ▶ Blood and immune disorders
- ▶ HIV/AIDS
- ▶ Meningitis
- ▶ Chronic kidney diseases
- ▶ Neurological disorders
- ▶ Neonatal conditions

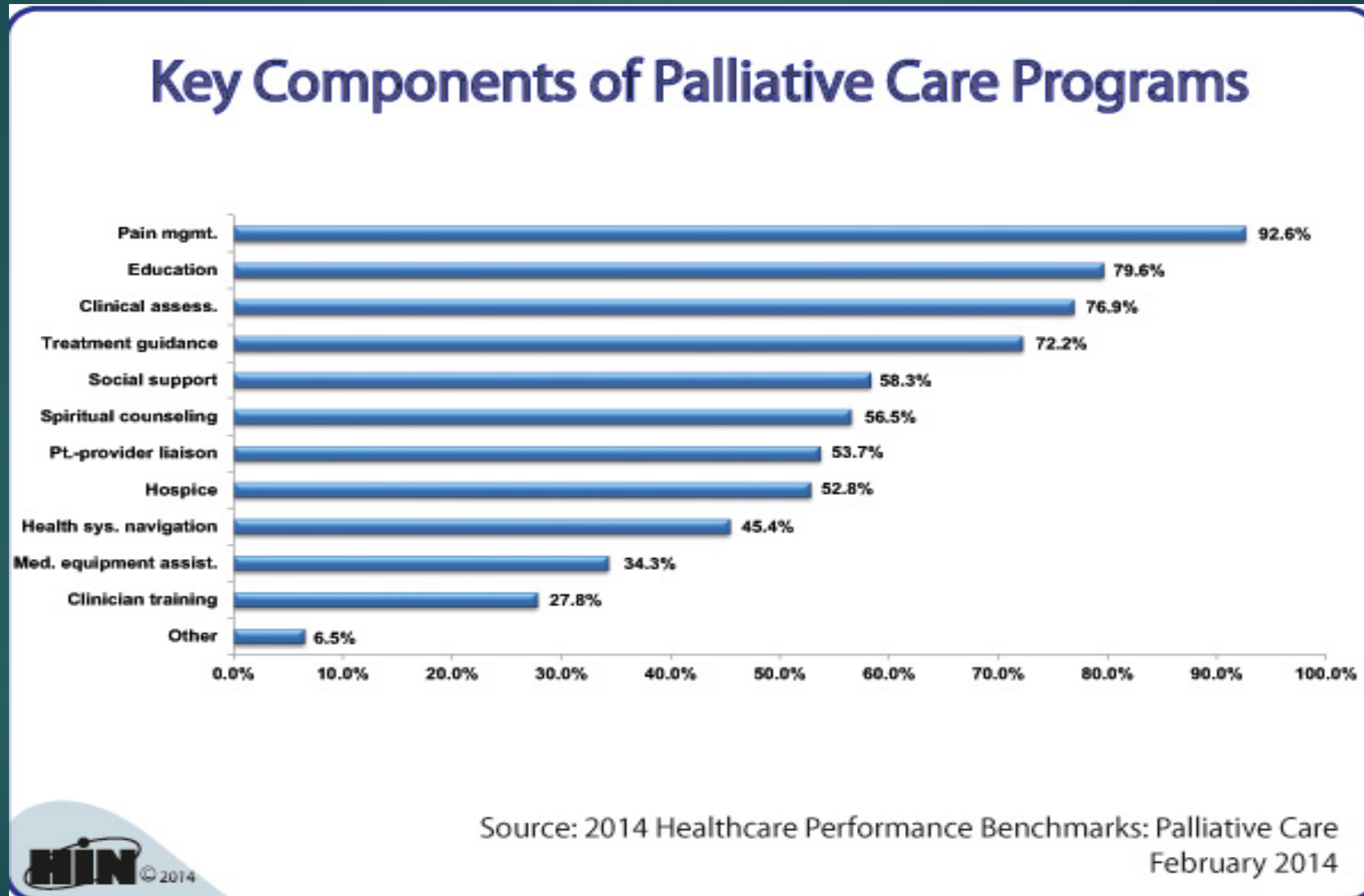


Distribution of children in need of palliative care by disease groups

Palliative care contd.

- ▶ Research has shown that if a person who has advance cancer discusses his or her options for care with a doctor early on, that person's level of stress decreases and their ability to cope with illness increases.
- ▶ A palliative care specialist works as part of a multidisciplinary team to coordinate care. This team may consist of doctors, nurses, dieticians, pharmacists and social workers. Many teams include psychologists or a hospital chaplain as well.

Key Components of Palliative Care

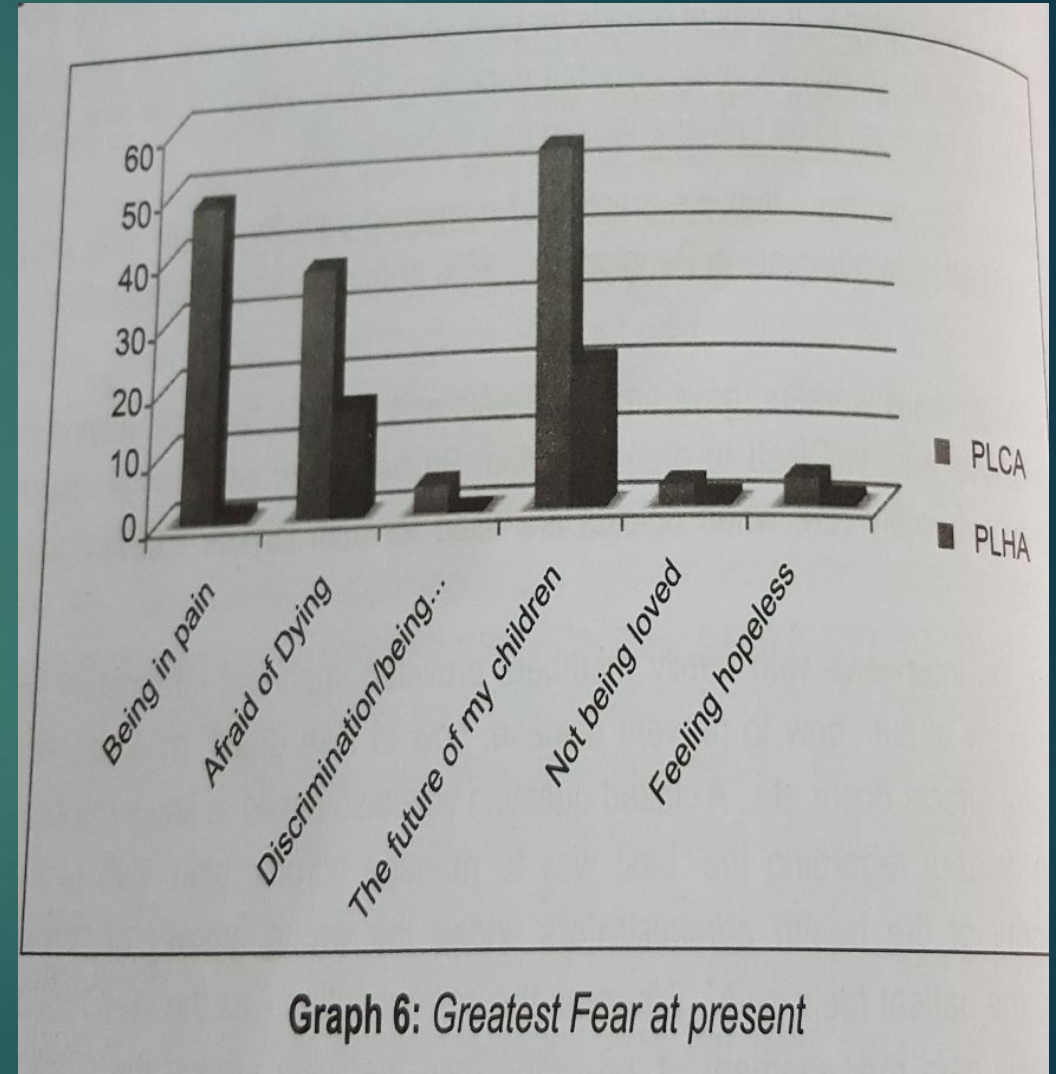


Palliative care contd.

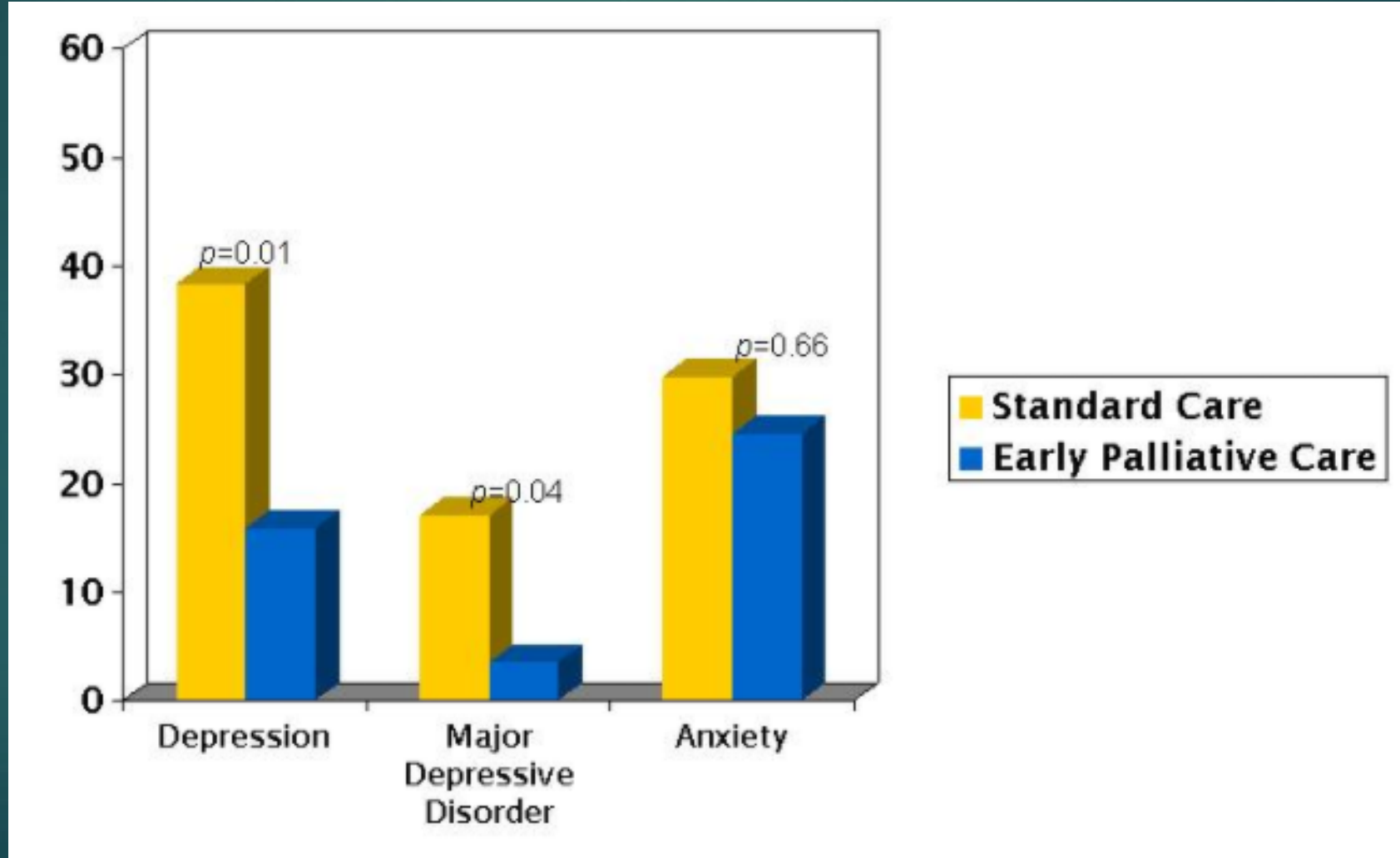
- ▶ Comprehensive palliative care will take the following issues into account for each patient such as physical, emotional, spiritual, practical etc.
- ▶ Physical : Common physical symptoms include pain, fatigue, loss of appetite, nausea, vomiting, shortness of breath and insomnia. Many of these can be relieved with medicines or by using other methods such as nutrition therapy, physical therapy, or deep breathing techniques. Also chemotherapy, radiation therapy or surgery may be used to shrink tumours that are causing pain and other problems.

Palliative care contd.

- Emotional and coping : Palliative care specialists can provide resources to help patients and families deal with the emotions that come with a cancer diagnosis and cancer treatment. Depression, anxiety and fear are only a few of the concerns that can be addressed through palliative care. Experts may provide counselling, recommend support groups, hold family meetings or make referrals to mental health professionals.



Effect of Early Palliative Care on 12-Week Psychological Distress



Comparison of patients who had received end-of-life counselling and who hadn't

Making a Difference

A comparison of 123 advanced cancer patients who had received end-of-life counseling and 209 who hadn't

◆ Preferences and planning

	Had counseling	No counseling
Accepts illness is terminal	53%	29%
Wants to know life expectancy	84	67
Values comfort over life extension	85	70
Against death in intensive-care unit	49	28
Completed do-not-resuscitate order	63	29
Completed living will, durable power of attorney or health-care proxy	72	46

◆ Care received in the last week of life

	Had counseling	No counseling
ICU admission	4.1%	12%
Ventilator use	1.6	11
Resuscitation	0.8	6.7
Chemotherapy	4.1	6.7
Feeding tube	8.9	7.3
Outpatient hospice used	76	57
Outpatient hospice of a week or more	66	45

Source: Alexi A. Wright et. al, JAMA, Oct. 8, 2008

THE WALL STREET JOURNAL.

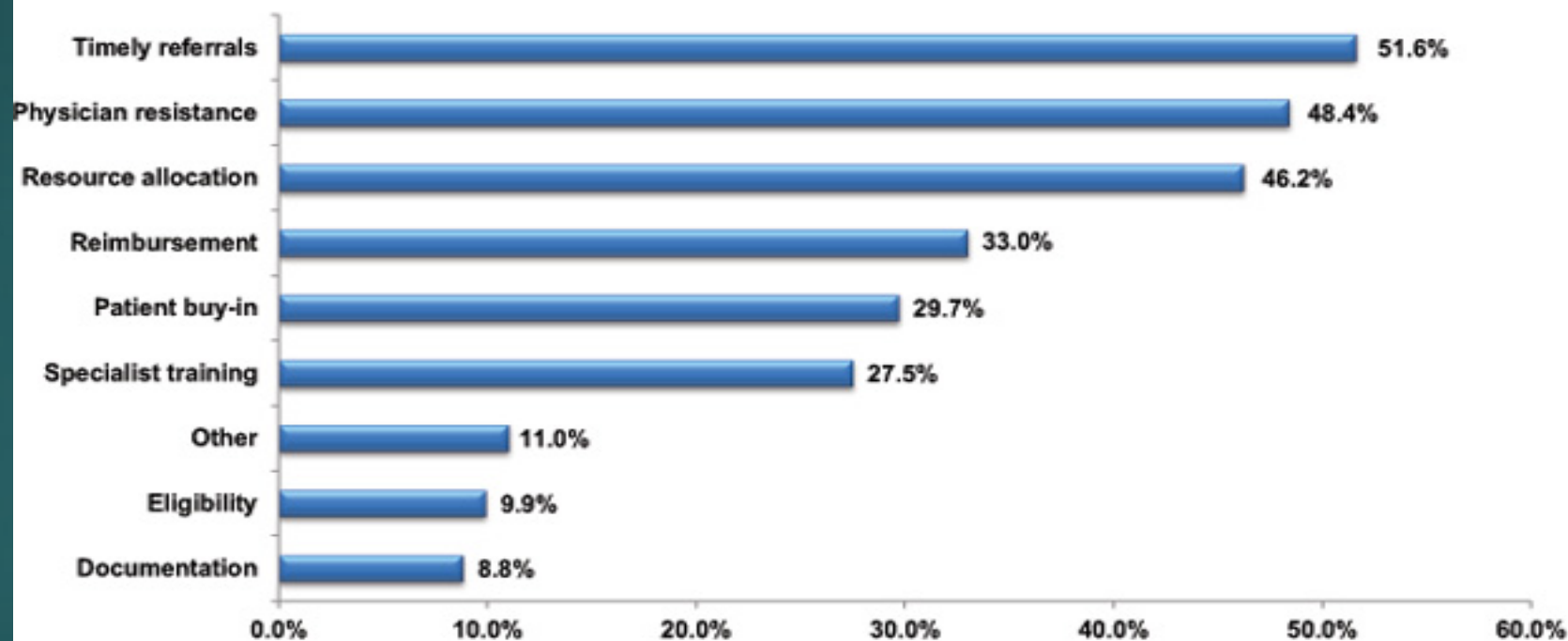
Palliative care contd.

- ▶ Spiritual : With a cancer diagnosis, patients and families often look more deeply for meaning in their lives. Some find the disease brings them more faith, whereas others question their faith as they struggle to understand why cancer happened to them. An expert can help people explore their beliefs and values so that they can find essence of peace or reach a point of acceptance that is appropriate for their situation.
- ▶ Practical : Cancer patients may have financial and legal worries, insurance questions, employment concerns and concerns about completing advance directives. For many patients and families, the technical language and specific details of laws and forms are hard to understand. To ease the burden, the palliative care team may assist in coordinating the appropriate services.

Key Challenges

Key Challenges of Palliative Care

What are the key challenges in implementing palliative care?



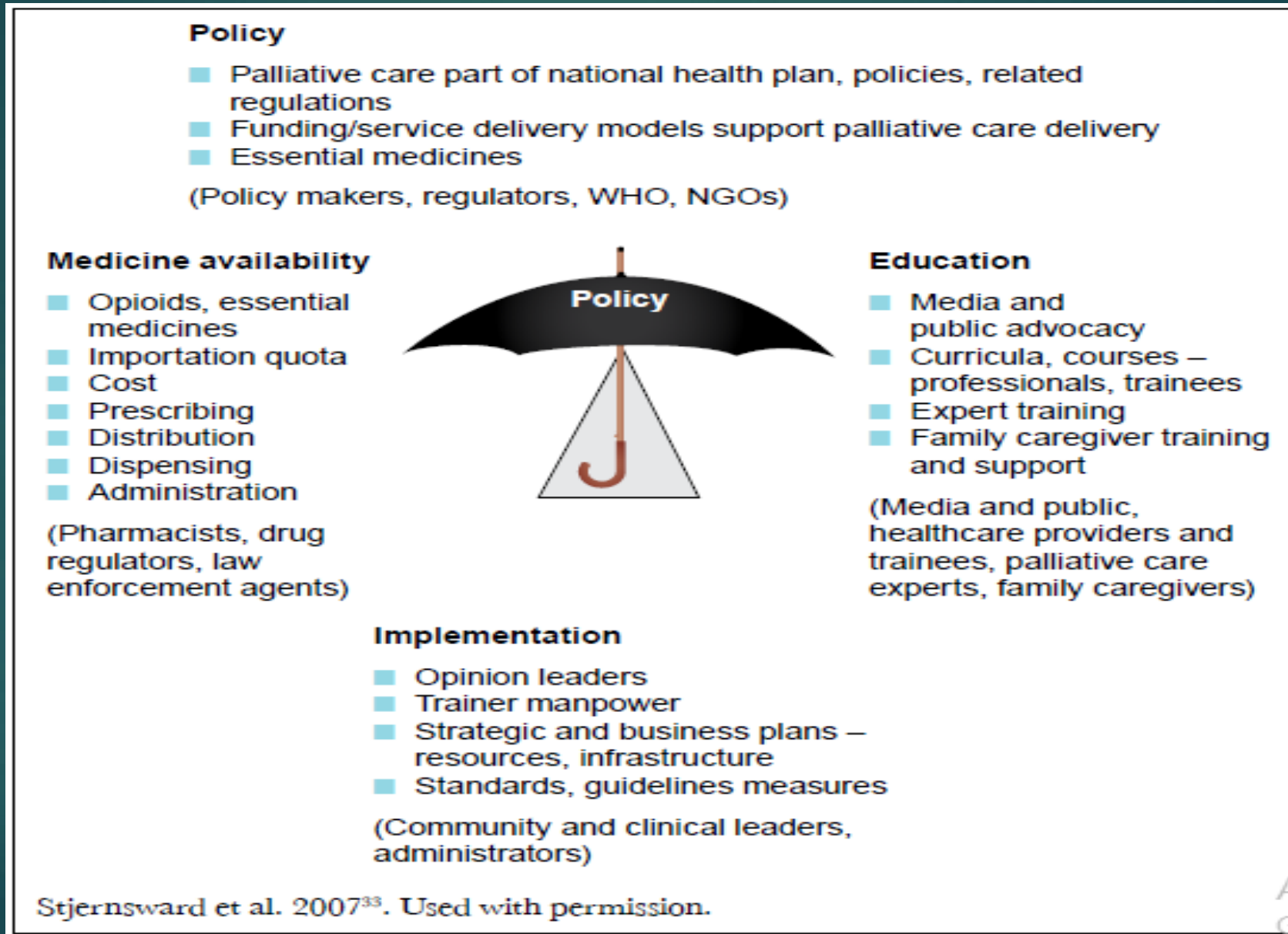
Carers need to know

- ❖ Some ways to provide emotional support to a person in need of end of life care :
 - ▶ Everyone has different needs, but some worries are common to most patients. Two of these concerns are fear of abandonment and fear of being a burden. They also have concerns about loss of dignity and loss of control.
 - ▶ Keep the person company. Talk, watch movies, read or just be with him or her.
 - ▶ Allow the person to express fears and concerns about dying such as leaving family and friends behind. Be prepared to listen.
 - ▶ Be willing to reminisce about the person's life.

Carers need to know contd.

- ▶ Avoid withholding difficult information. Most patients prefer to be included in discussions about issues that concern them.
- ▶ Reassure the patients that you will honour advance directives such as living will.
- ▶ Ask if there is anything you can do.
- ▶ Respect the person's need for privacy.
- ▶ Support the person's spirituality. Let them talk about what has meaning for them. Pray with them if they'd like and arrange visits by spiritual leaders if appreciated. Keep objects that are meaningful to the person close at hand.

Public Health Model For Palliative Care Development



Hospice care

- ▶ It is one sort of end of life care. It is provided to the sick especially to the terminally ill.
- ▶ The goal of the care is to help people who are dying have peace, comfort and dignity.
- ▶ It can take place at home, hospice center, hospital or a skilled nursing facility.
- ▶ It is provided by a team of health care professionals who maximize comfort by reducing pain and discomfort and addressing physical, psychological, social or spiritual needs.
- ▶ Patients' families are also important focus of hospice care and services are designed to give them assistance and support.

Difference between Hospice and palliative care

- ▶ Although hospice and palliative care share the same principles of providing comfort and support for patients, palliative care is available throughout a patient's experience with cancer, whereas hospice is offered only toward the end of life.
- ▶ A person's cancer treatment continues to be administered and assessed while he or she is receiving palliative care, but with hospice care the focus has shifted to just relieving symptoms and providing support.

The need for Palliative Care in Bangladesh

- ▶ There is no nationwide reliable data on the magnitude of the problem.
- ▶ Conservative estimation following the universally accepted method of 0.3 to 0.4% of total population or 60% of total death points to a figure of 6,00,000 people who would be benefitted with an organized nationwide palliative care program.
- ▶ Only 1070 patients accessed pain and palliative care treatment they need.
- ▶ In Bangladesh, cancer related death rate was 7.5% in 2005 and is expected to be 13% in 2030.
- ▶ 80-90% of patients when go to the oncologists for the first time are already in a state of incurability, when only option would be to get palliative care.

The need for Palliative Care in Bangladesh contd.

- ▶ In 2014, WHA resolution (no.67.19) on palliative care urges member states to integrate palliative care services in the continuum of care, across all levels with emphasis on primary care, community and home-based care and universal coverage schemes. Bangladesh has signed the resolution.
- ▶ There are only seven palliative care facility in Bangladesh, which are patchy, incompetent and suffers from lack of resources.
- ▶ Palliative care is not included in the health policy of Bangladesh.

The need for Palliative Care in Bangladesh contd.

- ▶ Post graduate faculty has been opened in Bangabandhu Sheikh Mujib Medical University (BSMMU). Post graduate course of 5-year duration has been launched.
- ▶ In BSMMU, Indoor, outdoor, home care and 24-hour call service has been introduced.

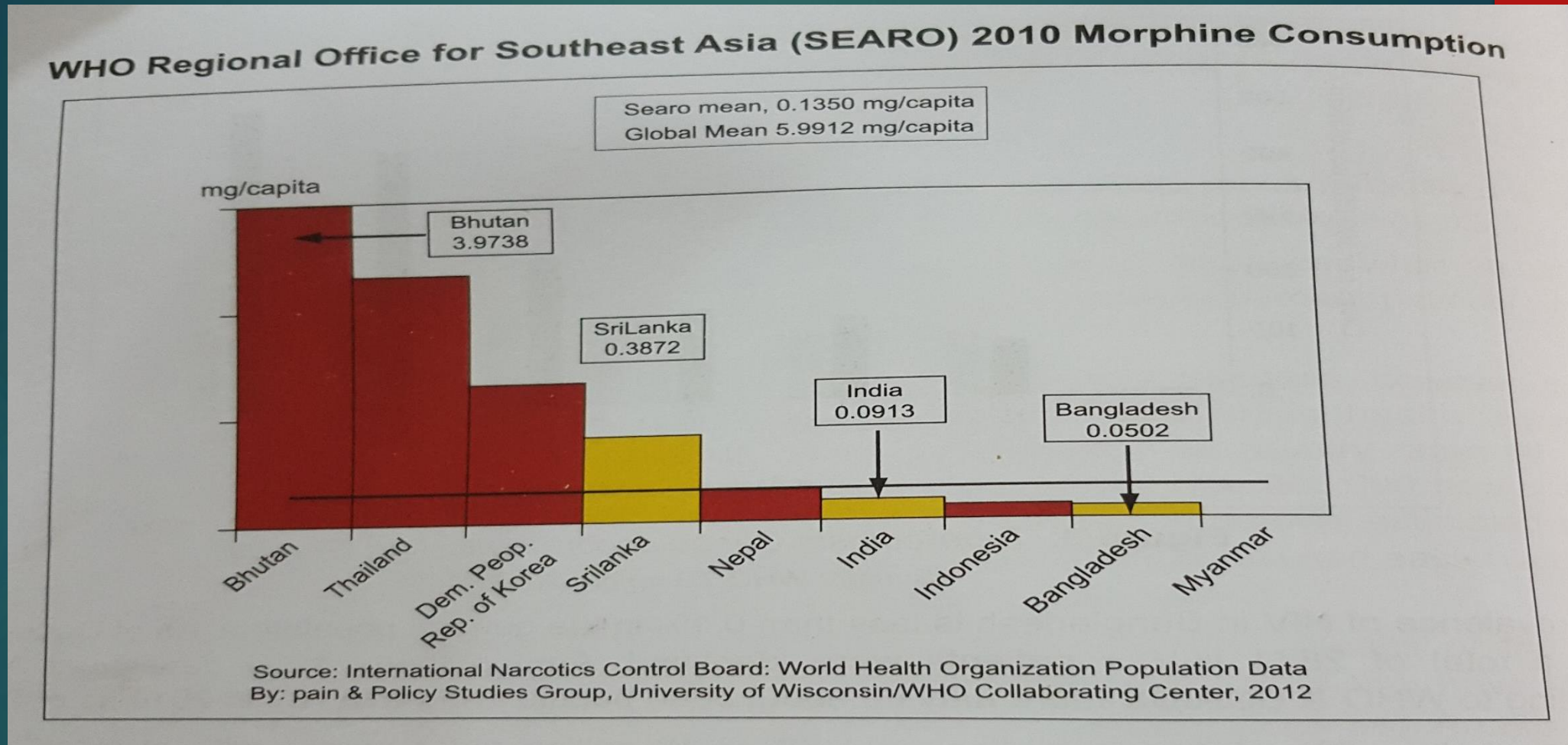
Opoids in palliative care

- ▶ Access to pain-relieving medication is being increasingly recognized as a human right by WHO, International Association for the study of pain and Worldwide Palliative Care Alliance.
- ▶ It is known that 70-90% of patients suffering from cancer, experience moderate to severe pain. Opoids are essential , safe and effective means of relief.
- ▶ 90% of the global consumption of opoids is utilized by only a few developed countries. According to Human Development Index, 83% of the countries have low to non-existent access to opoids; 4% have moderate access and only 7% have adequate access.
- ▶ According to WHO, morphine consumption is an important indicator of a country's situation and progress in relief from cancer pain.

Opoids in palliative care contd.

- ▶ Since 1977, morphine has been designated by WHO as an essential medicine.
- ▶ A number of healthcare workers, govt. officials and parents fear that having morphine available to relieve pain will lead to drug addiction. Studies show that addiction or psychological dependence is extremely rare when opoids are used for pain.
- ▶ Empirical evidence suggests, however, that not only do opoids not hasten death, but that adequate relief from pain can actually improve quality of life and survival.
- ▶ Prescription drug misuse should be prevented but the comfort of seriously ill patients cannot be sacrificed for fear of it.
- ▶ Majority of the health administrators chose the wrong answer of 'providing pain medicine when the patient feels pain', whereas WHO recommended method of chronic pain management is 'providing pain medicine round the clock to prevent breakthrough pain'.

Morphine Consumption

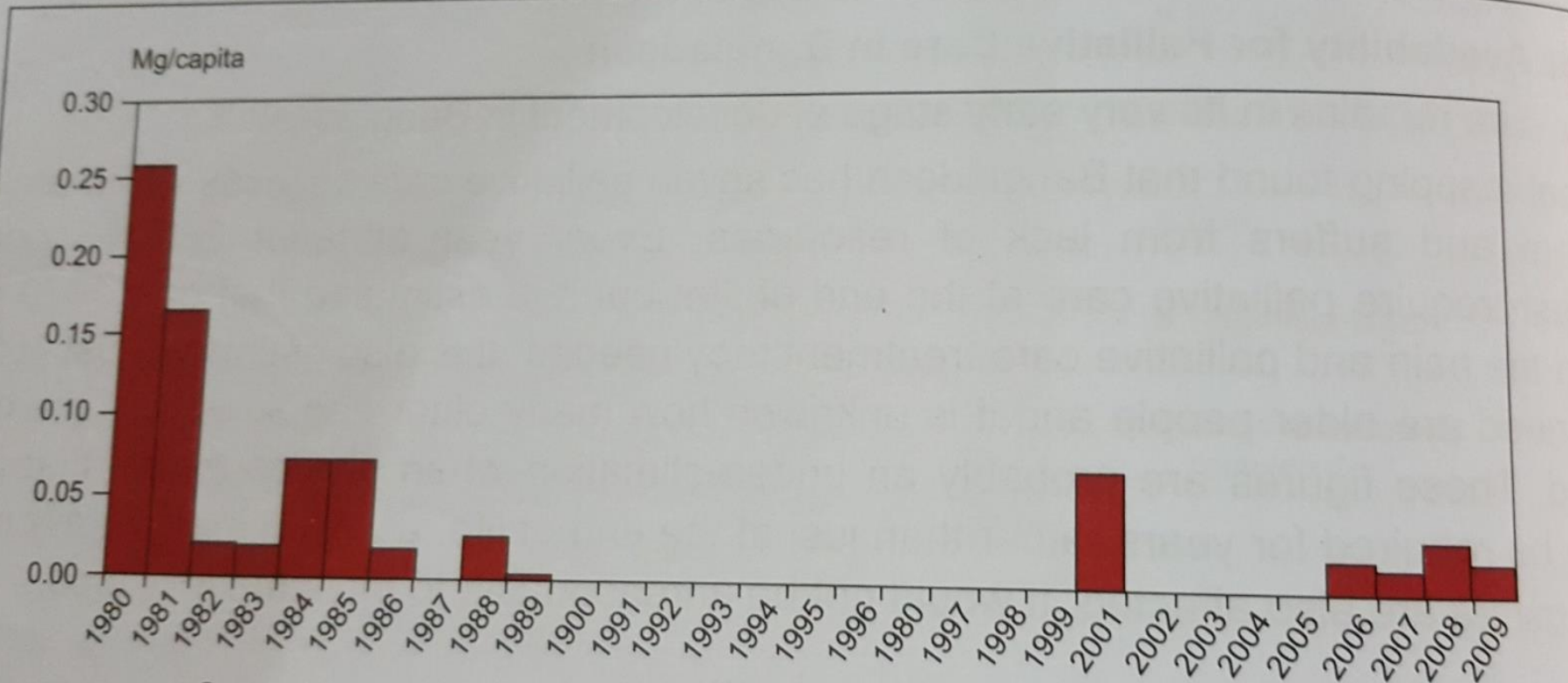


Bangladesh would require 1200 kg of morphine every year to effectively treat pain of its cancer patients. The use is only 10 kg implying that most of the cancer patients are forced to accept a painful death despite the fact that pain relief is possible.

Morphine Consumption contd.

Region.

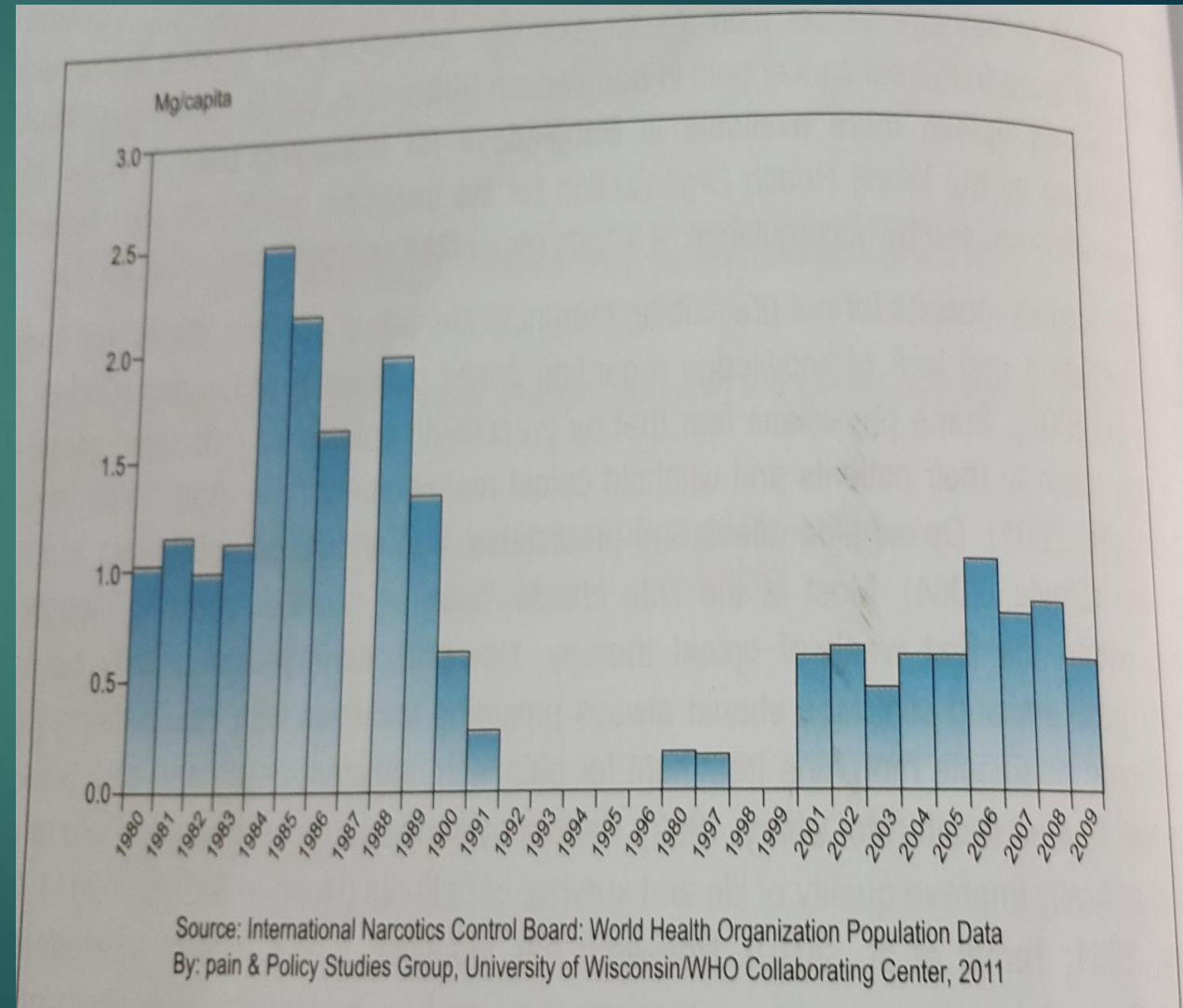
**Mg/capita Consumption of Morphine,
Bangladesh, 1980-2009**



Source: International Narcotics Control Board: World Health Organization Population Data
By: pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2011

Pethidine Consumption in Bangladesh

One study done in Bangladesh shows that 85% of the physicians preferred to prescribe pethidine, when patients needed opioids for severe pain. 57% practicing physicians had a misconception that pethidine causes less harmful side effects amongst all the opioids. Similarly, 84% of them had wrong perception about drug tolerance and addiction.



Public Health Approach in Palliative Care

- ▶ It has been widely acclaimed that a public health approach to palliative care with community empowerment and community ownership remains the ultimate solution in the developing world.
- ▶ Bangladesh may lack adequate medical resources but has a strong cultural, ritualistic, community and family support systems to look after its critically ill patients. If this attribute can be properly supplemented with an appropriate health care intervention along with family and community empowerment, it will go a long way for a nationwide coverage.



Thank you