



living in fear, dying in despair – how can we help?

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This presentation

Palliative care principles

Relief of suffering

Pain management

Desire for hastened death (DHD)

Dignity in healthcare

Ethical issues in end-of-life care

How can we help?

Assisted suicide – is this the only choice?

International discussions

Wish to help people with terminal illness, sense of compassion

Disagreement on how we should offer this help

We do not have to kill the sufferer to end the suffering

Palliative care practitioners assist patients to achieve best possible quality of life; dignity in living and in dying; physical comfort during the dying process; emotional and spiritual support to patients and family

Palliative care affirms life

Improves the **quality of life** of patients and their families

Affirms life and regards dying as a normal process

Offers a support system to **help patients live as actively as possible** until death

Will enhance the quality of life, and will also **positively influence the course of illness**

Regards dying as a normal process

We will all die

What will be the quality of our dying?

What are our patients preference as to the place of death, their goals of care, their treatment options

Do we discuss these preferences or do we avoid the conversation?

The Stransthram-Ford case & Fabricius ruling have provided a space for these important discussions

Neither hastens nor postpones death

Hastened death: Euthanasia is not a palliative care practice (HPCA position paper Euthanasia & PAS 2013)

Postponing death: It is not appropriate to initiate or continue futile treatment that does not improve quality of life & may negatively affect quality of life or prolong the dying process

There is a world of difference between:

- 1) withholding or withdrawing futile treatment and providing appropriate palliative care to allow a natural death and
- 2) the administering of lethal drugs to cause premature death

Palliative care principle to Allow Natural Death – AND rather than DNR

President Nelson Mandela

Nelson Mandela did not require euthanasia

He required that his medical team, family and proxy decision-maker(s) agree to allow natural death without extraordinary measures that did not add to his quality of life and personal dignity

Not to have his life/dying prolonged by artificial means



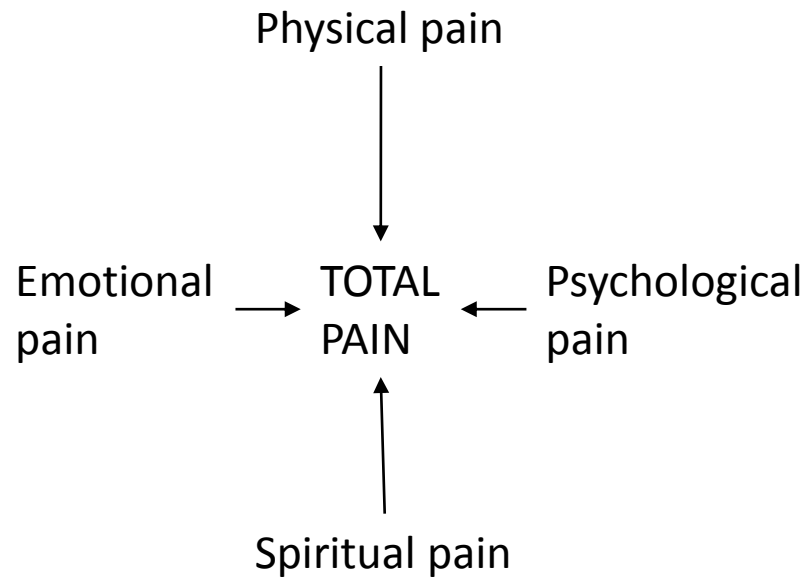
WHO Definition of Palliative Care

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 **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.

In a nutshell:

Palliative care is the relief of suffering

Total pain requires holistic response



Palliative care: the relief of suffering

Suffering	Care
Pain	Treatment of pain
+ other physical symptoms	& other physical symptoms
+ psychological problems	& psychological problems
+ social difficulties	& social difficulties
+ cultural issues	& cultural issues
+ spiritual concerns	& spiritual concerns

Who defines the suffering?

Suffering is a subjective experience, we should not impose our judgement of another's suffering but rely on their description

It is necessary to explore each person's experience of illness, to understand their context, preferences, choices; also fears, concerns and anxieties.

The desire for death is often driven by fear and imaginings, not knowing what will happen

The right to die



There are compelling arguments for the 'right to die'

But if we were to legalize euthanasia we would be crossing a line – that of agreeing that it is OK to kill another person

My own doubts have always been about Motor Neurone Disease although there are people like Stephen Hawking and closer to home Joost van der Westhuizen that challenge my 'paternalistic' view of this illness

HPCA position paper on euthanasia & assisted suicide (2013)

Euthanasia is not a palliative care practice

The duty of doctors is to heal, where possible; and to relieve suffering

The primary responsibilities in end-of-life care are to assist the patient in maintaining an optimal quality of life through controlling pain and other distressing symptoms and addressing psychosocial and spiritual needs, and to enable the patient to die with dignity and in comfort.

Details the discussion points when talking to a patient about a Desire for Hastened Death

Living in fear

The most compelling argument people have for wanting the choice to end their lives is the fear and imaginings of how dreadful the experience of dying will be

Loss of dignity is a central concern

The sense of being a burden on others

The fear of unbearable pain is the most pressing concern

Is there another choice?

Is the choice unbearable pain OR euthanasia?

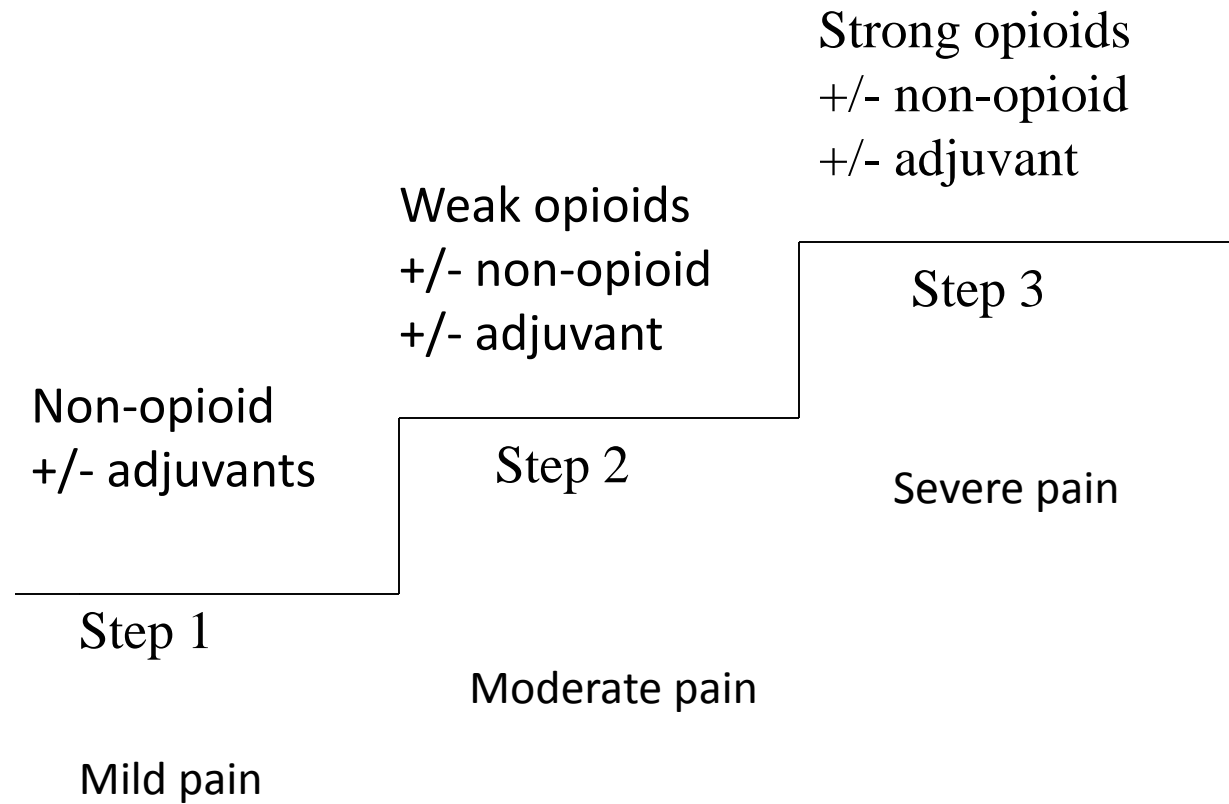
The ethical & compassionate response is surely effective pain management

90% of cancer pain can be effectively controlled with complete freedom from pain through the simple measures described in the WHO manual cancer pain control

Additional measures can alleviate difficult to control pain such as nerve blocks and other measures

Can we ensure that everyone has access to effective pain control and palliative care when needed?

Pharmacological approach to pain management (WHO)



Pain control – a public health emergency

Pain can be seen as a public health challenge for reasons of prevalence, seriousness, disparities, vulnerable populations, the utility of population health strategies, and the importance of prevention at both the population and individual levels

Dr Stephen Connor, of the WHPCA, stated: “This is a public health emergency and an intolerable situation. People around the world are dying in unnecessary pain and distress.”

All doctors and nurses should be trained in pain management and pain medication should be available in all health facilities

Adv Stranstham-Ford

The application brought by Adv Stranstham-Ford included the fact that he suffered severe pain and the Fabricius ruling was made with the statement that the applicant was suffering intractably

The application was written before Adv Stranstham-Ford requested and received palliative care.

Adv Stranstham-Ford experienced adequate pain control actively engaging with his palliative care doctor as to the limits of treatment

Other problems were more difficult to manage and his last few weeks were tough although his family described that his symptoms were greatly alleviated through palliative care

He wanted to live to see his application through – his palliative care doctor says that this contributed to his sense of dignity & meaning at the end of his life

Dying in despair

In contrast to the expectation that people want to die because of severe pain or loss of dignity research has shown the most common causes of sustained desire for hastened death are hopelessness & depression

Rodin: “the will to live tends to be preserved in cancer patients prior to the end of life, in spite of significant emotional and physical suffering”

2% of study participants reported high Desire for Hastened Death (DHD) all of whom reported elevated levels of hopelessness and depression

Finlay: so often hope is restored by careful attention to the values of the individual, restoring sense of personal worth, helping them to achieve unfinished goals

Research into DHD in the disability community

Chochinov (current research): Patients with head & spinal cord injury – adjustment to new reality

On average 7 months before they stated I am glad I could not take my own life

Risk to disability community

In their submission to the House of Lords Select Committee on Assisted Dying for the Terminally Ill in the UK, disability groups Disability Awareness in Action & People First stated that “assisted living legislation” is required rather than “assisted dying legislation”



A burden to others

Chochinov (2007): A strong association between sense of burden to others and an expressed wish for hastened death.

Strategies that target meaning and purpose, depression, and level of fatigue could lessen this source of distress and enhance quality, dignity-conserving care.

In Oregon, 1 in 700 deaths is by PAS, “not for the relief of intractable symptoms but more for those who feel a great need to be in control, with fear of being a burden becoming a more prominent reason over recent years” Finlay (2005)

Family member, following admission of her husband to hospital: “I felt that my arms were empty”

Dignity in healthcare

Illness, in particular, serious life-threatening illness, challenges a person's sense of self

Chochinov – loss of personhood can result in sense of despair and he challenges clinicians to ensure that humanity and compassion are part of healthcare delivery

How are patients treated by HCPs? – with respect and compassion; impersonally; with rudeness

Important to affirm a patient's value as a person to assist in maintaining or restoring dignity



Societal attitudes towards death & dying

We try to avoid death, we try not to think about it, not to talk about it, to avoid people who are facing this life experience and to avoid the bereaved

This means we are unprepared for the experience of serious illness and have not discussed our preferences for end-of-life care

An Advance Directive or Living Will helps this discussion; but should be reviewed frequently because we change our minds

Attitudes towards death

Extremes:

Vitalism – life at all costs

Nihilism – “I’d rather be dead”, (or more dangerous “I think you’d be better off dead”)

Most people are in between these extremes and the option offered by palliative care good quality of life and natural death appears to be a good choice for the majority of people

For the most of the patients in hospice care, knowing their time is short, each day is precious especially if it can be lived free of distressing symptoms

Disrupting our life story

Serious illness as with many life crises disrupts our personal narrative

Our view of the future, our plans, our goals, our personal world is shattered

As doctors we often try to help people restore their old life, their previous world

The role of palliative care is to help people rescript their life stories

People adapt to the circumstances they experience and people change their minds

Dr BJ Miller TEDMED talk



Rev Christian Busch - pendulum

The right to know

Benefit

Hope

The will to live

Revolt

Control

Joy

The right not to know

Loss

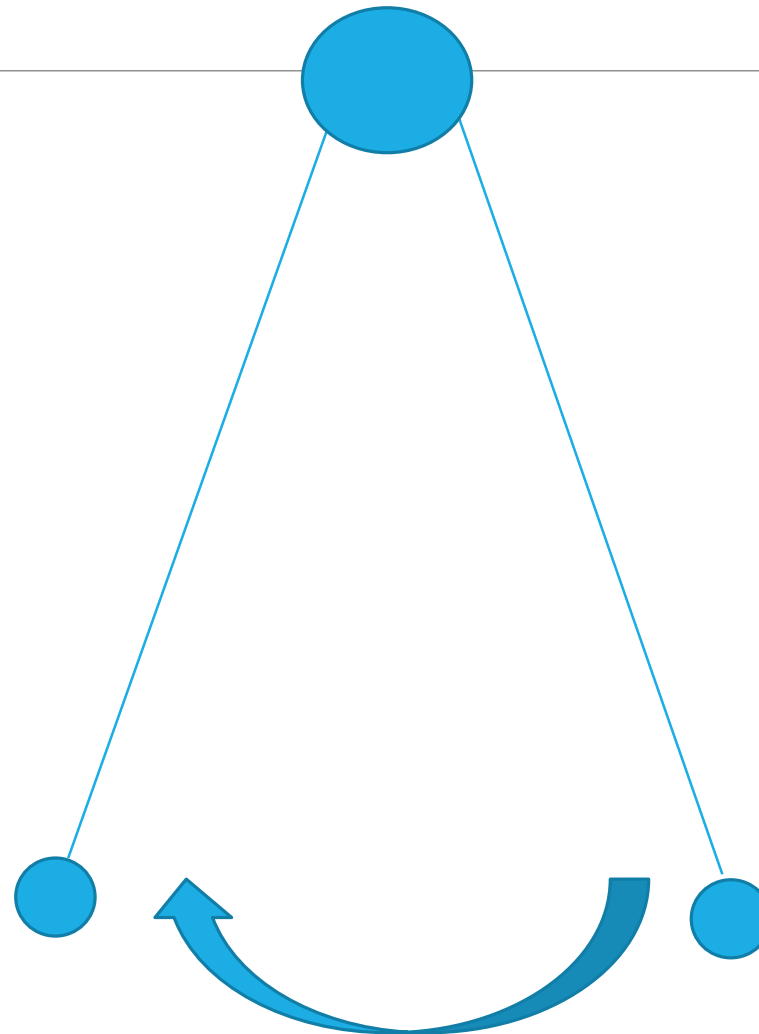
Realism

The wish to die

Submission

Powerlessness

Sorrow



Ethics of end of life decision making

Bioethical principles:

Beneficence

Non-maleficence

Autonomy

Justice

Beneficence

Provide benefit to patient, control pain and other distressing symptoms; in management of cancer pain we can usually ensure patients are pain-free without distressing symptoms and titrate doses of medicines to ensure the patient is alert and “living as actively as possible until death”

In all health care, balance risk vs benefit

WHO resolution A67.19 recommends palliative care training to “all health care workers who routinely work with patients with life-threatening illnesses,..”

If the doctor is not trained in palliative care or pain management and cannot provide comprehensive advice/counselling that includes psychological and spiritual support, refer for palliative care consultation or pain consultation

Non-maleficence

‘Do no harm’

Treatment can only be justified if there is benefit to the patient, we should withhold or withdraw futile treatment

To quote Dr Philippa Whitford, MP UK parliament “As a doctor, I know that death is not a good treatment for anything”

Hastening death is of significant harm to our patient

“Acting with the primary intention to hasten a patient’s death would be difficult to reconcile with the medical ethical principles of beneficence and non-maleficence” GMC

“Doctors are doing it anyway”

Justice

Distributive justice – to ensure access to palliative care for all people in South Africa

Legal justice – laws should benefit society, risk to the wider population in SA if assisted suicide is legalised; what might be the impact on vulnerable members of the community?

Prof Daniel Ncayiyana (2012) wrote in SAMJ that in South Africa there is a “pervasive lack of an ethos of respect for human life.” This uncomfortable reality, together with “severe constraints on health care facilities”, means that there is “a real risk of euthanasia becoming a substitute for proper care” in the South African situation.

Justice

The Fabricius ruling appears to have been made in haste: the application was brought to the court on Monday, the ruling was made on Thursday without approaching HPCA for advice regarding palliative care.

In New Zealand a very similar case was dismissed by the NZ court after seeking advice from many sources including international experts – Professor Baroness Ilora Finlay (UK) Prof Harvey Chochinov (Canada)

Autonomy

'self-rule' / deliberated self-rule, informed decisions

Does autonomy trump other considerations?

Based on good communication, understanding the patient's context, choices, preferences, assessment of patient's understanding, exploring fears and misconceptions, providing information

Limits to autonomy so that one person's autonomy does not compromise another's

Autonomy

Submission to UK Select committee made the statement that autonomy is only valid when it recognizes other moral values such as the respect for human life

Serious illness impacts/compromises our autonomy through pain, insomnia, depression, emotional problems. It is important to address these issues to enhance autonomy

PEOPLE CHANGE THEIR MINDS: Adv Strantham-Ford asked “if the ruling is in my favour, do I have to go through with it”

Who will make the decision?

The World Medical Association (WMA) declared in 2013 that “euthanasia... is unethical and must be condemned by the medical profession”

However, this is a societal debate and has escalated to the law courts or to parliament as it would require a change in the laws

Will the medical profession be involved in the decision?

Lawyers, judges & MPs do not have depth of knowledge of medicine and palliative care but will decide legality of euthanasia/assisted suicide

The burden of carrying out this legal decision if it becomes law is likely to fall on the medical profession

Palliative care & pain relief – basic human rights

Palliative care and pain relief have been recognised as basic human rights

Obligation of the government is to ensure access to palliative care through development of policies for palliative care, training of health care workers, access to essential medications, development of palliative care services

The South African government as a member of the WHO executive committee sponsored a resolution at the World Health Assembly in May 2014

“Strengthening of palliative care as a component of integrated treatment within the continuum of care”

A burden to others

Giles Fraser (canon of St Paul's cathedral, London and writer for The Guardian):

“I want to be a burden on my family as I die, and for them to be a burden on me”

He writes of our common humanity that “when we are this vulnerable that we have little choice but to allow ourselves to be loved and looked after”

“My problem with euthanasia is not that it is an immoral way to die, but that it has its roots in a fearful way to live”

How can we help?

Palliative care can help a great deal to alleviate physical, psychosocial and spiritual suffering

Hospice care is provided by trained professionals in the patient's home or place of care.

Society can include death in conversations, recognise dying as a part of life and support people in their illness and families in caring and in bereavement, affirming the worth of individuals even if they are disabled, ill, elderly

Health care professionals can ensure they have the knowledge and skills to relieve suffering and refer to palliative care & pain specialists if they are faced with complex problems

The government can ensure implementation of the WHO resolution on palliative care

We do not have to kill the sufferer in order to end the suffering

Dame Cecily Saunders

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”



Thank you for your attention

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Required reading: Being Mortal Dr Atul Gawande

Recommended viewing: The Intouchables 2011 French film directed by Olivier Nakache & Eric Toledano, starring Francois Cluzet & Omar Sy

http://www.ted.com/talks/bj_miller_what_really_matters_at_the_end_of_life#t-928714