Palliative care

A healthcare worker perspective

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This presentation

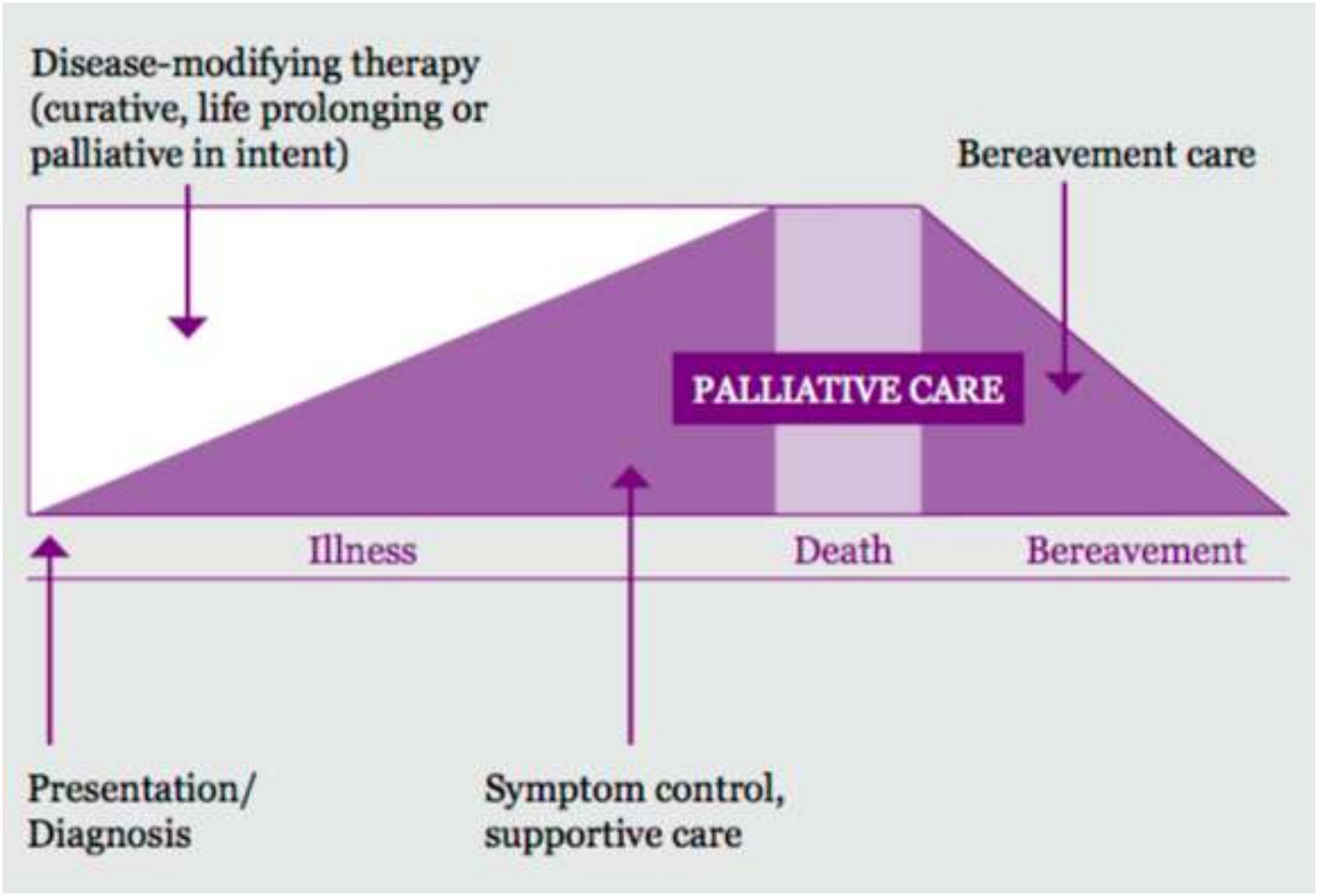
1. **Define** palliative care
2. **Focus on** palliative care, HIV, and care interventions
3. **Consider the future**

Palliative care

What is palliative care?

- Palliative care is: is the **active holistic care of patients with advanced progressive illness**. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount.
- The goal of palliative care is: achievement of the best quality of life for patients and their families. **Many aspects of palliative care are also applicable earlier** in the course of the illness in conjunction with other treatments.

[Source: NICE (UK), 2016]



Standard Continuum of Care (AMA, Institute for Medical Ethics, 1999)

Palliative care in the context of HIV

Core interventions in HIV palliative care

- Management of symptoms (e.g., fatigue, pain)
- Treatment of adverse effects (e.g., nausea, vomiting)
- Psychosocial support (e.g., depression, advance care planning)
- End-of-life care (less common if ART available)

HIV palliative care objectives

- Palliative care is an **approach that helps people living with a life-limiting illness to live as actively as possible**, from the point of diagnosis to end of life, as well as offering a support system to help families cope during the patient's illness and after death through bereavement support.
- HIV palliative care is an **holistic and comprehensive approach to care and support** that includes physical, psychosocial, spiritual, economic and legal support from the point of diagnosis until the end of life with the aim of improving quality of life.

[Source: StopAIDS, 2013]

What about palliative care in the era of ART?

- With advances in HIV-specific therapy and care, HIV infection is no longer a rapidly fatal illness. Instead, patients who are able to tolerate antiretroviral therapy (ART) usually experience a manageable, chronic illness.
- [But] in many parts of the world, patients still are **not able to obtain specific treatments for HIV** or opportunistic illnesses, and supportive or palliative care may be the primary mode of care available to patients with advanced AIDS.
- Regardless of access to disease-specific treatment, **people living with HIV continue to experience symptoms from HIV disease** and its comorbid conditions, and those taking ART may experience adverse effects**.**
- **Integrating palliative care and disease-specific care** is important for treating patients with HIV in order to promote quality of life and relieve suffering.

[Source: Rutgers School of Nursing, 2014]

‘Suffering’ and AIDS [sic]

Ethical and emotional responses to AIDS are collective representations of how societies deal with suffering, which extends from those [who are affected] to their families and intimates, to practitioners and institutions who care for them, and to their neighborhoods and ultimately the rest of society. (Farmer & Kleinman, 1989)

HIV palliative care interventions

- Everyone **living with HIV would benefit from receiving palliative care**, from the time of diagnosis of HIV infection and in conjunction with taking anti-retroviral drugs.
- People living with HIV **may experience both physical and psychosocial pain and suffering** - requiring a comprehensive approach to care and support
- Taking a palliative approach to HIV care has been shown to support **better patient outcomes** and to improve adherence to ART.
- Palliative care **is not a substitute for HIV treatment**, it is part of the package of services that patients on ART (as well as those unable to access treatment) may need, and have a right to access throughout their lifetime.
- **Early palliative care can be provided by clinicians and staff in an HIV clinic**. Staff should be trained in palliative care so that they can manage pain and other distressing symptoms, psychosocial and spiritual problems and can identify when to refer the patient to a palliative care service.

[Source: StopAIDS, 2013]

Country examples

Aspects of care: symptom management and emerging issues




Country examples: Belgium

- Doctors are specialised in HIV but also work as a specialists in general internal medicine, so they can work to prevent or treat co-morbidities between HIV and ageing.
- Life style **counselling** is a core business of every member of the HIV team and needs a place in the **total approach** to improve ageing with HIV.
- We discuss with patients
  - **General laboratory results** [at each consultation] with information and reassurance as necessary
  - **Kidney and liver function** with advice as required to protect renal function, and information about fluid and diet (and for the liver) the impact of alcohol/ medication
  - Discussing **viral load-compliance**: giving **positive feedback and taking an encouraging and empowering approach**
  - **Cardiovascular advice** yearly or more often depending on result and lifestyle
  - **Sexual health screening**: giving positive and empowering information and feedback
- Additionally, as required
  - **Neurocognitive questionnaire** and referral to neurological team if needed
  - **Depression questionnaire** and referral psychologist/psychiatrist if needed
  - **Dementia scale**
  - **Quality of life assessment**: Antwerp Institute is developing a tool for assessing quality of life

Country examples: Denmark

- “My experience is that people living with HIV over 50 feel more lonely and depressed than others at the same age (like us?) and it is a challenge for doctors to combine HIV treatment with routine ageing problems.” [HIV Nurse, Demark]
- Results from Danish ageing study: “Severe age-related diseases are highly prevalent in people with HIV, and continued attention and strategies for risk reduction are needed. [But] the findings from our study do not suggest that accelerated ageing is a major problem in the HIV-infected population.” (Rasmussen *et al*, 2015)

Country examples: Finland

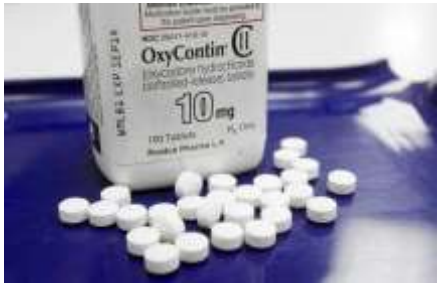
- The occurrence of HIV in people aged over 50 years require greater attention from professionals; older adults [in this low prevalence country] are **not believed to be at HIV risk**.
- When a diagnosis is known, **prejudice and moral devaluation** can become a burden for older people living with HIV.
- This **threat to the emotional wellbeing** may be specifically present in older age groups who already have to face the negative stereotyping: 'ageism'.
- Double negative stereotyping may lead **to various negative outcomes** e.g. reduced Quality of Life, increased feelings of depression, loss of social support or increased loneliness.
- Therefore, much **quality of life work** is being undertaken in Finland – findings should be disseminated across Europe.

Country examples: UK

- Mildmay Hospital in London is a leading centre for **HIV Associated Neurocognitive Disorders** (**HAND**).
- A proportion of PLHIV on ART continue to experience HAND.
- **Asymptomatic Neurocognitive Impairment (ANI)** is diagnosed if testing shows HIV-associated impairment in cognitive function, but everyday functioning is not affected.
- **Mild Neurocognitive Disorder (MND)** is diagnosed if testing shows HIV-associated impairment in cognitive function, and mild interference in everyday functioning.
- **HIV-associated Dementia (HAD)** is diagnosed if testing shows marked impairment in cognitive function, especially in learning of new information, information processing, and attention or concentration. This impairment significantly limits an ability to function day-to-day at work, home, and during social activities.

Critical issue: access to opioids

- A critical component of palliative care is the ability to manage physical pain. **Oral morphine** is included as an analgesic in the WHO list of essential Medicines and the IAHPC list of essential Medicines for Palliative Care.
- Yet morphine availability and accessibility **varies considerably between and within countries**. It is estimated that one million end-stage HIV and AIDS patients live in countries with low or no access to controlled medications and have no or insufficient access to treatment for moderate to severe pain (StopAIDS, 2013)
- For example, UKRAINE: 'Condemned to Excruciating Pain' – "When she pleaded for a fourth dose, doctors at one hospital accused her of selling the medications on the street." (HRW, 2011)



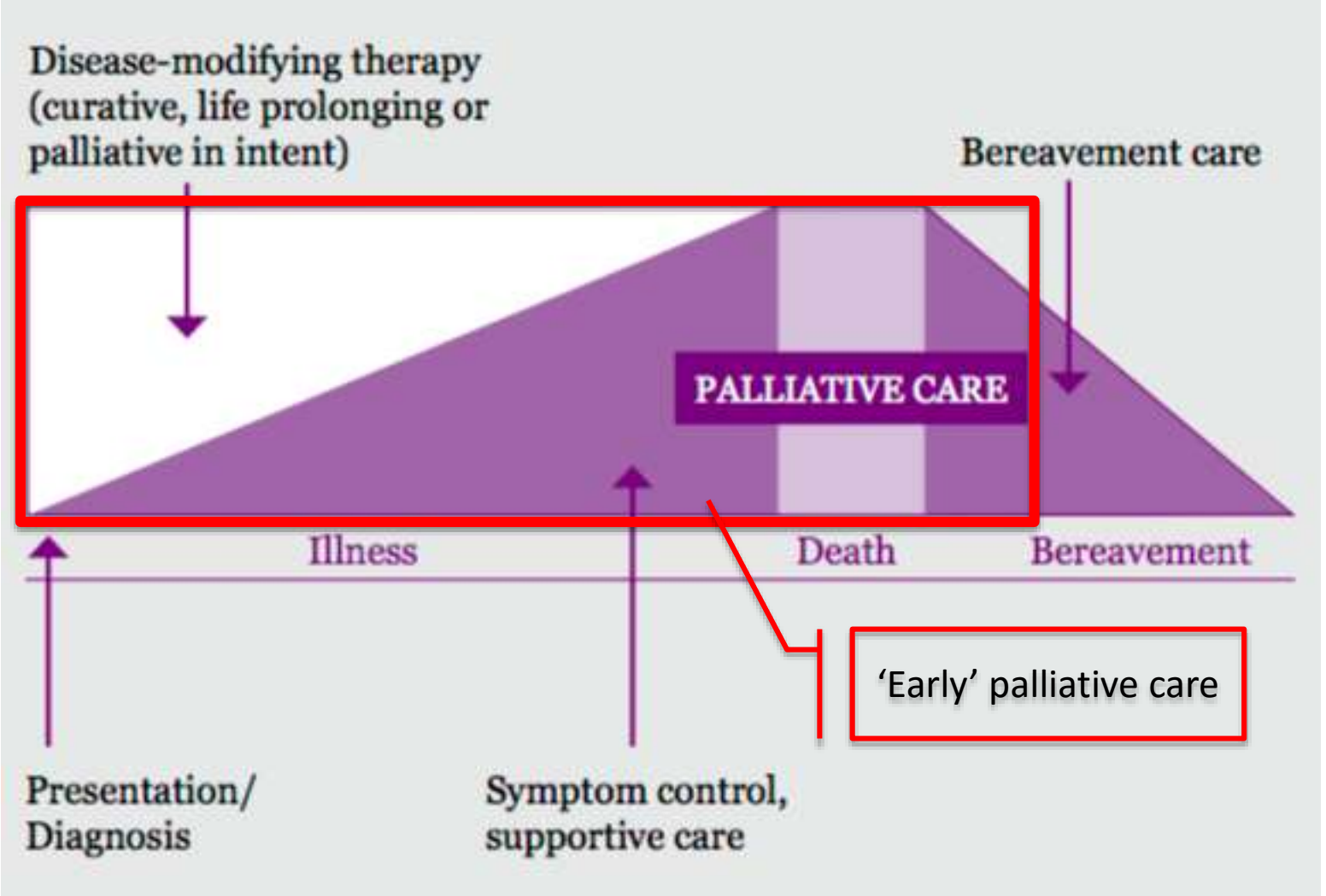
The future

Challenges for healthcare workers

- Nursing care for patients with HIV is **no more complicated than other aspects of care** for ageing patients with associated pathologies. For HIV and ageing, core care challenges are:
  - Stigma of old age (additional to HIV stigma)
  - Issues of inheritance
  - Physical changes
  - Social changes
  - Psychological changes
  - Pharmacological aspects

Expanding early palliative care

- '**Early palliative care**' can address symptomatic and psychosocial effects of disease that are often missed by routine clinical care, and of special significance in the context of ageing.
- Early palliative care may "narrow [the] gap between providers' and patients' **perceptions of needs** through good communication and targeting barriers, such as housing instability, which are vital to overcome for consistent long-term follow up." (Lofgren *et al*, 2015)



Standard Continuum of Care – modified for HIV

Conclusions

- Successful ageing is composed of eight factors: length of life, biological health, cognitive efficiency, mental health, social competence, productivity, personal control, and life satisfaction. **HIV and medication side effects can compromise these factors**, thus diminishing one's capacity to age successfully with this disease. (Vance, 2011)
- Adopting an 'early' palliative care approach in health care promotes a constellation of care interventions that can address the **person's** perception of needs and be broadly beneficial.
- Existing models of care for ageing people can be integrated with approaches to supporting older HIV patients [but **context** can impact on effectiveness – e.g. access to ART, or pain relief].

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