مروری بر مبانی مراقبت تسکینی

حدیث اشرفی زاده

دکترای پرستاری، فلوشیپ مراقبت های تسکینی

Palliative Care Definition

- “The active total care of patients whose disease is not responsive to curative treatment.
- Control of pain, of other symptoms, and of psychological, social and spiritual problems, 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 anti-cancer treatment.”

Introduction to Palliative Care

- **Palliative Care is an attempt to improve the health and wellbeing of patients with incurable illness.**
- Through addressing biological, psychological, social, and spiritual determinants of the illness experience

ضرورت ارائه مراقبت های حمایتی و تسکینی از دیدگاه WHO

- مراقبت های حمایتی و تسکینی باید از اولویت های برنامه های سلامت عمومی و مدیریت بیماری های کشورها باشد.
- کشورها باید با وضع قوانین مناسب، اجرای آن را تضمین کنند.
- مراقبت تسکینی حق همه انسان ها است.

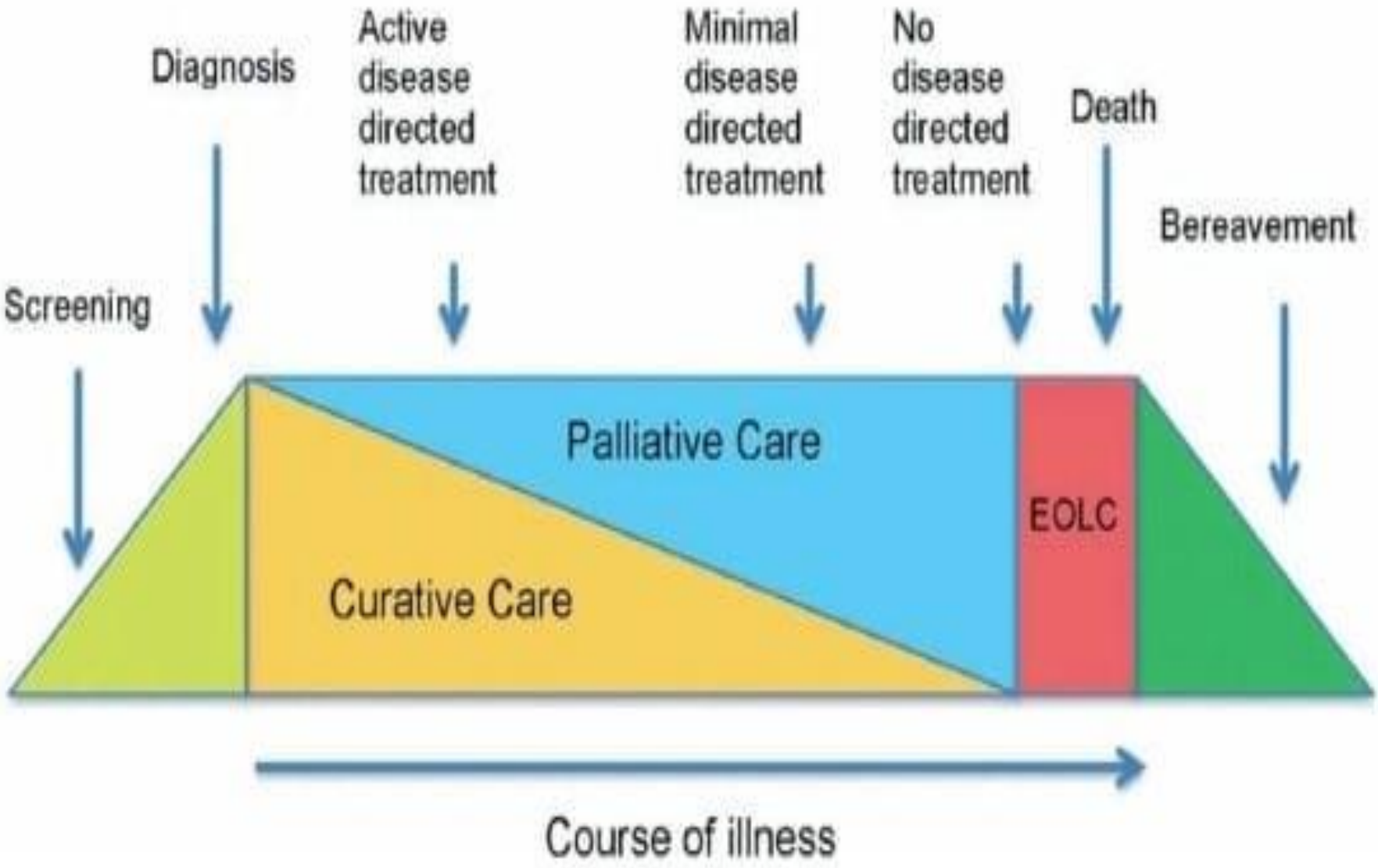
کیفیت زندگی

- کیفیت زندگی مفهومی است که به عواطف و احساسات و رفاه اجتماعی و جسمی افراد و توانایی های آنها برای انجام وظایف معمولی روزانه آنها اشاره دارد.
- نشان دهنده واکنش فردی به اثرات جسمی، روانی و اجتماعی بیماری در زندگی روزانه است و بر ارتقای رضایت فرد از شرایط زندگی خود، تاثیر می گذارد.
- کیفیت زندگی مطلوب نقطه مرکزی مراقبت تسکینی است.

عوامل مؤثر بر کیفیت زندگی

- علایم جسمی و عملکردی
- عملکرد اجتماعی، عاطفی و رفاهی
- شرایط اقتصادی- باورهای فرهنگی

Palliative Care Continuum



اصول مراقبت تسکینی

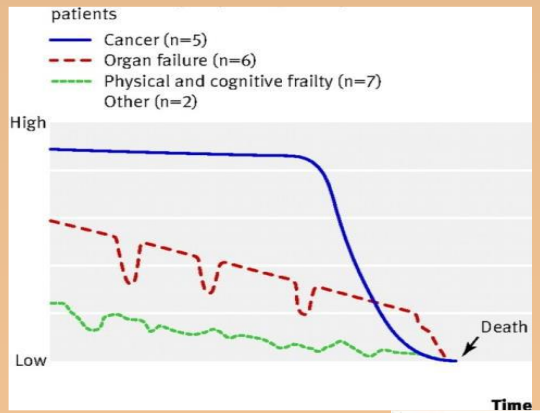
- بیمار و خانواده به عنوان واحد مراقبت
- توجه به نیازهای جسمی، روانی، فرهنگی، اجتماعی، اخلاقی و معنوی
- رویکرد تیمی و میان رشته ای
- آموزش و حمایت از بیمار و خانواده و انتقال مسؤولیت و وظایف تیم به آن ها
- در بیماری های مختلف و در عرصه های گوناگون ارایه می شود.
- حمایت از سوگ
- ارایه هم زمان اقدامات تسکینی و پروسیجرهای درمانی
- در هر مرحله از بیماری مناسب بوده و صرفا مربوط به مرحله انتهایی و علاج ناپذیری نیست.
- پیش آگهی کمتر از شش ماه صرفا به مراقبت مراحل پایان زندگی مربوط بوده و برای دریافت مراقبت تسکینی، اهمیتی ندارد.
- به معنای دستور عدم احیا (DNR) نیست.
- هدف آن افزایش طول عمر بیمار نیست.

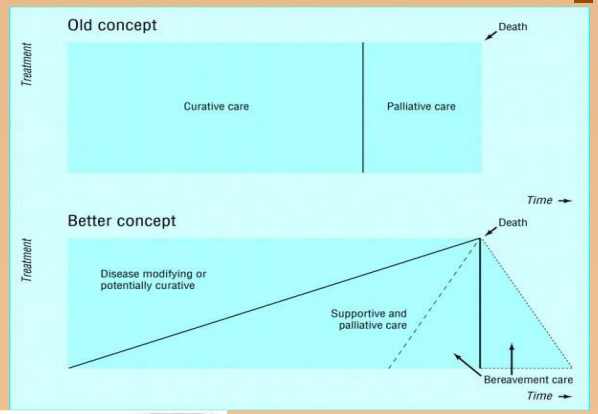
The Palliative Care Team

Primary Care can deliver Palliative Care

5 ALLs

- 1.All illnesses
- 2.All times
- 3.All dimensions
- 4.All settings
- 5.All nations





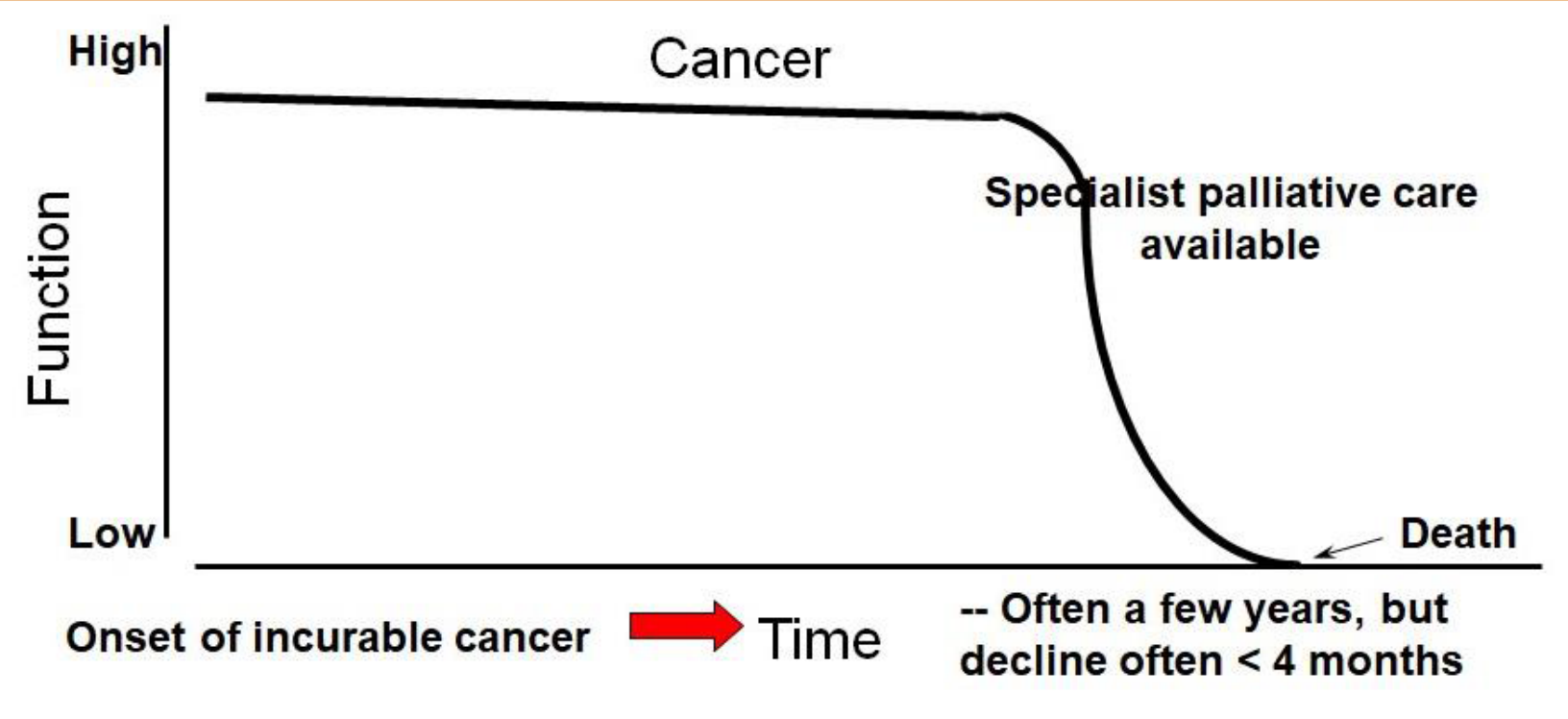
1. All illnesses

3 illness trajectories

- •Acute –typically cancer
- •Intermittent –typically organ failure
- •Gradual decline –typically frailty, dementia

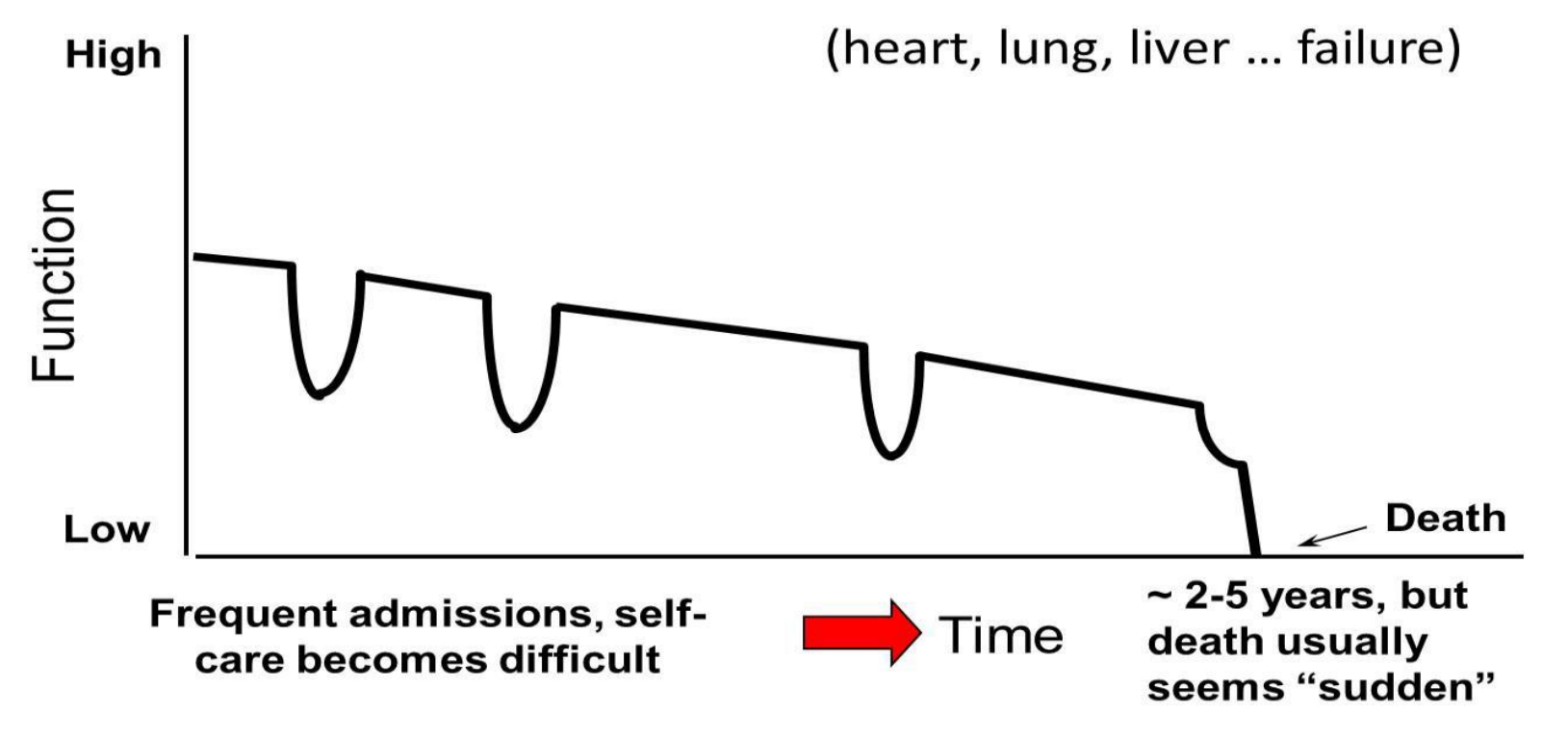
Acute Trajectory

Generally predictable course, lung, stomach, bowel, brain, breast, cervix



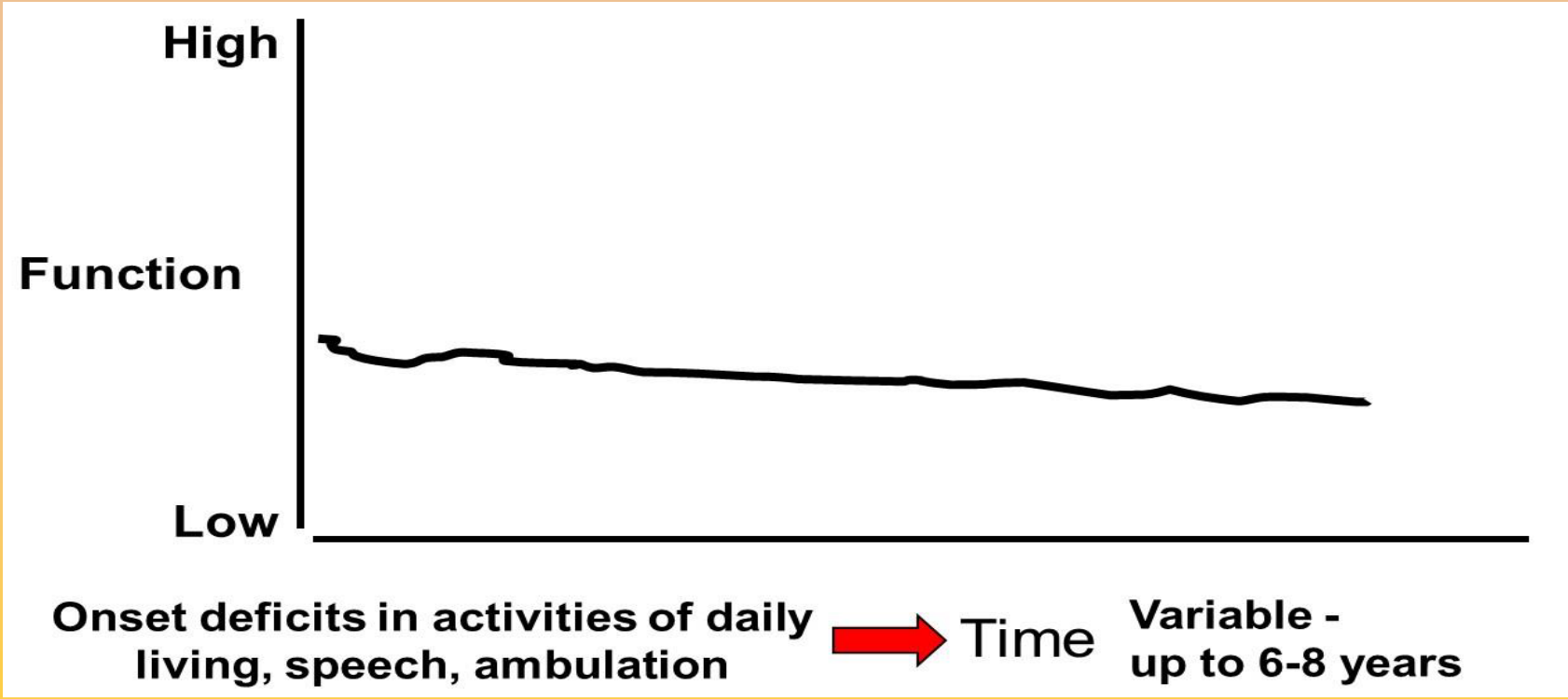
Organ System Failure Trajectory

Conditions: Heart, lungs, liver, renal failure, drug resistant TB

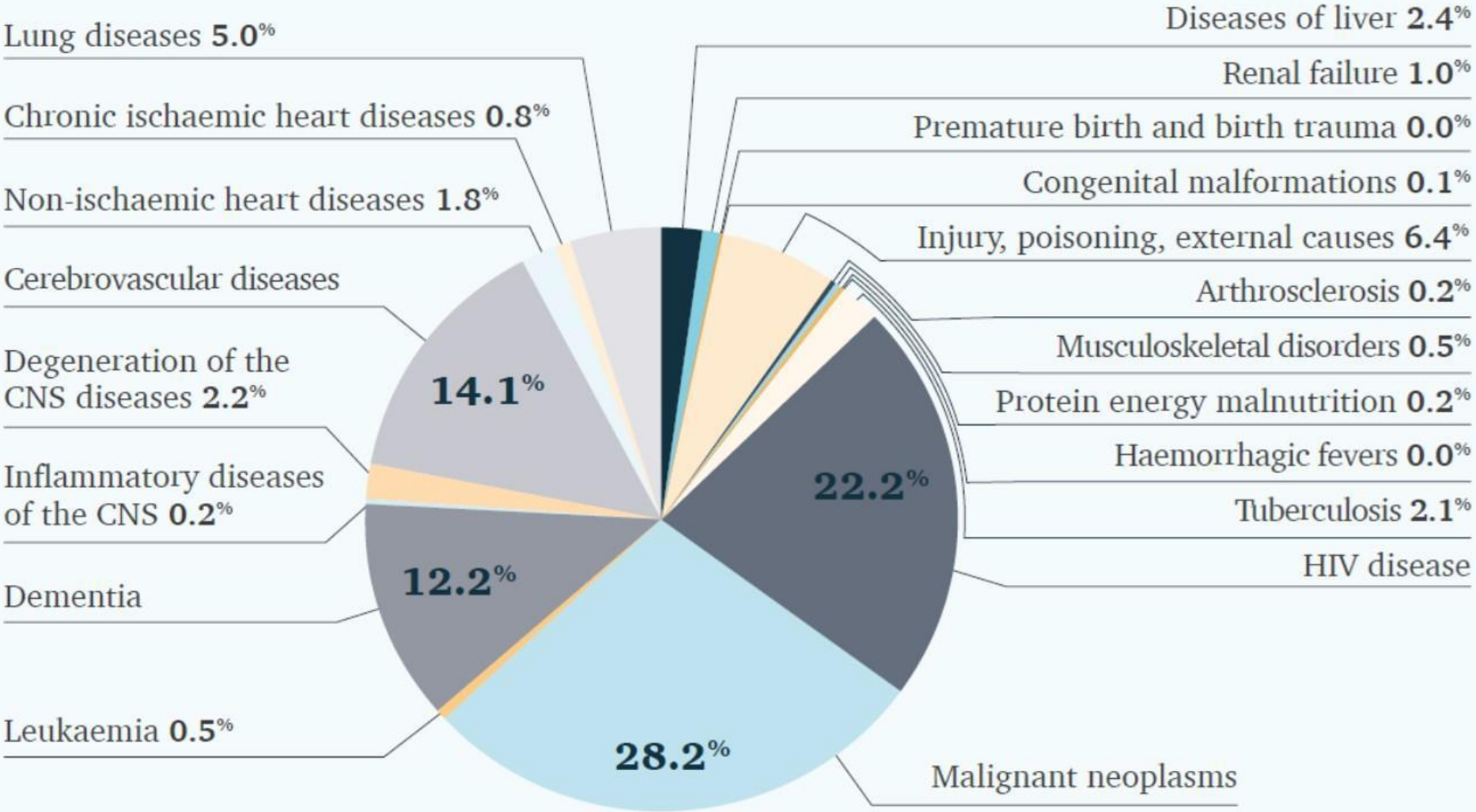


Dementia/Frailty Trajectory

Conditions: Dementia, frailty, stroke, progressive neurological



Worldwide Palliative Care Need –World Atlas 2020

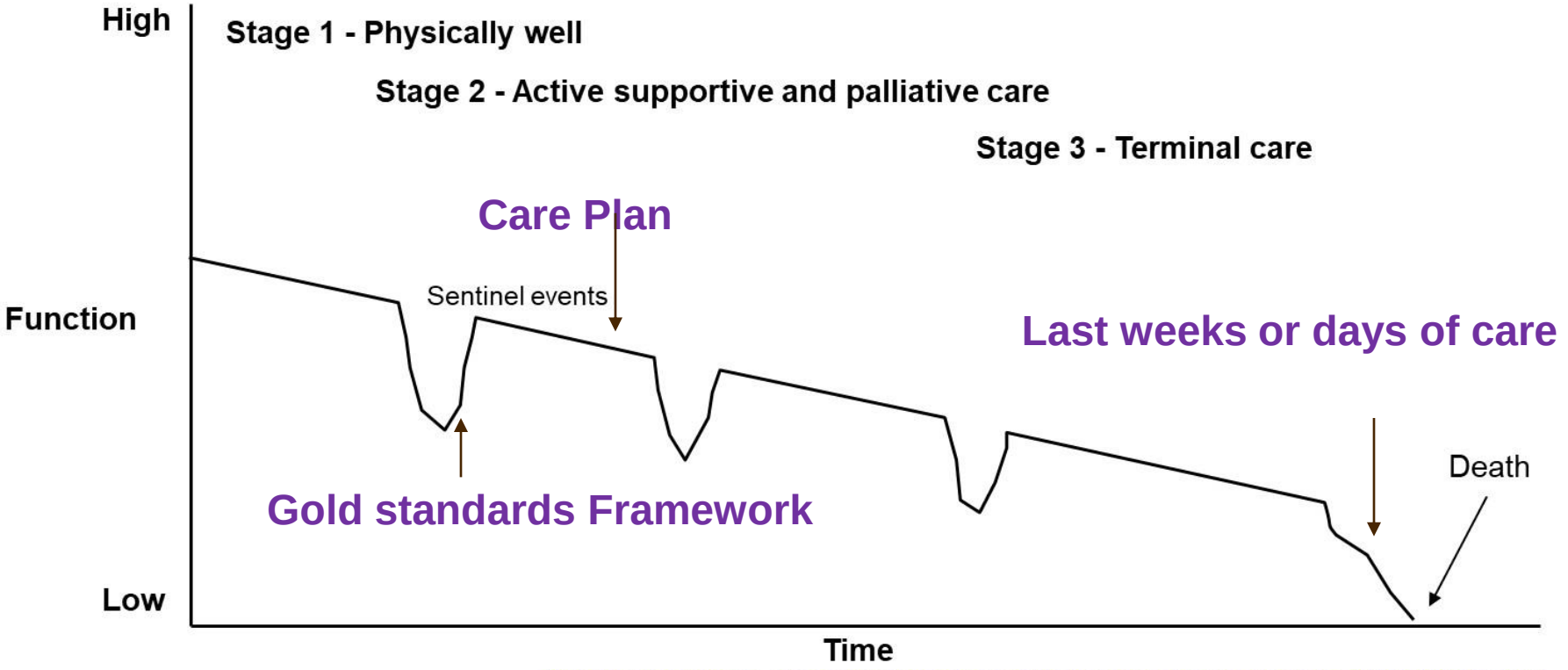


Who will benefit from palliative care?

- Cancer: **Improved the prognosis and pain control strategies**
- COPD
- CHF
- Dementia
- Renal Failure
- Diabetes
- AIDS
- Multiple sclerosis (MS)
- …

2. All times

- **From diagnosis to death**
- •Needs early identification
- **Caring for people with organ failure: 3 stages**



Boyd K and Murray SA . Recognising and managing key transitions in end of life care. *BMJ* 2010;341:c4863.

2. All times

When is a patient palliative?

- Would you be surprised if Mrs A were to die within the next 12 months?
- Avoid “prognostic paralysis*
- Can start and then stop of person improves
- According to need not prognosis or diagnosis

3. All settings

- **Primary care** -in clinics, at patients' homes, in care homes –nursing and residential
- **In hospital wards and clinics** –a palliative care approach
- **In hospices** -but remember all illnesses
- **Unscheduled/Out-of-Hours/Emergency Care**

مدل های ارایه مراقبت تسکینی

- سرویس مراقبت تسکینی در منزل
- سرویس مراقبت تسکینی مبتنی بر جامعه
- سرویس مراقبت تسکینی در بیمارستان
- سرویس مراقبت تسکینی هاسپیس (مراقبت آسایشگاهی)

3. All settings

Scottish Care Homes project

- Routine advance care planning from admission to care homes
- Increase in DNAR status documented from 8 to 71% in patients who died
- Reduction of nearly 50% (from 15% to 8%) of residents dying in hospital
- Interviewed bereaved relatives reported better care

4. All nations

All Nations and Countries

- High income
- Low and middle income
- **International Inequities and Differences**

4. All nations

Edinburgh, Scotland

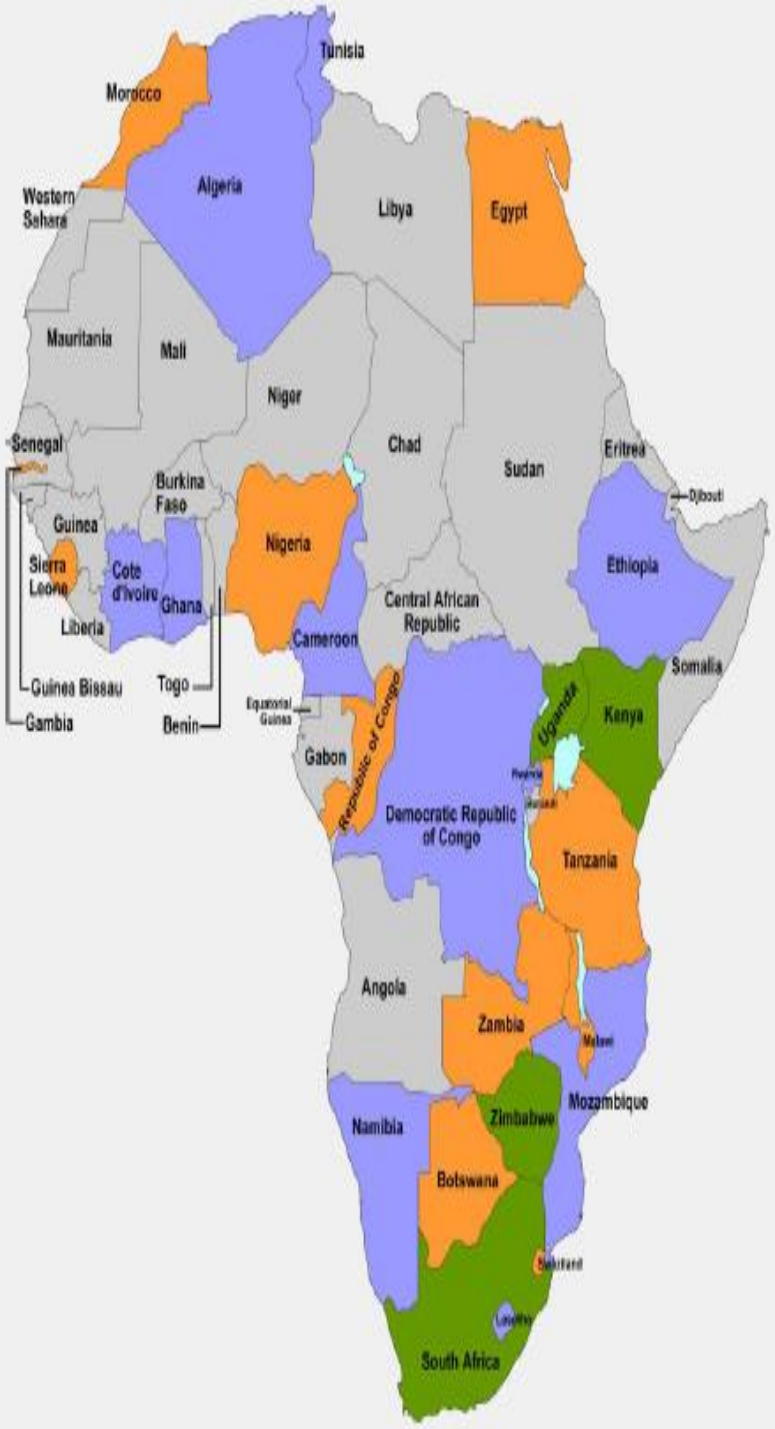
- Main issue existential or spiritual distress
- Analgesia effective
- Anger in the face of illness
- *"Just keep it to myself"*
- Spiritual needs evident but unmet

Chogoria, Kenya

main issue physical suffering, especially pain

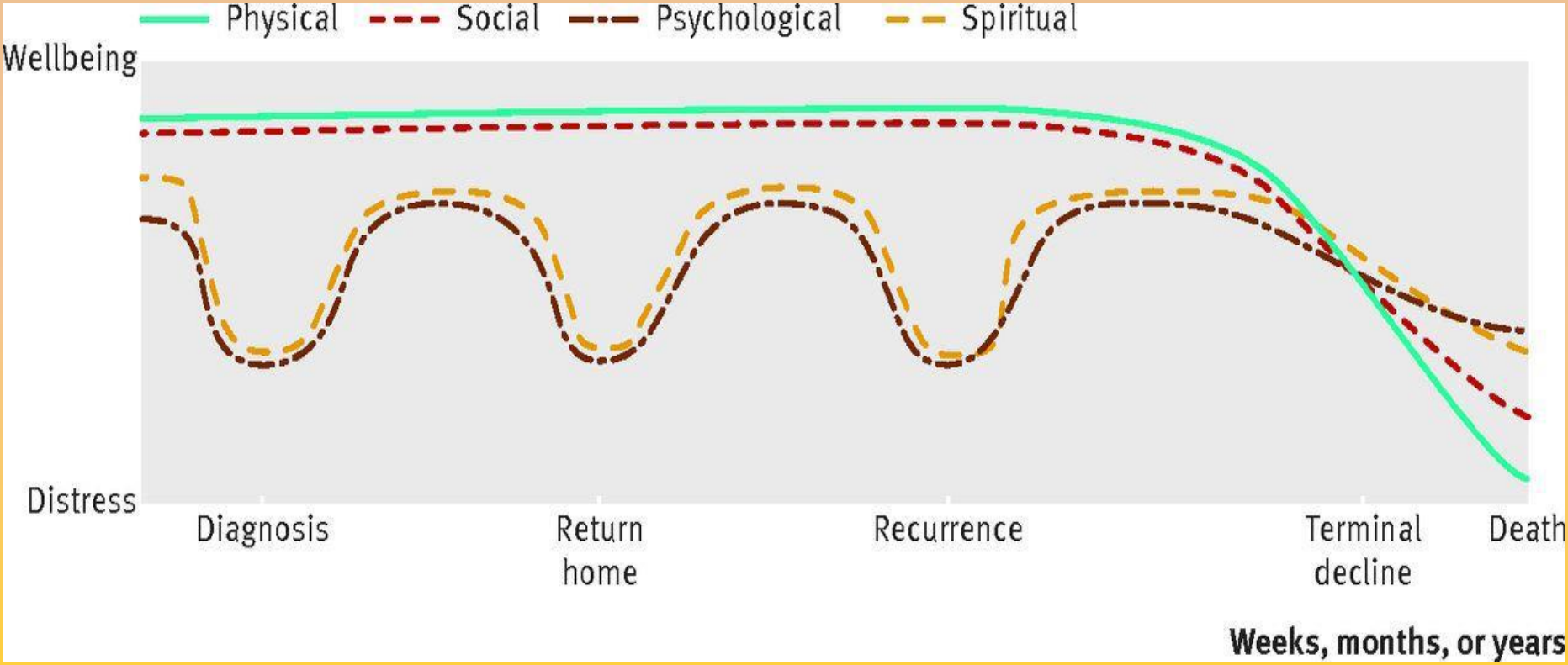
- analgesia unaffordable
- acceptance rather than anger
- community support accepted
- patients comforted and inspired by belief in God

- Approaching integration (n=4)
- Localised provision (n=11)
- Capacity building activity underway (n=11)
- No hospice-palliative care activity yet identified (n=21)



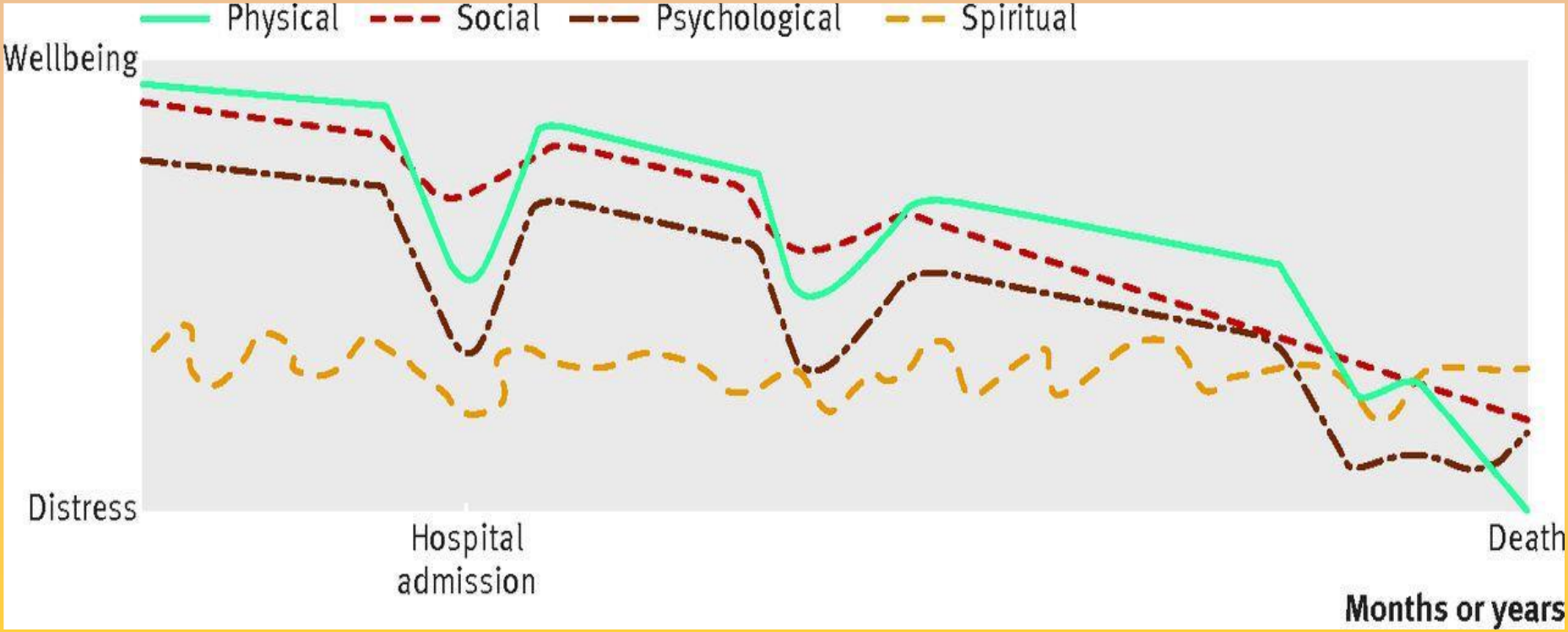
5. All domains

- **Wellbeing trajectories in patients with conditions such as cancer causing rapid functional decline.**



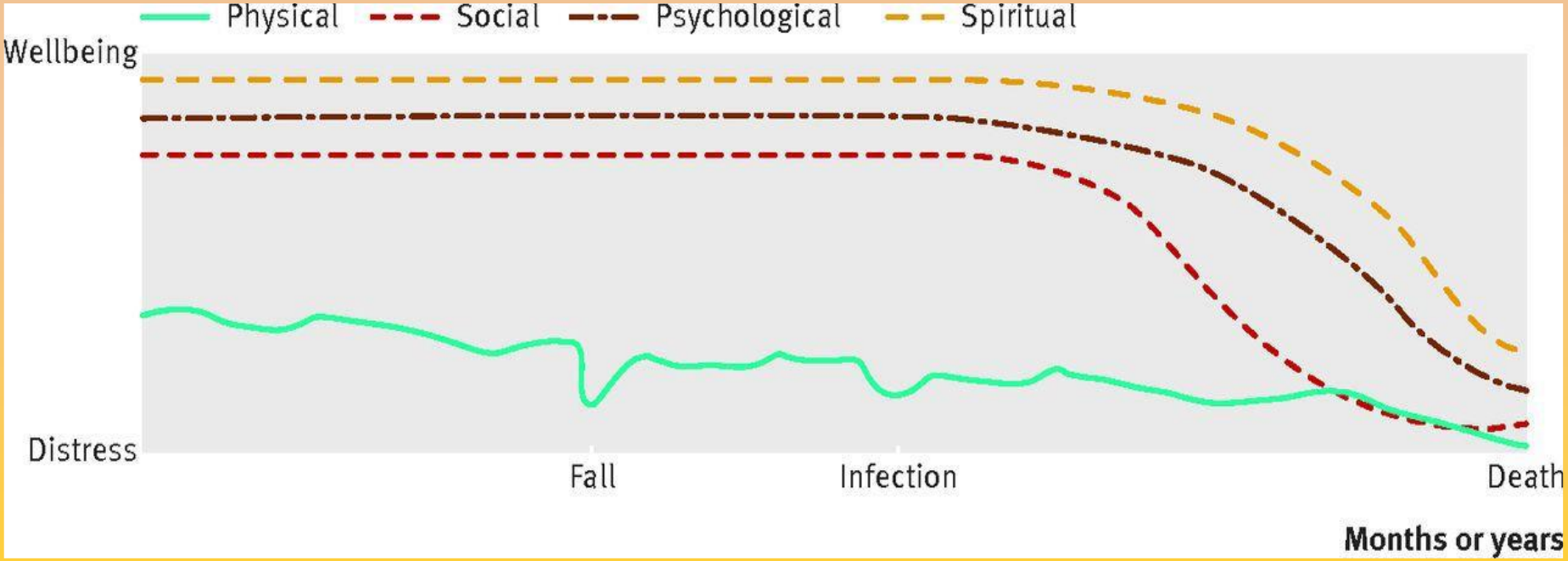
5. All domains

- **Wellbeing trajectories in patients with intermittent decline (typically organ failure or multimorbidity).**



5. All domains

- **Wellbeing trajectories in patients with gradual decline (typically frailty or cognitive decline).**



Palliative Care: Targets for Care

- Addresses needs in the multiple domains inherent in quality of life
- Physical: Symptoms, progressive impairments
- Psychological: Symptoms, psychiatric disorders, mood and worries, adaptation and coping, body image, sexuality

Palliative Care: Targets for Care

- Addresses needs in the multiple domains inherent in quality of life
  - **Social:** Role functioning, family integration, intimacy
  - **Spiritual:** Religion and faith, meaning, values, need to contribute, transcendence
  - **Others:** Economic

Palliative Care: Targets for Care

- Addresses needs that may become most prominent as death approaches
  - **Death preparation**
  - Assurance of comfort
  - Support for autonomy, decision making consistent with values, and preparation for surrogate decisions
  - Intensifying family support

Specifically: Palliative Care Is

- ✓ Excellent, evidence-based medical treatment
- ✓ Vigorous care of pain and symptoms throughout illness
- ✓ Care that patients want *at the same time* as efforts to cure or prolong life, when appropriate

Palliative Care Is NOT

- ☒ Not "giving up" on a patient
- ☒ Not in place of curative or life-prolonging care
- ☒ Not the same as hospice
- ☒ Does not require a DNR order


WEB SHOTS

Physical Aspects of Palliative Care

Symptoms Experienced by Patients At the End of Life

- Whether the disease is curable or not, we should be able to control symptoms

- Pain
- Fatigue
- Nausea Vomiting
- Fungating Wounds
- Bed sores
- Incontinence
- Confusion
- Breathlessness

symptom prevalence in advance care

Symptom	Number of patients	Percentage with symptom
Pain	10,379	35 to 96
Depression	4378	3 to 77
Anxiety	3274	13 to 79
Confusion	9154	6 to 93
Fatigue	2888	32 to 90
Breathlessness	10,029	10 to 70
Insomnia	5606	9 to 69
Nausea	9140	6 to 68
Constipation	7602	23 to 65
Diarrhea	3392	3 to 29
Anorexia	9113	30 to 92

It's not just cancer Symptoms experienced in the last year of life in non-cancer conditions

	Cancer %	Heart disease %	Stroke %
Pain	88	77	66
Breathlessness	54	60	37
Nausea and vomiting	59	32	23
Difficulty swallowing	41	16	23
Constipation	63	38	45
Mental confusion	41	32	50
Pressure sores	28	11	20
Urinary incontinence	40	30	56
Bowel incontinence	32	17	37
Total Number	2063	683	229

Addington-Hall, J. (1996). Heart disease and stroke: lessons from cancer care. In G. Ford, & I. Lewin, Managing Terminal Illness London: Royal College of Physicians.

Physical Care

- The assessment and management of symptoms and side effects are contextualized to the disease status.
- Treatment plans are developed in context of disease, prognosis, and functional limitations
- Patient and family/surrogate understanding of illness is assessed in relation to patient-centered goals
- Patient/family understanding of illness and treatment options assessed with consideration to culture, cognitive function, and developmental stage

Social Aspects of Palliative Care

Social Well Being

Addressing social determinants of suffering

- Social isolation
- Problems caused by gaps in social cohesion around the patient
- The final solution is a society which
- Works towards the well being of all its members
- Fights exclusion and marginalization
- Creates a sense of belonging
- Promotes trust
- Offers its members the opportunity of upward mobility

Social Well Being

- Relationship/role description
- Caregiver burden
- Sexuality concerns
- Impact on children
- Financial concerns

GENERAL PROCESSES OF CARE

- Enable patients to make ***informed decisions*** about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.

- Provide ***education and support to families*** and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.

SOCIAL ASPECTS OF CARE

- Conduct *regular patient and family care conferences* with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care, disease prognosis, and advanced care planning, and offer support.

- *Develop and implement a comprehensive social care plan* which addresses the social, practical and legal needs of the patient and caregivers, including but not limited to: relationships, communication, existing social and cultural networks, decisionmaking, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.

مصاحبه و ارتباط با بیمار و خانواده

- استفاده از سؤالات باز و گفتگوی آزاد، خلاصه و غربالگری، روشن کردن این که کدام یک از نگرانی ها در حال حاضر بیشترین اولویت را دارند.
- عدم همدلی یعنی خود را جای بیمار قرار ندهید.
- حضور هر فردی که بیمار او را امین یا خانواده خود می داند.
- عدم برآورد میزان عمر باقیمانده بیمار (کمتر از شش ماه، ...) و اظهار این نکته که بهتر است دنبال پیش بینی نباشیم و آنچه در توان داریم برای راحتی و آرامش و احترام وی و بر آورد خواسته هایش انجام می دهیم.
- توجه به دیسترس معنوی و روانی بیمار مثلا توجه به اظهاراتی نظیر: "من خیلی نگران همسرم هستم".
- اقدامات مربوط به مشکلات روانی یا معنوی پیشرفته، در صورت لزوم پس از مشاوره با روانپزشک و درمانگر معنوی مورد توجه قرار گیرد.

SPIKES Protocol

S Setting and listening skills

P Patient's *perception* of condition/seriousness

I Invitation from patient to give information

K Knowledge in giving medical facts

E Explore emotions and empathize as patient responds

S Strategy and summary

Baile et al., 2000

Psychosocial Aspects of Palliative Care

Psychosocial Care

- Basic communication skills to talk to the patient and family in a supportive way
- Health Care professionals involved in the care
- Family, friends, neighbors, colleagues with whom the patient spends most of his/ her time

Psychosocial Care

- Cancer affects people and families
- 35-70% of people with cancer suffer from anxiety and depression
- Communication impacts patient and family outcomes including adjustment and healing.

Improving Psychosocial Outcomes

- Nurses often hear the concerns of patients and families
- Nurses often lack confidence in addressing psychosocial concerns
- Nurses communication often improves quality of life and adjustment.
- Nurses have flexible communication styles to meet patient needs.

Psychosocial Issues

- Concerns
- Fears
- Distress
- Anxiety (Suicide thoughts)
- Sadness and depression
- Grief
- Anger

Spiritual Aspects of Palliative Care

What is Spirituality?

- A personal search for meaning and purpose in life, which may or may not be related to religion
- "Spirituality" is rarely used – difficult to understand
  - Stories about life
  - Relationships with self and others
  - Relationships with music and nature
  - Relationship with God or a higher being
  - Hope, meaning, and purpose in life
  - Religion

راهبردهای ارتقای امید و معنای زندگی

- ارتباط مثبت با مراقبین سلامت
- شوخ طبعی و خوشبینی
- یاد آوری خاطرات خوش
- خلق اثر و افزودن پدیده ای به جهان
- خدمت به انسان ها و جامعه و دستگیری نیازمندان
- تجربه درد و رنج و سختی (رشد پس از سانحه)

❑موارد ایجاد کننده ناامیدی:

- کاهش استقلال فردی برای کار روزانه
- دردی که کنترل نمی شود
- انزوا و گوشه گیری