

# **Innovative European practices and strategies in the field of palliative care**

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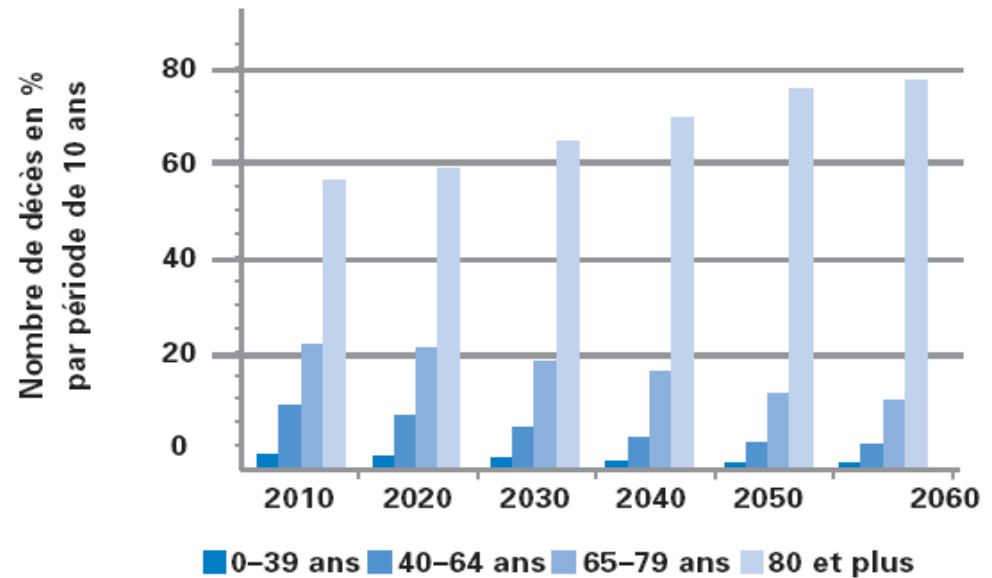
# Definition of palliative care

- Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.
- Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.
- Palliative care is explicitly recognized under the human right to health. It should be provided through person-centered and integrated health services that pay special attention to the specific needs and preferences of individuals.



# Number of patients

**Fig. 3 : Evolution des décès par âge 2010-2060**



Source : Office fédéral de la statistique (OFS)

# Number of patients

## Nombre de patients en soins palliatifs en Suisse en 2012 et 2032 (estimation)

Années	2012	2032	En %
Nombre total de décès en Suisse	60 000	80 000	+33%
<b>Total des patients en soins palliatifs</b> (estimation : deux tiers)	<b>40 000</b>	<b>53 000</b>	<b>+32%</b>
dont patients en soins palliatifs de premier recours (estimation : 80%)	32 000	42 000	+31%
Patients en soins palliatifs avec soins palliatifs spécialisés (estimation : 20%)	8 000	11 000	+37%

Observatoire national de la fin de vie (2012) : Rapport 2011 « Fin de vie : un premier état des lieux »

## FACTS

### QUELLES SONT LES LACUNES ?



**86%**

des personnes qui  
ont besoin de soins  
palliatifs n'en  
bénéficient pas



**83%**

de la population  
mondiale n'a pas  
accès au soulagement  
de la douleur



**98%**

des enfants ayant  
besoin de soins  
palliatifs vivent dans  
des pays à revenu  
faible ou intermédiaire

# FACTS

## QUELS SONT LES OBSTACLES ?



Connaissance insuffisante du public de l'aide pouvant être apportée par les soins palliatifs



Obstacles culturels et sociaux, comme les croyances sur la douleur et la mort



Compétences et moyens insuffisants des agents de santé



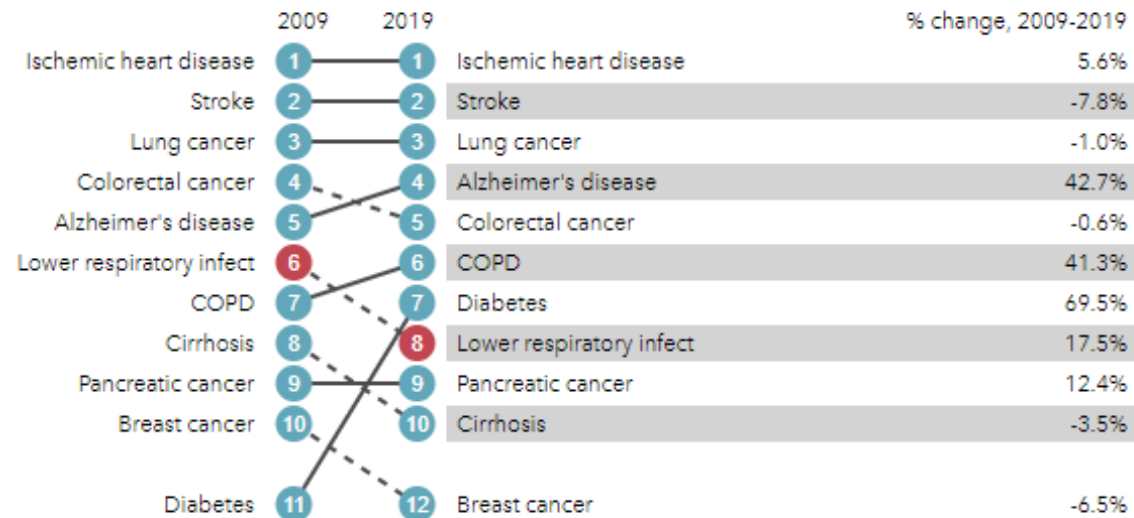
Réglementation trop restrictive sur le soulagement de la douleur par les opioïdes

# Causes of deaths (1)

## What causes the most deaths?

- Communicable, maternal, neonatal, and nutritional diseases
- Non-communicable diseases
- Injuries

## MULTIMORBIDITIES NON CANCER



Top 10 causes of total number of deaths in 2019 and percent change 2009-2019, all ages combined

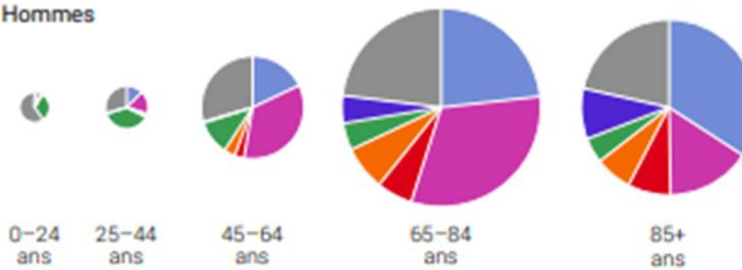
See related publication: [https://doi.org/10.1016/S0140-6736\(20\)30925-9](https://doi.org/10.1016/S0140-6736(20)30925-9)

# Causes of deaths (2)

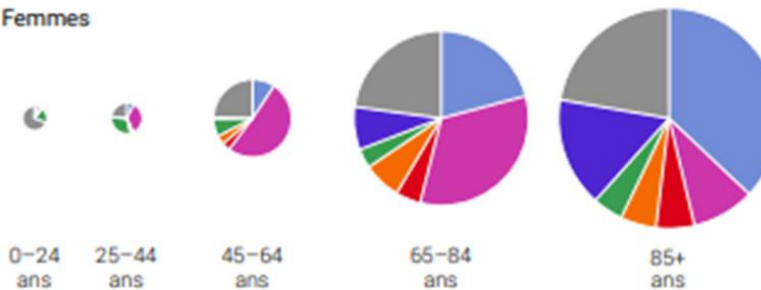
## Principales causes de décès selon le groupe d'âge, en 2022



### Hommes

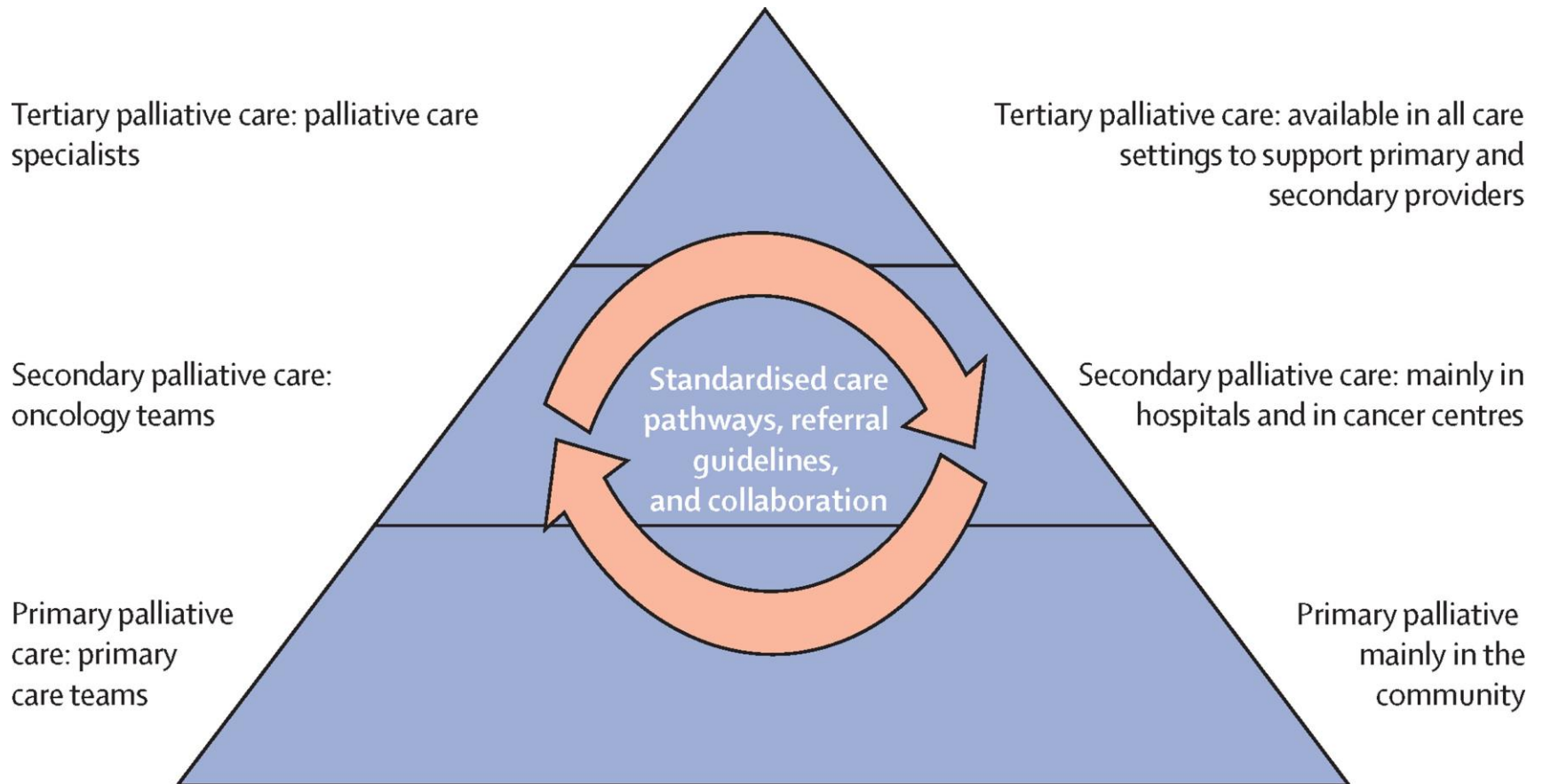


### Femmes



Les surfaces sont proportionnelles au nombre absolu de décès.





# CHALLENGES

- Mostly cancer 70 / 30%
- Mostly in palliative care services
- Late
- Median length survival 2-3 months
- Late Identification in Pal Care services
- Reactive / after crisis / Post acute
- Emergencies
- Fragmented care

- Mostly non-cancer 85 / 15%
- Mostly in community services
- Early
- Median length survival 24 months
- Preventive / Planned
- Timely identification in the Community
- Advance care planning
- Case management
- Integrated care

Current model: "Late, Reactive and Fragmented"

Proposed model "Early, Preventive and Integrated"

# CHALLENGES identification

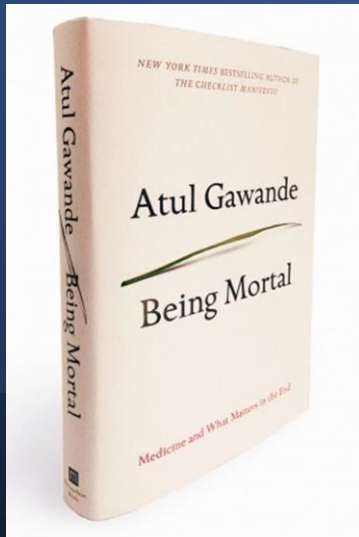
1. Does the Patient Have A Life-Limiting Illness? (Check All Items that Apply)	
<input type="checkbox"/>	<b>Advanced Dementia or CNS Disease</b> (e.g. history of Stroke, ALS, Parkinson's): Assistance needed for most self-care (e.g. ambulation, toileting) <i>and/or</i> Minimally verbal.
<input type="checkbox"/>	<b>Advanced Cancer:</b> Metastatic <i>or</i> locally aggressive disease.
<input type="checkbox"/>	<b>End Stage Renal Disease:</b> On dialysis <i>or</i> Creatinine > 6.
<input type="checkbox"/>	<b>Advanced COPD:</b> Continuous home O2 <i>or</i> chronic dyspnea at rest.
<input type="checkbox"/>	<b>Advanced Heart Failure:</b> Chronic dyspnea, chest pain <i>or</i> fatigue with minimal activity or rest.
<input type="checkbox"/>	<b>End Stage Liver Disease:</b> History of recurrent ascites, GI bleeding, <i>or</i> hepatic encephalopathy.
<input type="checkbox"/>	<b>Septic Shock</b> (i.e. signs of organ failure due to infection): Requires ICU admission <i>and</i> has significant pre-existing comorbid illness.
<input type="checkbox"/>	<b>Provider Discretion - High chance of Accelerated Death:</b> <i>Examples:</i> Hip fracture > age 80; Major trauma in the elderly (multiple rib fractures, intracranial bleed), Advanced AIDS, etc
<input type="checkbox"/>	
<b>No Checked Items?</b> STOP! Screening is Complete	<b>ONE or More Checked Items?</b> CONTINUE screening!

Figure 1: Identification of an individual with a life-limiting illness.

2. Does the Patient Have TWO or More Unmet Palliative Care Needs? (Check All the Apply)	
<input type="checkbox"/>	<b>Frequent Visits:</b> 2 or more ED visits or hospital admissions in the past 6 months.
<input type="checkbox"/>	<b>Uncontrolled Symptoms:</b> Visit prompted by uncontrol symptom: e.g. pain, dyspnea, depression, fatigue, etc.
<input type="checkbox"/>	<b>Functional Decline:</b> e.g. loss of mobility, frequent falls, decrease PO, skin breakdown, etc.
<input type="checkbox"/>	<b>Uncertainty about Goals-of-Care and/or Caregiver Distress</b> Caregiver cannot meet long-term needs; Uncertainty/distress about goals-of-care.
<input type="checkbox"/>	<b>Surprise Question:</b> You would not be surprised if this patient died within 12 months.
<input type="checkbox"/>	
<b>Less than TWO checked Items?</b> STOP! Screening is Negative	<b>TWO or more checked Items?</b> PC Referral Recommended!

Figure 2: Identification of unmet PC needs.

# CHALLENGES



- *We're good at addressing specific, individual problems: colon cancer, high blood pressure, arthritic knees.*
- *Give us a disease, and we can do something about it.*
- *But give us an elderly woman with high blood pressure, arthritic knees, and various other ailments besides—an elderly woman at risk of losing the life she enjoys—and we hardly know what to do and often only make matters worse.”*

# CHALLENGES symptoms



## Edmonton Symptom Assessment Scale (ESAS) Tool

Name: \_\_\_\_\_ Phone Number: \_\_\_\_\_

Address: \_\_\_\_\_ Completed By: \_\_\_\_\_

Please circle a number that best describes how you feel:

0 1 2 3 4 5 6 7 8 9 10

← No pain

→ Worst possible pain

0 1 2 3 4 5 6 7 8 9 10

← Not tired

→ Very tired

0 1 2 3 4 5 6 7 8 9 10

← No nausea

→ Very nauseous

0 1 2 3 4 5 6 7 8 9 10

← Not depressed

→ Very depressed

0 1 2 3 4 5 6 7 8 9 10

← Calm

→ Very anxious

0 1 2 3 4 5 6 7 8 9 10

← Not drowsy

→ Very drowsy

0 1 2 3 4 5 6 7 8 9 10

← Normal appetite

→ No appetite

0 1 2 3 4 5 6 7 8 9 10

← Best feeling of well-being

→ Worst possible feeling of well-being

0 1 2 3 4 5 6 7 8 9 10

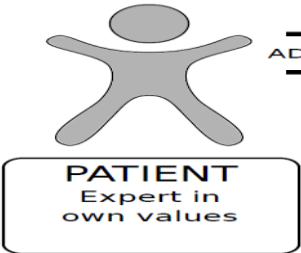
← No shortness of breath

→ Very short of breath

0 1 2 3 4 5 6 7 8 9 10

← Other problem

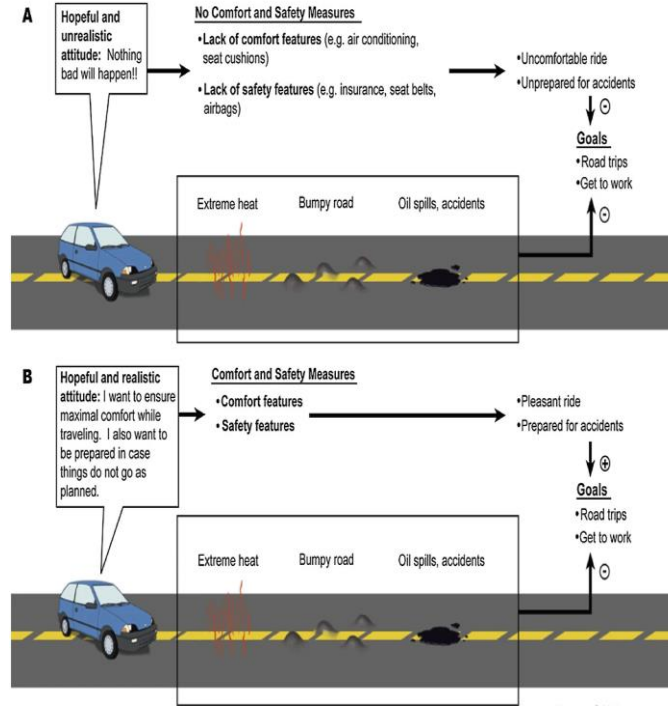
# CHALLENGES



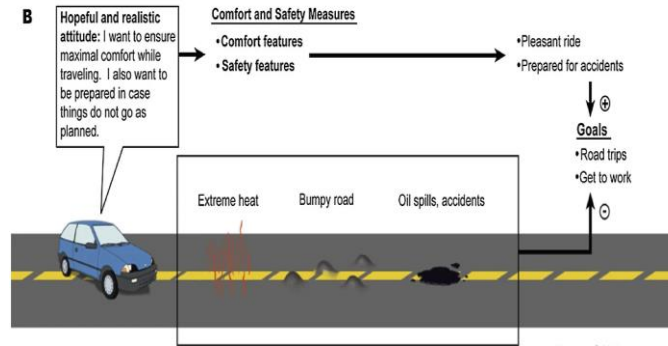
ADVANCE CARE PLANNING



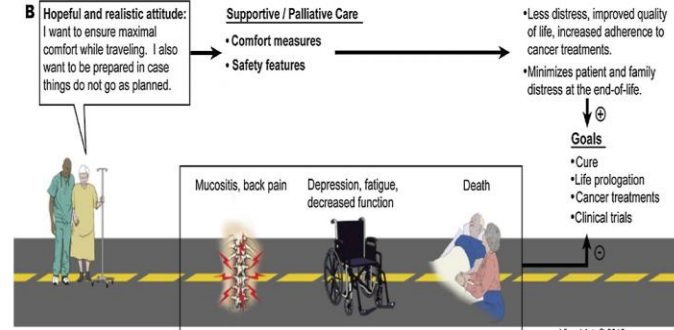
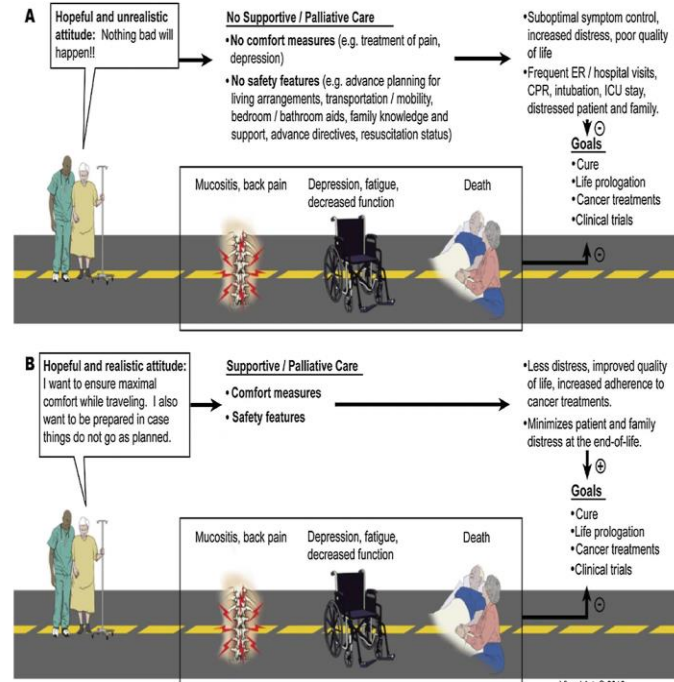
### From: Palliative Care in Critically Ill Cancer Patients



Visual Art: © 2010  
The University of Texas  
M. D. Anderson Cancer Center

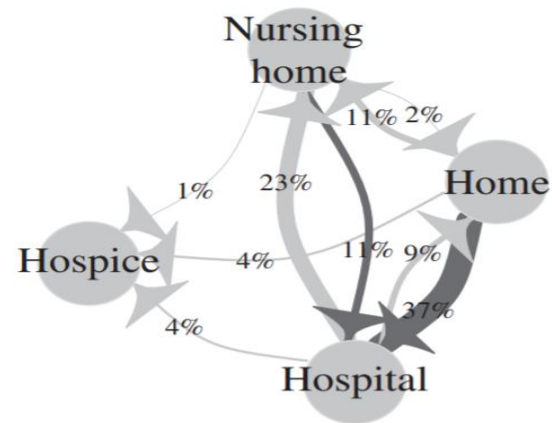


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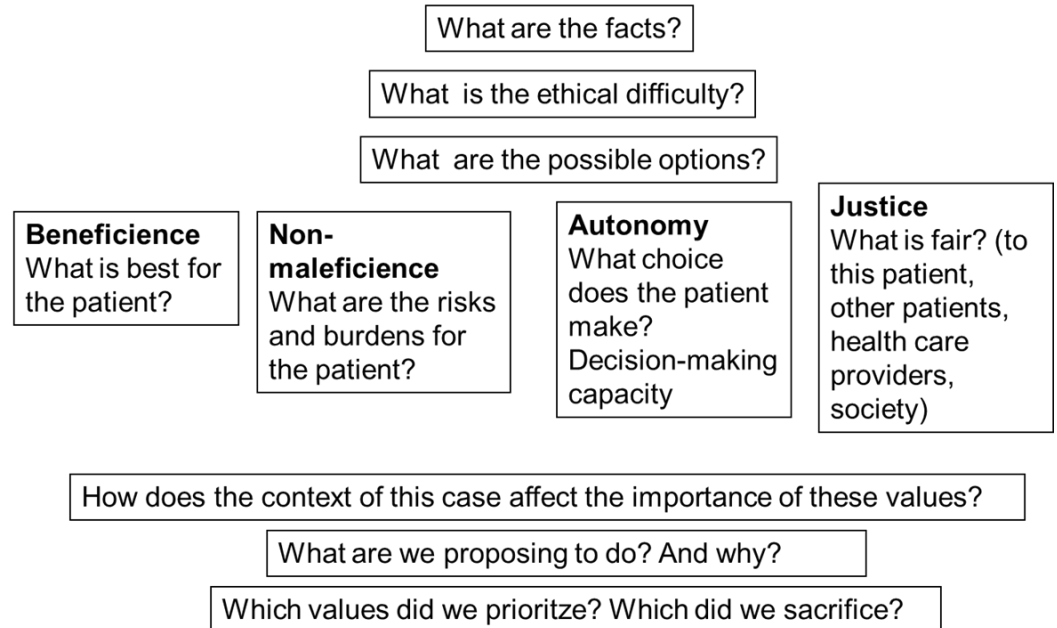
# CHALLENGES trajectories



**FIG. 1.** Graph of transfers of end-of-life patients with the edges (arrows) representing the proportion of frequent referrals (often/very often) one to three weeks before death for each pathway.



# CHALLENGES ethical



# What does it mean?

- A lot of patients- detection
- Functional help
- Proms- share information- Advance care planning
- Symptom assessment of patients with cognitive impairment