

Challenges in communication about the end of life with older people and people with dementia

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Communicating about the end of life: why, what, when

- Talking about the end of life enables people to make their wishes known about their care
- Topics can include
 - Treatment goals and preferences
 - Preference for place of care or place of death
 - Proxy decision-makers
 - Circumstances in which people do or do not wish to be resuscitated

Communicating about the end of life: why, what, when

When to talk? The 'right time' is hard to define!

- Healthcare professionals don't want to cause undue distress by talking about the end of life early in the disease trajectory
- BUT wait for an adverse event as a 'trigger' and you may miss your chance entirely!

Also known as:
Advance care planning

“Advance care planning is a process of communication by which a person may make their wishes and goals for future care known to their healthcare providers, informal carers and next-of-kin, anticipating future health issues and potential loss of decision-making capacity.”

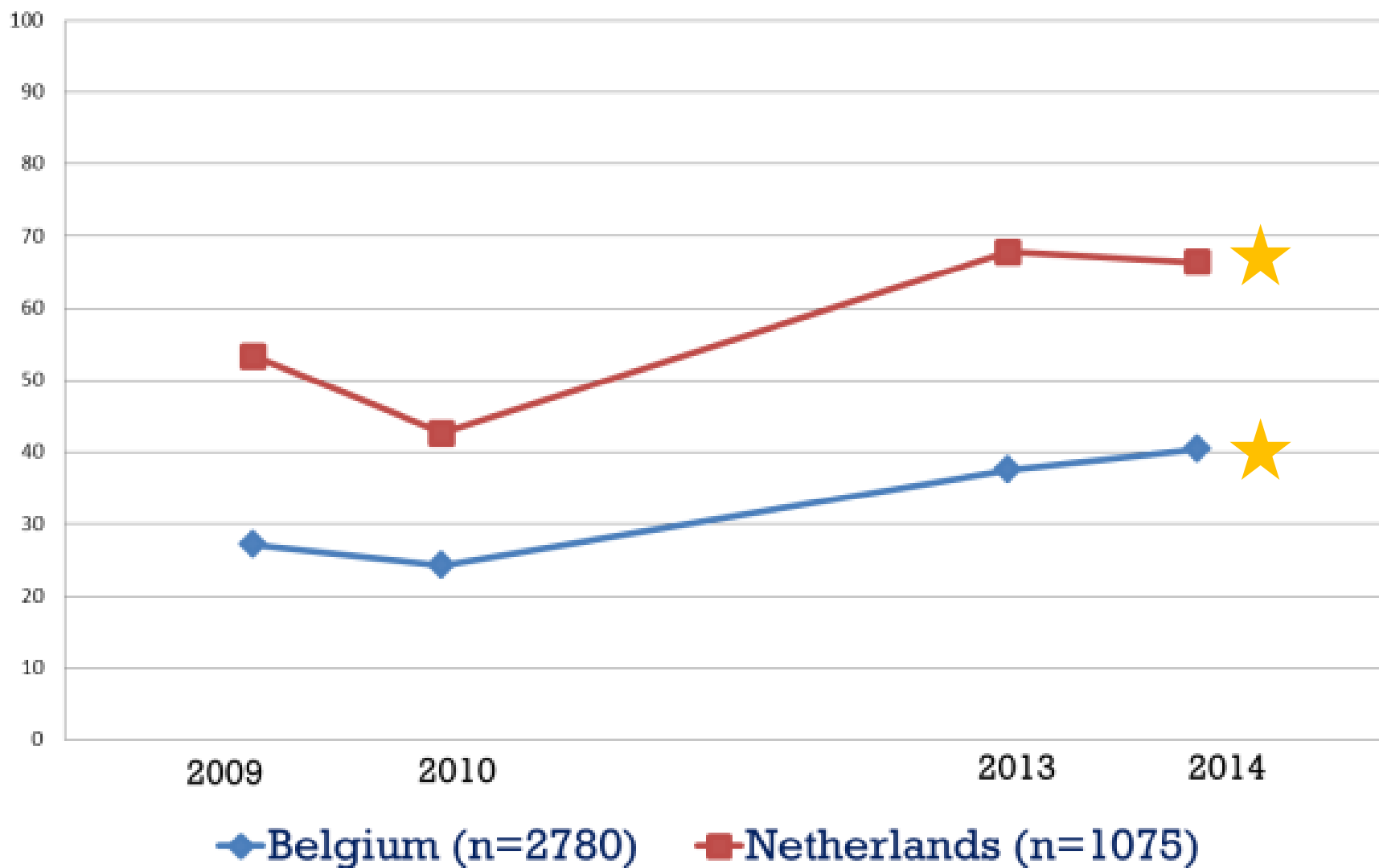
Methods

- GP Sentinel networks
 - Retrospective survey via network of general practitioners about deceased patients
 - Belgium, Netherlands, Italy and Spain
- Dying Well with Dementia
 - Retrospective surveys by GP, nursing home staff and next of kin about deceased nursing home residents

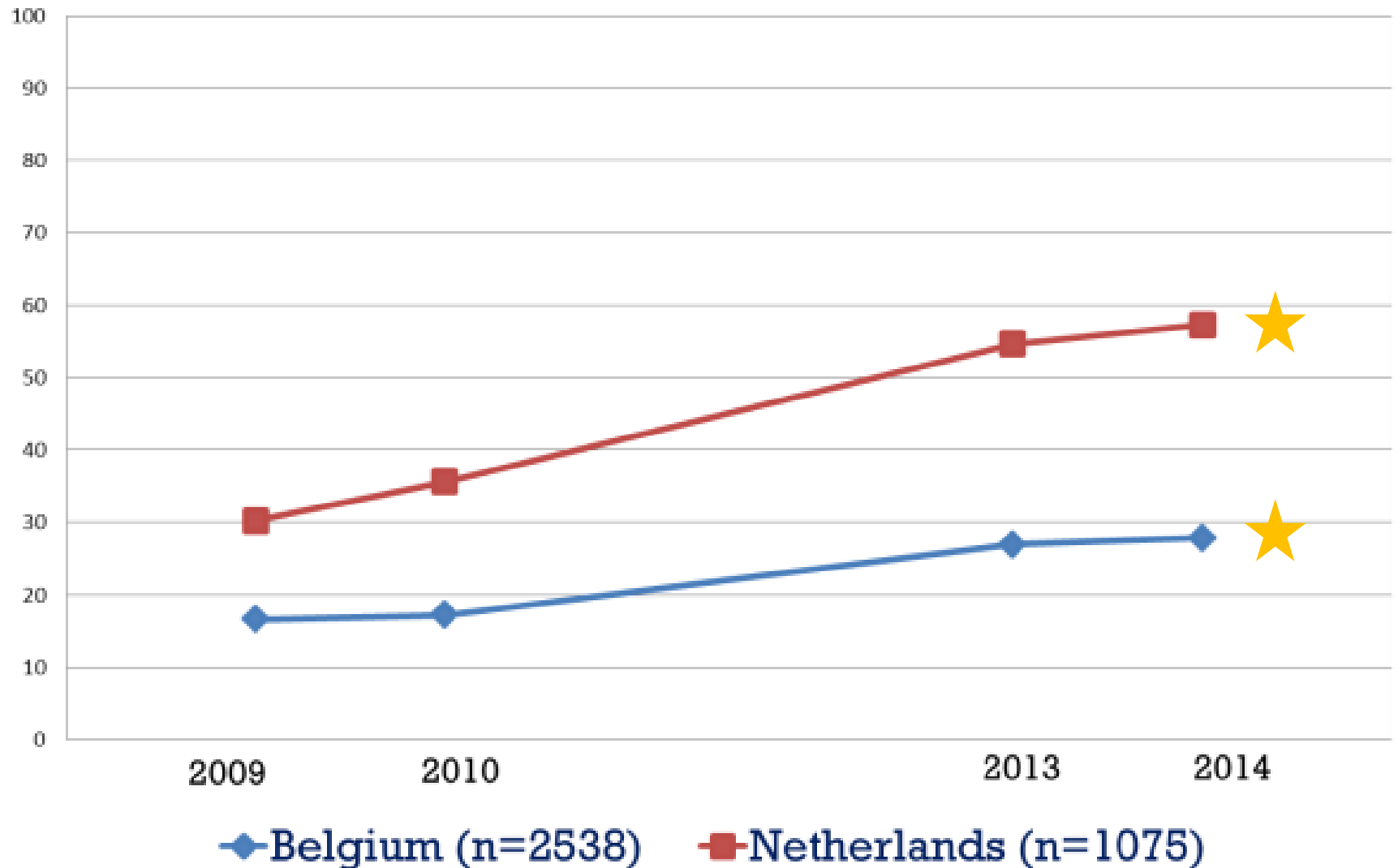
Trends in communication

Are there trends in the rate of occurrence of advance care planning for older people (65+) in Belgium and the Netherlands between 2009 and 2014?

Preference for medical treatment at the end of life: + 13 percentage point



**Preference for proxy decision-maker:
+ 14 percentage point in BE, +27 percentage point in NL**



However, differences between patient groups increased

In Belgium, non-cancer patients, the oldest old (85+) and people with dementia showed smaller increases in % GP aware

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Increasing inequality?

The role of family carers

Involving family in communication has many advantages:

- They are likely to become proxy decision makers
- The impact on family plays a role in many decisions about end-of-life care (e.g. when the patient does not want to “be a burden” to family)
- They experience uncertainty about their loved one’s wishes as a burden

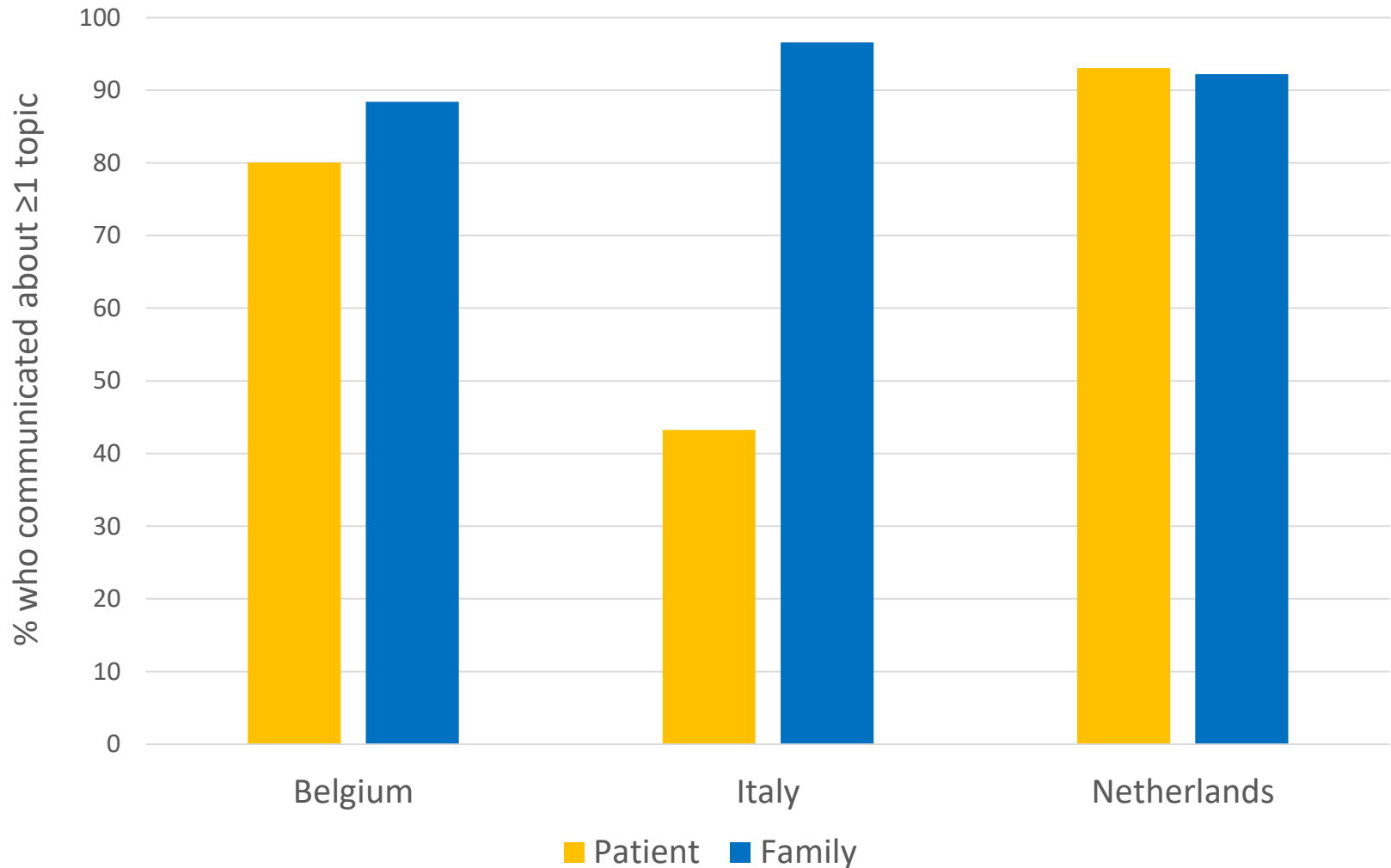
Communication about:

- Diagnosis
- Prognosis
- Approaching the end of life
- Advantages and disadvantages of treatments
- Options for end-of-life care
- Spiritual/existential issues
- Psychological or social issues

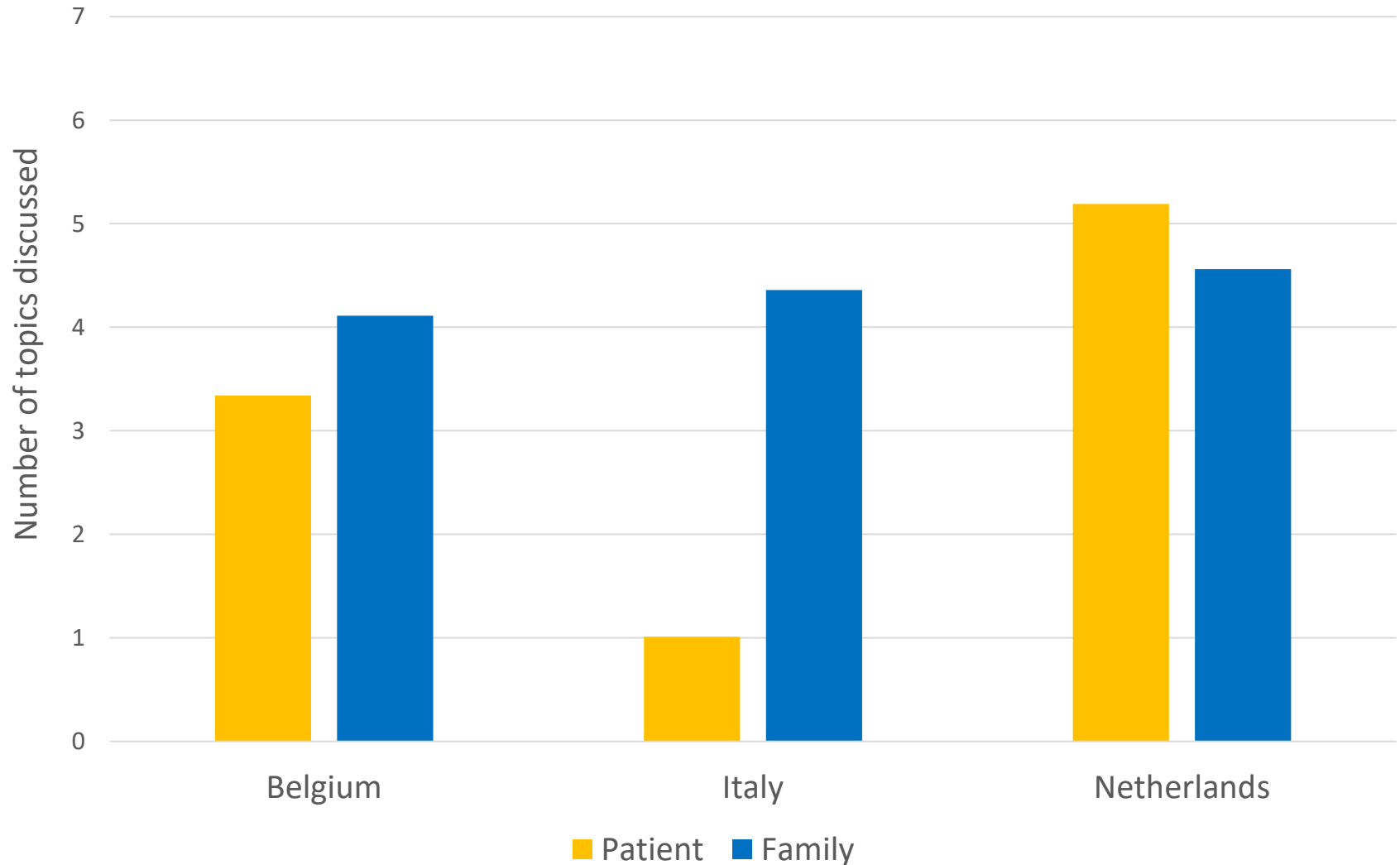
Sample

- 65+ (median age between 83 and 87)
- Between 13% (Netherlands) and 41% (Italy) had dementia
- Most common causes of death were cancer (BE: 44%, IT:26%, NL: 59%) and cardiovascular disease (BE: 22%, IT: 32%, NL: 16%)

Communication with family more frequent than or as frequent as communication with older people themselves

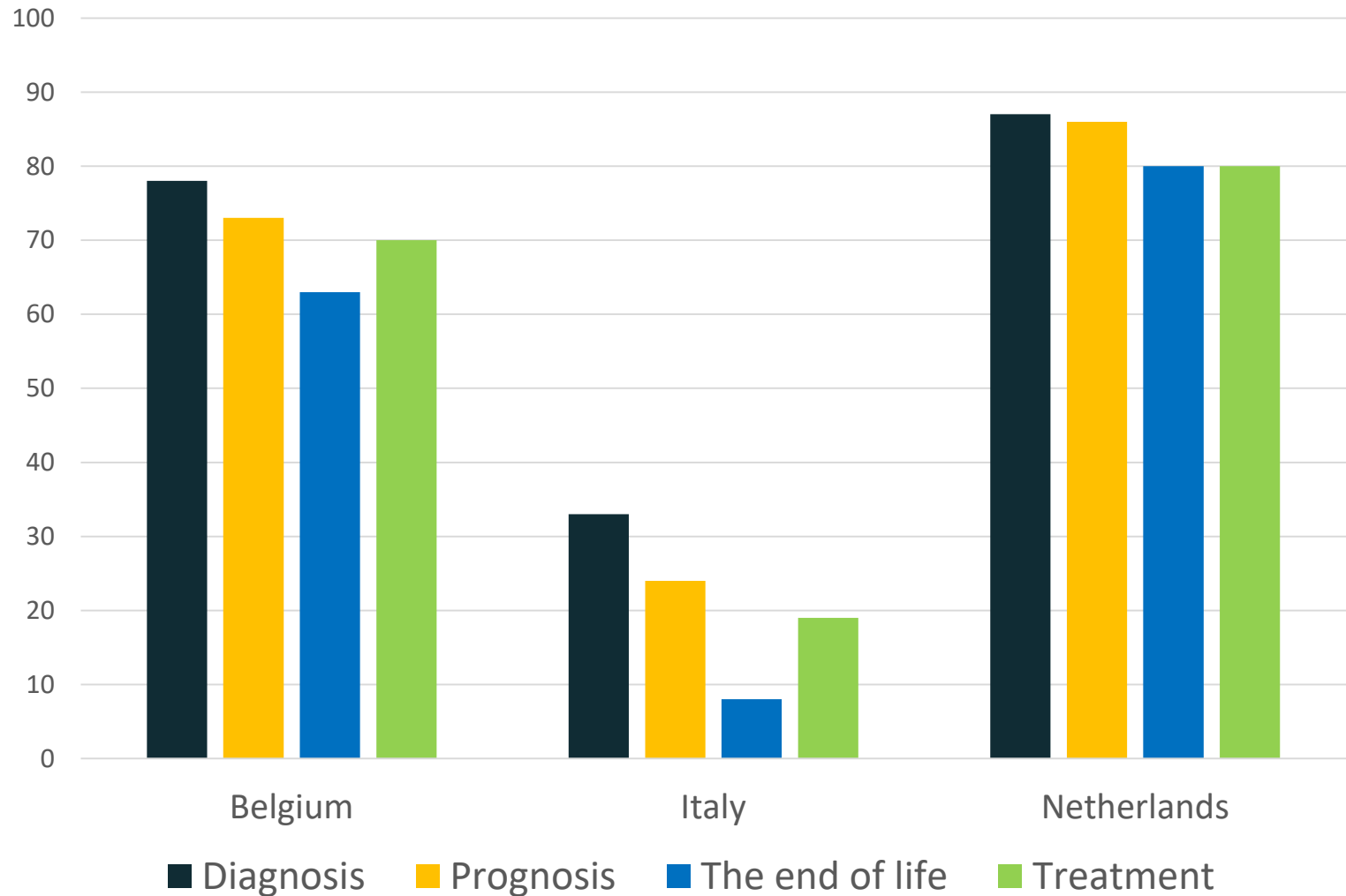


Number of topics discussed with family also higher in Belgium and Italy

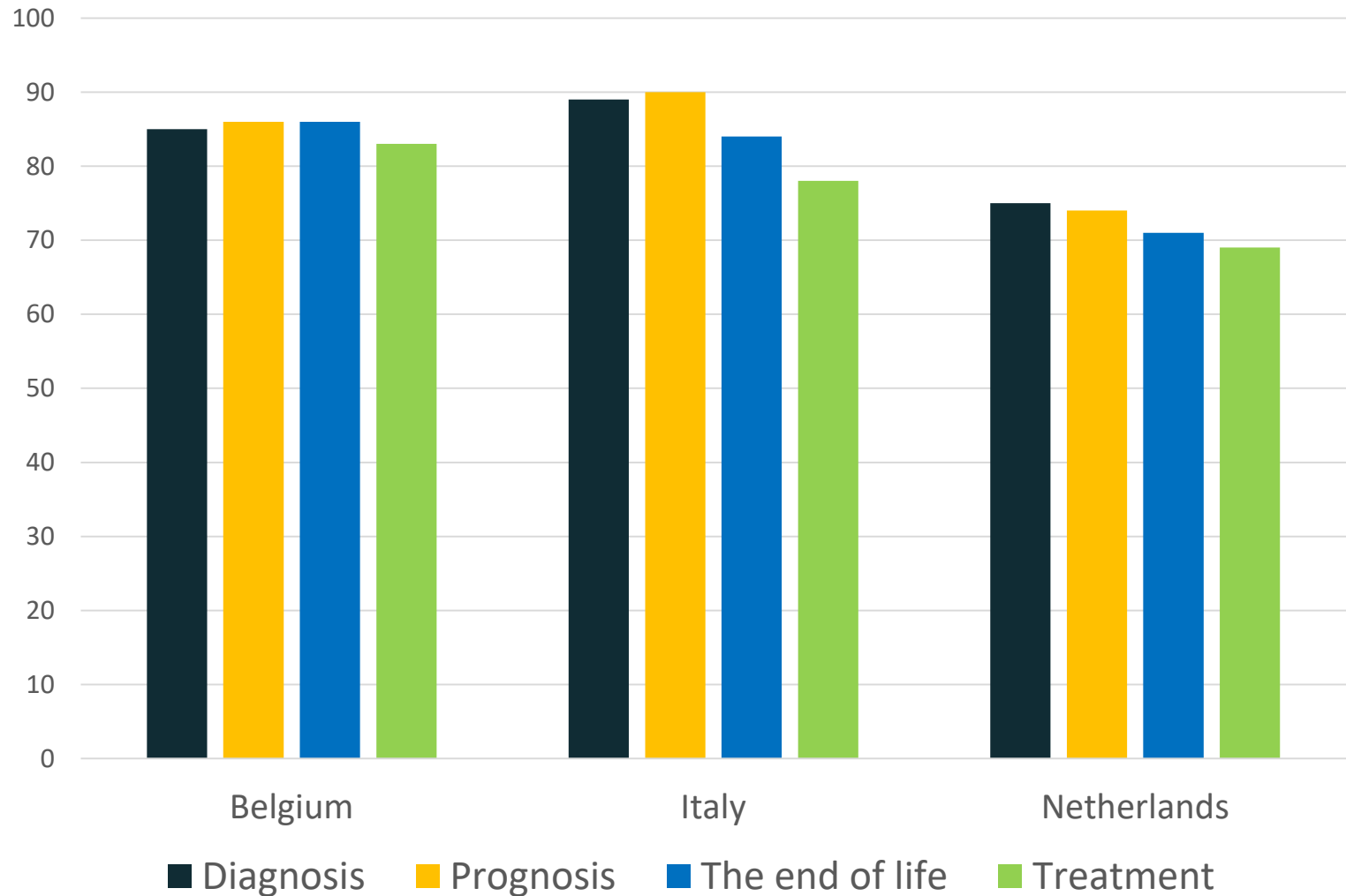


- In Belgium and Italy, all topics were more likely to be discussed with the family than with the patient ($p < 0.001$)
- In the Netherlands, only options for end-of-life care were more frequently discussed with the family than with the patient ($p < 0.001$)

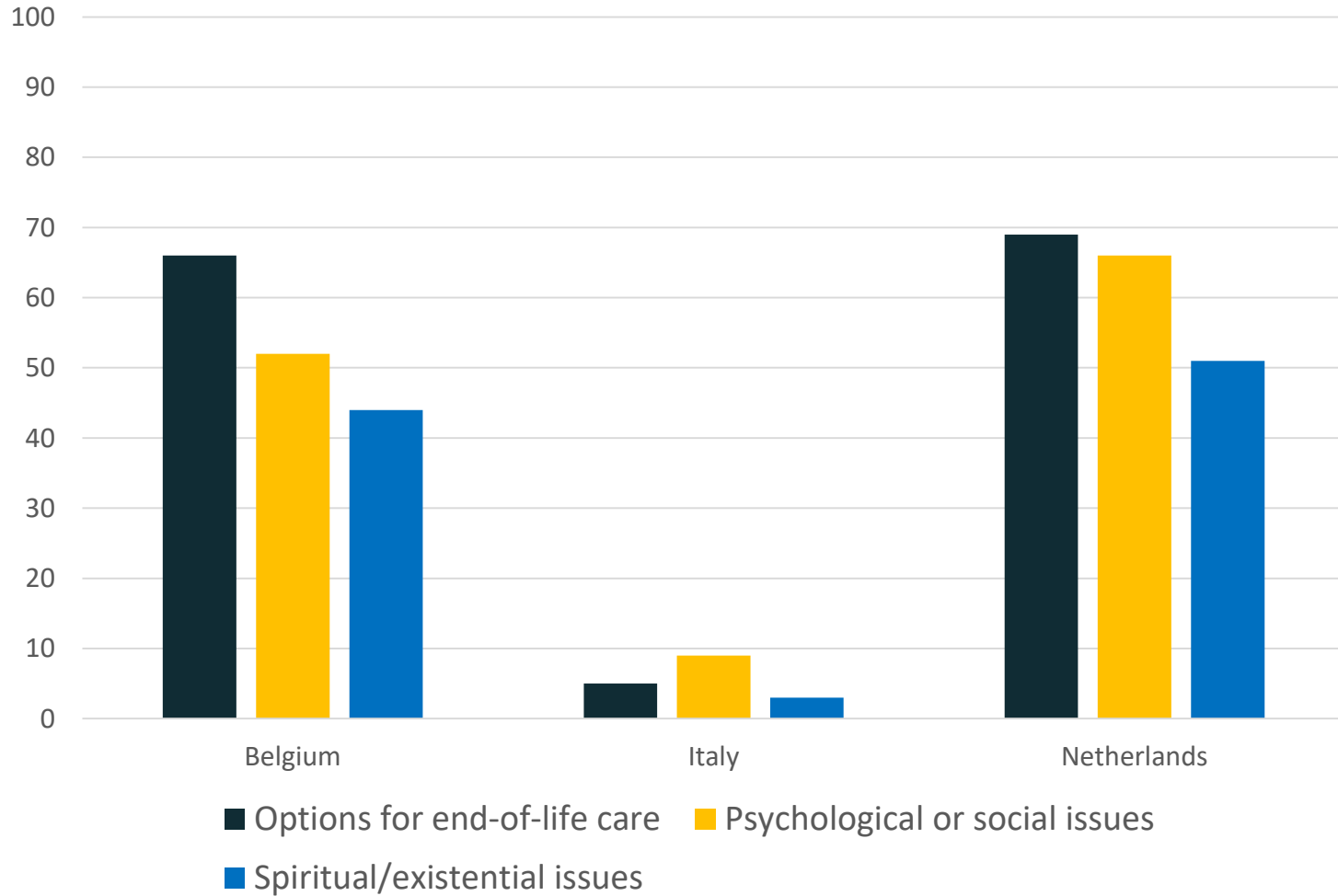
Most frequently discussed topics: patient



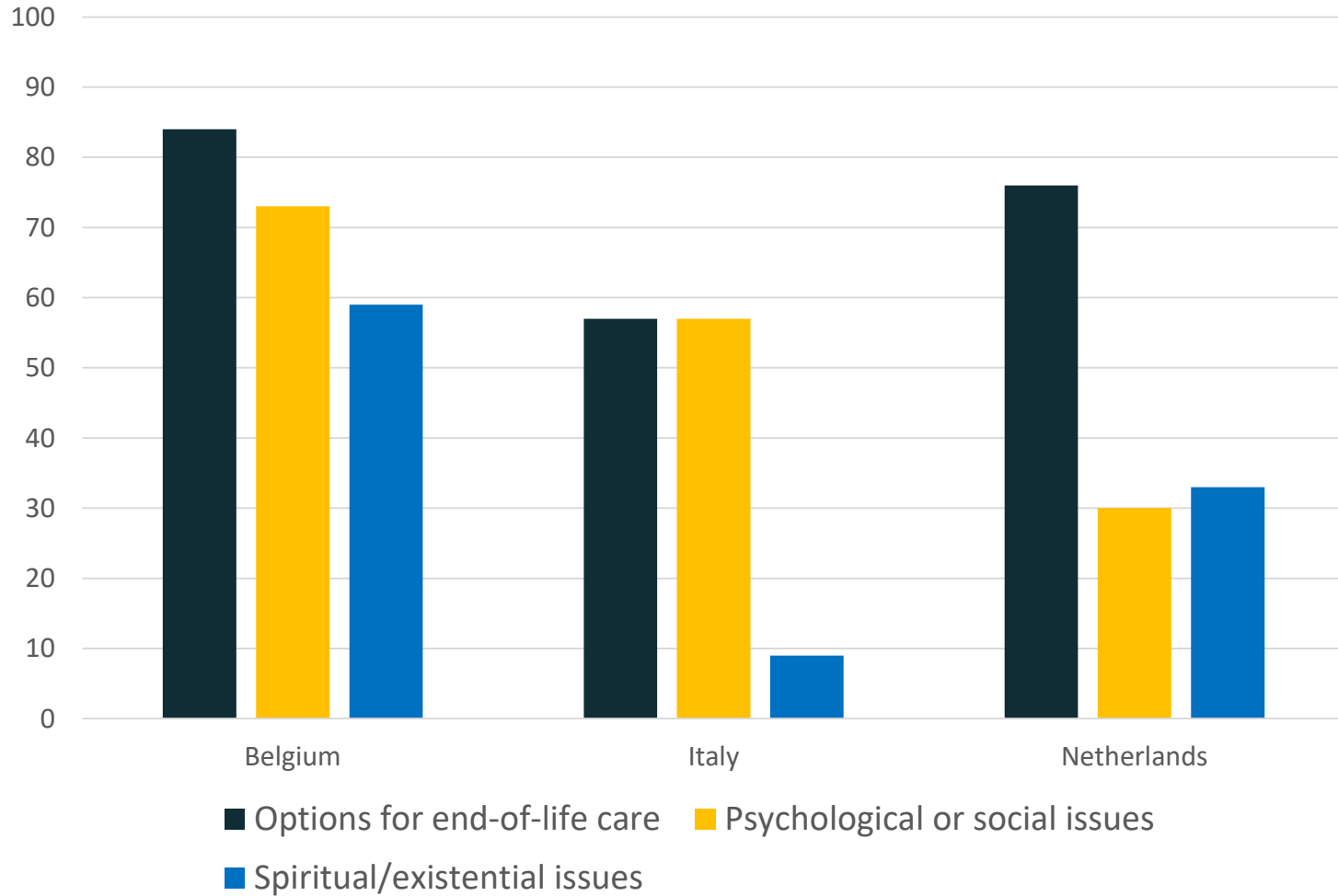
Most frequently discussed topics: family



Least frequently discussed topics: patient



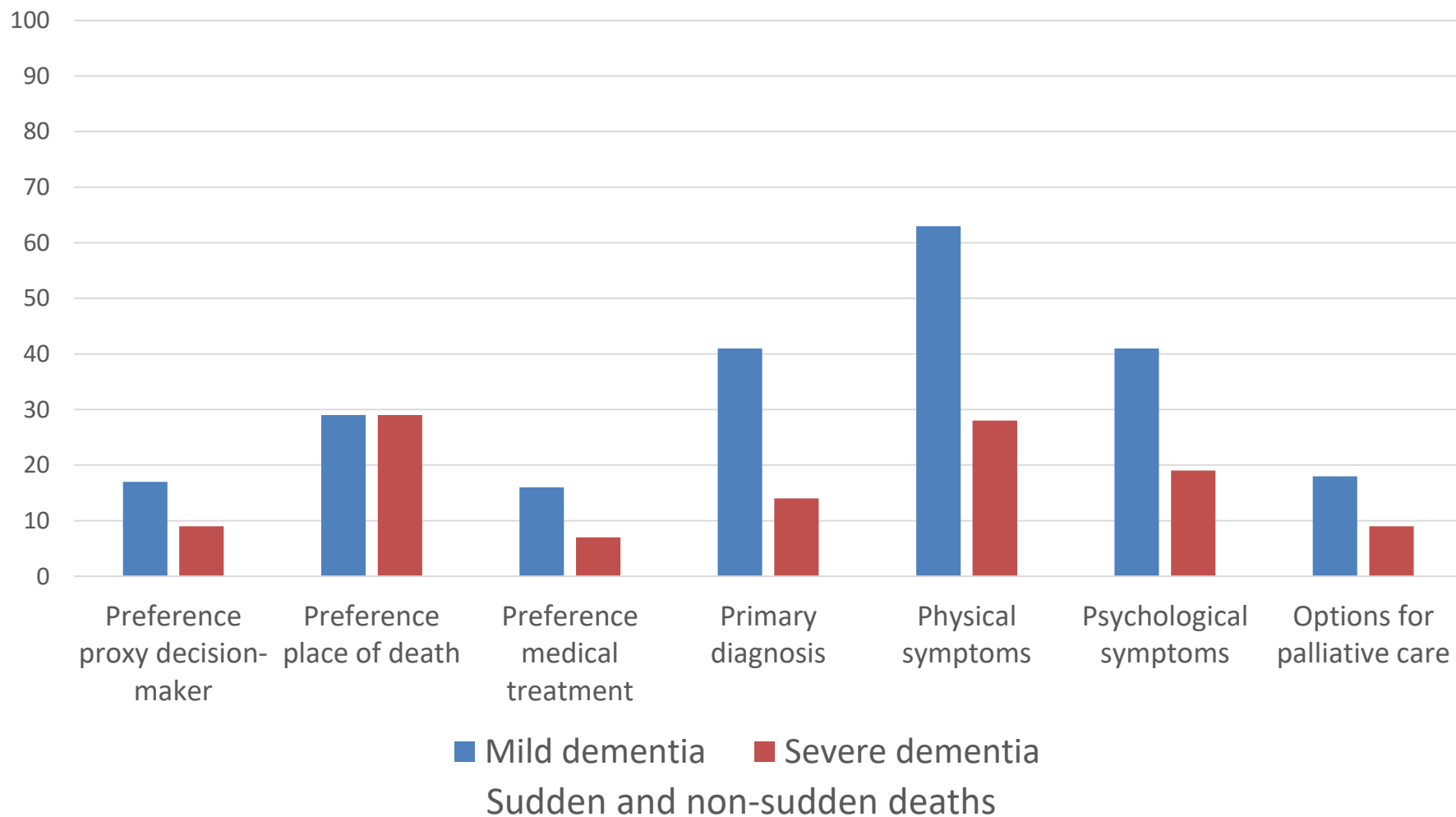
Least frequently discussed topics: family



Communication with family carers can be a solution for people with dementia

However, in practice this does not always work well...

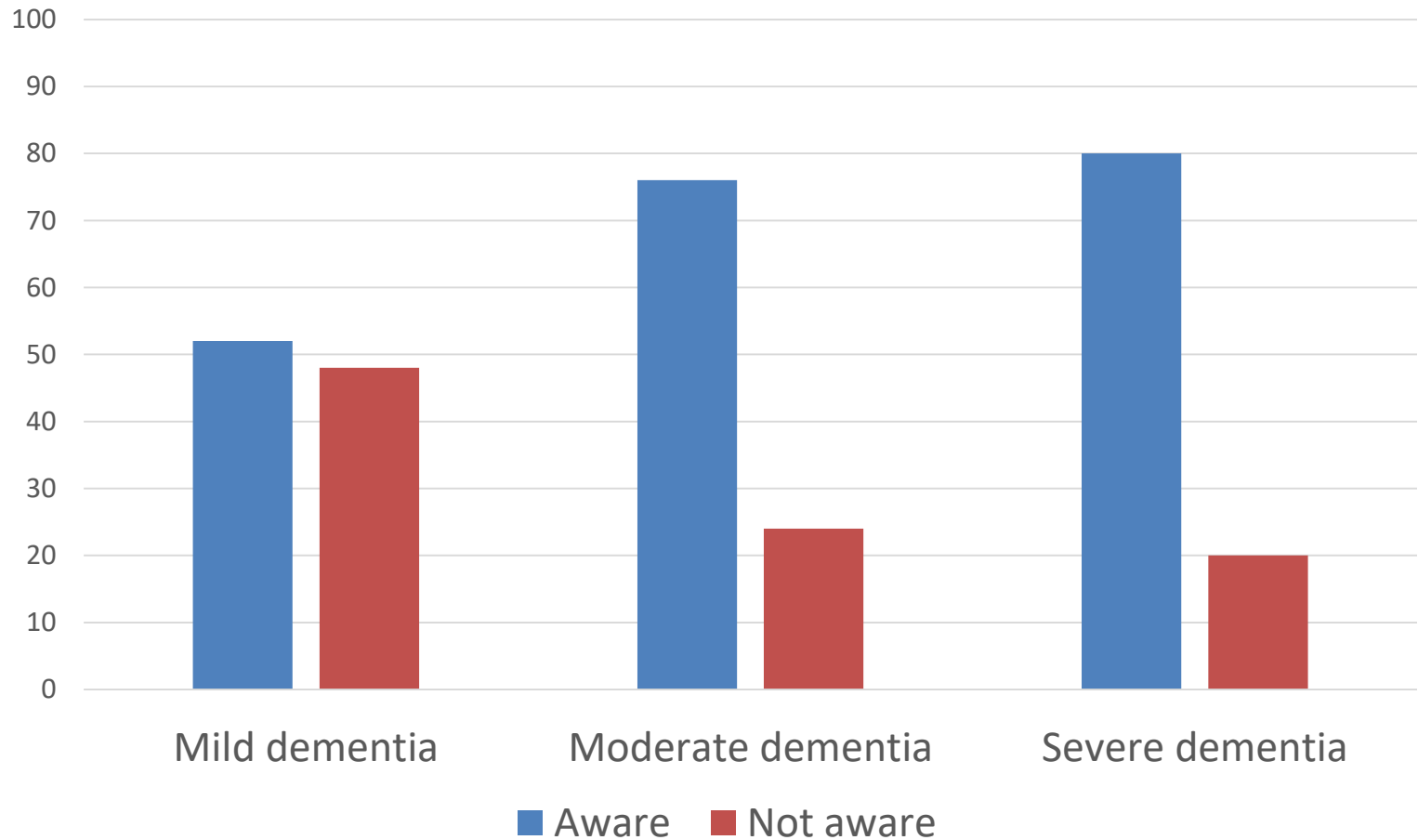
Communication with people with dementia in Belgium is low



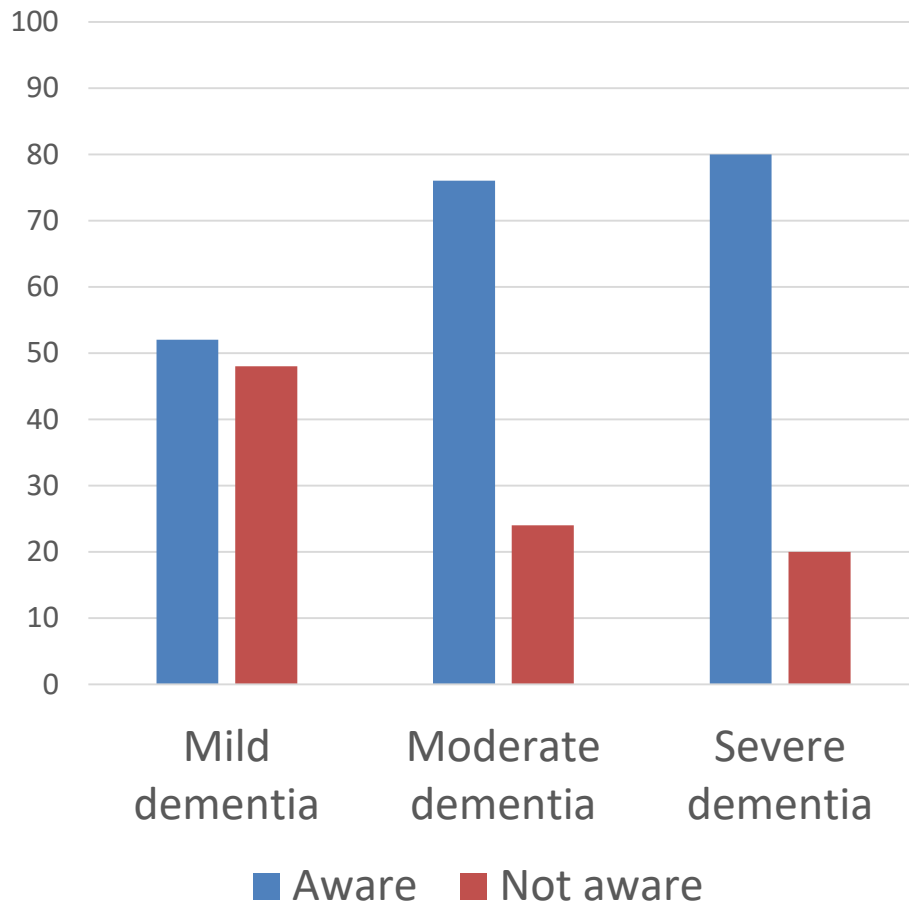
A preference for a proxy decision-maker was known in only **17%** of cases for people with mild dementia and **9%** of people with severe dementia in Belgium

This is *lower* than for older people in general, even though people with dementia have *more* need of a proxy decision-maker

28% of family carers not aware next-of-kin had dementia at death



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Awareness less likely

- the longer the admission
- the longer after admission dementia occurred

To do's:

- Communicate with people with dementia – start early!
- Communicate not just about physical symptoms, but also psychosocial issues and options for end-of-life care
- Keep family in the loop, especially family of nursing home residents

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PDF version of '**Old age, dementia and end-of-life care**' available on request

