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**Rose Miranda**

End of Life Care Research Group  
Vrije Universiteit Brussel & Ghent  
University, Brussels, Belgium

Comfort and clinical events at the  
end of life of nursing home residents  
with advanced, non-advanced and  
without dementia



## **Clinical events**

**Examples:** pneumonia, intake problem, febrile episodes

## **Comfort at the end of life**

May differ between residents with advanced, non-advanced and without dementia

## **Different clinical events**

## **Different levels of comfort**

## **Research aims**

- the occurrence rates of clinical events in the last month of life
- their associations with comfort in the last week of life



**Epidemiological after-death survey (2015)**

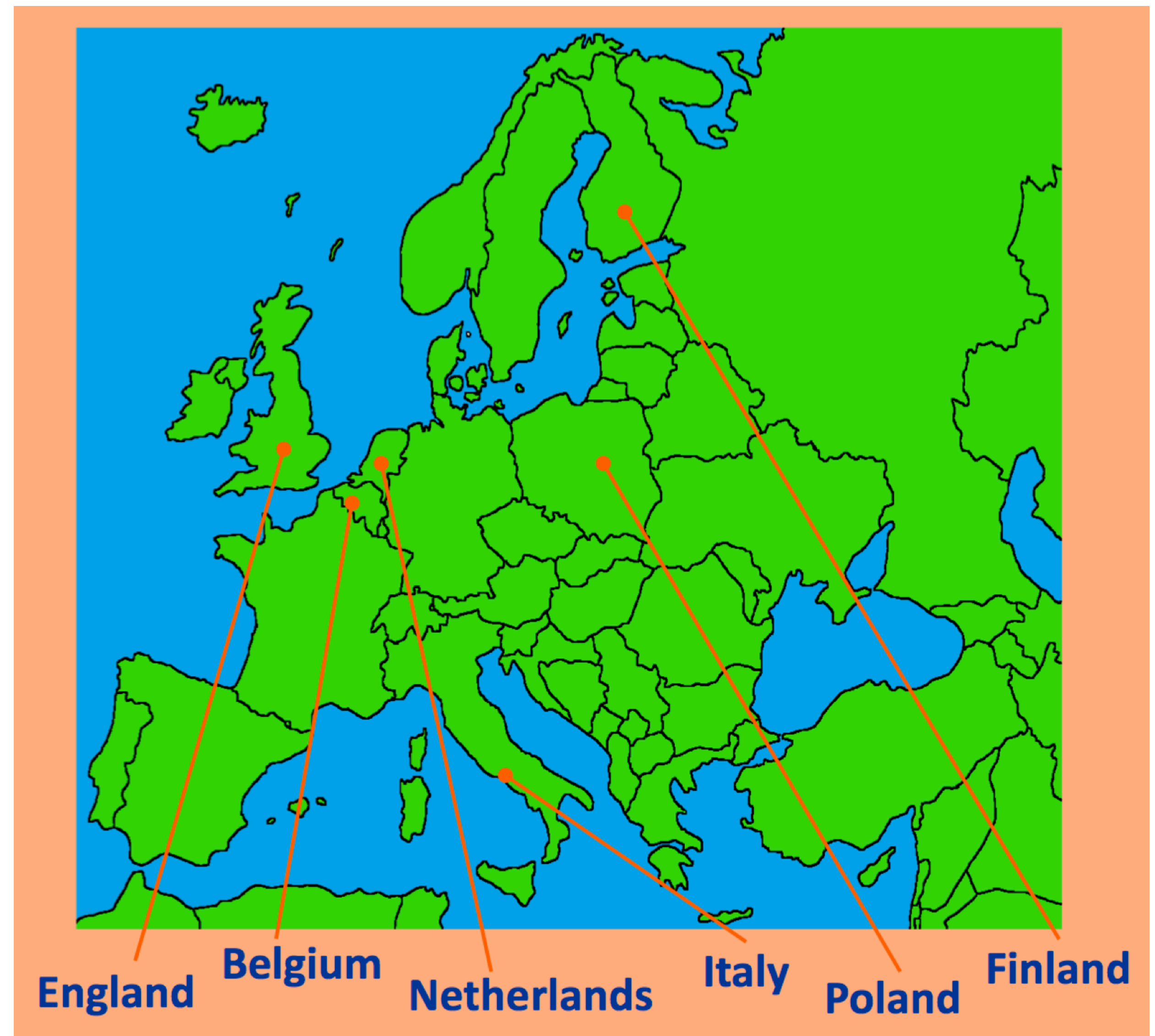
322 representative nursing homes

**Proportional stratified random sampling**

Region, nursing home type and  
bed capacity

**Nursing home administrator**

Identified residents who died in the  
previous three months.



## Methods



### After-death questionnaires

Nursing home staff  
General practitioner  
Administrator

### Presence of dementia

Estimation of the nursing home staff  
and/or the general practitioner

### Severity of dementia

Cognitive performance scale (CPS)  
Global deterioration scale (GDS)

### Clinical events in the last month of life

Pneumonia  
Febrile episodes  
Intake problems  
Other clinical events (e.g. hip fracture  
or muscular atrophy)

### Comfort in the last week of life

Comfort Assessment in Dying End of  
Life in Dementia (CAD-EOLD) scale  
  
Physical distress, dying symptoms,  
emotional distress, and well-being

### Multilevel mixed model analyses

Clustering of data  
Adjusted models

## Resident characteristics

	advanced dementia N=401	non-advanced dementia N=377	without dementia N=419	P-values
Average age (years)	85.5	86.6	82.4	<0.001
Female (%)	68	63	60	0.04
Stayed in nursing homes for more than 1 year (%)	63	58	50	<0.001
Died in nursing homes (%)	78	72	69	0.001

## Overall association between comfort and clinical events

**Discomfort was observed in residents who developed:**

- Pneumonia ( $P < 0.001$ )
- Febrile episode ( $P = 0.001$ )
- Intake problem ( $P < 0.001$ )

**But not**

- Any other clinical events ( $P = 0.83$ )



# Pneumonia – not specific in advanced dementia

**Pneumonia** occurred in about a quarter of the residents

Occurrence rates of pneumonia	advanced dementia	non-advanced dementia	without dementia	P-values
	25%	27%	24%	0.91

**Developing pneumonia** is associated with discomfort in all resident groups

PNEUMONIA	DISCOMFORT IN THE LAST WEEK OF LIFE			
	advanced dementia	non-advanced dementia	without dementia	P-values
	YES	YES	YES	0.33



# Pneumonia

## Distressing respiratory symptoms

- **Dyspnea**
- **Laboured/rapid breathing**
- **Dry/hacking cough**
  
- Breathing difficulties remain easily observable



# Intake problems – hallmark of advanced dementia

Intake problems occurred most often in advanced dementia

Occurrence rates of intake problem	advanced dementia	non-advanced dementia	without dementia	P-values
	74%	55%	48%	0.24

Developing intake problems is not associated with discomfort in residents with advanced dementia

INTAKE PROBLEMS	DISCOMFORT IN THE LAST WEEK OF LIFE			
	advanced dementia	non-advanced dementia	without dementia	P-values
	NO	YES	YES	0.03

Cause and origin of  
intake problems may  
differ between  
residents with and  
without advanced  
dementia

- Gradual versus sudden
- **Supports recommendations to forego tube-feeding in residents with advanced dementia**

## Implications of findings

### Pneumonia

- ✓ Better awareness for physicians and nurses
- ✓ Symptom relieving treatments, e.g. oxygen
- ✓ Myriad of potential causes – no single approach

### Future research

To develop and evaluate interventions that could improve comfort in residents with pneumonia

### Intake problems

- ✓ Rigorous clinical assessment
- ✓ High-calorie supplements and oral feeding options – as an alternative to tube feeding in residents with advanced dementia
- ✓ Goals of care

### Future research

To explore the cause and origin of intake problems and pneumonia and their association with comfort

## **KEY** MESSAGE

**We could promote comfort at the end of life of residents by identifying and managing symptoms of clinical events associated with discomfort, especially pneumonia in residents with and without dementia.**



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**Rose Miranda**

rose.miranda@vub.be

@eolc\_research

@fp7PACE

