

Palliative and end-of-life care in people with and without intellectual disabilities in primary care, with a focus on dementia

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Background

- Good quality end-of-life (and palliative) care is crucial for people with dementia as they may not be able to express their symptoms and needs [1]
- People with intellectual disabilities, particularly Down syndrome, are more likely to have Alzheimer's disease [2] and already have communication challenges [3]

Aims

- We investigated differences between people who were assigned an **end-of-life care record** in primary care and those who died without an end-of-life care relation to:
 - Comorbidities
 - Causes of death from dementia (underlying and contributing causes of death)
- We also looked at any differences according to whether the person also had **intellectual disabilities**

Methods



- We used a large primary care database called the **Clinical Practice Research Datalink (CPRD)**, linked with hospital episode statistics and mortality data in England
- We compared adults (≥ 18 years) with intellectual disabilities and a comparison group without intellectual disabilities who had been flagged as having end-of-life care needs by the GP practice
- We looked at people who did not have an end-of-life care record, but who died within 12 months, to find any differences in characteristics of these patients and causes of death
- We took account of age and gender differences between groups using standardisation (generalised linear models and Poisson 95% confidence intervals).

Results

- We identified **9,858** people with intellectual disabilities and **1,103,871** people without intellectual disabilities
- At baseline (first end-of-life care record or 12 months prior to death [where no end-of-life care record]), the intellectual disability group was generally younger and there were more males (**Table 1**)

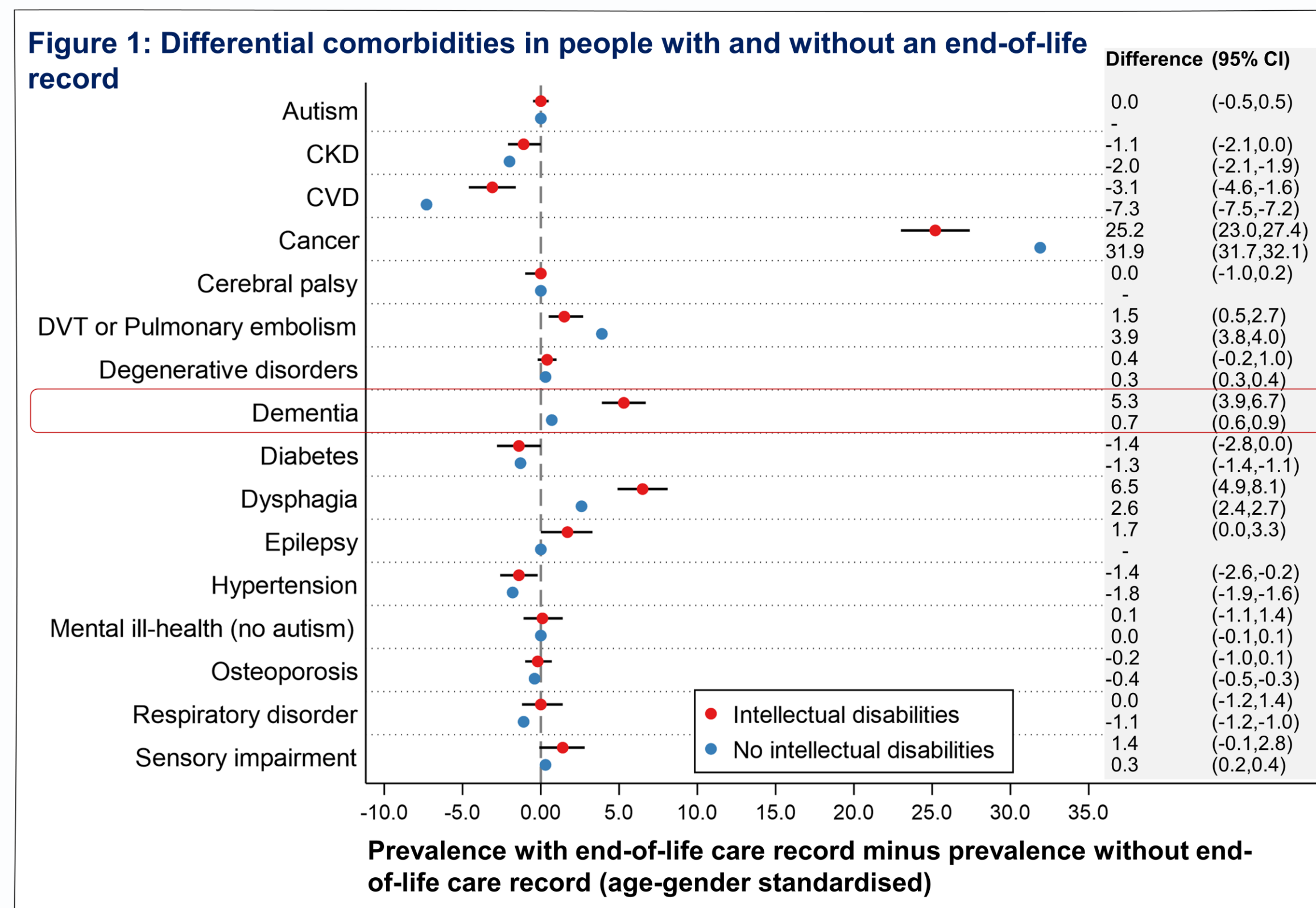
Table 1: Characteristics of study population

Baseline characteristics	End-of-life care record		No end-of-life care record	
	Intellectual disabilities n=2,147	Comparison n=313,847	Intellectual disabilities n=7,711	Comparison n=790,024
Age (Years), Median	66	81	61	79
Gender, %:				
Male	50.2	47.0	57.9	49.2
IMD quintile: Most deprived	25.1	19.6	27.7	21.2
BMI: Obese (≥ 30 kg/m ²)	26.1	20.1	32.5	25.5
Smoking status: Non-smoker	66.1	36.4	64.9	38.9
Comorbidities (≤ 2 years from baseline)				
Cancer	34.0	49.6	8.8	17.8
Dysphagia	14.9	6.0	8.4	3.4
Epilepsy	14.3	1.3	12.6	1.4
Dementia (any)	12.3	12.1	7.1	11.5
Alzheimer's Dementia	10.9	7.3	4.9	5.6
Sensory impairment	11.1	6.3	9.7	6.0
Cardiovascular diseases	10.4	15.1	13.5	22.4

BMI: body mass index; IMD: index of multiple deprivation

- Around **12% of people with an end-of-life care record had dementia in both groups**
- More people with intellectual disabilities (12% vs 7%) had dementia** if they did not have an end-of-life care record

- Dementia was more common among people with an end-of-life care record, particularly in the intellectual disability group (+5.3 percentage points higher) (Figure 1)**



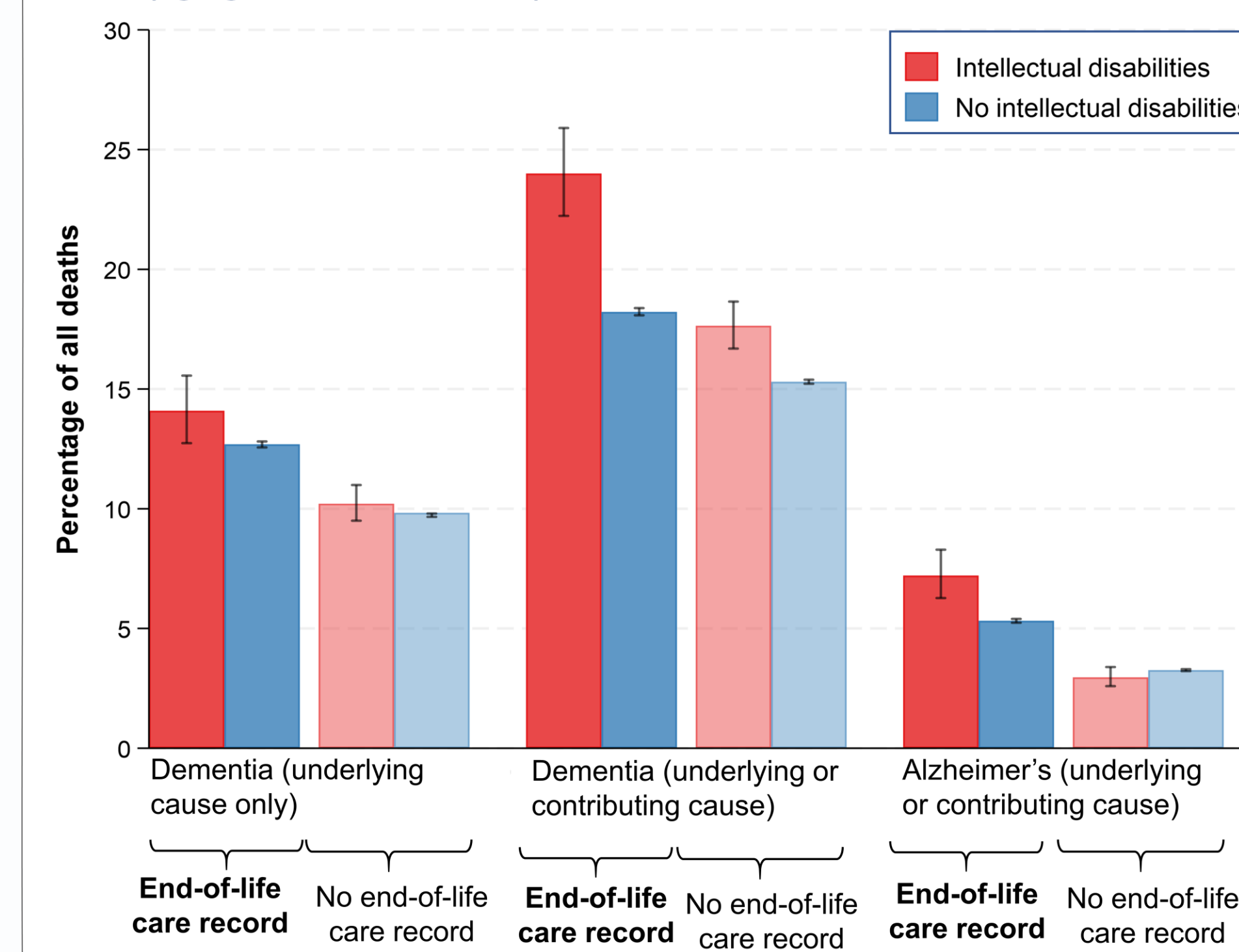
- Most deaths from dementia (65% intellectual disabilities and 57% no intellectual disabilities) were recorded as “unspecified dementia” (ICD-10 code: F03)

- A similar proportion of people with and without intellectual disabilities had dementia recorded as the underlying cause of death (**Figure 2**)

- When contributing causes of death were included (i.e., underlying or contributing cause), **deaths from dementia and Alzheimer's were more common in the intellectual disability group (p<0.001)**

- Where Alzheimer's disease was listed as the contributing cause of death, the most common underlying cause of death reported was:
 - Down syndrome** ([ICD10: Q90] for intellectual disabilities (65%))
 - Cancers** (ICD10: C00-D48) (30%) and **Circulatory system diseases** [ICD10: I00-I99] (30%) for the comparison group

Figure 2: Causes of death by intellectual disability and end-of-life care record status (age-gender standardised)



Conclusions

- Dementia and Alzheimer's are common among people with end-of-life care needs, particularly among people with intellectual disabilities where Down syndrome is often recorded as the underlying cause of death
- We recommend proactive end-of-life care planning for people with intellectual disabilities who have dementia and skilled communication support for symptom management

References

- [1] Leniz J et al. (2021). Identification of palliative care needs among people with dementia and its association with acute hospital care and community service use at the end-of-life: A retrospective cohort study using linked primary, community and secondary care data. *Palliat Med* **35**(9):1691-1700
- [2] Salehi A et al. (2016). The link between Alzheimer's disease and Down syndrome. a historical perspective. *Curr Alzheimer Res* **13**(1):2-6
- [3] Smith N et al. (2020). Communication difficulties in adults with Intellectual Disability: Results from a national cross-sectional study. *Res Dev Disabil* **97**:103557