BP-HSR-04

Impact of a specialised palliative homecare programme for advanced dementia: Comfort and satisfaction with care at the end-of-life

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Background

Dementia patients experience high symptom burden at the end-of-life, but they are unable to verbalise their discomfort. Comfort is key for optimal palliative care in dementia and it is associated with families' satisfaction with care. Our specialised palliative homecare programme for advanced dementia aims to keep dying patients comfortable at home and support families.

Aims

1. To identify modifiable factors associated with comfort and satisfaction with care at the end-of-life.
2. To examine the change in patients' comfort and families' satisfaction with care post bereavement.

Methods

This is a prospective cohort study from October 2014 to April 2019. Dementia in- and outpatients at Stage 7 on the Functional Assessment Staging (FAST) Scale, with albumin<35g/L, enteral feeding or pneumonia were enrolled.

Dependent variables

- Comfort Assessment in Dying with Dementia (CAD-EOLD): Assessed every home visit until patients passed away.
- Satisfaction with Care at the End-of-Life in Dementia (SWC-EOLD): Evaluated 2 months post bereavement.

Independent variables

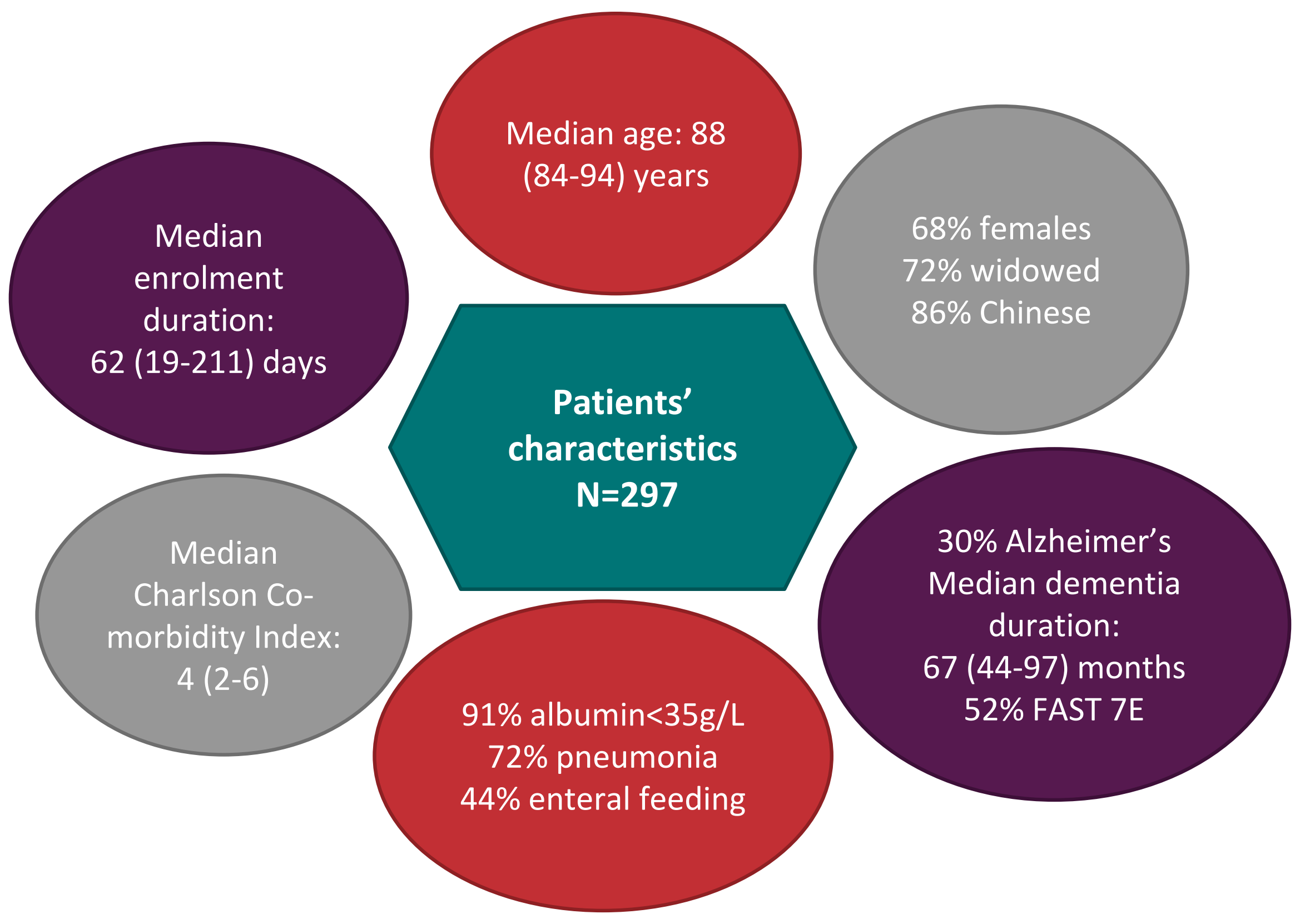
- Patients' characteristics
- Programme enrolment duration, place of death, care preferences
- Infections and medical interventions in the last 2 weeks of life
- CAD-EOLD score was also an independent variable for SWC-EOLD

Statistical analysis

1. Descriptive statistics:
   - Continuous variables: Median (IQR) or mean (SD) to show changes
   - Categorical variables: Frequencies (%)
2. Bivariate analysis:
   - Mann Whitney U, Kruskal Wallis, Chi-square tests and Spearman's Rho correlation
3. Multi-variate regression:
   - Gamma and logistic
4. Wilcoxon rank-sum test: Change in scores

Significance level was set at 0.05 for all statistical analysis performed with SPSS v21 and STATA v15.

Results


Median age: 88 (84-94) years

68% females
72% widowed
86% Chinese

30% Alzheimer's
Median dementia duration:
67 (44-97) months
52% FAST 7E

91% albumin<35g/L
72% pneumonia
44% enteral feeding

Median Charlson Co-morbidity Index:
4 (2-6)

Median enrolment duration:
62 (19-211) days

Patients' characteristics
N=297

Figure 1. Major characteristics of patients.

Median age of family caregivers was 59 (52-65) years. Most were children (86.9%), lived with patients (69.0%), and had domestic help (93.3%). Median SWC-EOLD score was 38 (34-40).

Table 1. Infections, medical interventions and care plans.

Variables	Total N=294[a]
Place of death	
Home	232 (78.9)
Hospital	30 (10.2)
Hospice	25 (8.5)
Emergency department	7 (2.4)
Fever ≥38 degrees	152 (51.7)
Hypotension (BP <90/50 mmHg)	144 (49.0)
Poor oral intake	138 (46.9)
Presence of infection	218 (74.1)
Use of antibiotics	154 (52.4)
Number of courses of antibiotics used	1 (0-1)
Standby medications prescribed	
Opioids	228 (77.6)
Non-opioid analgesics	228 (77.6)
Anticholinergics	128 (43.5)
Enteral feeding	131 (44.6)
Presence of a documented care plan	289 (98.3)
Do Not Resuscitate order honoured	281 (97.2)
Medical intervention honoured	272 (94.1)
Place of Care honoured	276 (95.5)
Place of Death honoured	256 (88.6)

[a]3 missing data.

Table 2. Factors associated with comfort and satisfaction with care at the end-of-life.

	Gamma[a]		Logistic[b]	
With CAD-EOLD (N=202)	**β Coeff (95% CI)**	**P-value**	**Odds Ratio (95% CI)**	**P-value**
Hypotension*	0.874 (-0.131 – 1.879)	0.088	0.890 (0.349 – 2.274)	0.808
Opioid prescribed	-2.179 (-4.107 – -0.251)	0.027[c]	0.459 (0.069 – 3.034)	0.419
Anti-cholinergic prescribed*	1.823 (0.660 – 2.986)	0.002	2.200 (0.597 – 8.104)	0.236
Antibiotic courses* (dichotomised into ≤/>1)	-1.968 (-3.196 – -0.740)	0.002	0.673 (0.181 – 2.504)	0.555
Programme enrolment duration*	0.002 (-0.001 – 0.004)	0.240	1.001 (0.999 – 1.003)	0.206
With SWC-EOLD (N=167)				
CAD-EOLD before death*	0.149 (0.012 – 0.286)	0.033	1.160 (1.032 – 1.305)	0.013
Medical intervention honoured	3.969 (1.485 – 6.453)	0.002	13.024 (2.242 - 75.650)	0.004
Place of care honoured	5.073 (-1.132 – 11.278)	0.109	1	NA
Place of death honoured	-4.028 (-7.900 – -0.156)	0.041[d]	1	NA

SWC-EOLD: Satisfaction with Care at the End-of-Life in Dementia is a 10-item scale assessing family caregiver's satisfaction with care in advanced dementia. Each item is rated from 1-4 as follows: strongly disagree, disagree, agree, and strongly agree. Total scores range from 10-40 with higher scores indicating greater satisfaction with care.
[a]Distribution of CAD-EOLD and SWC-EOLD scores were skewed and non-negative. [b]CAD-EOLD scores were dichotomised into comfortable (CAD-EOLD=42) and not comfortable (CAD-EOLD<42); and SWC-EOLD scores were dichotomised into satisfied (all questions were rated as agree or strongly agree) and not satisfied. [c]P=0.172 and [d]P=0.048 in Robust Regression analysis. *Variables that were significant in the initial bivariate analysis.

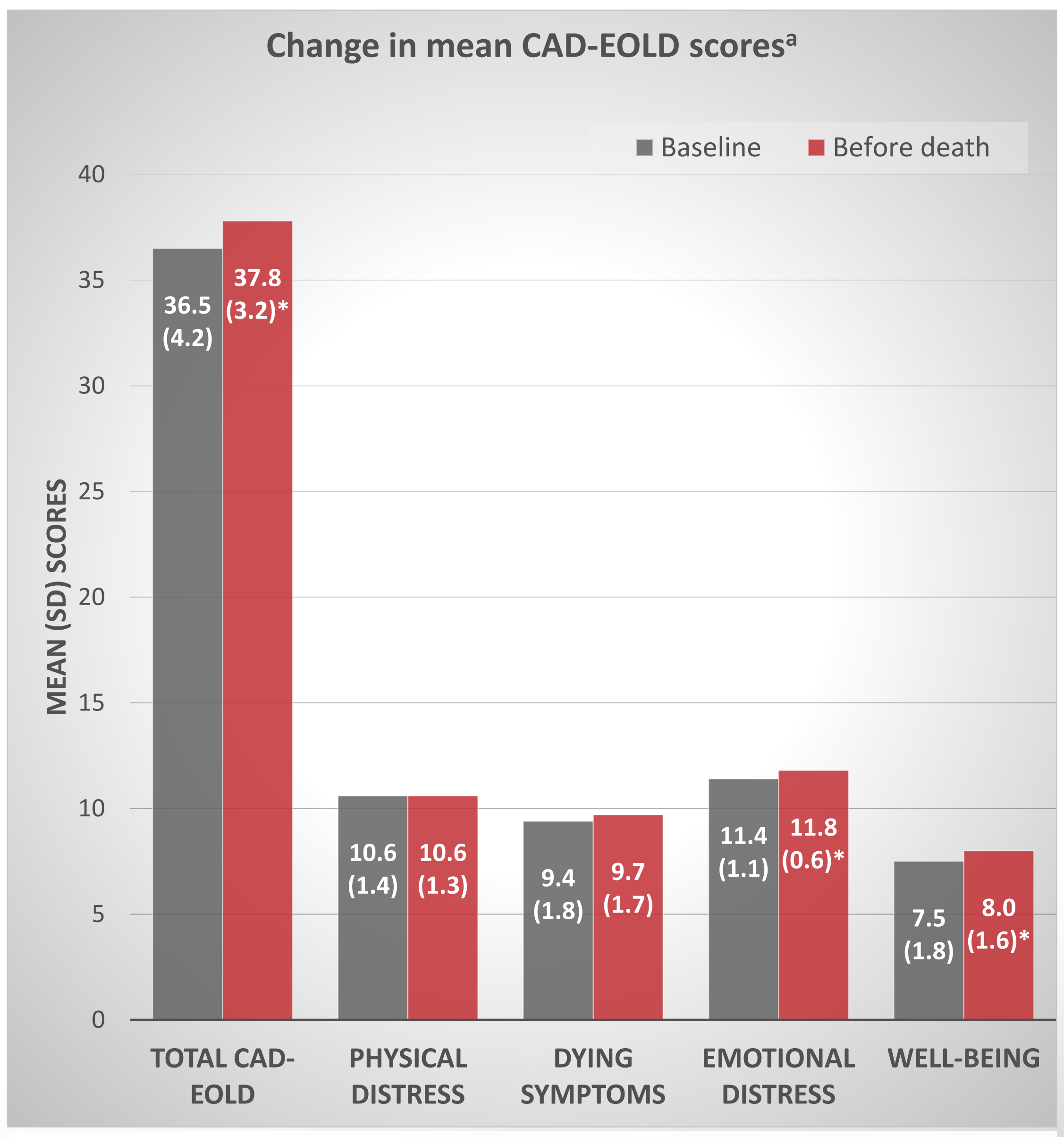
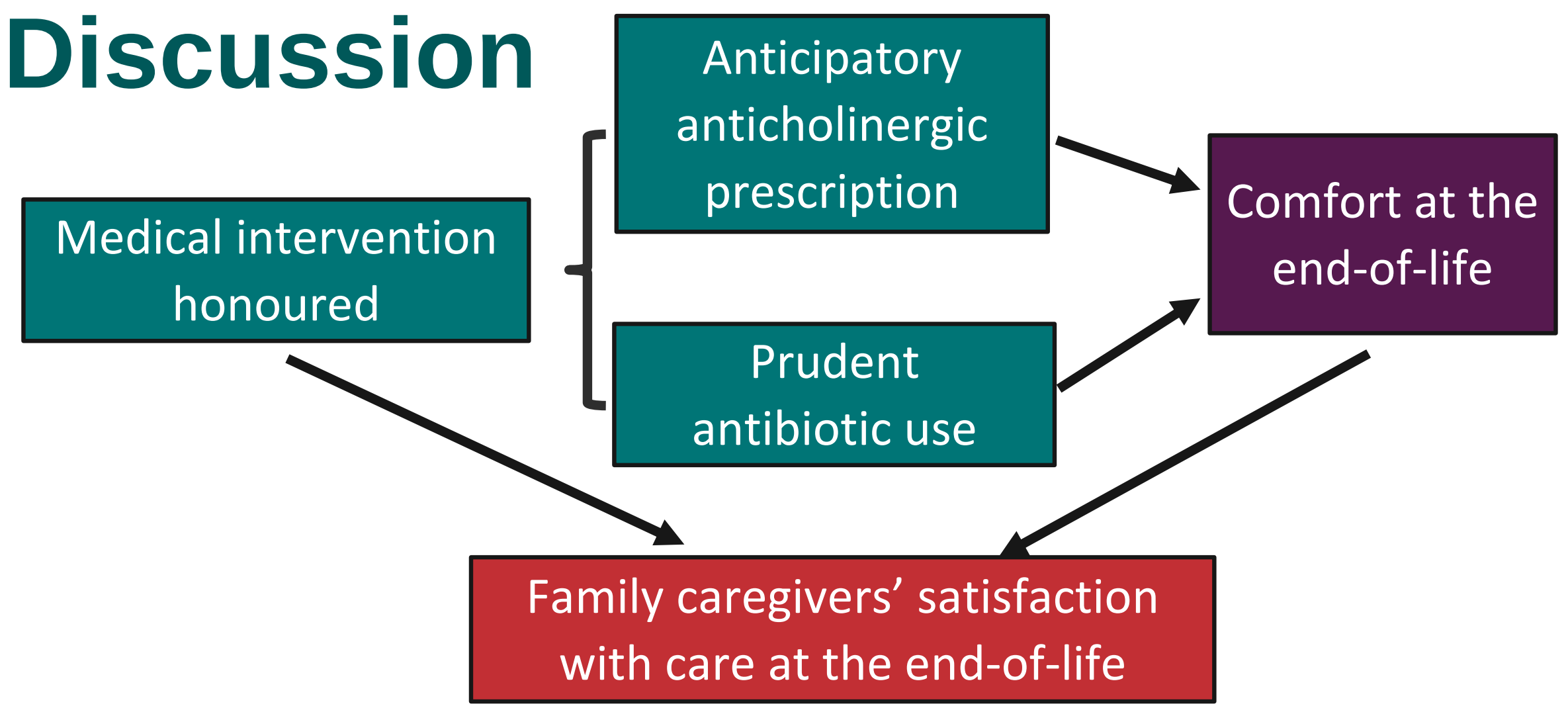


Figure 2. Change in mean CAD-EOLD scores from baseline till death.

CAD-EOLD: Comfort Assessment in Dying with Dementia is a 14-item scale assessing the quality of dying. It has four factors: physical distress (4 items); dying symptoms (4 items); emotional distress (4 items); and well-being (3 items). Each item is rated from 1-3 and total scores range from 14-42. Higher scores indicate better comfort. [a]Number of patients with comfort assessed more than once before death=130. *Indicates statistically significant change from baseline.

Discussion


Anticipatory anticholinergic prescription

Medical intervention honoured

Prudent antibiotic use

Comfort at the end-of-life

Family caregivers' satisfaction with care at the end-of-life

Figure 3. Factors associated with comfort & satisfaction with care of home-dwelling dementia patients at the end-of-life.

Strength and limitations

The pragmatic study design demonstrated its feasibility. However, there was no control group and causation could not be established from associations. Sample size was not calculated but it appeared sufficient with at least ten observations per variable for regression analysis. The clinical relevance of a 1-point increase in CAD-EOLD score was unclear without evidence informing the scale's minimal clinically important difference. Comfort was not assessed for 32% of deceased patients due to prognostic uncertainty.

Conclusions

A palliative homecare programme for advanced dementia honoured families' preferences, by instituting medical interventions with palliative intent associated with comfort, which determined families' satisfaction with care at the end-of-life. Patients' comfort improved and family caregivers were satisfied post bereavement. Prognostication in advanced dementia remains elusive and requires further study because of its potential implications on comfort and satisfaction.