*Original Article*

# Comfort and Satisfaction With Care of Home-Dwelling Dementia Patients at the End of Life

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## *Abstract*

**Context.** Despite the preference to pass away at home, many dementia patients die in institutions, resulting in a paucity of studies examining end-of-life care outcomes in the home setting.

**Objective.** The objective of this study was to identify modifiable factors associated with the comfort of dementia patients dying at home and families' satisfaction with care.

**Methods.** This is a prospective cohort study conducted from October 2014 to April 2019 in Singapore. Dementia patients at Stage 7 on the Functional Assessment Staging Scale, with albumin <35 g/L, enteral feeding, or pneumonia, were recruited from a palliative homecare program. Independent variables included demographics, medical information, and care preferences. The Comfort Assessment in Dying with Dementia scale assessed dying patients' comfort, whereas the Satisfaction with Care at the End-of-Life in Dementia scale evaluated family caregivers' satisfaction two months after bereavement. Gamma regression identified factors independently associated with comfort and satisfaction.

**Results.** The median age of 202 deceased patients whose comfort was assessed was 88 years. Anti-cholinergic prescription (60.4% of patients) [β (95% CI) = 1.823 (0.660−2.986), $P = 0.002$] was positively associated with comfort, whereas opioid prescription (89.6%) [β (95% CI) = −2.179 (−4.107 to −0.251), $P = 0.027$] and >1 antibiotic courses used in the last two weeks of life (77.2%) [β (95% CI) = −1.968 (−3.196 to −0.740), $P = 0.002$] were negatively associated. Independent factors associated with families' satisfaction with care were comfort [β (95% CI) = 0.149 (0.012−0.286), $P = 0.033$] and honoring of medical intervention preferences (96.0%) [β (95% CI) = 3.969 (1.485−6.453), $P = 0.002$].

**Conclusion.** Achieving comfort and satisfaction with care for dementia patients dying at home involves an interplay of modifiable factors. Honoring medical intervention preferences, such as those with palliative intent associated with patients' comfort, determined families' satisfaction with care. J Pain Symptom Manage 2020;59:1019−1032.

***Key Words***
*Dementia, end-of-life, home-dwelling, comfort, satisfaction with care*

## *Key Message*

This article describes a prospective cohort study that identifies modifiable factors associated with comfort and satisfaction with care of dying dementia patients in a previously understudied setting—the home. The results indicate that modifiable factors, such as medical interventions with palliative intent, are associated with comfort, which in turn determined satisfaction with care.

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## Introduction

Dementia is a life-limiting condition.[1,2] Many people will die with or from dementia owing to the exponential rise in prevalence from an aging population.[3,4] Symptom burden is high near the end of life resulting in poor comfort when dying with dementia.[5–8] Relieving these complex symptoms such as pain and dyspnea[9] is challenging as advanced dementia patients are unable to verbalize their discomfort and poor symptom control may increase distress and worsen quality of life.[5] However, symptom management and maximizing comfort have consistently been identified as necessary for optimal palliative care in dementia.[10–13] In addition, comfort at the end of life is commonly associated with families' satisfaction with care,[14–16] and any acute illness that affects comfort is associated with a lower satisfaction.[17] Provision of information about disease progression and involvement in goals of care conversations also increased families' satisfaction, while feeling unprepared for the death of a loved one with dementia because of the inability to provide comfort[18] was linked to complicated grief after death.[19]

Although a qualitative review revealed a preference for home death in people with dementia,[20] they are more likely to die in hospitals or long-term care facilities,[21–23] as the high care needs that accompany disease progression overwhelm caregivers, increasing the risk of institutionalization.[24,25] When interviewed about their death preferences, 77% of Singaporeans wish to die at home but only 27% did so.[26] Inconsistent level of community support is a barrier to patients receiving care and dying at home.[27,28] When dying is protracted,[29] emotional and practical support is particularly needed to help families manage dementia-specific end-of-life symptoms at home.[10] At present, there is a lack of home-based palliative care program specialized for advanced dementia in many countries, including Singapore.[30,31] Although many studies on end-of-life care for advanced dementia have been conducted in nursing homes, few explore care at home.[32,33] Hence, palliative care research for home-dwelling dementia patients at the end of life deserves urgent attention.[10,31]

The primary objective of this study was to identify modifiable factors associated with the comfort of home-dwelling dementia patients at the end of life and families' satisfaction with care. The secondary aim was to evaluate the change in patients' comfort from baseline to death as they are supported by a palliative homecare program, and families' satisfaction with care after bereavement.

## Methods

This is a prospective cohort study conducted from October 2014 to April 2019, approved by the institutional ethics committee (reference number: 2014/00577). Written informed consent was obtained from the legally appointed representatives of recruited patients.

### *Patient Recruitment*

Patients were recruited from a palliative homecare program[34,35] in Singapore. Details of the program are outlined in Appendix Table 1. The inclusion criteria were patients with dementia at Functional Assessment Stage (FAST)[36] 7A and above (characterized by the loss of communicative and ambulatory abilities and apathy), with at least one of the following prognostic criteria[37] for one-year mortality in advanced dementia: serum albumin<35 g/L (an indicator of poor nutritional status), an episode of pneumonia in the year before enrollment into the homecare program, or on permanent enteral feeding. Sample size was not calculated as this was an observational cohort of patients and we wanted to include the data of all eligible patients enrolled into the program. Patients were followed from the time of program enrollment till death. Those who were alive at the time of data analysis were excluded.

### *Dependent Variables*

*Comfort at the End of Life.* When patients' survival was predicted to be less than a month by the clinical team, the Comfort Assessment in Dying with Dementia (CAD-EOLD)[38] scale would be used to assess patients' comfort in consultation with their caregivers as part of clinical care. Patients not predicted to be dying within a month would not be assessed with the CAD-EOLD. The CAD-EOLD is a 14-item, validated and reliable[39] scale that assesses the quality of dying.[40] It has better psychometric properties and user-friendliness than other similar measures.[41] The scale has four factors: physical distress (discomfort, pain, restlessness, and shortness of breath); dying symptoms (shortness of breath, choking, gurgling, and difficulty swallowing); emotional distress (anxiety, fear, moaning, and crying); and well-being (serenity, peace, and calm). Total scores range from 14 to 42 with higher scores indicating greater comfort.[38] Comfort was assessed at every home visit until patients died or were transferred to another setting.

*Satisfaction With Care.* Two months after bereavement, family caregivers were interviewed over the phone by a researcher who is not part of the care team using the Satisfaction with Care at the End-of-Life in Dementia (SWC-EOLD)[38] scale. A two-month duration was chosen to avoid the immediate postdeath period, yet short enough for end-of-life care experiences to be readily recalled.[42] The SWC-EOLD is a valid and reliable scale[39] that quantifies satisfaction with care in advanced dementia. It has sufficient sensitivity to detect differences in response to clinically meaningful changes in key outcomes.[43] It includes questions on satisfaction with decision-making, medical and nursing care, communication with health care professionals, and understanding of patient's condition. Each of the 10 items is measured on a four-point Likert scale ranging from 1 to 4 as follows: strongly disagree, disagree, agree, and strongly agree. Total SWC-EOLD scores range from 10 to 40, with higher scores indicating greater satisfaction.[38]

### *Independent Variables*

Patients' and family caregivers' demographics, dementia etiology, FAST staging, enrollment criteria, duration of dementia since diagnosis, and comorbidities assessed using the Charlson Comorbidity Index (CCI)[44] were collected at baseline from the homecare digital medical records by the research team. Information regarding site of death, care preferences, infections, and medical interventions received in the last two weeks of life was also retrieved from the digital records after a patient's demise. Data collection regarding infections and medical interventions was limited to the last two weeks of life as this timeframe would best identify pertinent events in the dying phase.[45]

### *Statistical Analysis*

Descriptive statistics such as frequencies with percentages and median with interquartile range were used to summarize categorical variables and nonnormally distributed continuous variables, respectively.

Bivariate analysis was conducted to examine the associations of each independent variable with the outcome variables for comfort (CAD-EOLD) and satisfaction with care (SWC-EOLD). Continuous variables including CCI, dementia duration, number of antibiotic courses used, program enrollment duration, and CAD-EOLD scores were transformed into categorical variables for further comparison. The median scores determined the subdivisions for CCI, dementia duration, and number of antibiotic courses used, while a quarter of a year was used as the cutoff for program enrollment duration. Without any study to inform the CAD-EOLD threshold which deems a patient as being comfortable, anything less than a full score would indicate the presence of discomfort for the purpose of this study.

Mann-Whitney *U* and Kruskal Wallis tests were used for two-group and more than two-group comparisons of continuous variables, respectively, whereas chi-square test compared categorical variables between groups. Spearman's rho correlation determined the relationships between two continuous variables.

Significant variables at $P < 0.05$ from the bivariate analysis and clinically related variables were considered for multivariate regression analysis using generalized linear models.[46] In cases where there were multiple comparisons, Bonferroni adjustment was made to the alpha level of significance to control for Type 1 error.[47] Owing to the skewed distribution and nonnegative nature of CAD-EOLD and SWC-EOLD scores, gamma regression was used for multivariate analysis.[46] Factors that were consistently not significant were removed from the final regression analysis. For variables that were inconsistently significant, robust regression which takes into account outliers and skewed distribution of residuals[48] was additionally used. Logistic regression[49] was undertaken as an exploratory analysis using categorized CAD-EOLD (CAD-EOLD = 42 or <42) and SWC-EOLD [satisfied (all questions rated as agree and strongly agree) vs. not satisfied (all questions rated as disagree and strongly disagree)] scores as the dependent variables.

Wilcoxon signed-rank test analyzed changes in CAD-EOLD scores from baseline to death.[47] Mean with SD was additionally reported to demonstrate changes in CAD-EOLD scores.

To explore and provide insight into the differences between patients who were and were not assessed using CAD-EOLD, their baseline characteristics, care preferences, and medical events in the last two weeks of life were compared using Mann-Whitney *U* and chi-square tests for continuous and categorical variables, respectively.

The significance level was set at 0.05 for all statistical analyses performed using SPSS version 21 (IBM Corp, Armonk, NY) and STATA version 15 (StataCorp LLC, College Station, TX).

## **Results**

From October 2014 to April 2019, 488 patients from the palliative homecare program met the inclusion criteria. However, 118 patients were not recruited as their legally appointed representatives did not give consent for study participation, whereas 73 surviving patients were excluded (Fig. 1).

### *Background Characteristics of Patients and Family Caregivers*

The median age of the 297 deceased patients was 88 (84–94) years. About 70% were females and widowed with the majority being Chinese (86.2%). Close to one-third had Alzheimer's disease (30.0%) with the median duration of dementia from the time of diagnosis at 67 (44–97) months. More than half were at FAST 7E (51.9%) at program enrollment. The majority were malnourished (91.2%) with a median serum

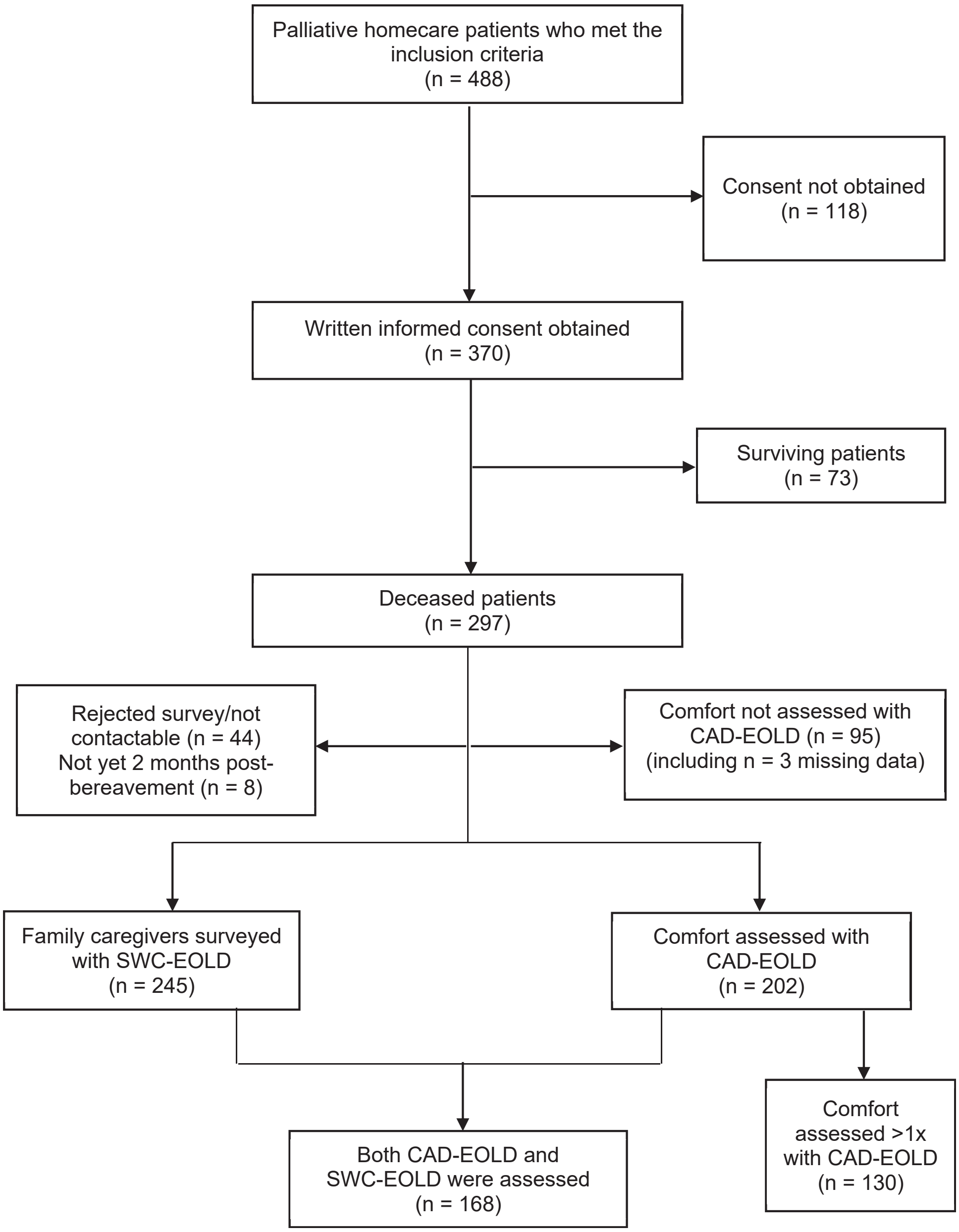

Fig. 1. Flowchart of patients recruited for the study. CAD-EOLD = Comfort Assessment in Dying with Dementia is a 14-item scale which assesses the quality of dying. Each symptom intensity is rated as follows: not at all (3), somewhat (2), a lot (1). Total scores range from 14 to 42 with higher scores indicating better comfort level; SWC-EOLD = Satisfaction with Care at the End-of-Life in Dementia is a 10-item scale that assesses family caregiver's satisfaction with care in advanced dementia. Each item is measured on a four-point Likert scale ranging from 1 to 4 as follows: strongly disagree, disagree, agree, and strongly agree. The total scores range from 10 to 40 with higher scores indicating greater satisfaction with care.

albumin level of 29 (25–32) g/L. Median CCI score was 4 (2–6) and median program enrollment duration was 62 (19–211) days. The median age of family caregivers was 59 (52–65) years. Most of them were patients' children (86.9%), lived with them (69.0%), and had domestic help (93.3%) (Table 1).

Of the 297 patients who died during the study follow-up, only 202 patients underwent CAD-EOLD assessment by the medical team (68%). Patients assessed ($N = 202$) had a shorter duration of dementia diagnosis [median (IQR) = 61 (40–90) months] than patients not assessed with the CAD-EOLD ($N = 95$) [median (IQR) = 73 (50–110) months, $P = 0.019$]. They were also enrolled in the homecare program for a shorter duration of time [56 (19–181) vs. 126 (30–281) days, $P = 0.003$]. A higher proportion were in the most advanced stage of dementia (57.4% vs. 40.0%, $P = 0.007$) (Table 1).

*Table 1*
**Characteristics of Deceased Patients and Family Caregivers**

| Variables | Total ($n = 297$) | CAD-EOLD Assessed[a] ($n = 202$) | CAD-EOLD Not Assessed[a] ($n = 95$) | *P*-value |
|---|---|---|---|---|
| Age (yrs), median (IQR) | 88 (84–94) | 88 (84–94) | 88 (84–93) | 0.985 |
| Female, *n* (%) | 203 (68.4) | 141 (69.8) | 62 (65.3) | 0.515 |
| Marital status, *n* (%) | | | | 0.886 |
| Widowed | 215 (72.4) | 148 (73.3) | 67 (70.5) | |
| Married | 71 (23.9) | 47 (23.3) | 24 (25.3) | |
| Single | 7 (2.4) | 4 (2.0) | 3 (3.2) | |
| Divorced | 4 (1.3) | 3 (1.5) | 1 (1.1) | |
| Race, *n* (%) | | | | 0.012 |
| Chinese | 256 (86.2) | 171 (84.7) | 85 (89.5) | |
| Indian | 26 (8.8) | 22 (10.9) | 4 (4.2) | |
| Malay | 6 (2.0) | 1 (0.5) | 5 (5.3) | |
| Eurasian | 5 (1.7) | 4 (2.0) | 1 (1.1) | |
| Others | 4 (1.3) | 4 (2.0) | 0 | |
| Family caregiver's age (yrs), median (IQR) | 59 (52–65) | 60 (53–65) | 58 (52–64) | 0.216 |
| Family caregiver's relationship, *n* (%) | | | | 0.878 |
| Children | 258 (86.9) | 175 (86.6) | 83 (87.4) | |
| Spouse | 20 (6.7) | 15 (7.4) | 5 (5.3) | |
| Siblings | 3 (1.0) | 2 (1.0) | 1 (1.1) | |
| Others | 16 (5.4) | 10 (5.0) | 6 (6.3) | |
| Family caregiver staying with patient, *n* (%) | 205 (69.0) | 139 (68.8) | 66 (69.5) | 1.000 |
| Presence of foreign domestic helper, *n* (%) | 277 (93.3) | 191 (94.6) | 86 (90.5) | 0.209 |
| Dementia etiology, *n* (%) | | | | 0.849 |
| Alzheimer's disease | 89 (30.0) | 58 (28.7) | 31 (32.6) | |
| Vascular dementia | 85 (28.6) | 61 (30.2) | 24 (25.3) | |
| Mixed dementia | 79 (26.6) | 54 (26.7) | 25 (26.3) | |
| Parkinson's disease | 9 (3.0) | 5 (2.5) | 4 (4.2) | |
| Lewy body | 1 (0.3) | 1 (0.5) | 0 | |
| Others | 34 (11.4) | 23 (11.4) | 11 (11.6) | |
| Duration of dementia (months), median (IQR) | 67 (44–97) | 61 (40–90) | 73 (50–110) | 0.019 |
| Functional Assessment Stage (FAST), *n* (%) | | | | 0.007 |
| 7C (chair bound) | 31 (10.4) | 22 (10.9) | 9 (9.5) | |
| 7D (bedbound) | 112 (37.7) | 64 (31.7) | 48 (50.5) | |
| 7E (loss of facial expression) | 154 (51.9) | 116 (57.4) | 38 (40.0) | |
| Enrollment criteria, *n* (%) | | | | |
| Serum albumin <35 g/L | 271 (91.2) | 182 (90.1) | 89 (93.7) | 0.424 |
| Enteral feeding | 132 (44.4) | 94 (46.5) | 38 (40.0) | 0.351 |
| Pneumonia | 214 (72.1) | 153 (75.7) | 61 (64.2) | 0.054 |
| Number of enrollment criteria fulfilled, *n* (%) | | | | 0.200 |
| 1 criterion | 80 (26.9) | 48 (23.8) | 32 (33.7) | |
| 2 criteria | 114 (38.4) | 81 (40.1) | 33 (34.7) | |
| 3 criteria | 103 (34.7) | 73 (36.1) | 30 (31.6) | |
| Serum albumin level (g/L), median (IQR) | 29 (25–32) | 29 (24–32) | 29 (25–32) | 0.966 |
| Comorbidities, *n* (%) | | | | |
| Cerebrovascular accident | 273 (91.9) | 186 (92.1) | 87 (91.6) | 1.000 |
| Diabetes mellitus | 112 (37.7) | 80 (39.6) | 32 (33.7) | 0.421 |
| With end organ damage | 77 (25.9) | 57 (28.2) | 20 (21.1) | |
| Without end organ damage | 35 (11.8) | 23 (11.4) | 12 (12.6) | |
| Moderate-severe chronic kidney disease | 105 (35.4) | 70 (34.7) | 35 (36.8) | 0.812 |
| Charlson Comorbidity Index,[b] median (IQR) | 4 (2–6) | 4 (2–6) | 3 (2–5) | 0.500 |
| Program enrollment duration (days), median (IQR) | 62 (19–211) | 56 (19–181) | 126 (30–281) | 0.003 |

CAD-EOLD = Comfort Assessment in Dying with Dementia is a 14-item scale which assesses the quality of dying. Each symptom intensity is rated as follows: not at all (3), somewhat (2), a lot (1) and the total scores range from 14–42. Higher scores indicate better comfort level; IQR = interquartile range; Charlson Comorbidity Index is a weighted index of a list of comorbid conditions. It includes a list of 17 conditions including age. Comorbidities are weighted from 1 to 6 depending on the ability of a particular condition to predict risk of death.

[a] Patients whose survival was predicted to be less than one month would be assessed by the clinical team using CAD-EOLD, whereas patients not predicted to be dying within a month would not be assessed using CAD-EOLD.

[b] The scores excluded the scores for age and dementia.

### *Infections, Medical Interventions in the Last Two Weeks of Life and Alignment With Care Plans*

Approximately 80% of our patients died at home. Those who died in the hospital or hospice had a median length of stay of 8 (4–12) days. In the last two weeks of life, about half experienced fever (51.7%), hypotension (49.0%), and poor oral intake (46.9%). Infection was prevalent (74.1%) but only slightly more than half (52.4%) used antibiotics. The median number of antibiotic courses was 1 (0–1), and oral administration was the commonest route (60.4%). Opioid and nonopioid analgesics were often prescribed (both 77.6%) while anti-cholinergic prescription was less common (43.5%). About one-fifth underwent investigations such as blood tests (23.8%), swabs (21.1%), and X-rays (18.7%). Close to half (44.6%) were on enteral feeding at the end of life. Almost all (98.3%) had a care plan documented and they were honored most of the time: do not resuscitate (97.2%), medical intervention (94.1%), place of care (95.5%), place of death (88.6%) (Table 2).

A higher proportion of patients whose comfort was assessed using CAD-EOLD died at home (85.1%) compared to those who were not assessed (65.2%), $P < 0.0001$. More of them were also febrile (57.4% vs. 39.1%, $P = 0.005$), hypotensive (56.4% vs. 32.6%, $P = 0.001$), had an infection (80.7% vs. 59.8%, $P < 0.0001$), were prescribed opioids (89.6% vs. 51.1%, $P < 0.0001$), and were prescribed anti-cholinergic medications (60.4% vs. 6.5%, $P < 0.0001$) than those who were not assessed. A higher proportion also had their care plans honored: do not resuscitate (100% vs. 90.9%, $P < 0.0001$), preferred place of care (98.0% vs. 89.8%, $P = 0.005$), preferred place of death (95.5% vs. 72.7%, $P < 0.0001$) (Table 2).

### *Comfort at the End of Life*

In bivariate analysis, program enrollment duration ($P = 0.038$), hypotension ($P = 0.037$), number of antibiotic courses used (categorized as ≤1 or >1) ($P = 0.017$), and anti-cholinergic prescription ($P = 0.031$) were significantly associated with CAD-EOLD scores (Table 3). These factors as well as clinically related variables (use of antibiotics, opioid and nonopioid analgesic prescription) were modeled using gamma[46] and logistic regression.[49] As nonopioid analgesic prescription and antibiotic use were consistently not significant, they were removed from the final regression analysis. Hypotension, opioid and anti-cholinergic prescription, categorical number of courses of antibiotic used, and program enrollment duration were entered into the final multivariate model. Anti-cholinergic prescription was positively associated with patients' comfort [β (95% CI) = 1.823 (0.660–2.986), $P = 0.002$], while more than one antibiotic courses used in the last two weeks of life [β (95% CI) = −1.968 (−3.196 to −0.740), $P = 0.002$] and opioid prescription [β (95% CI) = −2.179 (−4.107 to −0.251, $P = 0.027$) were negatively associated. However, as opioid prescription was not significant in the bivariate analysis ($P = 0.813$), its significance in robust regression[48] was considered ($P = 0.172$). In exploratory analysis using logistic regression,[49] none of the variables was associated with comfort (Table 4).

### *Satisfaction With Care*

In bivariate analysis, only CAD-EOLD scores were significantly associated with SWC-EOLD ($P = 0.029$). Hence, independent variables approaching significance such as opioid prescription ($P = 0.252$) and honoring of medical intervention preferences ($P = 0.190$) were considered for multivariate modeling with gamma[46] and logistic regression[49] (Table 5). Clinically related factors such as medications (use of antibiotics, anti-cholinergic and nonopioid analgesic prescription) and other aspects of care plan (resuscitation order, preferred place of care and death) were also entered. However, all medication-related factors were not significant in the preliminary model. Honoring of resuscitation order was also omitted owing to multicollinearity. Hence, for the final multivariate model, CAD-EOLD scores, honoring of medical intervention, and place of care and death preferences were entered. Higher CAD-EOLD scores [β (95% CI) = 0.149 (0.012–0.286), $P = 0.033$] and honoring of medical intervention preferences [β (95% CI) = 3.969 (1.485–6.453) $P = 0.002$] were positively associated with satisfaction with care. Family caregivers had a 1.160 (95% CI: 1.032–1.305, $P = 0.013$) and 13.024 (95% CI: 2.242–75.650, $P = 0.004$) odds of being satisfied with care when their loved ones were comfortable and when preferences regarding medical interventions were honored, respectively. Honoring of place of death preferences was negatively associated with satisfaction [β (95% CI) = −4.028 (−7.900 to −0.156), $P = 0.041$]. However, it was not significant in the bivariate analysis ($P = 0.963$) and preliminary model and was borderline significant ($P = 0.048$) in robust regression[48] (Table 6).

### *Change in CAD-EOLD Scores and SWC-EOLD Scores*

Comfort at the end of life was assessed more than once in 130 patients (Fig. 1). Median CAD-EOLD scores increased from 37 (34–40) to 38 (36–40) and the mean increased from 36.5 (4.2) to 37.8 (3.2), $P = 0.001$ from baseline to death. Specifically, the mean scores on the emotional distress and

*Table 2*
**Care Plans, Infections, and Medical Interventions in the Last Two Weeks of Life**

| | | CAD-EOLD | | |
|---|---|---|---|---|
| Variables | Total ($n = 294$) | Assessed[a] ($n = 202$) | Not Assessed[a] ($n = 92$) | *P*-value |
| Place of death, *n* (%) | | | | <0.0001 |
| Home | 232 (78.9) | 172 (85.1) | 60 (65.2) | |
| Hospital | 30 (10.2) | 11 (5.4) | 19 (20.7) | |
| Hospice | 25 (8.5) | 19 (9.4) | 6 (6.5) | |
| Emergency department | 7 (2.4) | 0 | 7 (7.6) | |
| Length of stay in hospital/hospice (days), median (IQR) | 8 (4–12) | 6 (4–11) | 10 (4–19) | 0.160 |
| Fever (≥38°), *n* (%) | 152 (51.7) | 116 (57.4) | 36 (39.1) | 0.005 |
| Hypotension (BP < 90/50 mmHg), *n* (%) | 144 (49.0) | 114 (56.4) | 30 (32.6) | 0.001 |
| Poor oral intake, *n* (%) | 138 (46.9) | 102 (50.5) | 36 (39.1) | 0.092 |
| Presence of infection, *n* (%) | 218 (74.1) | 163 (80.7) | 55 (59.8) | <0.0001 |
| Respiratory tract infection, *n* (%) | 184 (62.6) | 145 (71.8) | 39 (42.4) | <0.0001 |
| Urinary tract infection, *n* (%) | 53 (18.0) | 34 (16.8) | 19 (20.7) | 0.013 |
| Skin infection, *n* (%) | 21 (7.1) | 9 (4.5) | 12 (13.0) | <0.0001 |
| Use of antibiotics, *n* (%) | 154 (52.4) | 109 (54.0) | 45 (48.9) | 0.498 |
| Number of courses of antibiotics used, median (IQR) | 1 (0–1) | 1 (0–1) | 0 (0–1) | 0.531 |
| Route of antibiotics administration, *n* (%) | | | | 0.640 |
| Oral | 93 (60.4) | 68 (62.4) | 25 (55.6) | |
| Intravenous | 53 (34.4) | 35 (32.1) | 18 (40.0) | |
| Topical | 8 (5.2) | 6 (5.5) | 2 (4.4) | |
| Standby medications prescribed, *n* (%) | | | | |
| Opioids | 228 (77.6) | 181 (89.6) | 47 (51.1) | <0.0001 |
| Nonopioid analgesics | 228 (77.6) | 160 (79.2) | 68 (73.9) | 0.391 |
| Anti-cholinergic | 128 (43.5) | 122 (60.4) | 6 (6.5) | <0.0001 |
| Investigations, *n* (%) | | | | |
| Blood | 70 (23.8) | 47 (23.3) | 23 (25.0) | 0.860 |
| Swab | 62 (21.1) | 40 (19.8) | 22 (23.9) | 0.518 |
| X-ray | 55 (18.7) | 36 (17.8) | 19 (20.7) | 0.678 |
| Urine | 32 (10.9) | 20 (9.9) | 12 (13.0) | 0.548 |
| Others | 20 (6.8) | 13 (6.4) | 7 (7.6) | 0.904 |
| Enteral feeding, *n* (%) | 131 (44.6) | 92 (45.5) | 39 (42.4) | 0.706 |
| Presence of a documented care plan, *n* (%) | 289 (98.3) | 201 (99.5) | 88 (95.7) | 0.060 |
| Do not resuscitate (DNR) | 289 (100) | 201 (100) | 88 (100) | — |
| DNR honored | 281 (97.2) | 201 (100) | 80 (90.9) | <0.0001 |
| Medical intervention, *n* (%) | | | | <0.0001 |
| Comfort | 113 (39.1) | 95 (47.3) | 18 (20.5) | |
| Limited | 175 (60.6) | 105 (52.2) | 70 (79.5) | |
| Full | 1 (0.3) | 1 (0.5) | 0 | |
| Medical intervention honored, *n* (%) | 272 (94.1) | 193 (96.0) | 79 (89.8) | 0.071 |
| Preferred place of care (PPOC), *n* (%) | | | | <0.0001 |
| Home | 195 (67.5) | 152 (75.6) | 43 (48.9) | |
| Trial of treatment at home before hospital | 62 (21.5) | 27 (13.4) | 35 (39.8) | |
| Hospice | 26 (9.0) | 19 (9.5) | 7 (8.0) | |
| Hospital | 6 (2.1) | 3 (1.5) | 3 (3.4) | |
| PPOC honored, *n* (%) | 276 (95.5) | 197 (98.0) | 79 (89.8) | 0.005 |
| Preferred place of death (PPOD), *n* (%) | | | | 0.046 |
| Home | 250 (86.5) | 178 (88.6) | 72 (81.8) | |
| Hospice | 25 (8.7) | 18 (9.0) | 7 (8.0) | |
| Hospital | 8 (2.8) | 3 (1.5) | 5 (5.7) | |
| No preference | 6 (2.1) | 2 (1.0) | 4 (4.5) | |
| PPOD honored, *n* (%) | 256 (88.6) | 192 (95.5) | 64 (72.7) | <0.0001 |

CAD-EOLD = Comfort Assessment in Dying with Dementia is a 14-item scale which assesses the quality of dying. Each symptom intensity is rated as follows: not at all (3), somewhat (2), a lot (1) and the total scores range from 14 to 42. Higher scores indicate better comfort level; IQR = interquartile range.

[a] Patients whose survival was predicted to be less than one month would be assessed by the clinical team using CAD-EOLD, whereas patients not predicted to be dying within a month would not be assessed using CAD-EOLD.

*Table 3*
**Bivariate Analysis of Possible Factors Associated With CAD-EOLD Scores**

| Possible Factors | Median (IQR) CAD-EOLD Scores | *P*-value |
|---|---|---|
| Home death | | 0.097 |
| Home | 38 (35–40) | |
| Nonhome | 36 (35–39) | |
| Family caregiver relationship with patient | | 0.532[a] |
| Children | 38 (35–40) | |
| Spouse | 38 (35–40) | |
| Sibling | 36 (33–38) | |
| Others | 38 (37–40) | |
| Family caregiver living arrangement with patient | | 0.500 |
| Staying with patient | 38 (35–40) | |
| Not staying with patient | 37 (35–40) | |
| Dementia etiology | | 0.405[a] |
| Alzheimer's disease | 38 (36–40) | |
| Vascular dementia | 37 (35–40) | |
| Mixed dementia | 38 (34–39) | |
| Parkinson's disease | 39 (37–42) | |
| Lewy body | 40 | |
| Others | 38 (36–40) | |
| Charlson Comorbidity Index age category | | 0.530[a] |
| 51–60 years | 40 | |
| 61–70 years | 37 (36–38) | |
| >70 years | 38 (35–40) | |
| Charlson Comorbidity Index scores[b] | −0.099[c] | 0.154[c] |
| Categorical Charlson Comorbidity Index scores[b] | | 0.443 |
| Score ≤ 3 | 38 (36–40) | |
| Score > 3 | 38 (35–39) | |
| Program enrollment duration | 0.144[c] | 0.038[c] |
| Categorical program enrollment duration | | 0.576 |
| ≤100 days | 38 (35–40) | |
| >100 days | 38 (36–40) | |
| Fever | | 0.295 |
| Febrile | 38 (36–40) | |
| Afebrile | 38 (35–39) | |
| Hypotension | | 0.037 |
| Hypotensive | 38 (36–40) | |
| Not hypotensive | 36 (35–39) | |
| Oral intake | | 0.956 |
| Poor | 38 (35–40) | |
| Adequate or fair | 38 (35–40) | |
| Infection | | 0.164 |
| Presence of infection | 38 (35–40) | |
| No infection | 38 (36–40) | |
| Respiratory tract infection | | 0.183 |
| Yes | 37 (35–40) | |
| No | 39 (36–40) | |
| Urinary tract infection | | 0.694 |
| Yes | 38 (35–39) | |
| No | 38 (35–40) | |
| Skin infection | | 0.680 |
| Yes | 39 (35–40) | |
| No | 38 (35–40) | |
| Use of antibiotics | | 0.334 |
| Yes | 38 (35–40) | |
| No | 38 (36–40) | |
| Number of courses of antibiotics used | −0.129[c] | 0.068[c] |
| Categorical number of courses of antibiotics used | | 0.017 |
| ≤1 course | 38 (36–40) | |
| >1 course | 36 (33–39) | |
| Route of antibiotics administration | | 0.335[a] |
| Oral | 38 (35–41) | |
| Intravenous | 37 (33–39) | |
| Topical | 37 (35–40) | |
| Opioids | | 0.813 |
| Prescribed | 38 (35–40) | |
| Not prescribed | 38 (36–40) | |
| Nonopioid analgesics | | 0.602 |
| Prescribed | 38 (36–40) | |
| Not prescribed | 36 (35–40) | |
| Anti-cholinergic | | 0.031 |
| Prescribed | 38 (36–40) | |
| Not prescribed | 36 (35–39) | |
| Enteral feeding in the last two weeks | | 0.606 |
| On enteral feeding | 38 (35–40) | |
| Not on enteral feeding | 38 (36–40) | |

CAD-EOLD = Comfort Assessment in Dying with Dementia is a 14-item scale which assesses the quality of dying. Each symptom intensity is rated as follows: not at all (3), somewhat (2), a lot (1) and the total scores range from 14 to 42. Higher scores indicate better comfort level; Charlson Comorbidity Index is a weighted index of a list of comorbid conditions. It includes a list of 17 conditions including age. Comorbidities are weighted from 1 to 6 depending on the ability of a particular condition to predict risk of death.

[a] Kruskal-Wallis test was used, all other bivariate analysis used Mann-Whitney *U* test unless otherwise indicated.

[b] The scores excluded the scores for age and dementia.

[c] Spearman's rho correlation was used, expressed as correlation coefficient.

well-being subscales increased from 11.4 (1.1) to 11.8 (0.6), $P < 0.0001$ and from 7.5 (1.8) to 8.0 (1.6), $P = 0.007$, respectively. There was no significant change on the physical distress and dying symptoms subscales (Table 7).

About 85% of family caregivers were interviewed with SWC-EOLD two months after bereavement (Fig. 1). Median SWC-EOLD score was 38 (34–40) and mean was 36.5 (3.8) (Table 7).

## *Discussion*

Slightly more than half of our home-dwelling advanced dementia patients experienced a febrile episode in the last two weeks of life, comparable to the rate found among U.S. nursing home residents with advanced dementia in the CASCADE study.[9] However, pneumonia was more prevalent in our study population, coinciding with the relatively higher frequency of enteral feeding use.[50] The practice of enteral feeding use in advanced dementia requires reflection as it has not been found to confer benefits[51,52] with experts and relevant national associations discouraging its use[53] for quality palliative care in advanced dementia.[54]

Anti-cholinergic medication is used for the management of secretions and its prescription was independently associated with the comfort of our

*Table 4*

**Factors Associated With Comfort at the End of Life**

| | Gamma Regression[a] ($n = 202$) | | Logistic Regression[b] | |
|---|---|---|---|---|
| Factors | β Coefficient (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 |
| Opioids prescribed | −2.179 (−4.107 to −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 (categorized into ≤/>1) | −1.968 (−3.196 to −0.740) | 0.002 | 0.673 (0.181−2.504) | 0.555 |
| Program enrollment duration | 0.002 (−0.001−0.004) | 0.240 | 1.001 (0.999−1.003) | 0.206 |

[a] Used gamma regression (family of generalized linear model) as the distribution of CAD-EOLD scores was not normal and nonnegative.

[b] Exploratory analysis using logistic regression where CAD-EOLD scores before death were categorized into comfortable (CAD-EOLD = 42) and not comfortable (CAD-EOLD < 42).

[c] *P*-value = 0.172 in robust regression analysis.

home-dwelling dementia patients at the end of life. With disease progression, patients develop difficulty swallowing resulting in increased secretions. Aspiration pneumonia is a frequent cause of death in advanced dementia,[55] with high symptom burden[5] and discomfort in the days preceding death.[45,56] The homecare team anticipated acute distress from secretions in the last hours to days of life[17] and prescribed anti-cholinergic medications in preparation. Hence, caregivers could administer it to manage patients' secretions when needed. However, there is scope for more patients to benefit from this practice as less than half of our patients had anti-cholinergic medications at their disposal. With more patients having prompt access to anticipatory medications, they can avoid being subjected to potential discomfort.[29] Although the American Geriatrics Society Beers Criteria® recommends the avoidance of its prescription in older adults with dementia, this recommendation may be circumvented for the immediate relief of symptoms in actively dying patients[57] and should be further studied.

The limited use of antibiotics (≤1 course) in the last two weeks of life was also independently associated with the comfort of our dying patients. Antibiotics are frequently prescribed for suspected infections in advanced dementia although the rate varies widely across settings and countries.[58] Its impact on patients' comfort is uncertain[45,59] and its life-prolonging effect warrants consideration.[10] Hence, when determining the appropriateness of its use in dementia, clinicians should weigh the risks and benefits of treating the infection, consider its effect on comfort, as well as patients' treatment preferences and prognosis. For dying patients whose primary goal of care was comfort, a deliberated approach regarding antibiotic use should be adopted.[60]

It is unclear why opioids which are commonly prescribed to alleviate pain and breathlessness was a negative predictor of comfort in this study. It is postulated that these symptoms might be resistant to further interventions in the days before death, particularly in pneumonia.[5,45,56] This potentially accounted for the perception of discomfort and the absence of significant change on the physical distress and dying symptom subscales of CAD-EOLD. The focus of comfort during the dying phase might be shifted toward allaying patients' anxieties and fear, with improvements noted on the nonphysical domains of emotional distress and well-being instead. It was also possible that opioids were not prescribed for patients who were assessed as being comfortable. However, association is not a proof of causation; hence, we should be prudent about establishing causality from these findings.

The comfort data of about 30% of our patients were missing as clinicians were not able to predict that they were entering the terminal phase. Their baseline characteristics and experiences in the last two weeks of life such as fever, infection, and anticipatory medications were different from those who were predicted to be dying and had their comfort assessed with the CAD-EOLD. The inclusion of their data if their comfort had been assessed could potentially affect the outcomes.

Comfort at the end of life was in turn an independent factor associated with satisfaction with care, consistent with the findings of studies conducted in nursing homes.[14,16] This highlights the importance of comfort for dying dementia patients as it affects them[10–13] and their families. Honoring medical intervention preferences also determined families' satisfaction with care. Participation in[42] and greater frequency of goals of care conversations,[61] where the desirability of medical interventions including artificial nutrition and hydration and the use of antibiotics could be discussed, gave families a sense of contribution to their loved ones' comfort at the end of life, increasing their satisfaction with care.[42] In our study, although caregivers did not want overly aggressive measures such as resuscitation, about 60% wanted some form of medical interventions for their loved ones as these could be viewed as being beneficial and necessary for prolonging their loved ones' lives.[42]

*Table 5*

**Bivariate Analysis of Possible Factors Associated With SWC-EOLD Scores**

| Possible Factors | Median (IQR) SWC-EOLD Scores | *P*-value |
|---|---|---|
| Family caregiver relationship with patient | | 0.427[a] |
| Children | 38 (34–40) | |
| Spouse | 38 (32–40) | |
| Siblings | 32 (31–35) | |
| Others | 37 (32–40) | |
| Family caregiver living arrangement with patient | | 0.893 |
| Staying with patient | 38 (34–40) | |
| Not staying with patient | 38 (34–40) | |
| Dementia duration | −0.042[b] | 0.526[b] |
| Categorical dementia duration | | 0.350 |
| ≤60 months | 39 (34–40) | |
| >60 months | 38 (33–40) | |
| CAD-EOLD scores before death | 0.169[b] | 0.029[b] |
| Categorical CAD-EOLD scores before death | | 0.691 |
| CAD-EOLD score = 42 | 37 (32–40) | |
| CAD-EOLD score < 42 | 38 (34–40) | |
| Enteral feeding in the last two weeks | | 0.946 |
| On enteral feeding | 38 (34–40) | |
| Not on enteral feeding | 38 (34–40) | |
| Program enrollment duration | 0.068[b] | 0.287[b] |
| Categorical program enrollment duration | | 0.556 |
| ≤100 days | 38 (34–40) | |
| >100 days | 38 (34–40) | |
| Fever | | 0.111 |
| Febrile | 39 (34–40) | |
| Afebrile | 37 (33–40) | |
| Hypotension | | 0.630 |
| Hypotensive | 38 (34–40) | |
| Not hypotensive | 38 (34–40) | |
| Oral intake | | 0.508 |
| Poor | 38 (34–40) | |
| Adequate or fair | 38 (33–40) | |
| Infection | | 0.690 |
| Presence of infection | 38 (34–40) | |
| No infection | 38 (34–40) | |
| Respiratory tract infection | | 0.826 |
| Yes | 38 (34–40) | |
| No | 38 (34–40) | |
| Urinary tract infection | | 0.677 |
| Yes | 39 (34–40) | |
| No | 38 (34–40) | |
| Skin infection | | 0.868 |
| Yes | 38 (33–40) | |
| No | 38 (34–40) | |
| Use of antibiotics | | 0.692 |
| Yes | 38 (34–40) | |
| No | 38 (33–40) | |
| Route of antibiotics administration | | 0.535[a] |
| Oral | 38 (35–40) | |
| Intravenous | 38 (32–40) | |
| Topical | 37 (33–40) | |
| Number of antibiotic courses used | −0.008[b] | 0.904[b] |
| Categorical number of antibiotic courses used | | 0.260 |
| ≤1 course | 38 (34–40) | |
| >1 course | 38 (32–40) | |
| Opioids | | 0.252 |
| Prescribed | 38 (34–40) | |
| Not prescribed | 38 (33–40) | |
| Anti-cholinergic | | 0.527 |
| Prescribed | 38 (34–40) | |
| Not prescribed | 38 (34–40) | |
| Non-opioid analgesics | | 0.729 |
| Prescribed | 38 (34–40) | |
| Not prescribed | 38 (34–40) | |
| Do-not-resuscitate order | | 0.164 |
| Honored | 38 (34–40) | |
| Not honored | 40 (37–40) | |
| Medical intervention preference | | 0.190 |
| Honored | 38 (34–40) | |
| Not honored | 37 (32–39) | |
| Preferred place of care | | 0.350 |
| Honored | 38 (34–40) | |
| Not honored | 37 (34–39) | |
| Preferred place of death | | 0.963 |
| Honored | 38 (34–40) | |
| Not honored | 38 (34–40) | |
| Home death | | 0.482 |
| Home | 38 (34–40) | |
| Nonhome | 39 (35–40) | |
| Comfort assessed with CAD-EOLD | | 0.492 |
| Assessed | 38 (34–40) | |
| Not assessed | 38 (33–40) | |

SWC-EOLD = Satisfaction with Care at the End-of-Life in Dementia is a 10-item scale that assesses family caregiver's satisfaction with care in advanced dementia. Each item is measured on a four-point Likert scale ranging from 1 to 4 as follows: strongly disagree, disagree, agree, and strongly agree. The total scores range from 10 to 40 with higher scores indicating greater satisfaction with care; CAD-EOLD = Comfort Assessment in Dying with Dementia is a 14-item scale which assesses the quality of dying. Each symptom intensity is rated as follows: not at all (3), somewhat (2), a lot (1), and the total scores range from 14 to 42. Higher scores indicate better comfort level.

[a] Kruskal-Wallis test was used, all other bivariate analysis used Mann-Whitney *U* test, unless otherwise indicated.

[b] Spearman's rho correlation was used, expressed as correlation coefficient.

Attempting a time-limited trial of intervention such as a course of antibiotics in the event of an infection might help them reconcile their conflicting considerations surrounding these interventions,[11] increasing their satisfaction when their preferences were honored. Those who failed to influence care reported high levels of grief after death and experienced guilt and regret.[42] In our study, the rate of goals of care discussion was high, with care preferences discussed and wishes regarding medical interventions honored more than 90% of the time.

The negative association between the honoring of families' preferred place of death for their loved ones and satisfaction with care requires further exploration. Facilitating home death can be physically and emotionally challenging for family caregivers. The ability to manage these challenges may influence their perception of home as the most ideal place for their loved ones to receive care in the last days of life,[62] and consequently their satisfaction with care. However, this finding should be interpreted with caution as it was not consistently significant. Further research will be required to confirm the association.

*Table 6*

**Factors Associated With Satisfaction With Care at the End of Life**

| | Gamma Regression[a] ($n$ = 167[c]) | | Logistic Regression[b] | |
|---|---|---|---|---|
| Factors | β Coefficient (95% CI) | *P*-value | Odds Ratio (95% CI) | *P*-value |
| CAD-EOLD before death | 0.149 (0.012–0.286) | 0.033 | 1.160 (1.032–1.305) | 0.013 |
| Medical intervention honored | 3.969 (1.485–6.453) | 0.002 | 13.024 (2.242–75.650) | 0.004 |
| Preferred place of care honored | 5.073 (−1.132 to 11.278) | 0.109 | 1 | NA |
| Preferred place of death honored | −4.028 (−7.900 to −0.156) | 0.041[d] | 1 | NA |

CAD-EOLD = Comfort Assessment in Dying with Dementia is a 14-item scale which assesses the quality of dying. Each symptom intensity is rated as follows: not at all (3), somewhat (2), a lot (1), and the total scores range from 14 to 42. Higher scores indicate better comfort level.

[a] Used gamma regression (family of generalized linear model) as the distribution of SWC-EOLD scores was not normal and nonnegative.

[b] Exploratory analysis using logistic regression where the SWC-EOLD scores were categorized into satisfied [all questions rated as 3 (agree) and 4 (strongly agree)] vs. not satisfied [all questions rated as 1 (strongly disagree) or 2 (disagree)].

[c] Number of patients and caregivers assessed with both CAD-EOLD and SWC-EOLD = 168 (Figure 1), of which $n$ = 1 did not have a care plan documented.

[d] *P*-value = 0.048 in robust regression analysis.

The homecare team supported patients through the dying phase and kept them comfortable. A higher comfort level was reported compared to studies conducted in nursing homes, which ranged from 30.5 to 35.1 on CAD-EOLD.[17,39,63,64] After bereavement, families were satisfied with the care provided by the homecare program, with higher SWC-EOLD scores documented compared to the means reported in other studies, which ranged from 30.4 to 31.9.[16,17,39,43,64]

*Table 7*

**CAD-EOLD and SWC-EOLD Scores**

| Assessments | Baseline | Before Death | *P*-value |
|---|---|---|---|
| Total CAD-EOLD ($n$ = 130[a]) | | | 0.001 |
| Median (IQR) | 37 (34–40) | 38 (36–40) | |
| Mean (SD) | 36.5 (4.2) | 37.8 (3.2) | |
| Physical distress subscale | | | 0.974 |
| Median (IQR) | 11 (10–12) | 11 (10–12) | |
| Mean (SD) | 10.6 (1.4) | 10.6 (1.3) | |
| Dying symptoms subscale | | | 0.105 |
| Median (IQR) | 9.5 (8–11) | 10 (9–11) | |
| Mean (SD) | 9.4 (1.8) | 9.7 (1.7) | |
| Emotional distress subscale | | | <0.0001 |
| Median (IQR) | 12 (11–12) | 12 (12–12) | |
| Mean (SD) | 11.4 (1.1) | 11.8 (0.6) | |
| Well-being subscale | | | 0.007 |
| Median (IQR) | 9 (6–9) | 9 (6–9) | |
| Mean (SD) | 7.5 (1.8) | 8.0 (1.6) | |
| SWC-EOLD ($n$ = 245) | | | |
| Median (IQR) | 38 (34–40) | | |
| Mean (SD) | 36.5 (3.8) | | |

CAD-EOLD = Comfort Assessment in Dying with Dementia is a 14-item scale which assesses the quality of dying. It has four factors: physical distress (discomfort, pain, restlessness, and shortness of breath); dying symptoms (shortness of breath, choking, gurgling, and difficulty swallowing); emotional distress (anxiety, fear, moaning, and crying); and well-being (serenity, peace, and calm). Each symptom intensity is rated as follows: not at all (3), somewhat (2), a lot (1). The three items on well-being are reverse coded. Total scores range from 14 to 42 with higher scores indicating better comfort level; SWC-EOLD = Satisfaction with Care at the End-of-Life in Dementia is a 10-item scale that assesses family caregiver's satisfaction with care in advanced dementia. Each item is measured on a four-point Likert scale ranging from 1 to 4 as follows: strongly disagree, disagree, agree, and strongly agree. The total scores range from 10 to 40 with higher scores indicating greater satisfaction with care; IQR = interquartile range.

[a] Number of patients with comfort assessed more than once using CAD-EOLD before passing away.

### *Strengths and Limitations*

There has been a lack of specialized palliative homecare service for advanced dementia patients[30] and a paucity of studies examining end-of-life care outcomes for this population in the home setting.[32,33] This is one of the few studies to do so. Besides controlling for potential confounding variables, the use of different multivariate regression models allowed us to identify factors from a variety of perspectives. The practical study design demonstrated the applicability of the findings in a real-world setting, although its generalizability was limited by the single-center study design.

There are several limitations. Causative relationships could not be established as the identified factors were associative in nature. Sample size was not calculated, though it appeared to be sufficient based on the crude principle of having at least 10 observations per variable for regression analysis.[65] There was also no control group for comparison, and hence, we were unable to attribute the improvements in patients' comfort to the palliative homecare intervention. In addition, assessor bias could not be ruled out as the clinicians and caregivers looking after patients were also the ones evaluating their comfort. However, their dedicated involvement in patients' care placed them in the most suitable position to detect any change in patients. It was unclear if the one-point statistically significant increase in CAD-EOLD scores from baseline to death translated to a clinical relevance without evidence informing us of the scale's minimal clinically important difference. The 15% of caregivers who did not respond to the SWC-EOLD might rate their satisfaction differently from those who did. Finally, the comfort of about 30% of patients at the end of life was not assessed owing to prognostic uncertainty,[66–68] highlighting the difficulty with prognostication for this population of patients and limiting the applicability of our study findings.

Future studies should look at prognostication for advanced dementia to better predict patients' survival.[67,68] This will allow variables such as the frequency and intensity of homecare contacts during the dying phase to be collected, and their association with comfort and satisfaction with care to be investigated. Expectedness of death which is one of the factors influencing caregiver's experience[42,69] can additionally be explored. With increased prognostic certainty, caregivers can be better prepared when death is imminent, reducing the likelihood of depression, anxiety, and complicated grief.[19]

## Conclusion

Although dementia is a terminal condition requiring palliative care, there has been little evidence exploring the effects of palliative care interventions in advanced dementia.[70] The care experienced by people with dementia and their families can potentially be improved when knowledge built upon evidence can be translated into action and applied.[71] Our study found that achieving comfort and satisfaction with care for home-dwelling dementia patients at the end of life involves an interplay of modifiable factors[72] that can be targeted to improve palliative homecare programs, enabling advanced dementia patients to receive quality care at home.

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# Appendix

*Appendix Table 1*

**Description of the Palliative Homecare Program Specialized for Advanced Dementia**

| Categories | Details |
|---|---|
| Overview of the program | Pertinent elements of optimal palliative care in dementia[10] are incorporated into the program. It consists of a multidisciplinary team trained with the use of dementia-specific tools to assess patient's symptoms and quality of life. These assessment tools are administered by the doctors or nurses during home visits in consultation with patients' caregivers.<br>The team attends geriatric and palliative care—related courses to enhance their knowledge about dementia disease trajectory and end-of-life issues pertinent to advanced dementia. Advance care planning facilitation workshops equip them with the knowledge and skills to discuss goals of care with families.<br>The team also collaborates closely with patients' primary physicians from the referring hospital to facilitate direct admission without going through the emergency department if appropriate. In Singapore, inpatient hospice admission typically requires a referral from the tertiary hospital during an episode of admission. However, the close partnership of the homecare program with the inpatient hospice similarly allows patients to be admitted directly for respite or end-of-life care when care becomes too challenging at home, thus avoiding hospital admission and ensuring care continuity.[34,35] |
| Program enrollment criteria | Patients who fulfill the below criteria as assessed by their primary physicians are eligible for the homecare program:<br>(a) having a clinical diagnosis of dementia, with the etiology determined by their geriatricians or neurologists;<br>(b) being at the advanced stage of dementia, defined by Stage 7 on the Functional Assessment Staging Scale[36];<br>(c) having at least one of the following: a serum albumin level $< 35$ g/L, an episode of pneumonia in the past one year, or on enteral feeding[37];<br>(d) be home-dwelling; and<br>(e) family caregivers must accept a palliative approach to care for patients. |
| Referring source | Patients who fulfill the program enrollment criteria are referred by their primary physicians from the geriatric and palliative wards and outpatient clinics of a tertiary care hospital in Singapore. |
| Composition of the clinical team | The multidisciplinary team consists of geriatric and palliative trained physicians, nurses, and medical social workers. The program director who is trained in both palliative and geriatric care provides advice and makes home visits for complicated cases once to twice a week. |
| Services provided | During office hours, nurses schedule regular phone calls and home visits once a week or every fortnight to review patients. Home visits may also be arranged on an "as-needed" basis for issues that cannot be resolved over a phone consult. For symptoms and conditions deemed medically complex, doctors will make a home visit alongside the nurses. Medical social workers provide psychosocial and emotional support and apply for financial assistance for families if required. There are also weekly multidisciplinary team meetings where new and complex cases are reviewed and discussed.<br>After office hours and on weekends, a doctor is on standby to ensure that support is available all-hours through an emergency phone number. In addition to providing phone consults, the doctor makes home visits if required. |
| Caseload | On average, there are about 70 to 80 patients under the care of the homecare team at any one time. |
| Fees | As this is the first homecare program for advanced dementia in Singapore, the funding model has changed along the way since it began in October 2014. The initial three-year funding came from an endowment fund of a government-linked investment company. Subsequently, the Singapore Ministry of Health took over the funding of the program by subsidizing up to 80% of the program cost based on per capita household income. |