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ORIGINAL ARTICLE

Advanced cancer and concomitant dementia: access to specialized palliative care, emergency room, hospital care, and place of death

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ABSTRACT

Background: Dementia and advanced cancer are complex, life-limiting conditions that benefit from specialized palliative care (SPC) interventions at the end of life. The objective was to study possible differences in care for patients with concomitant advanced cancer and dementia (CA-DEM) or cancer only (CA) regarding access to SPC, acute hospital care, and place of death.

Materials and methods: A retrospective observational registry study on health care consumption data from the Stockholm Regional Council involving logistic regression analyses of age, sex, living arrangements, comorbidities, dementia diagnosis, and socio-economic status.

Results: Of the 12,667 persons aged ≥65 years who died from advanced cancer between 2015 and 2019, 605 had concomitant dementia. Of these, 76% of patients with CA and 42% of patients with CA-DEM had access to SPC ($p<.0001$). There were more admissions to palliative care for persons not living in nursing homes ($p<.0001$), women ($p<.0001$), socioeconomically privileged patients ($p<.05$), those with fewer comorbidities ($p<.0001$), and younger patients (<85 years) ($p<.0001$). Access to SPC reduced ER visits, hospitalizations, and acute hospital deaths for CA, whereas access to SPC only reduced hospital deaths in the CA-DEM group.

Conclusions: The probability of being admitted to SPC was lower in cancer patients with known dementia. Access to SPC reduced emergency room visits and acute admissions to hospitals for the whole group, and hospital deaths both for CA and CA-DEM.

Abbreviations: BPSD: behavioral and psychological symptoms in dementia; CA: patients with cancer; CA-DEM: patients with cancer and concomitant dementia; CCI: Charlson Comorbidity Index; EOL: end-of-life; ER: emergency room; ICD: International Classification of Diseases; n.s.: not significant; OR: odds ratio; SPC: specialized palliative care; STROBE: strengthening the reporting of observational studies

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Cancer; dementia; palliative care; place of death

Background

Dementia is a progressive, life-limiting condition. As both dementia and cancer prevalence increase with increasing age, a number of cancer patients will have concomitant dementia, although the incidence of Alzheimer's disease seems somewhat lower in cancer patients, compared to the general public, for unclear reasons [1,2].

At the end-of-life (EOL), people with dementia suffer from neuropsychiatric symptoms, often referred to as behavioral and psychological symptoms in dementia (BPSD), eating problems including dysphagia, infections, breathlessness, and pain [3]. As reviewed by Katrien Moens et al., also other symptoms such as constipation, nausea, fatigue, anxiety, and depression occur in varying frequencies [4]. In parallel, their cognitive decline hampers communication, including assessment of symptoms. In summary, people with dementia have palliative care needs similar to those with malignant diseases [3,4], and for dementia patients who have access to hospice, the quality of care, as well as quality of dying, seem to be improved [5]. However, most persons with dementia are less likely to be referred to specialist palliative care [6,7].

In contrast, palliative care has gained growing acceptance in oncology for more than five decades [8–10]. Access to palliative care for cancer patients is known to reduce hospital care and is considered a factor for improved symptom control and quality of life [11–13]. There is also increasing evidence that the early introduction of palliative care may be beneficial to patients' quality of life and the distress of their next of kin [10,14,15].

In Sweden, attempts have been made to increase awareness of the benefits of palliative care strategies in end-of-life (EOL) situations, regardless of diagnosis or care location [16,17]. Acute hospitals, but also nursing homes, which usually have round-the-clock access to nurses and doctors on a consulting basis, are expected to provide general palliative care when needed. In outpatient settings, general palliative home care is offered by primary care and is staffed mainly

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by district nurses, supported by general practitioners, during office hours.

For individual patients with more complex symptoms and greater needs, specialized palliative care (SPC) is offered, mainly in the form of advanced palliative home care, or in the form of hospital palliative inpatient care. Both types of care are staffed by physicians, registered nurses, physiotherapists, occupational therapists, dietitians, and others, of which physicians and nurses are available around the clock [18]. Specialized palliative consulting teams that support hospitals or nursing homes are, however, lacking in the Stockholm region.

In patients with a combination of both cancer and dementia diagnoses, findings indicate a lower likelihood of active diagnostics and cancer treatment with curative intent [6,19], as well as poorer cancer-related clinical outcomes, including late diagnosis and higher mortality rates, despite greater use of health services [6,20]. In EOL, these individuals obviously have palliative care needs, but we do not know to what extent they are referred to SPC. To the best of our knowledge, there are no studies on whether affiliation to SPC differs between patients with cancer and those with both cancer and dementia, and whether a difference in affiliation would entail differences in equality of care, where emergency room visits, hospital admissions, and place-of-death could be seen as proxies for this. Therefore, our research question was to investigate whether patients with cancer and concomitant dementia gained access to SPC to the same extent as patients with cancer and how their SPC affiliation then affected their care.

Aims

Our aim was to retrospectively compare two groups of $\geq$65 years old deceased patients with cancer and patients with concomitant cancer and dementia at EOL regarding their access to SPC. Secondary aims were to study their emergency room visits, hospital admissions, and place of death.

Materials and methods

The methods and results are, when possible, reported based on the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) criteria [21].

Study design

We conducted a retrospective observational registry data study based on the VAL, the Stockholm Region's central data warehouse. Data were collected for those who died during the 5 consecutive years, 2015–2019. Various aspects of healthcare consumption were compared between those who died from cancer and those with cancer in combination with dementia. The data were analyzed in relation to age, sex, living arrangements (residents in nursing homes versus all others), comorbidities, dementia diagnosis, and socio-economic status by means of Mosaic. Mosaic is a system that divides a county or a city into small socio-economic areas (Mosaic groups 1–3), where Mosaic group 1 corresponds to the most affluent areas [22–24].

Population

All patients over the age of 65 years who had died between 2015 and 2019 with a diagnosis of advanced cancer were included. The age limit of 65 years was chosen to make the groups (cancer only versus cancer with concomitant dementia) more comparable, as cancer deaths are common below the age of 65 years, whereas dementia diagnoses are few. Advanced cancer was defined as either metastasized disease or diagnoses of malignant brain tumors, hematological malignancies, or pancreatic cancer. This was done because brain tumors and hematological malignancies in most cases lack a code for secondary tumors in the International Classification of Diseases (ICD-10), due to their patterns of spread. Pancreatic cancer was included with or without a secondary diagnosis, as the prognosis is very poor, and secondary diagnoses are not always registered in the case records, especially in nursing homes (empirical observation).

Variables

Access to SPC during the last 3 months of life and emergency room visits, admission to acute hospitals during the last month of life, and death in acute hospitals were used as outcome measures. Geriatric clinics located in acute hospitals or in separate geriatric hospitals were not counted as acute hospitals. As explanatory variables, age, sex, living arrangements (nursing home residents versus all others), Charlson Comorbidity Index (CCI), dementia diagnoses, and Mosaic groups were used. All the included patients had advanced cancer; therefore, this was not added to the CCI index. The CCI is a method of categorizing comorbidities of patients based on the ICD-10 diagnosis codes found in administrative data and is often used as a proxy for comorbidity burden [25]. Mosaic provides socio-economic information, and based on this, the council can define and allocate different areas of residence to three different socio-economic classes (Mosaics 1–3). This is mainly based on income, education, and cultural aspects, lifestyle, and living arrangements. The county of Stockholm is divided into 1300 small areas, and each area is classified as Mosaic 1, 2, or 3. The three groups are approximately equal in size.

Selection bias

Dropouts

As reporting of data to VAL is mandatory for each clinic/care unit, data are complete, and very few values are missing. Each person who has used public health care during the study years is included in the VAL database, which also includes most forms of private care, as private care providers have economic agreements with the regional council.

Nursing home residents

To identify nursing home residents, registrations of medical interventions by doctors were identified. There are exclusive codes for physician care in nursing homes. It is unlikely that a resident living in a nursing home would not have a single registration during the last year of life. If so, they were not included in the study.

Charlson Comorbidity Index

The nature of VAL ensures that the comorbid conditions relevant to the index are considered, and the risk of missing individuals is considered negligible.

Study size

The study included all deaths from cancer during 2015–2019. Therefore, no power calculations were performed.

Statistical methods, missing data

t-Tests and chi-square tests were used to compare the proportions. There were few missing data (mainly the Mosaic classification, in 88 patients), and they were, therefore, not substituted. Initially, univariable logistic regression analyses were performed for relevant variables, which were then entered into multivariable stepwise logistic regression models, with a forward selection. The SAS 9.4/Enterprise guide 8.2 was used for statistical analysis.

Ethics

The study was approved by the Regional Ethical Review Authority (EPN 2017/1141-31).

Results

During 2015–2019, there were 12,667 persons aged 65 years or older who died of advanced cancer in Stockholm County. Of these, 12,062 had cancer only (CA) and 605 had both cancer and dementia (CA-DEM). Patients with CA-DEM were older, with a mean age of 83 years, compared to 77 years for CA patients ($p<.0001$). 49% of CA patients were women, and the corresponding figure was 53% for CA-DEM patients ($\chi^2=183$, $p<.0001$). 11% of CA and 54% of CA-DEM patients lived in nursing homes. See Table 1 for further characteristics of the main study group.

Access to specialized palliative care

During the last 3 months of life, 76% of CA and 42% of CA-DEM patients had access to SPC ($\chi^2=367$, $p<.0001$) (Table 1). In an initial univariable analysis, the likelihood of being admitted to SPC services during the last 3 months of life was significantly lower for persons with dementia, but higher for women, persons belonging to higher socioeconomic classes (Mosaic 1 and 2), younger age, and patients with fewer comorbidities. The greatest difference was related to residency in a nursing home: patients who were nursing home residents had an OR of only 0.13 to have access to SPC (Table 2). When introduced in a multivariable model that included the same explanatory variables, all significant associations remained significant, although some were weakened (Table 2).

Emergency room (ER) visits during the last month of life

During the last month of life, 5027 of the patients in the main study group made at least one emergency room visit. A concomitant dementia diagnosis did not affect the likelihood of ER visits (Table 1). In the univariable analysis, the likelihood of visiting an ER was significantly lower for women, persons in the highest socio-economic group, younger persons, persons with few comorbidities, and those with access to palliative care or living in a nursing home (Table 3). In the multivariable model, the associations were confirmed, except for age.

Admissions to acute hospitals during the last month of life

In multivariable analysis, the figures for admissions to emergency hospitals during the last month of life were similar to the figures for emergency room visits, except for younger age, which meant an increased probability of admission (Table 4). No significant difference was observed between

Table 1. Characteristics and care utilization of patients ≥65 years of age dying with advanced cancer[a] in Stockholm County 2015–2019.

	Patients with advanced cancer and dementia (CA-DEM)	Patients with advanced cancer only (CA)	Total	*p*-Value
Deaths, *n*	605	12,062	12,667	
Women (%)	319 (53)	5867 (49)	6186 (49)	<.0001
Age, all, years, mean (SD)	82.9 (7)	77.2 (8)	77.5 (8)	<.0001
Women	83.4 (7)	77.4 (8)	77.7 (8)	<.0001
Men	82.4 (6)	77.1 (8)	77.4 (8)	<.0001
Care in nursing homes (%)	325 (54)	1358 (11)	1683 (13)	<.0001
Age, nursing home residents, years, mean (SD)	83.8 (7)	82.2 (8)	82.5 (8)	<.0001
Access to SPC, *n* (%)	253 (42)	9193 (76)	9446 (75)	<.0001
ER visits last month of life (%)	259 (43)	4768 (40)	5027 (40)	.11
Acute hospital admissions last month of life (%)	259 (43)	5575 (46)	5834 (46)	.10
Place-of-death: acute hospitals (%)	81 (13)	1910 (16)	1991 (15)	.11

CA: patients with cancer; CA-DEM: patients with cancer and concomitant dementia.
[a]Advanced cancer; patients with a metastasized disease, diagnosis of pancreatic, brain or hematological cancer.

Table 2. Access to specialized palliative care.

	Univariable analysis		Multivariable analysis	
	OR (95% CI)	*p*-Value	OR (95% CI)	*p*-Value
Sex				
Female	1.23 (1.13–1.33)	<.0001	1.28 (1.18–1.40)	<.0001
Male	Ref.		Ref.	
Socioeconomic status				
Mosaic group 1	1.17 (1.05–1.30)	.003	1.15 (1.03–1.29)	.02
Mosaic group 2	1.17 (1.07–1.29)	.001	1.12 (1.01–1.24)	.03
Mosaic group 3	Ref.		Ref.	
Age group				
65–74 years	2.61 (2.35–2.90)	<.0001	1.59 (1.42–1.79)	<.0001
75–84 years	1.93 (1.74–2.14)	<.0001	1.43 (1.28–1.61)	<.0001
85 years or older	Ref.		Ref.	
Charlson Comorbidity Index				
0–1	1.78 (1.64–1.93)	<.0001	1.42 (1.29–1.55)	<.0001
2 or more	Ref.		Ref.	
Nursing home				
Residency	0.13 (0.12–0.15).	<.0001	0.17 (0.15–0.19)	<.0001
Non-residency	Ref.		Ref.	
Concomitant dementia diagnosis				
Yes	0.22 (0.19–0.26)	<.0001	0.5 (0.41–0.60)	<.0001
No	Ref.		Ref.	

Odds ratio (OR) of the probability of having access to specialized palliative care for patients ≥65 years of age dying with advanced cancer[a] in Stockholm County 2015–2019.
The analyses are based on 12,579 cases, as there were missing data on 88 patients with regards to the Mosaic group.
Ref.: Reference.
[a]Advanced cancer; patients with a metastasized disease, diagnosis of pancreatic, brain or hematological cancer.

Table 3. Emergency room visits.

	Univariable analysis		Multivariable analysis	
	OR (95% CI)	*p*-Value	OR (95% CI)	*p*-Value
Sex				
Female	0.85 (0.79–0.91)	<.0001	0.91 (0.85–0.98)	.02
Male	Ref.		Ref.	
Socioeconomic status				
Mosaic group 1	0.86 (0.78–0.94)	.0012	0.89 (0.81–0.98)	.013
Mosaic group 2	0.92 (0.84–1.00)	.047	0.95 (0.87–1.03)	.23
Mosaic group 3	Ref.		Ref.	
Age group				
65–74 years	0.86 (0.78–0.94)	.0013	ns.	ns.
75–84 years	0.91 (0.83–1.00)	.054		
85 years or older	Ref.			
Charlson Comorbidity Index				
0–1	0.65 (0.60–0.70)	<.0001	0.68 (0.63–0.74)	<.0001
2 or more	Ref.		Ref.	
Nursing home				
Residency	0.79 (0.71–0.88)	<.0001	0.46 (0.41–0.52)	<.0001
Non-residency	Ref.		Ref.	
Access to palliative care				
Yes	0.44 (0.40–0.48)	<.0001	0.37 (0.34–0.41)	<.0001
No	Ref.		Ref.	
Concomitant dementia diagnosis				
Yes	1.15 (0.97–1.35)	.11	ns.	ns.
No	Ref.			

Odds ratio (OR) for the probability of patients, ≥65 years dying with advanced cancer[a] in Stockholm County 2015–2019, to visit an emergency room (ER) at an acute hospital during the last month of life.
The analyses are based on 12,579 cases, as there were missing data on 88 patients with regards to the Mosaic group, of these 5027 had ER visits.
ns.: not significant; Ref.: reference.
[a]Advanced cancer; patients with a metastasized disease, diagnosis of pancreatic, brain or hematological cancer.

the CA and CA-DEM groups, or between different Mosaic groups.

Hospitals as the place of death

In the multivariable analysis, access to palliative care, living in a nursing home but also female sex, having fewer comorbidities (CCI), as well a dementia diagnosis, were associated with a lower probability of having an acute hospital as a place of death, whereas lower age was associated with a higher probability (Table 5).

CA-DEM: subgroup analyses

As CA-DEM was our group of special interest, additional analyses were made between those with and without access to SPC. SPC did not influence ER visits or acute hospitalizations during the last month of life but affected place of death: Among those with and without access to SPC, there were 3 and 21%, respectively of hospital deaths ($p<.0001$, Table 6).

Discussion

In summary, CA had access to SPC almost twice as often as CA-DEM, despite similar advanced cancer trajectories. Moreover, admission to SPC was more probable for women, younger patients, those from more affluent socioeconomic areas, patients with fewer comorbidities, and those with ordinary living arrangements. For the whole group (CA + CA-DEM), access to SPC reduced ER visits, hospitalizations, and

Table 4. Admissions to acute hospital.

	Univariable analysis		Multivariable analysis	
	OR (95% CI)	*p*-Value	OR (95% CI)	*p*-Value
Sex				
Female	0.86 (0.81–0.93)	<.0001	0.93 (0.87–1.00)	.047
Male	Ref.		Ref.	
Socioeconomic status				
Mosaic group 1	0.96 (0.88–1.01)	.43	ns.	ns.
Mosaic group 2	0.91 (0.84–0.99)	.03		
Mosaic group 3	Ref.			
Age group				
65–74 years	1.33 (1.21–1.47)	<.0001	1.39 (1.26–1.54)	<.0001
75–84 years	1.20 (1.10–1.32)	.0002	1.21(1.10–1.34)	.0001
85 years or older	Ref.		Ref.	
Charlson Comorbidity Index				
0–1	0.70 (0.65–0.75)	<.0001	0.69 (0.64–0.75)	<.0001
2 or more	Ref.		Ref.	
Nursing home				
Residency	0.61 (0.55–0.68)	<.0001	0.41 (0.37–0.47)	<.0001
Non-residency	Ref.			
Access to palliative care				
Yes	0.55 (0.50–0.59)	<.0001	0.42 (0.38–0.46)	<.0001
No	Ref.		Ref.	
Dementia diagnosis				
Yes	0.87 (0.74–1.03)	.10	ns.	ns.
No	Ref.			

Odds ratio (OR) for the probability of patients, ≥65 years of age dying with advanced cancer[a] in Stockholm County 2015–2019, to be admitted to an acute hospital in Stockholm County during the last month of life.
The analyses are based on 12,579 cases, as there were missing data on 88 patients with regards to the Mosaic group.
ns.: not significant; Ref.: reference.
[a]Advanced cancer; patients with a metastasized disease, diagnosis of pancreatic, brain or hematological cancer.

Table 5. Place of death.

	Univariable analysis		Multivariable analysis	
	OR (95% CI)	*p*-value	OR (95% CI)	*p*-Value
Sex				
Female	0.71 (0.64–0.78)	<.0001	0.82 (0.73–0.92)	.0007
Male	Ref.		Ref.	
Socioeconomic status				
Mosaic group 1	0.85 (0.75–0.96)	.009	ns.	ns.
Mosaic group 2	0.84 (0.75–0.94)	.002		
Mosaic group 3	Ref.			
Age group				
65–74 years	1.49 (1.30–1.70)	<.0001	2.29 (1.94–2.70)	<.0001
75–84 years	1.27 (1.11–1.46)	.0007	1.62 (1.38–1.91)	<.0001
85 years or older	Ref.		Ref.	
Charlson Comorbidity Index				
0–1	0.61 (0.55–0.67)	<.0001	0.65 (0.58–0.74)	<.0001
2 or more	Ref.		Ref.	
Nursing home				
Residency	0.59 (0.50–0.69)	<.0001	0.17 (0.14–0.20)	<.0001
Non-residency	Ref.		Ref.	
Access to palliative care				
Yes	0.09 (0.08–0.10)	<.0001	0.05 (0.04–0.06)	<.0001
No	Ref.		Ref.	
Concomitant dementia diagnosis				
Yes	0.82 (0.65–1.04)	.11	0.66 (0.50–0.88)	.004
No	Ref.		Ref.	

Odds ratio (OR) for the probability of patients, ≥65 years of age dying with advanced cancer[a] in Stockholm County 2015–2019, to have an acute hospital as a place of death.
The analyses are based on 12,579 cases, as there were missing data on 88 patients with regards to the Mosaic group.
ns.: not significant; Ref.: reference.
[a]Advanced cancer; patients with a metastasized disease, diagnosis of pancreatic, brain or hematological cancer.

Table 6. Subgroup analysis of hospital care consumption for CA-DEM, between those with and without access to SPC ($n = 601$).

Hospital utilization	CA-DEM with SPC $n = 253$	CA-DEM without SPC $n = 348$	*p*-Value
ER visits last month (%)	106 (42)	153 (44)	.61 (ns.)
Hospitalizations last month (%)	117 (46)	142 (41)	.18 (ns.)
Hospitals as place-of death (%)	8 (3)	73 (21)	<.0001

CA: patients with cancer; CA-DEM: patients with cancer and concomitant dementia; ns.: not significant.

hospital deaths, whereas access to SPC for the subgroup of CA-DEM only reduced the probability to die in acute hospitals.

This is of interest as studies have shown that most patients with advanced diseases prefer to die in their homes, especially if offered access to specialized palliative care [26–29]. In our study, the probability of having an acute hospital as place-of-death was low for both groups, 13% for CA-DEM and 16% for CA, which is probably explained by the fact that CA-DEM persons were cared for to a great extent in nursing homes, whereas CA patients often were admitted to SPC, two variables that reduce hospital consumption, in general. As shown, acute hospital deaths were less likely for those with access to SPC, both in the CA and in the CA-DEM group.

The proportion of persons with dementia was 4.8%, which is lower than for the general population with figures of about 8%, but in good agreement, for example, with a study on breast cancer where a figure of 4.6% of dementia was reported [30,31]. This is partly explained by a lower mean age in dying cancer patients, in our study 77.5 years, compared with the average age at death which is 82.5 years in Sweden [32]. As a further explanation, the risk of Alzheimer's disease has been reported to be reduced in cancer patients compared to cancer-free controls [1,2,33].

In our study, the probability of obtaining SPC was lower for CA-DEM. This may be a disadvantage as patients with advanced cancer are likely to have complex palliative care needs, which are preferably handled by staff with expert knowledge of symptom control. Exactly to what extent SPC also masters combined diseases varies and the results from studies on palliative care in dementia cannot be easily transferred to the group of patients who also have very advanced cancer, not least regarding end-of-life trajectories [34]. Still, the fact that patients with combined diagnoses have less access to SPC can be considered a marker of unequal access to an adequate level of care, as we only included cancer patients with metastatic disease in both groups, and patients with disseminated cancer are known to have complex symptoms.

Patients with CA-DEM can be expected to have different palliative care needs than patients with dementia only, and neither group does really fit into the SPC offered in the Stockholm region today, as SPC is mainly designed for cognitively intact persons. Staff in SPC generally lack training in dementia care, whereas nursing homes are mainly staffed by assistant nurses with more appropriate training in dementia care, but nursing homes do not have adequate medical staffing for more complex symptom control. Moreover, Stockholm region has no system for SPC consultations in nursing homes.

This should be an incitement to train staff in nursing homes in palliative care issues, as some of these patients probably prefer to stay in their well-known environment but need knowledgeable palliative care [7,35–38]. Another possible solution would be the development of a new type of palliative care, for example in the form of consulting. This would imply that, when needed, specialized palliative home care teams or specialized palliative geriatric care services could be consulted. In this way, the residents would both receive knowledgeable dementia care and palliative care expertise, when needed.

Strengths and limitations

As reporting to the VAL databases is mandatory and includes all ICD-10 diagnoses from hospitals, outpatient, and primary care, there are a few missing values which is a strength. The chosen period, 2015–2019, means that the results are up to date and are still not affected by the COVID-19 pandemic, which started in 2020.

A limitation of this study is that the patients were identified by their main diagnosis (cancer and/or dementia) and secondary diagnoses (metastases), but we did not have access to actual death certificates. Therefore, the immediate cause of death may have been conditions other than advanced cancer in a few cases.

A possible confounder is that CA-DEM to a high degree were cared for in nursing homes, which affects the probability of ER visits and hospital admissions. Patients with dementia in the Stockholm region may be followed by a specialized dementia clinic during the first year after diagnosis whereafter both dementia patients living at home and in nursing homes are cared for primarily by the primary care's general palliative care and with nursing interventions *via* the local municipality.

Conclusions

In conclusion, access to SPC was better for patients with advanced cancer than for those with concomitant dementia. Access to SPC reduced emergency room visits and admissions to acute hospitals, for the whole group, but this was not seen for the subgroup of CA-DEM. SPC was associated with fewer hospital deaths for both groups.

Increased access to palliative care for staff in nursing homes, for example in the form of interventions by palliative consulting teams, could probably improve palliative care for the vulnerable group of patients with cancer and concomitant dementia.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

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Data availability statement

The data that support the findings of this study are available from the corresponding author, [PF], upon reasonable request.

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