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End of life care for people with dementia and comorbid cancer: recent studies and research gaps

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ABSTRACT

Purpose of review: This narrative review examines recent research on end of life (EOL) care for people with dementia and comorbid cancer, highlighting the complexity and challenge of providing effective EOL care for this group and areas of interest for future research.

Recent findings: People with cancer and dementia and their family/supporters have more complex care and support needs at EOL that are less well met than those of older adults with cancer alone, including questionable use of aggressive EOL care interventions, poorer access to specialist palliative care teams and poor pain management. Those diagnosed with dementia at the same time as or after their cancer diagnosis are at greater risk of aggressive EOL care and EOL cancer treatment and care plans that are not able to meet their care needs as dementia progresses.

Summary: There is a lack of research on EOL care for people with cancer and dementia. There is little understanding of what good care for this population looks like and if and how EOL care can best meet the needs of people with cancer and dementia or their carers/supporters. More research is needed to inform improved care for this population.

Keywords: Alzheimer’s disease, dementia, cancer, palliative care, end-of-life care

INTRODUCTION

As many countries experience population ageing with consequent multimorbidity, end of life (EOL) care is required by a growing number of people living with dementia (PLWD) and serious comorbidities such as cancer(1-4). Our recent study using UK primary care record data found 7.5% of a sample of 41,585 PLWD aged ≥75 years had coexisting cancer(5), though such prevalence figures inevitably underestimate the size of this comorbid patient group, due to dementia underdiagnosis and underdiagnosis of cancer in PLWD(6-10). A recent survey of relatives of patients attending a memory clinic in Japan found that cancer was the second most common cause of death after pneumonia among patients with dementia or mild cognitive impairment(4). Recent years have seen an increase in research examining cancer-related care and outcomes for PLWD, that indicates this comorbid patient group and their families, are likely to have high levels of complex needs including for palliative and EOL care.

Palliative care aims to optimise physical, psychological, social, and spiritual quality of life for patients and their families facing life-limiting illnesses, usually when curative treatment is not, or no longer, considered a feasible or desirable option(11). EOL care is a form of palliative care provided as people approach the end of their lives, generally considered to be the last year of life, encompassing a person’s final months, weeks, days, and hours(12). Studies have shown that, compared to people without dementia, PLWD are significantly more likely to have cancer diagnosed following emergency presentation and at an advanced stage, or without staging information; to receive no or less extensive cancer treatment; and to have poorer survival after a cancer diagnosis, including higher mortality within the first year(13, 14). Studies also highlight the additional emotional and workload toll of comorbid cancer on family carers, who can find it very challenging to help manage cancer symptoms and sequalae in PLWD (e.g., administering medications, caring for wounds and stomas) (15, 16). Carers can also find decision-making around cancer-related investigations and treatment difficult, ethically dilemmatic, and stressful, especially if there are disagreements with other family members, and many can feel dissatisfied with their level of involvement in care decisions, often feeling marginalized by clinicians, though in some cases feeling overburdened by shared responsibility for decision-making(15, 17-19).

The additional presence of cancer may increase the already substantial complexities and challenges of providing effective EOL care to PLWD(20, 21). PLWD are more likely to have advanced cancers which commonly cause pain, and dementia impedes presentation and communication of pain symptoms increasing vulnerability to analgesic undertreatment(10, 13, 22-25). Indeed, several studies have found that patients who have cancer who also have dementia receive significantly fewer opioid and nonopioid analgesics than those without dementia, including in the final months and weeks of life(26-28). PLWD and comorbid cancer often have additional comorbidities (e.g., diabetes, stroke), and more than people with either dementia or cancer alone, increasing symptom burden and competing illness workload demands(5, 29). Also, there is significant potential for caregiver burden and distress among family members, including around cancer-related decisional burden, conflict, and rumination(15, 17, 18).

Previous reviews of research examining cancer-related care and outcomes for PLWD have included no or little focus specifically on EOL care(13, 14, 30, 31). Research in this area has tended to focus predominately on the prevalence of comorbid dementia and cancer, and on cancer diagnosis routes and characteristics, cancer treatment decision-making and delivery, and cancer survival, in PLWD. Research examining EOL care for this comorbid patient group has been more limited, and largely examined cancer-related pain management and health care utilisation through retrospective review of routine datasets, predominately in the US and Asia. Such studies have shown lower provision of analgesic medication and hospice care among PLWD and comorbid cancer, compared to people with cancer alone(27, 32-35).

This paper aims to provide an overview of some of the most recent research studies examining EOL care provision, issues, and outcomes for PLWD and comorbid cancer and their families. We searched CINAHL complete, MEDLINE and PSYCHInfo using a combination of search terms for cancer (e.g. cancer, oncology), dementia (e.g. dementia, Alzheimer's) and EOL (e.g. end of life, palliative) for papers published from 1 Jan 2022 to 31 Jan 2024. After screening papers at title, abstract and full paper, six studies were included in this review. Three were conducted in the US, two in Japan and one in Sweden. The studies covered three areas of EOL care for people with cancer and dementia: 1) the care needs of people with cancer and dementia and their carers/supports, 2) EOL care quality and outcomes and 3) Service use and care costs. We summarise the key findings and highlight areas of interest for future research.

The care needs of people with dementia and cancer and their carers/supporters

The studies exploring care needs of people with dementia and cancer and their family carers/supporters indicate more complex needs, greater care burden and poorer experiences compared to those with cancer or dementia alone.

Harrison et al (36) explored US hospice care quality experiences in the last month of life via a cross-sectional analysis of National Health and Aging Trends Study data linked to Medicare hospice claims. Of those enrolled in hospice care (n=1105) 40% had dementia alongside a co-existing terminal illness, and 16% had dementia as their primary diagnosis for EOL care. Cancer was the primary diagnosis of 38% of those who had co-existing dementia. Harrison et al identified significantly more complex needs including higher functional needs in those with dementia whether as a primary or secondary diagnosis. Those with co-existing dementia had greater multimorbidity and higher levels of clinical needs than those with dementia alone. They were also less likely to have their pain and anxiety/sadness managed well, or to have appropriate patient and/or family input into care decisions. Around one third of patients (and/or their family) who had a co-existing dementia diagnosis were unaware of this diagnosis, putting them at risk of having EOL care plans that did not consider potential dementia-specific needs.

Takao et al (37) surveyed the experiences of Japanese carers of people with cancer who had died in a hospice palliative care unit, comparing carers of people with cancer only (n=587) to those caring for someone with cancer and comorbid dementia (n=83). This cross-sectional survey found that carers of people with cancer and dementia experienced significantly higher caregiver burden overall, and particularly higher time-sacrificing burden, than the cancer-only carers group. Increased burden for carers of people with comorbid dementia and cancer was associated with poor mental and physical health of the family carer, cancer treatment duration of 12+ months and the presence of pain and dyspnoea. Takeo et al note that while caregiver burden scores were lower than previous research in Japan and Korea, suggesting a potentially positive impact of support received via the specialist palliative care unit, more support is needed for this carer group including emotional support and encouragement of self-care. Takeo et al recommend palliative care services need to particularly consider decisions around anticancer treatment and deliver improved symptom management in people with cancer and dementia. They conclude further research is needed to support improved care and support for family carers of people with terminal cancer and dementia.

These studies thus suggest people with cancer and dementia and their family/supporters have specific care and support needs that are more complex but less well met than for older adults with cancer alone at EOL.

End of life care quality and outcomes

Two studies explored care quality and outcomes at EOL. Hirooka et al (38) used Japanese national inpatient medical records (n=16,758) to examine quality of EOL care for people with non-small cell lung cancer, with (26.9%) and without (73.1%) co-existing dementia, who died in hospital. They found lower aggressive intervention, in the form of incidence of mechanical ventilation and CPR use, in people with cancer and dementia. However, compared to patients with cancer alone, those with cancer and comorbid dementia also received lower opioid use and fewer palliative care consultations, putting them at risk of poor pain management, increased symptoms such as agitation and lower quality of life. The authors note being pain free is a core component of a good death and the need to ensure appropriate referral for palliative care consultation to support pain management for this population.

Weng et al (39) analysed US SEER-Medicare data for people aged 65+ who had died 2005-2016 comparing aggressive EOL care treatments (e.g. hospital admission, ICU stay, death in hospital, chemotherapy in last 14 days of life, emergency department use) in those with cancer and dementia (n=67,690, 28.7% of total sample) versus a matched sub-sample with cancer alone (primary cancer diagnosis of female breast, colorectal, prostate or lung). Patients with dementia were significantly older at death and had longer survival (34 vs 27 months). Overall rates of aggressive EOL care treatments were over half in both groups, but those with dementia and cancer were slightly less likely to receive any form of aggressive EOL care (54.1% vs 57.8%) and overall were significantly less likely to receive aggressive EOL care than those with cancer alone. Those who had a dementia diagnosis pre cancer diagnosis were significantly less likely to receive aggressive EOL care than those diagnosed at the same time or after their cancer diagnosis. The authors suggest later dementia diagnosis may introduce new dementia-related neuropsychiatric symptoms that may make discernment of cancer care needs more difficult and increase likelihood of aggressive EOL care use. The authors conclude care providers should consider the effects of aggressive EOL care on the quality of life of patients with dementia and account for cognitive impairment in EOL care planning. They identify further research is needed to explore dementia severity and the sequences of cancer and dementia diagnosis on EOL care.

These studies indicate that people with cancer and dementia are at risk of not receiving optimal EOL care compared to older people with cancer alone including questionable use of aggressive EOL care interventions, and poorer access to specialist palliative care teams and appropriate pain management. Those diagnosed with their dementia at the same time or after their cancer diagnosis are at greater risk of potentially unnecessary aggressive EOL care use.

Service use and care costs

Two studies explored service use and costs of EOL care for people with cancer and dementia. Furst et al (40) conducted a Swedish retrospective observational registry study of people aged 65+ who had died with a diagnosis of advanced cancer in 2015-2019 (n=12,667). They compared access to specialist palliative care during the last 3-months of life, emergency room visits, acute hospital admissions in the last month of life and death in an acute hospital in cancer and dementia (n=65, 4.8%) vs cancer alone populations. The cancer and dementia population were older, more likely to be female and to live in a care home (54% vs 11%) and were less likely to access specialist palliative care. There was equal likelihood of making an emergency room visit or being admitted to hospital across groups. In the cancer and dementia group lack of access to specialised palliative care significantly increased the likelihood of dying in hospital. The authors argue that people with cancer and dementia are likely to have more complex palliative care needs and so are disadvantaged by reduced access to specialist palliative care services and staff who are skilled in cancer symptom management. They note the need for palliative care staff to access dementia training and for nursing home staff to access palliative care training. They suggest providing specialist community geriatric palliative care consultation services may ensure the complex palliative care needs of people with cancer and dementia can be most appropriately met.

Weng et al (41) explored US Medicare claims expenditure in the last 12m of life in 67,690 people with cancer and dementia and a matched group of 67,690 participants with cancer alone. The average expenditure of people with cancer and dementia was $407 higher than for the cancer only group, except in the last 2-months of life when expenditure increased for both groups, but was higher for the cancer only group. Aggressive EOL care increased costs by c.30%. Expenditure was higher for those with dementia and cancer for specialist nursing facilities, home healthcare services and hospice care, while for those with cancer alone payments were higher for outpatient care and medical equipment. In patient care costs were similar for both groups. Those diagnosed with dementia prior to cancer diagnosis had significantly lower EOL care costs. The authors suggest higher hospice care costs for people with cancer and dementia may relate to EOL care provision that is comfort-based, validated by lower out-patient use in this population indicating less use of curative or palliative treatments, particularly for those whose dementia is more severe at time of cancer diagnosis. The authors conclude diagnosis of dementia prior to cancer may mean dementia is more severe at the time of cancer diagnosis and so fewer treatment options may be available, allowing more time for families to make EOL care plans and lesser uptake of aggressive EOL care. Whereas dementia diagnosis at the time or after cancer diagnosis may mean treatment plans made before the dementia diagnosis may no longer be feasible. This suggests different consideration for cancer EOL care planning may be required depending on dementia stage and time of diagnosis.

These studies indicate people with cancer and dementia are more likely to need to access specialist nursing and palliative care and hospice services, which may be more costly than active treatment delivered via outpatient care, but more suited to their needs for comfort and quality of life. Those diagnosed with dementia at the time or after a cancer diagnosis are at risk of planned EOL cancer treatment and care plans no longer being able to meet their EOL care needs.

Conclusion

Research on EOL care for people with cancer and dementia is limited. Available research indicates people with cancer and dementia are at risk of worse EOL care outcomes than people with cancer alone including poor pain management. Little is known about what good care looks like although this is most likely to be provided by specialist palliative and EOL care teams. More research is needed to better understand EOL care for people with cancer and dementia to provide an evidence base for improved EOL care for this population.

Key points

- As many countries experience population ageing with consequent multimorbidity, end-of-life (EOL) care is required by a growing number of people living with dementia (PLWD) and serious comorbidities such as cancer.
- Limited research has examined EOL care for people with dementia and their families, predominantly using retrospective examination of routine datasets, mainly from the US and Asia.
- The research indicates people with cancer and dementia are at risk of worse EOL care than people with cancer alone including suboptimal pain management and EOL care plans that do not take into account their dementia-related needs.
- Carers and families may experience high levels of unmet needs for practical and psychosocial support.

- Further research is warranted, particularly studies collecting primary empirical data, using prospective and longitudinal designs, and employing mixed methodologies including qualitative and ethnographic methods.

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Conflicts of interest

None

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