


REVIEW ARTICLE

Cancer care for people with dementia: Literature overview and recommendations for practice and research

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Abstract

As many countries experience population aging, patients with cancer are becoming older and have more preexisting comorbidities, which include prevalent, age-related, chronic conditions such as dementia. *People living with dementia* (PLWD) are vulnerable to health disparities, and dementia has high potential to complicate and adversely affect care and outcomes across the cancer trajectory. This report offers an overview of dementia and its prevalence among patients with cancer and a summary of the research literature examining cancer care for PLWD. The reviewed research indicates that PLWD are more likely to have cancer diagnosed at an advanced stage, receive no or less extensive cancer treatment, and have poorer survival after a cancer diagnosis. These cancer disparities do not necessarily signify inappropriately later diagnosis or lower treatment of people with dementia as a

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group, and they are arguably less feasible and appropriate targets for care optimization. The reviewed research indicates that PLWD also have an increased risk of cancer-related emergency presentations, lower quality processes of cancer-related decision making, accessibility-related barriers to cancer investigations and treatment, higher *experienced* treatment burden and higher caregiver burden for families, and undertreated cancer-related pain. The authors propose that optimal cancer care for PLWD should focus on proactively minimizing these risk areas and thus must be highly person-centered, with holistic decision making, individualized reasonable adjustments to practice, and strong inclusion and support of family carers. Comprehensive recommendations are made for clinical practice and future research to help clinicians and providers deliver best and equitable cancer care for PLWD and their families.

KEYWORDS

cancer, comorbidity, dementia, geriatric oncology, health disparities, multimorbidity

INTRODUCTION

As many countries experience population aging, patients with cancer are becoming older and have more preexisting comorbidities,¹ which include prevalent, age-related, chronic conditions such as dementia. *People living with dementia* (PLWD) are vulnerable to health disparities, and dementia has high potential to complicate and adversely affect cancer presentation and diagnosis; cancer treatment decision making and delivery; patient autonomy, and patient experience, morbidity, and mortality outcomes.

Recent years have seen a surge in research literature examining the effect of preexisting dementia on cancer care and outcomes,²⁻⁴ to which we have contributed.⁵⁻²² The current report offers a timely synthesis and overview of this research, summarizing current knowledge about: dementia and its prevalence among patients with cancer; the effect of dementia on cancer diagnostic routes and delays, cancer stage at diagnosis and survival, and cancer treatment decision making, delivery and complications; and the cancer-related experiences of PLWD and family carers, including pain management. We also reflect on the ethical challenges that can arise in caring for this patient group, and we note key points people with dementia and families want cancer clinicians to know about supporting PLWD, co-authored with patient and carer representatives from our research advisory groups. Finally, we make comprehensive recommendations for clinical practice and future research to help optimize cancer care for PLWD and their families.

OVERVIEW OF DEMENTIA

Dementia types, risk factors, and prevalence

Dementia is an umbrella term for over 100 different neurodegenerative conditions that affect memory, perception, and reasoning

beyond what might be expected as part of normal aging. The most common types of dementia are Alzheimer disease, vascular dementia, Lewy body dementia, frontotemporal dementia, and mixed dementia (attributed to multiple causes). Less common forms include Parkinson dementia, Huntington disease, and Korsakoff disease. There are numerous risk factors for dementia, many of which are often-termed lifestyle behaviors (e.g., smoking, physical inactivity, excessive alcohol consumption) or associated illnesses (e.g., midlife obesity, diabetes, hypertension), which overlap considerably with cancer risk factors. Other identified dementia risk factors include less education in early life, traumatic brain injury, and genetic susceptibility. Many risk factors are interrelated, and research indicates that having more risk factors confers a greater risk for developing dementia.^{23,24}

It is estimated that there are currently over 50 million PLWD globally, and this figure is projected to increase to 152 million by 2050.²⁵ Like most cancers, dementia predominantly affects older people, with prevalence estimates for those aged 60 years and older (standardized to the Western European population structure) ranging from 4.7% in Central Europe to 8.7% in North Africa/Middle East, and clustering between 6.7% and 6.9% in Western Europe, the United States, and Australasia.²⁶ Dementia prevalence rates increase steeply with age, approximately doubling every 5 years after age 65 years.²⁶ In the United Kingdom, for example, the number of PLWD is estimated to be nearly one in 50 people aged 65–69 years (1.7%), rising to nearly one in three people aged 90–94 years (29.9%).²⁷ Although dementia mainly affects older people, up to 8% of cases are estimated to be in individuals who have younger-onset dementia (younger than 65 years).²⁶ However, prevalence figures are likely underestimates because research indicates a high rate of undiagnosed dementia globally.²⁸ Research indicates there is reluctance to raise and discuss dementia symptoms among those affected, relatives, and family physicians because of multifaceted barriers, including denial, stigma and fear, normalization of

symptoms, lack of knowledge, preserving autonomy, and therapeutic nihilism.^{29,30} After potential dementia symptoms have been presented to, or noticed and raised by, a health care professional (e.g., a general practitioner), the process of diagnosis may be managed by general practitioners in primary care and/or may involve referral to specialist services (e.g., memory clinics led by psychologists and/or psychiatrists).^{31,32} Initial assessment involves ruling out illnesses with similar symptoms (e.g., depression, delirium, hearing loss) and checking for reversible dementia syndromes with treatable etiologies (e.g., B₁₂ deficiency, hypothyroidism, normal pressure hydrocephalus).³³ An eventual diagnosis of dementia is generally based on clinical evaluation of the combined results from multiple further assessments (e.g., a medical history, cognitive tests, possibly brain imaging scans).

Dementia symptomatology and management

Dementia affects people differently, and various types of dementia have somewhat different symptomatology. However, common symptoms include problems with reasoning, communication, decision making, personality changes, and, for many types of dementia, effects on short-term and long-term memory. Dementia can make it difficult to cope with changes to familiar routines and environments, and some rarer types of dementia can also cause visual and auditory hallucinations and visuospatial and visuo-perceptual impairments (e.g., dementia with Lewy bodies and posterior cortical atrophy). Dementia is not currently curable, although there are four licensed drugs (donepezil, rivastigmine, galantamine, and memantine) intended to temporarily reduce, or slow down progression of, some of the cognitive symptoms of some types of dementia.³⁴ In the United States, aducanumab has also recently been approved by the US Food and Drug Administration as the first disease-modifying treatment for early-stage Alzheimer disease, although its use is currently controversial, and evidence for its efficacy is limited.³⁵

Because of the difficult symptoms caused by dementia and other factors, such as living environments and care that do not meet their needs, PLWD can experience fear, anxiety, and depression, which may be expressed through behaviors related to agitation and aggression.³⁶ These often-termed *behavioral and psychological symptoms of dementia* (BPSD) can be very distressing for PLWD and caregivers. Antipsychotic medications were often used to manage these behaviors, but accumulating evidence highlights an attendant increased risk of adverse effects, including falls, stroke, and death.^{23,37} High-quality, person-centered care, including psychosocial interventions, is now recognized as the first line of prevention and treatment for BPSD and for supporting quality of life generally in PLWD, with medication used as a carefully monitored, short-term, last resort in specific cases.^{23,36}

All types of dementia are progressive and, over time, will lead to more severe cognitive and physical impairment, with consequent increasing dependency on caregivers for help with activities of daily living. The terms early-stage/mild, middle-stage/moderate, and late-

stage/advanced/severe dementia are commonly used to informally descriptively categorize PLWD based on the severity of experienced symptoms.^{25,27} In this review, we use the term *early-stage/mild dementia* for people experiencing milder symptoms (e.g., difficulty thinking of the right word or name) with minimal functional impact; *moderate dementia* for people with more pronounced symptoms (e.g., confusion about where they are or what day it is), who will require some assistance with daily activities; and *late-stage/advanced dementia* for people who have severe symptoms (e.g., loss of awareness of their surroundings), many of whom live in care or nursing homes. Comorbidity is common among PLWD, and PLWD who have coexisting cancer tend to have more additional comorbidities than people with either dementia or cancer alone.^{10,38-42} A recent meta-analysis found that the mean \pm standard deviation survival time for people with Alzheimer disease was 7.6 ± 2.1 years from onset and 5.8 ± 2.0 years from diagnosis, with both of these figures approximately 1 year shorter for those who had non-Alzheimer dementias.⁴³

Prevalence of dementia among patients with cancer

Estimates of the prevalence of dementia among people with cancer vary considerably. A systematic review in 2018 found that dementia prevalence rates varied from 0.2% to 28.4% in 31 studies that examined samples of patients with cancer using mainly hospital and registry data, predominantly from the United States.³ The review included 34 studies, but the other three studies examined cancer-dementia prevalence from a different angle (e.g., the prevalence of cancer in a sample of patients with dementia). As noted in the review, such variable prevalence figures are likely caused by the considerable heterogeneity in the sample inclusion criteria and methodologies of the studies, many of which used small or geographically restricted data sets focused on a single cancer type. Seven of the eight studies in the review that reported the lowest dementia prevalence rates, of $\leq 1\%$ across multiple cancer types, all analyzed data from Denmark. The largest study in the review that was appraised as being higher quality reported a preexisting dementia prevalence rate of 7% among 106,061 patients from the US Surveillance, Epidemiology, and End Results (SEER) registry aged 68 years or older who had breast, prostate, or colorectal malignancies.³⁹ A more recent study using UK primary care records similarly found coexisting dementia in 7.5% of 41,919 patients aged 75 years and older with any type of cancer.¹⁰ Studies reporting higher dementia prevalence figures have generally examined subgroups of patients with cancer who were older (e.g., aged 80 years or older) or residing in nursing homes. For example, in a US-based study of 21,573 nursing home residents with any type of cancer, 52% also had dementia.⁴⁴ Collectively, studies to date show that dementia prevalence rates do not vary in any consistent way between common age-related cancer types (e.g., breast, colorectal, prostate).

Intriguingly, epidemiological studies indicate an inverse association between dementia and cancer, such that PLWD seemingly have

a reduced likelihood of developing cancer, and vice versa. Several reviews, including meta-analyses, indicate the robustness of this inverse relation, although its exact nature and the underpinning etiology are not fully understood.⁴⁵⁻⁴⁷ Hypothesized biologic mechanisms include a focus on shared genes and pathways that are dysregulated in different directions (e.g., underexpression vs. overexpression; activation vs. suppression) to promote tumorigenesis (cancer) or neurodegeneration (dementia) and a focus on shared pathophysiology, such as inflammation, oxidative stress, and DNA damage, which promote proliferation in peripheral cells (cancer) but apoptosis in neurons (dementia).^{47,48} Although there is accumulating evidence consistent with a biologic explanation, research also indicates that methodological biases contribute to the inverse relation, notably surveillance bias (e.g., cancer diagnosis is pursued less frequently in PLWD) and survival bias (i.e., cancer reduces the likelihood of living long enough to develop dementia).^{46,49,50} The extent of the influence of such biases on the inverse association remains unclear and divides opinions, but it is reasonable to assume that dementia prevalence rates among patients with cancer tend toward underestimation because of cancer 'underdiagnosis' in PLWD as well as dementia underdiagnosis in general.²⁸

CANCER DIAGNOSTIC ROUTES AND DELAYS AMONG PEOPLE LIVING WITH DEMENTIA

Emergency cancer presentations

Systematic reviews repeatedly indicate that PLWD experience sub-optimal routes to cancer diagnosis. Compared with people without dementia, PLWD are significantly more likely to present with cancer as an emergency and are also more likely to have cancer diagnosed by chance (i.e., incidental discovery) or not until after death.^{2,3,51} For example, Wallace et al. found that, apart from older age, dementia was the strongest individual risk factor for emergency cancer presentation above several other comorbidities and sociodemographic factors examined in a sample of 82,777 patients in England.⁵² Emergency presentation is associated with poorer clinical and patient experience outcomes.^{51,53,54} We are not aware of research on this issue, but emergency route outcomes may be particularly poor for PLWD, who have a higher risk of poorer acute care outcomes, including worsening of dementia-related symptoms and functioning.⁵⁵ In the sections below, we consider key potential explanatory factors for these dementia-related disparities in cancer diagnostic routes.

Cancer screening participation

Cancer screening is unlikely to have a major role in dementia-related cancer diagnostic disparities because most cancers are not currently screen-detected,^{53,56} and screening eligibility is low in the age groups in which dementia is most prevalent. Countries with

organized screening programs (e.g., the United Kingdom) typically have upper age limits of around 65–75 years, depending on the type of cancer screening, and countries with largely opportunistic screening (e.g., the United States) generally recommend eligibility for people with at least 10 years' life expectancy.

Relatively few studies examining cancer screening participation have included PLWD, although more studies have included older adults with cognitive impairment defined by performance on study tests or questionnaires. A 2018 meta-analysis of nine studies, seven of which were US-based, found lower participation in breast, colorectal, and cervical cancer screening among older PLWD or people with cognitive impairment compared with those without, although these differences (i.e., pooled odds ratios) were statistically significant only for breast cancer screening.⁵⁷ Two more recent studies similarly showed significantly lower rates of breast and prostate cancer screening among PLWD in the United States⁵⁸ and significantly lower rates of mammography screening among PLWD in Taiwan.⁵⁹

As dementia advances, the potential harms of cancer screening (e.g., false positives, burden of investigation and diagnosis of cancers unlikely to cause harm in a patient's remaining life expectancy) may understandably be deemed to outweigh the potential benefit of early cancer detection. Although little research has examined decision making about cancer screening participation for PLWD, two US-based interview studies found that family carers tended to view cancer screening as important for people with mild-moderate dementia but viewed it as unjustifiably burdensome as dementia advanced and quality, not quantity, of life was prioritized.^{60,61} These qualitative studies highlight that there is scope for improving decision support around cancer screening for PLWD. For example, some carers were committed to screening even if they did not envisage pursuing treatment for a discovered cancer, whereas others noted difficulty ceasing screening when physician recommendations or the momentum of the system encouraged continued screening. Decision support may be especially relevant in the United States, which, in contrast to the United Kingdom, for example, does not have an upper age limit for screening and recommends screening at more regular intervals. Accordingly, Fowler et al. in the United States recently developed a decision aid to support breast cancer screening decisions for caregivers of PLWD that aims to reduce decisional conflict and increase decision-making self-efficacy.²¹ This decision aid is currently being tested in the randomized controlled Decisions About Cancer Screening in Alzheimer's Disease (DECAD) trial (ClinicalTrials.gov identifier NCT03282097), which hypothesizes that the decision aid will reduce screening mammography use among PLWD.

Help-seeking for potential cancer symptoms

The most common route to cancer diagnosis is symptomatic presentation.^{53,56} Dementia has potential to impede effective symptom presentation. PLWD may have difficulties with noticing a new symptom (especially early on), recognizing it as a potential sign of cancer, and

appreciating the seriousness of cancer, and thus may not communicate symptoms to family caregivers and clinicians. When PLWD do communicate symptoms, they may be unable to effectively describe the nature and severity of their experienced symptoms. Dementia could also delay symptomatic diagnosis of cancer by presenting, for all involved parties, competing demands (i.e., attention is dominated by dementia-related care needs) or an alternative explanation (i.e., dementia provides a reasonable alternate explanation, such as for symptoms of brain malignancies) or by diagnostic overshadowing (i.e., symptoms are ascribed to dementia without due consideration of alternative explanations). High levels of additional comorbidities among PLWD who have coexisting cancer^{10,38-42} further increase the risk of cancer symptoms being overlooked or misattributed.

Although no or delayed help-seeking for cancer symptoms is potentially a key contributor to emergency presentations, very little research appears to have examined this issue in PLWD. Iritani et al. examined the impact of dementia on routes to cancer diagnosis using hospital records data from 134 surgical patients in Japan, 50 of whom had dementia, and found that just 8% of PLWD had sought medical consultation for physical symptoms compared with 63% of those without dementia.⁶² In some qualitative studies examining the cancer care experiences of PLWD and their families, relatives have noted their driving role in observing and instigating help-seeking for cancer symptoms and, in some cases, have described how they were delayed by dementia-related communication difficulties and/or initially misattributing cancer symptoms to other causes (e.g., attributing blood in underwear to menstruation, not colorectal cancer).^{18,63} However, because the cancer diagnostic pathway was outside the stipulated focus of these qualitative studies, it was not examined in any depth nor systematically with all participants.

Clinician recognition and referral of potential cancer symptoms

Retrospective studies have examined the impact of dementia on the time to cancer diagnosis from first symptomatic presentation and on missed opportunities for earlier diagnosis. These studies show that dementia is not associated with diagnostic delay once cancer symptoms have been presented in primary care, although the number of PLWD included in these studies is extremely small ($n = 7-22$)⁶⁴⁻⁶⁶ or was not reported.⁶⁷ For example, in a UK-based study, dementia was not one of the 18 examined comorbidities associated with a longer time to diagnose colorectal cancer from first symptom presentation,⁶⁷ and, in a US-based study, dementia was not more prevalent among patients judged to have missed opportunities for an earlier diagnosis of lung cancer.⁶⁶ It may seem surprising that dementia does not appear to prolong the *diagnostic interval* (i.e., between symptom presentation to a clinician and ultimate diagnosis). However, this is understandable if there is no or delayed help-seeking among PLWD because more advanced cancer symptoms are less likely to be overlooked or misattributed and may simply bypass primary care and present as emergencies. Lower cancer referrals among PLWD may also be an

explanatory factor because studies will likely not capture any delays in clinicians' recognition of cancers that remain *suspected* and do not go on to receive a *confirmed* diagnosis.

No research appears to have directly examined the rate of primary care referrals for cancer diagnostic investigations among PLWD nor the factors that influence decision making about this. However, there is some evidence that PLWD may be less likely to be referred for investigation of suspected cancer. In a recent systematic review examining factors affecting the decision to investigate potential cancer symptoms in older adults, a thematic synthesis of qualitative findings (25 studies) highlighted that patient cognitive impairment is likely to lower the likelihood of referral, but not inevitably so for all general practitioners.⁶⁸ More compellingly, a survey of physicians in the Netherlands found that 33% reported not referring the last nursing home resident they saw with suspected breast cancer, and advanced dementia was the most frequently cited reason (57%) for nonreferral.⁶⁹ Nevertheless, there is insufficient research to indicate the extent of cancer nonreferral among PLWD, and this may vary across countries because of factors such as different medicolegal climates (e.g., fear of malpractice liability and litigation may foster defensive practice, which favors referral-making).⁷⁰

As dementia advances, it is understandable that clinicians and/or PLWD and family carers may judge the burden of diagnostic investigations to outweigh the benefits of confirmed diagnosis, particularly if it is envisaged that cancer treatment would not be desired or tolerated. Although nonreferral may be entirely appropriate in some cases, it creates a somewhat *hidden* group, with care and research implications. Without confirmed cancer, PLWD are unlikely to be able to benefit from specialist oncology input into the management of their cancer and its symptoms and may have reduced access to cancer charities. Also, unconfirmed diagnoses are unlikely to be included in cancer statistics and research, biasing the evidence base.

Postdiagnostic survival and cancer staging among people living with dementia

Research from several countries examining multiple cancer types consistently indicates that dementia negatively affects survival after a cancer diagnosis. Corroborating the findings of previous reviews,^{2,3} the largest, most recent review by Caba et al. found that 31 of 33 analyses from 21 studies reported that PLWD who had coexisting cancer had worse all-cause and cancer-specific mortality compared with patients who had either cancer only or dementia only.⁴ One of the largest studies in the review, which analyzed US SEER registry data, found that 33.3% of PLWD died within 6 months of a cancer diagnosis (breast, prostate, or colon tumors) compared with 8.5% of people without dementia.³⁹ A more recent study, using UK primary care data, similarly found that PLWD who had coexisting cancer (any type) were more likely to die within the first year after a record of their comorbid diagnoses (31.5%) compared with people within the first year of a cancer only (22.6%) or dementia only (16.5%) diagnosis.¹⁰

Poorer survival is strongly predicted by more advanced cancer at diagnosis, and systematic reviews consistently show that PLWD are significantly more likely to be diagnosed with cancer at later stages and without staging information.^{2,3,51,71} Studies suggest that advanced stage at diagnosis contributes to, but does not predominantly underpin, the observed poorer survival of PLWD because the negative survival impact of dementia is apparent in analyses that adjust for or restrict cancer stage.^{39,40,72} For example, Raji et al. found that 16.4% of the excess mortality in PLWD who had breast cancer was explained by a more advanced-stage cancer diagnosis, and this figure was 13.6% and 0% for colon and prostate cancers, respectively.³⁹ More recently, Chen et al. found that preexisting dementia increased the risk of death by 45% in a sample of patients all with stage III colon cancer.⁴⁰ The negative impact of dementia on survival has also been found to be mediated by higher noncancer-related mortality among PLWD (dementia shortens life expectancy and often coexists with other life-shortening comorbidities)^{10,38-42} and dementia-related differences in cancer treatment.^{39,40} For example, in their examination of survival among patients with stage III colon cancer, Chen et al. calculated that 13% of the worse survival in patients with preexisting dementia could be explained by decreased odds of receiving postoperative chemotherapy.⁴⁰

CANCER TREATMENT DECISION MAKING AND DELIVERY FOR PEOPLE LIVING WITH DEMENTIA

Extent of cancer treatment provision

In survey studies with health care professionals, moderate-severe cognitive impairment is reported to be a key factor influencing cancer treatment decision making and one that is associated with more conservative treatment recommendations in hypothetical, vignette-type scenarios.^{16,22,73} These survey findings are borne out in real-world treatment data. Systematic reviews of numerous studies from multiple countries show that, compared with those without dementia, PLWD are more likely to receive no or less extensive cancer treatment across a range of cancer types and therapeutic modalities, including surgery, chemotherapy, and radiation.^{2-4,74} For example, using US SEER registry data, Gupta and Lamont found that PLWD were half as likely to receive surgical resection for colon cancer and 78% less likely to receive adjuvant chemotherapy.³⁸ More recently, a study in Japan found that PLWD had significantly higher odds of receiving supportive care alone (i.e., no anticancer therapies) for non-small cell lung cancer,⁷⁵ and a study of UK patients with breast cancer found that dementia was predictive of receiving mastectomy versus breast-conserving surgery, which the authors note may reflect a desire to avoid radiotherapy.¹⁷ In a recent meta-analytic review by Boakye et al. examining the association of different comorbidities with the provision of adjuvant chemotherapy in patients with stage III colon cancer, dementia was found to be the strongest individual predictor of chemotherapy nonuse, followed by heart failure and stroke.⁷⁴

Dementia-related diagnostic disparities likely contribute to these treatment differences because emergency presentation and advanced disease can reduce therapeutic options, especially for treatments with curative intent. The high levels of additional comorbidities among PLWD who have coexisting cancer^{10,38-42} and an increased prevalence of frailty among PLWD⁷⁶ also likely contribute to less aggressive treatment of cancer in this group. Frailty is characterized by declining functioning across multiple physiological systems alongside increased vulnerability to stressors (e.g., cancer and its treatment),⁷⁷ and is a risk factor for adverse health outcomes, though the optimal conceptualization and assessment of frailty are the subject of evolving debate.⁷⁷⁻⁷⁹ Uncertainty concerning the tolerability and outcomes of cancer treatments for older adults and PLWD, because of their substantial underrepresentation in cancer clinical trials,^{80,81} may also contribute to the provision of more conservative cancer treatment for PLWD. In addition, some PLWD and families choose not to pursue anticancer treatments for reasons such as prioritizing quality of life above prolonging life, although, to our knowledge, no qualitative studies have specifically focused on this group. Other explanatory factors are indicated by several recent qualitative studies examining cancer care for PLWD by undertaking interviews with cancer clinicians, PLWD, and/or family carers and, in some cases, also hospital-based ethnographic observations.^{5,11,13,14,18,82-85} These qualitative studies delineate various ways in which dementia complicates cancer treatment decision making and delivery for clinicians, patients, and family carers, although the studies are geographically restricted to the United Kingdom in all but one case.

Challenges for clinicians around cancer treatment decision making and delivery

Qualitative studies consistently highlight several interrelated challenges for oncology teams around cancer treatment decision making and administration for PLWD.^{5,11,13,14,18,82-85} Respecting patient autonomy, oncologists must determine whether PLWD lack capacity to give informed consent for cancer treatments and gauge the extent to which they are able and wish to be informed about and involved in treatment decision making. For PLWD, treatment decision making often also involves one or more family caregivers, who may or may not have legally appointed roles (e.g., in the United Kingdom, lasting power of attorney health and welfare; in the United States, medical power of attorney), which means clinical decision making must address multiple, sometimes conflicting, perspectives.^{6,8,13,82,84} The coexistence of dementia generally increases the number and complexity of factors to be woven into cost-benefit evaluations of treatment options, such as additional physical comorbidities,^{10,38-42} capacity to cope with behavioral requirements of treatment administration (e.g., an inpatient stay, laying still for long periods, not pulling out central lines), and the level of carer support to safely manage side effects at home. Administering cancer treatments to PLWD can require significant, and individualized, adjustments to usual practice. Examples of such adjustments, reported or observed

in qualitative studies, include scheduling appointments at a preferred time of day, trying to provide staff continuity (i.e., *familiar faces* who get to know the PLWD), conducting some appointments remotely to reduce hospital visits, and allowing caregivers to voice reassurances over the loudspeaker system during radiotherapy.^{5,7,63,84,85} Importantly, these and other examples provided in the qualitative studies show that making accessibility adjustments to typical practice is feasible and not necessarily resource-intensive.

The qualitative studies indicate that these challenges are compounded by three key problems, all of which are potentially addressable. (1) Oncology teams are often unaware of the coexistence of dementia or its severity, especially sufficiently early on in the cancer pathway by clinicians involved in treatment decision making.^{5,11} Pre-existing dementia is not always disclosed in referrals by primary care or by PLWD and their carers, and oncology teams do not generally ask patients about this comorbidity. Also, some patients may have symptoms indicative of dementia that have not yet been recognized or formally diagnosed, which is more likely for dementia at an early stage. Furthermore, even when known about, knowledge of a patient's dementia is not consistently shared by all staff involved in scheduling and administering cancer treatments because this comorbidity is not always documented in a readily visible and reliable way in oncology patient records.^{5,85} Poor identification of dementia in oncology settings was also highlighted by a recent survey of 103 UK-based cancer surgeons, in which 44.7% reported that they do not routinely ask about memory problems, and 65% indicated that they do not perform cognitive testing, in elective settings.¹⁹ (2) Oncology staff often have limited dementia knowledge and training, including in some cases limited understanding of family carers' legal proxy decision-making powers.^{5,7,12-14,18,85} Limited dementia education may mean many cancer clinicians also have limited understanding of the different types of dementia, the diverse nature of dementia symptoms, and the progressive functional impact and care needs across different stages of disease. (3) The standard length of oncology appointments is often insufficient for PLWD and their families⁷ (because of, for example, communication difficulties; more complex factors to delineate and consider in treatment decision making; more uncertainty to explain and discuss concerning treatment effects and outcomes due to a limited evidence base; more people's perspectives to hear and integrate). In addition, cancer treatment provision becomes extremely difficult, and may be viewed as unfeasible and unsafe, when PLWD do not have a supportive family carer(s) who knows them well and can accompany them to hospital appointments and assist with related care at home.^{5,8,9,11,12,84,85}

Experiences of people living with dementia and families around cancer treatment decision-making and delivery

Qualitative studies highlight how dementia increases the complexity and burden of the challenges and workload involved in the experience of patients who have cancer (e.g., understanding, retaining, and

appraising a lot of new, often complex information; making multiple journeys to and navigating unfamiliar hospital departments; monitoring and reporting side effects outside of appointments).^{5,11,13,14,18,82-85} These studies also highlight the emotional toll that cancer can have on PLWD and their families and that this is complex and individual. Studies show that PLWD can feel confused, frightened, and even *under attack* by cancer-related information and procedures, but they also show that, for other people or on other occasions, limited understanding can seemingly reduce cancer-related worry for PLWD.^{6,18,63} Caregivers can find cancer treatment decision making difficult and stressful, especially if they receive inconsistent clinical advice or disagree with other family members. Many carers feel dissatisfied with their involvement in care decisions, often feeling marginalized or excluded from decision making by clinicians, although, in some cases, they feel overburdened by shared responsibility for decision making.^{6,13,15,18,83} Carers can also find it very challenging, and, in some cases, a *daily battle*, to manage cancer symptoms and sequelae at home, which can involve trying to help PLWD take medication, care for stomas, and not pull out surgical stitches or devices.¹⁸ Because cancer comes on top of existing illness work and emotional impacts related to dementia, the cumulative *experienced* treatment burden for PLWD can become very high, as can the caregiver burden for relatives, some of whom can be near *breaking point* before the cancer diagnosis.^{5,7,8,13,18}

Qualitative studies also highlight three key aspects of cancer care that can exacerbate the challenges faced by PLWD and their carers but that are feasible targets for improvement. (1) The typical pace of cancer care can be very fast (e.g., information provision in appointments, time from diagnosis to treatment start), and many carers and PLWD have noted in research interviews that they require things to be *slowed down*, especially to allow enough time for inclusive, satisfactory decision making,^{7,63,84} which is important for respecting patient autonomy and may help to minimize decisional conflict and regret. (2) Hospital environments are often not *dementia-friendly* in their physical and organizational design, including car parking and hospital transportation (e.g., poor navigational signage; long periods of waiting in busy, sit-down areas with no or few occupying activities available; carers not always included as an escort in hospital transport bookings).^{5,9,83,85} A national audit of radiotherapy departments in Ireland also highlighted significant scope to improve clinical environments for PLWD, particularly in the areas of promoting orientation and confidence.²⁰ (3) Qualitative studies highlight that many carers have unmet information and support needs, especially concerning their particular situation of dealing simultaneously with cancer alongside dementia, and can feel they are coping alone and that their well-being is given little or no consideration by oncology teams.^{8,11,13,18}

Cancer treatment-related complications, including dementia worsening

Cancer treatments carry a risk of acute conditions to which PLWD have heightened vulnerability, especially during inpatient hospital

stays, such as infections and delirium, malnutrition, and bone fractures.⁵⁵ Cancer and its treatments also heighten key risk factors for falls, many of which may already be heightened in PLWD (e.g., cognitive impairment, functional disability).⁸⁶ PLWD also have an increased risk of polypharmacy,⁸⁷ and this can increase vulnerability to cancer treatment-related adverse events (e.g., because of drug-to-drug interactions) and associated unplanned hospital visits and stays.⁸⁸ In addition, because of difficulties recognizing and effectively reporting health-related problems, PLWD are vulnerable to treatment side effects and complications becoming advanced and potentially emergencies before they are recognized and managed. Comparative studies of health care use have generally found that PLWD who have comorbid cancer have higher rates of emergency department visits than those with dementia only and/or cancer only.^{10,41,89}

Because cancer clinical trials and treatment-focused research largely exclude PLWD,^{80,81} little research has examined the effect of dementia on the risk of cancer treatment complications, with too few studies to draw conclusions about vulnerability to specific complications. For example, a review of studies by Sattar et al. examining pretreatment cognitive impairment on chemotherapy toxicity revealed mixed findings and highlighted that such studies often exclude PLWD versus people who have milder cognitive impairment.⁹⁰ Consequently, Sattar et al. concluded that, to date, research has not adequately explored the effect of baseline cognition or cognitive impairment, particularly dementia.⁹⁰ Concerning other complications, single studies have found that dementia is associated with an increased risk of fractures after hormone therapy for prostate cancer,⁹¹ but not with an increased rate of systemic or local wound complications after breast cancer surgery.¹⁷

Insufficient research has examined cancer treatment-related effects on BPSD and on dementia-related symptoms and functioning more broadly. In some qualitative studies, family carers have mentioned increased BPSD after cancer treatment, but this issue was not examined in any depth in the studies nor systematically with all participants.^{12,18,63} A study in Japan reported that four in a sample of seven PLWD experienced exacerbated BPSD after chemotherapy for leukemia, but this is a very small study, and it does not describe how BPSD were defined or assessed.⁹²

Cancer-related pain management

Several studies have examined pharmacologic pain management in PLWD who have comorbid cancer in a range of countries and care settings, including postoperatively after cancer surgery and during the final weeks of life.^{42,62,93-99} These studies generally show that patients who have cancer with dementia receive significantly fewer analgesics than those without dementia, including opioids, non-opioids, and adjuvants like corticosteroids.^{42,62,94-97} Monroe et al., who did not include a nondementia control group, found a gradient of lower opioid administration with increasing dementia severity among patients with advanced cancer.^{98,99} In contrast, in a nursing home

study in Norway, Blytt et al. found no significant differences in pain medication use between PLWD and comorbid cancer and those who had cancer alone,⁹³ although a recent review of analgesic provision generally in PLWD found that studies in Nordic countries have reported few dementia-related differences in opioid prescribing relative to studies in the United States and Europe.¹⁰⁰

Three of the studies examining pain medication in this comorbid patient group also examined pain complaints or behaviors in care records and found significantly fewer recorded for PLWD compared with people without dementia^{62,94} or for people with advanced-stage versus earlier-stage dementia.⁹⁸ It has been hypothesized that PLWD have increased pain threshold and tolerance because of the neuro-pathologic changes underpinning dementia,^{101,102} and Iritani et al. assert that a reduced pain experience may be especially pronounced for cancer-related pain because it has a strong psychological dimension (e.g., fear that pain indicates disease progression), which may be diminished in PLWD.⁶² However, evidence concerning pain experience in PLWD is limited, complex, and equivocal, with several studies in fact indicating intensified pain processing in PLWD.^{103,104} Lower staff-observed pain complaints among patients who have cancer with dementia more likely reflect the well reported difficulties of pain communication and assessment in PLWD^{105,106} rather than PLWD genuinely experiencing less pain. PLWD can struggle to articulate the presence and nature of their pain, particularly as dementia advances, and nonverbal, pain-related behaviors may be misinterpreted as dementia symptoms. Also, the wider dementia literature shows that clinicians can have concerns about analgesic safety in PLWD.^{105,107} Lower analgesic provision to patients with cancer who have dementia thus likely signifies pain undertreatment, which is a well documented risk and concern in the wider dementia literature.^{100,106}

Ethical challenges of providing cancer care to people living with dementia

Qualitative studies highlight that making decisions about and providing cancer-related care in the context of preexisting dementia can feel ethically dilemmatic for clinicians and carers, who can ruminate on whether the *right* decisions were made and experience feelings of worry and guilt in relation to this.^{6,14,18} Dementia can make cancer care ethically challenging by complicating key ethical principles around nonmaleficence (doing no harm), beneficence (doing net good), patient autonomy, and justice (fairness).

Protection from harm is an intensified concern for PLWD because of their increased vulnerability to the potential harms inherent in receiving cancer screening, diagnosis, and treatment and because of concerns about additional harms uniquely related to preexisting dementia. Qualitative studies highlight that such additional harms include concerns that cancer treatment may precipitate worsening of dementia-related symptoms and functioning^{12,18,63} and that PLWD may forget cancer-related information and treatment and thus repeatedly suffer emotional distress each time they *re-receive*

the news that they have cancer or *re-observe* changes to their body because of treatment.^{5,18,63} Ensuring good outcomes for PLWD is complicated by the greater challenge of making cost-benefit judgments about cancer screening, diagnosis, and treatment (e.g., more factors to consider, poorer evidence base) and an intensified need for definitions of *good* outcomes to center holistic life quality, which is not easily assessed like life length, especially in PLWD.

Dementia threatens patient autonomy and equality of access to health care, inherently and potentially through intensified concern to protect PLWD from harm. People with more severe dementia who are unable to give informed consent for treatments are vulnerable to infantilizing or depersonalizing care, especially in high-task-load, time-pressured environments (e.g., other people conversing as if the person with dementia were not in the room, performing care tasks without efforts to explain what is happening or seek assent).^{108,109} Clinicians must take care to ensure that communication and interactions with PLWD uphold their dignity and demonstrate respect for their personhood (e.g., warm eye contact, active listening, sharing information). To enable maximum opportunity for PLWD to be included and involved in decision making and to access cancer care, personalized adjustments are required to information provision, decision-making processes, and treatment and care delivery. Therefore, to ensure cancer care is not discriminatory toward PLWD, it often will need to be different for PLWD. However, providing adjustments to cancer care for PLWD has resource implications and thereby also has opportunity costs for other patients. Thus higher cost care adjustments (e.g., double appointment slot) may raise an ethically challenging debate around the fair distribution of finite resources, particularly in very resource-constrained environments.

PRACTICE AND RESEARCH RECOMMENDATIONS TO OPTIMIZE CANCER CARE FOR PEOPLE LIVING WITH DEMENTIA

Comorbid preexisting dementia presents a multitude of challenges to defining and delivering best care across the cancer trajectory. Below, we make comprehensive recommendations for clinical practice and future research to help optimize cancer care for this complex patient group.

Targets and characteristics of optimal cancer care

The reviewed research indicates lower levels of cancer screening, investigations, and treatment among PLWD. Of course, this does not necessarily signify *undertreatment* of cancer in PLWD as a group (i.e., inappropriate treatment provision without net benefit).¹¹⁰ However, PLWD are a heterogeneous group, which includes people with advanced dementia, who may also have frailty and limited life expectancy, as well as people with early-stage dementia, who may be younger and fitter. Therefore, at the individual level, optimal cancer care for PLWD must tread a delicate path between underdiagnosis

and undertreatment and overdiagnosis and overtreatment, ensuring that a dementia diagnosis informs, but does not automatically rule out or specify any particular, courses of action.

Optimal cancer care for PLWD requires, to some degree, different quality indicators and targets. The reviewed research indicates that PLWD are more likely to have cancer diagnosed at an advanced stage, to receive no or less extensive cancer treatment, and to have poorer survival after a cancer diagnosis. These cancer disparities are arguably less feasible and appropriate areas of focus for care and improvement. We propose that optimal cancer care for PLWD should focus on minimizing and addressing the following research-indicated areas of increased risk for PLWD: (1) cancer-related emergency presentations (e.g., cancer diagnosis), (2) a lower quality process of cancer-related decision making (e.g., information not accessibly explained, time pressures, patient and/or carer involvement not aligned with their preferences and legal status), (3) inequitably lower access to diagnostic investigations and treatment (e.g., clinical environments that are not dementia-friendly, insufficient support for family carers), (4) higher *experienced* treatment burden for PLWD and higher caregiver burden for families (e.g., high levels of burden precancer, substantial role of carers, dementia complicates cancer-related tasks), and (5) underrecognized and undertreated cancer-related pain. To proactively address these risk areas, optimal cancer care for PLWD must be highly person-centered, with decision making based on multiple holistic factors, including the nature and stage of the dementia and cancer diagnoses; additional comorbidities, fitness, and functional status; available social support network; personal life priorities and goals; and, in best-interests proxy decision making, any advance care directives. Optimal cancer care for PLWD also requires individualized, reasonable adjustments to practice and strong inclusion and support of family carers. Below, we provide recommendations for actions that will help clinicians and providers optimize cancer care for PLWD.

Clinical practice recommendations

In Table 1 we make comprehensive practice recommendations for optimizing cancer-related care for PLWD and carers based on the reviewed literature and the experience and expertise of the authors. In Table 1, we also highlight freely available cancer care information and support resources that we or others have developed specifically for PLWD, and their families and clinicians.¹¹¹⁻¹¹⁸ Table 2 summarizes what PLWD and carers want cancer clinicians to know about supporting PLWD. Table 2 was co-developed with six patient and carer representatives (named in the acknowledgments) from one of our existing dementia research advisory groups, through a facilitated discussion (led by C.S. and R.K.). Table 2 includes all of the suggestions generated during the discussion (C.S. typed up the notes) concerned with what clinicians should know about supporting PLWD. Some practice recommendations concerning what clinicians should do (e.g., undertake training about dementia) were also made during the discussion, all of which were already included in Table 1.

TABLE 1 Clinical practice recommendations to optimize cancer-related decision making, care, and treatment for people with dementia and families

| Recommendations | Implementation strategies |
|---------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Identify preexisting comorbid dementia as soon as possible | |
| Implement ways to flag dementia for incoming patients | <ul style="list-style-type: none"> ➤ Prompt for information about dementia and its functional impact in advance, e.g.: <ul style="list-style-type: none"> - On clinical referral forms (e.g., cancer referrals from primary care) and - Using patient invitation letters (e.g., invites to screening or investigations might encourage people to get in touch about reasonable adjustments due to conditions like dementia). |
| Systematically ask new patients with cancer about dementia | <ul style="list-style-type: none"> ➤ Include a question(s) about dementia in first meetings with all patients, even if there <i>appear</i> to be no problems (e.g., add prompts to existing assessment forms). ➤ For older people, identifying comorbid dementia is ideally part of a comprehensive geriatric assessment—there are pragmatic tools to support such assessments (Mohile & Magnuson 2013,¹²² Garcia 2021¹²³). |
| Ask about dementia sensitively to minimize nondisclosure | <ul style="list-style-type: none"> ➤ Ask questions that help avoid nondisclosure of dementia or downplaying difficulties (e.g., because of denial, fear of stigma): <ul style="list-style-type: none"> - Ask initially about dementia-related difficulties rather than <i>dementia</i> (e.g., difficulties remembering a lot of new information, using stairs etc.), - Frame questions supportively (i.e., the information will help inform personalized support), and - Offer to discuss things later if preferred (i.e., allowing carers to discuss things separately). |
| Document comorbid dementia accessibly in patient records | <ul style="list-style-type: none"> ➤ Make dementia immediately visible on patient records (e.g., colored sticker on paper, icon and/ or pop-up electronically). ➤ Include designated space in patient records for making and reading notes about someone's dementia and related needs and support (including carer contact details). |
| Inform all staff about dementia at the point of care | <ul style="list-style-type: none"> ➤ Signify dementia discreetly on patient ID wristbands (i.e., using color or an icon). ➤ Offer other wristbands or badges for visits not requiring an ID band (same color or icon). ➤ Flag dementia clearly in multidisciplinary team (MDT) discussions of patients. |
| Be aware of the potential for symptoms indicative of dementia not yet diagnosed | <ul style="list-style-type: none"> ➤ Be mindful patients may have symptoms indicative of possible dementia, but not yet recognized or formally diagnosed as dementia, and which in fact could result from other conditions (e.g., delirium, hearing loss) or potentially <i>reversible</i> causes (e.g., B₁₂ deficiency, hypothyroidism; Bevins 2021³³). ➤ Establish and follow locally appropriate pathways for investigation, referral, or signposting of patients with dementia-indicative symptoms to support timely access to symptom assessment, diagnosis, and care (in specialist oncogeriatric services, including geriatricians, psychiatrists, etc., dementia assessment may be possible in-house). ➤ Patients with dementia-like symptoms as yet undiagnosed can still benefit from many of the practice recommendations in this table, and most can be implemented sensitively without any reference to <i>dementia</i>. |
| 2. Involve and support family carers of people with dementia | |
| Include carers during appointments and in decision making | <ul style="list-style-type: none"> ➤ Send a nominated carer copies of all clinical letters and appointment reminders. ➤ Involve carers in cancer-related decision making, as appropriate to any powers of attorney they hold and the preferences of the person with dementia and carer. ➤ Enable carers to be present during consultations and any procedures and treatments (e.g., to talk to their relative during radiotherapy over an intercom system). |
| Appreciate carers' support needs and signpost to help | <ul style="list-style-type: none"> ➤ Be aware of the potential for significant distress among carers. ➤ Ask after carers' own coping and well-being at routine appointments. ➤ Offer carers dedicated opportunities to comprehensively review and discuss their coping and related needs, including experienced distress, periodically across the duration of care. ➤ Signpost carers to support, especially: <ul style="list-style-type: none"> - Local providers who can care onsite for PLWD while carers participate in support sessions, - Resources tailored to PLWD and comorbid cancer and/or their family carers (Centre for Dementia Research at Leeds Beckett University 2021,^{114,115} Macmillan Cancer Support 2020,^{116,117} Alzheimer's Society 2022¹¹⁸), and - Advice on financial support opportunities. ➤ Offer carers experiencing distress a referral to available local psycho-oncology services (i.e., staffed by clinical psychologists, psychiatrists, counsellors etc.). |

TABLE 1 (Continued)

| Recommendations | Implementation strategies |
|---------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 3. Review decision-making capacity and related proxy powers | |
| Consider assessment of decision-making capacity for people with dementia | <ul style="list-style-type: none"> ➤ Follow jurisdiction-relevant rules and guidance on mental capacity assessments. ➤ Recognize that decision-making capacity is not absolute but decision-specific (i.e., it depends on the complexity of the decision). |
| Verify advance directives and carers' legal proxy decision-making powers | <ul style="list-style-type: none"> ➤ Document information about any advance care directives and carer powers of attorney in patient records. ➤ Recognize that powers of attorney can be domain-specific (e.g., finance, health) and do not necessarily cover health-related decision-making. |
| 4. Consider and make reasonable adjustments to cancer-related care and treatment | |
| Understand what dementia means for that person and their carer | <ul style="list-style-type: none"> ➤ Talk early on about functional limitations, personal routines and preferences, levels of family support, etc.—there are tools to facilitate such discussions (Alzheimer's Society 2022¹²⁴). ➤ Offer <i>trial</i> runs or visits to help gauge how PLWD may cope psychosocially with certain procedures or treatments and what related reasonable adjustments may be possible. |
| Offer reasonable adjustments to care delivery | <ul style="list-style-type: none"> ➤ These will differ per person, but areas for helpful adjustments commonly include: <ul style="list-style-type: none"> - Timing of appointments (e.g., always morning or afternoon, as best fits personal routines), and - Consistency of people and places (e.g., same nurse, same treatment room). |
| Factor into treatment decision making and planning possible accommodating adjustments to regimens | <ul style="list-style-type: none"> ➤ These will differ per person, but areas for consideration include: <ul style="list-style-type: none"> - Minimizing toxicity (e.g., use of short-acting anesthetic agents), and - Reducing hospital attendances (e.g., hypofractionated radiotherapy). ➤ Be prepared to consider responsive adjustments to regimens during treatment (i.e., if treatment is being tolerated less well or better than envisaged). |
| 5. Minimize the risk of poorly controlled pain and other symptoms and side effects | |
| Proactively assess and manage pain using dementia-specialist resources | <ul style="list-style-type: none"> ➤ Regularly assess pain. ➤ For patients who demonstrably cannot reliably verbalize their pain, use tools for nonverbal pain assessment in PLWD (Lichtner 2014¹²⁵). <ul style="list-style-type: none"> - Examples include the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC), the Pain Assessment in Advanced Dementia (PAINAD) scale, and the Abbey Pain Scale (Fuchs-Lacelle & Hajistavropoulos 2004,¹²⁶ Warden 2003,¹²⁷ Abbey 2004¹²⁸). - Consult dementia-specialist colleagues for initial guidance/training on tool selection, use, and interpretation. ➤ Proactively consider and address causes of pain (e.g., constipation, infection, metastases). ➤ Consult specialists to support effective and safe analgesic pain management in PLWD. |
| Support patients and carers with self-management tasks | <ul style="list-style-type: none"> ➤ Provide detailed guidance on self-management tasks, supported by leaflets with pictures and online videos. ➤ Offer hands-on practice of self-management tasks under supervision (e.g., catheter care). ➤ Ensure community-based support with self-management tasks (e.g., home nursing visits). |
| Review dementia-related decline among side effects | <ul style="list-style-type: none"> ➤ Ask about and document changes in dementia-related symptoms and functioning. ➤ Consider reasons for and respond to dementia-related decline (e.g., adjustments to treatment or analgesic regimens or care delivery, increased support for carers). |
| 6. Reduce the risk of emergency cancer presentation | |
| Assist people with dementia and carers to present potential cancer symptoms | <ul style="list-style-type: none"> ➤ Run community-based awareness campaigns for potential cancer symptoms targeted at PLWD and carers. ➤ Proactively ask PLWD and carers about potential cancer symptoms in community-based health consultations. ➤ Focus on common cancers; cancers with a higher risk of emergency presentation, such as bowel cancer; and cancer symptoms with known lower public awareness. |
| Monitor and risk-assess suspected but not referred cancers in people with dementia | <ul style="list-style-type: none"> ➤ Document and monitor suspected cancer symptoms in PLWD who are not referred for diagnostic investigations. ➤ Obtain oncologist input on suspected but not referred cancers, especially concerning risk and signs of an emergency trajectory. |

(Continues)

TABLE 1 (Continued)

| Recommendations | Implementation strategies |
|------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 7. Increase dementia knowledge and training among cancer clinicians | |
| Set up and maintain a dementia resources library | <ul style="list-style-type: none"> ➤ In one easy-access place, gather dementia-related information and resources, including: <ul style="list-style-type: none"> - Details of local referral pathways for memory assessment and support, and - Resources providing guidance specifically on cancer care for PLWD (Kuwata 2021,¹¹¹ Centre for Dementia Research at Leeds Beckett University 2021,^{112,114,115} Society and College of Radiographers 2020,¹¹³ Macmillan Cancer Support 2020,^{116,117} Alzheimer's Society 2022¹¹⁸). |
| Up-skill all staff with dementia training | <ul style="list-style-type: none"> ➤ Provide access to practical training on areas of low knowledge and confidence, e.g.: <ul style="list-style-type: none"> - Communicating with people who have dementia, - Assessing decision-making capacity and understanding powers of attorney, and - Common problems for PLWD receiving cancer treatment. |
| Create dementia specialists in cancer teams | <ul style="list-style-type: none"> ➤ Appoint some staff <i>dementia champions</i> who receive advanced dementia training. ➤ Employ a dementia nurse specialist(s) in cancer centers. |
| 8. Provide information and communicate in dementia-friendly ways | |
| Use simple language and pictures and recap | <ul style="list-style-type: none"> ➤ Use simple words and short sentences at a slower pace, and periodically recap key points. ➤ Mirror idiosyncratic terms used by the person with dementia (e.g., Big Machine). ➤ Use supporting visuals, e.g.: <ul style="list-style-type: none"> - Draw on an outline body to help describe tumor size and location, and - Give leaflets with photos and/or online videos to help explain procedures, equipment, etc. |
| Supply take-away summaries of key information | <ul style="list-style-type: none"> ➤ Provide bullet-point summaries of key discussion items, decision options, etc. ➤ Offer the option to audio record key parts of consultations (e.g., closing summary points). |
| Give warm, empathetic, nonverbal communication | <ul style="list-style-type: none"> ➤ Talk to PLWD, not only their carers (e.g., seat them closest in consultations). ➤ Have a warm and calm tone of voice and facial expressions (i.e., smiling, unhurried). |
| Communicate directly with other involved clinicians and keep them updated | <ul style="list-style-type: none"> ➤ Provide information/requests directly to other clinicians (i.e., avoid onus on the PLWD or carer to tell/ask). ➤ Send copies of key letters to other clinicians (e.g., from oncology to primary care). ➤ Provide other clinicians with written summaries/requests for their input at key points (e.g., discharge from hospital into community care). |
| 9. Allow more time to care for people with dementia | |
| Provide more clinical appointment time | <ul style="list-style-type: none"> ➤ Schedule longer slots for consultations, screening procedures, treatment sessions, etc. ➤ Offer extra appointments/contacts (e.g., follow-up calls to further discuss decision options or monitor well-being during treatment). |
| Enable enough time to consider decisions | <ul style="list-style-type: none"> ➤ Reassure PLWD and carers they can take the time they need to make decisions. ➤ Enable clinicians to have enough time for decision-making, e.g.: <ul style="list-style-type: none"> - Longer slots to discuss complex cases in MDT meetings, and - Delay/repeat discussion at MDT meetings to enable prior/more information gathering and discussion with PLWD and carers. |
| 10. Make clinical environments more dementia-friendly | |
| Promote easy navigation of clinical sites and carparks | <ul style="list-style-type: none"> ➤ Quick, low-cost improvements to support way-finding and orientation include: <ul style="list-style-type: none"> - Clearer signs for key amenities (toilets, exits, food, and drink), - Greater distinction between different areas (e.g., use color-coding), and - Easily visible clocks on walls that also show day and date. ➤ Implement guidance for creating dementia-friendly environments (Grey 2018,¹²⁹ Kirch 2021¹³⁰). |
| Ease the burden of onsite waiting periods | <ul style="list-style-type: none"> ➤ Offer PLWD regular updates/reassurance during waiting periods and check whether they need anything (e.g., drink). ➤ Provide opportunities for occupying activities in waiting areas (e.g., dementia-friendly books and activities like memory boxes). ➤ Consider specialist dementia-friendly waiting areas, supervised by staff/volunteers with dementia training, that are quieter spaces and have drinks/snacks facilities. |
| 11. Minimize and improve care-related travel for people with dementia | |
| Make use of remote and mobile care options | <ul style="list-style-type: none"> ➤ Offer some consultations remotely (e.g., follow-ups or additional check-ins). ➤ Consider mobile cancer care (e.g., cancer screening and chemotherapy treatment units that drive out to communities). |

TABLE 1 (Continued)

| Recommendations | Implementation strategies |
|---------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Reduce difficulties around making journeys and parking | <ul style="list-style-type: none"> ➤ Ask whether an escort seat (i.e., for carers) is needed on patient transport at the time of booking. ➤ Offer a site-provided permit to use disabled or reserved parking (i.e., for people without the standard permit), and ensure such parking spaces are plentiful. ➤ Broaden assistance at clinical site entrances so PLWD can be supported to wait while their carer parks/collects the car. |
| 12. Establish features, pathways, or models of cancer care that support caring for people with dementia | |
| Provide a consistent key worker/case manager | <ul style="list-style-type: none"> ➤ Ensure case managers are easily contactable, have case oversight, and have dementia training. ➤ Case managers can lead or support the implementation of many of the above recommendations. ➤ Give PLWD higher weighting in staff caseloads to enable more intensive support. |
| Value and document processes of decision making | <ul style="list-style-type: none"> ➤ Practice multidisciplinary, person-centered decision making. ➤ Document not only decisions made but also how (processes, people involved) and why (considered and influencing factors). |
| Design services to support multispecialty, shared care | <ul style="list-style-type: none"> ➤ Establish pathways or models for obtaining dementia specialist input into cancer care for PLWD (e.g., oncogeriatric clinics co-led by oncologists and geriatricians). ➤ Establish pathways or models for obtaining oncologist input into cancer managed in community care (e.g., suspected cancers not referred for investigation). |

Abbreviations: ID, identification; PLWD, people living with dementia.

Table 1 provides a two-level summary of actions for clinicians and providers, with further separate details on specific, pragmatic ways the wider suggested actions might be achieved. Table 1 can be used by practitioners and managers to help select, plan, and review over time locally required and feasible practice and service improvements. Many of the recommendations are widely applicable, implementable in the short-term, and low-cost, although inevitably some are site-specific, longer term initiatives or have greater resource costs. Concerning resource investment, we note that some of the recommendations are likely to also benefit people with mild cognitive impairment, characteristically similar comorbidities to dementia (e.g., autism, learning disabilities), and potentially patients with cancer in general (e.g., many dementia-friendly building design features).

Expanding the evidence base to inform optimal cancer care

There is a lack of clinical guidance and guidelines to support cancer-related decision making and care for PLWD at all stages of the cancer trajectory, including cancer screening, diagnostic investigations for suspected cancer, and cancer treatment. Some guidance for cancer clinicians who are caring for PLWD is slowly emerging but remains limited.¹¹¹⁻¹¹³ Clinical practice guidelines have traditionally focused on single diseases, which greatly limits their utility in patients with comorbidities, especially those with multiple serious illnesses, who require care that is person-centered rather than disease-focused.^{119,120} Moreover, clinical guidance

should be evidence-based, and there is a limited evidence base concerning cancer care for PLWD, especially the implications of dementia for cancer treatment risks and benefits. Historically, and still, older adults with comorbidities have been greatly underrepresented in, and PLWD have been largely excluded from, clinical trials evaluating the efficacy and safety of anticancer treatments.^{80,81} Thus much of the cancer trial evidence base cannot be assumed to be valid for older adults. Less knowledge and understanding of cancer treatment side effects and outcomes in older adults and PLWD greatly increase the complexity and uncertainty of cancer treatment decision making for this group. Therefore, there is a pressing need for cancer research to be more inclusive of PLWD, especially as newer and evolving targeted therapies and advances in supportive care offer potentially more tolerable side-effect profiles and thus potentially more scope for treating cancer in older adults and PLWD. Recent years have seen welcome calls for greater inclusion of older adults and PLWD in cancer trials and in research generally and the development of recommendations and resources to support this.^{81,121}

Future research recommendations

In addition to greater inclusion of PLWD in cancer research generally, there is also a need for more cancer research specifically focused on PLWD. We recommend the following priority areas for future research, based on the research to date and its gaps and shortcomings and what we consider to be targetable outcomes for PLWD.

TABLE 2 What people living with dementia and family carers want cancer clinicians to know about supporting people living with dementia

-
1. Dementia is not always obvious: you cannot assume you will easily recognize someone has dementia.
 2. People with dementia are individuals: experiences of living with dementia vary widely (e.g., depending on stage of dementia, social support).
 3. Never blame a person with dementia for not understanding something: you must learn about and practice effective ways of communicating.
 4. People with dementia need additional support: especially more time to understand and to do things and more patient, empathetic caregiving.
 5. Dementia *in and of itself* is not a good reason for decisions: it should not *determine* eligibility for cancer-related referrals, treatments, and care.
-
1. Elucidation of the barriers and enablers to earlier recognition of, and help-seeking for, potential cancer symptoms among PLWD and their carers: Are there feasible ways to reduce very delayed and emergency cancer presentations among PLWD?
 2. Larger scale, prospective examination of the reasons underpinning decision making across the cancer trajectory from the perspective of PLWD, family carers, and clinicians: To what extent are cancer-related decisions for PLWD (e.g., concerning referrals, planned treatment and dose adjustments, and supportive care, including pain management) influenced by potentially addressable sources of inequity in care access and provision?
 3. Assessment of associations between cancer-related decisions and care and patient-centered outcomes for PLWD and family carers: How do different cancer treatments and care (including targeted therapies with potentially better toxicity profiles) affect treatment complications and quality of life for PLWD, dementia-related symptoms and functioning, and carer burden and well-being?
 4. Analysis of routine cancer data sets examining longitudinal associations between cancer-related care and registry-based outcomes in PLWD: To what extent are cancer diagnostic routes and treatments predictive of health care use and survival outcomes among PLWD?
 5. Characterization of the *hidden group* of PLWD who have *suspected* cancer who are not referred for diagnostic investigations or treatment: What are the size and characteristics of this group, their cancer symptom management needs and outcomes, and their access to cancer-related information and support (e.g., from specialist clinicians, charities)?
 6. Implementation and evaluation of intervention strategies to improve cancer-related care and treatment for PLWD: What are the feasibility, beneficial effects, and cost effectiveness of making selected recommended changes to clinical practice and services (e.g., such as those listed in Table 1)?
 7. Development and evaluation of cancer decision-support aids for PLWD, family carers, and possibly clinicians: Can decision support improve the process and outcomes of decision making across the cancer trajectory for PLWD, carers, and clinicians (e.g., increase decision-making self-efficacy, reduce decisional conflict and regret)?
 8. Examination of different or adapted pathways or models of cancer care for PLWD: Could PLWD, particularly those not referred for cancer diagnosis or treatment, benefit from clearer or new cancer-related care pathways?
 9. Broaden the geographic locations of research on this comorbid patient group: To what extent are findings and recommendations based on geographically restricted data applicable in other countries with different health care systems, national cancer expenditures, and cultures?
 10. Explication of the inverse epidemiological relation between dementia and cancer and contributory underpinning biologic mechanisms: Can we capitalize on shared biologic etiological factors to inform new approaches to the prevention and treatment of both diseases?

CONCLUSION

Preexisting dementia complicates cancer care and increases the risk of poorer clinical and patient experience outcomes across the cancer trajectory. Coming years are likely to see cancer care for people with dementia become a bigger and more salient challenge because of population aging and as medical advancements (e.g., single blood test multicancer screening, targeted therapies with lower toxicity) potentially improve the feasibility and tolerability of cancer detection and treatment options. We make comprehensive recommendations for clinical practice and future research to help clinicians and providers deliver best and equitable cancer care for people with dementia and their families.

AUTHOR CONTRIBUTIONS

Conceptualization & project administration: Laura Ashley. Data curation: Laura Ashley, Mollie Price. Writing – sections of original draft: Laura Ashley, Claire Surr, Rachael Kelley, Mollie Price, Dana E. Giza, Charlene Martin, Jane B. Hopkinson, Katie Spencer, Lynda Wyld. Writing – review & editing: Laura Ashley, Claire Surr, Rachael Kelley, Alys Wyn Griffiths, Nicole R. Fowler, Dana E. Giza, Richard D. Neal, Charlene Martin, Jane B. Hopkinson, Anita O'Donovan, William Dale, Bogda Koczwara, Katie Spencer, Lynda Wyld.

ACKNOWLEDGMENTS

The authors acknowledge patient and carer representatives Jill Bateson, Steve Bateson, Ann Lomax, Ananga Moonesinghe, Joanna Moonesinghe, and Jill O'Connell; and Macmillan Dementia Nurse Consultant Lorraine Burgess (The Christie Cancer Centre, UK), who contributed to the clinical practice recommendations.

CONFLICTS OF INTEREST

Laura Ashley reports grants/contracts from Abbeyfield Research Foundation, the National Institute for Health Research, and the Alzheimer's Society outside the submitted work. Claire Surr reports grants/contracts from Macmillan Cancer Support, the Alzheimer's Society, the National Institute for Health Research, and the Abbeyfield Research Foundation outside the submitted work. Rachael Kelley reports personal fees from the National Institute for Health Research outside the submitted work. Nicole R. Fowler reports grants from the National Institute on Aging and personal fees from Biogen outside the submitted work. Jane B. Hopkinson reports grants/contracts from the National Institute for Health Research and personal fees from the Velindre University National Health Service Trust outside the submitted work. The remaining authors made no disclosures.

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How to cite this article: Ashley L, Surr C, Kelley R, et al. Cancer care for people with dementia: literature overview and recommendations for practice and research. *CA Cancer J Clin.* 2022;1-19. doi:10.3322/caac.21767