This is a repository copy of *How do people living with dementia make decisions about their cancer care?: A meta-ethnographic systematic review*.

White Rose Research Online URL for this paper:
https://eprints.whiterose.ac.uk/id/eprint/234854/

Version: Accepted Version

Article:

Quinn, G.-A., Griffiths, A.W. orcid.org/0000-0001-9388-9168 and Butchard, S. (2025) How do people living with dementia make decisions about their cancer care?: A meta-ethnographic systematic review. Aging & Mental Health. ISSN: 1360-7863

https://doi.org/10.1080/13607863.2025.2596770

© 2025 The Authors. Except as otherwise noted, this author-accepted version of a journal article published in Aging & Mental Health is made available via the University of Sheffield Research Publications and Copyright Policy under the terms of the Creative Commons Attribution 4.0 International License (CC-BY 4.0), which permits unrestricted use, distribution and reproduction in any medium, provided the original work is properly cited. To view a copy of this licence, visit http://creativecommons.org/licenses/by/4.0/

Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here: https://creativecommons.org/licenses/

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

How do people living with dementia make decisions about their cancer care?: A meta-ethnographic systematic review

Georgie-Anne Quinn[1,2], Alys Wyn Griffiths[3*], Sarah Butchard[1,2]

[1]Department of Primary Care and Mental Health, University of Liverpool
[2]Mersey Care NHS Trust
[3]School of Medicine and Population Health, University of Sheffield

*Corresponding author: Alys Wyn Griffiths, Sheffield Institute for Translational Neuroscience, The University of Sheffield, 385a Glossop Rd, Broomhall, Sheffield S10 2HQ. email: alys.griffiths@sheffield.ac.uk

Abstract

Objective: Living with comorbid dementia and cancer is linked with communication and decision-making challenges across the cancer care pathway and poor health outcomes. Oncology services may not be equipped to provide the holistic care required for individuals with dementia. This systematic review aimed to explore the experiences of people living with comorbid dementia and cancer (PLWCDC) when making decisions about their cancer care.

Methods: Six databases were searched using terms pertaining to dementia, cancer, decision-making and qualitative experiences. Studies that qualitatively explored cancer care decision-making experiences from the perspective of people living with comorbid dementia and cancer were included.

Results: The search yielded 3424 unique records, with ten articles meeting eligibility criteria. Data was synthesised using meta-ethnography, producing four higher-order themes: ‘challenges of processing cancer-related information’, ‘issues of inaccessible information and uninformed consent’, ‘the role of relatives’, and ‘the importance of individualised and consistent care’.

Conclusions: Decision-making experiences were complex and multi-layered. Dementia negatively influenced understanding and retention of information related to cancer diagnosis and care. Lack of consistency in staffing and the complexity of information provided were overwhelming. PLWCDC were vulnerable to not being meaningfully involved in their cancer-care decisions, due to the factors identified. Individualised and consistent care is required to improve outcomes for this population.

Key words: cognitive impairment; comorbidities; decision-making; treatment options

Over 50 million people live with dementia globally, with a projected increase to 152 million by 2050[1]. The prevalence of dementia increases significantly as people age[2], with heightened risk after individuals turn 65[3]. Indeed, in the UK, 7.1% of the population aged over 65 form a substantial proportion of the 850,000 living with this condition[3,4]. People with dementia often depend on caregivers for support with activities of daily living, particularly as their symptoms around memory loss develop[5]. There are approximately 540,000 unpaid caregivers for people with dementia in England, with one in three people likely to care for someone with dementia in their lifetime[3]. Furthermore, dementia prevalence is likely to be underreported as people with undiagnosed dementia, their caregivers, and family physicians, are reluctant to raise and discuss dementia symptoms[6] due to issues surrounding stigma and lack of knowledge[7]. With an ageing population and increasing life-expectancies, dementia is among the most important health and care issues globally[3].

The global incidence of cancer is increasing, with people aged 75 and over experiencing over a third of new cancer cases every year[8,9]. By 2050, 6.9 million new cancer cases are expected to be diagnosed in adults aged 80 or over worldwide[9]. The negative psychological impact of cancer is well documented[10]. Earlier diagnosis and improved treatments have yielded extended survival rates for cancer patients. Consequently, there are reports of increasing long-term side effects post-treatment[11], such as cognitive problems often referred to as “chemobrain”[12].

Due to the high prevalence of cancer and dementia as distinct conditions in older people, many people in England live with comorbid cancer and dementia. Collinson and colleagues[13] identified that of people aged 50 and over with cancer, 3.1% also had dementia, whilst 7.3% of people with dementia also had cancer. Of people with dementia and/or cancer aged 75 and over, 7.5% (1 in 13 people) had both conditions[13]. As the population continues to age, more people are likely to experience comorbid dementia and cancer[14]. However, these figures may be underestimated due to the impact of dementia and increasing inequalities.

This comorbidity creates additional challenges for people living with comorbid dementia and cancer (PLWCDC), their caregivers, and health care professionals. Due to memory or communication difficulties, assessing their pain and discomfort, ability to follow medical regimes, and capacity to provide informed consent to treatment, can be challenging[15,16,17]. Certain types of dementia can also directly impair decision-making[18].

Noticing and understanding cancer-related symptoms can be challenging for people with dementia[5] and they are likely to underreport cancer symptoms, leading to delayed medical attention and less hospital admittance[15,19]. Advanced dementia was described as the main cause of failure to refer patients with suspected cancer for further investigation[20].

NHS services for physical health problems, such as cancer, may not be equipped to provide the holistic care required for people with dementia[21]. Comorbid dementia creates many challenges across the cancer care pathway, including communication, environment, and cancer care decision-making[22]. Compared to people without dementia, people with dementia are diagnosed later[23,24], receive less or no treatment[25], experience more complications and have poorer survival rates[26].

Due to high prevalence of comorbidities for people with dementia, cancer symptoms risk being underrecognised[13]. Furthermore, the focus of dementia-related care may lead to attention being dominated by this, or cancer symptoms being attributed to dementia, known as diagnostic overshadowing[5]. Clinicians, caregivers, and patients may prefer less aggressive care and prioritise quality of life (QoL) over life expectancy[25]. People with dementia are 52% less likely to have surgical resection, 41% less likely to have radiation, 39% less likely to have chemotherapy and over twice as likely to receive no treatment, than those without dementia[24]. Clinicians are less likely to offer PLWCDC aggressive therapy due to concerns around informed consent[25], practical difficulties[26,27] discomfort[28], and clinicians having vague, conflicting, or limited guidance[29]. This highlights the uncertainty for this population in determining appropriate treatment, decision-making practices, and inequitable access to cancer treatment.

PLWCDC and their caregivers recognised having varied involvement in the decision-making process. PLWCDC tended to be less involved in cancer treatment decision-making, relying on caregivers to navigate decision-making and treatment information[30] through supporting communication regarding symptoms and treatment options with clinicians[25]. However, treatment preferences sometimes differed between PLWCDC and their caregivers, which causes emotional turmoil and exhaustion[21].

Witham and colleagues[32] explored the narrative experiences of caregivers for PLWCDC, highlighting how complex decision-making for PLWCDC could be within systems. Due to limited health professional involvement, caregivers attempted to convey complex cancer treatment information and negotiate options with PLWD. Caregivers described a gradual transition from supported decision-making to substitute decision-making. Whilst the Mental Capacity Act (2005)[33] for England and Wales allows for decision-making on behalf of adults lacking capacity, in practice this legal framework is inconsistently applied. Issues of confidentiality, data protection, bureaucracy, and rigidity, also contributed to compromised carers' decision-making abilities on behalf of PLWCDC.

Two recent reviews have explored the experience of living with comorbid cancer and dementia. Caba and colleagues[25] found that people living with dementia were less likely to receive curative treatment following a cancer diagnosis, and had a higher mortality rate than those with cancer alone. Whilst Caba and colleagues[25] reviewed many studies, most were quantitative and focused on caregiver perspectives, lacking lived decision-making experiences of PLWCDC. Halpin and colleagues[33] identified that there were challenges in ensuring patients were included in decision-making, and concluded that communication between PLWCDC, their caregivers and oncology staff is integral to meaningful treatment decisions and outcomes. Neither of these reviews specifically focused on the perspective of the person living with both conditions, and their experiences.

Aims

To date, qualitative research exploring the cancer care decision-making (i.e. making decisions around whether or not to seek cancer assessment and diagnosis, receive treatment, and stop treatment) experiences of PLWCDC from their own perspective has not been systematically reviewed, with assessment of research quality. Within this review, we sought to understand:

- What are the experiences of people living with dementia and cancer in relation to making decisions about their cancer care?
- What is the impact of dementia on the experiences of cancer care decision-making for PLWCDC?
- What are the implications of these experiences for clinical practice?

Methods

This review was conducted in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)[34]. The protocol is registered with the PROSPERO international prospective register of systematic reviews {redacted for review}.

Search strategy

The following search terms were used: dementia OR Alzheimer* OR “cognitive impairment” OR “memory problem*” AND cancer* OR neoplas* AND decision-making OR decision* OR “decision making” OR choice* OR choos* OR treatment* AND qualitative OR phenomenological OR experience* OR "grounded theory" OR observ* OR “focus group*” OR interview* OR ethnograph*.

PsycINFO, PubMed, AMED, CINAHL, MEDLINE and Web of Science databases were searched in November 2023 and May 2024 (where no further papers were identified). Forward and backward searching was conducted but yielded no additional papers.

Inclusion and exclusion criteria

Inclusion criteria: Qualitative studies and mixed-methods studies including any qualitative element were included. No time restrictions were placed on searches. Whilst we included studies which included PLWCDC along with others, such as caregivers and staff, only data pertaining to PLWCDC was extracted for analysis. Included data consisted of interview quotes from PLWCDC, researcher observational field notes of PLWCDC, and descriptive case notes regarding PLWCDC’s experiences of cancer treatment decision-making.

Exclusion criteria: Quantitative-only studies, studies not reported in English or for which full text was unavailable, study protocols, conference papers, and unpublished data, were excluded. Only studies that directly explored the experiences of PLWCDC were included. Papers which did not contain either direct qualitative data from PLWCDC or researcher field notes regarding PLWCDC were excluded, e.g., papers containing caregiver or staff perspectives only. For a review of the perspective of carers and staff please see Martin and colleagues review[35].

Data extraction

Returned records were exported into EndNote and duplicates removed. Studies were exported to Rayyan for title and abstract screening. Title and abstract screening were completed by one reviewer, with 10% of records double-screened. At the full-text screening stage, two reviewers independently screened all records against the eligibility criteria. Disagreements were managed through discussion, and if appropriate involved a third reviewer. Reasons for inclusion and exclusion were discussed between reviewers. Data were extracted by the lead reviewer into a bespoke data extraction tool, designed and agreed by all reviewers. This collated data characteristics, including author, year, aim, setting, sample, demographics, method, and analysis, pertaining to the experiences of cancer-care decision-making of PLWCDC. Study selection was recorded using a PRISMA flow diagram (see Figure 1).

Quality appraisal

The Critical Appraisal Skills Programme (CASP)[36] checklist for qualitative studies was used to examine the risk of bias and methodological quality of included studies. Butler and colleagues'[37] scoring system was used to translate scores into quality categories. Two reviewers independently completed the CASP checklist for each research paper. These were then systematically compared with any differences discussed and resolved. See Table 1 for overall CASP quality ratings.

Data synthesis

Qualitative data about decision-making experiences from the perspective of PLWCDC was synthesised using the seven steps of meta-ethnography[38,39]. Meta-ethnography was employed due to the qualitative nature of the data and flexibility for reviewers to reinterpret concepts based on primary data, developing higher order themes38,39. Synthesis of the relationships between studies was conducted. Conceptual data (e.g. themes, concepts or metaphors) created by the primary study were reinterpreted, comparing the meaning of concepts and themes, whilst considering participant quotes from the primary data. An overview of sample demographic characteristics is included for each study where available.

Synthesising a variety of data types (e.g., interview quotes, participant observations, case notes) may risk data being influenced by researcher or clinician perspectives. Careful selection of data was therefore undertaken by understanding sources of bias from case notes and observations. The advantages of synthesising a variety of data types are significant to ensure this review captured the broad spectrum of PLWD including those who are unable to communicate verbally or are at later stages of dementia. Creative research methods must be employed to support meaningful research participation of PLWD to amplify voices that are historically marginalised[40].

Results

Ten papers were included in the meta-ethnographic synthesis. CASP scores indicated that papers were of ‘moderate’ (n=5) or ‘high’ (n=5) quality[36], reflecting an overall robustness of included research. This suggests that individual study findings are likely to be credible and representative of decision-making experiences for PLWCDC. Although methodological approaches appeared appropriate given the aims, reasoning was not often sufficiently addressed. Furthermore, several papers did not explicitly consider the relationship between researcher and participants. This is particularly significant for qualitative approaches where the researchers’ interpretation is often defined by their unique context. As the reviewed papers were written by four research groups, it may be that data interpretations are viewed within a similar frame of reference, potentially explaining the alignment of themes.

Extracted study characteristics (see Table 2) provided context for interpreting results. Despite no limitations placed on study location, all participants were recruited from oncology services within the UK. In addition to the perspectives of PLWCDC, all papers included caregiver and staff perspectives. However, their data was excluded from this review alongside any data not relevant to decision-making experiences. Demographics including participant gender, age, ethnicity, dementia type, and cancer type were inconsistently reported and could not be synthesised.

All ten studies used semi-structured interviews. Eight studies combined these with focused ethnographic observations, and informal conversations, and six of these studies additionally incorporated medical note/record reviews. Across ethnographic observations, researchers incorporated both focused ethnography of specific areas of care, such as pre-treatment consultations and treatment appointments, with general observations of the environment and staff-patient observations. Less informally was provided about general observations, although all eight studies mentioned that these were conducted. Researchers analysed data using ethnographically-informed thematic analysis (n=4), focused ethnography (n=3), a combination of thematic analysis and framework matrices (n=2), and framework analysis (n=1). In some cases, insufficient information was provided to fully establish and understand the analysis process followed by researchers, for example whether coding was conducted inductively or deductively. However, most studies commented that data collection and analysis occurred concurrently.

Collectively, these ten papers drew upon data from four participant samples: dataset one[41-45], dataset two[46], dataset three[47-48] and dataset four[49-50]. Thirty-nine PLWCDC were included in total.

To consider the relationship between concepts across the studies, themes covering shared concepts were reviewed and reduced into relevant categories. These included first-order (participant's views) and second-order constructs (authors' interpretations). A descriptive label was assigned to each newly formed category. Each concept within each paper was systematically compared with others to explore commonalities or disparities (see Table 3 for translations).

Synthesising translations

Reciprocal translations were conducted with similarities and differences across themes summarised into third-order constructs (reviewers' interpretations). Four main concepts were generated (see Table 3). The relationship between concepts were considered, examined, and interpreted by reviewers.

Challenges of processing cancer-related information.

All studies described challenges PLWCDC faced in processing and retaining cancer care-related information. PLWCDC felt confused and uninformed, struggling to understand and retain information about their cancer diagnosis and treatment[41,49]. Griffiths and colleagues[42] noted that PLWCDC's awareness and understanding regarding their cancer diagnosis could fluctuate, which at times reduced worry for PLWCDC but at other times created more uncertainty and anxiety about what was wrong.

McWilliams and colleagues[50] recognised challenges PLWCDC faced in reaching a cancer diagnosis. Biopsies caused pain and distress in intimate clinical investigations, clearly remembered by PLWCDC[50]. Whilst necessary, the meaning of clinical investigative procedures was not always understood as helpful and PLWCDC felt assaulted and hurt during biopsies, asking professionals to stop[50]. Some PLWCDC were unsure whether to have a biopsy[49] with some choosing to refuse this completely[48] and others not wanting to return to hospital following a biopsy appointment, remembering the pain accompanying previous experiences[50].

Staff gave PLWCDC large amounts of information at once, lacking understanding and individualised care[41,50]. PLWCDC often did not seek clarification where they felt they did not have all the information[41] supporting the suggestion that PLWCDC may conceal or downplay their memory problems during cancer consultations[46]. Some PLWCDC became angry when caregivers disclosed memory problems to professionals[46].

Some PLWCDC found remembering medical information and following treatment-related instructions difficult[42,45,46,50]. During healthcare consultations, information was often requested such as medical history, cancer symptoms, previous therapies, and treatment side effects[46], however issues including marked memory loss (e.g., not being able to recall past appointments or surgical treatments[42,50]) reduced the success of these consultations[46], Whilst communication was an issue for some PLWCDC, recontextualised words and experiences could enable PLWCDC to express and make sense of them[49]. However, professional and caregiver ability to understand these communications was unclear. Furthermore, additional comorbidities (e.g., sight problems) added complexity to decision-making and associated healthcare appointments[45].

Issues of inaccessible information and uninformed consent.

Information delivery influenced decision-making abilities of PLWCDC[42,43,50]. Excessive quantities of irrelevant cancer treatment-related information were presented by professionals[42,43,50], overwhelming PLWCDC. Consequently, PLWCDC reflected that information was sometimes 'going over' their heads, resulting in them delaying decision-making or looking to relatives to steer or make decisions[42]. Some PLWCDC described spoken information as helpful but felt unable to engage with reading materials[50]. Treatment-related information offered in multiple formats, with adequate time to ensure understanding was helpful for PLWCDC[50], respecting that they may change their mind over time[42]. However, listening and understanding capacity could change and PLWCDC could be unable to recall information a few minutes later[50]. This emphasises caregivers' centrality through their longitudinal knowledge of, and effective communicative approaches for PLWCDC[50].

Several papers described the importance of 'balance' and 'evaluation' in treatment options[42,48,50]. PLWCDC felt confused, uninformed, and distressed during their cancer care, with difficulties in information retention and communication, leading Farrington and colleagues[48] to wonder whether PLWCDC could always engage in decision-making based on accurate information, mutual understanding, and how the right to treatment could be balanced with safety. Multiple researchers acknowledged the lack of decision-making agency provided to PLWCDC[42,48,49] who, at times, were not actively involved in decision-making processes, not given options, and left with unanswered questions[49].

Griffiths and colleagues[42] described how consideration of the 'bigger picture' was sometimes used to evaluate treatment options. PLWCDC noticed clinicians feeling ‘scared’ by dementia-related concerns, including the potential impacts of treatment, e.g., reluctance to give anaesthetic due to concerns about reactions[42]. Clinicians' concerns, therefore, pose an additional emotional burden for PLWCDC to tolerate. However, such concern could generate further specialist input to inform decision-making[42].

For other PLWCDC, cancer treatment risks did not outweigh the risk of death, cancer treatment options were immediate and clear-cut[50]. However, there could still be ongoing or lasting impacts of cancer-related decisions even following cancer treatment. McWilliams and colleagues[50] described how PLWCDC continued to make significant life adjustments following the transition from the cancer centre, such as moving into a nursing home or considering further cancer investigations. For some PLWCDC, the end of cancer treatment allowed for reflection highlighting the complexity of managing multiple diseases[50]. This may be due to underestimation or limited communication about the potential severity of treatment side effects[42,50].

The role of relatives.

Relatives’ views were influential in cancer care decision-making[42,46], even when perspectives regarding the ‘right’ decision did not align with those of PLWCDC[42]. This suggests relatives became more dominant than PLWCDC in decision-making. However, many papers described family networks playing an important role[41,44,46,49,50]. PLWCDC felt dependent upon their caregivers for cognitive and practical support with cancer management[44,46] including accessing, navigating, and undergoing treatment[41,44]. Relatives monitored symptoms, organised and attended appointments, provided emotional support and reassurance, and retained, relayed, and explained cancer treatment information to PLWCDC[41,44].

When accompanied by caregivers who were able to ‘fill the gaps’ in consultations that were created by dementia, PLWCDC were more likely to attend[44] and have ‘successful’ consultations[46]. PLWCDC felt involving ‘supporters’ in consultations should be standard, providing ‘back-up’ to repeat spoken information and reduce the risk of forgetting or not asking the ‘correct’ questions[49,50]. PLWCDC often turned to their caregivers during interviews when conveying such events for additional information or validation of descriptions being accurate. This highlights the importance of caregivers in reassuring, conveying information to, and including PLWCDC in their cancer-care decision-making, but leaves the question of how PLWCDC living alone experience and navigate this[50].

The importance of individualised and consistent care.

Individualised, person-centred, consistent care appeared incongruent with cancer care systems[41,43,47-50]. As PLWCDC were reliant on healthcare systems to manage their cancer care, they were forced to adapt to services not adapted for PLWCDC. This saw them ceding control of their cancer care to others[48]. This is pertinent when cancer care experiences of PLWCDC were shaped by the readiness of services to accommodate their dementia[47]. As services were not 'dementia-friendly' as standard, departments relied on advanced notice of PLWD attending to adjust, however, the extent of these efforts were variable[45,48].

Good communication was central to person-centred care. PLWCDC felt upset and withdrawn whilst they were present in consultations as they were ignored, spoken over, and about[43]. Furthermore, clinicians' communications did not always meet the needs of PLWCDC, e.g., asking complex questions, delivering excessive information quickly, or giving unclear instructions. This was perpetuated by use of complex medical language, leading to issues around dignity and inappropriate outcomes where information was misunderstood[43].

The unique needs of PLWCDC must be balanced with requirements of complex health systems[48]. PLWCDC required individualised, flexible care to understand and undergo cancer treatment[41]. This included the recognition and response to individual needs of PLWCDC and relatives, tailored communication including simplified and visual approaches, and continuity in staff, routines, and environments[41]. Courtier and colleagues[46] highlighted examples of clinic staff using different techniques to aid recall for PLWCDC, offering to practice self-care activities together, or seeking information from other sources when PLWCDC could not recall information.

Griffiths and colleagues[43] described how person-centred care involved knowing the person and providing flexible support with communication tailored to individual needs. For example, recording how dementia may impact cancer care on medical notes enhanced person-centred support and reduced the likelihood of distress[43]. Flexible and creative approaches to support PLWCDC during treatment, such as continuing conversations over speakers during radiotherapy, made PLWCDC feel calmer[43]. Proactively recognising needs, such as offering familiarisation visits ahead of treatment, facilitating family involvement, sharing education with families, or booking longer appointments, was important. Allowing additional time when communicating clinically relevant information whilst being mindful of information retention positively impacted patient understanding and decision-making[49]. However, such adaptations are at odds with delivering 'efficient' services[43].

High rates of staff turnover contributed to confusion[49,50], impersonal approaches, and insensitive diagnosis disclosure[43]. Having multiple staff members involved in the cancer care of PLWCDC created an accumulated burden for PLWCDC and caregivers to manage[43,47]. PLWCDC found continuity important, commenting on familiar corridors, treatment rooms and staff members as positive aspects of their experiences[43,50]. PLWCDC, therefore, requested consistency amongst hospital staff where possible[43]. The familiarity and personal knowledge from specific staff (e.g., named cancer nurse specialist) allowed for one point of contact for questions between appointments who would better organise joined-up care[43]. Developing trusting relationships increased PLWCDC's confidence in asking questions and indicating uncertainties.

Discussion

This meta-ethnographic review considered the perspective of PLWCDC in decision-making around their own care and provided an in-depth higher order interpretation of the existing literature. Only ten qualitative studies providing first-hand perspectives of PLWCDC were identified, which focused on four main concepts or themes.

The first theme of the review centres around the impact of dementia on processing cancer-care information. This set the context from which PLWCDC, professionals, and caregivers managed decision-making. PLWCDC struggled to understand, retain, and communicate cancer-related information. Cancer-related procedures caused confusion, pain, and distress for PLWCDC. This distress was perpetuated by inaccessible information, creating issues of engagement and uninformed consent in decision-making. When understanding of information was confirmed by PLWCDC in consultations, this could be forgotten shortly after. These findings are in keeping with evidence of memory and communication difficulties leading to challenges in assessing PLWCDC's pain and discomfort, ability to follow medical regimes, capacity to evaluate risks and benefits between different treatment options and provide informed consent[15-17].

Some PLWCDC associated hospital appointments with negative experiences and were less likely to re-attend. These findings support research highlighting the reduced likelihood of PLWCDC undergoing cancer treatment[24,25], emphasising inequitable access to cancer treatment. Collectively, this may contribute to poorer outcomes for PLWCDC surrounding timely diagnosis, treatment, and survival than people with cancer without dementia[26].

Whilst Caba and colleagues[25] described a preference from PLWCDC, caregivers, and clinicians for less aggressive care and prioritisation of QoL over life expectancy for PLWCDC, perspectives of PLWCDC did not correspond to this across the reviewed papers. However, sample characteristics may have influenced such outcomes. Many papers (e.g., dataset one) only recruited PLWCDC undergoing treatment, and not those who opted not to receive any treatment. Decision-making experiences of PLWCDC not receiving treatment or who have chosen not to have further treatment are currently not well-understood.

The lack of decision-making agency for PLWCDC throughout their cancer care was acknowledged, noting how they were left with unanswered questions, not given all options, and influenced by relatives' opinions. This aligns with evidence that PLWCDC are less involved in cancer treatment decision-making, relying on caregivers to navigate cancer decision-making and treatment information[30]. PLWCDC described caregivers as a source of support to communicate with clinicians, access, navigate and attend appointments, collect, retain, and relay health information, request additional treatment option information, and offer emotional support[25]. Due to the importance of caregivers, some PLWCDC felt unable to attend oncology appointments unaccompanied, and benefitted where flexibility around family members attending and supporting them throughout was offered.

Throughout interviews and clinical consultations, PLWCDC often turned to caregivers for additional information, clarification, reassurance, or to speak or make decisions on their behalf, reiterating caregivers' central role. Wolfe and colleagues[51] highlighted the importance of relationships for PLWD in getting their needs met. However, past relational experiences of PLWCDC may influence how they navigate relationships and their beliefs of autonomy and coping. Whilst entrusting others with decision-making suggests greater acceptance of living with dementia, reliance on others can create anxiety. As data was often collected from PLWCDC alongside their caregivers or professionals, it may not reflect PLWCDC's true experiences. However, the presence of caregivers may have been required for PLWCDC to feel appropriately supported to communicate, and due to concerns around ability and capacity to provide informed consent[52].

The importance of individualised and consistent cancer care for PLWCDC was widely reported. However, this was incongruent with 'efficient' healthcare systems which PLWCDC relied upon for cancer care. The MCA 2005 is inconsistently applied for adults lacking capacity[31], highlighting issues of power for PLWCDC. The MCA stipulates people must be given all reasonable support to make and communicate their decision before being considered to lack capacity. However, cancer professionals provided large amounts of information quickly, aligning with Kitwood's[53] malignant social psychological construct of 'outpacing', undermining the personhood and psychological wellbeing of PLWD. The evidence in this review of professionals' failing to adapt their communication to meet the needs of PLWCDC, inconsistencies in staffing, and ever-changing environments is far from reasonable help to empower PLWCDC in decision-making and violates the Mental Capacity Act[32].

Professionals undermined the human rights of PLWCDC. 'FREIDA' principles underpinning human rights[54] of fairness, respect, equality, identity, dignity, and autonomy were disregarded when PLWCDC were ignored, and spoken over and about in consultations. Accounts of PLWCDC consistently evidence their lack of power in comparison to caregivers whose voices were more often heard and understood; and professionals, who possessed knowledge and abilities to finalise decisions. Current practice raises significant issues diminishing the basic legal rights and decision-making power of PLWCDC.

Limitations

Whilst ten papers were reviewed, these were based on four datasets. This reflects the limited research in this area, particularly research that captures perspectives of PLWCDC. Methods that promoted the inclusion of PLWCDC were often used, such as ethnographic observations and informal conversations, however, at times the voice of PLWCDC was not present within results. Further research is required to develop insights into the unique decision-making experiences of PLWCDC. Inconsistencies in reporting were identified. Developing understanding of each sample was challenging due to poor reporting of demographic information, particularly around dementia diagnosis. This makes it unclear whether certain groups were differently represented or whether there are any groups whose experiences have not yet been considered. All papers incorporated views of professionals, caregivers and PLWCDC, some interviewing dyads or groups, reducing clarity around who contributed quotes and adding complexity around whether issues were raised by PLWCDC or other participants. Furthermore, some studies contained limited numbers of PLWCDC and reported either no or limited quotes from PLWCDC within their results sections. Reviewers had to rely on descriptive wording without primary participant data to evidence this at times, meaning data was challenging to integrate into the synthesis.

The review was conducted by three female reviewers, whose positionality aligns with prioritising person-centred care delivery and inclusion of people with dementia in their own care wherever possible. Each research reviewer’s feelings, assumptions and opinions were regularly discussed in supervision. However, we acknowledge that this may have influenced the review through less inclusion of perspectives that do not align with our positionality; efforts were made to avoid this.

Recommendations for future research

Increasing prevalence of both cancer and dementia[13] highlights the importance of better understanding cancer care decision-making experiences of PLWD to inform future practice. Limited research in this area speaks to the importance of further rich qualitative data focused on PLWCDC experiences. Whilst caregivers were central in enabling PLWCDC to navigate their cancer care and make decisions, it was unclear how PLWCDC living alone or without caregivers navigate this. Further research into their unique decision-making experiences would be a helpful addition to the research base. Concerns have also been raised around the lack of diversity within samples, particularly around ethnicity. Future research should focus on recruiting samples with more diverse experiences, report demographic information clearly around both cancer and dementia diagnoses, and clarify the contribution of PLWD to the research.

Clinical implications

The multi-layered impact of dementia on cancer care decision-making experiences for PLWCDC requires a multi-level approach to combat these issues. Whilst more specialised healthcare is required for PLWD due to the impact of dementia[14], NHS services for physical health problems including cancer, are not equipped to provide the holistic care required[21] due to communication, treatment decision-making, environment, and time-related issues[55]. Nonetheless, issues of HRs cannot be compromised. Ashley and colleagues[39] outlined clinical recommendations to improve cancer care for PLWCDC, conducive to informed decision-making. Further clinical implications are considered below based on the research synthesised in the present review.

PLWCDC are likely to defer decision-making to others or make decisions based on unclear information. This may contribute to poorer outcomes for PLWCDC[25] and emphasises the importance of dementia training for professionals across oncology services, particularly on areas of low confidence and knowledge, such as communication strategies, and assessment of decision-making capacity[40]. Specialised CDC training reflecting on power, HRs, person-centred care, treatment adaptations, and communication is necessary to empower PLWCDC to be active agents in their cancer decision-making. Identifying and offering advanced training to create dementia specialists within oncology services could support wider teams to embed dementia friendly approaches across the service[39].

PLWCDC and their families sometimes minimised the extent of dementia symptoms or attempted to conceal them. This meant professionals risked being uninformed about the cognitive abilities of PLWCDC. Memory problems should be asked about during appointments and medical notes must record dementia and associated needs for PLWD[39]. Balancing inclusion of carers and PLWCDC perspectives in decision-making was challenging for professionals. Whilst caregivers were helpful in supporting PLWCDC, they could also dominate decision-making, diminishing autonomy and rights of PLWCDC. Facilitating family involvement (e.g., being present during treatment) and sharing education with caregivers is important[39]. However, the additional emotional burden of this decision-making should be acknowledged[40]. Navigating conversations with PLWCDC and caregivers regarding their involvement whilst advocating for collective input may help to establish expectations and empower PLWCDC.

PLWCDC reported feeling overwhelmed, uncertain, worried, upset, withdrawn, stripped of their dignity, and emotionally burdened. Clinicians should focus on ensuring understanding by providing accessible written summaries of key information and discussions using visuals, terms used by PLWD, and short simple bullet points[39]. Increased prevalence of sight impairments for older adults mean alternative formats may be required, such as larger or different coloured fonts or paper, and voice recordings. PLWCDC and their caregivers should be signposted to additional support where required (e.g., psychological, peer) and offered follow-up care. Professionals should book longer appointments at a convenient time for PLWD, taking more time to communicate clinically relevant information to assist information understanding, retention, and decision-making experiences[40].

Dementia created difficulties for individuals when staff, routes and environments are changed. PLWCDC would benefit from consistency amongst hospital staff to have familiarity, personal knowledge, and a single point of contact to liaise with other staff and better organise joined up care. This will help develop trusting relationships and ultimately increase confidence for PLWCDC to ask questions, indicate uncertainties, and express decision-making preferences. Consistent consultation and treatment rooms should also be provided, with pre-treatment familiarisation visits and leaflets with pictures to show the department and equipment[39,43].

Conclusions

This is the first systematic review to explore qualitative cancer-care decision-making experiences from the perspectives of PLWCDC. Dementia symptoms can compromise the understanding and retention of cancer-related information making cancer care decision-making complex for PLWCDC and increasing demand on caregivers. Whilst person-centred, consistent care is required to support PLWCDC's decision-making, stretched and inflexible healthcare systems are not conducive to this and deny PLWCDC their basic rights. PLWCDC are disempowered from being involved in decision-making, whilst depending on others to navigate cancer care. Further research is required in this area with diverse samples. There are several straightforward and easy to implement implications for practice. Consistency in staff, locations of appointments and timing of appointments can support involvement of PLWCDC in decision-making5. Improved understanding amongst professionals and more accessible environments will also improve the quality of care delivered to PLWCDC. These improvements will lead to PLWCDC being better informed and effectively supported to make decisions about their own cancer care.

Conflicts of interest: The authors have no conflicts of interest to declare.

Funding: There is no funding associated with this work.

References

1. Nichols E, Steinmetz JD, Vollset SE, Fukutaki K, Chalek J, Abd-Allah F, Abdoli A, Abualhasan A, Abu-Gharbieh E, Akram TT, Al Hamad H. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. The Lancet Public Health. 2022 Feb 1;7(2):e105-25.

2. Prince M, Wimo A, Guerchet M, Ali GC, Wu YT, Prina M. World Alzheimer Report 2015. The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends. Alzheimer's Disease International.

3. NHS England. *Dementia*. 2024 https://www.england.nhs.uk/mental-health/dementia/

4. Wittenberg R, Hu B, Barraza-Araiza L, Rehill A. Projections of older people living with dementia and costs of dementia care in the United Kingdom, 2019–2040. London: Care Policy and Evaluation Centre, London School of Economics and Political Science. 2019 Nov;79.

5. Ashley L, Surr C, Kelley R, Price M, Griffiths AW, Fowler NR, Giza DE, Neal RD, Martin C, Hopkinson JB, O'Donovan A. Cancer care for people with dementia: Literature overview and recommendations for practice and research. CA: A Cancer Journal for Clinicians. 2023 May;73(3):320-38.

6. Mansfield E, Noble N, Sanson-Fisher R, Mazza D, Bryant J. Primary care physicians' perceived barriers to optimal dementia care: a systematic review. The Gerontologist. 2019 Nov 16;59(6):e697-708.

7. Parker M, Barlow S, Hoe J, Aitken L. Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. International Psychogeriatrics. 2020 May;32(5):611-34.

8. Cancer Research UK. *Cancer Incidence by Age Statistics*. 2021. www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/age#heading-Zero

9. Pilleron S, Soto-Perez-de-Celis E, Vignat J, Ferlay J, Soerjomataram I, Bray F, Sarfati D. Estimated global cancer incidence in the oldest adults in 2018 and projections to 2050. International Journal of Cancer. 2021 Feb 1;148(3):601-8.

10. NICE. *Improving Supportive and Palliative Care for Adults with Cancer: The Manual*. 2004. https://www.nice.org.uk/guidance/csg4

11. van der Willik KD, Schagen SB, Ikram MA. Cancer and dementia: Two sides of the same coin?. European Journal of Clinical Investigation. 2018 Nov;48(11):e13019.

12. Ahles TA, Root JC, Ryan EL. Cancer-and cancer treatment–associated cognitive change: an update on the state of the science. Journal of Clinical Oncology. 2012 Oct 20;30(30):3675-86.

13. Collinson M, Mason E, Kelley R, Griffiths A, Ashley L, Henry A, Inman H, Cowdell F, Hennell J, Jones L, Walsh M. Characteristics and general practice resource use of people with comorbid cancer and dementia in England: a retrospective cross-sectional study. BMC Primary Care. 2022 Nov 12;23(1):281.

14. Smith GE, Farias ST. APA handbook of dementia. American Psychological Association; 2018.

15. Iritani S, Tohgi M, Miyata H, Ohi G. Impact of dementia on cancer discovery and pain. Psychogeriatrics. 2011 Mar;11(1):6-13.

16. Monroe T, Carter M, Feldt K, Tolley B, Cowan RL. Assessing advanced cancer pain in older adults with dementia at the end-of-life. Journal of Advanced Nursing. 2012 Sep;68(9):2070-8.

17. Monroe TB, Carter MA, Feldt KS, Dietrich MS, Cowan RL. Pain and hospice care in nursing home residents with dementia and terminal cancer. Geriatrics & Gerontology International. 2013 Oct;13(4):1018-25

18. Darby RR, Dickerson BC. Dementia, decision making, and capacity. Harvard Review of Psychiatry. 2017 Nov 1;25(6):270-8.

19. McCormick WC, Kukull WA, van Belle G, Bowen JD, Teri L, Larson EB. Symptom patterns and comorbidity in the early stages of Alzheimer's disease. Journal of the American Geriatrics Society. 1994 May;42(5):517-21.

20. Hamaker ME, Hamelinck VC, van Munster BC, Bastiaannet E, Smorenburg CH, Achterberg WP, Liefers GJ, de Rooij SE. Nonreferral of nursing home patients with suspected breast cancer. Journal of the American Medical Directors Association. 2012 Jun 1;13(5):464-9

21. Hynes C, Hodges VJ, Wyld L, Mitchell C. Cancer treatment decisions for people living with dementia: Experiences of family carers, a qualitative interview study. Health Expectations. 2022 Jun;25(3):1131-9.

22. MacRae R, Papadopoulou C. Managing a dual diagnosis of cancer and dementia in an acute setting: considerations, implications, and future recommendations. Seminars in Oncology Nursing 2021 Dec 1 (Vol. 37, No. 6, p. 151233).

23. Gupta SK, Lamont EB. Patterns of presentation, diagnosis, and treatment in older patients with colon cancer and comorbid dementia. Journal of the American Geriatrics Society. 2004 Oct;52(10):1681-7.

24. Gorin, S.S., Heck, J.E., Albert, S. and Hershman, D., 2005. Treatment for breast cancer in patients with Alzheimer's disease. Journal of the American Geriatrics Society, 53(11), pp.1897-1904.

25. Caba Y, Dharmarajan K, Gillezeau C, Ornstein KA, Mazumdar M, Alpert N, Schwartz RM, Taioli E, Liu B. The impact of dementia on cancer treatment decision-making, cancer treatment, and mortality: a mixed studies review. JNCI Cancer Spectrum. 2021 Jun 1;5(3).

26. Hopkinson JB, Milton R, King A, Edwards D. People with dementia: what is known about their experience of cancer treatment and cancer treatment outcomes? A systematic review. Psycho-Oncology. 2016 Oct;25(10):1137-46.

27. Morin L, Beaussant Y, Aubry R, Fastbom J, Johnell K. Aggressiveness of end-of-life care for hospitalized individuals with cancer with and without dementia: a nationwide matched-cohort study in France. Journal of the American Geriatrics Society. 2016 Sep;64(9):1851-7.

28. Lee KC, Hsu WH, Chou PH, Yiin JJ, Muo CH, Lin YP. Estimating the survival of elderly patients diagnosed with dementia in Taiwan: A longitudinal study. PLoS One. 2018 Jul 25;13(7):e0178997.

29. Morgan JL, Walters SJ, Collins K, Robinson TG, Cheung KL, Audisio R, Reed MW, Wyld L. What influences healthcare professionals' treatment preferences for older women with operable breast cancer? An application of the discrete choice experiment. European Journal of Surgical Oncology (EJSO). 2017 Jul 1;43(7):1282-7.

30. Harrison Dening K, King M, Jones L, Vickerstaff V, Sampson EL. Correction: advance care planning in dementia: do family Carers know the treatment preferences of people with early dementia?. PLoS One. 2016 Aug 9;11(8):e0161142.

31. Witham G, Haigh C, Mitchell D, Beddow A. Carer experience supporting someone with dementia and cancer: a narrative approach. Qualitative Health Research. 2018 Apr;28(5):813-23.

32. Mental Capacity Act. 2005. https://www.legislation.gov.uk/ukpga/2005/9/contents

33. Halpin SN, Alain G, Seaman A, Stevens EE, Zhao H, Fowler ME, Zhang Q, Cadet T, Ye M, Krok-Schoen JL. Comorbid Dementia and Cancer Therapy Decision-Making: A Scoping Review. Journal of Applied Gerontology. 2024 Feb 12:07334648241233375.

34. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, Shamseer L, Tetzlaff JM, Akl EA, Brennan SE, Chou R. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021 Mar 29;372.

35. Martin C, Shrestha A, Burton M, Collins K, Wyld L. How are caregivers involved in treatment decision making for older people with dementia and a new diagnosis of cancer?. Psycho-oncology. 2019 Jun;28(6):1197-206.

36. Critical Appraisal Skills Programme. *CASP Qualitative Research Checklist*. 2018. https://casp-uk.net/checklists/casp-qualitative-studies-checklist-fillable.pdf

37. Butler A, Hall H, Copnell B. A guide to writing a qualitative systematic review protocol to enhance evidence-based practice in nursing and health care. Worldviews on Evidence-Based Nursing. 2016 Jun;13(3):241-9.

37. Noblit GW, Hare RD. Meta-ethnography: Synthesizing qualitative studies. Sage; 1988.

39. Sattar R, Lawton R, Panagioti M, Johnson J. Meta-ethnography in healthcare research: a guide to using a meta-ethnographic approach for literature synthesis. BMC Health Services Research. 2021 Dec;21:1-3.

40. Hogger L, Fudge N, Swinglehurst D. Supporting Inclusion and Participation for People Living With Dementia: Ethnographic and Participatory Research Methods. International Journal of Qualitative Methods. 2023 Jun 14;22:16094069231184773.

41. Ashley L, Kelley R, Griffiths A, Cowdell F, Henry A, Inman H, Hennell J, Ogden M, Walsh M, Jones L, Mason E. Understanding and identifying ways to improve hospital-based cancer care and treatment for people with dementia: an ethnographic study. Age and Ageing. 2021 Jan;50(1):233-41.

42. Griffiths AW, Ashley L, Kelley R, Cowdell F, Collinson M, Mason E, Farrin A, Henry A, Inman H, Surr C. Decision-making in cancer care for people living with dementia. Psycho-Oncology. 2020 Aug;29(8):1347-54.

43. Griffiths AW, Ashley L, Kelley R, Cowdell F, Collinson M, Mason E, Inman H, Henry A, Farrin A, Surr C. Balancing the needs of individuals and services in cancer treatment for people with dementia: a focused ethnographic study. International Journal of Nursing Studies. 2021 Sep 1;121:104006.

44. Surr CA, Kelley R, Griffiths AW, Ashley L, Cowdell F, Henry A, Collinson M, Mason E, Farrin AJ. Enabling people with dementia to access and receive cancer treatment and care: the crucial role of supportive networks. Journal of Geriatric Oncology. 2020 Sep 1;11(7):1125-31.

45. Surr C, Griffiths AW, Kelley R, Ashley L, Cowdell F, Henry A, Inman H, Collinson M, Mason E, Farrin A. Navigating cancer treatment and care when living with comorbid dementia: an ethnographic study. Supportive care in cancer. 2021 May;29:2571-9.

46. Courtier N, Milton R, King A, Tope R, Morgan S, Hopkinson J. Cancer and dementia: an exploratory study of the experience of cancer treatment in people with dementia. Psycho-Oncology. 2016 Sep;25(9):1079-84.

47. Farrington N, Dantanus K, Richardson A, Bridges J. Understanding the cultural environment of the outpatient care setting for patients with dementia receiving cancer treatment: a qualitative study. Health Expectations. 2023 Feb;26(1):98-107.

48. Farrington N, Richardson A, Bridges J. ‘A real fine balancing act’: A secondary qualitative analysis of power imbalance in comorbid cancer and dementia in an outpatient treatment setting. Journal of Advanced Nursing. 2023 Aug;79(8):2980-91.

49. McWilliams L, Farrell C, Keady J, Swarbrick C, Burgess L, Grande G, Bellhouse S, Yorke J. Cancer-related information needs and treatment decision-making experiences of people with dementia in England: a multiple perspective qualitative study. BMJ open. 2018 Apr 1;8(4):e020250.

50. McWilliams L, Swarbrick C, Yorke J, Burgess L, Farrell C, Grande G, Bellhouse S, Keady J. Bridging the divide: the adjustment and decision-making experiences of people with dementia living with a recent diagnosis of cancer and its impact on family carers. Ageing & Society. 2020 May;40(5):944-65.

51. Wolfe SE, Greenhill B, Butchard S, Day J. The meaning of autonomy when living with dementia: A Q-method investigation. Dementia. 2021 Aug;20(6):1875-90.

52. Perfect D, Griffiths AW, Vasconcelos Da Silva M, Lemos Dekker N, McDermid J, Surr CA. Collecting self-report research data with people with dementia within care home clinical trials: Benefits, challenges and best practice. Dementia. 2021 Jan;20(1):148-60.

53. Kitwood T. Dementia reconsidered: The person comes first. 1997.

54. Butchard S, Kinderman P. Human rights, dementia, and identity. European Psychologist. 2019.

55. MacRae R, Papadopoulou C. Managing a dual diagnosis of cancer and dementia in an acute setting: considerations, implications, and future recommendations. In Seminars in Oncology Nursing 2021 Dec 1 (Vol. 37, No. 6, p. 151233). WB Saunders.

Figure 1. PRISMA diagram of paper selection process.

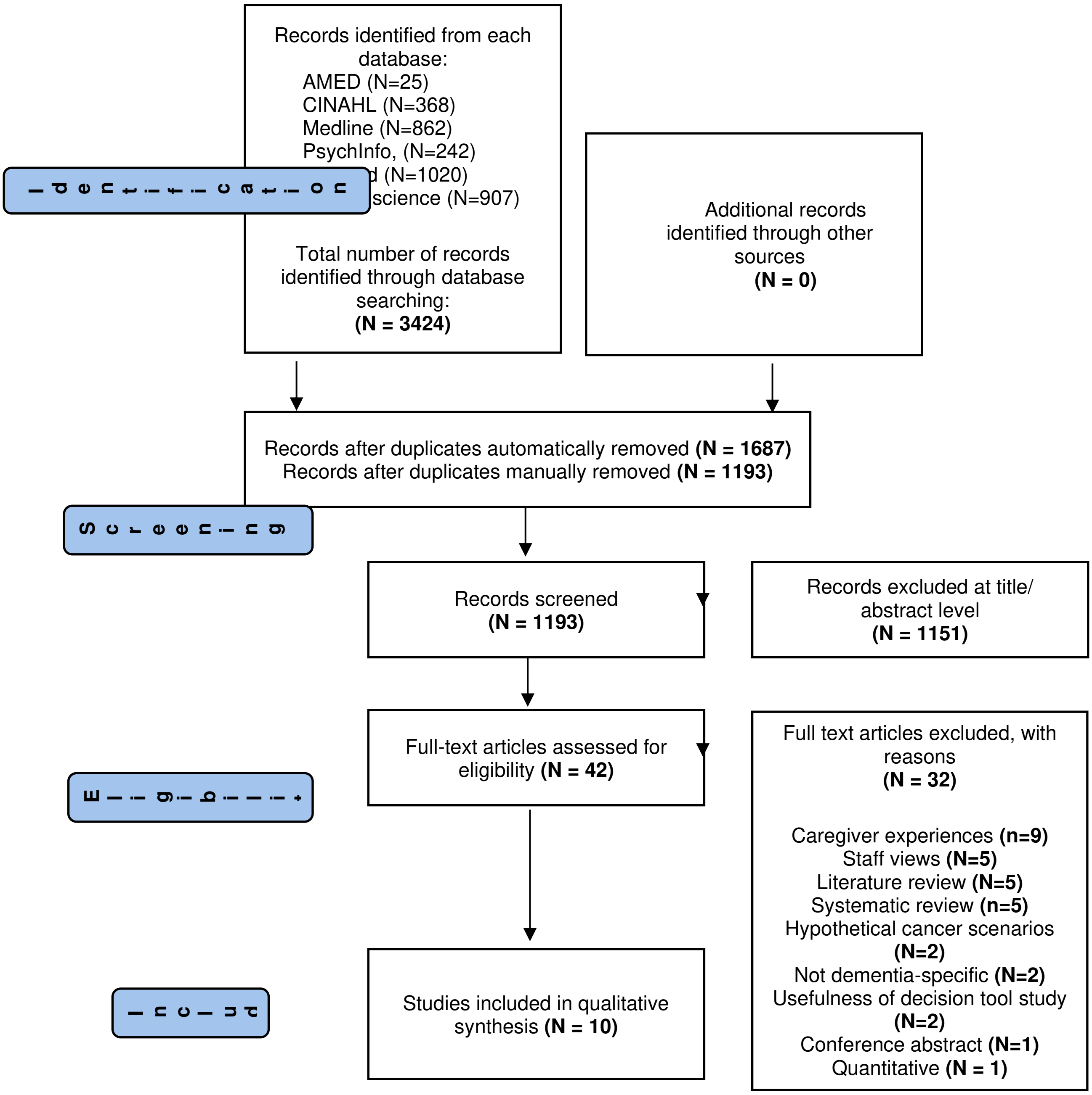

Table 1. CASP quality ratings.

Paper	Was there a clear statement of aims of the research	Is a qualitative methodology appropriate	Was the research design appropriate to address the aims of the research	Was the recruitment strategy appropriate to the aims of the research	Was the data collected in a way that addressed the research issues	Has the relationship between researcher and participants been adequately considered	Have ethical issues been taken into consideration	Was the data analysis sufficiently rigorous	Is there a clear statement of findings	How valuable is the research	Score*	Overall rating**
Ashley et al (2021)	Yes	Yes	Can't Tell	Yes	Yes	Can't Tell	Yes	Yes	Yes	Yes	9	High
Courtier et al (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9	High
Farrington et al (2022)	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	No	Yes	Yes	8.5	Moderate
Farrington et al (2023)	Yes	Yes	Can't Tell	Can't Tell	Yes	Can't Tell	Yes	Can't Tell	Yes	Yes	8	Moderate
Griffiths et al (2020)	Yes	Yes	Can't Tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9.5	High
Griffiths et al (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	High
McWilliams et al (2018)	Yes	Yes	Can't Tell	Yes	Yes	No	Yes	Yes	Yes	Yes	8.5	Moderate
McWilliams et al (2020)	Can't Tell	Yes	Can't Tell	Yes	Yes	No	Yes	Yes	Yes	Yes	8	Moderate
Surr et al (2020)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9	High
Surr et al (2021)	Yes	Yes	Can't Tell	Yes	Yes	No	Yes	Yes	Yes	Yes	8.5	Moderate

***Score**
Yes = 1 point
Can't tell = 0.5 point
No = 0 point

****Quality rating**
9-10 = High
7.5-8.9 = Moderate
<7.5 = Low

Table 2. Characteristics of included studies.

Ref	Aim	Setting	Number of PLWCDC	Sample demographics	Cancer/dementia type	Method	Analysis
Ashley et al (2021)	Examine challenges and support needs of PLWCDC in hospital-based cancer care.	UK	17	Age (n=13): mean = 75y/o, range = 45-88y/o. Sex: Female (n=10), male (n=7) Ethnicity: White British (n=16), Hispanic (n=1)	Cancer: lung (n=8), prostate (n=4), breast (n=1), gastrointestinal (n=1), other (n=3) Dementia not reported.	Semi-structured interviews, observations, conversations & medical record review.	Ethnographically informed thematic analysis (EITA)
Courtier et al (2016)	Explore experiences of PLWCDC accessing outpatient cancer treatment services.	UK	10	Gender: women (n=3), men (n=7) No age or ethnicity reported.	As Ashley et al. (2021)	Note review, observation, interviews, & recorded consultations.	Framework analytic approach
Farrington et al (2022)	Investigate provision of treatment, support, and experiences of PLWD receiving outpatient care.	UK	2	Sex: male (n=1), female (n=1) No age or ethnicity, information reported.	Not reported.	Semi-structured interviews, observations & document analysis.	Focused ethnography
Farrington et al (2023)	Examine how an imbalance of power is manifested where PLWCDC are being treated for cancer.	UK	2	Sex: male (n=1), female (n=1) No age or ethnicity, information reported.	Not reported.	Semi-structured interviews, observations & document analysis.	Focused ethnography
Griffiths et al (2020)	Explore cancer treatment decision-making experiences of PLWCDC.	UK	17	As Ashley et al. (2021)	As Ashley et al. (2021)	Observations, conversations, semi-structured interviews & medical notes review.	Ethnographically informed thematic analysis

Griffiths et al (2021)	Understand how oncology services balance needs and experiences of PLWCDC with those of the service.	UK	17	As Ashley et al. (2021)	As Ashley et al. (2021)	Observations, conversations, semi-structured interviews & medical notes review.	FE
McWilliams et al (2018)	Explore cancer-related information needs and decision-making experiences of PLWCDC.	UK	10	Age: mean = 73.6y/o, range = 39-93y/o Sex: female (n=5), male (n=5) Ethnicity not reported.	Cancer: gynaecological (n=1), colorectal (n=3), head and neck (n=3), urological (n=1), melanoma (n=1), haematology (n=1) Dementia: Alzheimer's Disease (n=5), Mixed Vascular and Alzheimer's Disease (n=2), Pick's Disease (n=1), HIV Related Dementia (n=1), Vascular Dementia (n=1)	Semi-structured interviews	Thematic analysis & framework matrices
McWilliams et al (2020)	Explore decision-making and treatment options for PLWCDC.	UK	10	As McWilliams et al. (2020)	As McWilliams et al. (2020)	Semi-structured interviews	Thematic analysis & framework matrices
Surr et al (2021)	Explore the challenges of navigating cancer treatment and care for PLWCDC.	UK	17	As Ashley et al. (2021)	As Ashley et al. (2021)	Observations, conversations & semi-structured interviews	Ethnographically informed thematic analysis
Surr et al (2020)	Explore the role of supportive networks in assisting and enabling PLWCDC to receive hospital-based cancer treatment and care.	UK	17	As Ashley et al. (2021)	As Ashley et al. (2021)	Observations, conversations & semi-structured interviews	Ethnographically informed thematic analysis

Table 3. Translations of constructs.

Descriptor (broad thematic headings)	First order data (participant quotes/ primary data from the studies)	Second order (themes developed by primary authors)	Third order (higher order concepts)
Confused and uninformed about symptoms and treatment	Staff (nurse): “call up on the Wednesday, get your bloods done and check they’re okay. Then if they’re okay come on the Thursday, but if they’re not okay don’t come otherwise it’s a long journey.” PLWCDC: “thanks.” Nurse walked out, PLWCDC turned to me: “I don’t have a clue what she means” (Observations)	Working without the full picture (Ashley et al., 2021)	***Challenges of processing cancer-related information.***
	Lady from a care home [appears to have dementia] comes to clinic alone, difficult for doctor to get any information, lady is muddling-up current and previous problems and unable to explain her situation. (Observations)	Reliance on supportive family networks (Ashley et al., 2021)	
	PLWCDC: “...I said my memory's – you'll have to excuse me 'cos (nurse) said something and I couldn't remember – and she said oh, you know, we can help you there, you know, we've got a (specialist dementia nurse)....”	Memory and the cancer clinic consultation: setting the scene (Courtier et al., 2016)	
	PLWCDC: “I don't know what they are going to do with me, that's what I'm anxious about. ... I try not to worry about it, because it just upsets me so much. I don't like it. I don't know what's happening to my body ... I don't know what to do to make myself better and that's what frightened me.”	Ethical dilemmas and challenges (Griffiths et al., 2020)	
	PLWCDC: “It’s actually throwing me [having lots of appointments] because there’s all them. It gets that I don’t know where I am some days with it. I mean, I think I’ve pre-op next week at Hospital 2 ... Then I’ve got Hospital 3 for my eyes. They want me to register as partially sighted.”	Navigating services, appointments and information (Surr et al., 2021)	
	PLWCDC: “I can listen alright like what you’re saying to me now I know that, but in a few minutes I can’t tell you what you’ve said.”	Communicating clinically relevant information (McWilliams et al., 2018)	

	PLWCDC: “That woman who ran around and hurt me. Well, she didn’t know what she were doing. ‘No!’ I kept saying to her. I said ‘It’s not right!’ Two people hit at me. Well, I had to go on to, you know … (pause) … and eh, I don’t, I weren’t bothered about doing it … (pause) … but when she started, you know, she was … (pause) … at me weren’t she? (turns to look at husband). So I was … what’s her name about that?”	Reaching a diagnosis of cancer (McWilliams et al., 2020)	
	PLWCDC: “You can get bombarded with irrelevant information … and then it all becomes too much...”	Weighing up the cancer treatment options (McWilliams et al., 2020)	
	Researcher: “I would like to ask you how you feel about your leg.” PLWCDC: “About what?” Researcher: “Your leg.” PLWCDC: “What about it? Alright … Why? What’s up with it?”	Undergoing cancer treatment (McWilliams et al., 2020)	
Decision-making dilemmas		Balancing safety with the right to treatment (Farrington et al., 2023)	***Issues of inaccessible information and uninformed consent.***
	PLWCDC: “I said I didn't want the treatment and they [family] more or less said yes you should … I said alright I'll have it, but I said no to start with didn't I?”	Whose decision? (Griffiths et al., 2020)	
	PLWCDC: “They were a bit scared of putting me [under anaesthetic] and then not knowing what my reaction was going to be when they're waking me up. Am I going to be confused? Am I going to get into a state because I don't know where I am, what's happened. Then they said we'll make an appointment with an anaesthetist. He'll go through things with you and then we'll decide.”	Evaluating treatment options (Griffiths et al., 2020)	
	PLWCDC: “All that was spoken about I took in. But they [had] given us these leaflets; they had to be read for me … ’cause I just can’t do it and sometimes I know that but I just can’t do it.” PLWCDC later clarified that his listening and understanding were situationally positioned ‘in the moment’ and that after a few minutes, he would simply be unable to recall what had been said.	Weighing up the cancer treatment options (McWilliams et al., 2020)	
	PLWCDC: “Yeah, they didn’t give you any option”	Communicating clinically relevant information (McWilliams et al., 2018)	

	PLWCDC: "…they want me to go for it but do I want to go for it? Surely that's my choice? I know we're only really going to know if I go for the biopsy, the scan, but do I really want to know that?"	After cancer treatment finishes (McWilliams et al., 2018)	
Reliance on relatives/others	Nurse held out the [catheter] tube to [PLWCDC]and asked 'do you want to have a go?' [PLWCDC] handed the tube straight to [daughter]. Nurse and [daughter] agreed it was easier for the supplies to go to Jane's house. (Observations)	Reliance on supportive family networks (Ashley et al., 2021)	***The role of relatives.***
	PLWCDC: "I used to go originally on my own – but the reason (daughter) comes with me is because I don't always remember what he says… So somebody accompanying, somebody in there to remember in case I forget, which I do forget, as you know."	Role of carer in cancer treatment (Courtier et al., 2016)	
	PLWCDC: "I can forget a few things and not ask the correct questions…it's good for somebody here to go with me"	Communicating clinically relevant information (McWilliams et al., 2018)	
	PLWCDC: "I felt as though if the doctor came to me and outlined what my problems were I'd forget that information".	Weighing up the cancer treatment options (McWilliams et al., 2020)	
	Interviewer: "But you prefer it if he's [husband] there?" PLWCDC: "I feel safer with him."	Reliance on family support (Surr et al., 2020)	
Individualised care	Caregiver (granddaughter): "a Doctor, Professor, you think well you've got to take your dictionary in with you, but he came down to our level." PLWCDC: "And my level"	Balancing person versus process (Ashley et al., 2021)	***The importance of individualised and consistent care.***
	Doctor: "We had a lady recently who said, 'I don't want a biopsy dear it clashes with my day at Waitrose'."	Balancing the system with the person (Farrington et al., 2023) Treatment (Farrington et al., 2022)	

Interviewer: “[Radiographer] used to speak to you over the tannoy. Did that make you feel calm?” PLWCDC: “That’s right, yes.” Interviewer: “Would you have been less calm if you were just there on your own?” PLWCDC: “I think it’s nice to have somebody... if they just have a word, you feel welcome then don’t you?”	Delivering person-centred care (Griffiths et al., 2021)
“The hormone therapy has affected him quite dramatically...Will speak to [Consultant] and try to arrange trial without catheter sooner. I have suggested he has one more monthly injection and we review the situation after that. I will arrange for him to be reviewed in the medical clinic before his next injection is due.” (Medical Notes)	Managing targets and processes (Griffiths et al., 2021)
“[Patient] told me ‘some things I find really easy to remember, but I really struggle with faces and names. I know [Nurse] in here but if I saw her outside of hospital I wouldn’t know who she was.’ I asked if the Nurse had introduced herself. [Patient] told me ‘she did the first week but I don’t know her name now, I just say hi. When she called me in she said “oh we’ve met before” and I’m thinking ‘have we?!’.’” (Observations)	Continuity of people, places and processes (Griffiths et al., 2021)
PLWCDC: “Something like that I think. I'm awful sorry, I thought I put (medicine bottle) in (my bag)” Staff: “that's alright, don't worry. I'll um, I can ring them, it's okay, don't worry.”	Management approach to cancer in people with dementia (Courtier et al., 2016)
PLWCDC "they talk to you a bit more slowly", which helped him feel more at ease.	Adjustments to cancer care (McWilliams et al., 2018)
PLWCDC: "you’re swapping about all the time aren’t you...you don’t seem to have the same one every time"	Lasting impact of treatment decisions (McWilliams et al., 2018)
Katherine (PLWCDC) had 47 discrete interactions with 24 different clinicians in oncology over 13 months. (Case note analysis)	The consultation (Farrington et al., 2022)
Emily, supporting her husband with CDC, found it difficult to remember the names of the different doctors they had seen, referring to one as ‘Dr, whose name begins with [x]’. Her husband found the lack of continuity problematic: He'll say afterwards, or later on, “I keep seeing different people”, and he finds that a bit confusing.	