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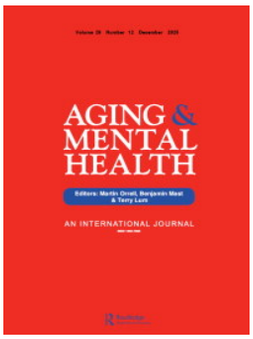

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How do people living with dementia make decisions about their cancer care?: A meta-ethnographic systematic review

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ABSTRACT

Objectives: Living with comorbid dementia and cancer is linked with communication and decision-making challenges across the cancer care pathway and poor health outcomes. This meta-ethnographic review aimed to explore the experiences of people living with comorbid dementia and cancer (PLWCDC) when making decisions about their cancer care.

Method: 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: Searches yielded 3424 unique records, with ten articles meeting eligibility criteria. After quality assessment, collated data was synthesised using a reciprocal synthesis. This produced 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', drawn together by a core concept of delivering and receiving person-centred cancer care in an inflexible healthcare system.

Conclusion: Decision-making experiences were complex and multi-layered. Dementia negatively influenced understanding and retention of information. Poor consistency in staffing and complexity of information provided were overwhelming. PLWCDC were not always meaningfully involved in their cancer-care decisions. Individualised, consistent care is required to improve outcomes for this population.

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Cognitive impairment; comorbidities; decision-making; treatment options

Introduction

Over 50 million people live with dementia globally, with a projected increase to 152 million by 2050 (Nichols et al., 2022). The prevalence of dementia increases significantly as people age (Prince et al., 2015), with heightened risk after individuals turn 65 (NHS England, 2024). Indeed, in the UK, 7.1% of the population aged over 65 form a substantial proportion of the 850,000 living with this condition (NHS England, 2024; Wittenberg et al., 2019). People with dementia often depend on caregivers for support with activities of daily living, particularly as their symptoms around memory loss develop (Ashley et al., 2023). 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 (NHS England, 2024). 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 (Mansfield et al., 2019) due to issues surrounding stigma and lack of knowledge (Parker et al., 2020). With an ageing population and increasing life-expectancies, dementia is among the most important health and care issues globally (NHS England, 2024).

The global incidence of cancer is increasing, with people aged 75 and over experiencing over a third of new cancer cases every year (Cancer Research UK, 2021; Pilleron et al., 2021). By 2050, 6.9 million new cancer cases are expected to be diagnosed in adults aged 80 or over worldwide (Pilleron et al., 2021). The negative psychological impact of cancer is well documented (NICE, 2004). 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 (van der Willik et al., 2018), such as cognitive problems often referred to as 'chemobrain' (Ahles et al., 2012).

Due to the high prevalence of cancer and dementia as distinct conditions in older people, many people in England live with comorbid cancer and

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dementia. Collinson and colleagues (Collinson et al., 2022) 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 (Collinson et al., 2022). As the population continues to age, more people are likely to experience comorbid dementia and cancer (Smith and Farias, 2018). 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 (Iritani et al., 2011; Monroe et al., 2012; Monroe et al., 2013). Certain types of dementia can also directly impair decision-making (Darby and Dickerson, 2017).

Noticing and understanding cancer-related symptoms can be challenging for people with dementia (Ashley et al., 2023) and they are likely to underreport cancer symptoms, leading to delayed medical attention and less hospital admittance (Iritani et al., 2011; McCormick et al., 1994). Advanced dementia was described as the main cause of failure to refer patients with suspected cancer for further investigation (Hamaker et al., 2012).

NHS services for physical health problems, such as cancer, may not be equipped to provide the holistic care required for people with dementia (Hynes et al., 2022). Comorbid dementia creates many challenges across the cancer care pathway, including communication, environment, and cancer care decision-making (MacRae and Papadopoulou, 2021). Compared to people without dementia, people with dementia are diagnosed later (Gupta and Lamont, 2004; Gorin et al., 2005), receive less or no treatment (Caba et al., 2021), experience more complications and have poorer survival rates (Hopkinson et al., 2016).

Due to high prevalence of comorbidities for people with dementia, cancer symptoms risk being underrecognised (Collinson et al., 2022). 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 (Ashley et al., 2023). Clinicians, caregivers, and patients may prefer less aggressive care and prioritise quality of life (QoL) over life expectancy (Caba et al., 2021). 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 (Gorin et al., 2005). Clinicians are less likely to offer PLWCDC aggressive therapy due to concerns around informed consent (Caba et al., 2021), practical difficulties (Hopkinson et al., 2016; Morin et al., 2016) discomfort (Lee et al., 2018), and clinicians having vague, conflicting, or limited guidance (Morgan et al., 2017). 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 (Harrison Dening et al., 2016) through supporting communication regarding symptoms and treatment options with clinicians (Caba et al., 2021). However, treatment preferences sometimes differed between PLWCDC and their caregivers, which causes emotional turmoil and exhaustion (Hynes et al., 2022).

Witham and colleagues (Mental Capacity Act, 2005) 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) (Halpin et al., 2024) 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 et al. (2021) 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 (Caba et al., 2021) reviewed many studies, most were quantitative and focused on caregiver perspectives, lacking lived decision-making experiences of PLWCDC. Halpin et al. (2024) 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 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 perceptions and experiences for clinical practice?

Methods

This meta-ethnographic review was conducted in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (NHS England, 2024) Wittenberg et al. (2019) and eMERGe guidelines for reporting meta-ethnography. The protocol is registered with the PROSPERO international prospective register of systematic reviews (CRD42024438152).

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 by GAQ, supported by AWG and SB (where no further papers were identified). Forward and backward searching was conducted but yielded no additional papers.

Inclusion and exclusion criteria

In recognition of this review's aim to understand the complex, multi-faceted nature of decision making in cancer care for PLWD the definition of decision making adopted was broad. Papers which considered a PLWD's role in receiving information, processing the information provided and communicating a decision about whether or not to seek cancer assessment and diagnosis, receive treatment, and stop treatment were considered.

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 (Martin et al., 2019).

Data screening and 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 (GAQ), with 10% of records double-screened by AWG. 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) (Critical Appraisal Skills Programme, 2018) checklist for qualitative studies was used to examine the risk of bias and methodological quality of included studies. Butler and colleagues' (Butler et al., 2016) 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 (Noblit

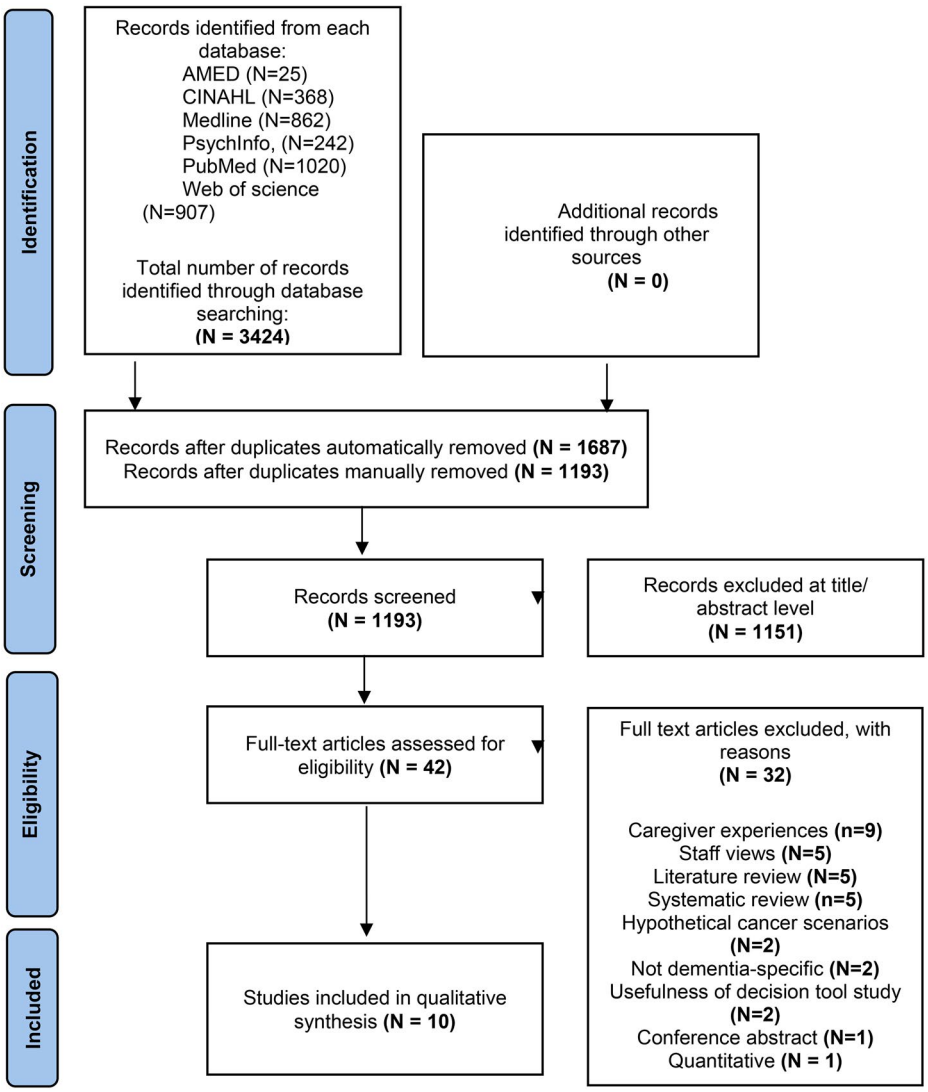

Figure 1. PRISMA diagram of paper selection process.

and Hare, 1988; Sattar et al., 2021). 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 themes with greater methodological decsription (Noblit and Hare, 1988; Sattar et al., 2021). Synthesis of the relationships between studies was conducted, led by GAQ through regular discussion and reflection with AWG and SB, to achieve consensus. 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, and 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 (Hogger et al., 2023). The included studies were sufficiently similar, which allowed a reciprocal synthesis to be conducted (Noblit and Hare, 1988). AWG and GAQ then developed a line-of-argument synthesis to identify a central concept underlying the data from the included studies. This involved comparing higher-order concepts and examining the relationships among them to generate new insights into how people with dementia participate in and experience decision-making regarding their cancer care (Noblit and Hare, 1988).

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 (Critical

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	**Quality rating
Yes = 1 point	9-10 = High
Can't tell = 0.5 point	7.5-8.9 = Moderate
No = 0 point	<7.5 = Low

Appraisal Skills Programme, 2018), 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 (Ashley et al., 2021; Griffiths et al., 2020; Griffiths et al., 2021; Surr et al., 2020; Surr et al., 2021), dataset two (Courtier et al., 2016), dataset three (Farrington, Dantanus, et al., 2023; Farrington et al., 2023) and dataset four (McWilliams et al., 2018; McWilliams

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 = 75 y/o, range = 45–88 y/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 = 73.6 y/o, range = 39–93 y/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

et al., 2020). 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, to develop a line-of-argument synthesis. Alternative interpretations were discussed by all authors and considered within translations.

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 (Ashley et al., 2021; McWilliams et al., 2018). Importantly, 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 (Griffiths et al., 2020).

McWilliams and colleagues (McWilliams et al., 2020) recognised challenges PLWCDC faced in reaching a cancer diagnosis. Biopsies caused pain and distress in intimate clinical investigations, clearly remembered by PLWCDC (McWilliams et al., 2020). 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 (McWilliams et al., 2020). Some PLWCDC were unsure whether to have a biopsy (McWilliams et al., 2018) with some choosing to refuse this completely (Farrington, Richardson, et al., 2023) and others not wanting to return to hospital following a biopsy appointment, remembering the pain accompanying previous experiences (McWilliams et al., 2020).

Staff gave PLWCDC large amounts of information at once, lacking understanding and individualised care (Ashley et al., 2021; McWilliams et al., 2020). PLWCDC often did not seek clarification where they felt they did not have all the information (Ashley et al., 2021) supporting the suggestion that PLWCDC may conceal or downplay their memory problems during cancer consultations (Courtier et al., 2016). Some PLWCDC became angry when caregivers disclosed memory problems to professionals (Courtier et al., 2016).

Some PLWCDC found remembering medical information and following treatment-related instructions difficult (Griffiths et al., 2020; Surr et al., 2021; Courtier et al., 2016; McWilliams et al., 2020). During healthcare consultations, information was often requested such as medical history, cancer symptoms, previous therapies, and treatment side effects (Courtier et al., 2016), however issues including marked memory loss (e.g. not being able to recall past appointments or surgical treatments (Griffiths et al., 2020; McWilliams et al., 2020)) reduced the success of these consultations (Courtier et al., 2016), Whilst communication was an issue for some PLWCDC, recontextualised words and experiences could enable PLWCDC to express and make sense of them (McWilliams et al., 2018). 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 (Surr et al., 2021).

Issues of inaccessible information and uninformed consent

Information delivery influenced decision-making abilities of PLWCDC (Griffiths et al., 2020; Griffiths et al., 2021; McWilliams et al., 2020). Excessive quantities of irrelevant cancer treatment-related information were presented by professionals (Griffiths et al., 2020; Griffiths et al., 2021; McWilliams et al., 2020), 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 (Griffiths et al., 2020). Some PLWCDC described spoken information as helpful but felt unable to engage with reading materials (McWilliams et al., 2020). Treatment-related information offered in multiple formats, with adequate time to ensure understanding was helpful for PLWCDC[51], respecting that they may change their mind over time (Griffiths et al., 2020). However, listening and understanding capacity could change and PLWCDC could be unable to recall information a few minutes later (McWilliams et al., 2020). This emphasises caregivers' centrality through their longitudinal knowledge of, and effective communicative approaches for PLWCDC (McWilliams et al., 2020).

Several papers described the importance of 'balance' and 'evaluation' in treatment options (Griffiths

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)	

(*Continued*)

Table 3. Continued.

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)
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?'	Reliance on family support (Surr et al. 2020)	
	PLWCDC: 'I feel safer with him'.		
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'.	Balancing person versus process (Ashley et al. 2021)	***The importance of individualised and consistent care.***
	PLWCDC: 'And my level'		
	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?'	Delivering person-centred care	
	PLWCDC: 'That's right, yes'.	(Griffiths et al. 2021)	
	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?'		
	'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)'	Management approach to cancer in people with dementia (Courtier et al. 2016)	
	Staff: 'that's alright, don't worry. I'll um, I can ring them, it's okay, don't worry'.		
	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.		

et al., 2020; Farrington et al., 2023; McWilliams et al., 2020). PLWCDC felt confused, uninformed, and distressed during their cancer care, with difficulties in information retention and communication, leading to questions over 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 (Farrington et al., 2023). Multiple researchers acknowledged the lack of decision-making agency provided to PLWCDC (Griffiths et al., 2020; Farrington et al., 2023; McWilliams et al., 2018) who, at times, were not actively involved in decision-making processes, not given options, and left with unanswered questions (McWilliams et al., 2018).

Consideration of the 'bigger picture' was sometimes used to evaluate treatment options (Griffiths et al., 2020). 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 (Griffiths et al., 2020). Clinicians' concerns, therefore, pose an additional emotional burden for PLWCDC to tolerate. However, such concern could generate further specialist input to inform decision-making (Griffiths et al., 2020).

For other PLWCDC, cancer treatment risks did not outweigh the risk of death, cancer treatment options were immediate and clear-cut (McWilliams et al., 2020). However, there could still be ongoing or lasting impacts of cancer-related decisions even following cancer treatment. McWilliams and colleagues (McWilliams et al., 2020) 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 (McWilliams et al., 2020). This may be due to underestimation or limited communication about the potential severity of treatment side effects (Griffiths et al., 2020; McWilliams et al., 2020).

The role of relatives

Relatives' views were influential in cancer care decision-making (Griffiths et al., 2020; Courtier et al., 2016), even when perspectives regarding the 'right' decision did not align with those of PLWCDC (Griffiths et al., 2020). This suggests relatives became more dominant than PLWCDC in decision-making. However, many papers described family networks playing an important role (Ashley et al., 2021; Surr et al., 2020; Courtier et al., 2016; McWilliams et al., 2018, McWilliams et al., 2020). PLWCDC felt dependent upon their caregivers for cognitive and practical support with cancer management (Surr et al., 2020,Courtier et al., 2016) including accessing, navigating, and undergoing treatment (Ashley et al., 2021; Surr et al., 2020). Relatives monitored symptoms, organised and attended appointments, provided emotional support and reassurance, and retained, relayed, and explained cancer treatment information to PLWCDC (Ashley et al., 2021; Surr et al., 2020).

When accompanied by caregivers who were able to 'fill the gaps' in consultations that were created by dementia, PLWCDC were more likely to attend (Surr et al., 2020) and have 'successful' consultations (Courtier et al., 2016). 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 (McWilliams et al., 2018; McWilliams et al., 2020). 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 (McWilliams et al., 2020).

The importance of individualised and consistent care

Individualised, person-centred, consistent care appeared incongruent with cancer care systems (Ashley et al., 2021; Griffiths et al., 2021; Farrington, Dantanus, et al., 2023; Farrington, Richardson, et al., 2023; McWilliams et al., 2018; McWilliams et al., 2020). 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 (Farrington, Dantanus, et al., 2023). This is pertinent when cancer care experiences of PLWCDC were shaped by the readiness of services to accommodate their dementia (Farrington et al., 2023). 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 (Surr et al., 2021; Farrington, Richardson, et al., 2023).

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 (Griffiths et al., 2021). Furthermore, clinicians' communications did not always meet the needs of PLWCDC, for example, 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 (Griffiths et al., 2021).

The unique needs of PLWCDC must be balanced with requirements of complex health systems (Farrington, Richardson, et al., 2023). PLWCDC required individualised, flexible care to understand and undergo cancer treatment (Ashley et al., 2021). 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 (Ashley et al., 2021). 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 were highlighted (Courtier et al., 2016).

Person-centred care involved knowing the person and providing flexible support with communication tailored to individual needs (Griffiths et al., 2021). For example, recording how dementia may impact cancer care on medical notes enhanced person-centred support and reduced the likelihood of distress (Griffiths et al., 2021). Flexible and creative approaches to support PLWCDC during treatment, such as continuing conversations over speakers during radiotherapy, made PLWCDC feel calmer (Griffiths et al., 2021). 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 (McWilliams et al., 2018). However, such adaptations are at odds with delivering 'efficient' services (Griffiths et al., 2021).

High rates of staff turnover contributed to confusion (McWilliams et al., 2018; McWilliams et al., 2020), impersonal approaches, and insensitive diagnosis disclosure (Griffiths et al., 2021). Having multiple staff members involved in the cancer care of PLWCDC created an accumulated burden for PLWCDC and caregivers to manage (Griffiths et al., 2021; Farrington, Dantanus, et al., 2023). PLWCDC found continuity important, commenting on familiar corridors, treatment rooms and staff members as positive aspects of their experiences (Griffiths et al., 2021; McWilliams et al., 2020). PLWCDC, therefore, requested consistency amongst hospital staff where possible (Griffiths et al., 2021). 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 (Griffiths et al., 2021). Developing trusting relationships increased PLWCDC's confidence in asking questions and indicating uncertainties.

Line of argument synthesis

PLWCDC sought to make decisions about their cancer care, but lacked decision-making agency, due to their symptoms of dementia, and the actions of those around them. Staff tried to delicately balance the communication and support needs of PLWCDC with delivering person-centred, individualised care, within stretched and inflexible healthcare systems. Staff found themselves increasingly relying on caregivers to support decision-making of PLWCDC, leaving these individuals disempowered from their own care.

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. Ten qualitative studies providing first-hand perspectives of PLWCDC were identified, which focused on four main concepts or themes, synthesised into a core argument of delivering and receiving person-centred cancer care in an inflexible healthcare system.

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 (Iritani et al., 2011; Monroe et al., 2012; Monroe et al., 2013).

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 (Gorin et al., 2005; Caba et al., 2021), 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 (Hopkinson et al., 2016).

Whilst one study described a preference from PLWCDC, caregivers, and clinicians for less aggressive care and prioritisation of QoL over life expectancy for PLWCDC (Caba et al., 2021), 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 (Harrison Dening et al., 2016). 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 (Caba et al., 2021). 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 (Wolfe et al., 2021) 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 (Wolfe et al., 2021).

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 (Mental Capacity Act, 2005), 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 (1997) 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 (2005).

Professionals undermined the human rights of PLWCDC. 'FREIDA' principles underpinning human rights (Butchard and Kinderman, 2019) 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.

Strengths and limitations

To the authors' knowledge, this is the first systematic review to explore qualitative cancer-care decision-making experiences from the perspectives of PLWCDC only, allowing exploration of their unique narratives. It is hoped that this will increase understanding and contribute toward better support for PLWCDC's inclusion in decision-making regarding their cancer care.

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. This means that at times, the data presented in the current review are using the words of researchers, rather than the words of PLWCDC themselves. 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.

Synthesising a variety of data types (e.g. interview quotes, participant observations and 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 their historically marginalised voices (Hogger et al., 2023).

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 (Collinson et al., 2022) 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 (Smith and Farias, 2018), NHS services for physical health problems including cancer, are not equipped to provide the holistic care required (Hynes et al., 2022) due to communication, treatment decision-making, environment, and time-related issues (MacRae and Papadopoulou, 2021). Nonetheless, issues of HRs cannot be compromised. Ashley and colleagues (Ashley et al., 2021) 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 (Caba et al., 2021) 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 (Hogger et al., 2023). 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 (Hogger et al., 2023).

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 (Ashley et al., 2021). 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 (Ashley et al., 2021). However, the additional emotional burden of this decision-making should be acknowledged (Griffiths et al., 2020). 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 (Ashley et al., 2021). 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 and 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 (Griffiths et al., 2021).

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 (Hogger et al., 2023; Griffiths et al., 2021; Surr et al., 2020).

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-making (Surr et al., 2020). 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.

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