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Systematic Review

Experience of decision-making for older adults, their significant others, and health care professionals after a diagnosis of cancer: A systematic review

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ABSTRACT

Introduction: Older age is associated with changes in physical, social, and psychological health in ways that influence treatment decisions, potentially impacting on quality and quantity of life. This systematic review explores the experiences of older adults, their significant others, and health care professionals when decisions regarding cancer treatment and support are made.

Materials and Methods: Synonyms relating to search terms Cancer, Older People, Complexity, and Qualitative research were used to search the databases CINAHL, Medline, Embase, and PsycINFO. The Mixed Methods Appraisal Tool (MMAT) identified strengths and limitations of the evidence allowing concurrent appraisal of qualitative, quantitative, and mixed methods studies. Data analysis and synthesis was conducted using narrative synthesis.

Results: Five hundred thirty-four articles were identified of which 64 underwent full text screening. Fourteen studies fulfilled the selection criteria and were included in the review. Narrative synthesis identified four themes: (1) Preconditions in decision making - identifying frailty and setting goals; (2) Preferences, choice, and the need to maintain independence; (3) The influence of information provision; (4) Support during the decision-making process, role distribution, and trust in physician. Most included studies reported the views of the older adult, or health care professionals. However, there was paucity of evidence representing the older adult's significant other.

Discussion: Research is urgently needed to understand how and why decisions are made regarding cancer treatment and support, as well as how older adults are involved in these decisions throughout their diagnosis and treatment trajectory. A comprehensive understanding would help healthcare professionals to prioritise the individual's healthcare preferences.

1. Introduction

The prevalence of older adults living with cancer is growing and by 2035 it is expected that 60% of all new cancer diagnoses will be made in individuals aged 65 and over [1,2]. Shared decision making (SDM) promotes the involvement of individuals or their advocates in decisions about their healthcare and ensures the preferences of the individual are included collaboratively with clinicians around the choice of investigations, treatments, and supportive management for their conditions [3]. Studies relating to SDM in healthcare have been published the United States, Germany, Canada, and the Netherlands [4].

Older age is associated with significant physiological, functional, physical, social, and psychological variability and this presents unique challenges for planning care and treatment, that can ultimately impact on quality and quantity of life. Yet, little evidence and understanding exists about how decisions are made by, with, or for older adults following a new diagnosis of cancer, or how health and social complexity informs treatment decisions. [5,6]. The variability in needs based on the presence of frailty, multimorbidity, functional and cognitive impairment underscores the importance of research to determine how to provide comprehensive care for older adults with cancer [7,8]. Previous studies have mainly explored the benefits of risk identification and decision making among the cancer inter-professional team to the exclusion of the older adult. Whilst it is important to identify frailty due

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to the increased risk of death and adverse effects of cancer treatment for people living with frailty, this must be done in ways that ensure treatment decisions are shared and align with the older individual's values and preferences [9,10]. Further, there is a paucity of published literature relating to older adults diagnosed with cancer who are culturally and linguistically diverse [11].

Despite the increasing number of older adults being diagnosed with cancer, they are underrepresented in clinical cancer trials as until recently, upper age limits and the presence of multi-morbidity were accepted exclusion criteria for therapeutic clinical trials [12]. Cancer treatment decisions for older adults are, therefore, based on clinical trial evidence gathered from younger or older adults who are otherwise well, which has exacerbated the uncertainty over optimal treatment options. Moreover, whilst mortality is a central outcome measure in cancer clinical trials, for many older adults, outcomes such as functional independence and quality of life can be more important [13,14]. A broader understanding of the wider literature has the potential to improve patient satisfaction and outcome, especially for older adults living with frailty and multi-morbidity [14,15].

This systematic review sought to explore the experiences of older adults, their significant others, and healthcare professionals (HCPs) in making treatment and support decisions after a diagnosis of cancer.

2. Materials and Methods

A search for literature was undertaken in June 2021 and repeated in June 2024 by LL from the inception of the electronic databases CINAHL, MEDLINE, EMBASE, and PsycINFO. The search terms used were in accordance with accepted concept mapping and CHIP search strategy [16]. (Context: discussions between older adults and cancer multidisciplinary team; How: qualitative accounts; Issues: experiences of individuals in treatment decision making regarding their care; Population: older people with cancer diagnosis and complex need) and were used to define synonyms based on key concepts relating to the review question detailed in Table S1 (Supplementary file). The search is detailed in Table S2 (Supplementary file). Inclusion and exclusion criteria are displayed in Table 1. Grey literature was excluded because it often lacks the rigorous peer-review process present in published research, potentially leading to concerns about methodological quality and reliability.

Table 1
Inclusion and exclusion criteria used in the review.

Include	Exclude
Empirical studies focusing on the individual person's experiences of decision making relating to their treatment	Application of geriatric assessment or frailty screening/identification tools, which do not discuss the inclusion of the older adults' experiences, involvement and concerns regarding treatment and care planning.
Articles relating to any cancer type	End of life care planning without existing or recently treated cancer diagnosis.
Focus on involvement of individuals in their decision making at any stage throughout the trajectory from diagnosis to recovery or end of life care planning.	Frailty or multi-morbidity without existing or recently treated cancer diagnosis.
Only articles published in English	Articles which focus on symptom management alone without discussing the preferences and concerns of the individual.
Study population – Adults (over 65 years) with a diagnosis of cancer	Articles where the topic is older adults living with dementia and cancer care decision making as the dominant focus
Treatment decisions for newly diagnosed cancer	Cancer decision making for younger adults (<65 years) Studies focusing on cancer recurrence. Grey literature including thesis, conference abstracts, case studies

2.1. Search outcome and study selection

For the 2024 search, the web-based tool Rayyan was used to import the search results from the relevant databases. This enabled the online collaboration between reviewers through the process of importation of citations, eliminating duplicates, screening abstracts and extracting the full text data and helped to resolve disagreements regarding inclusion suitability [17].

Following deduplication of 534 studies three reviewers LL, KH, and RW independently screened the titles and abstracts against the inclusion criteria, marking as include, exclude or maybe, they then met to agree consensus. Full text versions were reviewed by LL, RW, and KH and discrepancies were discussed and agreement reached for the final included articles. The updated search in 2024 yielded two further relevant studies [18,19].

The search yielded one conference abstract, but this had not been published as a full manuscript elsewhere. Initial screening identified 470 articles that did not meet inclusion/exclusion criteria. Sixty-four articles were read in full and their adherence to inclusion/exclusion criteria ascertained; 14 articles met these criteria and were included in the review. The results are presented in the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) flow diagram in Fig. 1. [20]. Information about each individual study specific to the research question obtained (Table 2).

2.2. Data extraction

The data were extracted into the reference manager Endnote, key details were added onto pre-determined data forms in word to manually analyse the literature, Table 2, Characteristics of the included studies.

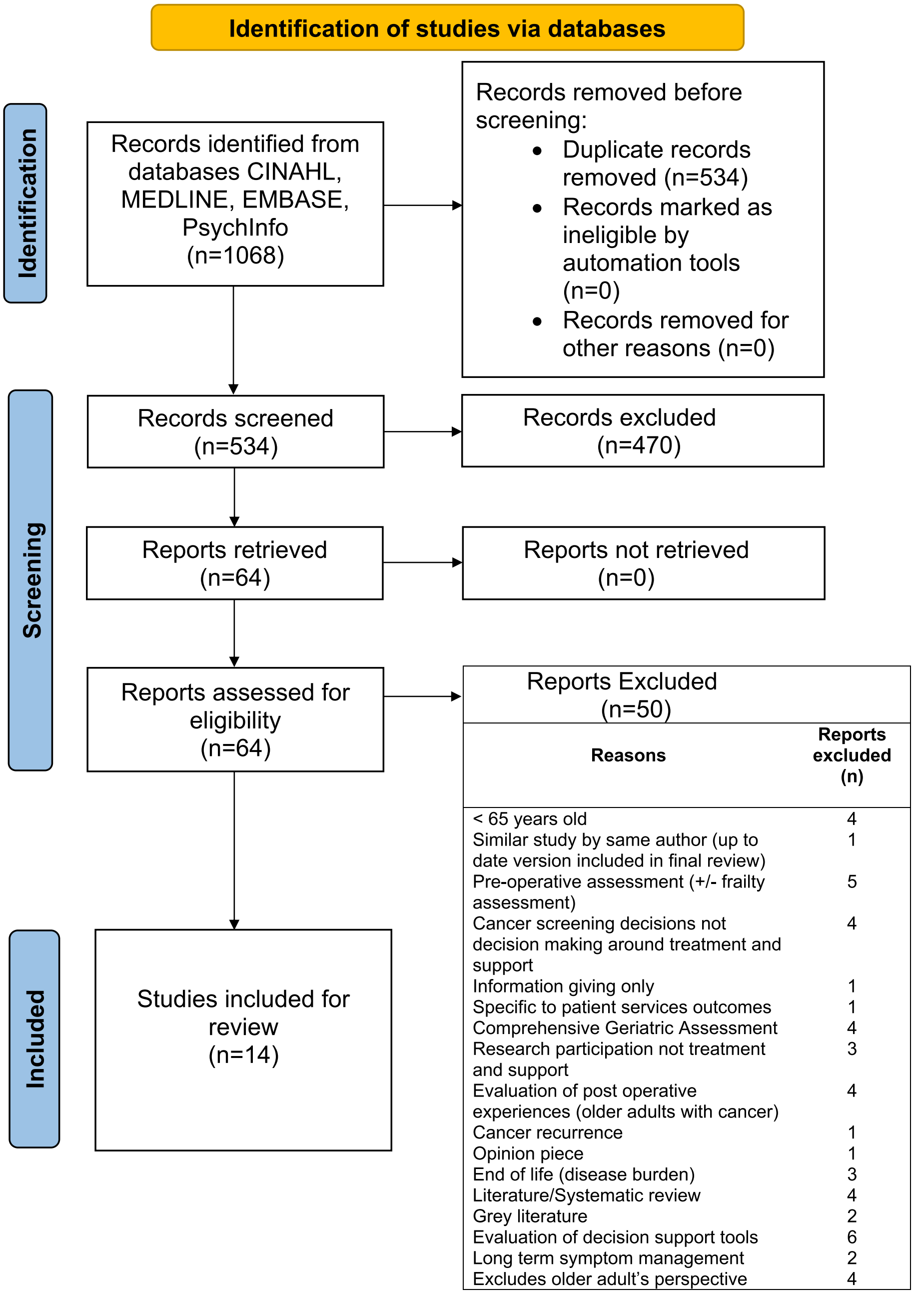
2.3. Quality appraisal

A further data abstraction form was used to critique all articles individually in greater depth. Table S3 provides an example of this. The Mixed Methods Appraisal Tool (MMAT) was used by LL to assess the methodological quality of included studies (including the two identified by the update searches), allowing concurrent appraisal of qualitative, quantitative, and mixed methods studies [21]. RW further critiqued 20 % of the studies [22–24]. As unanimous agreement was reached at that stage, no further duplication of assessment was conducted. As all included studies were of good methodological quality, none were excluded from the synthesis based on MMAT scores. Studies were given equal weighting in the analysis. MMAT was used to assess reporting bias, the range of published articles included in the review indicates that publication bias was not of great concern.

2.4. Data analysis and synthesis

A narrative synthesis approach, rather than meta-synthesis, was used to summarise the findings because of the heterogeneity of studies and diversity of hypotheses and research questions [25]. The textual method of narrative syntheses is suitable for mixed methods reviews as it supports the handling of statistical data, as well as allowing the ‘story’ to be told. Thematic analysis was used to aggregate data from the narratives by enabling identification of common themes within the dataset, emphasising the exploration of relationships in the data following the development of a preliminary synthesis [26].

Data were extracted onto a table to create a dataset, and familiarisation with the data was conducted. This involved reading and re-reading, and the generation of analytic notes and initial ideas about coding. The whole dataset was then coded and codes organised into categories [27]. The next stage involved identifying categories of codes which were of interest to the research question to form preliminary themes [28,29]. Preliminary themes were compared for similarities and overlap and checked against codes to generate the final themes. The



Reasons	Reports excluded (n)
< 65 years old	4
Similar study by same author (up to date version included in final review)	1
Pre-operative assessment (+/- frailty assessment)	5
Cancer screening decisions not decision making around treatment and support	4
Information giving only	1
Specific to patient services outcomes	1
Comprehensive Geriatric Assessment	4
Research participation not treatment and support	3
Evaluation of post operative experiences (older adults with cancer)	4
Cancer recurrence	1
Opinion piece	1
End of life (disease burden)	3
Literature/Systematic review	4
Grey literature	2
Evaluation of decision support tools	6
Long term symptom management	2
Excludes older adult's perspective	4

Fig. 1. PRISMA flow diagram for included studies.

Results of the review are presented by theme, to demonstrate the patterns in the data [30]. This process is presented in Fig. 2 Model of coding for synthesis.

3. Results

Fourteen studies were included in the review, published between 2007 and 2023. These included a range of qualitative and mixed methods approaches including qualitative interviews [18,22,24,32,34,39], a focus group [33], a prospective observational study [23], and surveys [19,31,35–38]. Studies were conducted in the United Kingdom [24,31], a range of European countries [33,34,37,40], Canada [38], the United States of America [18,23,32,35,39,41], Australia [36], and China [22]. A range of cancer types were included from a variety of clinical settings.

The total number of older adult participants across all studies is 2740 and 86% of participants were female. Five included studies focused on breast cancer [19,31,35,39], one of which featured a large sample size ($n = 1329$) [23], explaining the predominance of females. One study did not report on sex ($n = 22$) [33]. Half of the studies did not specify race or ethnicity [31,35–38,40]. For those that did it was listed as: 89% White [23] 91% non-Hispanic White [39] and 100% non-Hispanic [18,22].

3.1. Different perspectives

Seven of the papers collected data from older adults alone [19,24,31,36,37,39]. Four studies included the perspectives of both older adults and healthcare professionals who were reported as physicians or oncologists [23,32,34,35]. Two studies included family members in addition to older adults [22,33]. Only one study considered decision making from the perspective of older adults, healthcare professionals and relatives of older adults [38]. HCPs were listed as either

Table 2
Characteristics of the included studies.

Author, Year, Title	Country	Setting & Cancer Type	Aim of Study	Sample	Design, Data Collection & Analysis	Main Findings	From Whose Perspective is Decision-Making Discussed?
Burton et al. (2017) [31] Information needs and decision-making preferences of older women offered a choice between surgery and primary endocrine therapy for early breast cancer	United Kingdom	10 breast cancer units	To establish older women's (>75 years) information preferences regarding breast cancer treatment & to quantify women's preferences for the mode of information preference & decision-making style.	Convenience sample 101 female participants mean age 82 years.	Retrospective, cross-sectional survey of women, ≥ 75 years, who had been offered a choice between primary endocrine therapy and surgery at diagnosis of breast cancer. 101 questionnaires were returned.	Preference for face-to-face information. Written formats were also helpful but not computer- based resources. Preference for involvement and expressed low levels of decision regret.	The women making decisions about treatment options.
Elkin et al. (2007) [32] Desire for information and involvement in treatment decisions: Elderly cancer	United States of America	Single outpatient department metastatic colorectal cancer (crc)	How involved older adults want to be in making treatment decisions and how physicians perceive	39 male and 34 females aged over 70 diagnosed with metastatic crc within 16 weeks of recruitment. Mean age 76 years.	Structured interviews about chemotherapy treatment decision-making. Preferences for prognostic information and for involvement in treatment decision making.	Physicians' perceptions are often inconsistent with patients stated preferences. Explicit discussion of preferred decision-making styles may improve patient-physician encounters.	Older adults with cancer and physicians
Geessink et al. (2017) [33] Key elements of optimal treatment decision-making for surgeons and older patients with colorectal or pancreatic cancer: A qualitative study’	The Netherlands	Primary and secondary care; colorectal (crc) and pancreatic cancer (pc)	To identify key elements of optimal treatment decision-making for surgeons and older patients with CRC or pancreatic cancer (PC).	Purposive sampling method to recruit 23 physicians, 22 patients Mean age focus groups - 73.5 years, interviews −80.6 years. and 14 relatives	Focus groups: 3 with older adults with crc/pc, 3 with physicians. Supplementary in-depth interviews with 7 patients. Framework analysis was used to identify key elements in decision- making.	1. Identifying frailty and goal setting, emotional and coping styles and patient's mental capacity. 2. Doctor's capacities – Trustworthiness, 3. Practical information, doing nothing/noninvasive treatment. 4. Role distribution in decision making, role of general practitioners	Older adults and family members
Gironés et al. (2012) [34] Lung cancer chemotherapy decisions in older patients: the role of patient preference and interactions with physicians	Spain	Hospital oncology unit, lung cancer	To examine the relationships between preferences and chemotherapy use in older adults with lung cancer.	Eighty-three people over 70 years old with lung cancer asked to choose one of the four therapeutic options. Mean age 77 years.	Questionnaires in short interviews (20 mins) with same oncologist during clinic appointment.	If older adults diagnosed with lung cancer could choose their treatment options, they would select chemotherapy to prolong their survival. People living with frailty showed a conservative attitude towards active treatment.	Older adults and oncologists
Gong et al. (2021) [22] Treatment decision-making for older adults with cancer: A qualitative study	China	2 tertiary hospitals. Various cancer types.	To analyse the treatment decision-making process and formation mechanism for older cancer patients within the cultural context of Chinese medical practice.	Purposive sampling to recruit participants aged over 65 years diagnosed with cancer. Mean age 69 years	Qualitative study (interviews) with thematic analysis	Differences between older adults and family members views regarding treatment decision making. Intergenerational negotiation Family members think “survival” is a priority over everything The body is not only his or her own but also that of the whole family.	Older adults and their family members
Javid et al. (2012) [35] A prospective analysis of the influence of older age on physician and patient decision-making when considering	United States of America	8 geographically diverse institutions (5 academic and 3 community based) breast cancer.	To determine physician- and patient perceived barriers to breast cancer clinical trial enrolment for older adults	Women over 18 with breast cancer were recruited prior to systemic treatment decision making. 27 % of participants >65 years	Prospective survey study conducted between 2004 and 2008. Patient questionnaires and physician questionnaires	Treatment related concerns: people concerned re side effects of chemo. Institution/provider related concerns: the belief that being in a clinical trial would result in worse treatment follow up	From perspective of older adults' younger adults and physicians.

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Table 2 (*continued*)

Author, Year, Title	Country	Setting & Cancer Type	Aim of Study	Sample	Design, Data Collection & Analysis	Main Findings	From Whose Perspective is Decision-Making Discussed?
enrolment in breast cancer clinical trials						care. Personal/family related concerns. Financial/logistics concerns.	
Jorgensen et al. (2013) [36] Adjuvant chemotherapy for colorectal cancer: age differences in factors influencing patients' treatment decisions	Australia	Surgical department in a single tertiary hospital. Colorectal cancer (crc).	To identify potential barriers to adjuvant chemotherapy, use in older patients by examining the associations between patient age, factors influencing chemotherapy treatment decisions, and preferences for information	Sixty-eight patients who underwent surgery for crc. Either categorised as <65 Mean age 49 years or > 65 years Mean age 73.9 years	Self-administered survey. Using a 10 cm visual analogue scale, participants were asked to rate how important various factors were (or would be) when deciding about chemotherapy treatment	Health concerns may add to complexity of balancing risks and benefits of treatment for older adults Without formal assessment, physicians might assume that older patients would not travel for adjuvant chemotherapy or that they do not want information on their prognosis and treatment.	Perspective of younger and older adults undergoing surgery for crc
Karuturi et al. (2022) [19] Exploring and supporting older women's chemotherapy decision-making in early-stage breast cancer	United States of America	Cancer centre. breast cancer.	To investigate perspectives of older adults with breast cancer on neo/adjuvant chemotherapy decision making process	26 women aged between 65 and 92 with a breast cancer diagnosis. Mean age 74 years.	Survey: sociodemographic/ health literacy/ numeracy /Shared decision-making and semi structured interviews exploring perspectives, experiences, and values regarding treatment.	Need for information regarding disease and treatment. Previous experience of friends and family with cancer diagnosis. Self-perception of health and chemotherapy. Maintaining quality of life throughout treatment	From the perspective of the older woman with breast cancer
Mandelblatt et al. (2012) [23] Patient and physician decision styles and breast cancer chemotherapy use in older women: Cancer and leukaemia group B protocol 369,901	United States of America	75 hospital s/practices affiliated with cancer and leukaemia Group B (CALGB) cooperative group. breast cancer.	To evaluate associations between patient and physicians decision-making styles and actual treatment (older adults and cancer)	1174 women (Mean age 73 years) seen by 212 oncologists	Observational study. Data collected from women treated outside of clinical trials for newly diagnosed stage I to III breast cancer (83% response). Physicians completed a survey (91% response), and clinical data were abstracted from charts.	One-third of women preferred to make their own treatment decision. Patient and physician decision styles were independently associated with chemotherapy.	Older women with breast cancer and oncologists
Paillaud et al. (2017) [37] Preferences about information and decision- making among older patients with and without cancer	France	Teaching hospital Various cancer types.	To compare older patients with and without cancer regarding their preferences about medical information, decision- making and surrogate designation	Older adults with cancer group 133. Mean age 80 years.	Intention-to-act questionnaire was completed by patients $\geq$70y enrolled in the Elderly Cancer Patients cohort between January and June 2013 and by patients in the same age group enrolled in a cross-sectional survey conducted in 2005 in acute geriatric wards.	Older patients with cancer expressed a strong preference for receiving information and participating in decisions about their care.	Older adults with cancer (various tumour sites)
Puts et al. (2017) [38] Chemotherapy treatment decision-making experiences of older adults with cancer, their family members, oncologists, and family physicians: a mixed methods study	Canada	Cancer centre. various cancer types	To better understand the treatment decision process from perspective of older adults with cancer, their families and healthcare providers.	Purposeful sampling. 38 70–79 and 80 years. Mean age not stated.	Mixed method longitudinal study. Semi-structured interviews and surveys.	Themes per each group: Older adults – • Relationship with the oncologist • perceived benefits and harms/discomfort • Treatment experience s of important others/ family influences	Older adults with cancer, their families, and healthcare providers.
Schonberg et al. (2014) [39] Older women's experience with breast cancer treatment decisions	United States of America	3 breast imaging centres	To better understand older women's experience with breast cancer treatment decisions.	English speaking women, not living with dementia, over the age of 65	Longitudinal study. Women interviewed at the time of breast biopsy (before they knew their results) and 6 months later	Older women are less engaged in breast cancer treatment decision-making than younger women and tend to accept	Older women with breast cancer

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Table 2 (*continued*)

Author, Year, Title	Country	Setting & Cancer Type	Aim of Study	Sample	Design, Data Collection & Analysis	Main Findings	From Whose Perspective is Decision-Making Discussed?
				years. Mean age not stated.		treatments recommended by their physicians. Ideally, older women's breast cancer treatment decisions would consider life expectancy, risk of recurrence, and preferences	
Sowerbutts et al. (2015) [24] Why are older women not having surgery for breast cancer? A qualitative study	United Kingdom	Teaching hospital. breast cancer.	To explore reasons why older women are not having surgery for breast cancer.	Twenty-eight women over 70 years old. Mean age 86 years.	In-depth interviews were conducted with operable breast cancer receiving primary endocrine therapy as their primary treatment. The interviews focused on their perceptions of why they were being treated with PET rather than surgery. Transcripts were analysed using the Framework method.	Patient declined surgery - Perceptions about age, attitude to diagnosis, attitude to operations/ hospital stays. Patient considered surgery - Surgery as a fallback option, adjuvant treatment, aftereffects of operation, influence of wider family. Surgeon decided against surgery.	From the perspective of the older woman with breast cancer
Yilmaz et al. (2023) [18] The role of self-perceived age in older adults considering adjuvant chemotherapy	United States of America	Cancer institute and affiliated satellite locations. various cancer types	Exploration of how decisions about adjuvant chemotherapy vary with or are related to older adults' self-perceived age.	21 older adults aged between 71 and 91 (mean age 78 years old).	Secondary analysis of a multi phased feasibility pilot using convenience sampling with medical professionals, patients, and caregivers. Primary study interviews to gain better understanding of how older adults make decisions about adjuvant chemotherapy. Analysed using constant comparison method	Decision making about chemotherapy is influenced by self-perceptions of age.	Older adults

geriatricians, or physicians [38].

3.2. Methodological quality

The Mixed Methods Appraisal Tool (MMAT) features five questions for each methodology: qualitative studies, quantitative descriptive studies and mixed methods studies [21]. Criteria were fulfilled for all studies concluding all studies were of sufficient quality which may improve the reliability of the analysis. There was adequate discussion in all the studies of the evidence both for and against the researcher's arguments [18,19,22,24,31,33,38,39].

3.3. Summary of findings

The studies have been characterised by groupings rather than describing each study individually, this allows for identifying patterns within the body of reviewed evidence [30] The results demonstrate consistencies in the data.

3.4. Results of the synthesis

The synthesis generated four themes supported by 11 subthemes.

1. Preconditions in decision making - identifying frailty and setting goals.
2. Preferences, choice, and the need to maintain independence.
3. The influence of information provision.
4. Support during the decision-making process, role distribution, and trust in physicians.

1. Preconditions in decision making - identifying frailty and setting goals

The risks and benefits of cancer treatment can be influenced by a person's level of frailty, which may increase with chronological age [6], and some of the studies in this review considered this a factor when setting cancer treatment goals with older adults [33,34,38]. In the study that included older adults with cancer, their relatives and their health professionals, the influence of frailty was not discussed by any of the participants [38]. One oncologist referred to a person's “frail status” when considering which treatment to recommend but most reported they rarely had any difficulty in making a recommendation for treatment, despite several of them not considering functional status (performance status) when weighing up risks and benefits [38].

No studies evidenced the discussion of frailty with older adults or their family members during their consultations with the cancer care team. However, one study observed that people living with frailty and lung cancer were more likely to convey a conservative view towards active treatment and that poor health was a significant factor in whether to opt for lung cancer treatment [34].

Contrasting views about the importance of considering overall health status in decision-making were observed between the various people involved. Older individuals with a range of cancer types, their family members, and oncologists did not consider multi-morbidities when making decisions, while family physicians considered the existence of

Codes identified
Information needs to support decision making
Source and format of preferred information
Ideal information sources and formats
Preconditions in decision-making - Identifying frailty and goal setting
Doctor's capacities – Trustworthiness
Content of decision-making process, impact treatment opinions in daily life
Facilitators of the decision making process – Role distribution in decision making
Training and education – Identifying frailty, shared decision making and general communication.
Correlation between improved care and good communication
Preference and choice
Role distribution

Categories identified: findings related the efforts and contributions associeated with decsion making (People felt more empowered to make decsions when .... happened); findings relating to the views about relationships between clinican and patient (People have greater trust in a phsycians's recoemndations when...) ; findings realting to the feelings and views about role and contributions (People identified their own role in decsion making but having ....as part of the decsion making team helped); and findings relating to communication and decision making (decision making can be improved when communication is....)

Themes
1. Preconditions in decision making - identifying frailty and setting goals.
2. Preferences, choice and the need to maintain independence
3. The influence of Information provision
4. Support during the decision-making process, role distribution and trust in physicians

Fig. 2. Model of coding for synthesis.

multi-morbidities highly relevant [38]. Reasons given for this were that their long-term conditions were being treated (patient group), multi-morbidities played no role in the process of making decisions about treatment (family members), or that most of the patients were regarded as fit, therefore, multi-morbidity was not relevant (oncologists). Instead, oncologists used the phrase "fit enough" (for treatment) [38].

Colorectal and pancreatic cancer physicians consisting of surgeons and geriatricians as well as general practitioners (family physicians) and residents discussed the requirement of identifying frailty using frailty identification instruments [33]. This was done within the context of talking to older adults about their life goals when considering treatment options, although the term frailty was not explicitly used:

> *"We need to look at the goals and expectations of the life that still needs to be lived, and the wishes of the person living it."* Internist 1, [33]

The same surgeons also acknowledged they needed more support and training to be able to identify frailty in the older population with cancer:

> *"The other thing I would really like to do is spend a day with you all at the Geriatric clinic, just to see what you all do."* Surgeon 1 [33]

Multi-morbidity was a factor that family physicians believed was not seriously considered during the cancer treatment decision making process. Although the importance of identifying frailty and multimorbidity was considered by clinicians in some studies, they did not discuss it with the older adults and their family members under their care to help inform their decision making or provide rationale for why some treatment decisions were made [33,34,38].

2. Preferences, choice, and the need to maintain independence.

This theme explores how older adults navigate treatment decisions and highlights the importance of respecting older adult's preferences, the role of clinician communication skills and the critical value placed on maintaining independence and quality of life over simply prolonging life.

Ensuring older adults were given time and space to make choices based on their preferences for treatment was discussed in some but not all the included studies [31,39,40]. In one study, several women reported not being given a choice of treatments, though the authors dismissed this as due to issues with the respondent's recall or differences of perception regarding what choice is within this context [31]. They suggested that two treatments may have been offered which would represent a choice, but the physician would place emphasis on one treatment over the other. Indeed, the greater the level of discussion between the surgeons and women, the more choice is perceived to have been offered [39].

In addition to information giving about the disease and the risks and benefits of treatment, patient preferences were included as one of the main factors required when discussing treatment options of lung cancer [40]. Patient preferences, physicians' attitudes, and patient-physician communication are important factors to consider together, especially when the risks and benefits of treatment are equal [31].

Maintaining independence, or quality of life over quantity of years, featured in some of the studies, particularly as some participants with breast cancer reported not wishing to receive treatment that would impact on their current fitness levels [24]. Older adults with breast and colorectal cancer [36] reported that maintaining a good quality of life during treatment and returning to normal quality of life following treatment were important factors when making decisions about treatment.

> *"When you decide on treatment, you weigh the quality of what you have left of your life. I want the quality of my life to be more fun. I want to go swimming and golfing and visiting and doing the fun things I want to do. I don't want to sit with a needle in my arm, being sick and having chemotherapy…" P26* [19]

Being provided with information about how treatment would affect independence was deemed helpful by women with breast cancer across the full age range (75–99 years) [31]. Independence was even a factor in some women who were over 80 years old (mainly over 85 years) who declined breast cancer treatment [24]. While prolonging life was not always viewed as a realistic aim for women in this study, maintaining their current level of independence was:

> *"It's very important that I keep not depending on people, I know I depend on shopping and all that but it's such as changing and taking me to the toilet".* PT6 [24]

Study participants did not always explicitly refer to independence or quality of life as a consideration in decision-making, although not wanting invasive treatments to negatively affect precious time left was a common reason to decline treatment [24]. While some older adults are offered choices in treatment, others feel their preferences are overlooked or shaped by physician bias. Effective communication enhances the perception of choice, especially when treatment risks and benefits are balanced. Across various cancer types, many older adults prioritise maintaining independence and quality of life over aggressive treatments that may compromise their current well-being. Even among those aged 85 and older, preserving autonomy in daily activities often outweighs the goal of life extension. However, the idea of treatment as a means to *increase* independence was notably absent from the literature.

3. The influence of information provision

Four studies identified that the act of information giving and how this is done has the potential to influence how older adults make decisions [31,35,37,38]. For instance, older women with breast cancer expressed regret that they had not been given more information about further treatment and duration of ongoing treatments [31]. There was age variation in preference for information about cure rates: 82% of those aged 90 years and above cited the helpfulness of this information compared with 35% in the younger age group of 75–79 years [31]. However, whilst older adults with cancer have different information preferences, these preferences do not always impact how much they are involved in decision making about treatment options and supportive care [37].

The provision of sufficient information to make an informed decision was important for older adults in this review. Being fully informed about their diagnosis and treatment was a top priority as they considered it would facilitate their full involvement in decision-making about treatment and care [37]. However, many older adults did not feel that they received sufficient information, with one study reporting that the majority of participants believed they would receive more detailed information about their breast cancer if they participated in a clinical trial [35]. Family play an important role in decision-making and in the gathering of information to support informed choices. Adult children were often actively involved in sourcing additional information regarding treatment options, and more so than spouses [38].

The optimum form of information giving was face to face during clinic appointments and most preferred this to be with a doctor rather than a nurse (81% compared with 37%) [31]. Although verbal information provided by healthcare professionals was considered most helpful, additional information in the form of leaflets and booklets, enhanced by conversations with their family physicians, family and friends were regarded as useful sources of information to inform treatment decision making [31]. Family members preferred not to receive information over the phone as they feared it could lead to miscommunication [38]. The availability of internet access was an important influence on preference, with one study reporting that many participants did not have access [31].

4. Support during the decision-making process, role distribution and trust in physicians

The support systems that influence older adult's cancer treatment decision-making processes may be multifaceted. The literature conveyed different roles played by family members, healthcare professionals, and the importance of trust in physicians, highlighting how emotional, relational, and informational factors shape decision-making dynamics. Many of the older adults in the included studies found that having a family, friend, or healthcare professional such as specialist nurse or family physician to share decision making was a great support during the process. Although 70% of older adults diagnosed with cancer expressed a wish to have a role in the decision-making process, they found it would be acceptable to defer decision making authority to a surrogate such as a family member in the event of losing competence to make decisions [37]. Having a third person, usually a family member present during the consultation process was deemed essential [33]. This was because older adults felt that emotions associated with their cancer diagnosis could impact the decision-making process, while family members were often less affected by emotions so able to summarise the information and ask crucial question [32]. Some family members felt uncomfortable asking questions specifically about prognosis, even though they wished that treatment would lengthen life [38].

Although having family members to either offer practical support with decision making or to act as a surrogate decision maker was often viewed as helpful, there were instances of differing views between the person diagnosed with cancer and their family member. For instance, older adults often preferred conservative management to aggressive treatment because their main goal was to improve the quality of their lives rather than prolonging their life with painful interventions which would involve lengthy rehabilitation. Their family members however, preferred aggressive interventions in the hope that it would extend their relative's life [22].

Having a specialist nurse to recap on what was discussed, help explain the information provided in more detail, and offer psychosocial support was also considered helpful:

> *"Yeah, there are so many meetings, and you get so much information, at a certain point it starts going in one ear and out the other. But my son came with me a few times, and he asked whether the meeting could be recorded, so he could listen to it at home again afterwards."* P475 [33]

In addition to specialist nurses and family members, the family physician's role in the decision-making process was highlighted [33,38]. This was because the family physician's wealth of background knowledge amassed from their longer relationship with the older adult meant they could share information regarding their frailty, their medical history, and knowledge of their home situation. One family physician felt that viewing the person's needs together with the specialist; and taking into consideration their life goals and expectations, can support older adults in their decision-making by summarising information about treatment options and risks versus benefits [38]. While women in that study voiced a willingness to be more involved in treatment decision making, highlighting the importance of being included earlier in the diagnostic process rather than solely towards the end of life, their oncologists felt that family physicians could not add value to the decision-making process because they lack specialist cancer experience and knowledge [38].

As people often delegate decision making to the physician as the expert, trust is a significant factor in the decision-making process and was introduced in several studies [19,33,36,38]. Good communication skills and showing empathy led older people and their significant others to experience greater trust in their physician [33]. Given that they often believed they had to defer decision-making to their physician, trust was cited as an essential component of decision-making. Trust was required in choosing to make decisions on their own or delegating decisions to health care professionals. A study of chemotherapy decisions for breast cancer reported contrasting findings: 30% of women preferred to make these decisions by themselves with some input from their physician, whilst 41% opted for decision making to be equally shared [23]. Trusting in the medical team's expertise and being assigned a doctor with whom older individuals felt comfortable asking questions was reported in two studies. [19,33].

> *"To weigh the treatment options, we count on intelligent doctors advising us"* NC, P09 [19]

Trust is not only an important factor for the older adults with cancer, but family members also reported the importance of trust in their relative's oncologists to make the most appropriate recommendations based on their expertise [38].

Older adults often value shared decision-making, drawing support from family, friends, specialist nurses, and family physicians. While many wish to be involved in decisions, they are also open to delegating authority, especially in cases of cognitive decline. Family members frequently attend consultations to help process complex information, though their preferences may sometimes conflict with those of the patient—particularly when balancing quality of life against life-extending treatments. Specialist nurses and family physicians provide crucial emotional and contextual support, though their roles are sometimes undervalued by oncologists. Trust in physicians emerges as a central theme, influencing whether older adults choose to make decisions independently or defer to medical expertise. Effective communication and empathy are key to building this trust, which is also vital for family members who rely on clinicians to guide treatment choices [38].

4. Discussion

This review sought to explore the range and nature of published evidence exploring the experiences of older adults, their significant others, and healthcare professionals when decisions regarding cancer treatment and support are made. Fourteen studies were included, and four themes were generated from the synthesis, outlining the factors that impact decision-making for and with older adults diagnosed with cancer.

We found that older adults rarely reported the availability of choice in decision-making around cancer treatment and support. This is in stark contrast to studies of younger adults, suggesting that older adults with cancer experience a disadvantage in care marked by less involvement in decision-making [42]. There is a need to acknowledge the potential for ageism in cancer care [43]. We support the call for healthcare professionals to make a concerted and overt offer of choice to enable older adults to make informed decisions about their care [44]. This will require deeper relationships between older adults and their physicians to support them to build trust in those who provide their care [45].

There are recognised challenges to applying the principles of SDM within the context of older adults' healthcare. To do this process well, sufficient time is needed and may require several opportunities for information exchange between HCPs and individuals [46,47]. SDM may be negatively affected by the presence of cognitive impairment [46]. In such cases, involving family members in decision making at the point of investigation of cancer in primary care is recommended, and applying the principles of comprehensive geriatric assessment (CGA) can improve personalised care and support planning [46,48]. Whilst a feasibility study proved combining Question Prompt Lists (QPL) with geriatric assessment improved SDM in the oncology setting, a larger scale trial is required [49].

Improving cancer care for all is a priority, and CGA is acknowledged as a useful means to identify multi-morbidity and functional challenges in older adults. Applying the principles of CGA in cancer decision-making can support cancer clinicians to balance benefits and harms alongside the older adult's values and preferences [50]. Indeed, CGA within the context of oncology has shown to reduce treatment toxicity [13,51], improve treatment completion [52] and improve function [13,51–53]. Accordingly, the International Society of Geriatric Oncology and The American Society of Clinical Oncology recommend CGA in cancer care for older adults [54,55]. By using CGA to focus on functional status, multi-morbidity, nutritional status, cognitive impairment, and psychosocial support, it becomes possible to create individualised cancer treatment plans in collaboration with the older adult with cancer [56].

This review has found that the presence of a significant other or supportive healthcare professional who knows the individual well (cancer specialist nurse or family physician) during consultations is valued by many older adults as they make decisions around their cancer care. In some studies, this was less recognised by oncologists or surgeons to be a relevant factor, suggesting a mismatch between the preferences of older adults and those providing their care. This mismatch may also exist between the older adult and their family members, who may experience a high level of responsibility within the context of decision making with differing views from those of their relative [48]. Clinicians could attempt to overcome this by practicing the principles of SDM, promoting a co-productive approach between older adults, their significant others, and HCPs to promote trust between all contributing parties [57].

Only one study considered the perspective of older adults, their family members, and health care professionals [38]. There is a research need to understand the efforts and contributions to decision making from the perspective of the older adult, their significant others, and healthcare professionals and to characterise the communication relating to decision making between these three groups [58,59]. This under-representation has resulted in limited perspectives of interest holders with the potential of not capturing all views. Research which is predominantly physician focused could potentially neglect the collaborative nature of healthcare where nurses and allied health professionals have significant roles. Future studies are needed which specifically include significant others, nurses, and allied health professionals, particularly as these professionals are key members of the cancer multi-professional team [51,60,61]. Moreover, many of the studies took place in institutions through dedicated clinical trials that may not reflect the attitudes of older adults diagnosed with cancer within the broader general population.

5. Strengths and Limitations

There are several strengths to this review. The review employed systematic methods to identify relevant studies. The methods used to conduct the search and inclusion/exclusion criteria have been described in detail to convey the efforts taken to minimise bias where possible. A further strength is that the inclusion criteria captured multiple cancer types and geographic locations. While several studies involved multiple cancer types, many of the studies had a homogenous patient group, for example, breast cancer or lung cancer. This may compromise the transferability of the findings due to either being single sex or differing treatment/prognosis trajectories. To meet the inclusion criteria, studies had to have a lower age limit of 65 years. Two included studies included a younger adult comparison group to understand the role of age in cancer decision-making [35,36]. By setting the inclusion criterion as studies that included participants aged 65 and over, we may have included some studies with a relatively younger overall sample, meaning some studies with a mean age below 65 were retained. This could affect the transferability of the review's findings to older adults, as these samples may not fully represent the experiences of this age group. Transferability could be further reduced by the dominance of studies from North America and Europe, or by our exclusion of studies published in languages other than English.

The inclusion criteria deliberately excluded end of life care studies; we acknowledge that an opportunity to capture valuable data on why older adults might decide to decline active treatment has been missed. A software programme was not used to organise and code the large volumes of text which may have improved efficiency, enable depth and refinement of the analysis.

6. Conclusion and Recommendations

Most included studies reported the views of the older adult or health care professionals (predominantly physicians, either oncologists, surgeons or family physicians). However, there is a paucity of evidence representing the views of the older adult's significant other and exploring the efforts and contributions of all people involved in the process of decision-making.

Research is needed urgently to understand how and why decisions are made regarding cancer treatment and support, as well as how older adults are involved in these decisions throughout their cancer trajectory. Longitudinal studies should be used to determine decision-making over time and understand how they vary throughout the cancer trajectory.

Understanding this would assist healthcare professionals to prioritise an individual's healthcare preferences with the potential to positively influence service delivery and workforce development. Through greater understanding of perceived barriers to treatment and unique motivators for treatment choice, older adults may be better supported to make fully informed decisions. The recommendation would be for the principles of SDM to be at the forefront of cancer services accessed by older adults. If done well, the CGA process, particularly the aspect of person centred plans, promotes understanding between the HCP, the older adult, and their significant other and respects the capability and knowledge of all parties whilst equalising the balance of power [62]. Policy makers should work to include SDM as part of the CGA process as standard for all older adults accessing cancer care. The inclusion of HCPs specialising in the care of older adults and frailty as integral members of the cancer multi-professional team will be essential for the successful implementation of this model. Increased workforce training specific to identifying frailty, appropriate care planning, and SDM will enable this to be embedded into practice.

Author Contributions

LL, NF, HP participated in the conception and conduct of the study. LL coordinated the review. LL, KH, RW acquired and reviewed. All authors reviewed and edited the final version of the manuscript.

Ethics Approval and Consent to Participate

Not applicable.

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Declaration of Competing Interest

All authors declare that they have no competing interest.

Appendix A. Supplementary Data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jgo.2025.102716.

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