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General and Supportive Care

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# ABSTRACT

*Background:* Cancer is a disease that affects mostly older adults. Older adults often have other chronic health conditions in addition to cancer and may have different health priorities, both of which can impact cancer treatment decision-making. However, no systematic review of factors that influence an older cancer patient's decision to accept or decline cancer treatment has been conducted.

*Materials and methods:* Systematic review of the literature published between inception of the databases and February 2013. Dutch, English, French or German articles reporting on qualitative studies, cross-sectional, longitudinal observational or intervention studies describing factors why older adults accepted or declined cancer treatment examining actual treatment decisions were included. Ten databases were used. Two independent reviewers reviewed manuscripts and performed data abstraction using a standardized form and the quality of studies was assessed with the Mixed Methods Appraisal Tool.

*Results:* Of 17,343 abstracts reviewed, a total of 38 studies were included. The majority focused on breast and prostate cancer treatment decisions and most studies used a qualitative design. Important factors for accepting treatment were convenience and success rate of treatment, seeing necessity of treatment, trust in the physician and following the physician's recommendation. Factors important for declining cancer treatment included concerns about the discomfort of the treatments, fear of side effects and transportation difficulties.

*Conclusion:* Although the reasons why older adults with cancer accepted or declined treatment varied considerably, the most consistent determinant was physician recommendation. Further studies using large, representative samples and exploring decision-making incorporating health literacy and comorbidity are needed.

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# Introduction

Cancer is a significant health problem in older persons. With the aging of the population there will be a considerable increase in the

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number of older adults diagnosed with cancer. It is estimated that 42% of all incident cases and over 60% of mortality due to cancer occur in persons aged 70 and over [1,2].

Older persons with cancer are under-represented in clinical trials, especially frail older persons with co-morbidities, leading to gaps in knowledge around optimal treatment [3–5]. Older adults who are included in clinical trials may not be representative of older adults with cancer in general. Research has shown that older adults suffering from cancer have been under-investigated and under-treated [6–9]. Cancer-directed treatment options have changed in recent years and more "elderly-friendly" treatments have been developed (e.g. oral single-agent chemotherapy)

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[10–13]. The older population is very heterogeneous with regard to health, functional, psychological, social, cultural and economic status. Physiologic functions such as renal, cardiac and pulmonary function decline with age, and these influence the risks and benefits of treatment. Studies have shown that there is more variation in treatments offered (including therapeutic adaptations and number of treatments offered) by cancer specialists to adults with increased age and declining health, suggesting increasing difficulty in identifying and recommending the most appropriate treatments in this population [14–17]. The treatment decision for older adults can be difficult, as older adults often have other diseases in addition to cancer. These other diseases can impact on life expectancy, treatment effectiveness as well as treatment tolerability. Beyond comorbidities, other factors may influence treatment decisions differently in older adults compared to younger adults; older adults have different social support systems, sensory impairment, changes in cognition, lower levels of education, and possibly lower levels of health literacy which can all affect treatment decisionmaking. In addition, older adults may have different priorities than younger adults (e.g. less willing to trade quality of life for survival prolongation [18].

Refusal of recommended therapy and underuse of treatment have been shown to be more common in older adults and these have been shown to lead to negative outcomes, such as increased cancer recurrence rates and poorer survival rates which have been studied most extensively in older women with breast cancer [8,19,20]. There have been several studies examining older adults' decision-making processes and reasons for refusing cancer treatment, and several narrative reviews of treatment decision-making [21–23], as well as a recent review by Tariman et al. [24] that focused on decision-making models in cancer treatment decision-making. However, until now no systematic review of factors influencing older cancer patients' decisions to accept or decline cancer treatment has been performed. Understanding these factors is of clinical relevance to health care professionals trying to enhance treatment adherence, reduce errors, and improve outcomes. Gaps in current understanding are also important to identify as they can inform future research. Therefore, we conducted a systematic review with the primary objective of synthesizing all factors influencing older adults' decisions to accept or decline cancer treatment proposed by their physicians. In particular, we were interested to determine if the factors influencing older adults' decisions to accept or decline cancer treatment varied by cancer stage, cancer type, cancer treatment, and age (younger old (65-74) and older old (75+)).

# Materials and methods

#### Search strategy and selection criteria

This review was based on a systematic, comprehensive search of ten databases from inception to February 2013 including the Cochrane Central Register of Controlled Trials (CENTRAL), MED-LINE, EMBASE, Cumulative Index to Nursing and Allied Health (CINAHL), Allied and Complementary Medicine (AMED), Psych-INFO, Ageline, Sociological Abstracts, Web of Science, and Applied Social Sciences Index and Abstracts (ASSIA) databases. A study was eligible for inclusion if it reported on reasons why older adults with cancer (i.e. mean age study population 65 years or over or if the study mean/median age was <65 but reported results on a subgroup analysis of older adults with a mean/median age  $\ge 65$ ) accepted or declined cancer treatment and were published in English, Dutch, French or German. Study designs could be quantitative or qualitative, cross-sectional or longitudinal. Editorials, case studies, reviews, expert opinion papers and studies that were published as abstracts only were excluded from the review. The following sets of keywords or free text words were used in combination with subject headings where available: cancer (including the keywords/ subject headings and free text words including cancer, neoplasm, oncology, etc. all combined with OR) AND aged 65 and older (including the keywords/subject headings aged, geriatrics, older adults, elderly etc. all combined with OR) AND decision making (including the keywords/subject headings decision making, choice behavior, patient acceptance of health care, patient participation, treatment refusal, etc. all combined with OR). See Appendix A for the search strategy as used in Ovid Medline. The literature search was performed by an experienced university librarian.

The final studies included in this review were selected in two steps (see Fig. 1). During the initial study selection process, two independent reviewers selected manuscripts for subsequent full text review based on their titles and abstracts. When at least one reviewer was uncertain about whether the article fulfilled the inclusion criteria, it was included for full-text review. In the second selection step, the full-text articles were reviewed independently by the same authors. Disagreements between reviewers were resolved by consensus (this process was used for eight studies). If multiple articles reported similar results, only the article with the most complete information was retained. For all articles for which no mean/median age was reported, we contacted the study authors to obtain details on age. If no response was received after at least three attempts, the articles were not included.

We also reviewed the reference lists of all selected articles to identify any additional relevant articles, but no additional studies were identified. When an article referred to additional publications for more details concerning study methods and design, those publications were also acquired.

During the data abstraction process it became clear that the studies examining factors influencing acceptance or refusal of recommended cancer therapy using the actual treatment situation of the study participants (e.g. reflecting on why they had made the treatment decisions they had for their cancer until the time of the study) were conceptually and methodologically distinct from those examining cancer patients who were presented with a hypothetical cancer treatment situations and were asked to make

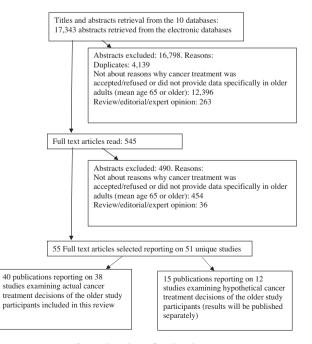


Fig. 1. Flow chart of study selection.

treatment decisions while imagining having this cancer (i.e. the participant could be asked to make a cancer treatment decision for a different cancer diagnosis and stage than their own diagnosis). Thus, considering the large amount of data and methodological differences, it was decided to separate the review results into two papers and results concerning hypothetical decision-making will be summarized in a separate paper.

#### Data abstraction

The same reviewers who performed the article selection process conducted independent data abstraction. The abstracted information included study design, aim of study, location of study, sampling method, source of data, recruitment type and timeline, characteristics of study participants, details on cancer diagnosis and treatment, details on how reasons for accepting/declining cancer treatment were collected, and details of statistical analysis, source of funding and whether or not authors had declared any conflict of interest. If any aspect of the study design was unclear, the authors of the study were contacted.

#### Quality assessment

Both guantitative and gualitative studies were included in the review. To determine the quality of the individual studies included in the review, two reviewers (MP and BT) independently scored studies using the Mixed Methods Assessment Tool (MMAT) [25] which can be used for mixed methods research and mixed studies reviews (MSR). The reliability of the MMAT [25] was tested by the scoring system's developers, and inter-rater reliability was found to be moderate to excellent. The tool was also found to be very user-friendly. The 2011 MMAT scoring system contains five types of mixed methods study components or primary studies in a MSR context, each with its own set of methodological quality criteria based on existing published criteria. For each item the answer categories were 'yes', 'no', or 'can't tell' followed by comments. The five types of mixed methods study components or primary studies included in the MMAT are (1) qualitative; (2) quantitative randomized controlled trials; (3) quantitative non-randomized; (4) quantitative descriptive; and (5) mixed methods. No study was excluded based on the quality assessment as we wanted to provide an overview of all factors important to older adults reported in the literature.

# Results

We reviewed 17,343 titles and abstracts for eligibility in the first step in which we selected (see Fig. 1). Fifty-five manuscripts reporting on 51 unique studies were selected; 40 publications reporting on 38 unique studies examined factors influencing the older adult's decision to accept or decline treatment examining the actual cancer treatment decision taken by the study participant and are included in this manuscript [19,26–64], the 12 other studies examined hypothetical treatment decisions and will be reported separately. The percentage identified below refers to the total of 38 studies in the results section. In four manuscripts, there were two publications reported on the same qualitative study but reporting new results, and thus both manuscripts were included for both studies [26–29]. All but two of the included manuscripts were written in English, the other two were written in French [28,29].

#### Quality assessment

The quality of the studies ranged from poor to good but was moderate for most studies, see Table 1. We tried to contact study authors of most studies to get additional information on study methods used, but as many studies had been published a while ago when reporting standards were less clear, for most studies one or more aspects of the methodology used were not described in sufficient detail. For the qualitative studies, there was little information provided on the data analysis, the context in which the data were collected and the interaction between researcher and participants [28,29,32-34,36,39,42,48-50,52,54,59,63]. For the quantitative studies (n = 20), response rates were not reported (40%) or were below 60% (10%), the sample strategy method was unclear (20%), the measurement instrument used was newly developed and no information was provided on the psychometric properties for this new tool [19,30,31,37,38,41,44,45,47,51,53, 57,58,60,61].

## Characteristics of the included studies

Characteristics of the included studies are shown in Tables 2 and 3. Eighteen studies used a qualitative study design [28,29,32– 36,42,43,48–50,52,54,59,63–65], eight studies used a retrospective observational design [19,30,38,44,46,51,53,55], seven studies used a cross-sectional observational design [45,47,58,60-62], and five studies used a prospective observational design [31,37,40,41,57]. Almost all studies used primary data collection [26-29,31-33,35-50,52-54,57-60,63-65] or retrospective chart reviews and/or administrative databases [19,30,51,55,61]. Two studies used random sampling techniques [37,38], five used consecutive sampling techniques [41,53,57,60-62], four studies used convenience sampling techniques [34,42,56,58], 13 studies used purposive/other qualitative sampling techniques [26,27,32,33,35,36,39,43,49, 50,52,54,59,63,64], four studies used other methods [19,46,51,55] and nine studies [28-31,40,44,45,47,48] did not describe the sampling methods used. Sample sizes in the studies using qualitative methodologies ranged from six [33] to 102 [48] and the response rate varied from 12.5% [34] to 100% [54] and was not reported for five studies. The sample sizes for studies using quantitative methodologies ranged from 20 [40] to 5339 [19] and the response rate varied from 57% [44] to 90% [37] and was not reported for eight studies.

#### The characteristics of treatment decisions studied

See Tables 2 and 3 for the description of the studies and Tables 4 and 5 for a description of the treatments studied. For 19 studies it was not reported if cancer patients had received cancer treatment prior to the time the study was conducted [19,26–30, 33,34,36,38,46,49,51,53–55,57,59,63,64], in nine studies participants had not yet received cancer treatment [31,35,37,39–41, 44,45,60], and in ten studies some or all participants had already received treatment [32,42,43,47,50,52,56,58,61,62]. For the five quantitative studies which reported the number of study participants declining treatment, it varied between 0% [31,41,44,45] and 50% [51]. In six qualitative studies the percentage of participants that declined treatment varied between 0% [39,48,50,52] to 100% [59,64] (these studies focused on reasons for decline only).

In terms of what treatment-decision making was studied, one of 38 studies focused on the treatment decision making process for cancer in general in participants with mixed cancers [26,27]. Two studies focused on a specific cancer treatment [28–30] (i.e. surgery or chemotherapy) for patients with mixed cancers. One study focused on cancer treatment decisions without specifying the type of cancer treatment in participants who had cancer but the type of

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Quality assessment using the Mixed Methods Appraisal Tool.<sup>a</sup>

•	rType of study	Screening questions	5:	Qualitative				Quantitative	descriptive		
published		A. Are there clear qualitative and quantitative research questions, or a clear mixed- methods research question?	B. Do the collected data address the research question?	1.1 Are the sources of qualitative data relevant to address the research question?	for analyzing qualitative data	1.3 Is appropriate consideration given to how findings relate to the context in which data were collected?	1.4 Is appropriate consideration given to how findings relate to researchers' influence through interaction with participants?	4.1 Is the sampling strategy relevant to address the research question?	of the population	4.3 Are measurements appropriate (clear origin, or validity known, or standard instrument)?	4.4 Is there an acceptable response rate (60% or above)?
Anchisi [29] <sup>b</sup>	Qualitative	No	Yes	Can't tell	Can't tell	Can't tell	Can't tell				
Anchisi [28] <sup>b</sup>	Qualitative	Yes	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell				
Ashley [30]	Cross- sectional	Yes	Yes					Yes	Yes	Can't tell	Yes
Cassileth [31]	Cohort	Yes	Yes					Can't tell	Can't tell	Yes	Can't tell
Chapple [32]	Qualitative	Yes	Yes	Yes	Can't tell	Yes	Yes				
Chouliara [33]	Qualitative	Yes	Yes	Yes	Yes	Yes	Can't tell				
Ciambrone [34]	Qualitative	Yes	Yes	Yes	Yes	Yes	Can't tell				
Cohen [35]	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes				
Crooks [36]	Qualitative	Yes	Can't tell	Can't tell	Yes	Can't tell	Can't tell				
Cykert [37]	Cohort	Yes	Yes					Can't tell	Can't tell	Yes	Can't tell
yran <mark>[38]</mark>	Retrospective Observational		Yes					Can't tell	Can't tell	Yes	No
Davison [39]	Qualitative	Yes	Yes	Yes	Yes	Yes	Can't tell				
Denberg [40]	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes				
iefenbach [41]	Cohort	Yes	Yes					Can't tell	Can't tell	Yes	Yes
ocherty [42]	Qualitative	Yes	Yes	Yes	Yes	Yes	Can't tell				
lit [43]	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes				
Gorin [44]	Cohort	Yes	Yes					Can't tell	Can't tell	Can't tell	No
Gwede [45]	Cross- sectional	Yes	Yes					Can't tell	Can't tell	Can't tell	Yes
Iall [46]	Cross- sectional	Yes	Yes					Yes	Yes	Yes	Yes
Hardy [47]	Cross-	Yes	Yes					Yes	Can't tell	Yes	Can't tell
Johnshee [40]	sectional	Vee	Vee	Vee	Vee	Vee	Capit tall				
Holmboe [48]	Qualitative	Yes	Yes	Yes	Yes	Yes	Can't tell				
Iusain [49]	Qualitative	Yes	Yes	Yes	Yes	Yes	Can't tell				
Kreling [50] .im [51]	Qualitative Retrospective	Yes Yes	Yes Yes	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	Can't tell	Yes
	Cohort	V	V	V.	V	X	N-				
O'Rourke [52] Petrisek [53]	Qualitative Retrospective Cross-		Yes Yes	Yes	Yes	Yes	No	Yes	Yes	Can't tell	Yes
	sectional										
Pieters [54]	Qualitative	Yes	Yes	Yes	Yes	Yes	No				
Richert-Boe [55]	Retrospective Cohort		Yes					Yes	Yes	Can't tell	Yes
anders [56]	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes				
andison [57]	Prospective Cohort		Yes		-		-	Yes	Yes	Can't tell	Can't tell
Schulman [58]	Cross- sectional	Yes	Yes					Can't tell	Can't tell	Can't tell	Can't tell
harf [59]	Qualitative	Yes	Yes	Yes	Yes	Yes	No				
inding [27] <sup>c</sup>	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes				
Sinding [26] <sup>c</sup>	Qualitative	Yes	Yes	Yes	Yes	Yes	Yes				
Fang [60]	Cross-	Yes	Yes	105	105	105	103	Yes	Yes	Yes	Can't tell
	sectional	103	103					105	103	103	Can't tell

cancer of the participants was not reported [33]. The other 34 studies focused on treatment decisions in a particular type of cancer. Eighteen studies focused on treatment decisions for prostate cancer; 12 for early/localized prostate cancer [32,35,39–41,44– 46,52,55,62,63] and three for advanced/metastatic prostate cancer [31,47,48] and three on treatment for all stages of prostate cancer [42,58,64]. Ten studies focused on breast cancer treatment decisions; six on early stage [38,49,53,54,57,61], none on advanced stage, and four were on breast cancer treatment in general or a particular breast cancer treatment [19,34,36,50]. There were three studies focused on treatment decisions for lung cancer [37,59,60], one for recurrent ovarian cancer [43], and two for colorectal cancer [51,56].

Reasons why older cancer patients accepted the recommended cancer treatment

See Tables 4–6 for a complete overview of reasons why older adults accepted the recommended treatment. Reasons included treatment convenience (16 studies), expectations about side effects (16 studies), treatment success rates (14 studies), being aware of the disease and prognosis (treatment is considered necessary to live, wanting to get rid of disease) (14 studies), trust/faith in the doctor (13 studies), treatment experiences of significant others (13 studies), physician's advice/recommendation (12 studies), wanting to live as long as possible and/or continue current lifestyle (7 studies), previous positive personal treatment/hospital experiences (6 studies), information received about the treatment (4 studies), and family support (2 studies). The reasons for acceptance were fairly similar across qualitative and quantitative studies, see Table 6.

Reasons why older cancer patients declined the recommended cancer treatment

See Tables 4–6 for a complete overview of all reasons why older adults declined recommended cancer treatments. Reasons for decline included fear of side effects (16 studies), unclear benefits of treatment (7 studies), having seen family members and friends experience side effects of treatment (7 studies), feeling high risk for treatment due to comorbidities/other medical issues (7 studies), feeling too old for treatment, current quality of life and comfort most important at their age (6 studies), belief in nonconventional treatments (4 studies), financial reasons (4 studies), distrusting physician/poor communication with physician/lack of information about the treatment (3 studies), transportation issues/travelling needed for treatment (3 studies), and side effects of treatment would make them dependent/burden on others 3 (studies), negative personal treatment experiences (2 studies).

The reasons for decline were fairly similar across qualitative and quantitative studies, see Table 6.

# Results of studies comparing different treatment options for one type of cancer

The studies focused on early stage prostate cancer comparing the different treatment options such as surgery, radiation, active surveillance/watchful waiting showed that important reasons for participants choosing surgery over other treatments included wanting to do something [32], best chance of cure [41,48], positive treatment experience of friends and family [41]. For choosing brachytherapy, reasons included minimal side effects and local treatment [40,46,63], less invasive and more convenient than surgery [41,48]. For participants choosing active surveillance/watchful waiting, reasons included trust in the physician [39], fear of incontinence or impotence, and lack of scientific evidence that other treatment options are better [32,39,44,48].

Yes Yes Can't tell Yes	Yes Yes Yes Yes	Yes Yes Can't tell Yes	Yes Can't tell Yes Yes	<sup>a</sup> As there were no randomized studies, quantitative non-randomized or mixed methods studies, these criteria are omitted from this table. <sup>b</sup> Anchisi [28.29] reports on the same study.
			Yes Yes	ed methods st
			Yes Yes	omized or mix
Yes	Yes	Yes	Yes Yes	ntitative non-rand
Yes	Yes	ve Yes	Yes Yes	l studies, quai e same study.
Cross- sectional	k Cross- sectional	Retrospectiv Database	keview Qualitative Qualitative	to randomized reports on the
Tang [61]	Van Tol Geerdink Cross- 1621	Verkooijen [19] Retrospective Yes	Ward-Smith [63] Qualitative Yes White [64] Qualitative Yes	<sup>a</sup> As there were no randomized studies, quan <sup>b</sup> Anchisi [28,29] reports on the same study.

Description of the qualitative studies.

First author & year published	Country	Study aim	Sample size & response rate	Mean/median age, years SD (range) <sup>a</sup>	% Women	Type of cancer & stage
Anchisi [29] <sup>b</sup>	France	To explore the process of patient's choice including goals, resources and constraints	21 66%	Median age women 76.5 (range 70–83) men 71.5 (range 70.3–75)	57	Mixed cancers All stages
Anchisi [28] <sup>b</sup>	France	To explore psychosocial factors that impact the chemotherapy decision	21 66%	Median age women 76.5 (70–83) men 71.5 (70.3–75)	57	NR NR
Chapple [32]	UK	To explore how men with prostate cancer make the decision to accept or decline watchful waiting recommended for their early prostate cancer	50 NR	(71-85)	0	Prostate All
Chouliara <mark>[33]</mark>	UK	To explore treatment decision making in older people with cancer	6 NR	(65–96)	67	NR NR
Ciambrone [34]	USA	To identify factors associated with primary therapy decision-making and how support persons influence women's choices	30 12.5%	Mean 77	100	Breast NR
Cohen [35]	UK	To explore the treatment decision-making experience of recently diagnosed men with early-stage prostate cancer	19 NR	Mean 74.42	0	Prostate Early (Stages 1 & 2)
Crooks [36]	Canada	To explore how older women live with breast cancer, integrate cancer into their lives and understand these experiences	20 NR	(66–94)	0	Breast Early (Stages 1 & 2)
Davison [39]	Canada	To identify and describe how men decided to go on active surveillance for their prostate cancer	25 56%	Mean 66	0	Prostate Early (Stage 1 & 2)
Denberg [40]	USA	To examine how men from working and middle-class make treatment decisions for localized prostate cancer (Veterans hospital patients)	20 NR	Mean 65 (54-80)	0	Prostate Early (Stage 1 & 2)
Docherty [42]	UK	To examine the impact of patient knowledge and awareness of prostate cancer on their medical process from initial symptom presentation to post treatment	9 patients and 3 spouses NR	Mean age of patients and their wives 71	0 for patients	Prostate NR
Elit [43]	Canada	To explore the treatment decision making process of	26	Mean 69	100	Ovarian Advensed (Steers 2, 4)
Holmboe [48]	USA	women with recurrent ovarian cancer To identify what factors men consider important when choosing treatment for prostate cancer and to assess why men reject active surveillance as a treatment option	67% 102 96%	Mean 66.4	0	Advanced (Stage 2–4) Prostate Early (Stage 1 & 2)
Husain [49]	UK	To examine why women aged 70 years and older chose primary endocrine therapy or surgery for breast cancer	21 70%	Mean 83.4	100	Breast Early (Stage 1 & 2)
Kreling [50]	USA	To examine attitudes of older breast cancer patients toward chemotherapy and the factors that influences their decision to accept or decline this treatment modality	34 NA	NR sample aged 65 or older	100	Breast Non-metastatic
O'Rourke [52]	USA	To examine how newly diagnoses prostate cancer patients and their spouses make initial treatment selections	18 couples 95%	Mean patients 67.6, wives younger	0 for patients	Prostate Early (Stage 1 & 2)
Pieters [54]	USA	To understand how older women aged 70 and over who have received early breast cancer treatment had experienced treatment decision-making	18 100%	Mean 76	100	Breast Stages I–III
Sanders [56]	UK	To explore which factors influenced patient involvement in the treatment decision-making process	49 observations NR	Subgroup older patients 65– 80 years	33	Colorectal Duke B, C, D
Sharf [59]	USA	To examine why patients declined further recommendations for diagnosis or treatment of lung cancer	9 43%	Mean 69.6 (48–80)	0	Lung Of the seven patients with a confirmed diagnosis, none had brain metastases
Sinding [27] <sup>c</sup>	Canada	To examine how older age affects cancer care from the perspectives of older women	15 35%	NR, all > 70	100	Breast & Gynecologic No evidence of metastatic disease
Sinding [26] <sup>c</sup>	Canada	To examine how older women with cancer make treatment decisions and how this is influenced by social locations	15 older adults and 4 health care professionals 40%	NR, all > 70	100	Breast & Gynecologic NR
Ward-Smith [63]	USA	To explore the impact of brachytherapy on quality of life	7 78%	Mean 69.5	0	Prostate Localized
White [64]	Canada	To examine why men with prostate cancer declined conventional treatment and choose CAM	78% 29 67%	Mean 67.5	0	Prostate NR

NR = not reported, NA = not applicable. <sup>a</sup> If mean/median age was available this information is reported with SD but if not the age data that was available from the study is reported. <sup>b</sup> Anchisi [28,29] reports on the same study. <sup>c</sup> Sinding [26,27] reports on the same study.

Description of the quantitative studies.

First author & year published	Country	Study design	Study aim	Sample size & response rate	Mean/Median age, years SD (range) <sup>a</sup>	% Women	Type of cancer & stage
Ashley [30]	USA	Retrospective	To evaluate the effect of our preoperative protocol and	200	Mean age 66 (14–91)	21	Mixed
		observational	patient selection on the relative frequency of continent urinary diversion and incontinent urinary diversion in patients treated with radical cystectomy	NA			NR
Cassileth [31]	USA	Prospective	To explore the feasibility of offering patients the	147	Median age patients on goserelin 69	0	Prostate
		observational	opportunity to select their own treatment	NR	(48–96), median age orchiectomy patients 71 (53–85)		NR
Cykert [37]	USA	Prospective	To identify potentially modifiable factors re surgery in	386	Mean 66	44	Lung
		observational	early-stage lung cancer and to explore why blacks undergo surgery less often	90%			Early (Stages 1 & 2)
Cyran <mark>[38]</mark>	USA	Retrospective	To describe factors associated with the type of surgical	198	Mean 72	100	Breast
		observational	procedure performed in older women with early-stage breast cancer	58%			Early (Stage 1 a 2)
Diefenbach [41]	USA	Prospective	To examine treatment decision-making among men	654	Mean 66	0	Prostate
		observational	with early prostate cancer	72%			Early (Stage 1 & 2)
Gorin [44]	USA	Retrospective	To study why patients on Active Surveillance had	105	Mean 65.5	0	Prostate
		observational	selected this treatment option	57%			Early (Stage 18 2)
Gwede [45]	USA	Cross-	To examine the treatment decision-making process in	119 (67 with brachytherapy	Mean study age 62 but for patients in	0	Prostate
		sectional	men with early prostate cancer and which demographic, clinical, cognitive and affective factors were associated	and 52 with radical prostatectomy) 84%	the subgroup brachytherapy 65.2		Early (Stage 1 2)
Hall [46]	USA	Retrospective	with the treatment selected? To examine if patients would choose the same treatment	262	Radical prostatectomy group mean	0	Prostate
	UJA	observational	again	75%	62, Brachytherapy only mean 66, brachytherapy in combination with external radiotherapy mean 70	0	T1c-T3
Hardy [47]	USA, UK, France, Spain,	Cross-	To explore the attitudes of men with locally advanced or	382	36% were aged 61–70, 34% aged 71–	0	Prostate
	Italy, Germany	sectional	metastatic prostate cancer toward diagnosis and treatment	NR	80 and 9% 81 years and older		Locally advanced and metastatic
Lim [51]	Australia	Retrospective	To examine long-term outcomes of elderly patients	48	Median 76 (49–94)	27	Rectal
			treated with RT or chemo radiation	NA			TI–III
Petrisek [53]	USA	Retrospective	To understand how older women with early-stage breast		NR	100	Breast
		observational	cancer made the treatment decision and gain better insights into age-related differences	84%			Stages I–IIIa
Richert-Boe [55]	USA	Retrospective	To determine whether differences existed in prostate	237	Mean 66 years at diagnosis for	0	Prostate
		observational	cancer treatments received by White and African American men at a Health Maintenance Organization	NA	African American, mean 68 for white at diagnosis		Stages I–III
Sandison [57]		Drospostivo	and to determine the reasons for these differences	50	NR complex 70	100	Broast
Sandison [57]	UK	Prospective observational	To examine treatment preference for breast cancer in women aged 70 years and older	50 NR	NR, sample > 70	100	Breast Stages I–III
Schulman [58]	Germany, Italy, Spain,	Cross-	To examine patient beliefs as barrier for optimal	200	Mean 70.1	0	Prostate
	Netherlands, France	sectional	management of their disease in men with prostate cancer	NR		C	NR (Patients had to be receiving LHRI agonist treatment)
Tang [60]	Singapore	Cross-	To examine patients preference of radiation treatment	92	Mean 68	15	Lung
	01	sectional	schedules	NR			Advanced
		sectional	Schedules				(Stage 2-4)

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Table 3 (continued)							
First author & year Country published	Country	Study design Study aim	Study aim	Sample size & response rate	Sample size & response rate Mean/Median age, years SD (range) <sup>a</sup> % Won	% Type of Women & stage	Type of cancer & stage
		sectional	investigate the treatment decision-making process	NA			Early (Stage 1 & 2)
Van Tol Geerdink The Netherlands [62]	The Netherlands	Cross- sectional	To examine treatment choices between two Radiation 150 but only 119 wanted to Mean 70 treatment options in men with localized prostate cancer choose own therapy 75%	150 but only 119 wanted to choose own therapy 75%	Mean 70	0	Prostate T1–3, NOMO
Verkooijen [19]	Switzerland	Retrospective observational	To compare patient and tumor characteristics and survival between women who accepted and who declined surgery for breast cancer	5339 NA	Mean 68	100	Breast All stages

If mean/median age was available this information is reported with SD but if not the age data that was available from the study is reported.

NR = not reported, NA = not applicable.

Studies comparing reasons why participants chose mastectomy over lumpectomy showed that fear of recurrence, wanting to have treatment completed and physician recommendation were important [38,49]. Reasons for choosing lumpectomy over mastectomy included keeping the breast, equivalent survival and physician recommendation [38]. A study comparing surgery to primary endocrine therapy (PET) showed that reasons for choosing surgery included positive personal experiences or for important others with surgery, whereas reasons for choosing PET included having had painful biopsies and wanting to carry on life as before [49]. A study comparing surgery, radiation and chemotherapy showed that patients chose PET for feelings of unfitness for surgery and having no time for surgery. Those who declined all treatment felt asymptomatic, and too old or high risk due to comorbidities [61].

Factors reported to have no impact on the decision in individual studies

In one or more studies, factors such as previous medical conditions [39], side effects of treatment [29,33,40,43], support of friends/family [29,33], support of the family physician [29], age of the patient [29] had no impact on the treatment decision.

Studies comparing the treatment decision making process in young old vs. older old

This was explored in seven studies and one study reported no differences based on age [49]. Two studies reported that younger patients with prostate cancer chose surgery more often than older patients [41,52]. Schulman studied reasons for choosing hormonal treatment for prostate cancer in patients who were all receiving luteinizing hormone-releasing hormone (LHRH) agonist (80% receives an injection every three months and the other 20% monthly) and showed that younger patients preferred hormonal treatment with less frequent injections due to having fewer reminders of the disease, and less discomfort and less impact on daily life compared to older men [58]. Chapple et al [32] reported that younger patients felt pressured by surgeons to have surgery instead of watchful waiting for prostate cancer, whereas this was not reported by older participants. Tang et al [61] studied breast cancer treatment decisions and showed that older patients felt unfit to undergo treatment; whereas this was not reported by younger patients. The study by Petrisek et al showed that for the group of older women with breast cancer, fear of recurrence, physical aspects of the treatment and everyday responsibilities in life were significantly less important compared to the younger old women [53].

Were there differences in reasons for accepting or declining by cancer stage?

Only one study by van Tol-Geerdink [62] studied participants with high risk and low risk prostate cancer and reported that those with a better prognosis/low risk disease were more likely to choose low dose RT instead of high dose RT compared to patients with poorer prognosis/high risk disease.

# Discussion

To our knowledge, this is the first systematic review focusing on reasons why older adults with cancer accept or decline cancer treatments. The results showed that important factors in the decision to accept or decline the recommended cancer treatment included the physician's recommendation, trust in the physician, communication with the physician, expectations about side effects

Factors associated with cancer treatment decline or acceptance in qualitative studies.

First author & year published	Previous treatment received	Type of treatment studied	Type of analysis used	Percentage/number declining treatment	Factors associated with decline of treatment	Factors associated with acceptance of treatment	Other factors studied but not important for acceptance or refusal
Anchisi [29] <sup>a</sup>	NR	Chemotherapy and for some chemo radiation	NR	14%	NR	Older adults accepted treatment because of their awareness of the disease and prognosis, their discussion with the oncologist about the aim and side-effects of treatment and the possibility to stop the treatment	Side effects, support of the family and family physician, age of the patient
Anchisi [28] <sup>a</sup>	NR	Chemotherapy and for some chemo radiation	NR	14%	Transportation difficulties was a reason for refusal	The will to live was a strong motivation for receiving treatment, as was having family support to undergo treatment, the treatment was seen as necessary to live and therefore accepted	NR
Chapple [32]	Some participants were diagnosed many years ago with experience with a wide range of treatments	Watchful waiting	Qualitative methods, not further specified	NR	Wanted to do something positive & fix the problem, had seen what cancer had done to others and were afraid of the consequences of any delay, pressure from families to pursue active treatment	Avoidance of incontinence and impotence, worry about the side effects of treatment, scientific evidence that physicians don't really know whether outcomes of treatments are more positive	NR
Chouliara [33]	NR	NR	Framework analysis	NR	If side effects would make them a burden on their loved ones	Participants wanted as much treatment as they could receive as they wished to prolong their life as much as possible with average quality of life (which meant enjoying life, no severe pain, cancer, no disruption in normal life) and if treatment is effective for their disease and physical status, and if still offered, and if they are able to physically and cognitively able to tolerate it, belief in the effectiveness of treatment, not wanting to become a burden by leaving their illness untreated, following the doctor's advice, being optimistic and expecting things to improve over time	Significant others had no impact. Side effects were seen as an unavoidable and necessary part of treatment by some
Ciambrone [34]	NR	All breast cancer treatments	Grounded theory methodology	Some participants declined, but exact number declining NR	Older women did not want chemo or radiation as they felt that comfort and quality of life was more important than extending their lives, the potential side effects were not worth it at their age, not being convinced of chemo/rad efficacy, knowing friends that had had chemo/rad The need for travelling every day to the hospital for treatment	Most women followed the advice of the physician, getting rid of cancer was the first priority. Women who choose the treatment themselves also wanted to get rid of the cancer and most chose treatment on the basis of the treatments they wished to avoid because of side effects or experiences of others with that treatment. Women had trust in	NR

Table 4 (continued)

First author & year published	Previous treatment received	Type of treatment studied	Type of analysis used	Percentage/number declining treatment	Factors associated with decline of treatment	Factors associated with acceptance of treatment	Other factors studied but not important for acceptance or refusal
Cohen [35]	No	Surgery, watchful waiting, radiation therapy and hormonal	Qualitative analysis not further specified	NR	NR	their physician and therefore accepted the treatment decision Faith in doctors; physician decided treatment	NR
Crooks [36]	NR	therapy Surgery, radiation	Grounded theory	NR	Those who had parents and	NR	NR
		therapy and chemotherapy	methodology		spouses who had received chemotherapy were more likely to decline the treatment as a result of these experiences		
Davison [39]	No	Active surveillance	Phenomenology	0%	Reasons for declining active prostate cancer therapy and choosing active surveillance: potential for impotency, incontinence, chances of developing side effects and advice from friends about side effects. One person on active surveillance wanted to go off due to the perceived seriousness of the disease, if it was cancer it should be treated	When the different specialist recommendations concurred and when specialists were highly renowned or published, it was easier to follow advice	Previous medical conditions did not influence how men perceive their ability to undergo active treatment
Denberg [40]	No	Radical prostatectomy, external beam radiation therapy, brachytherapy, hormonal therapy and watchful waiting	Grounded theory methodology	NR	Treatment success and side effects only evident at some point in future, fear of surgery and its consequences, inconvenience of administration; perceived side effects. Those who chose surgery did not choose other options such as RT as they felt it was less immediate treatment, less visible, and indefinite compared to surgery. Some patients did not like the daily treatment and uncertainty of the external beam RT	Anecdotes (others' stories) exerted strong sway over patients' feelings about their own prostate cancer, treatment preferences; profound fear and uncertainty (desire to receive treatment as quickly as possible); influential misconceptions about treatments; perceived importance of "getting the tumor out". Patients preferred brachytherapy because the treatment was directly in the prostate, minimal side-effects and minimal inconvenience while others just accepted the recommendation of the urologist as they trusted him/her	None of patients explicitly compared treatments in terms of their relative likelihood of causin side effects. 9/20 minimized concerns about side effects altogether, deeming these entirel irrelevant to decision-making process
Docherty [42]	Yes, most have received treatment at the time of study	Radiation therapy, surgery and hormonal treatments	Thematic analysis	NR	Potential impact of treatment on sex life	To avoid the impact of other treatments on their sex life	NR
Elit [43]	Yes	Chemotherapy	Inductive data analysis	NA	NR	An important factor for most in facilitating their treatment process and forward-looking approach was the kinds of support they had available to them; imp sources of information that factored into treatment decision were medical team, family (particularly those that were	The authors noted that Impact o side effects was not mentioned b participants

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						had had cancer experiences) and medical literature. As the participants had a recurrence, their treatment experiences impacted on their decision, as well as their trust in their physician and accepting the recommended treatment	
Holmboe [48]	No	The actual treatment which had been chosen by each participant which could be brachytherapy, external beam radiation, radical prostatectomy or watchful waiting	A clinimetric approach to classify responses in three taxonomies	0%	Radical Prostatectomy: risk of incontinence, impotence and invasiveness of procedure, long recovery times, previous negative treatment experiences and global patients concerns. For external beam radiation, dislikes were the long duration and the concern for radiation as well as the belief that using this therapy precluded other therapies in the future. For brachytherapy, the main dislike was the weakness of the evidence supporting this approach. Men rejected watchful waiting because you need to combat tumor, relative young age, fear of tumor spreading, and physician recommendation against watchful waiting	Radical Prostatectomy: the most commonly reported likes were removal of the tumor and strength of the evidence. For External beam radiation: the likes was the track record of therapy and noninvasiveness. The most common likes for brachytherapy were short duration, limited invasiveness and targeting the treatment	NR
Husain [49]	NR	Surgery	Framework analysis	NR	NR	Physician recommendation, experiences of family members with certain treatments. Specifically reasons for choosing surgery included previous positive experiences with surgery or positive hospital experiences. Reasons for choosing PET included painful biopsies, not wanting more surgical intervention, and surgery could always be an option if PET failed. It was important they were able to carry on life as before	Participants didn't consider what impact decision would have on social circumstances, being burden on others
Kreling [50]	Yes	Chemotherapy	Thematic analysis	0%	Hurried appointments and talking down to patient, not enough specific info, and too much written info, lack of family support, negative experiences and expectations, problems with employment and insurance act as barriers to chemotherapy use	Health status, good communication with the physician (able to express preferences, fears and expectations, enough time, family included and information and translation of materials), good information about process of chemotherapy and how side effects will be managed, family support, patient experiences with chemo, death, expectations about chemo and side effects and employment and insurance coverage promote chemotherapy use	NR
O'Rourke [52]	No	Surgery, watchful	Qualitative	0%	NR	Trust in physician, beliefs about	NR

health care professionals or who

Table 4 (continued)

First author & year published	Previous treatment received	Type of treatment studied	Type of analysis used	Percentage/number declining treatment	Factors associated with decline of treatment	Factors associated with acceptance of treatment	Other factors studied but not important for acceptance or refusal
		waiting, radiation therapy and hormonal therapy	methods not further specified			cure, positive experiences of others and impact of treatment in terms of side effects affected the choice of treatment	
Pieters [54]	NR	Surgery, radiation therapy, chemotherapy and hormonal therapy	Grounded theory methodology	All women received some treatment but some declined a second treatment, the number of which was NR	NR	Obtaining information from physician who the older woman feels she can trust. Age of health care provider also important. Treatment experience of person and other important persons are important	NR
Sanders [56]	Yes, most had received surgery	Chemotherapy and radiotherapy	Grounded theory methodology	Some patients declined treatment but the number is NR	Fears of undertaking chemotherapy, unclear benefits, not wanting to be a guinea pig, other medical issues; Negative preconceptions of chemotherapy, uncertainty about the impact it would have on his health and whether it would be of benefit, concern that too much treatment could be harmful to their recovery; "just can't go on going through all of this"; chemotherapy was presented to patient as a choice not as a 'necessity' which might explain why he felt able to reject it; having already agreed to have radiotherapy (could have strongly affected his decision not to undertake chemo)	Patients who believed in cure found treatment important	NR
Sharf [59]	NR	Radiation therapy, chemotherapy or surgery	Grounded theory methodology	All patients declined treatment	The participants declined treatments because they did not trust their physician, based on their own and important experiences, belief in other non- medical treatments, wanting to avoid pain and prioritizing current quality of life, not believing treatment will be effective	NA, study focused on refusing treatment only	NR
Sinding [27] <sup>b</sup>	NR	Hormone treatment, surgery, chemotherapy, radiation therapy	Grounded theory methodology	27%	Feeling that at their age, they would not live forever, the treatment increases risk of other problems due to the presence of comorbid conditions, cancer treatments will exacerbate symptoms of comorbid conditions, fear of losing independence and becoming dependent on family members	NR	NR
Sinding [26] <sup>b</sup>	NR, ten were within 1 year of diagnosis and four between 1–	Surgery, radiation therapy and chemotherapy	Grounded theory methodology	One out of 15 participants declined all treatment, other participants	Caregiver roles for others, knowledge from experience (memories, emotions and relationships), financial costs, fear of losing independence	Medical evidence, knowledge from experience	NR

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		2 years and one between 2–3 years			declined some treatments offered (chemo, surgery or radiation)			
W	ard-Smith [63]	NR	Radiation; patients have received brachytherapy	Colaizzi's phenomenological approach	0%	Invasiveness and lengthy recovery time of surgery, frequency of hospital visits required for traditional radiation which would cost time and money, and would require assistance from others to attend appointments, inability to lie flat on traditional radiation machine and experiences of others who were experiencing side effects of surgery and traditional radiation	Individual lifestyle was most important for choice of treatment (chose brachytherapy as it would interfere with their life the least). Recommendations made by television show also affected decision	NR
	hite [64]	NR	Surgery, radiation therapy or brachytherapy	Qualitative content analysis	100%	Reasons for refusal included fear of long-term side effects, the experiences of others with complementary and alternative medicine and conventional treatment, some of whom were viewed as victims who had lost their social and sexual identities, and quality of life. Refusing conventional treatment for complementary and alternative medicine gave a sense of control and well-being. At times, treatment did not match with the spiritual beliefs of patient	NA, study focused on refusing treatment only	NR

NR = not reported, NA = not applicable. <sup>a</sup> Anchisi [28,29] reports on the same study. <sup>b</sup> Sinding [26,27] reports on the same study.

Factors associated with cancer treatment decline or acceptance in quantitative studies.

First author & year published	Previous treatment received	Type of treatment studied	Type of analysis used	Percentage/number declining Treatment	Factors associated with decline of treatment	Factors associated with acceptance of treatment	Other factors studied but not important for acceptance or refusal
Ashley [30]	NR	Surgery	Descriptive	0%	NA, all participants were asked about the reasons why they chose a particular type of surgery for their cancer	Personal reasons for accepting radical cystectomy included fear of incontinence, not wanting to do self- catheterization, believing that self- catheterization was too complicated and the fear that the catheterization would impact outdoor activity	NR
Cassileth [31]	No	Surgery or Hormonal Therapy	Descriptive	0%	Participants were recruited to the study after they had selected surgical therapy or hormonal therapy	The drug was chosen to avoid surgery; success of treatment, convenience, and physician's advice were also important factors. Those who chose surgery chose convenience as the most important reason, with the success of treatment being another important reason	NR
Cykert [37]	No	Surgery	Generalized linear model	15/386 declined surgery, and 42 did not have surgery due to comorbidities	Comorbid illness, religiosity (faith alone can cure), perception of uncertain diagnosis, belief that quality of life would be worse because of surgery, perception of lower-quality cancer communication, anticipation of a worse prognosis 1 year after surgery	Not studied, the study aim was to explore why Blacks undergo surgery less often than Whites	NR
Cyran [38]	Treated with mastectomy or lumpectomy	Surgery	Descriptive	0%	All participants had received cancer treatment (that was inclusion criteria) and where asked why they selected either mastectomy or lumpectomy	Reasons for choosing mastectomy over lumpectomy: fear of recurrence, wanting to get treatment over with, and physician recommendation. Reasons for choosing Lumpectomy over mastectomy: keeping the breast, equivalent survival, and physician recommendation	NR
Diefenbach [41]	No	All types of treatment	Descriptive	0%	NA, patients were asked why they had chosen their current cancer treatment	Reasons for choosing external beam radiation therapy were that the treatment was less painful, less invasive and fewer side effects and more convenient than surgery. Reasons for choosing surgery were that it would offer the best chance of cure, and patients knew somebody who had received the same treatment and they saw their disease as more serious	NR
Gorin [44]	No	Active surveillance	Descriptive	0%	Concern about incontinence and impotence related to treatments	"Doctor thought it was a reasonable alternative", "I felt I could still be cured with treatment if my cancer progressed", "I have researched the alternatives and this one seems the best for the type of prostate cancer I have"	NR
Gwede [45]	No	Radical Prostatectomy or brachytherapy	Logistic regression	0%	NA, participants were asked why they had chosen their treatment, all had received treatment	Chance of cure a treatment offered, treatment invasiveness, avoidance of the side effects of other treatments, painfulness, convenience of treatment, avoidance of surgery	NR
Hall [46]	NR	Radical prostatectomy, brachytherapy as monotherapy (BT) or	Descriptive	For 14 patients the treatment received was unknown	NA, all participants are asked to choose between 2 treatment regiments	43% of BT monotherapy patients choose this treatment because it was the best procedure to cure the cancer, and 60%	NR

Hardy [47]	Yes, 48% had previous RT and 43% had previous surgery for their prostate cancer	brachytherapy with external beam boost Hormonal therapy	Descriptive	NA	NA, all participants are currently receiving hormonal therapy for their disease	indicated this for the BT plus external beam boost group. 40% chose BT because of the side effect profile as most important reason and 26% in the BT plus external beam boost group The most important factor for choosing their hormonal therapy (patients were using several different hormonal regimens) were: 39% wanted control of their disease, 31% wanted the highest chance to outlive their disease and 12% wanted to maintain an active life as long as possible, 8% chose it as the therapy has been proven to improve survival, 4% choose it for being the most powerful therapy, 3% choose it for symptom relief, and 3% chose it as it has few side effects	NR
Lim [51]	NR	Chemo radiation	Descriptive	50%	Reasons for refusing surgery included desire to avoid a permanent stoma, and fear of operative morbidity or mortality	NA, chart review of reasons for decline	NA
Petrisek [53]	NR, patients had nonrecurring disease	Surgery, radiation therapy, chemotherapy and hormonal therapy	Logistic regression, Chi Square tests	NR		Transportation issues affected the choice of older women, financial issues were important for those without private insurance, physician recommendation, not having the problem return, family and experience of others important in treatment selection	For older women fear of recurrence, physical aspects of treatment and responsibilities were significantly less important as compared to those younger
Richert-Boe [55]	NR	Radical prostatectomy or radiotherapy	Descriptive	Seven of the 66 African American men and 12 of the 149 White American men offered treatment with curative intent declined it	Advanced age, low-risk disease, desire to try alternative therapies	NA, the study focused on comparing if there were racial differences in why African men compared to white men received less treatment with curative intent	NA
Sandison [57]	NR	Tamoxifen alone vs. local excision and tamoxifen vs. modified radical mastectomy and tamoxifen vs. local excision, radiation therapy and tamoxifen	Descriptive	NA	NA, participants were asked why they chose their treatment for their breast cancer	Physician recommendation, to avoid the "trouble" of local excision with radiation therapy	NR
Schulman [58]	Yes, currently receiving LHRH agonists	Hormonal therapy	Descriptive	0%	Not studied, all patients were asked about hormone treatment preferences	Trust in physician, ability of treatment to lower testosterone levels, simpler and fewer injections, low levels of discomfort or pain, higher quality of life, fewer reminders of the disease, ability to maintain their lifestyle during treatment by allowing for more ability	NR
Tang [60]	No	Radiation	Logistic regression	0%	Not studied, patient preference for different radiation schedules were studied	to undertake activities w/o restriction 39 Gy in 13 daily fractions: longer survival advantage offered, better local control and less psychological distress. 17 Gy in 2 fractions: shorter treatment duration, lower cost of treatment and better symptom control	NR
Tang [61]	Some patients have a history of other	Surgery, hormonal therapy, radiation therapy and chemotherapy	Descriptive	4 patients declined all treatments offered	Those who declined surgery and choose PET did it because of feelings of unfitness, refusal to have surgery, and	Those who choose surgery choose it because of perceptions of more favorable outcomes, feeling the need of	NR

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First author & year published	Previous treatment received	Type of treatment studied Type of analysis used	Type of analysis used	Percentage/number declining Treatment	Factors associated with decline of treatment	Factors associated with acceptance of treatment	Other factors studied but not important for acceptance or refusal
	cancers				personal commitments disallowing post-operative recovery time. Those who declined all treatments did so because they were asymptomatic, felt "too old" and were at high risk with any treatments due to comorbidities	physically getting rid of the cancer, and experiences of others with this treatment	
Van Tol Yes, 74% Geerdink [62] adjuvant hormonal therapy	Yes, 74% has adjuvant hormonal therapy	Radiation	Descriptive	N	NA, patients are asking to choose between 2 radiation treatment options	Quality of life, survival, chance of tumor recurrence, probability of severe GI or GU problems, probability of sexual problems, number of treatment sessions were all important decision-making factors	NR
Verkooijen [19]	NR	Surgery	Descriptive	1.3% declined surgery	Reasons for refusal included psychological problems, mainly depression, having chosen alternative therapy, other medical problems, considering self "too old" for surgery and lack of medical insurance	NA, chart review of reasons for decline	ЧЧ
NR = not reported, NA = not applicable.	VA = not applicabl	j.					

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and treatment experiences of significant others. Many study participants followed the treatment recommended by their physician. This review also showed that many of the reasons which could lead the patient to either accept or decline treatment were the same factors (e.g. trust in physician could be high in which the treatment was accepted or low and this could lead to decline of treatment). Very few studies have investigated age differences in the reasons for accepting or declining treatment between the young old and older old study participants, but there were some subtle differences (e.g. older adults declined more often for reasons of comorbidities and transportation issues). There was only one study by Hussain et al. [49] with a mean age > 80 years. As benefits and risks of treatment are different for a 65 and 85 year old, and with the rapidly increasing octogenarian population in many countries around the world, it is important to study the oldest old as well to allow development of interventions to support treatment decision-making for all older patients. There were no studies comparing factors important to accept or decline cancer treatments across cancer types, and only one study focused on differences by stage.

Despite the emphasis on shared-decision making in Western countries, studies showed that most older adults accepted the treatment recommendation from their oncologist. A recent systematic review showed that the training of health care providers in shared decision making varies widely [66]. It is thus very important that health care providers in the oncology setting involved in the treatment decision-making process realize their impact on the patient's cancer treatment decision and thus cancer treatment outcome and this should be included in health care professionals training for decision making with older adults. The communication gap between oncologist and patient has been known for some time [67]. The quality of communication impacts a patient's quality of life and his/her awareness of the prognosis [68,69]. A recent Cochrane meta-analysis showed that there are several existing interventions to improve patient-oncology health care provider communication, but it is also noted that the long-term effect (e.g. sustainability) is not yet known [70]. No subgroup analysis examining the effect for older patients was conducted as part of this Cochrane metaanalysis and due to the prevalence of classical geriatric factors such as cognitive changes and sensory impairment, it is possible that interventions need to be tailored further to suit the needs of the elderly cancer population, hence this should be studied formally.

As there is no measurement tool to measure reasons for acceptance or declining of cancer treatment, most studies had developed a measurement tool specific for their study and almost no study had actually included the tool in the publication. Similarly, for the qualitative studies almost no study had included the interviewer/moderator topic guide. Furthermore, most of the studies were not aimed at specifically examining reasons why older adults accepted or declined the recommended treatment. Thus it is unclear if factors that were not reported in the studies included in this review were really not important or just not studied until now. Important geriatric health conditions such as cognition and sensory impairment were not reported. Furthermore, few studies reported on the role of comorbid conditions as a reason to decline treatment. Lastly, it has been reported that older adults may have lower levels of health literacy [71–73], and this could be expected to impact why older adults accept or decline cancer treatment, and thus should be studied. Furthermore, with the development of more oral cancer treatments particularly for frail older adults and with the aging of the population, there will be an increase in the number of older adults facing a cancer treatment decision which is different from the ones studied in the included studies. It is thus important that larger studies of higher methodological quality are conducted, particularly taking into account classical geriatric factors such as comorbidities and cognition, as well as health literacy and populations other populations than Caucasians as most studies

Table 5 (continued)

Summary of factors influencing the decision to accept/decline active treatment.

Reasons for acceptance of active cancer treatment	Qualitative studies (18 studies)	Quantitative studies (20 studies)
Treatment related factors Treatment convenience Expectations about side effects Treatment success rate	10 studies [29,32-34,40,42,48-50,52]	11 studies [30,31,38,41,45,53,57,58,60–62] 6 studies [30,45–47,58,62] 10 studies [31,38,41,44,45,47,53,58,60–62]
Physician related factors Trust in physician Treatment recommended by oncologist Information received about treatment		3 studies [31,44,58] 5 studies [31,38,44,53,57]
Patient related factors Awareness of the disease and prognosis and thus the necessity of treatment/wanting to get rid of cancer/if it is cancer it should be treated/belief about cure	9 studies [28,29,32-34,39,40,48,52,56]	5 studies [38,41,46,47,61]
Treatment experience of family members/friends Wanting to live as long as possible/continue current lifestyle Previous personal positive treatment experience/hospital experience Family support Pressure of family members to have treatment Not wanting to be a burden by leaving illness untreated		3 studies [41,53,61] 3 studies [30,47,58]
Reasons for decline of active cancer treatment	Qualitative studies (18 studies)	Quantitative studies (20 studies)
Treatment related factors Expectations about side effects	<b>12 studies</b> [32,34,36,39,40,42,48,50,56,59,63,64]	4 studies [37,44,51,61]
Physician related factors Unclear benefits of treatment Distrusting physician/poor communication/information about treatment	6 studies [32,34,40,48,50,56,59] 2 studies [50,56,59]	1 study [37] 1 study [37]
Patient related factors Treatment experience of family members and friends Feeling high risk due to comorbidities/other medical issues Quality of life and comfort is most important at their age/feeling too old for treatment	7 studies [26,34,36,39,40,63,64] 3 studies [27,34,56] or 3 studies [27,34,59]	4 studies [19,37,51,61] 3 studies [19,55,61]
Belief in non-conventional treatments Financial reasons Wanting to avoid becoming dependent on others/fear of losing independer Personal negative treatment experiences	2 studies [48,50]	2 studies [19,55] 1 study [19]
Transportation issues Not wanting to be a guinea pig Care giving responsibilities Belief that faith alone can cure disease Feeling asymptomatic	2 studies [28,63] 1 study [56] 1 study [26]	1 study [37] 1 study [61]
Depression Having low-risk disease Lack of family support	1 study [50]	1 study [19] 1 study [55]

Fields have been left blank where no studies assessed a specific factor (e.g. previous positive experience in quantitative studies).

have focused on Caucasians. More insight into reasons why older adults declined treatment is important to determine if interventions to enhance the quality of the treatment decision-making process are warranted. However, only two small qualitative studies focused on older adults who declined cancer treatment [59,64]. It is thus important that more studies explore this issue using larger samples. More importantly, a validated measurement tool to reliably assess reasons for accepting or declining cancer treatment should also be developed. Patients can make fully informed and autonomous decisions to decline treatment. However, if treatments are declined because of reasons of distrusting the physician, feeling at high risk due to age or communication, poor communication and inadequate information about the treatment risks and benefits received, this should be addressed as those patients are at risk for potentially avoidable poorer outcomes of cancer. Furthermore, as almost all studies have focused on treatment decisions for breast and prostate cancer, very little is known about which factors are important reasons to accept or decline treatment for other cancers common in older adults, such as lung, colorectal or hematological malignancies. Additionally, as these studies have only included women or men, it is not known if there are differences based on sex and this may be important when developing interventions to enhance the quality of the treatment decision-making process. Further studies are needed to examine treatment decision-making in participants diagnosed with other cancers.

This systematic review has several strengths. Although there had been previous narrative reviews on treatment decision making in older adults, none used a systematic approach to appraise the literature [21–23]. In this review, two independent reviewers reviewed abstracts and abstracted the data. We included ten databases and four languages, we included both qualitative as well as quantitative studies and no study was excluded based on the quality assessment scores. However, this review also has limitations. As in any review, the findings are limited by the methodological quality of the included studies. And many of the studies included were conducted some time ago and as the reporting standards were not as developed as they are today, there were few studies of excellent methodological quality. We were not able to calculate how many patients refused for a particular reason, only report the number of studies reporting a particular reason due to a lack of details included in the manuscript. No meta-analysis was conducted as the studies were too heterogeneous with regard to study population and data collected.

In conclusion, the reasons why older adults with cancer accepted or declined treatment varied considerably. Further studies using large representative samples with different cancer types and race and exploring treatment decision making incorporating health literacy and comorbidity are needed.

#### **Conflict of interest**

The authors have declared no conflict of interest. All authors contributed to: (1) the conception and design of the study, the data collection and analysis and interpretation of data, (2) drafting and revising the article critically for content, (3) approved of the final version to be submitted.

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## Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.ctrv.2014.12.010.

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