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Multidisciplinary decision-making in older patients with cancer

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Multidisciplinary decision-making in older patients with cancer

Balancing benefit, harm, and patient priorities

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rijksuniversiteit
 groningen

Multidisciplinary decision-making in older patients with cancer

Balancing benefit, harm, and patient priorities

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CHAPTER 1

Introduction

INTRODUCTION

The incidence of cancer rises dramatically with age, with an eleven-fold increase after the age of 65.^{1,2} With the ageing of the population, the percentage of older patients referred for cancer treatment will increase and, by 2030, 70% of patients with newly diagnosed cancer are expected to be over age 65.³ Older patients with multiple age-related disorders are underrepresented in clinical trials and guidelines, and when they are represented, relevant endpoints, such as quality of life and retaining independence, are often missing.⁴⁻⁷ Older patients are at risk of both overtreatment and undertreatment, especially when decision-making is based on calendar age, disregarding relevant comorbidities, frailty, and patient priorities.⁸ This makes deciding on the most optimal oncological treatment plan for older patients complex. The question underlying this thesis is how to best tailor treatments to the individual older patient in order to optimize outcomes and provide patient-centered care.

FRAILITY AND GERIATRIC ASSESSMENT

Age, and other one-dimensional measures such as co-morbidity or performance status, do not adequately capture the diversity of older patients.⁹⁻¹¹ Frailty, a state of decreased physiological reserve due to accumulation of deficits in physical, cognitive, social, and functional domains, is a better measure of biological aging and a better predictor of the ability to cope with stressors.¹²⁻¹⁴ It is therefore a better predictor of unwanted outcomes, such as mortality, complications, and loss of function.^{15,16} More than half of the older cancer patients are frail or pre-frail.¹⁵ Geriatric assessment (GA) is a method to evaluate multiple patient characteristics using standardized methods to help characterize individual complexity and can be used to discriminate between fit and frail patients.^{17,18}

A distinction can be made between a Comprehensive Geriatric Assessment (CGA), a GA, and geriatric screening. A CGA is an extensive assessment of different domains (somatic, psychological, social, and functional), performed by a healthcare professional with expertise in geriatrics, usually in an interprofessional team, and aimed at possible interventions. A GA can be defined as a shorter assessment of domains, is aimed at prognostication and risk prediction, and can be performed by other health care workers, for instance, a nurse. A geriatric screening is a short measure or a combination of short measures used to identify patients who would benefit from a CGA.^{19,20} However, these terms are often used interchangeably in literature.

GA has been shown to have an impact on decision-making in older cancer patients.²¹ In recent years, there has been an increased awareness of the added value of GA for oncological treatment decisions in older patients.^{17,22-24} There is, however, still a paucity

of data on the improvement of outcomes after implementation of GA in decision-making.²⁵ Since patients have different priorities regarding what is considered an optimal outcome of treatment, it is still unknown which outcome measure captures 'optimal treatment' best.

PATIENT GOALS AND PREFERENCES

Due to the risk of complications and functional decline following surgery, radiation therapy, systemic or multimodality treatment, decision-making in older patients with cancer comprises trade-offs.^{26,27} To guide patients in the process of shared decision-making, it is important to assess their priorities regarding treatment outcomes in order to align the treatment to these priorities.²⁸⁻³⁰ However, it has been shown that healthcare professionals often have limited knowledge of the goals, preferences, and values of their patients.³¹⁻³³ A decision aid that can support a goal-setting conversation is the Outcome Prioritization Tool (OPT, figure 1). The OPT uses four universal health outcomes and is thereby neither disease nor treatment specific. This makes the tool usable in different settings, and for patients with multiple coexisting conditions.³⁴ The four health outcomes used in the OPT are: extending life, maintaining independence, reducing pain and reducing other symptoms (such as dyspnoea or nausea). Health outcome prioritization has been shown to be feasible for older patients.³⁵ The OPT uses a trade-off principle for competing outcomes, i.e. the notion that reaching a certain outcome can have a negative impact on another outcome.³⁶ Using the OPT, the patient is invited to prioritize between the four health outcomes and rate these in order of importance.³⁷ The OPT has mostly been studied in older patients with multimorbidity.^{37,38} Little is known about the use of the OPT in clinical decision-making regarding intensive treatments (such as cancer therapy or surgery).

MULTIDISCIPLINARY DECISION-MAKING IN CANCER CARE

The Netherlands, and many other countries, have national guidelines requiring multidisciplinary discussion of cancer patients. Between 80-99% of oncological patients are discussed in a multidisciplinary team (MDT) meeting.³⁹⁻⁴¹ Oncological MDTs, or tumor boards, are usually organized by tumor type and consist of a group of professionals from different disciplines, including surgeons, medical oncologists, radiation oncologists, pathologists, radiologists, and nurses.⁴² Most MDTs meet weekly. The aim of these MDTs is to standardize and optimize cancer care according to current guidelines and facilitate complex decision-making. These MDTs play an important role in the decision-making for patients with cancer. It has, however, been shown that the process to come to the optimal treatment advice in oncological MDTs can be suboptimal for older patients, by lacking patient-centered information, such as information about the patient's context, level of frailty, and the goals and preferences.⁴³⁻⁴⁶

Figure 1. An example of the Outcome Prioritization Tool (OPT)

IMPLEMENTING GERIATRIC ASSESSMENT AND THE ASSESSMENT OF PATIENTS PRIORITIES IN MULTIDISCIPLINARY DECISION-MAKING

With an increasing number of older adults and limitations in the availability of geriatricians, it is not feasible to refer all these patients to a geriatrician for a CGA. This is also undesirable from a patient's perspective. To implement patient-centered care in clinical practice it is important to use the available resources well and develop care pathways to implement GA in an efficient and effective way.

Different strategies to implement GA in clinical practice can be considered. (figure 2) All older patients can be referred to a geriatrician. However, with the aging of the population, the number of older patients will increase and this will not be feasible. An often-used option is a two-step approach: a short frailty screening (e.g. using as a GFI or G8), followed by a (comprehensive) GA. It has been shown that in this two-step approach, a (comprehensive) GA is needed in about 50% of patients.⁴⁷ Another possibility is to

integrate GA, performed for instance by nurses, into standard care for all older patients with cancer.^{48,49} This might be more time consuming, but can lead to relevant information about the patient’s health status and preferences, that can be used in shared decision-making and to optimize the treatment trajectory for all older patients.⁴³

Figure 2. Different pathways to implement geriatric assessment into oncology.

At the ÛMCG, the implementation of a nurse-led geriatric assessment and an onco-geriatric MDT was started in 2014. In this MDT both disease and patient-specific information are discussed in a stepwise manner regarding disease and patient factors. Furthermore, the treatment options are put into a time perspective by estimating the remaining life expectancy of the patient and the time to benefit of the treatment. (figure 3)

Stepwise approach to treatment decision-making	
1.	How strong is indication for the recommended treatment?
2.	What would the estimated life expectancy of this patient be without the current disease?
3.	What is the estimated life expectancy without treatment?
4.	What is the expected burden of the disease if it is left untreated?
5.	Does treatment add to the life expectancy?
6.	Does the patient have physical complaints that are likely to be resolved after treatment?
7.	What is the burden of the treatment (hospital admissions and visits, complication risk)?
8.	What are the alternative treatment options (including palliative treatment)?
9.	What are the goals, preferences and expectations of the patient? What is the influence of the proposed treatment on these goals?

Figure 3. stepwise approach to decision-making

OUTLINE OF THE THESIS

In order to explore how to best tailor treatments to the individual older patient we conducted the studies that are described in this thesis.

In the first part, chapter 2, we will present the current situation in oncological multidisciplinary decision-making. For this we observed multidisciplinary decision-making in different oncological MDTs, or tumor boards, at the University Medical Center Groningen. We assessed whether the presented information, contribution of different team members, and the decision-making process differed between older and younger patients.

Assessment of patient preferences is an important aspect of shared decision-making. In the second part, chapters 3, 4 and 5, we focus on the assessment of patients preferences, using the OPT tool. For chapter 3 we conducted a review of the available literature about this tool. In chapter 4 we present the results from the use of the OPT tool in our own clinical practice and describe how patients prioritised health outcomes when facing a complex treatment decision. In chapter 5, we describe how well medical specialists and general practitioners have knowledge of the main goals of their patients.

In the third part, chapter 6 and 7, we describe the new care trajectory that was developed in order to tailor decision-making for the individual older patient with cancer. A nurse-led GA and assessment of patients goals and preferences were incorporated in clinical treatment decision-making in an onco-geriatric MDT. The treatment decisions provided by the onco-geriatric MDT were compared to the advice provided by the (conventional) tumor board. In chapter 6 we present data on the effect of this new care trajectory on treatment decisions. In chapter 7 we assess the outcome of a modified treatment advice as a result of the new care trajectory versus unchanged treatment advice. For this, we looked at one-year mortality, postoperative complications and days spent in hospital.

In chapter 8 we will summarize the results of the studies mentioned above, discuss the main findings and provide recommendation for the future.

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PART I

CURRENT
MULTIDISCIPLINARY
DECISION-MAKING
IN ONCOLOGY

CHAPTER 2

Multidisciplinary decision-making
in older patients with cancer, does it
differ from younger patients?

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ABSTRACT

BACKGROUND

In order to tailor treatment to the individual patient, it is important to take the patients context and preferences into account, especially for older patients. We assessed the quality of information used in the decision-making process in different oncological MDTs and compared this for older (≥ 70 years) and younger patients.

PATIENTS AND METHODS

Cross-sectional observations of oncological MDTs were performed, using an observation tool in a University Hospital. Primary outcome measures were quality of input of information into the discussion for older and younger patients. Secondary outcomes were the contribution of different team members, discussion time for each case and whether or not a treatment decision was formulated.

RESULTS

Five-hundred and three cases were observed. The median patient age was 63 year, 32% were ≥ 70 . In both age groups quality of patient-centered information (psychosocial information and patient's view) was poor. There was no difference in quality of information between older and younger patients, only for comorbidities the quality of information for older patients was better. There was no significant difference in the contributions by team members, discussion time (median 3.54 min) or number of decision reached (87.5%).

CONCLUSION

For both age groups, we observed a lack of patient-centered information. The only difference between the age groups was for information on comorbidities. There were also no differences in contributions by different team members, case discussion time or number of decisions. Decision-making in the observed oncological MDTs was mostly based on medical technical information.

KEYWORDS

multidisciplinary teams, oncology, older patients, decision-making, patient specific information, patient view.

INTRODUCTION

Many countries have national guidelines demanding multidisciplinary discussion of cancer patients. In the Netherlands between 80-99% of oncological patients are discussed in an MDT meeting.¹⁻³ Oncological MDTs, or tumour boards, are usually organised by tumour type and consist of a group of professionals from different disciplines, including surgeons, medical oncologists, radiation oncologists, pathologist, radiologists and nurses.⁴ Most MDTs meet weekly. The aim of these MDTs is to standardise and optimise cancer care according to current guidelines and facilitate complex decision-making. Discussing cancer patients in an MDT has been shown to result in more appropriate staging, timely treatment, and improved survival.⁵

It has, however, been shown that decision-making in oncological MDTs can be suboptimal for older patients, by lacking specific geriatric information.⁶⁻¹⁰ This information is important in decision-making for older patients. Due to differences in the aging process, there is increased heterogeneity between older patients, making chronological age an insufficient marker of biological age. Decision-making based on chronological age alone can lead to both under- and overtreatment.^{11,12} Another factor complicating decision-making for older patients, is that most guidelines are based on studies where older patients were excluded.¹³ This emphasises the need for tailored decision-making, that is not solely based on cancer characteristics, age, and comorbidity.¹⁴ Incorporating patient specific information into multidisciplinary decision-making has been shown to have an impact on treatment decisions, with alteration of treatment in about a quarter of cases.¹⁵⁻¹⁷ It can also complicate the decision-making, leading to longer discussion time and fewer decisions made.^{18,19} Not including this information, however, leads to lower implementation of the MDT recommendations.²⁰

With the increasing evidence supporting the importance of patient-centred care, taking the patient's context and preferences into account in the decision-making process, we aimed to assess whether this is reflected in the decision-making process in oncological MDT meetings in current practice. We did this by observing different MDT on the quality of the different information used in the decision-making process (both medical technical information such as pathology or radiology as well as patient-centered information) and assessed whether this differed between older and younger patients. We also observed the contribution to the discussion of different team members, time spent on case discussion, and the number of decisions reached.

MATERIALS AND METHODS

SETTING AND PATIENTS

Between March 2017 and June 2019 observations of different oncological MDTs (colorectal, bone and soft tissue, upper gastro-intestinal, hepatobiliary, thyroid, breast and the head and neck) were performed by independent observers in the University Medical center Groningen, The Netherlands. The UMCG is a tertiary university hospital, delivering complex care. According to Dutch guidelines, at least 90% of patients with cancer have to be discussed in an MDT meeting prior to the start of their oncological treatment. These MDTs are organised by tumour type and have to meet weekly. The mandatory professionals differ by tumour type, but minimally consist of a medical oncologist, surgeon, radiation oncologist, radiologist, pathologist, and a nurse.³ There are no clear guidelines regarding the preparation for other participants for each case, only for the presenting specialist.²¹ Within the different MDTs, discussion of all patient cases were observed, independent of age. Patient cases could be presented for the first time, or for follow-up during treatment.

MATERIALS

Each MDT was observed by an independent, non-participating observer, using a validated scoring list; the 'Metric for the Observation of Decision-making (MDT-MODE)' (figure 1).^{22,23} This is a tool to evaluate the quality of information presented (case history, radiology, pathology, psychosocial, comorbidities, and patient views (i.e. the patient's wishes or opinions regarding treatment)). It also evaluates the contribution to the discussion of different specialties (surgeon, oncologist, pathologist, radiologist and nurse) and whether a decision was reached. The MDT-MODE has been shown to have an interrater agreement varying from high agreement for radiology information and contributions from oncologists, pathologists, and nurses, moderate agreement for case history and contribution of surgeons, and poor agreement for pathology information.²³ The original tool can be found on the website of the 'Center for Patient Safety and Service Quality' of Imperial College London.²⁴ For our study we used an adjusted version of the MDT-MODE: age was added in order to make an age-based comparison and 'nurses input' was added to the information section since we were interested as to whether patient specific information was brought into the MDT by nurses (figure 1).

Using the observation tool, information regarding the quality of input of different information and contributions to the discussion was rated on a 5-point Likert scale with a rating of 5 representing optimal quality of presented information or optimal contribution. The instrument uses predefined anchor (example) behaviors regarding the level of quality in order to facilitate the rating of the observations (figure 1). A rating of 1 represents low quality of information or contribution, a rating of 3 average quality of information or contribution, and a rating of 5 good quality of information or

contribution. Similarly, the contribution of different team members in the discussion was rated. Because the function of chair was performed by one of the oncological specialists, input was scored for the role of chair. The patient's age and gender were noted, as well as the time it took to discuss each case. It was also noted whether the MDT reached a decision, or whether this was deferred or not reached/unclear. The information was observed and scored by one of the three trained observers. In order to evaluate interrater reliability, four MDTs were observed by two observers at the same moment, blinded to each other's ratings. The responsible chair of the different MDTs was contacted and approved the study. The other participants were unaware of the observations. Since the observations performed concerned the quality of information discussed by the members of the MDT and patient files were not studied, no patient consent was necessary. The study was registered in the UMCG research register under number 202000352.

NR	INFORMATION									DISCUSSION							DECISION	TIME		
	age	gender	MDT	Hx	Xray	path	Psy/soc	comorb	Pt view	nurse	chair	surg	radioth	oncol	nurse	radiol	path	MDL	y/n/d	time
1																				
2																				
3																				
4																				

History (Hx)	5	Fluent, comprehensive case history	Patient view	5	Comprehensive first-hand knowledge of patient's wishes or opinions regarding treatment
	3	Partial case history		3	Vague first-hand knowledge or good second-hand knowledge of patient's wishes or opinions regarding treatment
	1	No patient case history		1	No knowledge of patient's wishes or opinions regarding treatment
Radiology (X-ray)	5	Radiological images	Nurse input (input of information)	5	Input of good first-hand information about the patient
	3	Radiological information from report/account		3	Input of vague first-hand or good second-hand information about the patient
	1	No provision of radiological information		1	No input of information about the patient
Pathology	5	Histopathological information from pathologist	Chair	5	Good leadership enhanced team discussion and decision making
	3	Histopathological information from report/account		3	Leadership neither enhanced or impeded team discussion and decision making
	1	No provision of histopathological information		1	Poor/inadequate leadership impeded team discussion and decision making
Psychosocial	5	Comprehensive, first-hand knowledge of patients' personal circumstances, social and psychological issues	Members (input in the case discussion)	5	Clear contribution of specialty
	3	Vague first hand-knowledge or good second-hand knowledge of personal circumstances, social and psychological issues		3	Contribution inarticulate or vague
	1	No knowledge of personal circumstances, social and psychological issues		1	No contribution
Comorbidity	5	Comprehensive first-hand knowledge of past medical history and performance status	Decision	Y	Clear decision about treatment(s) to be offert
	3	Vague first-hand knowledge or good second-hand knowledge of personal circumstances, social and psychological issues		D	Decision to defer to next MDT
	1	No knowledge of personal circumstances, social and psychological issues		N	No decision/decision unclear

Figure 1. The tool that was used for the quantitative observations: adjusted 'Metric for the Observation of Decision-making'

OUTCOME MEASURES

The primary outcome was the quality of information and whether this differed between older (≥ 70) and younger patients. The secondary outcome measures were

the contribution of the different MDT members, the single case discussion time and the number of decisions reached (versus a deferred decision or no decision). These outcomes were also compared between older and younger patients.

STATISTICAL ANALYSIS

Characteristics of patients' cases and MDTs observations were analyzed using descriptive statistics and were described as numbers and percentage or median and IQR, as appropriate. For comparison between older and younger patients, Pearson's Chi-square tests were applied for categorised data, and independent T-tests and Mann-Whitney U tests for continuous variables. The MDT-mode provides a 5 point Likert scale, but we found that only scores for which an anchor question was provided (1,3 and 5) for quality of information and contribution in discussion, were rated. These variables were therefore analyzed as categorical and tested with Chi-square tests per item.

Agreement on whether or not a decision was reached was calculated both in an absolute way and using the unweighted kappa. For agreement regarding time spent per case, the intraclass correlation coefficient (ICC) was used. Inter-rater reliability for the quality of information presented (case history, radiology, pathology, psychosocial, comorbidities, patient views, and nurses input) and the input of different participants in the discussion was calculated in an absolute way and using the weighted quadratic kappa. A p-value smaller than 0.05 was considered significant. Data analysis was performed using the software package IBM SPSS Statistics, version 23.0 for Windows (SPSS, Inc., Chicago, IL, USA).

RESULTS

PATIENTS

In total 503 patient cases were observed; 342 (68%) were younger than 70 years and 161 (32%) were 70 years and older. Table 1 shows the characteristics of the patient cases observed, stratified by age. Median age was 63 (IQR 51-72) for the total group; 56 years (IQR 46-63) for the younger group and 75 years (IQR 72-79) for the older group. In the total group, 253 (50.3%) were male and 250 (49.7%) female, with a higher percentage of males in the older group (59% vs 46.2%, $p=0.007$).

Table 1. Baseline characteristics of the patients stratified by age.

Variable		<70 (n=342)	≥70 (n=161)	p
Age (median, IQR)		56 (46-63)	75 (72-79)	na
Gender	Male	158 (46.2)	95 (59.0)	0.007
Tumour type	Colorectal	83 (24.3)	48 (29.8)	<0.001
	Bone and soft tissue	70 (20.5)	18 (11.2)	
	Upper GI	51 (14.9)	30 (18.6)	
	Hepatobiliary	51 (14.9)	26 (16.1)	
	Thyroid	36 (10.5)	4 (2.5)	
	Breast	32 (9.4)	9 (5.6)	
	Head and Neck	19 (5.6)	26 (16.1)	

All numbers are given as n(%) unless otherwise specified, na = not applicable, GI =gastro intestinal

MDT MEETINGS

Table 2 shows the characteristics of the different MDTs. MDTs for the following tumour types were observed: colorectal (131 cases; 26%), bone and soft tissue (88 cases; 17.5%), upper gastro-intestinal (81 cases; 16.1%), hepatobiliary (77 cases; 15.3%), thyroid (40 cases ; 8%), breast (41 cases; 8.2%), and the head and neck MDT (45 cases; 8.9%). The number of patients of 70 years and older differed between the different MDTs, with the highest relative number of older patients in the head and neck MDT (57.8%), followed by the upper GI (37%) and the colorectal MDT (36.6%). Discussion time was slightly longer for older (median time 4:09 min, IQR 02:30-05:38) than for younger patients (median time 3:50 min, IQR 02:20 -5:38) for the whole group and for the different MDTs, but this was not statistically significant ($p=0.2$). Median discussion time per patient was longest in the breast MDT (04:32 min) and upper GI MDT (04:29 min) and shortest in the colorectal (03:20 min, IQR 02:13-05:10) and bone and soft tissue MDT (03:24 min, IQR 01:42-04:43). (table 3) For two patients, the discussion time was unavailable.

Table 2. Characteristics of the observed MDTs

Tumour MDT	Cases (n,%)	Age, median(IQR)	Time per case, median (IQR)		p
Tumour type			Age <70	Age ≥70	
Colorectal	131 (26.0)	64 (55-74)	03:16 (02:13-05:07)	03:44 (02:15-05:27)	0.7
Bone and soft tissue	88 (17.5)	58 (33.5-68)	03:15 (01:23-04:46)	03:31 (02:27-04:44)	0.4
Upper GI	81 (16.1)	66 (61-74.5)	04:22 (03:35-05:44)	05:00 (03:13-06:11)	0.6
Hepatobiliary	77 (15.3)	66 (52.5-72)	04:15 (02:25-06:26)	04:31 (02:35-06:25)	0.8
Thyroid	40 (8.0)	50 (29.8-63.5)	03:39 (01:57-05:50)	04:02 (02:23-05:59)	0.7
Breast	41 (8.2)	53 (46.5-69)	04:27 (02:58-05:44)	04:45 (03:33-07:28)	0.5
Head and Neck	45 (8.9)	71 (59.5-83)	03:06 (02:00-04:45)	04:00 (02:16-04:45)	0.5

QUALITY OF INFORMATION

Figure 2 shows the quality of information on different items stratified by age. For the whole group the information was most comprehensive for case history (good quality in

65.6%), radiology (good quality in 81.7%) and pathology (good quality in 38.9%), and lowest on psychosocial information (good quality in 2%), patients view (good quality in 3%), and nurse input (good quality information in 0%). On comorbidity, there was good quality information for 15.9%. Only for comorbidities, there was a significant difference in the quality of information between older and younger patients (good quality in 18.6% and low quality in 47.2% for older patients versus good quality in 14.6 % and low quality in 61.1% for younger patients, $p=0.01$). The quality of information on the other items was similar between older and younger patients.

Figure 2. Quality of information presented during the MDTs on different variables (%)

When dividing the discussion time in high and low by using the mean discussion time (3.54 min) as a cut-off between these two categories, there were no significant differences for quality of information on case history, pathology, patient-centered information (psychosocial information and patient views) and nurses input. For comorbidities and radiology, information was slightly better when the discussion time was longer (comorbidities: comprehensive in 21.9% for a longer discussion time versus 10% for a shorter time, $p<0.001$, radiology: 89.6% versus 74%, $p<0.001$). Median discussion time for comorbidities ranged from 03.28 minutes for low quality information to 04.46 min for high quality information. For radiology information the median time ranged from 02.28 min for low quality information to 04:09 min for high quality information. (data not shown)

CONTRIBUTION OF MEMBERS

Figure 3 shows the contribution to the discussion for different specialties. The chair and the surgeons had the largest contribution in the observed MDT and were present the most. Nurses were present in 65.9%, but their contribution to the discussion was poor for both age groups. The attending nurses were all oncology nurses and sometime nurse practitioners.

Figure 3. contribution to the discussion of different MDT members
Other = other team members such as gastroenterologist, endocrinologist

DECISIONS REACHED

For 63 patient cases (12.5 %) no decision was reached during the MDT meeting; for 60 cases (11.9%) the decision was deferred, and for three patient cases (0.6%) a decision was not reached/unclear. For one patient this information was missing. The number of patients where a decision was not reached/deferred was similar in the older group vs the younger group (14.4% vs 11.7%, $p=0.4$). There were different reasons for a decision to be deferred. Sometimes patients needed additional investigations (like a biopsy or scan) and sometimes they needed to be referred to a different specialist, or both. In some cases, the treating physician wanted to discuss the case in their own team before making a final decision.

INTERRATER RELIABILITY

Interrater reliability was calculated for 46 cases from four different MDTs. Absolute agreement for the rating of the quality of information ranged from 71.7% to 100%,

with an exception of pathology with an absolute agreement of 47.8%, with a moderate weighted quadratic kappa of 0.505. Weighted quadratic kappas were moderate to good for radiology, comorbidities, and patient views. There were low kappa values on case history and psychosocial information due to a lack of variance in measurements. For nurses input, a kappa could not be calculated since there was zero variance between the observers. Absolute agreement on the observations of the contribution in the discussion of different members of the MDT between observers ranged from 58.7% to 97.8%. Agreement was poor for the observations of the contribution of the chair, possibly due to the fact that this was mostly one of the team members who performed another role in the MDT as well. There was zero variance in observations of the nurses' role (no role). Agreement was fair to moderate for the contribution of the surgeon, pathologist, and radiologist and good to very good for the observations on the contribution of the medical oncologist, pathologist, and radiologist. Agreement on time measurements could be calculated for 33 cases. There was excellent interrater reliability for time spend per case, ICC = 0.966 (0.932-0.983). There was a good agreement for whether or not a decision could be reached (91.3% absolute agreement, unweighted kappa=0.701). (table 3)

Table 3. Interrater reliability between the reached decisions, discussion time, observed quality of information, and observed quality of input.

Observed item	Patients (n)	absolute agreement (%)	test
Decision	46	91.3	0.701 (0.434-0.968) ¹
Time	33	-	0.966 (0.932-0.983) ²
Information:			
Case history	46	71.7	0.160 (-0.80-0.400) ³
Radiology	46	91.3	0.618 (0.279-0.957) ³
Pathology	46	47.8	0.500 (0.286-0.713) ³
Psych/social	46	91.3	0.176 (-0.144-0.496) ³
Comorbidity	46	76.1	0.738 (0.549-0.926) ³
Patient view	45	97.8	0.904 (0.686-1.123) ³
Nurse input	37	100	NA ⁴
Contribution in discussion:			
Chair	46	58.7	0.027 (-0.218-0.273) ³
Surgeon	46	80.4	0.466 (0.184-0.749) ³
Radiation oncologist	46	97.8	0.973 (0.918-1.028) ³
Medical oncologist	46	93.5	0.898 (0.760-1.036) ³
Nurse	46		NA ⁴
Radiologist	46	73.9	0.584 (0.367-0.800) ³
Pathologist	46	89.1	0.337 (-0.153-0.828) ³
Other	46	80.4	0.645 (0.411-0.878) ³

1= Unweighted kappa (95% CI), 2= Intraclass correlation (95%CI), 3= Weighted quadratic kappa, 4= zero variance.

DISCUSSION

This study assesses the quality of information discussed in oncological MDTs and whether this differed between older and younger patients. To our knowledge, this is the first study comparing the discussion of older patients with the discussion of younger patients in MDTs. We had expected more patient-centered information and a longer discussion time for older patients, reflecting the higher level of frailty and multimorbidity in this age group, but found no differences between younger and older patients. The focus of the MDTs was mostly disease-centered and technical. These findings do not necessarily mean that patient-centered information is not considered and weighed by the individual specialist in the decision-making process. However, by leaving this out of the MDTs, the gathering and interpretation of this information is left up to the individual medical specialist and therefore not guaranteed for all patients.

There were also no differences in contribution of different team members, or number of decisions reached between the older and younger patients. Discussion time for each individual case varied between MDTs, but was short (median 3.54 min). The short discussion time might have impacted the availability and information quality. For radiology information and information on comorbidities we found a relation between quality of information and discussion time. However, we cannot assess whether this was due to the fact that patients with more (complex) disease and comorbidity were discussed more extensively, or that a longer discussion time led to providing more comprehensive information.

The short discussion time per case could be a result of a high case load in the MDTs and the limited available time of attending specialists. In the Netherlands, guidelines state that all patients have to be discussed in a multidisciplinary setting in order to provide optimal quality treatment proposals for all patients, however, this also puts a burden upon oncological specialists, as these meetings are often time consuming. There was a difference in contribution of different team members, with surgeons contributing most often. This was likely due to the fact that the surgeon was often the presenting specialist or that surgery was the primary treatment modality in the discussed patients. The contribution of a radiologist and pathologist was mostly related to whether there were pathology or radiology results to discuss.

MDTs play an important role in cancer care. The impact of MDTs on outcomes is, however, still unclear. Systematic reviews have shown an impact on diagnosis and management, but mostly disease related such as improved staging and adherence to guidelines.^{25,26} The lack of patient-centered information we found is in line with other observational studies.^{27,28} Even information regarding comorbidities has been found

to be unstructured and often poor in oncological MDT discussions.^{29,30} To improve decision-making in MDTs, a minimum dataset has been suggested, based on a national survey in the UK among MDT members and on meetings with different stakeholders. This dataset should include diagnostic information (radiology and pathology), clinical information (i.e. comorbidities and psychosocial information), and patient history, views, and preferences (when known).^{31,32}

Appointing a patient advocate to represent the patient's perspective, for instance, a nurse, can also support patient-centered decision-making.^{10,28} Nurses often possess useful, patient-centered, information which makes them ideal as case managers. Providing them with a substantial role in MDTs, in order to share this information, might enhance tailored decision-making.^{33,34} Unfortunately, the input of nurses in the observed MDTs was also almost nonexistent as was the input of patient-centered information, such as patient preferences and psychosocial information. The limited input of nurses has been observed in other studies.³⁵ In MDT meetings, medical specialists are often dominant, and not everyone experiences an equal opportunity to provide their opinion.³⁶ A qualitative study revealed that, during oncology MDT meetings, nurses tend to only participate when asked specific questions and their opinions were sometimes given less weight.³⁷ The authors suggest that nurses should get a more prominent role in the discussion of every patient, as does another study among MDT participants.³¹ It has been shown that incorporating patient-centered information from nurses and involving geriatricians in an oncological MDT, led to a change in treatment plan in 25%.¹⁶ Due to the observational nature of the current study, we cannot assess if the absence of nurses input and the lack of information on patient specific information were related. We also do not know whether nurses talked to the patients about the patients perspective before the meetings. It is unclear why patient-centered information was lacking, but this might be related to a disease-centered focus and to a high number of patients that needed to be discussed within a limited amount of time.

In order to discuss patient specific information in MDTs, this information has to be gathered beforehand and shared in the discussion. For older patients, geriatric assessment (GA) is a manner of structurally assessing insight in age related problems and level of frailty and doing this has been shown to influence multidisciplinary decision-making.^{15,38,39} This can be performed by the oncology team supported by geriatric expertise, or by a geriatrician.¹⁶ General practitioners can also provide valuable contextual information.⁴⁰ We cannot assess whether a GA was performed in the discussed patients, however, this was not reflected in the observed MDTs and geriatricians did not attend these meetings. Knowing the patients context and preferences is equally important for younger patients with cancer, as age alone is an insufficient marker of frailty and assessing goals and preferences is an important aspect of shared decision-making for all patients.⁴¹

There are some limitations to this study worth mentioning. First, due to the observational nature of this study, the quality of information as discussed within the MDT could only be noted as it was observed. We do, however, not know whether participants received or read information beforehand or if patients were discussed with colleagues afterward. It is also unknown if patient-centered information was collected later on during the process of shared decision-making. Furthermore, the presence of an observer could have led to the 'Hawthorne effect', where the behaviour of teams is affected by the presence of an observer. However, since all observations were done in an academic center, most attendants of MDTs were comfortable with different people attending the MDT (such as students and trainees), and the effect has likely been small.

In conclusion, with the increasing number of older and frail patients presenting with cancer, the complexity of the decision-making will increase. Even though there has been increased attention to the importance of patient-centered information to optimise decision-making, this is was not reflected in the observed oncological MDTs. Establishing a minimum dataset of available information and appointing a patient advocate for all patients, such as a nurse, could be a means to optimise the decision-making process.⁴² Geriatric expertise can provide added value in the treatment decision-making for older patients. Incorporating patient-centered information into MDT decision-making and involving all relevant disciplines into these meetings, is an opportunity to deliver true patient-center care for all patients.⁴³ Future studies should focus on how to optimise MDT decision-making, without an increasing the burden upon oncology specialist of more or longer meetings. It should also be assessed how the treatment proposals formulated by the MDTs are translated to the shared decision-making process with the patient and whether this leads to improved outcomes from the patients point of view.

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PART II

ASSESSMENT OF PATIENT GOALS AND PREFERENCES

CHAPTER 3

Using the Outcome Prioritization Tool(OPT) to assess the preferences of older patients in clinical decision-making: a review.

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ABSTRACT

Shared decision making can guide patients facing difficult treatment decisions, making a trade-off between risks and benefits, and taking patient goals and preferences into account. The Outcome Prioritization Tool (OPT) was developed to discuss patient goals and preferences with older patients in an encompassing, non-disease-specific way. The OPT is used in both primary and secondary healthcare for several treatment decisions, but data regarding the tool are limited. A concise review yielded two developmental articles, four articles describing three studies using the OPT, and one study protocol. All studies were performed among older patients. In those studies, the majority of patients ranked maintaining independence as most important. The tool showed to be feasible for both patients and healthcare providers.

INTRODUCTION

Shared decision making (SDM) is recommended for patients facing difficult treatment decisions.^{1,2} SDM is defined as “a process to make decisions that are shared by clinicians and patients by informing patients using best evidence about risks and benefits including patient-specific characteristics and values”.³ There is evidence that an SDM process leads to enhanced knowledge of treatment options and outcomes among patients^{4,5} and better congruence between pursued treatment options and patients’ personal values.⁵ Many patients prefer a shared role in decision-making,^{6,7} and studies show that patient preferences vary and physicians notions of patient preferences are often incorrect.^{8,9} However, patients’ values and personal preferences are not routinely integrated in clinical care.¹ Older patients, however, often find it difficult to participate in SDM.¹⁰

In the last decade, several tools have been developed to facilitate SDM.^{4,5} Most of these tools are disease-specific and focus on explaining the costs and benefits of different treatment options, sometimes also taking into account personal values and preferences. An encompassing, non-disease-specific tool is the Outcome Prioritization Tool (OPT),¹¹ a decision aid to discuss meaningful goals and preferences with older patients. In the Netherlands, the OPT is used increasingly in both primary and secondary care to guide complex decision making (e.g. on transcatheter aortic valve replacement (TAVR), start of dialysis, and cancer treatment). To summarise the available evidence about the OPT, we performed a literature review. First, we will describe the instrument and the clinical experiences and thereafter the results of this mini review.

THE OUTCOME PRIORITIZATION TOOL (OPT)

The OPT is an instrument with four visual analogue scales, each representing a universal health outcome (Figure 1). The healthcare provider invites the patient to value and prioritise the different outcomes. Each outcome can be rated 0-100, with a higher score meaning higher importance. Two outcomes cannot be rated equally.

The OPT can aid with, but not substitute for a conversation. The guideline for healthcare providers for use of the OPT is described below:^{12,13}

1. Introduce the instrument and explain the reason for using the instrument.
2. Explain the different health outcomes to the patient.
 - Extending life.
 - Maintaining independence.
 - Reducing or eliminating pain.
 - Reducing or eliminating other symptoms, such as dyspnoea, nausea or itching.

3. Explain the trade-off principle: outcomes have to be prioritised in order of importance, if a patient prioritises one outcome (for example extending life), this means that they are willing to give up something on another outcome (e.g. maintaining independence).
4. Invite the patient to prioritise the health outcomes. During this process, patients are invited to explain what is important to them and why specific choices are made.
5. Check whether the results actually describe the patient's preferences.

3

Figure 1: Outcome Prioritization Tool

LITERATURE REVIEW

We will first discuss the articles reporting on the development of the OPT and thereafter describe the literature review.

The OPT was developed using qualitative research among older patients with multiple morbidities who were confronted with a trade-off. It was first described in 2011.¹¹ Pilot testing showed that participants understood the concept of prioritisation, but with a maximum of four outcomes.¹¹ The OPT captured what is important for older people when dealing with trade-offs, but test-retest validity was fair to poor.¹¹ Therefore, in a study among residents of senior centres, the instruction accompanying the tool was changed in order to emphasise the notion of trade-offs.¹⁴ This resulted in a test-retest agreement regarding the most and least important outcomes ranging from 85% to 100%.¹⁴ Although the testing was not performed in a clinical setting, the authors reported that maintaining independence was most often prioritised as most important outcome, in 42-76% of patients (Table 1).

In PubMed the search terms *Outcome priorit* tool* and *Health Outcome prior** were used and in Web of Science we searched for articles that cited one of the development articles.^{11,14} The inclusion criterion was the use of the OPT. We have not applied exclusion criteria. For all included studies, we extracted the following characteristics: design and aim, setting, characteristics of participants, the primary outcomes, how OPT outcomes were prioritised, and information about feasibility/experiences. The search, performed on November 6 2018, yielded four manuscripts describing three studies,¹⁵⁻¹⁸ and a protocol article¹⁹ which we will not describe. Two authors (MES and SF) assessed the quality of the studies as moderate using the GRADE-system.²⁰ Characteristics of all studies are shown in Table 1.

Case et al. performed a mixed-methods cross-sectional study of 356 persons aged 65 and older living at home and compared the OPT with two other tools: the 'Now vs Later' tool and the 'Attitude scale'.¹⁷ On the 'Now vs later tool', participants made a trade-off between quality of life at present or in the future. Using the 'Attitude scale', participants were asked if they agreed with statements regarding different health outcomes (e.g. enduring side effects now versus a better quality of life in the future). Fifty-two percent of the patients thought the OPT to be easy to use. When comparing the OPT to the other tools, most patients preferred the OPT (41%), although no specific reason was mentioned. In this study, 21% of the patients expected that the use of the OPT would change their care.

Table 1: Characteristics of the included studies

	Design and aim	Setting	Participants	OPT item ranked as most important outcome	Other outcomes
Developmental articles					
Fried, 2011 (PEC)	Qualitative study Aim: to pilot the OPT	Home dwelling Connecticut, USA	N=81 Aged 70 and older Cognitively intact persons with hypertension and fall risk	Life extension 27% Maintaining independence 42% Reducing pain 21% Reducing other symptoms 10%	Understanding of the instrument was rated as a 4 or a 5 (out of 5) for 73% of participants. Test-retest reliability fair to poor.
Fried, 2011 (Archives)	Qualitative study Aim: to pilot the OPT	Home dwelling (senior centers living facility) Connecticut, USA	N=357 Aged 65 and older	Life extension 11% Maintaining independence 76% Reducing pain 7% Reducing other symptoms 6%	Percent agreement regarding the most important and least important outcome ranged from 85% to 100%.
Articles in literature review					
Case, 2013	Mixed methods cross-sectional study Aim: to compare the OPT with two other tool	Home dwelling Connecticut, USA	N= 356 Aged 65 and older	Not applicable	41% preferred the OPT (vs 40% / 19% other tool). 21% of participants believed use of a tool would change care.
Van Summeren 2016 & Van Summeren 2017	Mixed methods non-controlled intervention study Aim: to evaluate the OPT during a polypharmacy conversation between patient and GP.	Primary care The Netherlands	N=58 (and their 13 GPs) Aged 69 and older Two or more chronic conditions (one of which had to be cardiovascular disease), and daily use of five or more medications	Life extension 31% Maintaining independence 35% Reducing pain 11% Reducing other symptoms 18%	92% found the OPT understandable 55% could easily prioritise between health outcomes After use of the OPT GPs proposed 34 changes of medication, mainly stopping, for 20 patients. At follow-up, 14 medication changes were observed for 10 patients.
Ramer, 2018	Quantitative cross-sectional study Aim: to examine the associations between priorities and self-reported health status and between priorities and acceptance of common end-of-life scenarios.	Secondary care New York, USA	N=271 Aged 60 and older Advanced non-dialysis-dependent chronic kidney disease	Life extension 35% Maintaining independence 49% Reducing pain 9% Reducing other symptoms 6%	Providers' perceptions about patients' top health outcome priorities were correct 35%

Table 1 continued.

Design and aim		Setting	Participants	OPT item ranked as most important outcome	Other outcomes
Articles in literature review					
Stegmann, 2017	Protocol article of a RCT Aim: to evaluate the effect of an OPT-conversation by the GP (intervention) on decision self-efficacy compared to patients who did not have this OPT-conversation (control).	Transmural The Netherlands	Aged 60 and older Patients with non-curable cancer, who need to decide about treatment	Not applicable	Not applicable

Ramer et al. performed a quantitative cross-sectional study amongst 271 outpatients aged ≥ 60 years with advanced non-dialysis-dependent chronic kidney disease to examine the associations between outcome priorities, self-reported health status, and acceptance of end-of-life scenarios (e.g. kidney dialysis, cardiopulmonary resuscitation). No information about patient experiences was provided.¹⁸

Van Summeren et al. performed a mixed methods non-controlled intervention study among 58 patients, aged ≥ 69 years, who used a large number of medications (polypharmacy).^{15,16} General practitioners (GPs) and patients discussed the medication list taking the OPT score into account, aiming for congruency between the indication, benefit and harm of the different medications and the patient's preferences.¹⁵ In this study, 73-92% of the patients thought the OPT was understandable.¹⁶

Considering healthcare providers, in the study by van Summeren GPs mentioned that the goals 'maintaining independence' and 'reducing other symptoms' were the most difficult to explain.¹⁶ They also perceived the OPT as time consuming; about half an hour was needed to elicit preferences, although less time was needed once experience was gained. However, GPs indicated that the OPT did result in a better understanding of the patient's life. Ramer showed that, without the use of the OPT, healthcare providers have limited awareness of the patients' most important health outcomes. Providers' perceptions what they considered patients' most important goals were correct in 35%, with an expected agreement of 25%, resulting in a weighted Cohen's k for patient-provider concordance of 0.10 (95% CI -0.21 to 0.40).¹⁸

The studies by van Summeren and by Ramer^{15,18} described OPT scores on the four health outcomes. In both studies, maintaining independence was most often prioritised as most important outcome (35-49% of the patients), followed by extending life (31-35%), reducing pain (9-11%) and reducing other symptoms (6-18%).

Effects of the use of a conversation in which the OPT was used on clinical care were assessed in the study by van Summeren. After the OPT-conversation, 34 changes in medication were proposed to 20 of the 58 patients, with mainly preventive medication being stopped.¹⁶

SUMMARY

The OPT is a promising instrument to guide treatment decisions in older patients. Because encompassing health outcomes are elicited, the tool can be used in different settings in both primary and secondary care. Data regarding the use of the instrument

and the effect of the OPT on treatment decisions are limited.

PRACTICE POINTS

- Treatment decisions in older patients can be complex and comprise trade-offs between risks and benefits.
- To reach tailor-made decisions it may be important to elicit patient goals and preferences in a structured way.
- The OPT is an instrument with four visual analogue scales, each representing an encompassing treatment goal, and uses a trade-off principle. It can be used in different healthcare settings where (complex) treatment-decisions have to be made.
- One study suggested that there is a low concordance between the goals and preferences of patients and healthcare providers' perceptions about this.

RESEARCH AGENDA

- To evaluate the effects of the tool on treatment-decisions in different healthcare settings.
- To evaluate the opinion of both patients and healthcare providers on the feasibility and usability of the OPT.
- To evaluate whether patients with a low education and low health literacy are able to understand this instrument.
- To monitor the prioritisation of outcomes over time, as this may change during treatment.
- To study whether the tool can be useful for younger patients as well.
- To investigate how patients and healthcare providers translate the generic health outcomes of the OPT to specific treatment decisions.

HIGHLIGHTS

- The Outcome Prioritization Tool (OPT) is an instrument with four visual analogue scales, each representing an encompassing treatment goal, and uses a trade-off principle.
- Although the tool is used in different healthcare settings, literature about the instrument is scarce.
- The studies reporting on the tool showed that OPT-conversations were feasible for both older patients and their healthcare providers.
- More research is needed to evaluate the effects of the OPT-conversations, for instance on how the tool is used in specific healthcare decisions.

ADDITIONAL INFORMATION

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CONTRIBUTORS

All authors contributed to the literature review and the writing and revision of the paper. The first authorship position is jointly shared between Mariken E. Stegmann and Suzanne Festen.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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CHAPTER 4

“What matters to you?”

Health outcome prioritisation
in treatment decision-making
for older patients

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ABSTRACT

BACKGROUND

For shared decision-making it is important to discuss of the patients' priorities in order to align treatment decisions with these priorities.

OBJECTIVE

To assess the most important health outcome for older patients on the verge of making a treatment-decision, using the Outcome Prioritization Tool (OPT). Secondary objectives were the feasibility of the OPT and patient variables associated with prioritising different health outcomes.

DESIGN

Retrospective cohort study.

SETTING AND SUBJECTS

At the University Medical Hospital Groningen, the Netherlands, 350 patients were included who visited the geriatric outpatient clinic during the work-up regarding a complex treatment decision (such as cancer treatment or heart valve replacement).

METHODS

During geriatric assessment, patients prioritised between four health outcomes, using the OPT.

RESULTS

Median age was 78.5 years, 172 (49.1%) were referred regarding a treatment decision for a malignant disease. Cognitive impairment was present in 23.6%. Most patients (55.2%) prioritised maintaining independence as their most important goal, followed by extending life in 21.1%. Only cognitive impairment was significantly associated with prioritising extending life as the most important health outcome. For 107 patients (30.6%) the OPT was not feasible; these patients more often had malnutrition and assisted living.

CONCLUSIONS

The main health outcome of older patients on the verge of making a treatment-decision, was maintaining independence, followed by extending life. Patients with cognitive impairment more often prioritised extending life. The OPT was feasible as a decision aid for most patients. For optimal shared decision-making it is crucial to take patient preferences into account.

KEY POINTS

- Using the Outcome Prioritization Tool (OPT) can support shared decision-making.
- Maintaining independence was the most important health outcome for older patients.
- Only patients with cognitive impairment prioritised 'extending life' more often.
- The OPT was feasible for most patients facing complex decisions.

INTRODUCTION

Assessing patient's goals and preferences is an important aspect of shared-decision-making. However, it has been shown that healthcare professionals often have limited knowledge of these goals and preferences.¹⁻³ A decision aid might support engaging a conversation about goals and preferences.

The Outcome Prioritization Tool (OPT) is such a decision aid. It assesses universal health outcomes and is thereby neither disease nor treatment specific. This makes the tool usable in different settings.⁴ The health outcomes used in the OPT are: extending life, maintaining independence, reducing pain or reducing other symptoms (such as dyspnoea or nausea). The OPT uses a trade-off principle for competing outcomes, i.e. the notion that reaching a certain outcome can have negative impact on another outcome.⁵ Using the OPT, the patient is invited to prioritise and rate the health outcomes in order of importance.⁶ The OPT has mostly been studied in older patients with multimorbidity.^{6,7} Little is known about the use of the OPT in clinical decision-making regarding intensive treatments (such as cancer therapy or surgery).

This study assesses the main health outcome prioritised by older patients on the verge of making a complex treatment-decision, using the OPT.

METHODS**SETTING**

This retrospective study was performed at the Department of Geriatric Medicine at the University Medical Center Groningen (UMCG). All patients referred to the geriatric outpatient clinic for co-assessment in treatment decision-making between April 2018 and October 2019 were included. There were no other inclusion or exclusion criteria. Patient and disease characteristics were extracted from the patient's medical records.

PATIENTS

There were three groups of patients referred for co-assessment: (i) patients aged ≥ 65 years with an aortic valve stenosis eligible for Transcatheter Aortic Valve Implantation (TAVI), (ii) patients with cancer, who were considered frail, based on a nurse-led geriatric assessment,⁸ and (iii) patients referred based on the clinical judgment of the treating physician.

COMPREHENSIVE GERIATRIC ASSESSMENT

At the geriatric outpatient clinic a Comprehensive Geriatric Assessment (CGA) was performed and patient preferences were assessed using the OPT. During the CGA, four geriatric domains were assessed (somatic, psychological, social and functional).⁹⁻¹⁵ (figure 1). Based on the results of CGA, the level of frailty was determined, defined as an accumulation of deficits on the geriatric domains.¹⁶

PATIENTS' PREFERENCES

The patients' preferred health outcomes were assessed using the OPT.⁶ On a VAS from 0-100, The patient is invited to prioritise and rank the four health outcomes. Due to the principle of trade-offs, no two health outcomes can have an equal score. For the analysis, the most important health outcome was registered. If, despite instructions, patients ranked two outcomes the same, these data were left out of the analysis of the main OPT goals.

OUTCOME MEASURES

The primary outcome was the main health outcome as prioritised by the patient. The secondary outcomes were the feasibility of the OPT and the associations between patient- and disease characteristics with the main OPT goal and with the feasibility of the OPT.

STATISTICAL ANALYSIS

Baseline characteristics, feasibility and main health outcome were analyzed using descriptive statistics. To assess the association between patient and disease characteristics and 1. main health outcome prioritization and 2. feasibility, univariate logistic regression was performed, followed by multivariate analyses for variables with a $p < 0.1$. A p-value smaller than 0.05 was considered significant. Statistical analysis was performed using IBM SPSS Statistics 23.

STATEMENT OF ETHICS

This study was conducted in accordance with the Declaration of Helsinki and Good Clinical Practice Guidelines. Permission was granted by the local medical ethical committee. A waiver of consent was obtained from the relevant institutional review board.

RESULTS

PATIENTS

Table 1 shows the characteristics of the 350 included patients. Median age was 78.5 years; the majority were male. Most patients with a benign disease were referred with an indication for transcatheter aortic valve replacement (TAVI). Other benign diseases included other heart and vessel disease, benign tumors, cochlear implant, hip/knee replacement and kidney failure.

Most patients with a malignant disease suffered from head and neck cancer.

COMPREHENSIVE GERIATRIC ASSESSMENT

Comorbidity was common (54.3%). Eighty-two patients (23.4%) were diagnosed with cognitive impairment based on the CGA and most patients were dependent in ADL and iADL. More than half of the patients were considered frail by the geriatrician (table 1).

PATIENTS' MAIN HEALTH OUTCOME

For 243 patients (69.4%), preferences could be assessed using the OPT, of which 20 ranked two or more outcomes equally. Of the 223 patients who prioritised one health outcome, more than half prioritised maintaining independence, followed by extending life, reducing pain and reducing other symptoms (figure 1).

In univariate analysis, a low education level, having a malignancy, cognitive impairment and frailty were associated with a higher odds of prioritising 'life extension' as the main goal. High comorbidity, cognitive impairment, ADL deficits and frailty were associated with a lower odds of prioritising 'maintaining independence' as a main goal. In multivariate analysis, having cognitive impairment was the only variable significantly associated with prioritising 'extending life' (OR 2.78, 95%CI 1.22-6.33, $p=0.02$) as well as with prioritising 'maintaining independence' less often (OR 0.46, 95%CI 0.22-0.97, $p=0.04$).

FEASIBILITY

In 107 patients (30.6%) the OPT could not be assessed. The results of the univariate and multivariate analysis are shown in Table 1. In multivariate analysis, assisted living and a high risk of malnourishment were significantly associated with not using the OPT.

Table 1. Baseline characteristics and CGA for the total group and association of the variables with feasibility of the OPT

Baseline characteristics and CGA (n=350)		Log regression for the OPT not being feasible (n=107)					
Variable	N(%)*	Univariate analysis			Multivariate analysis**		
		OR	95% CI	p	OR	95% CI	p
Baseline characteristics							
Age							
Median (IQR)	78.5 (73.0-82.25)						
>70	305 (87.1)	1.24	0.62-2.52	0.54			
Sex							
Male	195 (55.7)	0.97	0.61-1.53	0.89			
Reason for referral							
<i>Benign</i>	178 (50.9)						
TAVI ¹	137 (77.0)						
Cochlear Implant Placement	12 (6.7)						
Other benign disease ²	29 (16.3)						
<i>Malignant</i>	172 (49.1)	1.49	0.95-2.36	0.09	1.10	0.64-1.90	0.74
Head and neck tumor	85 (49.4)						
GI tumor ³	29 (16.9)						
Skin tumor	27 (15.7)						
Urogenital tumor	15 (8.7)						
Other malignancy ⁴	16 (9.3)						
<i>Tumour stage (n = 172)</i>							
I	15 (8.7)						
II	28 (16.3)						
III	39 (22.7)						
IV	55 (32.0)						
Missing, not applicable or unknown ⁵	35 (20.3)						
Geriatric assessment							
CCI⁶							
Median (IQR)							
≥ 3 points	190 (54.3)	1.38	0.87-2.19	0.17			
Malnutrition (MN-SF)⁷							
risk of malnutrition	137 (40.5)	2.39	1.48-3.87	<0.001	1.78	1.04-3.07	0.04
Leven of education⁸							
low	218 (64.9)	1.10	0.67-1.79	0.71			
Cognition							
Cognitive impairment ⁹	82 (23.6)	2.05	1.22-3.42	0.006	1.76	0.97-3.17	0.06
Mood							
Signs of depression ¹⁰	33 (9.6)	2.14	1.03-4.43	0.04	1.49	0.66-3.38	0.34
Marital status							
No partner	132 (37.8)	1.45	0.91-2.30	0.12			
No children	48 (13.7)	1.44	0.76-2.71	0.26			
Living situation							
Assisted	32 (9.2)	3.83	1.81-8.09	<0.001	2.88	1.22-6.75	0.02
Home care		1.72	1.01-2.90	0.04	0.19	1.52-0.82	2.84
(i)ADL¹¹							
ADL dependent (≥ 1)	189 (54.9)	1.14	0.72-1.81	0.59			
IADL independent (≥ 1)	221 (64.2)	1.59	0.97-2.62	0.07	0.96	0.53-1.74	0.88
Mobility							
TUG ¹² > 15 sec	61 (20.5)	1.25	0.67-2.33	0.49			
Walking aid	144 (41.4)	0.98	0.61-1.55	0.92			
Frailty							
Frail based on CGA ¹³	209 (59.7)	1.34	0.83-2.14	0.23			
VAS EQ5D¹⁴ (median)	70 (50-80)	1.01	0.99-1.02	0.46			

*all values are given as N(%) unless otherwise specified, ** variables with a p<0.1 in univariate analysis were entered in the multivariable model. 1: Transcatheter Aortic Valve Implantation. 2: liver or kidney

transplantation, vascular surgery, orthopedic surgery, benign head and neck surgery, benign neurosurgery, benign abdominal surgery 3: Gastrointestinal. 4: Sarcoma, breast cancer, hepatobiliary cancer, merkelcell carcinoma, hematological malignancy, unknown primary, suspected malignancy, but no definite diagnosis. 5: hematological malignancy, no pathological diagnosis, unknown primary, no staging. 6: CCI: Charlson Comorbidity Index, 7: MNA-SF: mini nutritional assessment, short form, 8: education level according to Verhage, 9: Cognitive impairment as determined by the internist geriatrician based on the Comprehensive Geriatric Assessment (CGA), 10: PHQ-2: Patients health Questionair-2, 11: (i)ADL: (instrumental) activities of daily living, assessed by the KATZ-15, a score of one or higher on the ADL and iADL subscale was considered as being dependent, 12: TUG: Timed Up and Go test, 13: Frailty as determined by the internist geriatrician based on the CGA, 14: Self assessed health based on the EQ5D VAS.

Figure 1. Main health outcomes, using the OPT. Main health outcome for (A) the total group (n = 223) and for the subgroup (B) with cognitive impairment (n = 43) and (C) without cognitive impairment (n = 179).

DISCUSSION

This study shows that most older patients facing a complex treatment decision regarding intensive treatments, prioritised maintaining independence as their most important health outcome, using the OPT. Since the intensive treatments are often aimed at life extension, this is an important finding. This is in line with previous research, that has shown that older patients facing a trade-off in decision-making often value retaining of independence, function and cognition over extending life per se.¹⁷ Assessment of

patients' preferences is considered an important aspect in shared decision-making.^{18, 19} However, research has shown that preference misdiagnoses are frequent^{2, 20} emphasizing the importance of discussing goals and preferences.^{20, 21} Using the OPT to discuss health outcome preferences was feasible for 7 out of 10 patients.

As far as we know, this is the first large cohort of patients in which the OPT was used in complex treatment decision-making. Only one previous study describes incorporating the OPT in treatment decision-making in older patients with cancer.⁸ The OPT has mostly been studied in older patients with multimorbidity and regarding decision-making on polypharmacy.⁶ Assessment of patient priorities in cancer patients, using other tools, has been shown to have a positive effect on communication, shared decision-making and patient satisfaction.²² In a recent study the use of the OPT by general practitioners in patients with non-curable cancer was associated with less anxiety and fatigue.²³ Priorities-aligned care might also improve patient outcomes by minimizing harm and treatment burden.²⁴

There was a higher number of patients prioritising extending life when cognitive impairment was present. Patients with cognitive impairment might find it more difficult to oversee different health outcomes and understand the trade-off principle. A study by Fazel et al. showed that patients with dementia more often indicate a preference for treatment interventions on realistic clinical vignettes.²⁵ It has also been shown that a decline in health status can lead to accepting a further decline more easily.²⁶ This might be explained by an adaptation to increased dependency, leading to a reprioritization response shift.²⁷ Furthermore, it is known that treatment-specific preferences can change over time as well as with a change in health status.²⁸

The OPT is a decision aid that in our sample was feasible for most older patients. Even if a patient is not able to prioritise the four health outcomes, introducing the tool might facilitate discussing preferences and trade-offs in order to align decision making. The OPT was less feasible for patients in assisted living and with malnourishment. This might be due to the fact that these patients were more ill and did not have the concentration to fill in the OPT, or this was perceived as such by the healthcare professional.

There are some limitations to our study. This was a selected group of patients with a high level of (suspected) frailty. Only the TAVI patients were unselected. The analysis was retrospective, and we were limited to information noted in the patient's files. It was therefore not always possible to assess the exact reason for not assessing the OPT. Furthermore, not using the OPT could be due to a selection bias of the doctor deciding not to use the OPT, for instance when the patient had cognitive impairment. Still, this reflects a real life setting in a heterogeneous geriatric population.

CONCLUSIONS AND IMPLICATIONS

The OPT is a decision-aid feasible for most patients facing complex treatment decision-making regarding intensive treatment. Maintaining independence was considered the most important health outcome by the majority of older patients, which is relevant to consider in treatment decisions. In order to align care to patients preferences, it is important to explicitly discuss these goals and preferences. Future research should be aimed at how priorities aligned care improves decision-making and patient outcomes.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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CHAPTER 5

How well do healthcare professionals know of the priorities of their older patients regarding treatment outcomes?

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ABSTRACT

OBJECTIVES

For shared decision making, it is crucial to identify patients' priorities regarding health outcomes. Our aim was to study whether healthcare professionals know these priorities.

METHODS

In this cross-sectional study we included older patients who had to make a treatment decision, their general practitioners (GPs) and their medical specialists. Agreement between the patients' main health outcome as prioritised by using the Outcome Prioritization Tool (OPT) and the perception of the same outcome by their healthcare professionals.

RESULTS

Eighty-seven patients were included. Median age was 76 years, 87.4% of patients presented with malignant disease. The majority prioritised maintaining independence (51.7 %), followed by extending life (27.6 %). The agreement between patients and healthcare professionals was low (GPs 41.7 %, kappa 0.067, $p = 0.39$), medical specialists 40.3 %, kappa 0.074, $p = 0.33$). Positively related to agreement was patient's age > 75 , and a longer relation with their patients (for GPs), and the patient having no partner (for medical specialist). Having a malignant disease, dependent living and functional deficits were negatively related to agreement.

CONCLUSIONS

Healthcare professionals have poor perceptions of their patients' priorities.

PRACTICE IMPLICATIONS

To realise patient-centered care, it is crucial to discuss priorities explicitly with all patients.

INTRODUCTION

Decision-making for older patients comprises a trade-off and weighing the risks and benefits of a specific treatment. There has been increased consensus on the importance of shared decision-making which involves tailoring treatments to the patient's situation and priorities.¹ The manner in which patients are involved in the decision-making process differs, and many patients find it difficult to participate in decision-making, leaving the final decision up to their healthcare professionals.² To guide patients in this process of shared decision-making, it is crucial to discuss their priorities regarding treatment outcomes, in order to align the treatment to these priorities. Previous research has shown that many older patients prioritize maintaining independence over extending life.³

Health care professionals, however, do not always have correct knowledge of their patients' priorities.⁴⁻⁶ GPs often know their patients for a longer time and therefore have better knowledge of the patients' context than medical specialists do.^{7,8} They also play an important role in the management of coexisting chronic diseases. Consequentially, GP's might have better knowledge of their patients' priorities. This study aims to assess to what extent GPs and medical specialists are aware of their patients' priorities regarding health outcomes in the setting of treatment decision-making.

METHODS

We performed a cross-sectional study among patients of the University Medical Center Groningen (UMCG) (the Netherlands) about to make a treatment decision, and their GPs and medical specialists. The treatment decisions were about starting a treatment (performing surgery, starting radiation therapy, chemotherapy or renal replacement therapy). The UMCG is a tertiary center providing complex patient care. The UMCG is also a head and neck center. All patients received a geriatric assessment (GA) during their visit to the outpatient clinic or were referred for a GA to the geriatrics outpatient clinic by their treating medical specialist. Patients were eligible when 1) they had to make a treatment decision and 2) the Outcome Prioritisation Tool (OPT) was used in the GA to assess patients' priorities. The decision-making process could be regarding a treatment for a malignant or benign disease or for renal replacement therapy.

The OPT (figure 1) is an instrument to assess patients' priorities regarding health outcomes. Patients are invited to prioritise between four universal health outcomes: extending life, maintaining independence, reducing or eliminating pain and reducing or eliminating other symptoms. During an OPT-guided conversation, patients value (0-

100) and prioritise the different outcomes.^{9,10} The outcome with the highest value is defined as the most important goal for this patient.^{9,10} In this study the OPT guided conversations were performed by either a trained nurse or a geriatrician.

Figure 1: Example of the Outcome Prioritisation Tool. Note that in this example of the Outcome Prioritisation Tool, the most important goal for this patient was to maintain independence.

The GP and the treating medical specialist (or resident) of each patient were contacted by phone and/or e-mail to provide their assumptions of their patient's priorities, as soon as possible after the OPT guided conversation had taken place. They did so by ranking the four goals of the OPT according to their assumption of their patient's priorities by placing them in order from 1 to 4 (1 for what they thought was the

patients most important health outcome). The healthcare professionals were blinded to the OPT scores of the patients. Furthermore, the healthcare professionals answered a questionnaire regarding their demographic characteristics, work experience and the duration of their relation with the patient.

Patients received a GA to support treatment decision-making, during which the OPT guided-conversation was performed. During the GA, information regarding four geriatric domains was assessed: somatic, social, psychological and functional. For the somatic domain, comorbidity was rated using the Charlson Comorbidity Index.¹¹ For the social domain, marital status, living situation and level of education were assessed. Independent living was defined as living without professional help. Level of education was classified using the Dutch classification system, according to Verhage.¹² Lower numbers reflect a lower level of education with a range of 1 - 7. For the analyses, level of education was dichotomised into low versus intermediate/high. For the psychological domain, cognition was assessed by using the 6 item Cognitive Impairment Test (6CIT), Mini Mental State Examination (MMSE) or Montreal Cognitive Assessment (MOCA)¹³⁻¹⁵ 'Cognitive deficits' was defined as a 6CIT score of 10 or higher, a MMSE score of less than 24 or a MOCA score of less than 26. For the functional domain, activities of daily living (ADL) and instrumental activities of daily living (iADL) were assessed. This could be either by the Katz Activities of Daily Living, the Lawton Instrumental Activities of Daily Living or the KATZ 15; a combined test of ADL and iADL. These measures were combined to a 'functional deficits' variable, with 'deficits' defined as 1 or more points on the combined score of ADL and iADL.¹⁶ The Groningen Frailty Index was used as a frailty screener, with a score of >4 considered as frail.¹⁷

Data were collected from 1 July 2019 to 1 January 2020. Consecutive patients were approached following the GA to inform them about the study and to obtain written informed consent. The prioritisation of health outcomes using the OPT was extracted from their medical record. For each patient the GP and treating medical specialist were approached. Patients were excluded if both their GP and their medical specialist refused to participate or failed to respond.

The study was conducted in accordance with the Declaration of Helsinki and Good Clinical Practice Guidelines. According to the Institutional Review Board of the UMCG, no approval was needed, as this non-invasive study was not subject to the Dutch Medical Research Involving Human Subjects Act.

Based on the disagreement proportion of 0.65 in former research⁴, an alpha of 0.05 and a beta of 0.20, we calculated our required sample size to be 87 patients.¹⁸ Characteristics of both patients and healthcare professionals were described. Agreement on the most

important outcome for both GP and patient and for medical specialist and patient was calculated both absolute and using Cohen's kappa. A kappa value ≤ 0 indicates no agreement, 0.01–0.20 none to slight agreement, 0.21–0.40 fair, 0.41–0.60 moderate, 0.61–0.80 substantial and 0.81–1.00 indicates almost perfect agreement. Furthermore, we calculated healthcare professionals agreement, which we defined as the percentage of cases for which at least one of the healthcare professionals prioritised the same health outcome as the patient, and agreement between general practitioner and medical specialist. To explore the correlations between patient and healthcare professional characteristics and agreement, univariate logistic regression analysis were performed. We considered variables with an OR >1.5 or <0.6 or a p value <0.05 as possibly related to agreement. Data analysis was performed using the software package IBM SPSS Statistics, version 23.0 for Windows (SPSS, Inc., Chicago, IL, USA).

RESULTS

During the study period, 105 consecutive patients were asked to participate, of whom 2 refused and 14 were excluded because they did not have an OPT-guided conversation. For 2 patients, neither healthcare professionals participated, leaving 87 patients for analysis. For 15 of these patients the GP did not participate and for 10 patients the medical specialist did not participate. The median age of the patients was 76 years (IQR 72–80), and 87.4% of patients presented with a malignant disease, of which most had a head and neck (25.0%) or colorectal malignancy (11.8 %). Of the 11 patients with a non-malignant disease, most presented with end stage renal disease ($n = 7$, 63.3%). Regarding comorbidities, the median CCI was 6 (IQR 5–8). Most patients (83.3 %) lived independently and had a partner (67.4%). The majority (72.5%) had a low level of education. Cognitive deficits were present in 15.5 %, and functional deficits in 47.4% patients. Frailty, based on the GFI was present in 14.6%. (Table 1)

Sixty-eight GPs were involved; in 4 instances GPs were involved in the care of 2 different patients from the sample. The median age of the GPs was 50 years (IQR 43–59.75) and 57.4% were male (table 2). Thirty-eight medical specialists, of whom 10 were residents, were involved; 17 were involved in the care of 2 or more patients from the sample. The median age of the medical specialists (or residents) was 39 years (IQR 33.5–48) and 71.1% were male. GPs usually had a longer relation with their patients than did the medical specialists (GPs median 11 years (IQR 5–18.5), medical specialists median 7 days (IQR 1–28)).

Table 1. Baseline characteristics and geriatric assessment (n = 87)

Variable			N (%) ^a	
BASELINE CHARACTERISTICS				
Age		<75	36 (41.4)	
		≥75	51 (58.6)	
Gender		Male	45 (51.7)	
		Female	42 (48.3)	
Diagnosis	Malignant	Tumor site	Head and Neck ^b	76 (87.4)
			Colorectal	26 (34.2)
			Upper gastrointestinal	9 (11.8)
			Sarcoma	8 (10.5)
			Breast	7 (9.2)
			Melanoma	7 (9.2)
			Other ^c	6 (7.9)
			I-II	14 (17.1)
			III-IV	23 (30.3)
	Tumor stage	No (full) staging available ^d	24 (31.6)	
		Benign	29 (38.2)	
		Type of disease	End stage renal disease	11 (12.6)
			Other ^e	7 (63.3)
GERIATRIC DOMAINS				
Somatic	Comorbidity	CCf ^f > 6	4 (36.4)	
Social	Marital status (n=86)	No partner	38 (43.7)	
	Living situation (n=78)	Dependent ^g	28 (32.6)	
	Level of education ^h (n=51)	Low ⁱ	13 (16.7)	
Psychological	Cognitive deficits (n=86)	Score of MMSE ^j , MOCA ^k or 6CIT ^l under norm (n=86)	37 (72.5)	
Functional	Functional deficits (n=79) ^m	Sum ADL ⁿ + IADL ^o > 1	13 (15.5)	
FRAILITY				
Frailty screening	Groningen Frailty Indicator (n=48)	GFI>4	37 (47.4)	
			7 (14.6)	

a= all variables are n(%) unless otherwise specified, b= oral cavity (n=13), squamous cell carcinoma (n=6), salivary gland (n=3), oropharyngeal (n=2), laryngeal (n=1), basal cell carcinoma (n = 1), c = gynecological, hepatobiliary, thyroid cancer, non-melanoma skin cancer, d= no (full) staging available in the patients file at the time of inclusion, e= chronic otomastoiditis, herniation, paresis of the recurrent nervus, thyroid struma, f= Charlson Comorbidity Index, g= Dependent: living at home with home care or living in a care facility. h= Verhage: level of education according to Verhage: higher number is higher level of education, range 0-7, i= low = Verhage 0-4, j= MMSE: Mini mental State Examination, k= MOCA: Montreal Cognitive Assessment, l= 6-CIT: 6-item Cognitive Assessment Test , m= Functional deficits measured by either the KATZ ADL and Lawton IADL or by the KATZ-15, a combined measure of ADL and IADL, n= ADL: Activities of Daily Living, o= IADL: Instrumental Activities of Daily Living.

Table 2. Characteristics of health care professionals (GP or GP in training, medical specialist or nurse specialist or medical specialist in training (resident))

Variable		GP ^a n=68	Medical specialist n=38
Age (median, IQR)		50 (43-59.75)	39 (33.5-48)
Gender	Female	29 (42.6)	11 (28.9)
	Male	39 (57.4)	27 (71.1)
Health care profession	Medical specialist		25 (65.8)
	Resident		10 (26.3)
	Nurse specialist		3 (7.9)
	GP	68 (100)	
Specialism	Surgery ^c		22 (57.9)
	Gynaecology ^d		3 (7.9)
	Head and Neck ^e		10 (26.3)
	Nephrology		3 (7.9)
Time (years) since completion of training	Median (IQR)	18.5 (9.25-25.5)	10 (5-17) ^b
Place of practice (GP)	Rural ^f	33 (47.1)	
	Semi urban ^g	27 (39.7)	
	Urban ^h	9 (13.2)	
Time relation (days) ⁱ	Median (IQR)	na	7 (1-28)
Time relation (years) ^j	Median (IQR)	11 (5-18.5)	na
Number of patients per specialist	1	64 (94.1)	21 (55.3)
	2	4 (5.9)	8 (21.1)
	>2	0 (0)	9 (23.7)

All variables are n(%) unless otherwise specified

a=GP: general practitioner,

b= years since completion of training for medical specialists and nurse specialists, not for residents.

c=including general surgery, abdominal surgery, hepatobiliary surgery, oncological surgery

d=including general gynaecology and oncological gynaecology

e=including general ear nose throat, oncological ear nose throat, dental surgery

f=<10.000 inhabitants, g=10.000-100.000 inhabitants, h=>100.000 inhabitants.

i= time relation in days between the patient and the health care professional. j= time relation in years (GP and patient).

The majority of the patients prioritised maintaining independence (51.7%) as their main health outcome, this was followed by extending life (27.6%), reducing or eliminating pain (13.8%), and reducing or eliminating other symptoms (6.9%). GPs rated maintaining independence the most important goal for 52.8 % of the patients, medical specialists did so for 45. %. Table 3a and 3b show the estimation of the GP and medical specialist of the patients main prioritized health outcome, compared to the actual main health outcome of the patient. Agreement between the GP and the patient (n = 72) was 41.7%, with a kappa of 0.067 (p = 0.39). The absolute agreement between the medical specialist and the patient (n = 77) was 40.3%, with a kappa of 0.074 (p = 0.33). In 51.7% of the cases, at least one healthcare professional agreed with the patient. In 53.2% of the cases, the GP and medical specialist prioritised the same goal for the patient (table 4).

Table 3a. Patients' (rows) priority and the GP's (columns) estimation of the patients' prioritized health outcome.

		GP's estimation of the patient's priority				
		Extending life	Maintaining Independence	Reducing pain	Reducing other symptoms	Total
Patient's priority	Extending life	4 (22.2)	8 (44.4)	3 (16.7)	3 (16.7)	18 (25.0)
	Maintaining independence	9 (22.5)	23 (57.5)	7 (17.5)	1 (2.5)	40 (55.6)
	Reducing pain	0 (0)	5 (50)	3 (30)	2 (20)	10 (13.9)
	Reducing other symptoms	2 (50)	2 (50)	0	0	4 (5.6)
	Total	15 (20.8)	38 (52.8)	13 (18.1)	6 (8.3)	72 (100)

All values are noted as n (%). GP: general practitioner

Table 3b. Patients' (rows) priority and the medical specialists (columns) estimation of the patients' prioritized health outcome.

		Medical specialists estimation of the patient's priority				
		Extending life	Maintaining Independence	Reducing pain	Reducing other symptoms	Total
Patient's priority	Extending life	6 (26.1)	14 (60.9)	2 (8.7)	1 (4.3)	23 (29.9)
	Maintaining independence	17 (42.5)	17 (42.5)	5 (12.5)	1 (2.5)	40 (51.9)
	Reducing pain	1 (10)	2 (20)	6 (60)	1 (10)	10 (13.0)
	Reducing other symptoms	0 (0)	2 (50)	0 (0)	2 (50)	4 (5.2)
	Total	24 (31.2)	35 (45.5)	13 (16.9)	5 (6.5)	77 (100)

*All values are noted as n (%).

Table 4. Level of agreement between the patient and the healthcare provider on the most important health outcome.

	Patient (n=87)	GP^a (n=72)	Medical specialist (n=77)
AGREEMENT			
Agreement patient – healthcare provider	Absolute agreement (%)	30 (41.7)	31 (40.3)
	Kappa	0.067 (p=0.39)	0.074 (p=0.33)
Agreement patient – both HCPs ^b together	Absolute agreement (%)		45 (51.7)
	Kappa		0.230 (p=0.001)
Agreement specialist and GP ^a (n=62)	Absolute agreement (%)		33 (53.2)
	Kappa		0.292 (p<0.001)

All values are noted as n (%) unless otherwise specified.

a= GP: general practitioner; b=HCP: health care providers

Table 5 shows the results of the explorative analysis between patient characteristics and agreement. For agreement between GPs and their patients, patients age ≥ 75 years (OR 3.03; 95 % CI 1.10-8.31) was significantly predictive of agreement and also a longer relationship was positively related (OR 1.54; 95% CI 0.47-5.13). Having functional deficits (OR 0.34; 95 % CI 0.12-0.96) was associated with a lower risk of agreement.

Table 5. Univariable analysis of predictive variables for agreement between patient and GP or patient and medical specialist on the patient's main health outcome. All analyses are given group compared to the (opposite) reference group.

		Pat-GP ^a agreement OR (95 % CI)	Pat-specialist agreement OR (95 % CI)
PATIENT CHARACTERISTICS			
<i>Baseline characteristics</i>			
Age	≥75	3.03 (1.10-8.31)^b	1.67 (0.65-4.25) ^c
Gender	Male	0.75 (0.29-1.92)	1.45 (0.58-3.61)
Diagnosis	Malignant	1.22 (0.27-5.53)	0.50 (0.12-2.01)
Tumor stage	III-IV	1.05 (0.28-3.92)	0.54 (0.16-1.83)
<i>Geriatric assessment</i>			
SOMATIC			
Comorbidity (CCI ^d)	>6	0.73 (0.28-1.90)	0.98 (0.39-2.50)
SOCIAL			
Marital status	No partner	0.81 (0.30-2.22)	2.88 (1.06-7.81)
Living arrangements	Dependent	0.28 (0.06-1.43)	0.80 (0.21-3.03)
Education level	Low	0.89 (0.23-3.46)	0.68 (0.18-2.60)
PSYCHOLOGICAL			
Cognitive deficits ^e	yes	0.61 (0.14-2.68)	0.76 (0.20-2.87)
FUNCTIONAL			
Functional deficits ^f	yes	0.34 (0.12-0.96)	0.71 (0.27-1.88)
FRAILITY			
GFI ^g	>4	0.88 (0.34-2.24)	1.21 (0.49-3.03)
HEALTH CARE PROFESSIONAL CHARACTERISTICS			
Time relation	> 3 years	1.54 (0.47-5.13)	NA
	> 7 days	NA	0.80 (0.34-2.05)

a= GP: General Practitioner, b=bold: statistical significant difference, c= Italic: OR>1.5 or <0.6, d= CCI: Charlson Comorbidity Index, e= Cognitive deficits: either a 6-CIT >10, MMSE <24 or MOCA <26), f= functional deficits: dependency in 1 or more items on a combination of ADL and IADL), g= GFI: Groningen Frailty Indicator. NA: not applicable.

DISCUSSION AND CONCLUSION

DISCUSSION

This study showed that there was poor agreement between patients and healthcare providers regarding health outcome priorities; both GPs and medical specialists had poor perception of the priorities of frail and/or older patients about to make a treatment decision. Because GPs often know their patients for a longer time and have better knowledge of the patients' context, we had expected a better agreement between patients and their GPs. A longer relation with the patient did have a tendency to better agreement for GPs, suggesting there might indeed be a continuity of care

effect. Unfortunately, we do not have data on the frequency of contacts or the quality of the relation as perceived by patient or GP. Agreement for both GP and medical specialist was better with older patients. This might be explained by the fact that healthcare professionals can imagine maintaining independence more easily as most important healthcare outcome for a patient with advanced age. In this study the main health outcome prioritised by the patients was maintaining independence, followed by extending life. These results are in line with previous studies regarding health outcome prioritization in older patients.^{19,20}

As far as we know, this is the first study that explored whether both GPs and medical specialists have correct knowledge of patients priorities. There is one previous study that explored the agreement between medical specialists and patients using the OPT, but GPs were not included.⁴ In this study nephrologists' perceptions about patients' priorities were correct 35% of the time, which is in the same order of magnitude as we found in our study. Healthcare professionals often assume that they know what patients find important, but studies have shown discordance of goals between patients and healthcare professionals in different settings.²¹⁻²³ This discordance could be due to several issues. For one, older patients sometimes perceive barriers to expressing their goals and preferences and engage in the decision-making process, such as feeling rushed, or not being able to express their wishes properly. Or they believe that their healthcare professional already has knowledge regarding their values.²⁴ Incorrect expectations regarding treatment outcomes might influence the expression of goals and preferences as well and patients' goals might change in the face of complex treatment decision.²⁵ Healthcare professionals can also find it difficult to discuss goals with their patients.²⁶

There are several limitations to this study. Since the geriatric assessment was part of the decision-making process, it might be possible that some medical specialists learned about the patients' priorities before providing their estimation of these priorities. Another limitation is that participation in this study might have led to increased awareness among participating healthcare professionals and therefore to asking the patients about their priorities more explicitly. However, in both cases the possible bias would lead to an overestimation of agreement, which could in reality then be even poorer than we showed. Furthermore, there was a selection of older and more frail patients, due to the fact that the OPT was used as part of a GA.

Patient-centered care involves aligning treatment decisions with the patients' priorities. Especially for decisions where important trade-offs are at stake, eliciting and these priorities is highly relevant for optimal shared decision-making.²⁷ Since preference misdiagnoses are frequent, it is crucial to explicitly discuss priorities. This can, however,

be difficult for both patients and healthcare professionals. Using a decision aid might facilitate this conversation. The OPT is a decision support that uses universal health outcomes. The tool can structure the goal-setting conversation, enabling patients to elicit their priorities and healthcare professionals to align treatment with these priorities. Future studies should investigate whether this leads to improved health outcomes from the patients point of view.

CONCLUSION

Healthcare professionals have poor knowledge of their patients priorities regarding health outcomes.

PRACTICE IMPLICATIONS

Structurally discussion patients' priorities, possibly by using a decision aid, might improve alignment of treatments to these priorities and improve patient-centered care.

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CONFLICTS OF INTEREST

The authors declare that there is no conflict of interest.

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PART III

ONCO-GERIATRIC
CARE TRAJECTORY

CHAPTER 6

How to incorporate geriatric
assessment in clinical decision-making
for older patients with cancer.
An implementation study.

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ABSTRACT

INTRODUCTION

With the accumulating evidence on the added value on prediction of outcomes of geriatric assessment (GA) in older patients with cancer, the question shifts from whether performing a GA is useful, to how to best implement this into standard practice. The effect of implementing GA and assessment of patient preferences on treatment recommendations by an onco-geriatric multidisciplinary team (MDT), was compared to the recommendation previously made by the tumor board (care as usual).

METHODS

Patients aged ≥ 70 with a solid malignancy who were referred to a tertiary care center for diagnosis and treatment recommendations, as provided by a tumor board, were included. The intervention consisted of: a nurse-led GA and assessment of patient preferences prior to the start of oncological treatment, discussing this in an onco-geriatric MDT and weighing all the information about the patient in a structured, stepwise manner. Treatment recommendations formulated by this onco-geriatric MDT were compared to the treatment recommendations by the tumor board.

RESULTS

197 patients were included. For 27%, treatment recommendations from the onco-geriatric MDT differed from the recommendations formulated by the tumor board. These modifications were mostly towards less intensive curative or palliative treatment. Thirteen percent of patients were subsequently referred to a geriatrician in order to reach a treatment recommendation.

DISCUSSION

Implementing an onco-geriatric care trajectory leads to modification of treatment recommendations in a quarter of patients. Thirteen percent needed subsequent referral to a geriatrician.

KEYWORDS

Geriatric assessment, Patient preferences, Clinical Decision-making, Older patients with cancer, Implementation, OPT tool.

ABBREVIATIONS

ADL (activities of daily living), CCI (Charlson Comorbidity Index), CGA (comprehensive geriatric assessment), GA (Geriatric Assessment), GARS (Groningen Activity and Restriction Scale), GFI (Groningen Frailty Indicator), iADL (instrumental activities of daily living), LFT (Letter Fluency Test), MDT (multidisciplinary team), Netherlands Trial Registry (NTR), OPT (Outcome Prioritization Tool), TUG (Timed-Up-and-Go test)

INTRODUCTION

Deciding on the most optimal oncological treatment plan for older patients is often complex and comprises trade-offs due to an increased risk of complications and functional decline following surgery, radiotherapy and/or systemic treatment¹. Age, and other one-dimensional measures such as co-morbidity or performance status, do not adequately capture the diversity in this patient group.^{2,3} Frailty, a state of decreased physiological reserve due to accumulation of deficits in physical, cognitive, social and functional domains, is a better measure of biological aging and a better predictor of the ability to cope with stressors.⁴⁻⁶ Geriatric assessment (GA) is a method to evaluate multiple patient characteristics using standardized methods to help characterize individual complexity and can be used to discriminate between fit and frail patients.^{7,8} In the nomenclature of geriatric assessment of patients, a distinction can be made between a Comprehensive Geriatric Assessment (CGA), a GA and geriatric screening. A CGA is usually performed by a geriatrician, assessing different domains and aimed at possible interventions. A GA is a shorter assessment of domains, and is aimed at prognostication and risk prediction and can be performed by other health care workers, for instance a nurse. Geriatric screening is mostly performed by a single screening instrument, where a positive score leads to further investigations (like a CGA).^{9,10} In recent years, there has been an increased awareness of the added value of GA for oncological treatment decisions in older patients.^{7,11-13} Despite accumulating evidence, broad implementation has not yet taken place.¹⁴ This might be due to concerns about GA being time-consuming, uncertainty about how to implement this into standard care, or limitations in the availability of geriatricians.

The incidence of cancer rises dramatically with age, with an eleven fold increase after the age of 65.^{15,16} Due to the aging of the population, the number of people 65 years or older in the United States is expected to be over 70 million in 2030. To care for all these patients, 30,000 geriatricians would be needed, with only 7300 geriatricians in practice in 2016.¹⁷ Consequently, the percentage of older patients referred for cancer treatment will increase and, by 2030, 70% of patients with newly diagnosed cancer are expected to be over age 65.¹⁸ With the increasing numbers of older patients with cancer, and the limited number of geriatricians, it will be impossible to refer all these older patients with cancer to a geriatrician. Performing a Comprehensive Geriatric Assessment (CGA) is time consuming and should be reserved for those patients most likely to benefit from it.^{19,20} Many short frailty screening instruments have been developed and studied, like the Geriatric 8 (G8), the VES-13 (Vulnerable Elders Survey) and Groningen Frailty Indicator (GFI), but sensitivity and negative predictive value are poor, and referring patients to a geriatrician based on these instrument leads to high referral rates.²¹ The challenge lies within using the available resources well and developing care pathways to implement GA in an efficient and effective way.

To solve this problem, a multicomponent onco-geriatric care trajectory for treatment decision-making for older patients with cancer was developed and implemented. In this care trajectory, oncology nurses performed a GA and assessed patient preferences. A treatment proposal was made after discussing this assessment in an onco-geriatric MDT. Referral to a geriatrician took place when additional assessment was needed. We compared the effect of this care trajectory on treatment recommendations to the recommendation previously made by the tumor board (care as usual), and assessed the number of referrals to a geriatrician.

MATERIALS AND METHODS

SETTING AND PATIENTS

A prospective cohort study was conducted and was funded by the Dutch Cancer Society. The University Medical Center in Groningen is the only university medical center in the northern Netherlands, covering a population of over three million people. Between September 2014 and July 2017 patients of 70 years or older, referred to the department of surgery or medical oncology for treatment of a solid malignancy were included. There were no other inclusion and exclusion criteria. Patients were invited to participate by a trained nurse, who obtained informed consent and performed the GA and assessment of patient preferences. Inclusion of the patients took place in the outpatient clinic, and was a convenience sample, based on time and availability of the oncological nurses.

METHODS

For this study, the treatment proposals following a multicomponent onco-geriatric care trajectory were compared to the treatment proposals made by the conventional tumor board (care as usual) (fig 1). In order to compare the treatment proposal between tumor board and onco-geriatric MDT, all patients were first discussed in the regular tumor board and secondly in the onco-geriatric MDT, with the additional information on GA and patient preferences.

CARE AS USUAL

Before the implementation of a onco-geriatric MDT, care as usual in treatment decision-making for older cancer patients consisted of a visit to the treating physician with additional diagnostic test when necessary. Afterwards the patient would be discussed in a multidisciplinary tumor board typically consisting of oncological specialists (surgeons, medical oncologists, radiation oncologist), radiologists and pathologists. In these tumor boards, information concerning individual patients is discussed and treatment plans are formulated. Treatment plans are mostly based on information regarding tumor characteristics, age and co-morbidity in accordance with

current guidelines. Nurses attend but do not usually actively participate in these tumor boards and patients are not present (figure 1, pathway A).²²⁻²⁴

Figure 1. A care as usual in decision-making for older cancer patients, B decision-making pathway in the implementation study.

A MULTICOMPONENT ONCO-GERIATRIC CARE TRAJECTORY

The multicomponent onco-geriatric care trajectory consisted of (1) a nurse-led GA and assessment of patient preferences, followed by (2) a onco-geriatric MDT, including a nurse and a geriatrician using a (3) stepwise method to reach a decision.

1. Geriatric assessment and patient preferences.

Geriatric Assessment.

At the patient's first visit to the outpatient clinic, following their appointment with the treating physician (surgeon or oncologist), a trained oncology nurse performed a GA and assessment of patient preferences. The nurses were trained in GA, assessment of preferences and in communication skills by a senior nurse and geriatrician prior to the start of the study. This training lasted half a day and consisted of a didactic sessions, explaining the concept of frailty and the use of the instruments used in the GA as well as the OPT tool. This was followed by practice session with a training actor, providing the possibility to practice the GA, but also to learn how to share the acquired information in a concise manner. The GA involved an evaluation on four domains: somatic, social, psychological and functional. This information was gathered by performing a semi-structured interview, combined with validated tests and questionnaires. Comorbidity was defined by the Charlson Comorbidity Index (CCI) and dichotomized into <2 and ≥ 2 ;

polypharmacy was defined as taking ≥ 5 prescription drugs. This could be both “when required” and scheduled drugs as listed by the treating physician.²⁵⁻²⁷ The GFI psychosocial subscale was categorized into <2 and ≥ 2 , with the latter being indicative for psychosocial problems.²⁸ The Letter Fluency Test (LFT) was used as a measure of cognition.²⁹ In this test patients are asked to produce as many words beginning with a specified letter as they can during one minute. This procedure is repeated twice (for 3 letters total). LFT scores were corrected for level of education and categorized into ‘low’ and ‘high’ with low defined as an age adjusted T-score of lower than 44 (the cut-off value for a “medium” test result).³⁰ Level of education was coded using the Dutch classification system, according to Verhage and the standard classification of education of the Dutch Central Bureau of Statistics. This coding system is most often used in Dutch neuropsychology and is similar to the International Standard Classification of Education (UNESCO).³¹ Level of education was categorized into low (Verhage 1-2), medium (Verhage 3-4) and high (Verhage 5-7). Mean Timed-Up-and-Go test (TUG) was recorded as a measure of mobility, and divided into <10 s, 10-20 s and >20 s.³² The Groningen Activity and Restriction Scale (GARS) is a combined ADL and iADL scale with a higher score meaning more dependency, ranging from 18-72 for the sum score, 11-44 for the ADL subscore and 7-28 for the iADL subscore.³³ Frailty was defined as GFI score ≥ 4 .³⁴

Patient preferences

Patient preferences were assessed using the Outcome Prioritization Tool (OPT).³⁵ The OPT is an instrument with four universal treatment goals rate on a visual analogue scale from 0-100. The goals presented are: life extension, preserving independence, reducing pain, and reducing other symptoms. The healthcare provider will explain the four goals and invite the patient to value and rank the different goals in order of importance according to the trade-off principle; meaning two goals cannot be equally rated.³⁶⁻⁴⁰

2. Onco-geriatric MDT.

In addition to the regular tumor boards (care as usual), all patients in the study were discussed in a weekly onco-geriatric MDT attended by the nurse, a surgeon, radiation oncologist, medical oncologist, palliative care specialist and a geriatrician. In our hospital the palliative care team consist of different specialist, among which a geriatrician and a medical oncologist who attended the onco-geriatric MDT. During the onco-geriatric MDT meeting, patients were discussed based on disease characteristics, comorbidities, GA outcomes and patient preferences. The surgeon or medical oncologist provided information on tumor characteristics and the treatment plan as previously formulated by the tumor specific MDT, which was also available from notes from the tumor board. The nurse presented the patient’s narrative and the full results of the GA, including the patient’s preferences regarding treatment goals. The geriatrician estimated the vulnerability of the patient based on the GA results and provided an estimation on the

remaining life expectancy, based on population statistics. Perioperative (frailty-related) risks (i.e. on post-operative delirium or progressive functional decline) were identified.

3. Step-wise discussion of patients in the onco-geriatric MDT.

Benefits and risks of different treatment options were discussed in a systematic, stepwise fashion (figure 2). An estimation of the prognosis with and without treatment was made, the likelihood of complications during treatment , and whether a complete (functional) recovery was to be expected was discussed. The time to benefit of the treatment options was related to the estimated life expectancy and patient preferences were taken into account. Possible treatment effects were translated into what this would mean for patient preferences on a day to day level (e.g. “will the patient still be able to live independently after treatment,” or “will the patient still be able to ride his bicycle after surgery”). After carefully weighing these expected risks and benefits of different treatment options and putting them in perspective of the patient’s vulnerability and preferences, a treatment recommendation was formulated by the team and a report of the meeting was provided in the patients’ medical record. This report was written by one of the attending physicians, but the recommendations were formulated with approval of all the participants of the onco-geriatric MDT. This treatment proposal could either support the proposal made by the conventional tumor board, or suggest modifications to its proposal (figure 1, pathway B). If geriatric problems were revealed, advice on non-oncological interventions was provided, for instance on delirium prevention or prehabilitation measures (optimization of functional capacity by exercise training and management of risk factors like malnutrition or anemia).⁴¹ Patients were referred to the geriatrics department if the information from the nurse-led GA provided insufficient insight to reach a treatment recommendation, or if more extensive assessment (for instance of cognition) seemed necessary. The formulated proposal and additional advice were communicated to the treating physician who discussed this with the patient. Together with the patient and their next of kin, the treating physician would reach a definitive treatment decision. Whenever possible the nurse would be present during this visit.

Stepwise approach to treatment decision-making	
1.	How strong is indication for the recommended treatment?
2.	What would the estimated life expectancy of this patient be without the current disease?
3.	What is the estimated life expectancy without treatment?
4.	What is the expected burden of the disease if it is left untreated?
5.	Does treatment add to the life expectancy?
6.	Does the patient have physical complaints that are likely to be resolved after treatment?
7.	What is the burden of the treatment (hospital admissions and visits, complication risk)?
8.	What are the alternative treatment options (including palliative treatment)?
9.	What are the goals, preferences and expectations of the patient? What is the influence of the proposed treatment on these goals?

Figure 2. Stepwise approach to treatment decision-making; questions to be answered.

OUTCOME MEASURES

The primary outcome was the treatment recommendation formulated by the onco-geriatric MDT as compared to the treatment recommendations previously formulated by the tumor board (care as usual). The secondary outcome was the number of referrals by the onco-geriatric MDT to the geriatric outpatient clinic.

STATISTICAL ANALYSIS

Patient characteristics and GA variables were described as numbers and percentages or median and range, as appropriate. To compare the patients with modified treatment recommendations due to the onco-geriatric MDT versus those without modifications in treatment recommendations, Pearson's Chi square tests were applied for categorized data, and Mann Whitney U tests for continuous variables. Data analysis was performed using the software package IBM SPSS Statistics, version 22.0 for Windows (SPSS, Inc., Chicago, IL, USA).

STATEMENT OF ETHICS

This study was registered in the Netherlands Trial Registry (NTR) under trial registration number NTR6660. The study was conducted in accordance with the Declaration of Helsinki and Good Clinical Practice Guidelines. Permission was granted by the local medical ethical committee.

RESULTS

PATIENTS

Between September 2014 and November 2016, 236 patients were included, of whom 200 were discussed in the onco-geriatric MDT after a treatment proposal was given by the tumor board. For 3 patient the advice given by the onco-geriatric MDT could not be retrieved, leaving 197 for the final analysis (figure 3). Thirteen (7%) patients were included at the medical oncology department and 184 (93%) were included at the surgical department. Baseline characteristics are shown in table 1. Median age was 78 years (range 70-93) and 56% (n=110) were male. 59 patients (30%) suffered from colorectal malignancies, 29 melanomas (15%) and 24 sarcomas (12%). The tumor board proposed treatment with curative intent in 159 (81%) of patients, 38 (20%) patients had a palliative treatment proposed.

Figure 3. Inclusion of patients

Table 1. Patient characteristics (n = 197)

Characteristic	
Age (years), median (range)	78.0 (70-93)
Male, N(%)	110 (55.8)
Nationality, N (%)	
Dutch	163 (82.7)
Living arrangements, N (%)	
Home dwelling	182 (92.4)
Assisted living	11 (5.6)
Nursing home	3 (1.5)
Missing	1 (0.5)
Social status, N (%)	
Married or living with partner	118 (59.9)
Unmarried, divorced, widowed	61 (31.0)
Missing	1 (0.5)
Level of education*, N (%)	
High	54 (27.4)
Medium	54 (27.4)
Low	85 (43.1)
Missing	4 (2.0)
Charlson Comorbidity Index (median, range)	2.0 (0-10)
Tumour Type, N (%)	59 (29.9)
Colorectal	23 (11.7)
Upper GI	22 (11.2)
Hepatobiliary	29 (14.7)
Melanoma	24 (12.2)
Sarcoma	6 (3.0)
Gynecological	7 (3.6)
Skin (PCC, BCC, Merkelcel)	5 (2.5)
Thyroid	4 (2.0)
Breast	5 (2.5)
Urologic	13 (6.6)
Other**	
Cancer stage (N,%)	
I	18 (9.1)
II	37 (18.8)
III	38 (19.3)
IV	55 (27.9)
No (full) staging available	46 (23.4)

*Level of education according to Verhage.**Other =Anal carcinoma, chordoma, GIST, NET, unknown primary and where PA showed no malignancy.

GERIATRIC ASSESSMENT

Results of GA are shown in table 2. Frailty was common: 53% (N = 103) of patients were classified as frail according to the GFI, with higher numbers of frailty in the modified treatment group ($p = 0.03$). Comorbidities and polypharmacy were also common, with a median of two comorbidities per patient (range 0–10) and polypharmacy occurring in 53% (N = 103) of patients. Both were significantly more prevalent in the deviated treatment group. The LFT was completed by 76 % (n = 148) of patients, with 49.5 % (N = 97) having low test scores. The mean TUG was 12 s, ranging from 3.9–33.7 s. The mean GARS-4 sum score, and ADL and iADL subscores were all significantly higher in the modified treatment group ($p < 0.05$).

Table 2. Geriatric assessment

		Number of patients evaluated	Treatment recommendations onco- geriatric MDT vs tumor board (N=197)		
			Unchanged, N = 143 (72.6%)	Modified, N = 54 (27.4%)	P
SOMATIC					
Charlson comorbidity index	≥2	197	96 (67.1)	38 (70.4)	0.66
Polypharmacy, N (%)	>5 medications	195	70 (49.0)	34 (63.0)	0.06
Weight loss	>10 kg	191	18 (12.6)	8 (14.8)	0.61
Pain, N (%)		196	58 (40.6)	26 (48.1)	0.30
SOCIAL					
Living arrangements, N (%)	Assisted living	195	10 (7.0)	4 (7.4)	NA
Social status, N (%)	Living without partner	179	41 (28.7)	20 (37.0)	0.30
Level of education, N (%)	Low	193	36 (25.2)	18 (33.3)	0.54
	Medium		39 (27.3)	15 (27.8)	
	High		64 (44.8)	21 (38.9)	
PSYCHOLOGICAL					
Memory problems, N (%)		193	13(9.0)	9(16.7)	0.12
Previous delirium, N (%)		193	16 (11.2)	11 (20.4)	0.10
Dementia diagnosis, N (%)		194	2 (1.4)	3 (5.6)	NA
Letter fluency test score, N (%)	Low	148	69 (48.3)	29 (53.7)	0.65
GFI psychosocial subscale	≥2	195	70 (49.0)	23 (42.6)	0.46
FUNCTIONAL					
Timed Up and Go	<10 sec	171	43 (30.1)	9 (16.7)	0.17
	10-20 sec		79 (55.2)	28 (51.9)	
	>20sec		7 (4.9)	5 (9.3)	
GARS-4 , median (range)	Sum score	194	23 (15-57)	28.0 (18-70)	<0.05
	ADL-component	193	13.0 (11-29)	16,0 (11-42)	<0.05
	iADL-component	186	10.5 (7-28)	14,5 (7-28)	<0.05
FRAILTY SCREENING					
Groningen Frailty Indicator, N (%)	≥ 4	195	68 (47.6)	35 (64.8)	<0.05

MDT: multidisciplinary team, GARS: Groningen Activity and Restriction Scale, GFI: Groningen Frailty Indicator

PATIENT PREFERENCES

Figure 4 shows patients' preferences as prioritized using the OPT. Maintaining independence and prolonging life were the two goals patients rated as most important. In the deviated treatment group versus the unchanged group, there was a similar percentage of patients prioritizing life extension (36% vs 38%), but a higher percentage prioritized preserving independence (46% vs 39%). Eighteen patients (9%) were unable to prioritize their preferences, and in thirty-two (16%) the OPT was not filled in.

Figure 4. Patients main treatment preference; highest prioritized goal using the OPT (N = 147)

TREATMENT RECOMMENDATION

In 73% (n = 143) of patients, the onco-geriatric MDT supported the treatment recommendation made by the tumor board. However, in 27% (n = 54) of the patients a modification of the treatment proposal was recommended by the onco-geriatric MDT. When a modified treatment was proposed, this was mostly towards less intensive curative or palliative treatment (e.g. radiotherapy instead of surgery, changing combination treatment of chemotherapy and radiotherapy into radiotherapy only, or converting major abdominal surgery into a colostomy), symptom relief or a wait-and-see policy (figure 5). In the group where a modified treatment was proposed, this was adopted by the treating physician (and the patient) in 76% (n = 41) of cases. In 12 patients (22%) the treatment advice proposed by the onco-geriatric team was

not followed by the treating physician and the patient and one patient (2%) refused treatment. Of the 12 cases in whom the onco-geriatric advice was not followed, for eight cases the advice had been to change from curative to palliative intent, in three cases to a less intensive curative treatment plan and in one case a different palliative treatment.

Figure 5. Change of oncological treatment advice between tumor board and onco-geriatric multidisciplinary team (onco-geriatric MDT) in the modified group (N = 54)

NON-ONCOLOGICAL INTERVENTIONS

In 41% (n = 81) of patients, advice regarding non-oncological interventions was given by the onco-geriatric MDT, for instance on delirium prevention, consultations by another medical specialist or by a psychologist, prehabilitation measures, dietary measures or advice on multiple domains. This non-oncological advice was provided in 26% (n = 14) of the patients with an altered treatment proposal, and in 47% (n = 67) of the patient with an unmodified treatment proposal.

REFERRALS TO THE GERIATRIC OUTPATIENT CLINIC

Based on the information discussed in the onco-geriatric MDT, 13% (n = 25) of patients were referred to the geriatrics outpatient clinic. This was an equal percentage in both treatment groups, seven in the modified treatment group and 18 in the group without treatment modifications.

DISCUSSION

With the rise in number of older patients with cancer in the years to come, there is a need for efficient care pathways, providing tailored patient care. To our knowledge, this study is the first of its kind, structurally integrating both GA outcomes and patient preferences in a multidisciplinary approach to reach a tailored treatment advice. The GA and assessment of patient preferences were nurse-led, and the nurses participated in the onco-geriatric MDT where they had an active role. This approach resulted in modified treatment recommendations in a quarter of cases, compared to the recommendations made by the tumor board. In the remaining 73% of patients, the onco-geriatric MDT supported the proposed treatment plan. This number is similar to previous studies on the effect of CGA on treatment decision-making.⁴² The patients for whom a treatment modification was recommended were similar to the patients in the group without modification of treatment recommendations with regards to age and comorbidities. There was, however, a difference in polypharmacy, functional status and level of frailty. Knowledge of patient preferences is important for shared decision-making.^{43,44} As is described in literature, many patients prioritized preserving independence as their most important treatment goal and this should be taken into account in decision-making.⁴⁵

Previous studies have focused mostly on the added value of GA or geriatric consultation in complex treatment decisions for onco-geriatric patients, but not on translating this into a practical format to implement such an approach into daily practice.⁴⁶⁻⁵² This study reports the results of a multi-component care pathway, introducing a nurse-led interview and geriatric assessment in a large cohort of older patients as the basis for treatment decision-making. In contrast to other studies, a geriatrician was involved in the decision-making process in all patients by participating in the onco-geriatric MDT, but did not necessarily see the patient. Because patients were discussed in a multidisciplinary setting, a decision was reached in most cases. Only a minority of patients (fourteen percent) needed further analysis by a geriatrician in order to reach a decision. This number would have been much higher if a two-step screening method had been used, where geriatric referrals are based on a frailty screening instrument. In our population this would have resulted in referral of 53% of the patients. This referral percentage would be similar or even higher with other commonly used frailty screening instruments in oncology, such as the G8, with reported positive scores ranging between 50- 82%.^{53,54} Despite the low referral rate in this study, there was a similar number of recommended treatment modifications compared to previous studies implementing GA.⁴² Of the proposed treatment alterations, 76% were adopted by the treating physician and the patients. An oncological MDT is an advisory board and the final treatment decision is made between the treating physician and the patient (and family). Many

factors could have led to the fact that in 23% the advice was not adopted; a change in the patient's situation, time to consider options and preferences and the opinion of the family could all have influenced the final decision made.

There are some limitations to this study. Inclusion of the patients took place in the outpatient clinic, and was based on time and availability of the oncological nurse. At the start, patients included were mostly treated by two surgeons involved in order to get nurses and staff accustomed to the new care trajectory. Bias due to availability sampling can therefore not be excluded. We do not know how many patients were approached that did not want to participate, so selection bias can also not be excluded. Most patients were included at the surgical outpatient clinic. There was no control of the nurse-led GA by a gold standard (CGA), which might have resulted in missing frail patients. However, during the onco-geriatric MDT the nurses reported not only the GA results and patients preferences, but also the patient's narrative, providing extensive information for the attending geriatrician. The impact of implementing the nurse led intervention and the onco-geriatric MDT on clinic workflow and was not formally assessed. Therefore, we do not know if adding these steps increased the time required for nurses and physicians to spend with the patients and if it had any impact on the start of treatment. Even though two of the attending specialist ate also palliative care specialists, which will likely have influenced palliative advices, there are no data available on formal palliative consultations. To investigate whether the onco-geriatric MDT is considered beneficial to patients from their own perspective, a follow-up study to investigate whether the onco-geriatric MDT impacts clinical outcomes and patient satisfaction is underway.

Time is often perceived as a barrier to implementing GA.¹⁹ Even though efficiently organized, implementing this multicomponent onco-geriatric care does require additional time. The nurse-led GA and assessment of preferences took time. Before implementation, however, nurses already spent time with the patients gathering information, but this information wasn't available in the decision making process, because nurses were given no active role in the tumor boards to share this information. In the multicomponent onco-geriatric care trajectory this information was used, supplemented by information on GA and patient preferences, increasing efficiency. In this study, patients were discussed both in the conventional tumor board as well as in the onco-geriatric MDT, in order to compare the treatment recommendations as well as for implementation purposes. This required extra time for both nurses and physicians. Ideally, the next step would be to implement this method into the regular tumor board meetings. Implementing such a care trajectory, however, requires that oncological medical physicians recognize the importance of regarding the context and preferences of a patients in the decision-making process. This will require a change in mind-set from a focus on technically possibilities, to a focus on what is the most fitting treatment option for this patient.¹⁹

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Conflicts of interest

There are no conflicts of interest to declare.

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CHAPTER 7

The effect of treatment modifications
by an onco-geriatric MDT on one-year
mortality, days spent at home and
postoperative complications

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ABSTRACT

OBJECTIVES

Decision-making in older patients with cancer can be complex, as benefits of treatment should be weighed against possible side-effects and life-expectancy. A novel care pathway was set up incorporating geriatric assessment into treatment decision-making for older cancer patients. Treatment decisions could be modified following discussion in an onco-geriatric multidisciplinary team (MDT). We assessed the effect of treatment modifications on outcomes.

MATERIALS AND METHODS

This retrospective study was performed in the surgical department of a University Hospital. Patients of 70 years and older with a solid malignancy were included. All patients underwent a nurse-led geriatric assessment (GA) and were discussed in an onco-geriatric MDT. This could result in a modified or an unchanged treatment advice compared to the regular tumor board. Primary outcome was one-year mortality. Secondary outcomes were post-operative complications and days spent in hospital in the first year after inclusion.

RESULTS

For the 184 patients in the analyses, the median age was 77.5 years and 41.8% were female. For 46 patients (25%), the treatment advice was modified by the onco-geriatric MDT. There was no significant difference in one-year mortality between the unchanged and modified group (29.7% versus 26.1%, $p = 0.7$). There were, however, significantly fewer days spent in hospital (median 5 vs 8.5 days $p = 0.02$) and fewer grade II or higher postoperative complications (13.3% versus 35.5% $p = 0.005$) in the modified group.

CONCLUSION

Incorporating geriatric assessment in decision-making did not lead to excess one-year mortality, but did result in fewer complications and days spent in hospital.

INTRODUCTION

Due to demographic changes, an increasing number of older patients with cancer is expected in the near future. Decision-making with older cancer patients can be complex, due to co-morbidities, frailty, and different preferences regarding treatment outcomes compared to younger patients. Older patients with cancer have an increased risk of adverse outcomes of cancer treatment, such as complications, functional decline, and a higher risk of mortality.¹⁻⁶ Frailty, a state of decreased reserves due to accumulation of deficits on different domains, is considered a measure of biological age and a better predictor of these adverse outcomes than calendar age.⁷ Older patients with cancer are at risk of both over- and undertreatment, especially if decision-making is based on calendar age alone.^{8,9} There are accumulating data emphasizing the importance of geriatric assessment and assessment of frailty in older patients with cancer to guide treatment decision-making.¹⁰⁻¹²

Implementing geriatric assessment into the work-up of older cancer patients has been shown to affect treatment decision-making, leading to an adjustment of treatment in a median 28% of patients, often toward a less intensive treatment modality or palliative care.¹³ Clinicians, however, tend to overestimate prognosis, leading to a focus on potentially curative and often intensive treatment regimes.¹⁴ It can therefore be difficult to refrain from intensive curative treatment, and often it is easier to “err on the side of life”.¹⁵ Clinicians often feel they need to give a patient a chance of survival, even if chances are slim and the risk of adverse functional outcomes high. Refraining from treatment is thus often a more difficult and uncertain decision.¹⁵ This is one of many factors that complicates broad implementation of geriatric assessment into current care.¹² Another complicating factor is the scarcity of evidence supporting implementation of frailty assessment to guide treatment decisions, for example by revealing better outcomes.¹⁶ When looking at improving outcomes, it is important to take the patients’ perspective into account. Treatment decision-making, especially with older cancer patients, comprises trade-offs, due to an increased risk of complications and functional decline following treatment.¹⁷ For many older patients, survival is not their main outcome of interest, and remaining independent is often considered more important.^{18,19} Days spent at home is regarded a novel patient-centered outcome measure, that is gaining attention.²⁰⁻²² Most patients would prefer to, when possible, spend their time at home rather than in a hospital or other care facility.²¹ Intensive oncological treatment with a high risk of postoperative complications and functional decline often leads to more days spent in a hospital or nursing home.²³

At the University Medical Centre Groningen, a nurse-led geriatric assessment and additional onco-geriatric multidisciplinary team meeting has been implemented,

in order to optimize and tailor decision making. This has shown to affect treatment decisions, with a modification in treatment proposals in about a quarter of patients. These modifications were mostly toward less intensive regimes or toward palliative treatment or wait-and-see.²⁴ We were interested to know how this new care pathway impacts on short and longer term outcomes of our patients. This paper presents the follow-up data of this cohort, looking at one-year mortality after modifying treatment and the effect on post-operative complications and days spent in hospital.

METHODS

SETTING AND PATIENTS

Patients of 70 years and older who were referred with a solid malignancy to the surgical outpatient clinic between September 2014 and July 2017 were included in the study.

METHODS

This study reports on the retrospective analysis of outcomes of a new care pathway that was started in 2014 at the University Medical Center in Groningen, the Netherlands.²⁴ A nurse-led geriatric assessment and assessment of patients' preferences was implemented in the decision-making process for all patients of 70 years and older with cancer referred the surgical outpatient clinic. This assessment was performed by a (trained) surgery nurse. In order to multidisciplinary discuss the results of this assessment, an onco-geriatric MDT was established, separate from the regular oncological MDTs (tumor boards). In this onco-geriatric MDT, nurses and a geriatrician attended, in addition to the oncology specialists (surgeon, medical oncologist, radiation oncologist). This enabled the fine-tuning and development of this new care pathway, but it also enabled comparison between the treatment proposal by the onco-geriatric MDT and the regular tumor board (which was care as usual until then).²⁴

Patient were included at the surgical outpatient clinic. All included patients underwent a nurse-led geriatric assessment (GA), performed by a trained nurse, at their visit to the surgical outpatient clinic. During this GA, information was gathered regarding four geriatric domains (somatic, social, psychological and functional). For the somatic domain, the Charlson Comorbidity Index (CCI) was used as a measure of comorbidity with a cut-off value of 3 for low versus high comorbidity.²⁵ Current cancer was not included in the CCI. Polypharmacy was defined as 5 or more prescription drugs. Recent weight loss was assessed and dichotomized between less than 10 kg, and 10 kg or more in the last 6 months.^{26,27} For the social domain patients were asked about living arrangements and marital status. For the psychological domain, cognitive status was assessed using the letter fluency test (LFT), adjusted for level of education.^{28,29} Level of education was classified

according to Verhage, which is comparable to the UNESCO and ranges from 1 to 7 with a higher score for a higher level of education.³⁰ Level of education was dichotomized into low (1 - 2) versus medium and high (3 - 7). Mood was assessed according to the subsection of the Groningen Frailty Index (GFI), with a cut-off of 2 out of 5 points.³¹ Patients and their families were also asked about known dementia and previous delirium. For the functional domain the Groningen Activity Restriction Scale (GARS-4) was used; a combined measure of instrumental activities of daily living (ADL) and instrumental activities of daily living (IADL). Combined scores ranged from 18 to 72: 11 to 44 for the ADL subscore and 7 to 28 for the IADL subscore. A higher score indicates more dependencies.³² The Timed-Up and Go (TUG) test was used as a measure of mobility, with a cut-off value of 15.³³ The GFI was used as a frailty screening tool. Frailty was defined as a GFI score ≥ 4 .³⁴ The nurses also structurally assessed the patient preferences regarding treatment outcomes, using the Outcome Prioritization Tool (OPT).¹⁹

All patients were discussed in a regular tumor board and in an onco-geriatric MDT after the nurse-led geriatric assessment (GA). The onco-geriatric MDT incorporated information from the nurse-led GA in the treatment discussion and formulated a treatment proposal based on tumor and patient characteristics, patients preferences and estimated life-expectancy. This information was discussed in the onco-geriatric MDT and an oncological treatment proposal was provided.²⁴ This proposal was compared to the treatment proposal by the regular tumor board. A modified advice was defined as different oncological treatment advice between the onco-geriatric MDT and the tumor board, an unchanged advice meant that no adjustments were proposed to the oncological treatment advice. When treatment modifications were proposed, these were mostly toward less intensive curative treatment or palliative treatment. Non-oncological advice was also provided, when appropriate. This advice could be regarding optimization (i.e. physiotherapy, dietary measures) or regarding risk reduction (i.e. delirium prevention, fall prevention). More details regarding the treatment modifications and non-oncological advice, can be found in our previous publication.²⁴ The final treatment decision was made between the treating physician and the patient in a process of shared decision-making.

OUTCOME MEASURES

For this follow-up study, data were analyzed regarding one year all-cause mortality, postoperative complications and hospital length of stay. These outcomes were compared between the modified and the unchanged group. Survival status was derived from the municipal registration, which in the Netherlands provides complete information on all deaths. Postoperative complications (30 days postoperative complications graded 0-IV according to the Clavien Dindo classification system³⁵) and days spent in hospital during the first year after inclusion were retrieved from the electronic patient records.

Primary outcome was one-year all-cause mortality. Secondary outcome measures were 30 days postoperative complications requiring treatment (defined as Clavien Dindo grade II and higher), and median days spent in hospital during the first year after inclusion (this was defined as days spent admitted to the hospital (any department) and did not include outpatient visits). We also compared low number of days spent in hospital (14 days or less) to high number of days (>14 days) as defined by Chesney and colleagues.³⁶

For the comparison of complications between the modified and unchanged group we looked at the subgroup who underwent surgery, but also at the entire group. For the latter, we regarded the patients who did not undergo surgery as having no complications.

STATISTICAL ANALYSIS

Baseline characteristics were presented as numbers and percentages or median and range, as appropriate. For comparison between patients with modified and unchanged treatment, Pearson's Chi square tests were applied for categorized data, and Mann Whitney U tests for continuous data. The Kaplan-Meier method was used to estimate time from inclusion to death between the modified and the unchanged group, and this was compared with a log-rank test. Cox proportional hazards regression model was used to estimate independent effects of different variables on one-year mortality. Variables with a p value ≤ 0.1 in the unadjusted analyses were entered into the multivariable model in addition to treatment modifications and age. Data analysis was performed using the software package IBM SPSS Statistics, version 23.0 for Windows (SPSS, Inc., Chicago, IL, USA). A p -value of <0.05 was considered statistically significant.

STATEMENT OF ETHICS

This study was registered in the Netherlands Trial Registry (NTR) under trial registration number NTR6660.²⁴ The study was conducted in accordance with the Declaration of Helsinki and Good Clinical Practice Guidelines. Permission was granted by the local medical ethical committee.

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RESULTS

PATIENTS

Initially 214 patients of 70 years and older were primarily seen at the surgical outpatient clinic. For 29, treatment advice from the onco-geriatric MDT could not be compared to the tumor board, since they were primarily discussed in the onco-geriatric MDT. For one patient data on treatment proposal were missing, leaving 184 patients for analysis.

Table 1 shows the baseline characteristics for both groups. For 46 patients (25%) the treatment advice was modified by the onco-geriatric MDT and for 138 patients (75%) the advice was unchanged compared to the advice of the tumor board. The overall median age was 77.5 years (interquartile range (IQR) 73-82), with a higher median age in the modified group [79.9 [IQR 75.0-83.0] vs 76.0 [IQR 72.0-81.0]; $p = 0.01$). Seventy-seven patients (41.8%) were female. Eighty-two (44.6%) of patients had a CCI of three or more. Most patients had soft tissue and skin malignancy ($n = 58$, 31.5%), colorectal carcinoma ($n = 57$, 31.0%), hepatobiliary cancer ($n = 18$, 9.8%) and upper GI malignancies ($n = 18$, 9.8%). One-hundred and six (57.6%) had stage III-IV cancers.

Table 1. Description of baseline characteristics of included patients, stratified by modified versus unchanged treatment ($n = 184$)^a

Characteristics		Modified ($n = 46$, 25%)	Unchanged ($n = 138$, 75%)
Age	Median, IQR	79.0 (75.0-83.0)	76.0 (72.0-81.0)^b
Comorbidity	CCI ≥ 3	20 (43.5)	62 (44.9)
Gender	Female	18 (39.1)	59 (42.8)
Tumor type	Soft tissue and skin	13 (28.3)	45 (32.6)
	Colorectal	18 (39.1)	39 (28.3)
	Upper GI	4 (8.7)	14 (10.1)
	Hepatobiliary	2 (4.3)	16 (11.6)
	Other ^c	9 (17.4)	24 (17.4)
Cancer stage	I-II	20 (43.5)	51 (37.0)
	III-IV	26 (56.5)	80 (58.0)
	Benign disease ^f	0	7 (5.1)

a: All values are numbers (%) unless otherwise specified. Not all percentage add up to 100 due to missing data.

b: Statistical significant difference ($p < 0.05$) between groups as assessed with Chi square for categorical variables, and Mann-Whitney-U test for continuous variables.

c: Other included: skin tumor other than melanoma (5), thyroid (5), breast (4), benign disease or no proven malignancy (4), urological (3), anal carcinoma (2) hepatocellular carcinoma (2), pseudomyxoma (2), chordoma (2), gastro-intestinal stromal tumor (1), gynaecological (1), multiple malignancies (1), and unknown primary (1).

f: All patients had a suspected malignancy but for 7 patients pathology turned out to be negative.

Abbreviations: IQR: interquartile range, CCI: Charlson Comorbidity Index, GI: Gastro-intestinal.

GERIATRIC ASSESSMENT

Table 2 shows the results of geriatric assessment. Ninety-five patients (52.2%) used five or more medications, with a higher percentage of polypharmacy in the modified group (64.4% vs 48.2%, $p = 0.06$). There were significant differences on GARS-sum score between the modified and unchanged group (median 28 (IQR 19-42) vs 24 (IQR 18-33.3), $p = 0.02$) and the GARS-4 ADL subscore (median 15 (IQR 12 - 22) vs median 12 (IQR 11-17); $p = 0.007$). Patients in the modified group had a higher percentage of previous delirium (24.4% versus 11.1% $p = 0.05$), but no significant differences on cognitive testing with the LFT and on known dementia. Based on the Groningen Frailty

Index, 92 (50.3%) patients were considered frail, with no significant differences between the two groups (modified 60.9%, unchanged 46.7%, $p = 0.1$). Regarding patients' preferences, there was a (non- significant) higher percentage of patients regarding maintaining independence as the main health outcome in the modified group, compared to the unchanged group (41.2% vs 37.9%). An equal number of patients regarded life extension as their main health outcome of interest (38.2% and 39.8%). There were no significant differences between the groups on the other geriatric measures.

Table 2. Results of the geriatric assessment, stratified by modified versus unchanged treatment (n= 184)^a

Variable		Modified (n = 46, 25%)	Unchanged (n = 138, 75%)
SOMATIC			
<i>Number of medications</i>	Median, IQR	6.0 (3-8)	4 (3-7)
<i>Polypharmacy (5)</i>	5 or more medications	29 (63.0)	66 (47.8)
<i>Weight loss previous 6 months</i>	< 10 kg	39 (84.8)	117 (84.8)
	≥10 kg	5 (10.9)	18 (13.0)
PSYCHOLOGICAL			
<i>Level of education</i>	High	18 (39.1)	62 (44.9)
	Medium	13 (28.3)	37 (26.8)
	Low	15 (32.6)	35 (25.4)
<i>Cognition</i>	LFT high	11 (23.9)	35 (25.4)
	LFT low	26 (56.5)	67 (48.6)
	Previous delirium	11 (243.9)	15 (10.9)^b
	Known dementia	3 (6.5)	2 (1.4)
<i>Psychological</i>	Psychosocial GFI subscale <2	27 (58.7)	70 (50.7)
	Psychosocial GFI subscale ≥2	18 (39.1)	67 (48.6)
SOCIAL			
<i>Living situation</i>	independent	42 (91.3)	126 (91.3)
	assisted	3 (6.5)	11 (8.0)
<i>Marital status</i>	Living with partner	29 (63.0)	85 (61.6)
	Living without partner	17 (37.0)	52 (37.7)
FUNCTIONAL			
<i>ADL & IADL</i>	GARS-4 sum, Median, IQR	28 (19-42)	24 (18-33.3)^b
<i>ADL</i>	GARS-4 ADL Median, IQR	15 (12-22.5)	12.5 (11-17)^b
<i>IADL</i>	GARS-4 iADL subscore	14 (7-19)	11 (7-16)
	Median, IQR		
<i>Mobility (TUG)</i>	Median, IQR	11.6 (10.3-14.0)	11.1 (9.6-13.1)
	<15	30 (65.2)	102 (73.9)
	≥15	6 (13.0)	22 (16.9)
FRAILITY			
<i>GFI frailty</i>	>4	28 (60.9)	64 (46.4)
PREFERENCES			
<i>Main preference (OPT)</i>	Extending life	13 (28.3)	41 (29.7)
	Maintaining independence	14 (30.4)	39 (28.3)
	Reduction of pain	5 (10.9)	15 (10.9)
	Reduction of other symptoms	2 (4.3)	8 (5.8)

a: All values are numbers (%) unless otherwise specified. Not all percentage add up to 100 due to missing data. b: statistical significant ($p < 0.05$) difference between the groups; chi square for categorical variables, Mann-Whitney-u test for continuous variables. Abbreviations: IQR interquartile range, (I)ADL: (instrumental) activities of daily living, LFT: Letter Fluency test, GFI: Groningen Frailty Indicator, GARS: Groningen Activity Restriction Scale, TUG: Timed-Up and Go test, OPT: Outcome Prioritization Tool.

TREATMENT

The treatment intention was curative in 129 (70.1%) patients, with a significantly lower percentage of curative treatment intent in the modified group (43.5% versus 79.0%, $p < 0.001$). One-hundred and eighteen patients (64.5%) underwent surgery, with a significantly lower percentage in the modified group (43.5% vs 71.1%, $p = 0.00$; Table 3). For 14 patients (30.4%), an adjusted curative treatment intention was advised. For 22 patients (47.8%), a modification from curative treatment intention to palliative treatment was advised (palliative oncological treatment ($n = 11$) or palliative symptom relief/wait and see ($n = 11$)). For ten patients an adjusted palliative treatment was advised (palliative treatment ($n = 4$) or palliative symptom relief/wait and see ($n = 6$)). Non-oncological advice was provided in 42.9% of patients. The percentage of patients for whom non-oncological advice was provided was higher in the unchanged group (47.1% vs 30.4%, $p = 0.05$; data not shown).

OUTCOMES

One-year mortality

Figure 1 shows the survival curve comparing the modified and unchanged group. One-year all-cause mortality was 28.8% ($n = 53$). There was no significant difference between the modified and unchanged group (26.1% versus 29.7%, $p = 0.7$). Outcomes stratified by treatment proposal are shown in Table 3. Table 4 shows the result for the univariable and multivariable analysis of variables prognostic for one-year mortality. Higher tumor stage (III - IV), weight loss of ≥ 10 kg and deficits in IADL were prognostic factors for one-year mortality in the univariable analysis. Age, comorbidity and treatment modifications by the onco-geriatric MDT were not. In multivariable Cox regression analysis, higher tumor stage (hazard ratio (HR) 2.52; 95% confidence interval (CI) 1.25-5.07; $p = 0.01$) and iADL deficits (HR 1.08; 95% CI 0.03-1.13; $p = 0.003$) remained individual prognostic factors for one-year mortality. (table 4)

Postoperative complications and days spent in hospital

Table 3 shows the differences in postoperative complications and days spent in hospital between the modified and the unchanged group. In the group of patients who underwent surgery, there was a lower percentage of grade II or higher complications in the modified group (31.6% versus 50.0%), but this did was not significant ($p = 0.7$). Comparison of postoperative complications between the modified and the unchanged group for all patients, with the non-surgical group regarded as having had no complications, did show a significant difference between the modified and the unchanged group (13.3% vs 35.3%, $p = 0.005$). The modified group spent significantly fewer days in hospital during the first year after inclusion (median 5 days (IQR 0-13.3) compared to the unchanged group (median 8.5 days, IQR 1.5-19.25; $p = 0.02$). There was also a significant difference between the groups regarding a high (> 14) number of days spent in hospital (17.4% vs 34.8%, $p = 0.03$).

Table 3. Treatment decisions and outcomes stratified by modified versus unchanged treatment (n= 184)^a

Variable	Modified (n = 46, 25%)	Unchanged (n = 138, 75%)	P ^b
Treatment variables:			
Curative treatment intention	20 (43.5)	109 (79.0)	<0.001
Surgical treatment	20 (43.5)	98 (71.1)	0.001
Outcome variables:			
Complications grade ≥ II (surgery group ^c)	6 (28.6)	53 (49.5)	0.2
Complications grade ≥ II (total group ^d)	6 (13.0)	48 (34.8)	0.005
Days spent in hospital ^e , median, IQR	5 (0-13.3)	8.5 (1.5-19.25)	0.002
Days spent in hospital, >14 days	8 (17.4)	48 (34.8)	0.03
One-year mortality	12 (26.1)	41 (29.7)	0.7

a: all values are numbers (%) unless otherwise specified.

b: Chi square for categorical variables, Mann Whitney U for continues variables.

c: 30 days complications, only for the patients who underwent surgery.

d: all patients; no surgery is counted as no complications (CD grade 0),

e: days spent in hospital during the first year after inclusion.

Abbreviations: IQR interquartile range

Figure 1. Kaplan-Meier plot of one-year survival between the modified (n=46) versus the unchanged (n=138) group.

Table 4. Predictive models for one-year survival (cox proportional hazards).

Variable	Univariable analysis		Multivariable analysis ^a	
	HR (95% CI)	p	HR (95% CI)	p
Treatment proposal				
Treatment proposal onco-geriatric MDT ^b				
Unchanged	1 ^c		1 ^c	
Modified	0.94 (0.49-1.79)	0.85	0.89 (0.43-1.85)	0.8
Baseline characteristics				
Tumor stage				
I-II	1 ^c		1 ^c	
III-IV	1.90 (1.04-3.450)	0.04	2.52 (1.25-5.07)	0.01
Age	0.98 (0.93-1.03)	0.32	0.97 (0.91-1.02)	0.2
Gender				
Male	1.33 (0.76-2.33)	0.32		
Comorbidity				
CCI<3	1 ^c			
CCI ≥3	0.68 (0.39-1.19)	0.18		
Geriatric assessment				
Polypharmacy (≥5)	0.88 (0.51-1.52)	0.65		
Weight loss previous 6 months				
<10 kg	1 ^c		1 ^c	
≥10 kg	2.41 (1.26-4.61)	0.01	1.75 (0.85-3.59)	0.1
Marital status				
No partner	1.07 (0.62-1.86)	0.81		
Living situation				
Assisted living	1.32 (0.53-3.32)	0.56		
Level of education				
High	1 ^c			
Low and medium	1.64 (0.93-2.89)	0.09		
Cognition				
LFT Low	1.64 (0.93-2.89)	0.09		
Previous delirium	1.10 (0.52-2.33)	0.81		
Dementia	0.05 (0.00-43.94)	0.38		
Mood				
GFI subscale ≥2	1.32 (0.76-2.29)	0.32		
ADL/iADL				
GARS-sum	1.02 (1.00-1.05)	0.50		
GARS-ADL	1.03 (0.98-1.07)	0.27		
GARS-IADL	1.06 (1.02-1.11)	0.07	1.08 (0.03-1.13)	0.003
Mobility				
TUG<15	1 ^c			
TUG ≥15	1.44 (0.72-2.89)	0.31		
Frailty screening				
GFI <4	1 ^c			
GFI ≥4	1.30 (0.75-2.25)	0.34		

a=Treatment modification, age and variables with a p value of <0.1 in univariable analysis were entered in to the multivariable model. b=treatment proposal as compared to regular tumor board (see text). c=Reference group (specified where relevant)

d=Charlson Comorbidity Index, e=Letter Fluency test, f=Groningen Activity Restriction Scale, g=Timed-Up and Go test, h=Groningen Frailty Indicator.

Abbreviations: HR = Hazard ratio, CI = confidence interval

The presented results represent the treatment advice provided by the onco-geriatric MDT. As we described in our previous paper, both the oncological and the non-oncological advice of the onco-geriatric MDT were not always followed by the treating physician. The oncological advice was initially followed in 78.3% of patients ($n = 36$). Leaving the 21.7% out of analysis did not lead to different results regarding mortality, complications and days spent at home (data not shown).

DISCUSSION

These follow-up data of an onco-geriatric surgical cohort show a high all-cause one-year mortality rate of 28.8% during the first year for all included patients. Outcomes were compared between a group of patients for whom the treatment advice, provided by an onco-geriatric MDT, was modified compared to the advice from the regular tumor board and a group of patients with an unchanged advice. Treatment modifications by the onco-geriatric MDT did not result in a higher one-year mortality rate. Poorer outcomes, such as excess mortality, are sometimes feared when treatment modifications are proposed, especially when these modifications are toward a less intensive treatment, as was the case in our cohort.²⁴ Our study does not support this fear of potential undertreatment.³⁷ The modified patient group also experienced less grade II or higher postoperative complications and less days spent in hospital in the modified group, with a median difference of 3.5 days, suggesting better patient centred outcomes as well.

Many studies report on frailty as an independent predictor of adverse outcomes.^{6,38-40} There is, however, still a paucity of data regarding the effect of incorporating geriatric assessment (thereby assessing frailty) in treatment decision-making on patient outcomes. Our study is one of few studies reporting on the outcomes of incorporating geriatric assessment into treatment decision-making in surgical patients. To our knowledge, only one other study in surgical patients reported reduced postoperative mortality after implementation of a frailty screening initiative and notifying clinicians when a patient was classified as frail. Whether this effect was due to treatment modifications, or a result of other optimization strategies, was unfortunately not assessed.¹⁶ Other studies report on better postoperative outcomes, following optimization (prehabilitation) strategies based on frailty assessment, but treatment modifications were not made.^{3,41,42} A recent RCT by Corre and colleagues, incorporating GA in lung cancer patients, found similar results to our study, namely unchanged mortality, but less toxicity and complications in the GA group.⁴³

There are some limitations to our study worth mentioning. Most importantly, we assessed differences in treatment advice between the tumor board and the onco-geriatric MDT.

We know, however, not all oncological and non-oncological advices were followed, due to different reasons (patient, disease or health care provider related). Treatments can also be altered due to the course of the disease or complications. Leaving out the patients where the advice was initially not followed did not lead to different results regarding mortality, complications and days spent at home. The patients were not randomized, as we describe the results of a new care pathway. Because treatment modifications were proposed based on disease characteristics as well as assessment of frailty and patients preferences, the modified group was more frail than the unadjusted group, introducing bias by nature. For the same reason, not all tumor types are included, since the new care pathway was not yet implemented in some departments. Since all patients of 70 years and older were included, there is heterogeneity in tumor types and stages. However, this also makes our data more widely applicable. We had no information on the causes of death available and can therefore only report on all-cause mortality. Because of the frailty of the population, we considered one-year survival as the best outcome measure; a longer follow-up time would have led to more patients being lost to follow-up due to the high mortality rates inherent to this frail patient group. However, for some tumor types, this time span may be considered short. We have no information on complications other than surgical complications, but the reported days spent in hospital are for all hospital wards, and serious complications leading to hospital admission were expected to show in this number. We can also only report on days spent in our hospital, and have no information on days spent in other institutions, for instance in a nursing home or rehabilitation center.

The aim of the geriatric assessment and onco-geriatric MDT was to tailor care to the individual patients, and improve outcomes. This involved spending extra time for patient assessment in the decision-making process. A nurse-led geriatric assessment is estimated to take up 30 min, and 40 min including MDT attendance. Time is sometimes considered a limiting factor to implementation of a geriatric assessment.¹² However, tailoring treatment decisions to frailty and patient preferences may improve patient outcomes and, as this study shows, does not lead to worse outcomes.¹² Costs of incorporating nurse-led geriatric assessment are low compared to other assessments during oncological work-up.¹² Since frailty is a marker of adverse outcomes, tailoring care to the level of frailty is expected to reduce costs caused by complications and prolonged hospital stay. This is supported by the results of this study. It is also expected to enhance patient relevant outcomes such as physical functioning and independence. Research has shown that for many older patients life extensions is not their main preference, and independence is often rated as a more important or equally important goal.¹⁹ Days spent at home has recently been identified as a relevant patient-centered outcome measure.^{20,21,44} Our study shows that patients in the modified treatment group spent fewer days in hospital, reflecting less dependence and better quality of life, but

not at the cost of higher one-year mortality. The next step is to reveal which patients-centered outcome measures are most relevant for patients and their families in order to further improve treatment tailoring and optimize care.

In conclusion, incorporating geriatric assessment in treatment decision-making improved patient outcomes, without increasing one-year mortality rate. These data support broader implementation of geriatric assessment in oncology care.

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CONFLICTS OF INTEREST

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There has been no role of a sponsor in the design, conduction or analysis of this study.

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CHAPTER 8

Summary and
general discussion

The question underlying this thesis was how to best tailor treatments to the individual older patient in order to optimize outcomes and provide patient-centered care.

SUMMARY OF MAIN FINDINGS

1. ASSESSMENT OF CURRENT MULTIDISCIPLINARY DECISION-MAKING

Multidisciplinary teams (MDTs) play an important role in treatment decision-making for cancer patients. In **chapter 2** we described the results of observations of oncological MDTs (tumor boards) on the quality of information discussed and we assessed whether this differed between older and younger patients. For both age groups, the presented quality of information regarding psychosocial information and the patients view (i.e. patient-specific information) was poor. Only the quality of information regarding comorbidities seemed slightly better for older patients. The information presented and discussed in the MDTs was mostly disease-centered and technical. There were no differences in case discussion time, contribution by different team members, and the number of decisions reached between the older and younger patients. Discussion time for each individual case varied between MDTs, but was short (median 3.54 min). Nurses, who have been suggested in literature as likely patient advocates in these meetings and who often possess useful, patient-specific, information, were often present, but had little contribution in the discussion.

2. PATIENT'S GOALS AND PREFERENCES, USING THE OUTCOME PRIORITIZATION TOOL (OPT)

In order to tailor care to the individual patient, it is important to assess the patient's goals and preferences. In the second part of this thesis, we describe the OPT as a means of assessing patient's goals and preferences. We conducted a review of the existing literature regarding the OPT in **chapter 3**. We found seven articles: two about the development of the tool, one study protocol and four articles describing the use of the OPT. The developmental articles were performed in home-dwelling elderly, as were two of the research articles. One study was performed amongst nephrology patients and their nephrologists and one was a protocol article for a study between primary and secondary care. The majority of patients in these studies rated maintaining independence as their most important goal. The tool had been shown to be feasible for both patients and health care providers.

In **chapter 4** we studied the health outcome prioritization of 350 older patients that were referred to our geriatric outpatient clinic to support decision-making. All these patients were facing a decision regarding an intensive treatment; half of them for a benign disease. More than half of the patients prioritized maintaining independence as

their most important health outcome followed by extending life and symptom reduction. Patients with cognitive impairment were the only subgroup of patients to prioritize extending life more often. The OPT proved feasible for most patients facing a complex treatment decision. Malnourishment and being in assisted living were associated with not using the OPT in a multivariable model.

For **chapter 5** we assessed how well healthcare professionals know their patients most important goal. We included 87 patients who prioritized their health outcome, using the OPT, in the process of decision-making for intensive treatments; mostly cancer treatment. The majority prioritized maintaining independence, followed by extending life. The patient's medical specialists and general practitioners (GP) were asked to state what they thought was their patient's main health outcome. All healthcare professionals had a poor perception of the most important health outcome of their patient. This emphasizes the importance of explicitly discussing goals and preferences.

3. ONCO-GERIATRIC MDT

In **chapter 6** we described the results of a novel care trajectory, incorporating geriatric assessment and assessment of preferences in treatment decision-making for patients of 70 years and older with a solid malignancy. Trained nurses performed a geriatric assessment (GA) and an assessment of patient goals, using the OPT, during a semi-structured interview. This patient-centered information was shared by the nurses in an onco-geriatric multidisciplinary team (MDT) meeting, attended by oncological specialists, nurses and geriatricians. In this MDT, patient-centered information was aligned with the disease characteristics and life expectancy was taken into account in a step-wise manner. The treatment advice from the onco-geriatric MDT was compared to the advice by the conventional tumor board. Oncological treatment advice was modified, compared to the tumor boards advice, in 27% of 197 patients, mostly towards less intensive or palliative treatment. In 41% non-oncological advice on patient optimization was provided. Only a small percentage of patients were referred to the geriatrics department for a Comprehensive Geriatric Assessment (CGA).

In **chapter 7** we present the follow-up data of the 184 surgical patients discussed in the onco-geriatric MDT. In these patients oncological treatment was modified in 25%. We found that one-year mortality was high (29%) in the whole group, emphasizing the frailty of these patients. Even though the treatment modifications tended mostly towards a less intensive treatment modality or palliative treatment, one-year mortality was similar in the modified and the unchanged treatment group. This is an interesting finding, since healthcare professionals often worry whether they might harm their patients when de-intensifying the treatment. The patients in the modified group experienced fewer complications and spent fewer days in the hospital.

GENERAL DISCUSSION

To tailor treatment decision-making to fit the needs of older patients with cancer we need to balance potential benefits and harms and align treatment decisions with patient goals and preferences. This can result in a deviation from current guidelines, which are often aimed at survival. Many older patients regard quality of life and retaining independence as the most important treatment outcome, even if the trade-off is a shorter remaining life expectancy. Currently, however, many frail older patients with cancer undergo major surgery and experience postoperative complications and readmissions, often leading to permanent functional loss and a decrease in quality of life. In treating the primary disease this way, we fail to produce tangible benefit for the patient (i.e., overtreatment). Equally, there can be an unjust withholding of treatment based on assumption that a patient is simply too old or too frail to undergo treatment (i.e. undertreatment).¹

The objective of this thesis was to assess how to best tailor treatments to the individual older patient with cancer in order to optimize outcomes and provide patient-centered care. In this thesis, we described the current situation and the implementation of a more patient-centered approach based on combining disease-specific information with patient-centered information and knowledge of the goals and preferences of the patient (figure 1).

Figure 1. The patient's context (general health status) and the patient's goals and preferences are added to the shared decision-making process to come to an individualized treatment plan. (Image used with courtesy of the Citrien fonds; regionale oncologienetwerken, thema passend behandelplan)

Observations of current multidisciplinary decision-making in tumor boards revealed that, currently, their focus is mostly technical and disease-centered. We had expected more patient-specific information and a longer discussion time for older patients, reflecting the higher level of complexity due to frailty and more comorbidities in this age group, but found no differences between younger and older patients. This is in line with other observational studies.^{2,3} These findings do not necessarily mean that patient-centered information is not considered and weighed by the individual specialist in the decision-making process. However, by leaving this out of the MDTs, this information is not structurally weighed in the multidisciplinary decision-making process and therefore not guaranteed for all patients. Establishing a minimum dataset of the available information in MDTs and appointing a patient representative, for instance a nurse, could optimize the decision-making process.³⁻⁶ Nurses often possess useful, patient-centered, information which makes them ideal case managers. Providing them with a substantial role in MDTs, in order to share this information, might enhance tailored decision-making.^{7,8} Unfortunately, the input of nurses in the observed MDTs was also almost nonexistent.

Assessment of patient goals and preferences is considered an important aspect in (shared) decision-making.^{9,10} In order to align care to patient goals and preferences, it is important to explicitly discuss them. Priorities assessment has been shown to have a positive effect on communication, shared decision-making and patient satisfaction.¹¹ We studied the OPT as a promising instrument to assess older patients' goals and preferences. By eliciting universal health outcomes, it is usable in different settings in both primary and secondary care. Thus far, it had been studied mostly in older patients with multimorbidity, who prioritize maintaining independence most often as their main health outcome.¹²⁻¹⁴ We found that this is similar for older patients facing an intensive treatment; more than half of these patients prioritized maintaining independence as their most important health outcome, compared to extending life or symptom reduction. Patients with cognitive impairment were the only subgroup of patients who prioritized extending life. These patients might find it more difficult to oversee different health outcomes and understand the trade-off principle. It has been shown that a decline in health status can lead to accepting a further decline more easily.¹⁵ This might be explained by an adaptation to increased dependency, leading to a reprioritization response shift.¹⁶ It is known that treatment-specific preferences can change over time as well as with a change in health status or when facing a complex treatment decision.^{17,18} Recently, an article was published that followed up on the OPT goals of patients with non-curable cancer over a period of 6 months, that found that these goals can change during the course of the disease.¹⁹ Patients in the last year before death less often prioritized extending life less often in an earlier phase of their disease. This change could be related to the disease, but also to other life events.¹⁹ It would be

interesting to know whether goals change in time for patients with curable cancer and what triggers these changes.

We also revealed that healthcare professionals had a poor perception of the most important health outcome of their patients in the light of treatment decision-making. It has been shown that preference misdiagnoses are frequent and discordance of goals between patients and healthcare professionals are frequent in different settings.²⁰⁻²³ This could be due to perceived barriers of older patients to express goals and preferences and engage in the decision-making process or the belief that healthcare professionals already has knowledge regarding their values.^{24,25} It could also be due to the fact that healthcare professionals find it difficult to engage in such a conversation or assume they already know their patients goals. However, our finding emphasizes the necessity of discussing priorities explicitly. Using a decision aid, such as the OPT, might facilitate and structure the goal-setting conversation, enabling patients to communicate their priorities and healthcare professionals to align treatment options with these priorities. In order to optimize decision-making for older patients with cancer, we need to structurally assess patient-centered information and patient goals and preferences. Geriatric assessment is a means to provide patient-centered information and assess the level of frailty.²⁶ It can support decision-making by giving a better estimation of risk and prognosis. Frailty is a known, independent, predictor of adverse outcomes.²⁷⁻³⁰ There is an increasing body of evidence on the predictive value of GA in older cancer patients, recommending a GA in geriatric oncology. The International Society of Geriatric Oncology (SIOG) published a guideline, recommending GA for older patients with cancer.³¹ More recently, the American Society of Clinical Oncology (ASCO) published a guideline for geriatric oncology, based on 68 studies, that states that a GA should be performed for patients ≥ 65 years, receiving chemotherapy.³²

There are multiple ways to integrate geriatric assessment in treatment decision-making.³³ We described a new care trajectory to integrate geriatric assessment and patients' goals and preferences in treatment decision-making, in which nurses play an important role and geriatricians are involved in multidisciplinary decision-making (figure 2). The new care trajectory resulted in an adjustment of oncological treatments in a quarter of patients, similar to the percentages described in a systematic review.³⁴ The number of patients referred to the geriatrics department for a CGA was small, compared to the often used two-step approach: performing a frailty screening, followed by a (more extensive and time consuming) CGA when positive.³³ Another benefit of structurally incorporating a GA and assessment of preferences in the care trajectory, is that patient-centered information is relevant for decision-making in all patients, not only those who are frail.

Figure 2. The new onco-geriatric care trajectory, incorporating patient-centered information from a nurse-led assessment of geriatric domains and patients preferences (OPT) in multidisciplinary decision-making. The new elements are shown in orange.

There is, however, still a paucity of data regarding the effect of incorporating geriatric assessment in oncology on patient outcomes. Furthermore, medical specialists often worry that, by deviating from guidelines and not proposing the treatment aimed at a maximal chance of survival, they harm their patients and research has shown that they often find it easier to “err on the side of life.”³⁵ By overestimating prognosis, they focus on potentially curative and often intensive treatments and refraining from treatment is often a more difficult and uncertain decision.^{35,36} Despite this worry of potential undertreatment, we found that in our patients the one-year mortality was similar between the modified and the unchanged treatment group, even though the treatment modifications tended towards less extensive or palliative treatment. The patients in the modified group also experienced fewer severe complications and days spent in hospital. Days spent at home is regarded as a novel patient-centered outcome measure, that is gaining attention.³⁷⁻³⁹ Most patients would prefer, when possible, to spend their time at home rather than in a hospital or other care facility.³⁸ Intensive oncological treatment with a high risk of postoperative complications and functional decline often leads to more days spent in a hospital or nursing home.⁴⁰

Only one other study on surgical patients reported reduced postoperative mortality after implementation of a frailty screening initiative; notifying clinicians when a patient was classified as frail. Whether this effect was due to treatment modifications, or a result of other optimization strategies, was unfortunately not assessed.⁴¹ Other studies report on better postoperative outcomes, following optimization (prehabilitation) strategies based on frailty assessment in surgical patients, but treatment modifications were not made.⁴²⁻⁴⁴ An RCT by Corre and colleagues, incorporating GA in lung cancer patients receiving chemotherapy, found similar results to our study, namely unchanged mortality, but less toxicity and fewer complications in the GA group.⁴⁵ Recently, six large randomized trials on GA for older adults were completed. Most of these studies showed a benefit of GA on different endpoints.^{46,47} The GOSAFE study is an ongoing, international, multi-center study examining the impact of frailty assessment on patient-reported outcomes (quality of life and functional recovery), as well as mortality and morbidity in oncological surgical patients.⁴⁸ The result of this study will likely provide valuable information on the effect of geriatric assessment and oncological treatment on patient-relevant outcomes.

FUTURE PERSPECTIVES

FROM DISEASE-CENTERED TO PATIENT-CENTERED; IMPROVING THE CARE TRAJECTORY FOR OLDER PATIENTS WITH CANCER

To improve care for older patients with cancer, the full cycle of care needs to be re-engineered based on the preferences and outcomes that are most relevant to patients. This means optimizing both pre-treatment and post-treatment assessment.

Pre-treatment assessment can be optimized by structurally assessing patient-centered information, such as the patient's context, the level of frailty, potential risk factors, and goals and preferences ("what matters to you?") and incorporating these into the shared decision-making process. Patients and their families need to be well informed about the care trajectory and encouraged to communicate their needs and values with health care professionals. Patient-specific information should be obtained early in the care trajectory, involving the general practitioner, who often has good knowledge of the patient's background and circumstances. Nurses should be trained to assess this patient-specific information and should be empowered to discuss this during the multidisciplinary decision-making process. Structured optimization (i.e. prehabilitation) of modifiable risk factors, such as malnutrition and low physical performance, should be facilitated for selected patients as well as prevention of adverse events, such as falls or delirium.

Post-treatment recovery can be enhanced by rehabilitation and by early detection of complications or functional decline, possibly supported by telemonitoring. Advanced care planning should be initiated for patients in the palliative care trajectory. (figure 3)

Figure 3. After shared decision-making, based equally on disease-specific and patient-specific information, patients can enroll in one of three care trajectories: (1) curative care; (2) care with prehabilitation/optimization; and (3) palliative care. In this example the treatment modality is surgery.

It is important that we increase our knowledge about the effect of these interventions on treatment and patient outcomes in order to enhance the decision-making process and improve meaningful outcomes for patients. Therefore we need to increase our knowledge of meaningful clinical outcomes from a patient perspective (“was it worth it?”). Ultimately, this care trajectory is not limited to older patients with cancer. Incorporating patient-specific information in decision-making will likely benefit all patients, irrespective of disease and age.

INCORPORATING GERIATRIC ASSESSMENT IN CANCER CARE

It is neither feasible nor desirable to refer all older patients with cancer to a geriatrician. Training nurses to perform a geriatric assessment is a means of embedding geriatric knowledge into cancer care for all older patients. Involving geriatricians in multidisciplinary teams is an opportunity to mutually exchange knowledge and

expertise; oncological specialists can gain geriatric knowledge and geriatricians can gain oncological knowledge. In a multidisciplinary setting, geriatricians can help with the interpretation of the geriatric measures and with the weighing of these measures as well as the comorbid conditions in the decision-making process. They can also provide advice regarding optimization of the patients and prevention of adverse events and determine which patients need an additional comprehensive geriatric assessment for a more in-depth assessment and possible interventions for the underlying conditions.

IMPLICATIONS FOR EDUCATION AND TRAINING

In order to change the care trajectory, healthcare professionals need to be taught about the importance of patient-specific information on treatment decisions and outcomes. They need to gain experience in assessing this information and in discussing goals and preferences with their patients. This requires a change of attitude from disease-centered to patient-centered care. Ideally, this is accomplished through teams-based training and learning, involving medical specialists and nurses.

IMPLICATIONS FOR THE ORGANIZATION

By investing in comprehensive patient-specific information at the start of the care trajectory, we can tailor treatment options to the individual patient, aimed at improving patient outcomes. This requires investing in trained nurses and in IT solutions to facilitate the reuse of available information and communication between the healthcare professionals. Since changing the care trajectory is expected to lead to better outcomes, the extra investment at the start is expected to ultimately lead to a lower healthcare burden and costs. Furthermore, the cost of a (nurse-led) GA is low, compared to other diagnostics, such as a CT or MRI scan, a biopsy, and genomic testing.⁴⁹ Health insurance companies and policymakers need to be involved to help find solutions to facilitate the implementation of this patient-centered care.

IMPLICATIONS FOR RESEARCH

We need to increase our knowledge on the effect of geriatric assessment on treatment outcomes in order to enhance the decision-making process and provide patients and their families with personalized outcome information.⁵⁰ There is still a paucity of data on outcomes that are relevant to patients as only 29% of clinical trials in oncology assess patient reported outcome measures (PROMS).⁵¹

- PROMS will need to be assessed to provide more accurate information on issues that matter to patients in their daily lives. The role of response shift as well as personality traits on experienced outcomes should be taken into account.
- We also need to assess how the information from an onco-geriatric MDT is

translated into the patient-physician decision-making process, and how to improve upon this.

- We need to increase our knowledge about the effect of optimization/prehabilitation and post-treatment interventions on disease- and patient outcomes.

Quantitative and qualitative measurements can be used to address the research questions mentioned above and help us understand what matters most to patients and their families. Qualitative research can help to understand patients and health care professionals thoughts and experiences. Topics such as decision-making and patient care, with the interplay of all sorts of contextual factors in the complex setting of everyday care, cannot be sufficiently understood with quantitative research alone.⁵² When designing and conducting research, patients and their caregivers and other stakeholders should be actively engaged.⁵³

This is relevant for older patients with cancer, but also for older patients facing other intensive treatments.

CONCLUSION

To optimize care for older patients with cancer, we need to change the care trajectory and optimize pre and post-treatment assessment. This includes structural consideration of the patient's background and goals, improvement of the decision-making process, optimization before treatment, and monitoring afterward. By doing this, we may prevent overtreatment and undertreatment and improve treatment outcomes. We need to increase our knowledge on the impact on treatment outcomes and whether these are ultimately worthwhile to the patients and their family members. In order to do this, we need to include patients in designing and conducting research and assess meaningful outcomes when doing so.

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CHAPTER 9

Dutch summary
Nederlandse samenvatting

INLEIDING

De onderliggende vraagstelling bij dit proefschrift was hoe we voor de individuele oudere patiënt het beste kunnen komen tot een passend behandelplan om zodoende de behandeluitkomsten te verbeteren en patiëntgerichte zorg te leveren.

SAMENVATTING VAN DE BELANGRIJKSTE BEVINDINGEN

1. HUIDIGE MULTIDISCIPLINAIRE BESLUITVORMING

Multidisciplinaire teams (MDO's) spelen een belangrijke rol bij de besluitvorming rondom behandeling voor patiënten met kanker. In **hoofdstuk 2** beschrijven we de resultaten van observaties van oncologische MDO's (tumorwerkgroepen) ten aanzien van de kwaliteit van ingebrachte informatie en onderzochten of dit verschilt voor oudere en jongere patiënten. De kwaliteit van informatie over de psychosociale omstandigheden en de mening van de patiënt (oftewel patiënt-specifieke informatie) was slecht voor beide leeftijdsgroepen. Alleen de informatie over comorbiditeiten was iets beter voor oudere patiënten. De insteek van de geobserveerde tumorwerkgroepen was met name ziekte-specifiek en technisch. Er waren geen verschillen in de besprekingsduur per patiënt, de kwaliteit van de bijdrage van de verschillende deelnemers aan het MDO en het aantal genomen besluiten tussen beide leeftijdsgroepen. De discussietijd per patiënt varieerde tussen de verschillende tumorwerkgroepen, maar was kort (mediane tijd van 3.54 minuten). Verpleegkundigen worden in de literatuur genoemd als mogelijke vertegenwoordigers van de patiënt in MDO's en hebben vaak waardevolle patiënt-specifieke informatie. Bij onze observaties bleken verpleegkundigen regelmatig aanwezig te zijn bij de tumorwerkgroepen, maar hadden ze nauwelijks een rol.

2. HET INVENTARISEREN VAN DOELEN EN VOORKEUREN VAN DE PATIËNT MET BEHULP VAN DE OUTCOME PRIORITIZATION TOOL (OPT)

Om te komen tot een passend behandelplan voor de individuele patiënt is het van belang om de doelen en voorkeuren van de patiënt in kaart te brengen. In het tweede deel van dit proefschrift bespreken we de OPT als een hulpmiddel om doelen en voorkeuren te bespreken. In **hoofdstuk 3** geven we een overzicht van de bestaande literatuur over de OPT. We vonden 7 artikelen; twee over de ontwikkeling van de OPT, één studie protocol en 4 artikelen die het gebruik van de OPT beschrijven. De meeste studies over de OPT werden uitgevoerd bij thuiswonende ouderen, één studie werd uitgevoerd onder nefrologie patiënten en hun nefroloog en één beschreef een protocol voor een studie in de eerste en tweede lijn. In deze studies bleek de OPT bruikbaar voor zowel patiënten als hun zorgverleners. De meerderheid van de patiënten prioriteerden behoud van zelfstandigheid als hun belangrijkste doel

In **hoofdstuk 4** beschrijven we de resultaten van het gebruik van de OPT bij 350 patiënten die waren verwezen naar de polikliniek geriatrie ter ondersteuning in de besluitvorming. Al deze patiënten moesten een besluit nemen over een intensieve behandeling; de helft betrof een goedaardige aandoening. Meer dan de helft prioriteerde behoud van zelfstandigheid als belangrijkste behandeluitkomst, gevolgd door levensverlenging en symptoom vermindering. Patiënten met cognitieve problemen vormden de enige subgroep die levensverlenging als belangrijkste doel noemden. Het gebruik van de OPT bleek haalbaar voor de meeste patiënten die voor een complexe besluit stonden. Ondervoeding en verblijf in een instelling (verzorgingshuis of verpleeghuis) waren in een multivariaat model geassocieerd met het niet (kunnen) gebruiken van de OPT.

In **hoofdstuk 5** onderzochten we hoe goed zorgverleners op de hoogte zijn van het belangrijkste doel van hun patiënt. We includeerden 87 patiënten die met behulp van de OPT hun behandeldoelen prioriteerden gedurende het proces van besluitvorming voor een intensieve behandeling. Dit betrof voornamelijk de behandeling van een maligniteit. De meerderheid prioriteerde behoud van zelfstandigheid, gevolgd door levensverlenging. Zowel de medisch specialist als de huisarts werd gevraagd om aan te geven welk doel ze dachten dat voor hun patiënt het belangrijkste was. Beide zorgverleners bleken een slechte perceptie te hebben van het belangrijkste behandelgoal van hun patiënt. Deze bevinding ondersteunt het belang van het expliciet bespreken van doelen en voorkeuren met een patiënt.

3. IMPLEMENTATIE VAN HET ONCO-GERIATRISCH MDO

In **hoofdstuk 6** beschrijven we de resultaten van een nieuw zorgtraject, waarin de resultaten van een geriatrisch assessment en het uitvragen van de doelen en verwachtingen van de patiënt werden geïncorporeerd in het besluitvormingsproces voor patiënten van 70 jaar en ouder met een solide maligniteit. Geschoolde verpleegkundigen voerden een geriatrisch assessment uit gedurende een semi-gestructureerd gesprek en brachten daarbij ook de doelen en verwachtingen van patiënten in kaart met behulp van de OPT. Deze patiënt-specifieke informatie werd vervolgens ingebracht in een onco-geriatrisch MDO, bijgewoond door oncologische specialisten, verpleegkundigen en internisten ouderengeneeskunde/geriaters. In dit MDO werden patiënt-specifieke informatie, ziekte karakteristieken en levensverwachting besproken en stapsgewijs gewogen, waarna een behandeladvies werd geformuleerd. Het advies van het onco-geriatrische MDO werd vervolgens vergeleken met het advies dat eerder was gegeven door de tumorwerkgroep. Bij 27% van 197 van de patiënten werd het behandeladvies aangepast ten opzichte van de tumorwerkgroep, voornamelijk richting een minder intensieve of palliatieve behandeling. Bij 41% van de patiënten werden niet-oncologische adviezen gegeven. Slechts een klein percentage werd verwezen naar de geriatrie voor een uitgebreid geriatrisch onderzoek (een Comprehensive Geriatric Assessment of CGA).

In **hoofdstuk 7** presenteren we de uitkomsten na verloop van tijd van de 184 chirurgische patiënten die werden besproken in het MDO. Bij 25% van deze patiënten was het behandeladvies aangepast ten opzichte van de tumorwerkgroep. De sterfte in het eerste jaar voor de hele groep (met en zonder aangepaste behandeling) was hoog (29%). Dit benadrukt de kwetsbaarheid van deze patiëntengroep. Ondanks dat de aanpassingen van het behandeladvies met name richting een minder intensieve behandeling waren, was de sterfte in het eerste jaar gelijk voor beide groepen. Dit is een interessante bevinding, aangezien zorgverleners vaak bezorgd zijn dat ze hun patiënten tekort doen als ze kiezen voor een minder intensieve behandeling. Bij patiënten met een aangepast behandeladvies traden ook minder complicaties op en ze brachten in het eerste jaar minder dagen in het ziekenhuis door.

DISCUSSIE

Om tot een passend behandelplan voor oudere patiënten met kanker te komen moeten we de potentiële voor- en nadelen zorgvuldig afwegen en zorgen dat de behandeling aansluit bij de wensen en voorkeuren van de individuele patiënt. Dit *kán* betekenen dat er wordt afgeweken van bestaande richtlijnen. Deze zijn vaak gericht zijn op overleving als belangrijkste uitkomst van een behandeling. Veel oudere patiënten beschouwen echter kwaliteit van leven en behoud van zelfstandigheid als de belangrijkste uitkomsten van een behandeling, zelfs als daar een kortere levensverwachting tegenover staat. Op dit moment ondergaan nog veel kwetsbare oudere patiënten met kanker grote chirurgie, met als gevolg postoperatieve complicaties en heropnames die resulteren in functionele achteruitgang en een verminderde kwaliteit van leven. De primaire ziekte op deze wijze behandelen levert niet altijd duidelijk voordeel op voor de patiënt (overbehandeling). Tegelijkertijd kan het ook zo zijn dat we oudere patiënten onterecht een behandeling onthouden door de aanname dat de patiënt te oud of te kwetsbaar is om deze behandeling te ondergaan (onderbehandeling).¹ De vraag die we met dit proefschrift wilden beantwoorden is hoe we het beste kunnen komen tot een passend behandelplan voor oudere patiënten met kanker, waarbij de uitkomsten optimaal zijn en de patiënt centraal staat. Hiervoor hebben de we huidige situatie in kaart gebracht en de implementatie van een meer patiëntgerichte aanpak beschreven, gebaseerd op het combineren van ziekte-specifieke informatie met patiënt-specifieke informatie en kennis van de doelen en voorkeuren van de patiënt (figuur 1)

Figuur 1. De context van de patiënt (gezondheidssituatie) en de doelen en voorkeuren worden toegevoegd aan de gezamenlijke besluitvorming om tot een passend behandelplan te komen (afbeelding gebruikt met toestemming van het Citrien fonds: regionale oncologienetwerken, thema passend behandelplan)

Observaties van de huidige multidisciplinaire besluitvorming in tumorwerkgroepen liet zien dat de focus op vooral technisch en ziekte gecentreerd was. We hadden bij de oudere patiënten een grotere inbreng van patiënt-specifieke informatie en een langere discussietijd verwacht, als uiting van de grotere complexiteit door kwetsbaarheid en multimorbiditeit in deze groep, maar vonden geen verschil tussen jongere en oudere patiënten. Dit is in lijn met eerdere observationele studies.^{2,3} Deze bevindingen hoeven niet te betekenen dat patiënt-specifieke informatie niet wordt meegewogen in de besluitvorming door de individuele medisch specialist. Echter, door dit niet te bespreken in de tumorwerkgroep wordt deze informatie niet structureel meegewogen in het multidisciplinaire besluitvormingsproces en is dit daarmee niet gegarandeerd voor alle patiënten. Het vaststellen van een minimale dataset van beschikbare informatie in MDO's en het aanwijzen van een patiënt vertegenwoordiger, bijvoorbeeld een verpleegkundige, zou het proces van besluitvorming kunnen optimaliseren.³⁻⁶ Verpleegkundigen bezitten vaak nuttige, patiënt-specifieke, informatie waardoor ze ideale casemanagers kunnen zijn. Door hen een substantiële rol te geven in de MDO's, zodat ze deze informatie kunnen delen, kan er meer besluitvorming op maat plaatsvinden.^{7,8} Helaas was er vrijwel geen inbreng van verpleegkundigen in de geobserveerde tumorwerkgroepen.

Het in kaart brengen van de doelen en voorkeuren van de patiënt is een belangrijke stap in (gezamenlijke) besluitvorming.^{9,10} Om de behandeling te kunnen laten aansluiten bij

de doelen en voorkeuren van de patiënt is het van belang deze expliciet te bespreken. Het is aangetoond dat het in kaart brengen van de prioriteiten van de patiënt een positief effect heeft op communicatie, gezamenlijke besluitvorming en patiënt tevredenheid.¹¹ We onderzochten de OPT als een veelbelovend instrument om de doelen en voorkeuren van oudere patiënten in kaart te brengen. Doordat met de OPT universele behandeluitkomsten in kaart worden gebracht, is het bruikbaar en verschillende settings in zowel eerste als tweede lijn. Het instrument bleek bij literatuuronderzoek met name te zijn bestudeerd bij oudere patiënten met multimorbiditeit, die behoud van zelfstandigheid het vaakst prioriteerden als hun belangrijkste behandeluitkomst.¹²⁻¹⁴ Uit onze bevindingen bleek dit ook te gelden voor oudere patiënten die een besluit moesten nemen voor een intensieve behandeling; meer dan de helft van deze patiënten prioriteerden behoud van zelfstandigheid als hun belangrijkste behandeluitkomst, vergeleken met levensverlenging of symptoom vermindering. Patiënten met cognitieve beperkingen vormden de enige subgroep die levensverlenging het vaakst prioriteerden. Deze patiënten vonden het mogelijk lastiger om verschillende uitkomsten te overzien en om het principe van “trade-off” te begrijpen. Eerder onderzoek heeft laten zien dat een achteruitgang in gezondheidssituatie kan leiden tot het makkelijker accepteren van een verdere achteruitgang.¹⁵ Dit kan worden verklaard doordat men zich aanpast aan de toegenomen afhankelijkheid, waardoor er een ‘respons shift’ ontstaat.¹⁶ Het is bekend dat behandelvoorkeuren kunnen veranderen; met de tijd, met een verandering van gezondheidssituatie of bij het moeten nemen van een complex besluit.^{17,18} Recent is een artikel verschenen waarbij de OPT doelen van patiënten met ongeneselijke kanker werden gevolgd gedurende een periode van 6 maanden. Hieruit bleek dat doelen kunnen veranderen gedurende het ziektebeloop. Patiënten in hun laatste levensjaar prioriteerden minder vaak levensverlenging dan patiënten in een eerdere fase van hun ziekte.¹⁹ Het zou interessant zijn te weten of de doelen van patiënten met behandelbare kanker ook veranderen in de tijd en wat deze veranderingen bepaalt.

Uit ons onderzoek kwam ook naar voren dat zorgverleners slecht inzicht hebben in de belangrijkste behandeluitkomst van hun patiënt rondom behandelbesluitvorming. Het is eerder aangetoond dat een verkeerde inschatting hiervan, waarbij de doelen van patiënten en zorgverleners niet overeen blijken te komen, regelmatig voorkomt.²⁰⁻²³ Dit kan een gevolg zijn van een drempel die oudere patiënten ervaren om hun doelen en voorkeuren uit te spreken en te participeren in gezamenlijke besluitvorming, maar ook van de aanname van patiënten dat zorgverleners al wel weten wat belangrijk voor hen is.^{24,25} Een andere mogelijke verklaring is dat zorgverleners het lastig vinden het gesprek met hun patiënt over doelen en voorkeuren aan te gaan, of denken dat ze deze al weten. Onze bevindingen benadrukken het belang van het expliciet bespreken van doelen en voorkeuren. Het gebruik van een gesprekshulp, zoals de OPT, kan dit gesprek faciliteren en structureren. Hierdoor krijgen patiënten de gelegenheid hun doelen en

voorkeuren te bespreken en kunnen zorgverleners de behandeling daarop aan laten sluiten.

Om de besluitvorming voor oudere patiënten met kanker te optimaliseren, is het dus van belang gestructureerd patiënt-specifieke informatie en doelen en voorkeuren in kaart te brengen. Geriatrich assessment is een manier om patiënt-specifieke informatie te verkrijgen en om een indruk te krijgen van de mate van kwetsbaarheid (frailty).²⁶ Door een betere inschatting van risico's en prognose kan daarmee de besluitvorming worden ondersteund. Frailty is een bekende onafhankelijke voorspeller van ongewenste uitkomsten.²⁷⁻³⁰ Er is toenemend bewijs voor de voorspellende waarde van geriatrich assessment bij oudere oncologische patiënten en dit wordt bij deze patiënten dan ook aanbevolen. De 'International Society of Geriatric Oncology' (SIOG) heeft een richtlijn gepubliceerd waarin een geriatrich assessment wordt aanbevolen voor alle oudere patiënten met kanker.³¹ Recent is ook door de 'American Society of Clinical Oncology' (ASCO) een richtlijn gepubliceerd met de aanbeveling om een geriatrich assessment uit te voeren bij patiënten van 65 jaar en ouder die in aanmerking komen voor chemotherapie.³²

Er zijn verschillende manieren om geriatrich assessment te integreren in besluitvorming ten aanzien van behandeling.³³ We beschreven en onderzochten een nieuw zorgtraject waarin geriatrich assessment en informatie over de doelen en voorkeuren van de patiënt werden geïncorporeerd in de besluitvorming. Hierbij speelden verpleegkundigen een belangrijke rol en waren geriater betrokken bij multidisciplinaire besluitvorming (figuur 2). Dit zorgtraject resulteerde in een aanpassing van de oncologische behandeling bij een kwart van de patiënten. Dit percentage is vergelijkbaar met een systematische review over geriatrich assessment bij oncologische patiënten.³⁴ Het aantal patiënten dat vervolgens werd verwezen naar de poli geriatrie was gering, vergeleken met de vaak gebruikte twee-staps methode: een frailty screening, die als deze positief is wordt gevolgd door een (uitgebreidere en tijds intensiever) CGA.³³ Een ander voordeel van het structureel inbedden van een geriatrich assessment en het in kaart brengen van doelen en voorkeuren van de patiënt in het oncologische zorgtraject, is dat patiënt-specifieke informatie relevant is voor alle patiënten en niet alleen voor de kwetsbare groep.

Figuur 2. Het nieuwe onco-geriatrie zorgtraject, waarbij patiënt-specifieke informatie vanuit een geriatrisch assessment en doelen en voorkeuren (OPT), verzameld door een verpleegkundige, worden meegenomen in multidisciplinaire besluitvorming. De nieuwe elementen zijn in oranje weergegeven.

Onderzoeksresultaten naar het effect van een geriatrisch assessment bij oncologische patiënten op uitkomsten van behandeling en/of: patiënt gerelateerde uitkomstmaten zijn echter nog schaars. Verder zijn medisch specialisten vaak bezorgd dat ze, door af te wijken van de richtlijnen en niet de behandeling aan te bieden met een maximale kans op overleving, hun patiënten mogelijk tekort doen. Het is aangetoond dat zorgverleners het vaak makkelijker vinden om ten onrechte te kiezen voor een maximale behandeling, dan dat ze deze, mogelijk ten onrechte, achterwege laten.³⁵ Door een overschatting van de prognose richten ze zich op potentieel curatieve, vaak intensieve, behandelingen. Ondanks deze zorgen ten aanzien van mogelijke onderbehandeling, bleek bij onze patiënten de sterfte in het eerste jaar niet te verschillen tussen de groep waarbij het behandeladvies was aangepast vergeleken met de groep waarbij dit onveranderd was gebleven, ondanks dat de aanpassingen vaak richting een minder intensief behandeltraject waren gedaan. De patiënten met een aangepast behandeladvies bleken ook minder dagen in het ziekenhuis door te brengen en hadden minder vaak ernstige complicaties. Dit is een interessante bevinding aangezien intensieve oncologische behandelingen een hoog risico geven op (postoperatieve) complicaties en functionele achteruitgang, leidend tot een langere opnameduur of een opname in

een verpleeghuis.⁴⁰ ‘Thuis doorgebrachte dagen’ wordt beschouwd als een patiënt-specifieke uitkomstmaat.³⁷⁻³⁹ De meeste patiënt brengen, indien mogelijk, hun dagen liever thuis door in plaats van in een ziekenhuis of andere instelling.

Slechts één andere studie bij chirurgische patiënten heeft een verminderde mortaliteit aangetoond na het invoeren van een frailty screening. In deze studie werd de hoofdbehandelaar verwittigd van de mate van kwetsbaarheid van de patiënt.⁴¹ Of de lagere mortaliteit een gevolg was van aanpassingen van de oncologische behandeling of van het inzetten van preoperatieve optimalisatie, is helaas niet bekend. Andere studies hebben wel een positief effect laten zien van preoperatieve optimalisatie (prehabilitatie) bij kwetsbare patiënten, maar hierin vonden geen aanpassingen van het behandelplan plaats.⁴²⁻⁴⁴ Een gerandomiseerde studie van Corre et al. liet vergelijkbare uitkomsten zien als onze studie van aanpassingen van de chemotherapie bij longkanker patiënten op basis van kwetsbaarheid. Zij vonden een gelijke mortaliteit, maar minder toxiciteit en complicaties, in de groep die een geriatrisch assessment had ondergaan.⁴⁵ Recent zijn er zes gerandomiseerd studies afgerond waarbij het effect van geriatrisch assessment op uitkomsten werd onderzocht. De meeste van deze studies lieten een positief effect zien op uitkomsten.^{46,47} Deze studies zijn echter nog niet gepubliceerd. De GOSAFE studie is een lopende internationale studie die het effect van het vaststellen van kwetsbaarheid op patiënt gerapporteerde uitkomsten onderzoekt (kwaliteit van leven en functioneel herstel) bij chirurgische patiënten.⁴⁸ De resultaten van deze studie zullen vermoedelijk waardevolle informatie geven over het effect van geriatrisch assessment en oncologische behandeling op patiënt relevante uitkomsten.

TOEKOMST PERSPECTIEF

VAN ZIEKTEGERICHTE NAAR PATIËNTGERICHTE ZORG; HET VERBETEREN VAN DE ZORG VOOR OUDERE PATIËNTEN MET KANKER.

Om de zorg voor de oudere patiënt met kanker te verbeteren moeten we het totale zorgtraject aanpassen, gebaseerd op zowel de voorkeuren van de patiënt als op de uitkomsten die er voor de patiënt toe doen. Hiervoor is zowel optimalisatie van het in kaart brengen van de patiënt voor de behandeling als monitoring van de patiënt nadien van belang.

Beoordeling voor de behandeling kan worden geoptimaliseerd door patiënt-specifieke informatie, zoals de context, mate van kwetsbaarheid, potentiële risicofactoren en doelen en voorkeuren (“wat is voor u van waarde”?) mee te nemen in gezamenlijke besluitvorming om tot een passend behandelplan te komen. Het is belangrijk om patiënten en hun naasten goed te informeren over dit zorgtraject en ze te helpen te

verwoorden wat voor hen van waarde is. Patiënt-specifieke informatie moet bij voorkeur zo vroeg mogelijk in het behandeltraject beschikbaar komen, waarbij de huisarts, die de patiënt vaak al vele jaren kent, een belangrijke rol kan spelen. Verpleegkundigen kunnen een belangrijke rol spelen bij het verzamelen van patiënt-specifieke informatie en het delen van deze informatie in MDO's. Structurele optimalisatie (bijvoorbeeld door prehabilitatie) van modificeerbare risicofactoren, zoals ondervoeding en een slechte conditie, kan van waarde zijn voor geselecteerde patiënten. En door preventieve maatregelen, indien van toepassing, in te zetten kan het risico op complicaties, zoals een delier of vallen, verlaagd worden.

Het herstel na behandeling kan verder worden geoptimaliseerd door revalidatie en het vroegtijdig opsporen van complicaties of functionele achteruitgang, bijvoorbeeld door middel van telemonitoring. Voor de patiënten die een palliatief traject ingaan kan proactieve zorgplanning worden geïnitieerd. (figuur 3)

Figuur 3: Gezamenlijke besluitvorming, op basis van ziekte-specifieke en patiënt-specifieke informatie, leidt tot een van 3 mogelijke zorgtrajecten: (1) curatieve behandeling volgens de richtlijn, (2) behandeling na prehabilitatie/optimalisatie en (3) palliatieve behandeling. In dit voorbeeld gaat het om chirurgische patiënten.

Het is belangrijk dat we kennis vergaren over het effect van deze interventies op behandeluitkomsten en patiëntuitkomsten om zo het besluitvormingsproces verder te kunnen optimaliseren en te komen tot betekenisvolle uitkomsten vanuit het perspectief van de patiënt. Het is daarvoor van belang dat we onze kennis vergroten over welke uitkomsten betekenisvol zijn voor de oudere patiënt zelf (“was het het waard?”).

Deze aanpassing van zorg is niet alleen relevant voor oudere patiënten, maar ook voor jongere patiënten. Alle patiënten, ongeacht ziekte en leeftijd, hebben zeer waarschijnlijk baat bij het meewegen van patiënt-specifieke informatie in de besluitvorming.

INCORPOREREN VAN HET GERIATRISCH ASSESSMENT IN DE ZORG VOOR OUDEREN MET KANKER

Het is niet haalbaar, maar ook niet wenselijk om alle oudere patiënten met een maligniteit te verwijzen naar een geriater. Door (oncologische) verpleegkundigen te scholen in het verrichten van een beperkt geriatrisch assessment kunnen we zorgen dat dit wordt ingebed in de zorg voor alle oudere patiënten met kanker. Door vervolgens gerieters te betrekken in multidisciplinaire besluitvorming kan er uitwisseling van expertise plaatsvinden; oncologen kunnen hun geriatrische kennis vergroten en gerieters hun oncologische kennis. Gerieters kunnen in de MDO setting ondersteunen bij het meewegen van de geriatrische informatie evenals comorbiditeiten in het besluitvormingsproces. Ze kunnen ook adviseren over optimalisatie en preventie en mede bepalen welke patiënten gebaat zijn bij een uitvoeriger geriatrisch assessment (CGA).

IMPLICATIES VOOR ONDERWIJS EN OPLEIDING

Om de zorg te kunnen veranderen is het van belang dat zorgprofessionals onderwijs krijgen over de relevantie van patiënt-specifieke informatie voor behandelbesluitvorming en uitkomsten van zorg, maar ook hoe ze deze informatie het beste kunnen uitvragen en hoe ze de doelen en voorkeuren met patiënten kunnen bespreken. Idealiter door middel van teamscholing waarbij zowel artsen als verpleegkundigen betrokken zijn. Hiervoor is een verandering in attitude nodig van een ziektegerichte focus naar een meer patiëntgerichte focus.

IMPLICATIES VOOR DE ORGANISATIE

Door te investeren in het verkrijgen van patiënt-specifieke informatie zo vroeg mogelijk in het zorgtraject ('aan de poort') kunnen we zorg op maat leveren voor de individuele patiënt en daarmee uitkomsten verbeteren. Hiervoor is een investering nodig in voldoende, getrainde, verpleegkundigen die tijd krijgen om met de patiënt in gesprek te gaan. Daarnaast is het van belang dat er goede IT ondersteuning is, om te zorgen deze informatie in principe eenmalig verzameld wordt en hergebruikt kan worden,

maar ook om de het delen van informatie en de communicatie tussen zorgprofessionals te ondersteunen. De verwachting is dat dit leidt tot betere uitkomsten van zorg waardoor deze investering vermoedelijk zal leiden tot lagere belasting van de zorg en lagere kosten. De kosten van een verpleegkundig geriatrisch assessment zijn laag vergeleken met andere diagnostiek zoals bijvoorbeeld een CT of MRI scan, een biopsie of een genetische test.⁴⁹ Door zorgverzekeraars en beleidsmakers te betrekken kan er worden gezocht naar oplossingen om de implementatie van deze patiëntgerichte zorg te faciliteren.

IMPLICATIES VOOR WETENSCHAPPELIJK ONDERZOEK

Door onze kennis te vergroten ten aanzien van het effect van een geriatrisch assessment op behandeluitkomsten, kunnen we de besluitvorming verdere optimaliseren en patiënten en hun naasten gepersonaliseerd uitkomstinformatie aanbieden.⁵⁰ Op dit moment ontbreekt een belangrijk deel van deze informatie, aangezien slechts 29% van oncologische trials patiënt gerapporteerde uitkomsten (PROMS) verzamelen.⁵¹

- Door PROMS structureel te verzamelen ontstaat er een beter inzicht in uitkomsten die er voor patiënten toe doen. Hierbij is het ook van belang rekening te houden met de rol van 'respons shift' (verandering in de tijd van antwoorden) en persoonlijkheidskenmerken op de ervaren uitkomsten.
- Nader onderzoek is nodige tav de vertaling van de adviezen van een onco-geriatrisch MDO naar de gezamenlijke besluitvorming in de spreekkamer en mogelijke verbeteringen hiervan
- Door meer kennis te vergaren over het effect van optimalisatie/prehabilitatie en verbeterde monitoring op ziekte- en patiëntuitkomsten kan het traject rondom een behandeling verder geoptimaliseerd worden.

Zowel kwalitatief als kwantitatief onderzoek is nodig om deze vragen te kunnen beantwoorden en te achterhalen wat voor de patiënt en zijn naasten werkelijk van belang is. Kwalitatief onderzoek heeft als voordeel dat het inzicht kan verschaffen in de gedachten en ervaringen van patiënten en zorgverleners. Vooral ten aanzien van een onderwerp als gezamenlijke besluitvorming, waarbij allerlei factoren interacteren en de context en de hectiek van de dagelijkse zorg een rol spelen, geeft kwantitatief onderzoek alleen te weinig inzicht.⁵² Verder is het van belang patiënten, hun naasten en andere stakeholders een actieve rol te geven bij het bedenken en tijdens het uitvoeren van wetenschappelijk onderzoek.⁵³

Bovengenoemde punten zijn van belang voor ouderen met kanker, maar zijn net zo relevant voor ouderen die voor een behandelbesluit ten aanzien van een andere aandoening staan.

CONCLUSIE

Om de zorg voor oudere patiënten met kanker te optimaliseren moet het hele zorgtraject worden aangepast. Door de context en persoonlijke doelen en voorkeuren van de patiënt structureel mee te wegen kan de behandelbesluitvorming worden geoptimaliseerd. Daarnaast is het van belang dat er structureel aandacht komt voor optimalisatie en preventie, voor en tijdens de behandeling, en goede monitoring van de patiënt achteraf. Door deze aanpassingen kunnen we hopelijk onderbehandeling als overbehandeling voorkomen en behandeluitkomsten verbeteren. Door wetenschappelijk onderzoek kunnen we onze kennis vergroten ten aanzien van de impact van deze aanpassingen op behandeluitkomsten en wat daarin voor patiënten en hun naasten van waarde is. Het verdient daarbij de aanbeveling patiënten in alle fasen actief te betrekken en structureel aandacht te hebben voor betekenisvolle uitkomsten vanuit het perspectief van de patiënt.

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APPENDICES

List of publications

Dankwoord (Acknowledgements)

Biografie (Biography)

LIST OF PUBLICATIONS

THIS THESIS

Festen S, van Twisk YZ, van Munster BC, de Graeff P. 'What matters to you?' Health outcome prioritisation in treatment decision-making for older patients. *Age Ageing*. 2021 Aug 3;afab160. Epub ahead of print.

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BIOGRAFIE (BIOGRAPHY)

Suzanne Festen werd op 17 juni 1970 geboren te Nijmegen om vervolgens haar jeugd door te brengen in Malden samen met haar ouders en haar jongere broer Sebastiaan. Haar middelbare school doorliep ze op het Elshof College te Nijmegen om vervolgens in 1989 geneeskunde te gaan studeren aan de Vrije Universiteit te Amsterdam. Na het afronden van haar studie werd ze ANIOS interne geneeskunde, eerst in het Spaarne ziekenhuis te Haarlem en vervolgens in het Twenteborg ziekenhuis in Almelo. Daar startte ze de opleiding interne geneeskunde die ze in Almelo en vanaf 2001 in Groningen (UMCG) doorliep. Aansluitend koos ze voor het aandachtsgebied ouderengeneeskunde en bleef na afronding (2006) daarvan als internist ouderengeneeskunde in het UMCG. Sinds 2014 houdt ze zich veel bezig met het behandeldilemma's en het optimaliseren van behandelbesluitvorming voor ouderen in samenwerking met verschillende afdelingen in het UMCG. Er is een nauwe samenwerking met de oncologische chirurgie rondom het project 'passend behandelplan' voor ouderen met een solide maligniteit. Inmiddels is deze werkwijze een van de voorbeelden van waardegedreven zorg in het UMCG en landelijk. Deze samenwerking heeft de basis gevormd voor in dit proefschrift.

Suzanne is getrouwd met Daniël Bosold die ze in 2002 ontmoette op de 'Friendship Highway'. Samen hebben ze twee dochters: Tara (2006) en Uma (2009).

Suzanne Festen was born on June 17th, 1970 in Nijmegen. For most of her childhood she lived in Malden with her parents and younger brother Sebastiaan. She graduated from Elshof College in 1989 and studied medicine at the Vrije Universiteit, Amsterdam. She completed her medical training in 1998 after which she became a resident in training in internal medicine at Twenteborg Hospital, Almelo, followed by the University Medical Center Groningen, where she specialized in geriatric medicine. In 2006 she became internist geriatrician and stayed at the UMCG. Since 2014 her focus has been on complex decision-making for older patients in collaboration with several departments at the UMCG. There is an ongoing collaboration with the oncological surgery in the project 'passend behandelplan.' This project focuses on the optimization of decision-making and care for older patients with a solid malignancy. This project is an example of valued-based healthcare at the UMCG and in the Netherlands. This collaboration has been the starting point of this thesis.

Suzanne is married to Daniël Bosold, whom she met in 2002 on 'The Friendship Highway.' Together they have two daughters: Tara (2006) and Uma (2009).