The role of the general practitioner in Shared Decision Making for cancer treatment

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Chapter 1

General introduction

A new paradigm: personalized cancer care

Worldwide, the burden of cancer is increasing.[1-2] As people are getting older and cancer diagnostics are improving, the number of patients diagnosed with cancer is expanding.[3] In addition, the effectiveness of cancer treatments is improving and, hence, the life span of patients with cancer is increasing.[4] This also means living longer with long-term consequences of treatment.[5] This challenges our healthcare system, (e.g. financial burden and increased workload) and to be able to ensure adequate care for this increasing group of patients, a new approach to cancer care is required.

Within the last couple of decades, one of the major changes in cancer care has been the increasing importance of a true personalized approach, with a shift from a paternalistic professional dominated attitude to a focus on true patient-centered care.[6-7] The possibility of personalized cancer care is created by the ever mounting scientific evidence that cancer is a very heterogeneous disease asking for a diverse range of targeted interventions.[8] This increase in treatment options might be complicated for patients, as they are faced with a complex treatment decision in the turbulent time after a cancer diagnosis. However, it might also enable patients to choose a treatment option that best matches with their personal preferences, their psychosocial context and health literacy.[9]

Patient involvement in treatment decision making

An essential element in personalized cancer care is to actively involve patients in decision making around their personal healthcare. Patient involvement has already been shown to be beneficial for several patient reported outcomes. Studies suggest that patients who were actively involved in treatment decision making reported a higher quality of life, less decision regret and higher satisfaction with treatment decision.[10-11] Furthermore, treatment adherence was higher for patients experiencing an adequate level of involvement in treatment decision.[12] Moreover, patients who reported a passive role in treatment decision making reported greater distress and lower quality of life.[13]

Shared decision making

Alongside the increasing importance of personalized cancer care, shared decision making (SDM) has become the new paradigm in many consultation rooms.[14] The possibility of SDM is thought to be key for personalized cancer care.[14-15] SDM aims to combine the physician's expertise and the patient's preferences into an informed shared decision in four essential steps[15]:

1. The physician creates awareness that a choice for treatment needs to be made;
2. The physician explains the treatment options, including advantages- and disadvantages of each option;

3. The patient is offered time and opportunity to reflect on the diagnosis and treatment options in the light of personal preferences;
4. The patient and physician make an informed shared decision.

Unfortunately, in current practice several essential steps for optimal SDM are insufficiently facilitated. First, patients are often not aware of their own role in choosing the most befitting treatment. One of the reasons might be that physicians are unable to create awareness among patients that there is a possibility to choose between treatment options. This may be caused by the habit of treating physicians to rely on their clinical judgement and protocols, in determining which treatment is the best option for the patient.[16] Second, in the complexity of cancer care patients always experience an information lag, and commonly the effects of treatment are not fully understood by patients.[17] This sometimes leads to crucial misconceptions, such as that palliative chemotherapy is a form of curative treatment.[17] Third, the rollercoaster after a cancer diagnosis generally leaves little room for patients to reflect on their personal preferences and expectations.[16] Consequently, the current treatment decision making process is mostly driven by the aim for maximal survival gain, instead of striving for optimal quality of life and pursuing individual preferences of the patient. Moreover, the option to refrain from treatment is often ignored, both by physicians, who have a strong tendency to act and not to withhold treatment, and by patients and their relatives, who regard not treating as an end of life decision.[16, 18-19] The latter may result in unintended overtreatment. Therefore, the current SDM process needs improvement to better facilitate personalized decision making and cancer care.

GP support in SDM

One of the facilitators in improving the SDM process is more involvement of the general practitioner (GP).[20-21] GPs generally have a longstanding personal relationship with their patients, especially in healthcare systems with the GP as the first point of contact for all medical questions. GPs are usually familiar with the patient and their social context, have knowledge about patient's personal and medical background and are often more aware of their patient's preferences.[21] From this position, the GP seems to be ideally positioned to support the patient in the SDM process. For instance, by creating a moment shortly after diagnosis to reflect on the treatment decision at hand. In this consultation, patient's priorities and preferences can be explored in the light of the possible treatment perspectives. Thereafter, the patient can be empowered to involve these preferences in the choice which is made in secondary care.

The Dutch situation

In the Netherlands, the GP, as gatekeeper, usually refers patients with symptoms suspected for cancer to the hospital. Generally, the diagnostic pathway and subsequent treatment and follow-up care are hospital-based. After the active treatment phase, care for long-term complaints, psychological consequences and end-of-life care are usually provided by the GP. After diagnosis, contact between GP and patient before and during the active treatment phase largely depends on the initiative of either the patient or the GP. Up until now, there are no guidelines, which describe how the GP can support the patient shortly after the diagnosis and what their role could be in supporting the patient in decision making for cancer treatment.

Due to the fact that the GP is currently insufficiently kept "in the loop" after a cancer diagnosis, the GP is hampered to provide optimal SDM support and to facilitate personalized cancer care.[16, 20-22] In order to improve SDM for cancer treatment, patients, healthcare professionals and policy makers advocate an increased role of the GP after a cancer diagnosis.[5, 8]

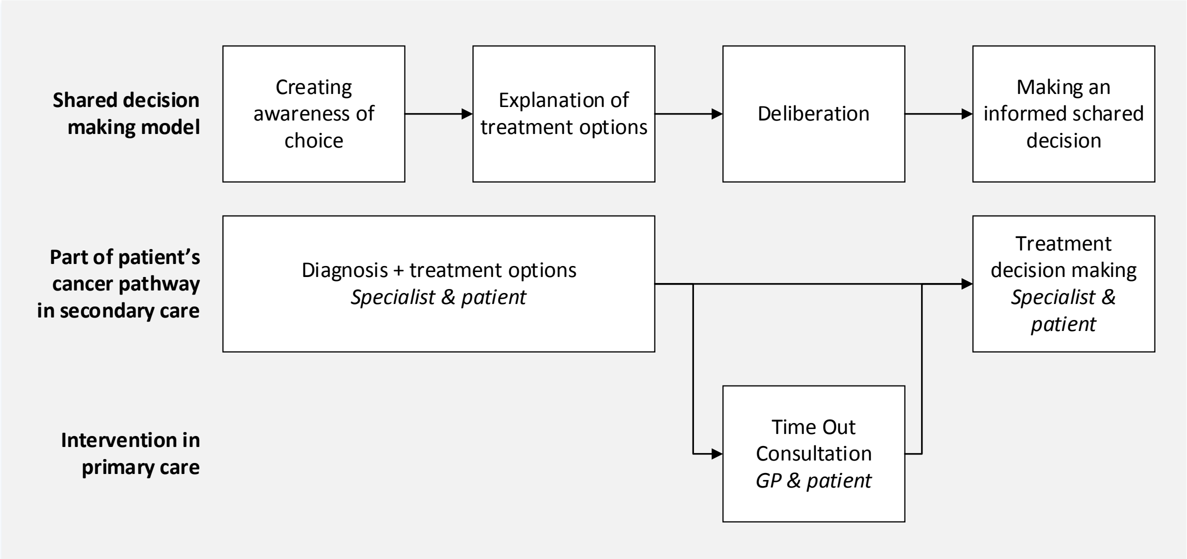

Figure 1. Schematic presentation of the shared decision making model[15] and the positioning of the "Time Out Consultation" in patient's cancer care pathway.

A Time Out Consultation with the GP

In order to enable the GP to support the patient to participate in decision making for cancer treatment, which is to be made in the hospital, we developed the "Time Out Consultation" (TOC). This TOC is situated in primary care, between the diagnosis and the therapy choice (Figure 1). This TOC is an extended GP consultation between diagnosis and subsequent treatment decision, with the aim to support the patient in SDM.[23] The suggested topics of a TOC are:

- Reflection on impact and consequences of the diagnosis;
- Discussion of personal preferences and priorities in the light of the expected prognosis, the treatment options and the choice which has to be made;
- Providing three questions which, if still unclear, need to be answered in the follow-up consultation with the medical specialist, to enable an informed choice:

- What are my options?
- What are the possible benefits and harms of those options?
- How likely are the benefits and harms of each option to occur in the patients' specific situation?

The use of the latter three questions model in decision making showed to be beneficial for the quality of information about treatment options and for patient involvement in decision making.[24]

Aim and outline of this thesis

The overall aim of this thesis is to explore the role of the GP in supporting the patient to participate in SDM for cancer treatment. Therefore, we will explore the needs and experiences of cancer patients with GP involvement in cancer care and in SDM in particular, as well as list the current knowledge on patient involvement in decision making for cancer treatment. Moreover, we will describe the first experiences with a TOC in primary care, including its effects on the SDM process. Furthermore, we will explore the treatment decision making process, including the patients' main considerations and their perceived role of the GP.

In **Part I**, we will explore cancer patients' needs and experiences concerning their involvement in decision making, and with the involvement of the GP in SDM. In *Chapter 2* we will present a literature overview of previous studies investigating patients' preferred and perceived level of involvement in decision making for cancer treatment and to what extent these roles match. In *Chapter 3* we will present results of a large national survey, which was distributed among cancer survivors by the Dutch Federation of cancer patient organizations (NFK). The results of this survey give insight into the needs of Dutch cancer patients for GP involvement in cancer care in general and specifically in SDM and whether GP involvement occurs.

In **Part II**, we will investigate the experiences with and effects of structured GP involvement (TOC) in two different setting. In *Chapter 4*, we will conduct a mixed methods study. In this study we will perform a pilot implementation of the TOC in daily practice for patients treated for cancer with palliative intent. The pilot aims to explore the uptake and the first experiences with a TOC, concerning experienced added value for SDM according to patients, GPs and specialists. In *Chapter 5,* we will present the results of the GRIP trial. The GRIP trial is a multi-center randomized controlled trial including cancer patients treated with curative intent. It aims to evaluate the effects of a TOC on perceived SDM, information provision and self-efficacy. In order to aid understanding of the results of the GRIP trial, we will conduct a qualitative interview study with cancer patients treated with curative intent. In *Chapter 6*, we will present the results of these interviews, in which we reflect with the patients on their treatment decision making process and the role of the GP shortly after diagnosis.

Finally, all results will be discussed and recommendations for future practice and research will be presented in the general discussion in *Chapter 7*.

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Part I: Patient and GP involvement in treatment decision making

Chapter 2

Patients' preferred and perceived level of involvement in decision making for cancer treatment: a systematic review

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Abstract

Background

Patient involvement in decision making is conditional for personalized treatment decisions. A previous systematic review demonstrated mismatch between patients' preferred and perceived level of involvement. We aim to provide an up-to-date overview of patients' preferred and perceived level of involvement in decision making for cancer treatment.

Patients and methods

A systematic search was performed in PubMed, EMBASE, PsycINFO and CINAHL for articles published between January 2009 and January 2020. Search terms were '*decision making', 'patient participation', 'oncology', 'perception'* and *'treatment'.* Inclusion criteria were: written in English, peer-reviewed, reporting patients' preferred and perceived level of involvement, including adult cancer patients and concerning decision making for cancer treatment. The number of patients preferring and perceiving an active, shared or passive decision role, overall (dis-)concordance and for each role separately, are presented as percentages for the individual studies, as well as for the median of all studies. Quality assessment was performed with a modified version of the New-Castle Ottawa Scale.

Results

Thirty-one studies were included. Most studies regarded early stage breast cancer patients. The median of all studies for the percentage of patients preferring a shared role in decision making was 46%, 25% for an active role and 27% for a passive role. The median of all studies for the percentage of patients perceiving a shared role was 39%, 27% for an active role and 34% for a passive role. The median concordance in preferred and perceived role of all studies was 70%. Disconcordance was highest for a shared decision role; 42%.

Conclusion

Patients' preferences for involvement in cancer treatment decision vary widely. A significant number of patients perceived a decisional role other than preferred, especially those who preferred a shared role. Physicians should explore patients' preferences for involvement in decision making in order to truly deliver personalized cancer care.

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Acknowledgements

We would like to thank our research assistant, Lianne Potters (LP) for her contribution to the screening and quality assessment of studies for this review.

Highlights

- Patients' preferences and perceptions of involvement in decision making for cancer treatment vary.
- Approximately one in three patients perceives a decisional role other than preferred.
- To optimize personalized cancer care, physicians should explore patients' preferences for involvement in decision making.

Introduction

As science continues to reveal the heterogeneity of tumors, the number of possible treatment options rises. This increases the potential for personalized cancer treatment and makes 'the best' treatment choice increasingly subject to preference. In the process of reviewing treatment options, evaluating them in the medical and psychosocial context of the patient and matching them with individual preferences and priorities is needed for personalized cancer care. Patient involvement is therefore required to make a deliberate choice.[1-2] Through this process of shared decision making (SDM), patients are enabled to play an active role in composing their individual cancer care.[3-5]

Patient involvement in decision making for cancer treatment has been shown to improve patient satisfaction and quality of life. Hack et al. showed that women experiencing active involvement in treatment decision for breast cancer reported a significantly higher quality of life than women experiencing passive involvement.[6] Moreover, among these women, decision regret was reported significantly more by women who experienced less involvement in treatment decision than they would have preferred. A passive role in treatment decision making led to greater distress and lower quality of life among breast and prostate cancer patients.[7] Also, satisfaction with treatment decision was positively influenced by level of involvement, with greater patient involvement leading to higher decision satisfaction.[8] Furthermore, treatment adherence is higher for patients experiencing a level of involvement that corresponds to their preference in treatment decision for breast cancer.[9]

In the last two decades, research in decision making for cancer treatment increasingly underlined the mismatch between patients' preferred and perceived level of involvement in decision making. In a previous systematic review on this topic, Tariman et al. concluded that there was disconcordance between the role that patients wanted to play in treatment decision making and the involvement they actually perceived.[10] Hence, more attention for actively involving patients in the SDM process in clinical practice was recommended.

Since 2009, the number of possible treatment options has further increased, which results in even more complex treatment decisions for patients with cancer. In parallel, societal demand for patient involvement in medical decision making has also increased.[11] Therefore, for this new era in which SDM seems more important, this systematic review aims to provide an up-to-date overview of patients' preferred and perceived level of involvement in decision making for cancer treatment and the concordance between preferred and perceived involvement.

Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2009 checklist was used to report this systematic review.[12]

Eligibility criteria

We included peer-reviewed articles published in English. Furthermore, studies needed to (i) include data on adult cancer patients, (ii) report both the preferred and perceived level of involvement in decision making, and (iii) concern decision making for cancer treatment. We excluded studies that performed a qualitative exploration of the role in decision making. If multiple publications were based on data of one study, we only included the publication that best reported the data of all participants.

Sources and search strategy

A literature search was carried out in PubMed, EMBASE, PsycINFO and CINAHL for articles published between January 2009 and January 2020 (previous review included studies until January 2009). We based our search on the search performed by Tariman et al., which included the medical subject heading terms '*decision making', 'patient participation'* and *'oncology'.*[10] To further detail the search strategy, we added two search terms *'perception'* and *'treatment'.* Key words and relevant terminology were based on the search terms, index terms and relevant terminology in title/abstract used in so-called 'key publications'. These key publications were selected before constructing the search strategy, as publications that answer the research question and should be identifiable in the search results. We validated the final search (Appendix A), by checking whether our 'key publications' would be identified in the results of the search. Finally, we performed backward and forward citation tracking to identify any potential relevant missed studies.

Study selection

Two researchers (EN & LP) independently performed title/abstract screening for eligibility with the use of the online tool 'Rayyan'. Any discrepancies in the selection of eligible studies based on title/abstract were discussed with a third researcher (CH). Full-text screening of selected papers was done by two researchers (EN & CH).

Data collection

The following data were extracted from the individual studies: 1) the percentage of participants preferring predefined levels of involvement, 2) the percentage of participants perceiving these levels of involvement, and - if provided - 3) the percentage of participants with a (within-person) disconcordance between their preferred and perceived level of involvement.

Level of involvement

The most commonly used scale in the included studies to measure the preferred and perceived level of involvement, is 'The Control Preference Scale' (CPS) designed by Degner et al.[13] The CPS asks patients to reflect on a specific decision and to select one of the 5 responses (A-E), which best corresponds with their preferred level of involvement (Table 1). These 5 responses are categorized into either an active, shared or passive decision role.

Other methods used in included studies to measure the level of involvement in decision making are the Shared Decision Making Questionnaire (SDM-Q-9)[14], the Patient Perception Scale (PPS)[15] and the Treatment Decision Making (TDM) examples, designed by Charles et al.[16-17] These measurements also allow making a distinction between an active, shared or passive role in decision making.

Table 1. The Control Preference Scale and the translation to decision roles.[13]

Response	**Control Preference Scale (CPS)**	**Decision role**
A	I prefer to make the final selection about which treatment I will receive	Active
B	I prefer to make the final selection of my treatment after seriously considering my doctor's opinion	Active
C	I prefer that my doctor and I share responsibility for deciding which treatment is best for me	Shared
D	I prefer that my doctor makes the final decision about which treatment, but seriously considers my opinion	Passive
E	I prefer to leave all decisions regarding treatment to my doctor	Passive

Data analysis

The three levels of involvement (active, shared, passive) were extracted from all studies. For studies presenting the percentages for the levels A-E (Table 1), we calculated the percentage of A plus B for an active decision role, and of D plus E for a passive decisional role. Additionally, if the percentage of concordance was not provided and if the data allowed, we calculated the overall concordance on an individual level and the disconcordance separately for the different levels of involvement.[1] Also, if individual studies presented their data in subgroups (such as for different age groups or different types of treatment), we calculated the overall percentages.

We calculated the median and interquartile range of all studies for the: 1) percentage preferred, 2) percentage perceived and 3) percentage disconcordance between preferred and perceived for an active, shared and passive role and 4) the percentage of overall (dis-) concordance. We present these medians and interquartile ranges for all included studies in total and for the following subgroups: cancer diagnoses (breast, haematologic, lung, (colo) rectal, prostate cancer), culture (Western, Asian), and stage of cancer (early, advanced).

Quality assessment

For all included studies the quality was independently assessed by two researchers (EN, LP). To assess the risk of bias we used the Newcastle-Ottawa Scale (NOS).[18] The NOS was originally designed to assess the risk of bias on outcome and study level for cohort and case-control studies. Previous studies tested[19] and used[20-21] a modified version of the NOS to fit cross-sectional studies. We modified these scales to fit our research (Appendix B). We used the modified version of the NOS for all included studies, as the measurement of the variables of interest (irrespective of study design) was comparable. Quality of studies was scored for the topics ‘selection of participants’ and ‘definition and assessment of the outcome’. Scores could range from 0-9 stars, with 0-3 stars corresponding with a poor quality, 4-6 with a fair quality and 7-9 with a good quality.

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[1] For example the percentage disconcordance for a shared decision role is calculated by: (number of patients perceiving an active + a passive role) / number of patients preferring a shared role * 100%

Results

Study selection

After removal of duplicates, 4,738 records were identified and screened on title and abstract (Figure 1). Sixty-eight studies were screened full-text, of which 28 were eligible. Backward and forward citation tracking yielded three additional studies, resulting in 31 studies for analysis. The main reasons for exclusion was the focus on a diagnosis other than cancer and a focus on decision-making for cancer care in general instead of cancer treatment specifically.

Study characteristics

In total, we included 31 studies, with 13,247 cancer patients participating. These patients reflected on 16,537 cancer treatment decisions. Table 2 provides an overview of the included studies. Most studies (*N*=13) included breast cancer patients[22-34], two studies included patients with haematologic cancer[35-36], two studies lung cancer patients[37-38], one study colorectal cancer patients[39], two studies prostate cancer patients[40-41] and others included various cancers [42-52]. More studies were performed in Western countries[23-27, 29, 31-32, 35-36, 38, 40-42, 44-52], as compared to Asian countries.[22, 28, 30, 33-34, 37, 39, 43] Most studies included early stage cancer patients.[22-29, 32-33, 38, 40] Five studies included advanced stage cancer patients[31, 37, 43, 45, 48], eight studies included all stages[30, 34, 42, 44, 49-52], and for six studies cancer stage was not reported.[35-36, 39, 41, 46-47] Most studies used a cross-sectional design in which patients' preferred and perceived decision role were measured after treatment decision.[22-23, 25-26, 28-29, 31, 33-39, 41-52] Five studies used a prospective study design and measured patients' preferred decision role before treatment decision and their perceived role afterwards.[24, 27, 30, 32, 40]

Quality of studies

Quality of the included studies ranged from 4 to 8 stars, with 12 studies having a good, 19 a fair and 0 a poor quality (Table 3). Most studies included a selected group of patients, lacked a sample size calculation and a description of the response rate and/or comparability with non-responders. Also, in some studies the sample was not described clearly, in these cases cancer stage was not reported. Furthermore, in three studies timing of the measurement of patients' preferred and perceived level of involvement was unclear.

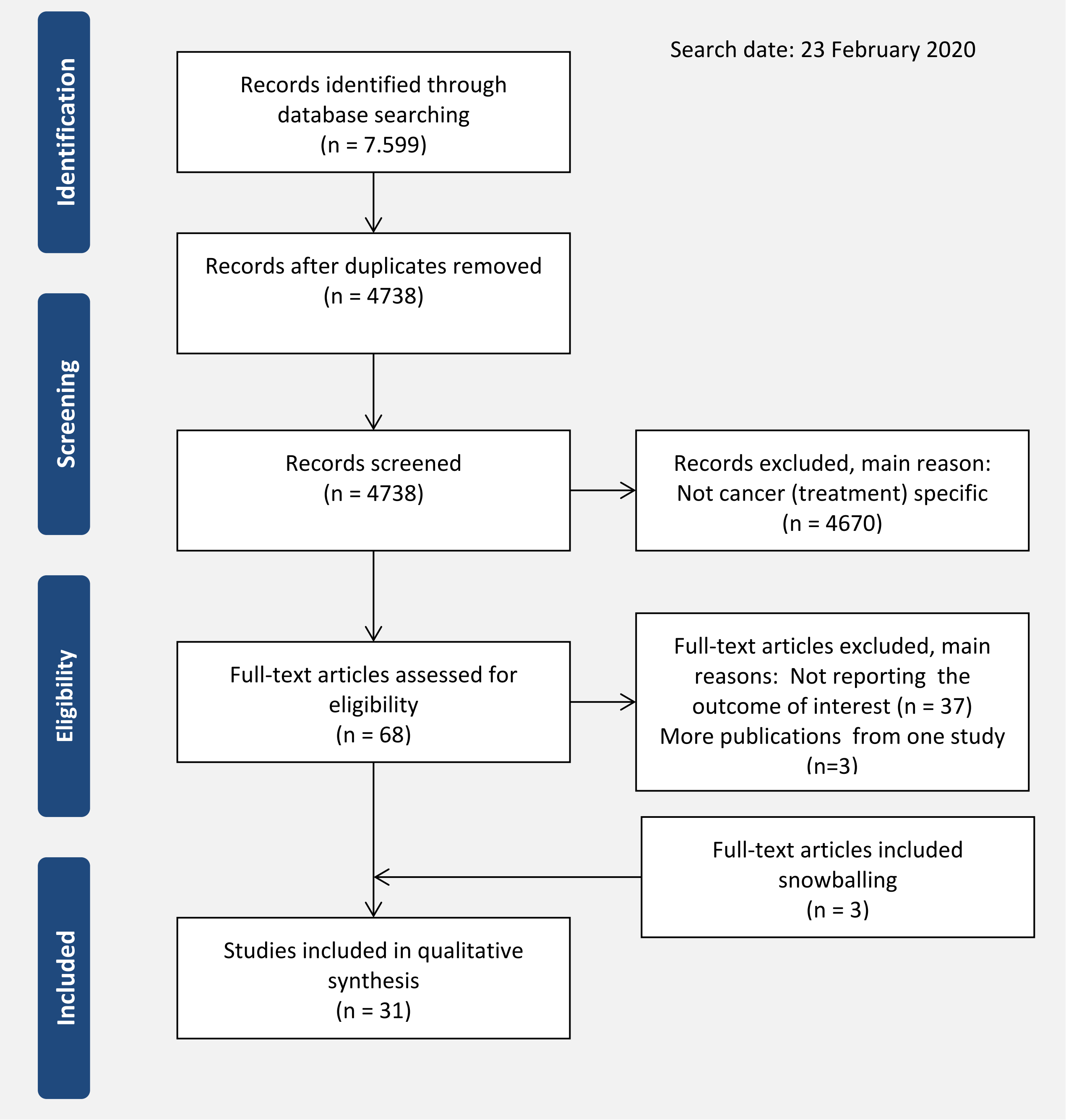

Figure 1. Flowchart for the selection of studies, based on Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).[12]

Table 2. Overview of the included studies, presenting study characteristics, the reported level of preferred, perceived involvement and disconcordance between the preferred and perceived level of involvement.

Reference	**Research design**	**Study population**	**Decision, moment, measurement**	**Preferred level of involvement**	**Perceived level of involvement**	**Disconcordance between preferred and perceived level of involvement**	**Disconcordance per level**
		N=number of participants, age, type of cancer, stage cancer, country	*Type of treatment decision* *Moment of measurement* *Questionnaire*	*N=number of decisions evaluated* *% of patient preferring an active, shared or passive role*	*N=number of decisions evaluated* *% of patient perceiving an active, shared or passive role*		
Aminaie[22]	Cross-sectional study	*N*=328, mean 46yr, breast cancer, stage I-II, Iran	Surgery Post decision CPS & SDM Q9	*N* =328 Active: 1% Shared: 8% Passive: 91%	*N* =328 Active: 8% Shared: 78% Passive: 14%	Not reported	
Atherton[42]	Cross-sectional study	*N*=594, mostly >60yr, various cancer, stage I-IV, US	Treatment Post decision CPS	*N* =594 Active: 35% Shared: 53% Passive: 13%	*N* =594 Active: 33% Shared: 50% Passive: 17%	Disconcordance: 12%	
Berger[23]	Cross-sectional study	*N* =873, mean 59yr, breast cancer, stage I-III, US	Adj. chemotherapy Post decision Modified version CPS	*N* =868 Active: 31% Shared: 51% Passive: 19%	*N* =873 Active: 28% Shared: 41% Passive: 31%	Disconcordance: 53%	
Bieber[51]	RCT	*N* =107, mean 64yr, breast & colon cancer, stage I-IV, Germany	Treatment Post decision CPS &PPS	*N* =96 Active: 19% Shared: 60% Passive: 21%	*N* =96 Active: 25% Shared: 51% Passive: 24%	Disconcordance: 28%	Active: 28% Shared: 26% Passive: 35%
Brown[24]	RCT	*N* =683, mean 54yr/57yr, breast cancer, early stage, Australia, New Zealand, & Switzerland, Germany, Austria	Adjuvant therapy 2w pre & 2w post consult CPS	*N* =683 Active: 24% Shared: 48% Passive: 28%	*N* =683 Patient: 28% Shared: 26% Passive: 46%	Disconcordance: 63%	Active: 69% Shared: 64% Passive: 57%

Burton[25]	Cross-sectional study	*N* =101, included ≥75yr, breast cancer, early stage, UK	Surgery vs. endocrine, Post decision CPS	*N* =93 Active: 39% Shared: 24% Passive: 38%	*N* =93 Active: 41% Shared: 14% Passive: 45%	Disconcordance: 26%	Active: 19% Shared: 59% Passive: 11%
Carey[35]	Cross-sectional study	*N* =268, mean 60yr, haematologic cancer, stage unknown, Australia	Last important decision Post decision Modified version CPS	*N* =235 Active: 25% Shared: 30% Passive: 46%	*N* =235 Active: 20% Shared: 22% Passive: 58%	Disconcordance: 23%	Active: 28% Shared: 44% Passive: 8%
Engelhardt[26]	Multicenter observational study	*N* =101, mean 61yr, breast cancer, stage I-III, The Netherlands	Adj. systemic treatment Post decision CPS & open question	*N* =101 Active: 38% Shared: 40% Passive: 23%	*N* =101 Active: 56% Shared: 9% Passive: 36%	Disconcordance: 51%	Active: 23% Shared: 83% Passive: 41%
Ghoshal[43]	Cross-sectional study	*N* =150, median 47yr, various cancer, advanced stage, India	Treatment Post decision Modified version CPS	*N* =150 Active: 27% Shared: 21% Passive: 53%	*N* =150 Active: 21% Shared: 19% Passive: 59%	Not reported	
Hamelinck[27]	Prospective study	*N*=122, mean 60yr, breast cancer, early stage, The Netherlands	BCS + RT vs. mastectomy Pre & post decision Modified version CPS	*N* =156 Active: 34% Shared: 51% Passive: 15%	*N* =156 Active: 45% Shared: 33% Passive: 22%	Disconcordance: 60%	Active: 47% Shared: 65% Passive: 71%
Herrmann[44]	Cross-sectional study	*N* =423, mean 64yr, various cancer, early & advanced stage, Australia	Last important decision Post decision Modified version CPS	*N* =416 Active: 31% Shared: 39% Passive: 30%	*N* =416 Active: 28% Shared: 36% Passive: 37%	Disconcordance: 20%	Active: 23% Shared: 27% Passive: 7%
Hitz[45]	Cross-sectional study	*N* =480, median 67yr, various cancer, advanced, Switzerland	New line palliative treatment Post decision CPS	*N* =463 Active: 11% Shared: 45% Passive: 44%	*N* =463 Active: 13% Shared: 38% Passive: 50%	Disconcordance: 29%	Active: 42% Shared: 37% Passive: 18%
Hotta[37]	Substudy of RCT	*N* =28, median 67yr, lung cancer, stage IIIb/IV, Japan	Chemotherapy Post decision Pre + Per: CPS	*N* =28 Active: 14% Shared: 61% Passive: 25%	*N* =28 Active: 29% Shared: 46% Passive: 25%	Disconcordance: 32%	Active: 25% Shared: 35% Passive: 29%

Hou[39]	Cross-sectional study	*N* =113, mean 63yr, colorectal cancer, stage unknown, China	Surgery Post decision Modified version CPS	*N* =113 Active: 10% Shared: 35% Passive: 54%	*N* =113 Active: 24% Shared: 18% Passive: 59%	Disconcordance: 28%	Active: 14% Shared: 54% Passive: 14%
Kehl[50]	Cross-sectional study	*N* =5315, included 18+, colon & lung cancer, stage I-IV, US	Surgery, CT, RT Post decision CPS	*N* =8191 decision by 5170 patients Active: 36% Shared: 59% Passive: 6%	*N* =8191 decision by 5170 patients Active: 40% Shared: 47% Passive: 13%	Disconcordance: 40%	Active: 38% Shared: 39% Passive: 52%
Mack[46]	Cross-sectional study	*N* =203, included 15-29yr*, various cancer, stage unknown, US *we only use data 18+	Treatment Post decision CPS	*N* =150 Active: 18% Shared: 63% Passive:19%	*N* =148 Active: 24% Shared: 42% Passive: 34%	Disconcordance: 34%	
Mansfield[47]	Cross-sectional study	*N* =355, mean 61yr, various cancer, stage unknown, Australia	Last important decision Post decision Modified version CPS	*N* =341 Active: 36% Shared: 32% Passive: 32%	*N* =341 Active: 33% Shared: 27% Passive: 40%	Disconcordance: 30%	Active: 25% Shared: 42% Passive: 23%
Moth[38]	Observational cohort	*N* =98, median 64yr, lung cancer, I-IIIB, Australia & New Zealand	Adj. chemo Post decision CPS	*N* =98 Active: 27% Shared: 47% Passive: 27%	*N* =98 Active: 24% Shared: 48% Passive: 28%	Disconcordance: 19%	Active: 27% Shared: 15% Passive: 19%
Moth[48]	Cross-sectional study	*N* =179, median 74yr, various cancer, advanced stage, Australia	Palliative chemotherapy Post decision CPS	*N* =172 Active: 39% Shared: 26% Passive: 35%	*N* =172 Active: 42% Shared: 22% Passive: 36%	Disconcordance: 25%	Active: 18% Shared: 42% Passive: 20%
Nakashima[28]	Cross-sectional study	*N* =104, majority >50yr, breast cancer, stage 0-III, Japan	Treatment Post decision CPS	*N* =104 Active: 18% Shared: 69% Passive: 13%	*N* =104 Active: 27% Shared: 43% Passive: 30%	Disconcordance: 41%	Active: 37% Shared: 46% Passive: 23%

Nguyen[29]	Cross-sectional Study	*N* =238, mean 56yr, breast cancer, stage I-II, France	Treatment Post decision TDM examples	*N* =216 Active: 3% Shared: 30% Passive: 67%	*N* =238 Active: 2% Shared: 10% Passive: 88%	Not reported	
Nicolai[52]	Prospective parallel-group cluster-randomized controlled trial	*N* =71, mean 64yr, breast & colon cancer, stage I-IV, Germany	Treatment Post decision CPS & PPS	*N* =71 Active; 21% Shared; 65% Passive; 14%	*N* =71 Active: 27% Shared: 52% Passive: 21%	Disconcordance: 34%	
Nies[30]	Cross-sectional study	*N* =204, mean 54yr, breast cancer, all stages, Malaysia	Treatment Pre + post decision CPS + PPS	*N* =204 Active: 10% Shared: 48% Passive: 43%	*N* =204 Active: 9% Shared: 52% Passive: 39%	Disconcordance: 9%	Active: 10% Shared: 4% Passive: 14%
Palmer [41]	Cross-sectional study	*N* =181, mean 61yr, prostate cancer, stage unknown, US	Treatment Post decision Modified version CPS	*N* =181 Active: 45% Shared: 39% Passive 16%	*N* =181 Active: 46% Shared: 39% Passive: 15%	Disconcordance: 3%	Active: 1% Shared: 3% Passive: 10%
Sepucha[31]	Pilot intervention study	*N* =32, median 55yr, breast cancer, advanced stage, US	Treatment Post decision Modified version CPS	*N* =32 Active: 7% Shared: 72% Passive: 21%	*N* =24 Active: 13% Shared: 42% Passive: 46%	Disconcordance: 62%	
Seror[32]	Cohort study	*N* =415, mean 39yr, breast cancer, stage 0-III, France	Surgery, chemotherapy, adjuvant endocrine therapy Pre + post start treatment CPS	*N* =945 decision Active: 14% Shared: 27% Passive 59%	*N* =945 decision Active: 2% Shared: 19% Passive: 79%	Disconcordance: 46%	Active: 95% Shared: 77% Passive: 21%
Stacey[49]	Descriptive study	*N* =192, mean 60yr, various cancer and stages, Canada	Chemotherapy, radiotherapy Post decision Modified version CPS	*N* =192 Active: 51% Shared: 33% Passive: 17%	*N* =192 Active: 55% Shared: 35% Passive: 10%	Not reported	

Van Stam[40]	Prospective, multicenter, observational study	*N* =454, mean 67yr, prostate cancer, cT1-cT2, Netherlands	Treatment options: AS, RP, external beam RT and Brachy Pre + post treatment CPS	*N* =454 Active: 89% Passive: 11%	*N* =454 Active: 87% Passive: 13%	Disconcordance: 17%	Active: 11% Shared: - Passive: 67%
Wang[33]	Cross-sectional study	*N* =154, mean 47yr, breast cancer, stage 0-II, Taiwan	Surgery Post decision Self-developed CPS	*N* =154 Active: 18% Shared: 55% Passive: 27%	*N* =154 Active: 12% Shared: 63% Passive: 25%	Disconcordance: 31%	Active: 59% Shared: 20% Passive: 36%
Yamauchi[34]	Cross-sectional study	*N* =650, included 20-69yr, breast cancer, stage 0-IV, Japan	Treatment Post decision CPS	*N* =650 Active: 37% Shared 50% Passive: 13%	*N* =650 Active: 48% Shared: 30% Passive: 22%	Disconcordance: 43%	
Yogaparan[36]	Cross-sectional study	*N* =31, mean 64yr, acute myeloid leukemia, stage unknown, Canada	Treatment Post decision CPS	*N*=31 Active; 16% Shared: 32% Passive: 52%	*N*=31 Active: 23% Shared: 39% Shared: 39%	Not reported	

Table 3. Quality assessment of the individual study, based on a modified version of the Newcastle-Ottawa Scale (NOS).

	Selection				**Outcome**		
	1 Clear description sample	*2 Representativeness sample*	*3 Sample size*	*4 Non responders*	*5 Clear variables*	*6 Outcome assessment*	*Total stars*
Aminaie	②	⓪	⓪	⓪	②	②	❻
Atherton	②	①	①	⓪	②	②	❽
Berger	②	①	⓪	⓪	②	②	❼
Bieber	②	⓪	⓪	⓪	②	②	❻
Brown	②	⓪	⓪	⓪	②	②	❻
Burton	②	⓪	⓪	⓪	②	②	❻
Carey	①	①	⓪	⓪	②	②	❻
Engelhardt	②	⓪	①	⓪	②	①	❻
Ghoshal	①	⓪	①	⓪	①	②	❺
Hamelinck	②	⓪	⓪	⓪	②	②	❻
Herrmann	②	⓪	⓪	①	②	②	❼
Hitz	②	①	①	⓪	②	②	❽
Hotta	①	⓪	⓪	⓪	②	②	❺
Hou	①	⓪	⓪	⓪	①	②	❹
Kehl	②	①	⓪	⓪	②	②	❼
Mack	①	⓪	①	⓪	②	②	❻
Mansfield	①	⓪	①	①	②	②	❼
Moth 16	②	①	⓪	⓪	②	②	❼
Moth 19	②	①	⓪	⓪	②	②	❼
Nakashima	②	⓪	⓪	⓪	②	②	❻
Nguyen	②	⓪	⓪	⓪	①	①	❹
Nicolai	②	⓪	⓪	⓪	②	②	❻
Nies	②	①	⓪	⓪	②	②	❼
Palmer	②	①	⓪	⓪	②	②	❼
Sepucha	②	⓪	⓪	⓪	②	②	❻
Seror	②	①	⓪	⓪	②	②	❼
Stacey	①	⓪	⓪	⓪	②	②	❺
van Stam	②	①	⓪	①	②	②	❽
Wang	②	⓪	⓪	⓪	②	①	❺
Yamauchi	②	⓪	⓪	⓪	②	②	❻
Yogaparan	①	⓪	⓪	⓪	②	②	❺

Number of stars for ‘selection of participants’ and ‘definition and assessment of the outcome’. [1]Maximum number of stars for selection = 5; [2]Maximum number of stars for outcome = 4. Number of stars 0-3: poor quality (red), 4-6: fair quality (yellow), 7-9: good quality (green) (note that this is based on an adapted scoring from the NOS).

Preferred level of involvement

The median percentage of patients preferring a shared role for all studies was 46%, 25% for an active role and 27% for a passive role (Table 4 and Appendix C). Subgroup analyses showed minor differences (Table 4). In both studies including haematologic cancer patients, the percentage of patients with a preference for a passive role was higher than for an active or shared role. For prostate cancer patients, the percentage of patients preferring active involvement was higher than for shared and passive involvement. The median percentage of patients preferring an active role was lower for Asian cancer patients (16%) than for Western cancer patients (31%). Patients with advanced cancer less often preferred an active role as compared to early stage cancer patients (median 14%, and 26%, respectively).

Perceived level of involvement

The median percentage of patients perceiving a shared role for all studies was 39%, 27% for an active role and 34% for a passive role (Table 4 and Appendix C). Subgroup analyses showed minor differences (Table 4). For haematologic cancer patients, both studies showed that the percentage of patients perceiving a passive role was higher than those perceiving an active or shared role. In addition, the median percentage of cancer patients perceiving a passive role is somewhat higher for Western patients (36%) as compared to Asians (28%). Also, advanced stage cancer patients perceived a passive role more often when compared to early stage cancer patients (median 46% versus 31%).

Concordance between the preferred and perceived level of involvement

Combining all studies, the median percentage of overall concordance between patients' preferred and perceived level of involvement in decision making for cancer treatment was 70%. Disconcordance was highest for patients preferring a shared role (median 42%), as compared to patients preferring an active (median 26%) or a passive role (median 22%) (Table 4). In subgroup analyses, the overall disconcordance levels were the highest for studies in patients with early stage (44%) and breast cancer (46%).

Table 4. The median of all studies for the percentage preferred and perceived active, shared and passive involvement, the disconcordance and the disconcordance per level presented for all studies and for subgroups.

		Active		**Shared**		**Passive**		**Disconcordance**			
		Preferred	**Perceived**	**Preferred**	**Perceived**	**Preferred**	**Perceived**	**Overall**	**Active**	**Shared**	**Passive**
N=number of studies	*N=number of participants & decisions*	*Median (IQR)*	*Median (IQR)*	*Median (IQR)*	*Median (IQR)*	*Median (IQR)*	*Median (IQR)*	*Median (IQR)*	*Median (IQR)*	*Median (IQR)*	*Median (IQR)*
All (*N*=31)	*N*=13247 *N*=16537	25 (14-36)	27 (20-41)	46 (32-56)	39 (22-47)	27 (16-44)	34 (22-46)	31 (22-44)	26 (18-41)	42 (26-59)	22 (14-40)
Breast (*N* =13)	*N*=4005 *N*=4561	18 (9-36)	27 (9-43)	48 (29-53)	33 (17-48)	27 (17-51)	36 (24-46)	46 (31-60)	42 (20-67)	62 (27-74)	30 (16-53)
Lung (*N* =2)	*N*=126 *N*=126	14 27	29 24	61 47	46 48	25 27	25 28	32 19	25 27	35 15	29 19
Haematologic (*N* =2)	*N*=299 *N*=266	25 16	20 23	30 32	22 39	46 52	58 39	23	28	44	8
Colorectal (*N* =1)	*N*=113 *N*=113	10	24	35	18	54	59	28	14	54	14
Prostate (*N* =2)	*N*=635 *N*=635	89 45	87 39	- 16	- 46	11 39	13 15	17 3	11 1	- 3	67 10
Western (*N* =23)	*N*=11516 *N*=14806	31 (18-38)	28 (23-42)	43 (32-55)	37 (22-43)	23 (16-38)	36 (21-46)	30 (21-50)	27 (19-42)	42 (27-64)	21 (11-52)
Asian (*N* =8)	*N*=1731 *N*=1731	16 (10-25)	23 (10-29)	49 (25-60)	45 (22-60)	35 (16-54)	28 (23-54)	32 (23-42)	25 (12-48)	35 (12-50)	23 (14-33)
Early (*N* =12)	*N*=3671 *N*=3907	26 (15-37)	28 (9-44)	47 (27-51)	33 (14-48)	27 (16-54)	31 (23-46)	44 (24-55)	37 (21-64)	62 (27-74)	36 (20-62)
Advanced (*N* =5)	*N*=869 *N*=845	14 (9-33)	21 (13-36)	45 (24-67)	38 (21-44)	35 (23-49)	46 (31-55)	31 (26-55)	25	37	20

Discussion

This systematic review presents an overview of studies exploring cancer patients' preferred and perceived level of involvement in decision making for cancer treatment and the (dis-) concordance between these levels. Pooled results demonstrate that patients' preferences for and perceptions of their decision role vary, but a majority of the patients preferred and perceived a shared role in decision making. About one in three patients perceived a decision role other than they preferred. Although the majority of cancer patients preferred a shared role in decision making, half of these patients perceived either an active or passive role.

In line with the previous systematic review, we found that patients' preferences and perceptions for involvement in decision making vary and that disconcordance between preference and perception occurs frequently.[10] Tariman et al. showed that the percentage of patients with prostate and breast cancer preferring a shared or active role is higher than for other cancer types (colorectal, lung, gynaecological).[10] Ten years later this is still the case for breast and prostate cancer patients. For lung cancer, the limited number of new studies suggests a minor shift from both preference for and perception of a passive role, to a more active role. In addition, for breast cancer patients, it seems that the percentage of patients preferring and perceiving passive involvement has decreased. Also, for prostate cancer patients, the percentage of patients perceiving a passive role is now somewhat lower. This is likely to be due to the increased attention for SDM in this field, which together with the rising number of treatment options available with comparable efficacy, urges for more patient involvement in individual treatment decisions.[53-54]

In summary, compared to the findings of Tariman et al, our review suggests that little progress has been made in actively involving most cancer patients in treatment decision making in the last decade. Furthermore, although Tariman et al. recommended to perform studies including patients with cancers other than breast cancer and to use a longitudinal design to measure patients' level of involvement, the majority of studies in our review included breast cancer patients and used a cross-sectional design.[10] Hence, still longitudinal exploration of patients' preferences and perceptions of involvement is needed, as preferences for involvement may change over time.[55] Also, studies should include more patients diagnosed with cancer other than breast cancer.

Our review highlights that even though most patients prefer shared or active involvement, some prefer a passive role more often. Haematologic cancer patients seem to be more likely to prefer and perceive a passive role in treatment decision making as compared to patients with other types of cancer. Ernst et al. suggest that for haematologic cancer this might be due to the complex treatment plan and the perception of the physician as the expert, both impeding patient involvement.[56]

Furthermore, in our results, the majority of the Asian cancer patients preferred and perceived a shared role. This is in contrast with the results of a review by Yilmaz et al., which concluded that most studies including Asian cancer patients (living in Western countries) reported that these patients preferred a passive role in decision making.[57] The difference in cultures between Asian countries might explain this difference, since our review included more Asian patients from Japan, whereas the review of Yilmaz et al. included mostly patients of Chinese origin.[57]

Although it seems that, in the past decade, some progress has been made in actively involving cancer patients in treatment decisions, the suboptimal concordance between patients' preferred and perceived decision role shows that it remains challenging to involve patients to the level of their preference. Several potential explanations for the disconcordance between patients' preferred and perceived level of involvement are described in literature. Insufficient creation of awareness among cancer patients that they do have choice[58] and inadequate exploration of patients' values and preferences by physicians are mentioned as barriers for involvement in SDM.[59] Creating awareness of choice is difficult, since it has been reported that even when a choice in treatment is offered, cancer patients do not always experience having a treatment choice.[60] It is also suggested that physicians incorrectly estimate to what extent their cancer patients want to be involved in treatment decision making, without explicitly asking them.[61] This is further complicated by potential differences in the perception of the extent of involvement between cancer patients and physicians.[37] External factors might also influence the level of involvement. Keating et al. showed that the more evidence based a specific treatment was, the more likely it was that decisions were shared.[62] Also, lack of time during consultations is mentioned by physicians as a barrier for patient involvement.[63-64] All these internal and external factors could lead to the involvement of patients in decision making for cancer treatment at a level other than preferred.

This review has its strengths and limitations. A strength of this review is the large number of studies included and the completeness of the data we retrieved from the studies. A limitation of this review, similar to the review of Tariman et al., is that the majority of the studies in our review included breast cancer patients.[10] Therefore, the overall trends we show in our data might not be generalizable to other cancer diagnosis.

That said, our findings highlight the variety in preferences for involvement in treatment decision making and challenges of attempting to match the preferred with the perceived level of involvement. Consequently, the main implication for practice is that more actively tailoring of patient involvement to individual preference is needed. This active exploration of preference should be performed at an early stage of the treatment decision process, to enable patients to take their preferred roles in shaping their personalized cancer care. Awareness of this need should be raised among physicians. The implementation of tools, such as the three question model[65], could support physicians in exploring patients' preferences and enable them to meet these preferences for involvement.

Conclusion

Patients' preferences for involvement in cancer treatment decision making vary, but the majority of patients prefers to be involved. A significant number of patients perceive a decisional role other than preferred, especially when patients prefer a shared role. Physicians should be made aware of the importance of exploring patients' preferences for involvement in decision making to truly deliver personalized cancer care.

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Appendix A

Search

PubMed

#1 – decision making

Decision making[MeSH Terms] OR Clinical decision-making[MeSH Terms] OR decision making, shared[MeSH Terms] OR decision*[Title/Abstract] OR choice*[Title/Abstract]

#2 – patient participation

patient participation[MeSH Terms] OR patient preference[MeSH Terms] OR role[MeSH Terms] OR prefer*[Title/Abstract] OR particip*[Title/Abstract] OR role*[Title/Abstract] OR involve*[Title/Abstract]

#3 - oncology

oncolog*[Title/Abstract] OR cancer*[Title/Abstract] OR malignan*[Title/Abstract] OR carcinoma[Title/Abstract] OR tumor[Title/Abstract] OR tumors[Title/Abstract] OR tumour[Title/Abstract] OR tumours[Title/Abstract] OR “medical oncology”[MeSH Terms] OR neoplasms[MeSH Terms]

#4 - perception

perception[MeSH Terms] OR perception*[Title/Abstract] OR perceive*[Title/Abstract] OR actual[Title/Abstract] OR experience*[Title/Abstract]

#5 - treatment

“General surgery”[MeSH Terms] OR Therapy[MeSH Subheading] OR therapeutics[MeSH Terms] OR therap*[Title/Abstract] OR treatment*[Title/Abstract] OR “palliative care”[Title/Abstract]

Combine search terms #1-#5, used filter: Publication date from 2009/01/01 to 2020/01/01

PsychInfo

#1 – decision making

exp Decision Making/ or decision*.ab,ti. or choice*.ab,ti.

#2 – patient participation

exp Preferences/ or exp Roles/ or prefer*.ab,ti. or particip*.ab,ti. or role*.ab,ti. or involve*.ab,ti.

#3 – oncology

exp Neoplasms/ or exp Oncology/ or oncolog*.ab,ti. or cancer*.ab,ti. or malignan*.ab,ti. or carcinoma.ab,ti. or tumor.ab,ti. or tumour.ab,ti. or tumors.ab,ti. or tumours.ab,ti.

#4 – perception

exp Perception/ or perception*.ab,ti. or perceive*.ab,ti. or actual.ab,ti. or experience*.ab,ti.

#5 – treatment

exp treatment/ or exp Surgery/ or exp Radiation Therapy/ or exp Radiation/ or exp Immunotherapy/ or exp Drug Therapy/ or exp Palliative Care/ or therap*.ab,ti. or treatment*.ab,ti. or palliative care.ab,ti.

Combine search terms #1-#5

Embase

#1 – decision making

'decision making'/exp OR 'clinical decision making'/exp OR decision*:ab,ti OR choice*:ab,ti

#2 – patient participation

'patient participation'/exp OR 'patient preference'/exp OR prefer*:ab,ti OR particip*:ab,ti OR role*:ab,ti OR involve*:ab,ti

#3 – oncology

oncolog*:ab,ti OR cancer*:ab,ti OR malignan*:ab,ti OR carcinoma:ab,ti OR tumor:ab,ti OR tumors:ab,ti OR tumour:ab,ti OR tumours:ab,ti OR 'neoplasm'/exp OR 'malignant neoplasm'/exp OR 'oncology'/exp OR 'carcinoma'/exp

#4 – perception

'perception'/exp OR perception*:ab,ti OR perceive*:ab,ti OR actual:ab,ti OR experience*:ab,ti

#5 – treatment

'therapy'/exp OR 'surgery'/exp OR therap*:ab,ti OR treatment*:ab,ti OR 'palliative care':ab,ti

Combine search terms #1-#5

CINAHL

#1 – decision making

(MH "Decision Making+") OR TI (decision# OR choice#) OR AB (decision# OR choice#)

#2 – patient participation

(MH "Patient preference+") OR (MH "Role+") OR TI (prefer# OR particip# OR role# OR involve#) OR AB (prefer# OR particip# OR role# OR involve#)

#3 – oncology

(MH "Neoplasms+") OR (MH "oncology+") OR TI (oncolog# OR cancer# OR malignan# OR carcinoma OR tumor OR tumour OR tumors OR tumours) OR AB (oncolog# OR cancer# OR malignan# OR carcinoma OR tumor OR tumour OR tumors OR tumours)

#4 – perception

(MH "Perception+") OR TI (perception# OR perceive# OR actual OR experience#) OR AB (perception# OR perceive# OR actual OR experience#)

#5 – treatment

(MH "Surgery, Operative+") OR (MH "therapeutics+") OR TI (therap# OR treatment# OR palliative care) OR AB (therap# OR treatment# OR palliative care)

Combine search terms #1-#5

Appendix B

Modified version New-Castle Ottawa scale for cross-sectional studies.

Selection of participants – max 5 stars

1. Clear description of the sample, including: cancer type, stage cancer, culture, age, decision setting

a) Clear description**

b) Somewhat clear description*

c) No clear description of the sample

2. Representativeness of the sample:

a) Truly representative of the average in the target population. * (all subjects or random sampling)

b) Somewhat representative of the average in the target population. * (non-random sampling)

c) Selected group of users.

d) No description of the sampling strategy.

3. Sample size:

a) Justified and satisfactory. *

b) Not justified or not reported.

4. Non-respondents:

a) Comparability between respondents and non-respondents characteristics is established, and the response rate is satisfactory. *

b) The response rate is unsatisfactory, and/ or the comparability between respondents and non-respondents is unsatisfactory.

c) No description of the response rate, and/ or the characteristics of the responders and the non-responders.

Definition and assessment of the outcome – max 4 stars

5. Clear variables: Clear description of the timing of the measurement preferred and perceived level of involvement

a) Both variables clearly defined including time period for measurement**

b) One or other variable clearly defined including time period for measurement *

c) Neither variable clearly defined including time period for measurement

6. Assessment of the outcome:

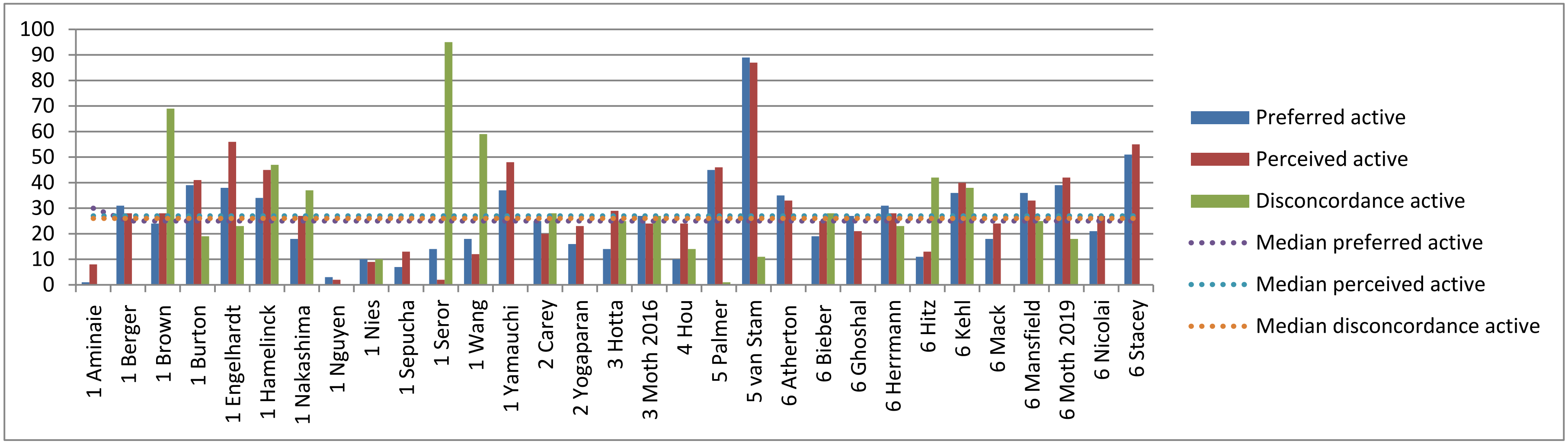
a) Validated measurement tool. **

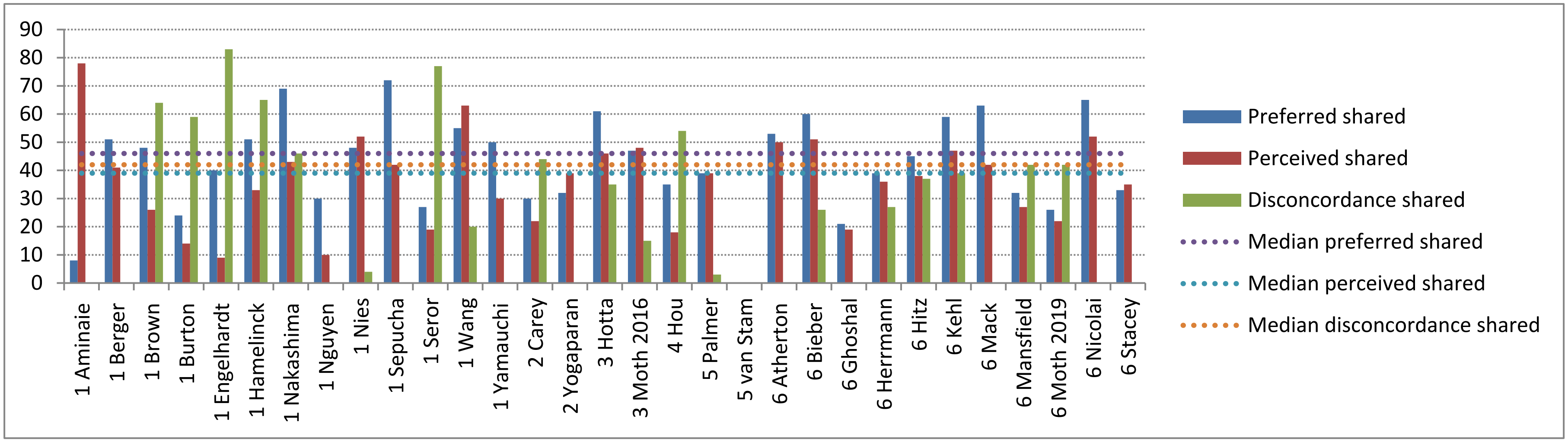
b) Non-validated measurement tool, but the tool is available or described.*

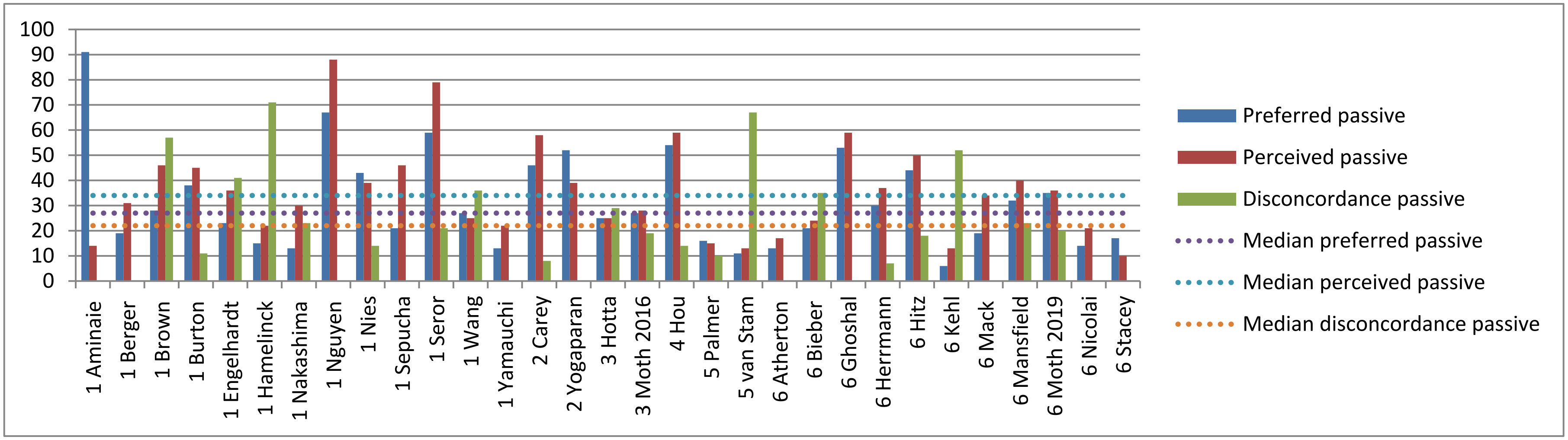
c) No description of the measurement tool.

Appendix C

The percentage of patients preferring and perceiving an active, shared and passive role and the disconcordance presented for all individual studies. The dotted lines present the median of all studies for the percentage of the preferred, perceived and disconcordance. Studies are categorized for type of cancer: 1=breast cancer; 2=haematologic cancer; 3=lung cancer; 4=(colo)rectal cancer; 5=prostate cancer; 6=various cancer.






100
90
80
70
60
50
40
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10
0
1 Aminaie
1 Berger
1 Brown
1 Burton
1 Engelhardt
1 Hamelinck
1 Nakashima
1 Nguyen
1 Nies
1 Sepucha
1 Seror
1 Wang
1 Yamauchi
2 Carey
2 Yogaparan
3 Hotta
3 Moth 2016
4 Hou
5 Palmer
5 van Stam
6 Atherton
6 Bieber
6 Ghoshal
6 Herrmann
6 Hitz
6 Kehl
6 Mack
6 Mansfield
6 Moth 2019
6 Nicolai
6 Stacey
Preferred passive
Perceived passive
Disconcordance passive
Median preferred passive
Median perceived passive
Median disconcordance passive

Chapter 3

GP involvement after a cancer diagnosis; patients' call to improve decision support

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Abstract

Background

Shared decision making (SDM) is considered important to realise personalised cancer care. Increased general practitioner (GP) involvement after a diagnosis is advocated to improve SDM.

Aim

To explore if cancer patients are in need of GP involvement in cancer care in general and in SDM, and whether GP involvement occurred.

Design and Setting

An online national survey distributed by the Dutch Federation of Cancer Patient Organisation (NFK) in May 2019.

Methods

The survey was sent to (former) cancer patients. Topics included GP involvement in cancer care in general and in SDM. Descriptive statistics and quotes were used.

Results

Among 4,763 (former) cancer patients, 59% (N=2,804) expressed a need for GP involvement in cancer care. Of these patients, 79% (N=2,193) experienced GP involvement. Regarding GP involvement in SDM, 82% of the patients (N=3,724) expressed that the GP should “listen to patient’s worries and considerations”, 69% (N=3,130) to “check patient’s understanding of information”, 66% (N=3,006) to “discuss patient’s priorities in life and the consequences of treatment options for these priorities”, and 67% (N=3,045) to “create awareness of the patient’s role in the decision making”. This happened in 47%, 17%, 15% and 10% of these patients, respectively.

Conclusion

The majority of (former) cancer patients expressed a need for active GP involvement in cancer care. GP support in the fundamental SDM steps is presently insufficient. Therefore, GPs should be made aware of these needs and enabled to support their cancer patients in SDM.

Acknowledgements

The authors are thankful to all participants of this study.

How this fits in

Little is known about cancer patients' needs for GP involvement in cancer care and in shared decision making (SDM), and to what extent GP involvement occurs. This study showed that the majority of (former) cancer patients has a need for GP involvement in cancer care and in SDM. However, GP involvement in SDM was infrequently experienced. Therefore, GPs should be made aware of these needs and enabled to support their cancer patients to make personalised cancer treatment decisions.

Introduction

Cancer treatment decisions become more complex, due to the increasing number of treatment options. This enables a more personalised approach.[1] Incorporating personal preferences in treatment decisions requires shared decision making (SDM). SDM aims at establishing a treatment decision that optimally matches a patient's personal preferences and expectations.[2] An effective SDM process consists of four steps: 1) awareness of choice, 2) explanation of treatment options, 3) time for deliberation, and 4) making an informed decision.[2]

Unfortunately, in the present hospital oriented cancer care pathway, essential steps for successful SDM are usually insufficiently supported. First, cancer patients are often unaware of their important role in choosing the 'best fitting' treatment.[3] Second, medical information, including treatment options, is often not understood by cancer patients.[4] Third, time for deliberation is often limited, since the short in-hospital pathway between diagnosis and treatment choice generally does not facilitate reflection. This leaves little room to consider treatment options in the light of patient's personal preferences and expectations.[3, 5-6]

General practitioners (GP) usually have longstanding relationships with their patients. Consequently, for many, the GP is the 'trusted health care professional', with longitudinal knowledge of their patients' medical and personal history.[1, 7] Hence, the GP is considered to be in the ideal position to guide the patient through the different steps of the SDM process.[1, 6] Cancer patients and GPs support this extended role for the GP in cancer treatment decision-making, e.g., through determining patient's preferences, discussing treatment options and explaining medical information.[8-10]

Positive effects of increased GP involvement after a cancer diagnosis have been described previously. Wallner et al. showed that patient's experience of GP engagement, i.e., how informed the patient felt the GP was about the diagnosis, was associated with higher satisfaction of treatment decisions in cancer.[11] Wieldraaijer et al. showed that a consultation with the GP between diagnosis and start of treatment is beneficial for patient's feelings of comfort and satisfaction.[12] We demonstrated earlier that a cancer related GP consultation before treatment decision may improve the SDM process of palliatively treated cancer patients according to patients, GPs and treating physicians.[13]

Despite this broadly shared call for more GP involvement in the process of making cancer treatment decisions, little is known about the cancer patients' perspective. Therefore, we aimed to explore cancer patients' needs for GP involvement after a cancer diagnosis in general and in SDM, and whether this GP involvement occurred.

Methods

Design

An online national survey was developed and distributed among (former) cancer patients in the Netherlands in May 2019 by the Dutch Federation of Cancer Patient Organisations (in Dutch: NFK).

Study population

NFK is an umbrella organisation of 19 cancer patient organisations. These cancer patient organisations together represent approximately 35,000 (former) cancer patients. The survey was distributed in several ways. First, the survey was dispersed to the affiliated cancer patient organisations, which represent adult cancer patients with a large variety in diagnoses. These cancer patient organisations were asked to distribute the survey among their members. This could either be directly to all members or indirectly through their newsletter. Second, a web link to the survey was distributed through social media accounts of NFK (Facebook, LinkedIn, Twitter and Instagram), via their website and via other relevant partner organisations (such as The Dutch Cancer Society and the website kanker.nl). Finally, a panel of (former) cancer patients, who were not a member of one of the cancer patient organisations, was sent an invitation to participate in the survey. These patients voluntarily registered to receive invitations for NFK surveys and were not selected for this specific survey.

Online survey

The online survey was developed by NFK, in cooperation with experts in the fields of cancer, primary care and SDM, including patients, clinicians, researchers and policy makers. The survey consisted of two parts; one part focussing on the role of the GP and the other on the role of the specialised oncology nurse. For this study we only used data of the GP related questions.

The survey started with a selection question, only participants who responded yes to the question 'Do, or did you have cancer?' were able to proceed with filling in the questionnaire. Then, eight general questions about patient- and disease characteristics followed. Hereafter, ten questions addressing the patient's personal needs for GP involvement in cancer care were posed. These questions covered the topics: 1) the need for GP involvement in cancer care at any time after diagnosis, 2) whether this GP involvement occurred, 3) the need to have SDM topics addressed in a GP consultation and 4) whether these topics were actually addressed. Finally, the survey assessed 5) the initiator of involvement of the GP in cancer care and 6) satisfaction with GP involvement in cancer care (see Supplementary document 1 for the survey).

GP involvement in cancer care was defined as: "Any type of long or short contact with the GP about the diagnosis, treatment and/or its consequences. This could either be via telephone, an appointment at the GP's office or a home-visit." The SDM topics included: "The GP should: (1) "Listen to my worries and considerations about the diagnosis, treatment and its consequences", (2) "Check if I understand the information about my diagnosis, treatment and its consequences", (3) "Discuss what I think is important in my life and the consequences of treatment options for these priorities" and (4) "Explain to me the importance of my own opinion when making a treatment decision."

The format of the questions was either closed (numeric, multiple choice) or open-ended. Needs and the occurrence of GP involvement were assessed with multiple choice questions and open-ended questions for clarification. Satisfaction with GP involvement in cancer care was scored on a 10-point number rating scale ranging from 1 (very unsatisfied) to 10 (very satisfied). The estimated time to complete the questionnaire was approximately 5-10 minutes. The data were collected with the online tool "Survey Monkey." Respondents participated anonymously in the survey. The survey was open for response for two weeks. Respondents could choose to answer only part of the questions. Only if the general questions and the question 'Did you have a need for contact with your GP about your cancer diagnosis, the treatment and/or its consequences?' was answered with 'yes', 'no' or 'don't know/n.a.', the survey was used in the analysis.

Analysis

Descriptive analyses of the closed questions were performed for the total population and for subgroups of the following characteristics: sex, age, education, type of cancer, cancer stage and time since last treatment. Statistical testing was not performed, since with the current number of patients small often not (clinically) relevant differences would already be statistically significant. Categorical variables are presented as numbers and percentages. Continuous variables are presented, depending on whether or not normally distributed, with means and standard deviations (SD) or medians and interquartile ranges (IQR). All analyses were performed with IBM SPSS Statistics version 25. Relevant quotes from the open questions were used to illustrate the results.

Results

Patient characteristics

The survey was completed by 4,763 (former) cancer patients. The mean age of respondents was 62 years (SD±12), 56% were female and 48% of the respondents had a high education level (Table 1). The majority of the respondents were diagnosed with either breast cancer (26%), haematological cancers (18%) or colorectal cancer (16%). The median time since the last received cancer treatment was 2 years (IQR 1-6) and 46% reported to be cured.

Table 1. Baseline characteristics of respondents.

	Total n=4763	
	n	*(%)*
Female	2686	(56)
Age; mean (±SD)	62	(±12)
Education		
High	2276	(48)
Middle	1908	(40)
Low	464	(10)
Other	61	(1)
Missing	54	(1)
Diagnosis		
Breast cancer	1231	(26)
Haematological cancers	874	(18)
Colorectal cancer	787	(16)
Prostate cancer	569	(12)
Bladder cancer	270	(6)
Gynaecologic cancer	179	(4)
Lung cancer	153	(3)
Melanoma	125	(3)
Esophageal cancer	105	(2)
Other	470	(10)
Years since last received cancer treatment; median (IQR)	2	(1-6)
Patients reported cancer stage		
Cured	2166	(46)
Will probably be cured	901	(19)
Will probably not be cured	1256	(26)
Don't know/n.a.	440	(9)

N.a. = not applicable, SD = standard deviation, IQR = interquartile range. Education is categorized as, high (university or higher professional education), middle (secondary education) and low (primary education or no education).

GP involvement in general

Of all respondents, 59% (N=2,804) expressed a need for GP involvement in cancer care any time after diagnosis (Table 2). GP involvement in cancer care was experienced by 79% (N=2,193) of these respondents. A relatively high need for GP involvement was reported by women (women: 64%; men: 52%). GP involvement occurred more often in men (82%) than in women (77%). A relatively high need for GP involvement was reported by patients with lung, esophageal and gynaecologic cancer (68-69%), versus other cancers (47-64%). A relatively small proportion of (former) patients with breast and gynaecologic cancer experienced GP involvement (74-76%), compared to other cancers (78-88%). Respondents who indicated “will probably not be cured” reported relatively high need of GP involvement (66%) compared to those who indicated to be “cured” (55%). The latter group reported less often reported GP involvement, resp. 75% vs. 85%. Quotes in Supplementary Box 1 illustrate the need for and lack of experiences with GP involvement in cancer care.

GP involvement in SDM

Table 3 shows the needs to have SDM topics addressed in a GP consultation and whether these topics were actually addressed. Eighty-two percent (N=3,724) of the respondents expressed that their GP should listen to their worries and considerations about the diagnosis, treatment and its consequences. This actually happened in 47% (N=1,744) of these cases. The majority of the respondents expressed that the GP should: “check understanding of information” 69% (N=3,310), “discuss patient’s priorities in life and the consequences of treatment options for these priorities” 66% (N=3,006), and “explain importance of patient’s opinion in decision” 67% (N=3,045). These topics were addressed in respectively 17% (N=542), 15% (N=461) and 10% (N=294) of these cases.

In all subgroups, the need for GP involvement in the SDM process was high. However, this GP involvement in SDM was infrequently experienced by respondents, especially by respondents older than 65, by those with low education, by those with breast, bladder, gynaecologic, haematological cancers, or colon cancer and by the “cured” group of respondents. Quotes that illustrate the need for GP involvement in SDM are presented in Supplementary Box 1.

Initiator & satisfaction

Among those who reported that their GP was involved in cancer care, this was initiated by the patient in 52% (N=1650), by the GP in 31% (N=987), by family and friends in 4% (N=116) and unknown in 13%

(N=421). In case of GP involvement, satisfaction with GP involvement in cancer care was evaluated with a mean of 7.4 (±2.4). This involvement was rated higher if the GP was the initiator (8.0±2.0), instead of the patient (7.0±2.4). This is illustrated by the final quote in Supplementary Box 1.

Table 2. Need for GP involvement in cancer care and whether GP involvement occurred. Presented for total and stratified per subgroup.

Need for GP involvement in cancer care any time after diagnosis					
		Need (yes)		*Contact occurred?(yes)**	
	Total	*Of total*		*Of need*	
	n	*N*	*%*	*n*	*%*
All respondents	4763	2804	(59)	2193	(79)
Male	2077	1073	(52)	873	(82)
Female	2686	1731	(64)	1320	(77)
Aged <65	2537	1577	(62)	1245	(80)
Aged ≥65	2226	1227	(55)	948	(78)
Low education	464	254	(55)	188	(75)
Middle education	1908	1134	(59)	849	(76)
High education	2276	1351	(59)	1105	(82)
Haematological cancers	874	478	(55)	380	(80)
Colorectal cancer	787	402	(51)	307	(78)
Bladder cancer	270	128	(47)	105	(83)
Gynaecologic cancer	179	121	(68)	91	(76)
Melanoma cancer	125	75	(60)	64	(85)
Breast cancer	1231	791	(64)	582	(74)
Prostate cancer	569	323	(57)	276	(86)
Lung cancer	153	105	(69)	83	(81)
Esophageal cancer	105	72	(69)	63	(88)
Last treatment ≤ 2years ago	2404	1462	(61)	1215	(84)
Last treatment ≥ 3 years ago	2359	1342	(57)	978	(74)
Cured	2166	1180	(55)	875	(75)
Will probably be cured	901	535	(59)	413	(78)
Will probably not be cured	1256	825	(66)	699	(85)

GP = general practitioner. *Percentage 'Contact occurred? (yes)' is calculated for those who responded to have a need for GP involvement and filled in the question 'Contact occurred?' Education is categorized as, high (university or higher professional education), middle (secondary education) and low (primary education or no education).

Table 3. Needs to have important topics in the shared decision making process for cancer treatment addressed in a GP consultation and whether this topic was addressed.

My GP should….		Listen to my worries and considerations about the diagnosis, treatment and its consequences.				Check if I understand the information about my diagnosis, treatment and its consequences.				Discuss what I think is important in my life and the consequences of treatment options for these priorities.				Explain to me the importance of my own opinion when making a treatment decision.			
		Need (yes)		*Topic addressed? (yes)**		*Need (yes)*		*Topic addressed? (yes)**		*Need (yes)*		*Topic addressed? (yes)**		*Need (yes)*		*Topic addressed? (yes)**	
	Total	*Of total*		*Of need*		*Of total*		*Of need*		*Of total*		*Of need*		*Of total*		*Of need*	
	n	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
All respondents	4526	3724	(82)	1744	(47)	3130	(69)	542	(17)	3006	(66)	461	(15)	3045	(67)	294	(10)
Male	1966	1561	(79)	755	(48)	1349	(69)	236	(18)	1274	(65)	217	(17)	1297	(66)	128	(10)
Female	2560	2163	(85)	989	(46)	1781	(70)	306	(17)	1732	(68)	244	(14)	1748	(68)	166	(10)
Aged <65	2434	2059	(85)	1008	(49)	1685	(69)	326	(19)	1639	(67)	257	(16)	1665	(68)	160	(10)
Aged ≥65	2092	1665	(80)	736	(44)	1445	(69)	216	(15)	1376	(65)	204	(15)	1380	(66)	134	(10)
Low education	422	326	(77)	127	(39)	308	(73)	51	(17)	296	(70)	33	(11)	296	(70)	32	(11)
Middle education	1810	1495	(83)	644	(43)	1305	(72)	221	(17)	1237	(68)	183	(15)	1239	(69)	119	(10)
High education	2185	1812	(83)	930	(51)	1439	(66)	260	(18)	1394	(64)	238	(17)	1435	(66)	138	(10)
Haematological cancers	832	680	(82)	311	(46)	530	(64)	90	(17)	512	(62)	75	(15)	507	(61)	38	(8)
Colorectal cancer	732	568	(78)	254	(45)	517	(71)	94	(18)	469	(64)	65	(14)	483	(66)	42	(9)
Bladder cancer	256	201	(79)	83	(41)	176	(69)	26	(15)	176	(69)	14	(8)	176	(69)	10	(6)
Gynaecologic cancer	170	141	(83)	66	(47)	119	(70)	16	(13)	119	(70)	17	(14)	127	(75)	11	(9)
Melanoma cancer	119	97	(82)	51	(53)	87	(73)	13	(15)	79	(66)	18	(23)	83	(70)	11	(13)
Breast cancer	1178	1002	(85)	442	(44)	818	(69)	143	(18)	801	(68)	104	(13)	804	(68)	76	(10)
Prostate cancer	543	447	(82)	229	(51)	384	(71)	70	(18)	358	(66)	67	(19)	377	(69)	52	(14)
Lung cancer	145	124	(86)	64	(52)	104	(72)	20	(19)	105	(72)	26	(25)	95	(66)	12	(13)
Esophageal cancer	104	84	(81)	54	(64)	76	(73)	15	(20)	75	(72)	19	(25)	78	(75)	12	(15)
Last treatment ≤ 2years ago	2307	1897	(82)	995	(53)	1532	(66)	289	(19)	1510	(66)	289	(19)	1497	(65)	171	(11)
Last treatment ≥ 3 years ago	2219	1827	(82)	749	(41)	1598	(72)	253	(16)	1496	(67)	172	(12)	1548	(70)	123	(8)
Cured	2035	1658	(82)	711	(43)	1438	(71)	228	(16)	1340	(66)	147	(11)	1398	(69)	99	(7)
Will probably be cured	867	708	(82)	329	(47)	606	(70)	116	(19)	570	(66)	81	(14)	598	(69)	52	(9)
Will probably not be cured	1208	1017	(84)	553	(54)	806	(67)	142	(18)	818	(68)	200	(24)	776	(64)	115	(15)

GP = general practitioner. *Percentage 'Topic addressed? (yes)' is calculated for those who responded to have a need for GP involvement and filled in the question 'Topic addressed?' Education is categorized as, high (university or higher professional education), middle (secondary education) and low (primary education or no education).

Box S1. Illustrative quotes of respondents.

Topics	Quotes of respondents
Need for GP involvement in cancer care	"Because you are so busy with life-threatening things, you hardly understand your own feelings. My partner and I needed a lot of extra care from our GP.” “Your GP is closer to you than a specialist and is often easier to reach.” "It's always nice to talk to the GP, so she's up to date and can think along."
Reflections on lack of GP involvement	“I never thought of contacting my general practitioner. In hindsight, it might have helped me.” “I had a need, but he didn't even contact me after the diagnosis when he himself had referred me to the hospital when I felt a lump.”
GP’s SDM support	"I was facing the decision to take hormones for five years. The decision was with me, but I did not know what to do. That’s when I went to my GP for a consultation." "I think the specific information should come from the treating physician. The GP can check if everything is clear and stress that the patient's opinion is important." "A GP is the right person to talk to you as patient about your expectations, possibilities, etc."
Initiator for GP involvement cancer care	“The doctor called me several times on his own initiative after the diagnosis and during treatment. That was nice and gave me the feeling that he was involved.”

Discussion

Summary

In the present study, we evaluated the needs of (former) cancer patients for GP involvement in cancer care. More than half of the respondents reported that they wanted the GP to be involved in cancer care after the diagnosis. GP involvement in cancer care was experienced in over three-quarter of these cases. As for GP involvement in SDM for cancer treatment, the balance is different. Although more than 80% expressed a need for the GP to listen to worries and considerations, this support was lacking in over half of these cases. Also, more than two-thirds of responding cancer patients indicated a need to have elemental SDM topics addressed in a GP consultation, such as explaining information, checking understanding and discussing priorities. This SDM support was only experienced in a small minority of cases. Finally, the initiator of GP involvement was mostly the patient, whereas satisfaction with GP involvement in cancer care was higher if the GP was the initiator.

Strengths and limitations

This study has several limitations. First of all, recall bias may have occurred, since the median interval between last received treatment and participation was two years. Among those treated longer ago (≥3years) the reported needs were similar to those treated ≤2years ago. However, those treated ≥3years ago less often reported GP involvement. This could be the result of an underestimation of the actual GP involvement, due to incorrect recall. Second, the network used to recruit cancer patients may have addressed a selective population. The survey was distributed among a group of (former) cancer patients who are in some way affiliated to a cancer patient organisation. Consequently, our respondents may have been relatively committed, active and critical, thus may have different needs than the average cancer patient and have a stronger drive to meet those needs. Within this population, selective response may have occurred, as those being very satisfied or unsatisfied with GP involvement may be more inclined to participate in a survey about corresponding needs. Selective participation is supported by the relatively high percentage of patients with a high education (48%). However, the percentage of women (56%) and the average age (62yr) in our sample is comparable with the Dutch population of cancer patients.[14]

The main strength of this study is the high number of (former) cancer patients who responded to this survey. The large population and the variety of cancer types support generalisability and enabled sub-group explorations.

Comparison with existing literature

To our knowledge, this is the first study among (former) cancer patients that combines an exploration of the needs for GP involvement in cancer care and specifically in SDM, and to what extent GP involvement occurred. Our findings are in line with the few studies that have addressed adjacent topics. It confirms the need for a supportive role of the GP as previously demonstrated.[10, 15] It also confirms the conclusion of Halkett et al., who reported that cancer patients see a role for the GP in SDM support after a cancer diagnosis.[10] Lang et al. reported that 34.5% of the cancer patients discussed diagnostic and therapy related decisions with the GP.[9] Also, Klabunde et al. showed that 64.2% of the GPs reported to explore patient’s preferences for treatment.[8] Both percentages are higher as compared to the 15% of the cancer patients who reported SDM involvement by the GP. This might be due to a different study population or due to differences in perception between GPs and cancer patients of what is actually addressed during consultation. Additionally, our results imply that GPs generally provide supportive care, mostly including the discussion of worries and considerations, but the discussion of the cancer treatment decision itself is often lacking. This might be caused by GPs' unawareness of patients' needs for SDM support, or by reluctance among GPs because of perceived lack of expertise.[13, 16]

Furthermore, our results show that satisfaction with GP involvement is scored higher if the GP is the initiator of contact. This is supported by findings in a qualitative study by Brandenbarg et al. among curatively treated colorectal cancer patients who expressed dislike when the GP did not initiate contact after treatment.[15] Also, cancer patients' preference for initiation of contact by the GP is expressed for other conversations, such as for advanced care planning.[17] In addition, previous studies show that cancer patients are more satisfied if the GP is informed about the diagnosis[11] and if there is a contact moment with the GP (a "time out consultation") before start of treatment.[12] Our findings also support and explain the potential positive effect on SDM of actively involving the GP between diagnosis and therapy choice, which was recently reported for palliatively treated cancer patients.[13]

Implications for practice

Treating physicians and GPs should actively explore patients' needs for GP involvement after a cancer diagnosis, particularly for SDM. GPs should be aware that patients wish to have cancer treatment decision related topics addressed by the GP. GP support could be enabled to support SDM in the hospital, for instance by actively offering a "time out consultation" with the GP with SDM tools. [12-13, 18-19] In addition, cancer patient organisations could support GP involvement by empowering patients to discuss preferred topics with their GP.

Conclusion

Even though patients experience GP support after a cancer diagnosis, their needs for support in the SDM process often remain unanswered. GPs can do better in checking understanding of information, discussing patients' priorities and preferences and explaining the importance of patients' own opinion in decision making. Since GPs seem adequately equipped to provide the desired SDM support, GPs and hospitals should join forces to make sure that GPs can and will support their patients in one of the most important medical decision that patients have to face.

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Supplementary document S1. Survey.

1. This survey is meant for people ever diagnosed with cancer. Is this applicable to your situation?
    a. Yes, I have (had) cancer
    b. No
2. Wat is your sex?
    a. Male
    b. Female
3. What year you were born?
4. What is the highest education you achieved?
    a. No education achieved
    b. Primary school
    c. Primary professional education
    d. Secondary general education
    e. Secondary professional education
    f. Secondary general education
    g. Higher professional education
    h. University
    i. I'd rather not say
    j. Otherwise, namely
5. What type of cancer do/did you have? (if you had multiple diagnosis, fill in the most recent one) ……
6. In what year did you receive the most recent treatment? ……
7. Which situation is now applicable in your case?
    a. I'm cured
    b. I will (probably) cure
    c. I will (probably) not cure
    d. I don't know/not applicable
8. In how many hospitals were you treated?
    a. One hospital
    b. Two hospitals
    c. More than two
9. From which hospital did you receive the most care?
10. Did you have a need for contact with your GP about your cancer diagnosis, the treatment and/or its consequences?
    a. Yes
    b. No
    c. I don't know/n.a.
    d. Comment….
11. When did you have a need for contact with your GP about your cancer diagnosis, the treatment and/or its consequences? (Multiple answers possible)
    a. Shortly after diagnosis
    b. During treatment
    c. After treatment, during follow-up in hospital
    d. After finishing follow-up in hospital
    e. I don't know/n.a.
12. What was your reason for not having a need for contact with your GP about your cancer diagnosis, the treatment and/or its consequences?

13. Did you have contact with your GP about your cancer diagnosis, the treatment and/or the its consequences?
    a. Yes
    b. No
    c. I don’t know/n.a.
    d. Comment….
14. When did you have contact with your GP about your cancer diagnosis, the treatment and/or its consequences? (Multiple answers possible)
    a. Shortly after diagnosis
    b. During treatment
    c. After treatment, during follow-up in hospital
    d. After finishing follow-up in hospital
    e. I don’t know/n.a.
15. How many times (on average) did you have contact with your GP about your cancer diagnosis, the treatment and/or its consequences?
    a. 5 or less times
    b. 6-10 times
    c. 11 times or more
    d. I don’t know/n.a.
16. Who was the initiator of contact with your GP (most of the time) about your cancer diagnosis, the treatment and/or its consequences?
    a. Me
    b. My loved ones
    c. My GP
    d. I don’t know/n.a.
    e. Other….
17. In which way did your GP support you with your cancer diagnosis, the treatment and/or its consequences? (Multiple answers possible)
    a. Listened to my worries and considerations about my diagnosis, treatment and its consequences.
    b. Asked if I understood the information about my diagnosis, treatment and its consequences.
    c. Discussed with me what I think is important in my life and the consequences of treatment options for these priorities.
    d. Explained to me the importance of my own opinion when making a treatment decision.
    e. Thought along with me about which hospital would be most suitable for me.
    f. Explained to me that no treatment is an option that I can choose.
    g. Explained to me that I can change or stop the treatment in between.
    h. Helped me with physical problems due to my diagnosis and treatment (e.g. fatigue or pain).
    i. Helped me with psychological problems due to my diagnosis and treatment (e.g. anxiety, anger or sadness).
    j. Helped me with cognitive problems due to my diagnosis and treatment (e.g. memory or concentration problems).
    k. Helped me with social problems through my diagnosis and treatment (e.g. problems in relationships or with sexuality).
    l. Discussed with me what my wishes and needs are in the last phase of life or around the end of life.

    m. Had attention for my loved ones when dealing with my diagnosis and treatment.
    n. I don't know/not applicable
    o. Otherwise, namely

18. How (un)satisfied are you with the support or your GP with your cancer diagnosis, the treatment and/or its consequences?
    a. 1-10, no opinion
    b. Comment
19. Below you find statements about the role of your GP by make a treatment decision regarding your cancer diagnosis, the treatment and/or its consequences. Describe below if you agree or disagree with these statements.
    a. My GP should listen to my worries and considerations about the diagnosis, treatment and its consequences.
    b. My GP should check if I understand the information about my diagnosis, treatment and its consequences.
    c. My GP should discuss with me what I think is important in my life and the consequences of treatment options for these priorities.
    d. My GP should explain to me the importance of my own opinion when making a treatment decision.
    e. Comment…

Part II: Effects of a Time Out Consultation with the GP

Chapter 4

Off to a good start after a cancer diagnosis: implementation of a Time Out Consultation in primary care before cancer treatment decision

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Abstract

Purpose

Supportive care for cancer patients may benefit from improving treatment decisions and optimal use of the family physicians' and specialists strengths. To improve shared decision making (SDM) and facilitate continuity of primary care during treatment, a cancer care path including a "Time Out Consultation" (TOC) in primary care before treatment decision, was implemented. This study assesses the uptake of a TOC and the added value for SDM.

Methods

For patients with metastatic lung or gastro-intestinal cancer, a TOC was introduced in their care path in a southern region of the Netherlands, from April until October 2016. Uptake of TOC was measured to reflect on facilitation of continuity of primary care. The added value for SDM and overall experiences were evaluated with questionnaires and semi-structured interviews among patients, family physicians and specialists.

Results

Of the 40 patients who were offered a TOC, 31 (78%) had a TOC. Almost all patients, family physicians and specialists expressed that they experienced added value for SDM. This includes a stimulating effect on reflection on choice (expressed by 83% of patients) and improved preparation for treatment decision (75% of patients). Overall added value of a TOC for SDM, only evaluated among family physicians and specialists, was experienced by 71% and 86% of these physicians, respectively.

Conclusion and implications for Cancer Survivors

The first experiences with a TOC in primary care before cancer treatment decision suggest that it may help to keep the GP 'in the loop' after a cancer diagnosis and that it may contribute to the SDM process, according to patients, family physicians and specialists.

Acknowledgements

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Introduction

The rapid developments in cancer treatment have facilitated opportunities for personalised cancer care.[1] Consequently, the optimal balance between the benefits and harms of treatment is increasingly linked to individual preference. Unfortunately, the current 'rollercoaster' cancer care pathway after diagnosis does not facilitate tailored treatment decisions, personalized to patient's individual preferences.[2] Additionally, the consequences of treatment are frequently not fully understood by patients.[3]

To enable personalised decision making, facilitating shared decision making (SDM) is key.[4] SDM encompasses several steps; (step 1) creation of awareness of choice, (step 2) sharing of treatment options, (step 3) time and space for deliberation to explore personal priorities and (step 4) making an informed shared decision.[4]

Involvement of the family physician may improve the SDM process.[5-6] Family physicians generally have a long-standing, personal relationship with their patients, including knowledge of comorbidities and personal circumstances and values. However, keeping the family physician "in the loop" after a cancer diagnosis, is currently insufficiently facilitated. This hinders possibilities for the family physician to support the SDM process and to safeguard personalised survivorship and supportive care.[2, 5-7]

To improve personalized decision making and facilitate continuity of primary care, we developed a cancer care pathway including a "Time Out Consultation" (TOC) with the family physician. This TOC is scheduled between the cancer diagnosis and the corresponding treatment decision in secondary care. It aims to support patients in making an optimal treatment decision.

We performed a pilot implementation of a TOC for patients with metastatic gastro-intestinal or lung cancer. This pilot study aimed to explore uptake and first experiences with a TOC concerning experienced added value for SDM according to patients, family physicians and specialists.

Methods

Study design

The implementation of the TOC in usual care was evaluated using a non-comparative intervention design, with questionnaires and semi-structured interviews among patients, family physicians and specialists, from April to October 2016, by the Quality of Life group; a collaboration of regional family physicians and the Elkerliek Hospital in Helmond, the Netherlands.

Study population

All patients visiting the Elkerliek hospital from April to October 2016 with a new diagnosis of metastatic gastro-intestinal or lung cancer or with changes in treatment perspective (e.g. progression from localized cancer) facing a new treatment decision were offered a TOC by their specialist.

Intervention: Time Out Consultation

If the patient agreed, the specialist or oncology nurse contacted the family physician's office. There, the assistant contacted the patient to plan the TOC. Before the TOC, the specialist provided the family physician with relevant information about diagnosis, treatment options including pros and cons, and if possible expected prognosis. The TOC consisted of a 20 minute consultation with the patient's family physician.

The TOC aimed to improve continuity of primary care and to support the SDM process. Suggested topics in the TOC were: (1) impact and consequences of the diagnosis, (2) personal preferences and priorities in the light of the expected prognosis and options, and (3) providing three key questions to be asked during the follow-up consultation with the specialist: (a) What are my options? (b) What are the benefits and harms of these options? and (c) How likely are these benefits and harms to occur in my situation? Incorporating these questions in a treatment decision consultation previously demonstrated to improve the SDM process.[8] The family physician provided the patient with a form including these three questions and room for remaining questions. After the TOC, the family physician informed the specialist in case of relevant information. The treatment decision generally occurred approximately one week after the TOC procedure started.

A short TOC instruction text, describing the aim and proposed topics of the TOC, was available for the family physicians on the hospital website. All family physicians were informed by a newsletter about the new TOC care pathway, the TOC instruction text and the study procedures, prior to the start of the pilot.

Outcomes and measurements

Uptake of the TOC was defined as the percentage of patients who were offered a TOC, that actually visited the family physician for a TOC. Experienced added value of a TOC for the SDM steps (e.g. the benefit which was experienced by the physician for reflection on choice and preparation for treatment decision making) was assessed using self-constructed, non-validated questionnaires and semi-structured interviews. The questionnaires were sent to all patients who were offered a TOC. After each TOC and treatment decision consultation in the hospital, questionnaires were sent to the corresponding family physician and specialist. One family physician or specialist could potentially fill in multiple questionnaires evaluating different TOCs. Semi-structured interviews were conducted with a random sample of family physicians and patients. These aimed to explore general experiences. Answers to the open ended questionnaire questions and data from the interviews were considered of comparable value. In these data, TOC related quotes referring to any of the steps of SDM were marked. These quotes were categorized to evaluate added value for each SDM step. Only the second SDM step "sharing of treatment options", was not taken into account since treatment options are shared in the hospital and this is not a topic of the TOC.

Ethical approval

All procedures performed were in accordance with the 1964 Helsinki declaration, its amendments and comparable ethical standards. As the implementation concerned an evaluation of new standard practice the Medical Research Human Subject Acts does not apply.

Informed consent

Informed consent was obtained from all study participants.

Results

Uptake of TOC

Of 40 eligible patients, 31 (78%) visited their family physician for a TOC. Of these patients 12 returned the questionnaires. We received 21 questionnaires from 18 family physicians evaluating 21 different TOCs and 21 questionnaires from 8 specialists evaluating 21 different TOCs. Semi-structured interviews were conducted with 9 patients and 5 family physicians (see figure 1).

Overall, added value of a TOC for SDM was experienced by family physicians in 15 out of 21 (71%) TOCs and by specialists in 18 out of 21 (86%) TOCs (figure 2).

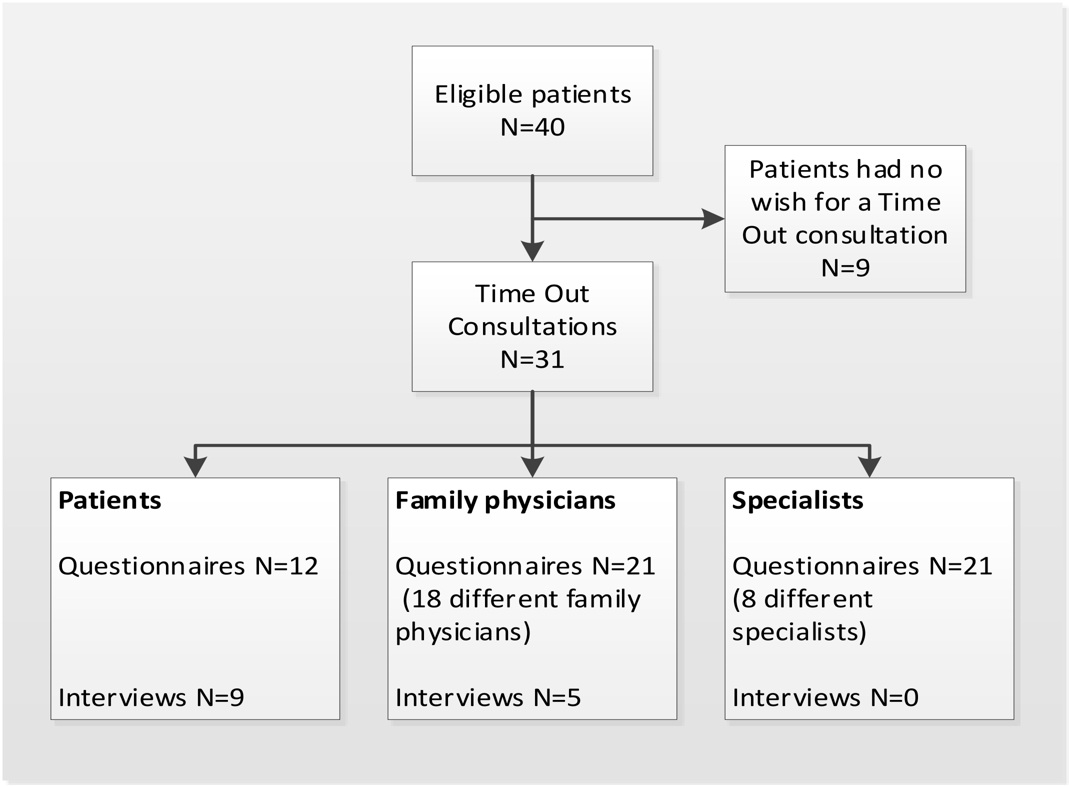

Figure 1. Number of eligible patients, Time Out consultations, received questionnaires from patients, family physicians and specialists and number of interviews.

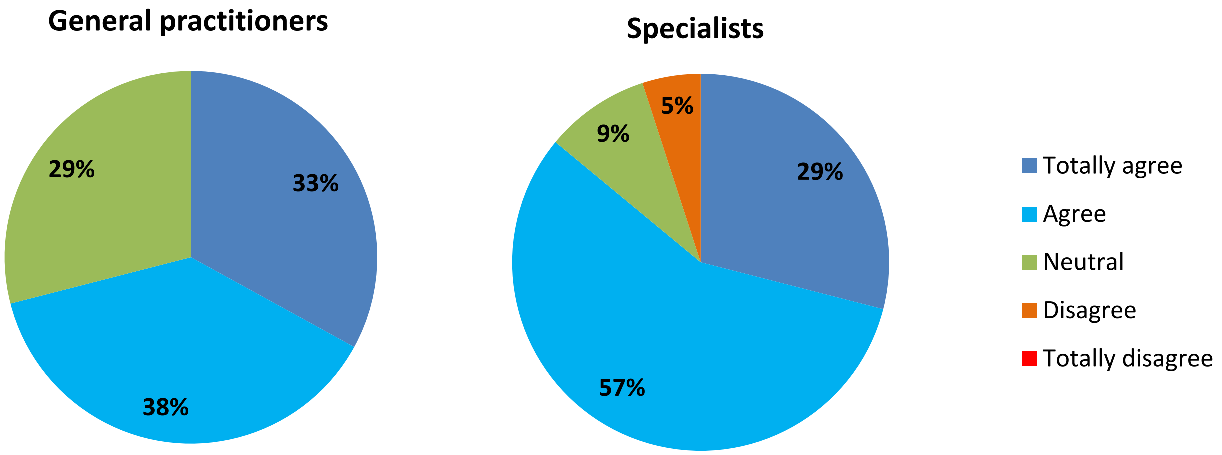

Figure 2. Answers of family physicians and specialists to the question if the Time Out Consultation contributes to shared decision making. Percentages are percentages of the number of consultations on which the family physicians (N=21) and specialists (N=21) reflect

SDM step 1 - Awareness of choice

Patients described that the TOC created the awareness that they make the final decision.

"We discussed the treatment options and it was communicated clearly that the choice is with me." (Patient)

Family physicians indicated that awareness was created for the option not to treat and that a TOC can reduce the risk of choosing the therapy preferred by the specialist out of loyalty, instead of the patients' own preference.

SDM step 3 - Deliberation

For the majority of the TOCs, patients (10/12) and family physicians (14/21) experienced that the 'TOC had added value for reflection on treatment decision.' Additionally, in most TOCs, patients (9/12) and about half of the family physicians (11/21) experienced that 'the patient is better prepared for the treatment decision consultation by the TOC.'

The qualitative data show that according to patients, preparation for treatment decision included (1) discussing patient's wishes, (2) creating clarity on possible treatment options, (3) asking questions to the family physician, (4) providing "three key questions" and (5) getting an independent advice from the family physician. Family physicians described the TOC as a pleasant moment to talk, to check patient's understanding of diagnosis and treatment and to reflect on priorities concerning quality of life.

"Definitely, a moment of reflection and time to think about what a patient wants in life, including the related quality of life." (Family physician)

Specialists indicated that a TOC created a moment of reflection to consider consequences and added value of therapy in the context of patient's personal circumstances.

SDM step 4 – Informed treatment decision

Patients responded that the TOC can influence treatment choice and can take away doubts or insecurities about treatment choice. This could entail an unchanged decision, a choice for less or no treatment, or a choice for more treatment.

“At first I didn’t want to do anything, but after the consultation (TOC) with my family physician I decided to accept chemotherapy. The birth of my grandchild also had to do with this.” (Patient)

Specialists stated that the TOC facilitated a well-considered treatment decision.

No statements addressing a negative effect of a TOC on ‘awareness of choice’, ‘deliberation’, or ‘informed treatment decision’ were made.

Opportunities and barriers

Patients and family physicians indicated that the family physician was better informed as a result of the TOC. Family physicians experienced more appreciation and information from the hospital and more involvement in the guidance of the patient. Family physicians mentioned that the format of the TOC and structural implementation of TOC facilitated family physicians in providing support.

A potential barrier for success is unclearness about the goal of the TOC, scheduling a TOC after treatment decision and insufficient information exchange between specialist and family physician.

Discussion

The first experiences with a TOC in primary care before cancer treatment decision suggest that it may help to keep the GP ‘in the loop’ after a cancer diagnosis and that it may contribute to the SDM process, according to patients, family physicians and specialists.

These positive experiences are in line with the results of a survey by the Dutch Federation of Cancer Patient Organizations (NFK), which shows that 66% of cancer patients indicated to want family physician support for cancer treatment decisions.[9] A recent Cochrane review summarizes the benefits of well-informed decision making as *“patients feel more knowledgeable, better informed, and clearer about their values.*“ [10] The observations in our evaluation confirm this.

This pragmatic assessment of a small pilot implementation does have limitations, e.g. the lack of a control arm and relatively small numbers. The results should therefore be considered explorative. Strengths of this study are the pragmatic design with implementation in a daily care setting directly reflecting impact on clinical practice and the combination of quantitative and qualitative data, which increases the understanding of the experienced added value. A strength of our pragmatic intervention is its simplicity and broad applicability. Therefore, while this study is focused on a TOC in patients with advanced disease at the initiation of therapy, there may be other decision moments throughout the cancer continuum (such as in times of diagnostic interventions) and in patients with different stages of the disease that could also benefit from a TOC. This deserves further exploration.

Conclusion

The first experiences with offering a TOC in primary care before cancer treatment decision, suggest that a TOC may help to keep the family physician in the loop after a cancer diagnosis. It may also stimulate the SDM process, thereby enabling more individualised cancer treatment decisions, according to both patients and physicians.

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Chapter 5

Effects of a Time Out Consultation with the general practitioner on cancer treatment decision making; a randomized controlled trial

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Abstract

Objective

Improving shared decision making (SDM) enables more tailored cancer treatment decisions. We evaluated a Time Out Consultation (TOC) with the general practitioner (GP), between cancer diagnosis and treatment decision, which aims at supporting SDM and improving continuity of primary care. This study aims to evaluate the effects of a TOC on perceived SDM, information provision and self-efficacy.

Methods

This randomised controlled trial included newly diagnosed patients with curable cancer (breast, lung, colorectal, gynaecologic, melanoma) from four Dutch hospitals. Primary outcome is perceived SDM and secondary outcomes are information provision and self-efficacy.

Results

154 patients (control n=77, intervention n=77), female: 75%, mean age: 61 (SD±11.9). In the intervention group 80.5% (n=62) had a TOC, of which 82.3% (n=51) took place after treatment decision. Perceived SDM was lower in the intervention group (-8.9 (95% CI, 0.6-17.1)). Among those with a TOC before treatment decision (n=11), perceived SDM was comparable to the control group (66.5±27.2 vs 67.9±26.1).

Conclusion

Even though patients are motivated to have a TOC, implementing a TOC between diagnosis and treatment decision is challenging. Effects of a timely TOC could not be established. Non-timely TOC decreased perceived SDM. Planning of the TOC should be optimised, and future research should establish if adequately timed TOC results in improved SDM in cancer patients.

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Background

Cancer is the second leading cause of death globally. In 2018, over 17 million people worldwide were diagnosed with cancer, a number that is expected to reach 21 million patients by the year 2030.[1] As cancer mainly affects the elderly, the increase is to a large extent caused by aging.

Cancer treatment should be personalised. This means that, besides tailoring treatment choice to tumour characteristics, for every patient the treatment option should be chosen which best fits a patient's preferences and circumstances. This is increasingly complex because of several reasons. First, the spectrum of treatment modalities for cancer expanded in recent years. Second, 70% of cancer patients has at least one co-morbidity, which may interfere with cancer treatment.[2-3] Furthermore, treatment decisions become more complex at higher age, due to co-morbidities, declining life expectancy and changing life perspectives and priorities. Consequently, personalised treatment decisions require a balanced decision-making process between patients and healthcare professionals, with thorough weighing of curative treatment options in the light of patient preferences and personal context.

Although many general practitioners (GPs) do participate in follow-up care after completion of cancer treatment, structural guidance and care by the GP starting from the moment of diagnosis onwards is uncommon.[4-5] In view of their position this seems to be a missed opportunity. GPs are well equipped to support the patient during their cancer care pathway: they usually have a longstanding and personal relationship with their patients and work with an integral and personalised approach, including psychosocial support. In that regard, of all care-givers involved, GPs are probably best positioned to balance treatment options in the perspective of the patient's medical history and personal preferences.[6-7] It is therefore that professional and patient organisations advocate a structured and expanded role for the GP in the cancer care pathway, starting from the moment cancer is diagnosed.[6]

Personalised cancer care requires active involvement of the patient in treatment decision by shared decision making (SDM). For successful SDM in complex decisions several steps are required; i.e. creating awareness of choice, explanation of treatment options, consideration of the treatment options provided and making an informed choice.[8] Research suggests that SDM improves knowledge and understanding of treatment options [9-11], creates more realistic expectations [9], and better matches patient's preferences and subsequent treatment decisions.[9] Moreover, patients feel better informed [12], are more determined on their personal values [12], and experience better communication with their practitioner.[9-11] Adequate SDM may also improve medication adherence[11], mental health-related quality of life[13] and reduce health care costs.[14] Several large studies have demonstrated that patients want to be involved in decision making.[15-17] Additionally, a recent survey in the Netherlands among 4 700 patients treated for cancer showed that the majority of patients prefer their GP to be involved, as the GP can help to create awareness of choice and can prepare the patient for the treatment decision in hospital.[18]

So far, the effectiveness of GP involvement in SDM for cancer treatment decisions has not been evaluated. In the randomized controlled GRIP trial, we evaluate the effects of providing structural follow-up care from primary care during cancer treatment. This follow-up care starts with a Time Out Consultation (TOC) between patient and GP immediately after cancer diagnosis. Here we report the effects of a TOC after a cancer diagnosis for patients treated with curative intent, on patient-perceived SDM, information provision and perceived self-efficacy.

Methods

Design

The GRIP trial is a multicentre randomised controlled trial following the patient from cancer diagnosis until three months after completion of primary treatment with a maximum of one year follow-up. The study was conducted in four Dutch hospitals between April 2015 and May 2017 in the region of Utrecht, the Netherlands. In addition to the usual hospital care, patients randomized to the GRIP intervention group were offered structured follow-up guidance from primary care consisting of two components: (1) a time out consultation (TOC) with the GP and (2) structured follow-up during cancer treatment by a primary care oncology nurse and the GP. For full exploration and understanding of the effects of the first component (TOC), we report these effects in this paper separately. As follow-up care was delivered after, and independently from the Time Out Consultation, we expect no interference. The GRIP study protocol was published previously.[19] The study protocol was assessed by the Medical Ethical Committee of the University Medical Center Utrecht and was considered non-eligible for full ethical review according to Dutch law (METC number: 15-075/C). This study was performed in accordance with the Helsinki Declaration 1975. The GRIP trial is registered in the ‘Netherlands Trial Register’ (Trial number: NTR5909).

Patient and Public involvement

The Dutch Federation of cancer patient organizations (NFK) was part of the GRIP project group. NFK contributed to the definition of research priorities, participated in the intervention and study design, including the choice of outcome measures (SDM). NFK also contributed to the writing of the manuscript.

Study population and setting

Patients were eligible for participation if they were aged 18 or over, newly diagnosed with either breast cancer, colorectal cancer, gynaecological cancer, lung cancer, or melanoma, and scheduled for curative treatment. Patients were excluded in case of major psychiatric diseases, personality disorders, inability to fill in questionnaires, or if the patient's GP worked outside the study area, did not agree to participate, or if the patient already started cancer treatment.

Recruitment and randomisation

After diagnosis, eligible patients were approached for participation by their treating physician or oncology nurse in the treating hospital. If patients consented, they were contacted by the researchers by phone the (working) day after diagnosis to verify eligibility and provide further study information. Upon confirmation of willingness to participate, patients were randomised. Equally allocated (1:1) randomisation was performed by using an online computerized randomization module provided by an independent data centre of the UMC Utrecht. Minimisation was applied to ensure balance between groups regarding treating hospital and cancer type. Due to the nature of the intervention, patients and health care providers could not be blinded for the intervention. All participants gave verbal and written consent for participation.

Usual care

All patients received cancer care as usual in the hospital, which is to a great extent protocolised. Protocols for curative treatment vary according to cancer type and patient and disease characteristics. In general, additional investigations are required such as determination of laboratory values and imaging, and multidisciplinary team discussions on treatment options. In one or more consultations with the medical specialist, the diagnosis is explained to the patient, information about cancer and treatment options is given, and the final treatment decision is made.

Involvement of the GP following primary cancer diagnosis varies between hospitals, specialists and GPs. In general, the GP is informed about the diagnosis by phone or by mail through Electronic Data

Interchange after the multidisciplinary team reaches consensus on the diagnosis and treatment. Thereafter, contact between the GP and the patient depends on the individual initiative of either the GP or the patient.

Intervention: the Time Out Consultation

In addition to usual care, patients in the intervention group were asked to schedule a TOC with their GP immediately after randomisation to prepare for the final treatment decision. The TOC was a 20-minute consultation with the GP. The aim of the TOC was to improve the SDM process and improve continuity of primary care. For this consultation, the GP was instructed to give psychosocial guidance, including discussing impact of diagnosis and consequences. Furthermore, the GP was instructed to check patient's understanding of information, to create awareness that a choice of treatment exists, and to stimulate the use of the 'three questions' model during the specialist consultation on the final treatment decision. The three questions model is used to support patient involvement and information exchange when discussing therapeutic options.[20] The three questions are: What are my options? What are the possible benefits and harms of those options? How likely are the benefits and harms of each option to occur for me?[20]

The GPs of patients who were randomised to the intervention group were notified by phone by the researcher after the patient consented to participate. During this telephone contact, the researcher provided the necessary instructions to perform a TOC. In addition, information on the steps GPs were expected to take was given by email and through a website.

Outcomes

To report the primary outcome (perceived level of SDM) and secondary outcomes (received information and perceived self-efficacy) patients filled in three validated questionnaires two weeks after inclusion (T1) online or, if preferred, on paper. Only perceived self-efficacy was measured at both baseline (T0) and T1. Non-responders were sent two automatic reminders by mail after two and five days, and were contacted by phone by the researcher if non-response maintained.

Primary outcome

The perceived level of SDM was measured using the Shared Decision-Making Questionnaire (SDM-Q-9), which contains nine items with a six-point Likert scale and focuses on the decision process in hospital.[21] A score was calculated, which ranged from 0-100 and a higher score indicated higher perceived SDM.

During the trial, we added a statement to specify the role of the GP in this process “My GP helped me make my choice of treatment”, which was analysed separately.

Secondary outcomes

Received information was assessed using the European Organisation for Research and Treatment of Cancer Quality of Life Group information questionnaire (EORTC-info 26), a 27-items cancer specific questionnaire with a four-point Likert scale.[22] This questionnaire assessed the amount of information received on multiple cancer-related themes (diagnosis, medical tests, treatments, other services, places of care and self-help), the satisfaction and usefulness of received information. With the items a score was calculated, which ranged from 0-100. A higher score indicates a better perceived information provision.

Self-efficacy is defined as “the individual's capacity to produce desired effects.”[23] Perceived self-efficacy was measured using the Perceived self-Efficacy in Patient-Physician Interactions (PEPPI-5) questionnaire, which contains 10 items with a five-point Likert scale.[24] With these items a score was calculated which ranged from 5-25. A higher score indicates higher perceived self-efficacy.

Intervention adherence

Adherence to the protocol for the content and planning of the TOC was assessed using the free text in the Electronic Medical Record (EMR) data of GP contacts in the intervention group. EMR data are registered for each GP consultation as part of usual care. Performance of the content of TOC according to protocol was confirmed if the free text noted referred to components of the TOC intervention. Timing of the TOC according to protocol was defined as a TOC between diagnosis and treatment decision. Dates from the primary care and hospital EMR were used. Consultations in the control arm were evaluated for contamination. All GP consultations within two weeks were registered in both groups.

Data collection

Patient characteristics were collected online directly after inclusion (baseline). Data extraction at baseline, including the number of GP contacts (year prior to inclusion), was performed in the free text and coded routine care data from the EMR of each GP practice. GP characteristics at T0 and rurality were collected from public Dutch online databases for GP experience.[25-26]

Comorbidities, date of diagnosis, cancer stage and treatment decision were extracted from the EMR in hospital. The moment of treatment decision was defined as the moment the patient agreed with or chose the treatment.

Sample size

The sample size was based on the primary outcomes of the GRIP study, i.e. satisfaction with care and healthcare utilisation at three months after the end of therapy (excl. hormone therapy) with a maximum of one year. We assumed a medium effect size (0.5) to be a relevant difference between the two study groups. Using a power of 0.8 and an alpha less than 0.05, at least 64 patients per study group were required. Accounting for an estimated dropout of 15%, 75 participants in each group were needed.[19]

Statistical analysis

The study population was described descriptively. Intervention effects compared to usual care were analysed following the intention-to-treat principle. Additionally, outcomes were described stratified for patients with a TOC before treatment decision (conform protocol), a TOC after treatment decision, and no TOC.

Paired sample T-test was used to calculate mean changes and 95% confidence intervals of self-efficacy from baseline to T1 within groups. ANOVA was used to calculate between-groups differences (i.e. intervention versus control group) at T1, adjusted for stratification factors (i.e. hospital and cancer type) and baseline measurements if present. Additional adjustment for comorbidity was done because of potentially relevant group differences at baseline.

All analyses were performed with IBM SPSS 25.0.0.2 and statistical significance was set at $p < 0.05$.

Results

Study population

In total 396 patients were approached for participation in the treating hospital (Figure 1). Sixty-five patients could not be included; 60 because they did not meet inclusion criteria and five because they could not be contacted. Of those invited to participate, 177 patients declined, with main reasons: "too much of a burden shortly after diagnosis" and "no extra guidance needed". Finally, 154 patients were randomized to either the intervention (n=77) or the usual care control group (n=77) (Table 1). The 154 patients were registered with 119 different GP's, from 79 different GP centres.

Patients in the intervention and control group were comparable with respect to baseline characteristics, except for the proportion of patients with co-morbidities, which was higher in the intervention group (67.5%) as compared to the control group (49.4%) (Table 1). The majority of patients had either breast (51%) or colorectal (25%) cancer. Most patients (75%) were female, and the mean age was 61 (SD ±11.9 years).

Most GPs of the study population worked in an urban setting (62%) and had a median work experience of 16 years (IQR 11-25.25).

Implementation of Time Out consultation

In the intervention group 80.5% (n=62) of the patients had a TOC (a GP consultation that included the elements of the TOC). However, only 17.7% (n=11) had the TOC scheduled according to protocol, i.e. between diagnosis and final treatment decision.

The median time from diagnosis to TOC was 7 days (IQR 6-12) in the 11 patients in whom the TOC could be scheduled according to protocol and 16 days (IQR 11-23) if the TOC was planned after the treatment decision. The median time from diagnosis to treatment decision was 13 days (IQR 8-14) for those with a TOC before treatment decision, 5 days (IQR 1.0-7.0) for those with a TOC after the treatment decision and five days (IQR 0.50-9.75) for patients without a TOC. In the intervention group, 22% (n=17) of the patients received the diagnosis and treatment decision on the same day, and 51% (n=39) within 7 days.

GP consultations (including non TOC) within two weeks after diagnosis took place in 53.2% (n=41) of the patients in the intervention group and in 33.8% (n=26) of the control group. Potential contamination (i.e. a GP seeing an intervention patient first, followed by a patient from the control arm) occurred in two patients in the control arm.

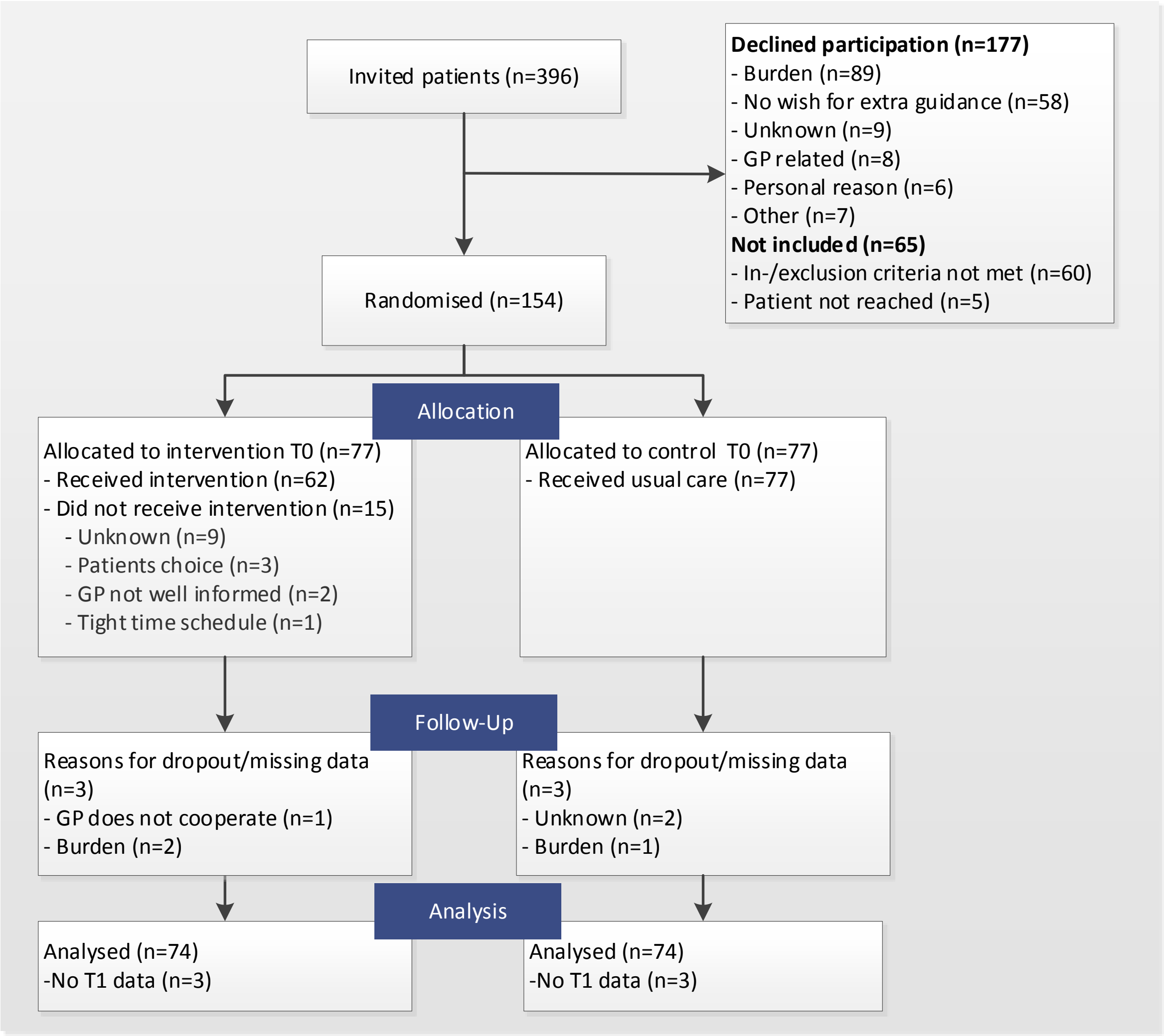

Figure 1. Consolidated Standards of Reporting Trials (CONSORT) flow diagram of the GRIP study after two weeks (T1).

Table 1. Baseline characteristics of the study participants, intervention patients divided into groups based on TOC timing.

	Intervention (N = 77)	TOC before treatment decision (n=11)	TOC after treatment decision (n=51)	No TOC (n=12)[1]	**Control (N = 77)**
Female N (%)	57 (74.0)	8 (72.7)	37 (72.5)	10 (83.3)	58 (75.3)
Age mean (±SD)	61.8 (11.4)	62.4 (8.7)	61.4 (11.0)	61.3 (15.6)	59.3 (12.2)
Cancer type N (%)					
Breast	38 (49.4)	6 (54.5)	24 (47.1)	8 (66.7)	40 (51.9)
Colorectal	20 (26.0)	4 (36.4)	14 (27.5)	2 (16.7)	18 (23.4)
Melanoma	13 (16.9)	-	9 (17.6)	2 (16.7)	11 (14.3)
Lung	3 (3.9)	-	3 (5.9)	-	2 (2.6)
Gynaecologic	3 (3.9)	1 (9.1)	1 (2.0)	-	6 (7.8)
Hospital setting N (%)					
Academic	22 (28.6)	6 (54.5)	13 (25.5)	2 (16.7)	24 (31.2)
Non academic	55 (71.4)	5 (45.5)	38 (74.5)	10 (83.3)	53 (68.8)
Cancer stage[2] N (%)					
0	2 (2.6)	-	2 (3.9)	-	2 (2.6)
I	34 (44.2)	4 (36.4)	21 (41.2)	7 (58.3)	34 (44.2)
II	22 (28.6)	2 (18.2)	15 (29.4)	4 (33.3)	27 (35.1)
III	18 (23.4)	5 (45.5)	12 (23.5)	1 (8.3)	14 (18.2)
IV	1 (1.3)	-	1 (2.0)	-	-
Education					
Low	32 (41.6)	5 (45.5)	20 (39.2)	5 (41.7)	25 (32.5)
Middle	13 (16.9)	1 (9.1)	10 (19.6)	2 (16.7)	18 (23.4)
High	32 (41.6)	5 (45.5)	21 (41.2)	5 (41.7)	34 (44.2)
Number of comorbidities (N %)					
None	25 (32.5)	5 (45.5)	15 (29.4)	5 (41.7)	39 (50.6)
≥1	52 (67.5)	6 (54.5)	36 (70.6)	7 (58.3)	38 (49.4)
Number of GP contacts (year prior inclusion) median (Q1-Q3)	7 (4.0-10.0)	7 (3.0-10.0)	6 (3.0-9.0)	8 (6.0-12.3)	6 (3.5-11.0)
Perceived self-efficacy (PEPPI-5) mean (±SD)	21.0 (±3.3)	21.3 (±2.4)	21.2(±3.0)	21.5 (±3.8)	21.5 (±3.0)
GP years of working experience median (Q1-Q3)	17 (12.0-25.5)	26 (10.0-34.0)	16 (12.0-22.0)	20 (12.3-27.5)	16 (10.5-24.5)
GP setting N (%)					
Urban[3]	51 (66.2)	7 (63.6)	36 (70.6)	6 (50)	45 (58.4)
Between rural - Urban[4]	14 (18.2)	1 (9.1)	9 (17.6)	3 (25)	15 (19.5)
Rural[5]	12 (15.6)	3 (27.3)	6 (11.8)	3 (25)	17 (22.1)

Abbreviations: SD; Standard deviation, Q1; Inter quartile range at 25%, Q3; Inter quartile rage at 75%. [1] Excluding lost to follow up n=3, [2] stage based on clinical TNM classifications, [3]1000 or more addresses per km^2, [4]1000-1500 addresses per km^2, [5]1000 or less addresses per km^2

Perceived Shared Decision Making

Perceived SDM was significantly lower in the intervention group compared to usual care (between-group difference: 8.9 [95% CI, 0.6-17.1]) (Table 2). Additional adjustment for comorbidity yielded a comparable non-significant between-group difference (8.4 [95% CI, -0.0-16.8]). In the 11 intervention patients with a TOC planned according to protocol, perceived SDM was comparable to the control group 66.5 (±27.2) versus 67.9 (±26.1) respectively.

Received information

Levels of perceived information provision in the two study arms did not differ for all topics: “Disease”, “Medical tests”, “Treatment”, “Other services”, “Places of care”, “Self-help”, “Satisfaction with the amount of information”, and “Helpfulness of information” (Table 2).

Self-efficacy

Self-efficacy in the intervention group improved significantly from baseline to T1, with a mean difference of 1.1 (95% CI, 0.4-1.8). For the control group this within mean difference was 0.5 (95% CI, -0.1-1.2). No significant between group difference was found: 0.4 (95% CI, -0.4-1.1) (Table 2).

Table 2. Results of perceived shared decision making, provided information assessment and self-efficacy.

	Intervention (n=74)	*TOC before treatment decision (n=11)*	*TOC after treatment decision (n=51)*	*No TOC (n=12)*	***Control (n=74)***	***Estimated mean difference between study groups (95%CI)***
Perceived shared decision making						
T1 mean score (±SD)	*59.2 (±27.9)*	*66.5 (±27.2)*	*55.7 (±28.7)*	*67.2 (±23.8)*	*67.9 (±26.1)*	*-8.9 (-17.1;-0.6)* *-8.4[1] (-16.8;0.0)*
GP involved in treatment decision*	*N=40*	*N=6*	*N=27*	*N=7*	*N=44*	
T1 percentage agreement						
- *completely disagree*	*70.0%*	*50.0%*	*66.7%*	*100%*	*68.2%*	
- *strongly disagree*	*12.5%*	*0.0%*	*18.5%*	*0.0%*	*6.8%*	
- *somewhat disagree*	*0.0%*	*0.0%*	*0.0%*	*0.0%*	*4.5%*	
- *somewhat agree*	*2.5%*	*0.0%*	*3.7%*	*0.0%*	*6.8%*	
- *strongly agree*	*7.5%*	*16.7%*	*7.4%*	*0.0%*	*6.8%*	
- *completely agree*	*7.5%*	*33.3%*	*3.7%*	*0.0%*	*6.8%*	
Information assessment of patients						
T1 mean score (±SD)						
- *Disease*	*58.1 (±22.6)*	*57.6 (±24.3)*	*56.4 (±21.9)*	*66.0 (±24.2)*	*59.9 (±21.7)*	*-1.4 (-8.7;5.9)*
- *Medical tests*	*73.4 (±24.0)*	*82.8 (±21.3)*	*71.7 (±24.7)*	*72.2 (±23.0)*	*75.5 (±22.2)*	*-2.2 (-9.8;5.5)*
- *Treatments*	*41.9 (±21.0)*	*49.4 (±25.1)*	*38.1 (±17.7)*	*51.2 (±26.7)*	*45.1 (±20.5)*	*-3.1 (-9.9;3.7)*
- *Other services*	*27.8 (±25.8)*	*26.5 (±20.7)*	*24.1 (±21.5)*	*44.4 (±39.5)*	*28.0 (±25.0)*	*-0.5 (-8.7;7.6)*
- *Places of care*	*27.9 (±33.6)*	*18.2 (±22.9)*	*28.8 (±32.7)*	*33.3 (±44.9)*	*22.5 (±28.7)*	*4.2 (-6.0;14.5)*
- *Self-help*	*40.1 (±35.7)*	*42.4 (±42.4)*	*38.6 (±32.9)*	*44.4 (±43.4)*	*43.7 (±32.6)*	*-4.3 (-15.5;6.9)*
- *Satisfaction with information*	*75.2 (±23.4)*	*75.8 (±26.2)*	*74.5 (±23.7)*	*77.8 (±21.7)*	*75.2 (±23.4)*	*-0.5 (-8.2;7.2)*
- *Helpfulness of information*	*79.3 (±21.9)*	*81.8 (±22.9)*	*77.8 (±22.8)*	*83.3 (±17.4)*	*76.6 (±21.9)*	*2.3 (-4.9;9.6)*
Perceived Efficacy in patient-physician interactions						
T1 mean score (±SD)	*22.3 (±2.4)*	*22.8 (±2.4)*	*22.1 (±2.5)*	*22.7 (±2.2)*	*22.1 (±2.9)*	*0.4[2](-0.4;1.1)* *0.3[3] (-0.5;1.1)*
Mean difference (±SD) T1-T0 within groups (95%CI)	*1.1(0.4;1.8))*	*1.5 (-0.7;3.8)*	*1.0 (0.1;1.9)*	*1.2 (-1.0;3.4)*	*0.5 (-0.1;1.2)*	

Abbreviations: TOC, Time Out Consult; T0, baseline measurement; T1, assessment after two week; CI, Confidence Interval; SD, standard deviation; * Question was added after the trial started; [1] added correction co-morbidities (None; ≥ 1 comorbidities); [2] added correction PEPPI at baseline; [3] added correction PEPPI at baseline and co-morbidities (None; ≥ 1 comorbidities)

Discussion

This study aimed to evaluate the effects of a TOC with a GP shortly after a cancer diagnosis for patients scheduled to be treated with curative intent, on perceived SDM, received information and perceived self-efficacy. Although the TOC was well accepted by patients (80.5% did make an appointment with the GP after diagnosis), only one fifth was adequately planned, i.e., before a treatment decision was made in treating hospital. Therefore, we could not adequately evaluate if there is a benefit from the TOC on the SDM process. A GP consultation post treatment decision resulted in lower SDM.

It appeared to be challenging to plan a TOC preceding the treatment decision. This can be explained by the fact that current time interval between diagnosis and therapy decision is (too) short. For 22% of the patients, who were mainly patients with breast cancer or melanoma, the treatment decision was made on the day of the diagnosis. For half of all patients, a decision was made within seven days. The assumption that a short time to decision hampers TOC planning according to protocol is supported by the observation that the time between diagnosis to therapy decision was short (median 5 days) for those patients who had the TOC after treatment decision. Also, participating clinicians report that the current cancer care pathway is focused on rapid diagnostics[27] and early start of treatment. Delayed TOC planning in this study may also be partly related to the time required for patients to consider study participation. Finally, delayed TOC planning may also be related to the pragmatic design of our study: instead of the research team or the hospital scheduling the TOC for the patient, we decided to leave this responsibility to the patient, thus reflecting current daily care practice. In the short and stressful period between diagnosis and therapy choice, scheduling a TOC may not have been feasible for the majority of patients.

Our results show that perceived SDM was lower if a TOC was planned after treatment decision. The most likely explanation is that patients perceive SDM more negatively if they are informed and coached on the added value and possibility of SDM, after the possibility to actually apply SDM has already passed.

Compared to the literature, the number of patient-initiated GP contacts after diagnosis was high. In previous studies, which aimed to involve the GP in cancer care, the uptake of interventions was generally between 27% and 60%, as compared to more than 80% in our intervention group.[28-30] Even though we did not find a beneficial effect on the SDM process, the TOC may have an effect on the second aim of the TOC: continuity of primary care. On the short term, patients visited their GP more often in the intervention arm compared to the control arm. Results on continuity of primary care along the cancer care continuum will be published elsewhere.

Study strengths and limitations

This study has several strengths and limitations. The present study contributes evidence from a pragmatic, well powered randomised controlled trial to the scarce knowledge on SDM interventions for curative cancer treatment involving the GP. Another strength is the full access to the free text and coded routine care data from the EMR of each general practitioner practice, therefore protocol adherence could be assessed. A limitation is that breast cancer patients are overrepresented, which might make the results less generalizable to the total cancer patient population.[31] Over-representation of breast cancer is often seen in cancer research[32], probably due to the high incidence of breast cancer, and the fact that the breast cancer care path is usually highly structured, which facilitates recruitment. Also, our study focuses on cancer patients treated with curative intent and findings cannot be generalised to those treated with palliative intent, because the SDM process and the added value of the GP may well be different. This is supported by a recent non-controlled study, which suggested that patients and health care workers (GPs and treating physicians) experienced improvements in the SDM process after implementing a similar TOC, among palliatively treated cancer patients.[33] One reason for a potential difference in effect is that curatively treated patients might not always experience having a treatment choice.[34-35] In addition, 66 (19.3%) of the eligible patients were not included in our study because they expressed “no wish for extra guidance” or “GP related” reasons. This selection resulted in a study population whose wish for additional contacts with their GP may be relatively strong. Furthermore, patients and health care providers could not be blinded due to the nature of the intervention, which might have influenced the outcomes. Moreover, we were not able to assess which actor or actors delayed the planning of the TOC. In addition, we cannot exclude that the GP provided contradicting information on the treatment decision. Last, during the development of the intervention, we involved the NFK and the participating general practitioners, but hospital care professionals had less input in the development of the intervention, which may have hampered implementation of the TOC.

Clinical implications

The clinical implications of this study are not easy to define. Our study demonstrated that in the present cancer care continuum it is logistically difficult to adequately plan a TOC in primary care between diagnosis and treatment. This seems mainly due to the urgency to start treatment after a cancer diagnosis. Besides hampering TOC implementation, this perceived urgency may impede the potential to reflect on the optimal therapy choice by obstructing the deliberation process. This study also showed that the majority of patients was motivated to consult the GP in preparation for the final treatment decision with the specialist. Hence, to evaluate the effects of a TOC, the planning of the TOC needs to be optimised. To ensure that the TOC is effectively incorporated in the decision process, the hospital team should probably be involved in the TOC planning.

Conclusion

In conclusion, planning a TOC in primary care between diagnosis and treatment decision for cancer patients treated with curative intent was challenging due to the short time between diagnosis and treatment choice. Although patients’ acceptance was high, the majority of TOC in our study was planned after the treatment decision has already been made. Effects of a timely TOC could therefore not be established. Non-timely TOC decreased perceived SDM. Planning of the TOC should be optimised, and future research should establish if adequately timed TOC result in improved shared decision making in cancer patients.

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Chapter 6

Treatment decision making and the added value of the general practitioner: a qualitative exploration of cancer patients' perspectives

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Abstract

Objective

Cancer patients are increasingly involved in decision making for cancer treatment. General practitioners' (GPs) support in this process is advocated. Therefore, GPs need to be aware of patients' treatment decision making process and their potential role. We aim to explore the treatment decision making process and the added value of GP involvement, from the perspective of cancer patients treated with curative intent.

Methods

A qualitative study was performed following the principles of the grounded theory. Semi-structured interviews were conducted with 20 purposively sampled Dutch cancer patients treated with curative intent.

Results

Patients' treatment decision making process was dominated by a focus on "safeguarding survival." Patients generally followed the treatment plan as proposed by their physician and did not always experience having a treatment choice. The majority of patients expressed added value for GP involvement. Mainly to provide psychological support, but also for providing shared decision making (SDM) support.

Conclusion

The treatment decision making process of cancer patients treated with curative intent is dominated by the urge to "safeguard survival." GPs should be aware of their added value in providing psychological support and their potential role to support SDM following a cancer diagnosis.

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Introduction

Following a cancer diagnosis, patients are usually faced with various treatment options. The recent increase in treatment options added complexity to the decision making process, but simultaneously increased the possibilities for personalized decision making.[1] In order to make an individual informed choice, shared decision making (SDM) is key. Recent studies, however, suggest that SDM is insufficiently facilitated in the current cancer care pathway.[2-4] Cancer patients are often not aware of different treatment options[3-4], and the time and support required for deliberation seem lacking.[4] Current treatment guidelines are generally focussed on an optimal gain in survival. Also, the option to refrain from treatment is often underexposed.[5] Consequently, an overview of options to choose from is often incomplete, and opportunities for reviewing and incorporating patients' priorities and preferences in the decision making process are insufficiently facilitated.

The SDM process and personalised decision making for cancer treatment may be improved by the involvement of the general practitioner (GP).[1] In general, the GP has a long-term relationship with the patient, resulting in optimal knowledge of the patient's psychosocial and cultural situation and medical history.[6] Because of the position of 'trusted professional', GPs are well equipped to support patients in the SDM process by elucidating patient's priorities in life and empowering the patient to include these priorities in their decision making process. Therefore, patients and GPs envision a role for the GP in treatment decision making[7-8], and both advocate more GP involvement to improve the SDM process after a cancer diagnosis.[9]

To be able to support their recently diagnosed cancer patients in the SDM process, GPs need to understand the patients' perspective on treatment decision making. Some aspects, such as the factors that influence the acceptance or decline of a proposed treatment, including treatment success rate, fear of side effects or the recommendation of the physician, are known.[10] To truly support a patient in the SDM process, understanding of the weighing of considerations (which and how) for treatment decision making is vital. Currently, detailed information about the SDM process from patients' perspective and the added value of the GP in this process is lacking. Therefore, we aim to explore the decision making process for cancer treatment and the perceived added value of the GP from the perspective of cancer patients treated with a curative intent.

Methods

Study design

A descriptive qualitative study was performed following the principles of the grounded theory approach.[11] The GRIP study and Time Out study were approved by the Medical Ethics Research Committee of the University Medical Centre Utrecht (GRIP METC protocol number 16-232/C, Time Out METC protocol number 16-654/C) and considered non-eligible for full ethical review according to Dutch law.

Sample and setting

Patients who were recently diagnosed with cancer and experienced the process of making a decision for cancer treatment with curative intent were eligible. Since we aimed to explore the support of the GP in this process at a distinct moment in time in their care path, we only included patients who consulted their GP shortly after the cancer diagnosis. Patients were purposefully selected from two ongoing projects on SDM in cancer, the GRIP[12] and the Time Out study. In both studies, patients had a consultation with their GP soon after they were diagnosed with cancer (Time Out Consultation – TOC), which was aimed to facilitate GP support in SDM and to discuss the proposed treatment options.[12] This TOC was intended to be planned before the moment of the final treatment decision with the treating physician in secondary care.

Patients in the GRIP study were invited by the coordinating researcher to participate in this follow-up interview study. Patients in the Time Out study were invited by their treating physician or nurse in the hospital. If willing and eligible, patients provided verbal and written consent for participation in the interviews.

Data collection

Semi-structured in-depth face to face interviews were conducted between May 2016 and January 2018 by one researcher (EN).[13] An interview guide (Table 1) was used, with predetermined questions based on the main topics: patient’s experiences with 1) the treatment decision making process, and 2) the added value of GP’s involvement shortly after the cancer diagnosis. The topics were based on the research aim and the clinical experience of the research team. This team includes a GP, a medical oncologist and researchers in the field of oncology and primary care.

Interviews had the character of an open conversation, with prompt questions to gain deeper insight into the experiences of the patient. The interview guide was adapted during the study based on the insights gathered during the analysis, by rephrasing or adding questions. Patients in the GRIP study were interviewed after GRIP study participation. Patients in the Time Out study were interviewed shortly after the treatment decision and were interviewed on average of six months (range 1-12) after diagnosis. Interviews took place at a location of patient's preference. Most patients were interviewed at home and two patients were interviewed at their hospital. During one interview the daughter and in four interviews the partner of the patient was present. The interviews were audio recorded. The duration of the interviews was on average 43 minutes (range 21-93 minutes). Directly after each interview, memos were written addressing observations and reflections on initial thoughts related to the emerging themes and alterations of the interview guide. Demographic characteristics were available from the GRIP and Time Out study files and included: sex, age, type of cancer, social situation and education. Data collection continued until data saturation occurred, i.e. no new themes emerged from the data.[14]

Table 1. Semi-structured interview topic list.

Topics treatment decision making process
1. Impact of diagnosis
2. Content of treatment decision
3. Involvement of patient him/herself in their treatment decision
4. Influencers, such as: - Social context - Life goals - Impact of treatment - Prognosis
5. Role of significant others in treatment decision
Added value of GP
6. General experiences with Time Out Consultation
7. Topics discussed during Time Out Consultation
8. Added value of the GP shortly after diagnosis, such as for: - Shared decision making - Final decision

Data analysis

All interviews were transcribed verbatim. To increase the credibility of the results and if desired by patients (n=11), a summary of the interview was sent to the patient and used as member check. One patient contacted the interviewing researcher for a minor revision afterwards. Data analysis was performed by two researchers (EN & SV) according to the principles of the grounded theory.[11] The constant comparative method was used; data collection and analysis were alternated and identified themes were continuously compared for differences and similarities within and between interviews.[11] In addition, memos were created during the analysis regarding the creation of themes and how these relate, which supported the analysis process.[15]

First, the interview texts were read out in full to get an overall picture and were reread to grasp the details. Secondly, the interview texts were open coded. Data was segmented and initial codes were identified and linked to the text fragments. After performing open coding of four interviews, axial coding was started. Initial codes were collated. Related codes were integrated and brought under broader categories, which were labelled with meaningful themes. In this phase, the first coding tree was established, and adapted during the analyses. Themes were further defined and reviewed based on the interview texts. Discrepancies in coding between the two researchers were discussed until consensus was reached. The data and the analysis were discussed regularly in joint meetings within the research team (EW, CH, AM, NW, EN).[16] NVivo 12.0 software (QSR International Pty Ltd, version 12, 2015) was used to support the analysis.

Results

In total, 68 patients were selected from both studies, of which 22 patients agreed to participate. The main reason for non-participation was that “participation was considered as too much of a burden.” Two patients were excluded after interviewing, as in both interviews patients were unable to provide in-depth answers for robust analysis; one due to cognitive problems and the other needed to be performed by telephone, which did not provide data of high enough quality (Figure 1). The majority of the patients was female (70%) diagnosed with breast cancer (45%) and on average 69 years old. The majority of the patients received high education (58%) and was married (63%) (Table 2).

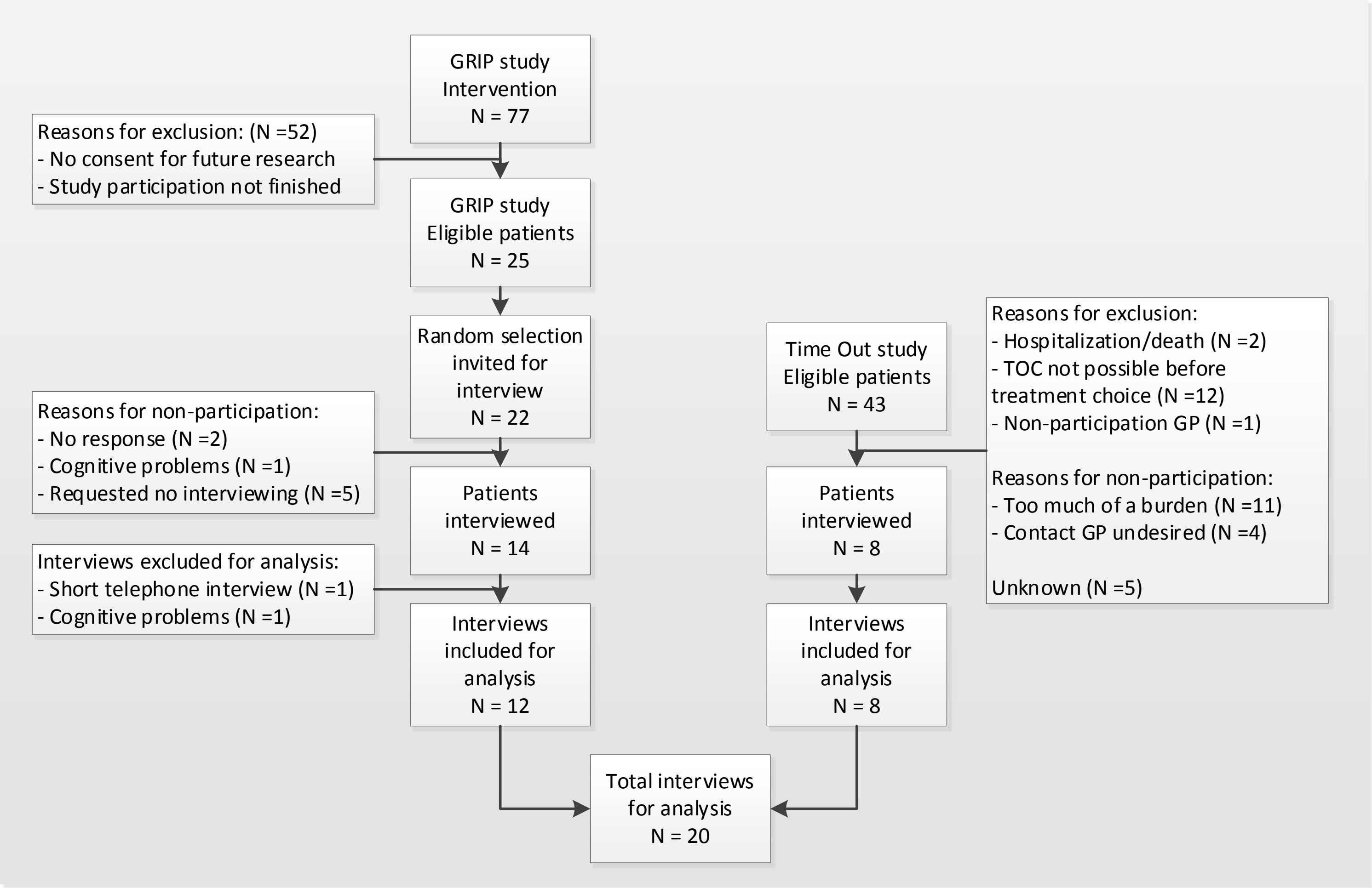

Figure 1. Overview of number of eligible patients, patients invited and patients interviewed in the GRIP and Time Out study.

Table 2. Characteristics of the participants.

Pt	**Study**	**Sex**	**Age (yrs)**	**Cancer type**	**Education**	**Social situation**	**Experienced treatment plan**	
01	GRIP	F	66	Melanoma	Low	Single	1 option	O
02	GRIP	F	68	Breast	Low	Married	Sequential steps	O→CT→RT
03	GRIP	M	65	Colon	High	Married	Sequential steps	RT→ CT→ O
04	GRIP	F	66	Breast	High	Married	Sequential steps	O→ CT
05	GRIP	F	69	Melanoma	Low	Married	1 option	O
06	GRIP	F	76	Breast	High	Married	Sequential steps	CT→O→ RT→HT
07	GRIP	F	72	Breast	High	Widow	Sequential steps	O→HT
08	GRIP	F	72	Breast	High	Married	Sequential steps	O→RT
09	GRIP	F	55	Breast	Low	Married	Sequential steps	O→RT
10	GRIP	M	55	Colon	High	Widow	Sequential steps	RT→CT→O
11	GRIP	F	54	Breast	High	Married	Sequential steps	O→CT→RT→HT
12	GRIP	F	59	Breast	High	Divorced	Sequential steps	CT→O→RT→HT
13	TO	F	69	Breast	Middle	Married	Sequential steps	RT→O→CT
14	TO	M	74	Prostate	Low	Married	>1 option	~~RT or CT or~~ O
15	TO	F	82	Lung	Low	Widow	>1 option	~~Doing nothing or O or~~ RT
16	TO	M	77	Prostate	High	Married	>1 option	~~RT or CT or~~ O
17	TO	F	81	Gynaecologic	High	Single	Sequential steps	O → ~~RT~~
18	TO	F	75	Gynaecologic	Middle	Single	Sequential steps	O → ~~RT~~
19	TO	M	74	Prostate	Middle	Married	1 option	RT
20	TO	M	73	Prostate	Middle	Married	>1 option	~~RT or~~ O

Pt = patient; TO = Time Out; F = female; M = male; RT = radiotherapy, CT = chemotherapy, O = operation, HT = hormonal therapy, "→" = treatment plan with sequential steps, "~~Treatment~~" treatment rejected.

The treatment decision making process

All patients described that their treating physician offered a treatment plan. Patients described the time in which the treatment plan was presented as a chaotic period in their life, they used words like a "circus", "surrealistic world", "rollercoaster", "automatic process" and "windmill". Three types of treatment plans could be distinguished: a treatment plan with 1) one treatment option, 2) multiple treatment options, or 3) sequential treatment steps (Table 2). The extent to which patients perceived having a treatment choice, differed per type of treatment plan. All patients who expressed that they were presented with one treatment option (type 1) perceived to have no choice. Patients with multiple treatment options (type 2) described that they felt they were offered with options to choose from. For patients presented with sequential treatment steps (type 3), the extent to which having a choice was perceived differed. Those who did feel they had a choice described their options as: acceptance of their treatment plan or not, acceptance of receiving adjuvant treatment or not, or choosing the type of surgery/radiotherapy. Patients who did not perceive having a choice expressed that following the proposed treatment plan was the only option. One patient suggested that, even though a choice was offered, the rollercoaster after diagnosis did not allow participation in treatment decision making.

The main theme in patients' treatment decision making process was: *"safeguarding survival".* This dominant theme determined all patients' treatment decision making processes, including the prioritisation of the considerations involved. A theme which was strongly related to *"safeguarding survival"* was *"trust in the physician",* which was often expressed as a reason to follow the physician's proposed treatment plan. Based on patients' considerations of safeguarding survival, strengthened by trust in the physician, patients accepted, at least partially, the treatment plan as proposed by the physician. They viewed this as the best way to safeguard survival. For patients who perceived having a choice and expressed that they actively made a treatment decision, the following themes were additionally important: "*burden of treatment", "feeling safe that the cancer is removed", "treatment option as plan B"* and "*previous experiences*". The themes determining the decision making process are explained in detail below.

Theme: Safeguarding survival

For all patients, the decision making process was strongly determined by the "urge to survive." Consequently, pursuing optimal survival to safeguard survival dominated their decision making process. Patients' desire to survive was expressed as the result of a deep-felt wish to live, to support children, or to realise plans for the future. This aim to safeguard survival led to a firm belief that abstaining from treatment was not a realistic option. Patients reasoned that leaving cancer untreated would lead to worsening of complaints and ultimately premature death. Patients also reasoned that, since their cancer was diagnosed in a relatively early and curable stage, aiming for survival was possible, which for them logically led to the acceptance of treatment. Moreover, patients mentioned that by accepting the proposed treatment plan, they would avoid regrets later in life in case of recurrence of cancer. Refusing treatment was felt to jeopardize their chance of survival, resulting in a clear wish to be treated (*see quote 1, table 3*).

Patients who did not perceive having a choice, expressed that they thought that the proposed treatment plan was the only and best approach for attaining survival *"this is what needs to be done."* Some patients said that the physician had stressed that this was the only option.

Some patients were faced with the decision to accept or decline adjuvant treatment. Again safeguarding survival was the main motivation to guide their decision. Two patients expressed that they felt their survival was already guaranteed by the primary treatment and therefore rejected adjuvant treatment. This was strengthened by the wish to prevent the potential side effects of treatment.

Theme: Trust in the physician

Patients expressed trust in the physician's expertise of what should be done to treat their cancer and safeguard survival. Consequently, most patients felt an urge to follow the initially proposed treatment plan, without reconsideration. A patient who had been offered multiple options, expressed disappointment since the physician did not propose 'the single best treatment option.' The treating physician is considered as the one with the required expertise to choose the best option to safeguard survival. Few patients felt incapable to make a choice since they did not experience having the required expertise themselves (*see quote 2, table 3*).

Theme: Burden of treatment

Even though safeguarding survival was dominant in the decision making process, patients who actively made a treatment decision did weigh the expected burden of the treatment against the potential gain in survival. Burden was described by patients as the potential side-effects of treatment (e.g. muscle damage or flushes). Patients also considered the duration of treatment, its impact on daily life (e.g. impact of erectile dysfunction on sexual behaviour) and the impact on physical status (e.g. influence of narcosis on cognition or adjuvant hormonal therapy on polyarthritis) as potential burden. Patients also considered practical issues, such as transportation to the hospital or hospital stay (overnight) as potential burden. However, the latter issues were not mentioned as decisive. As part of the considerations concerning burden, patients expressed that this was inevitable and they reasoned that treatment could always be discontinued if the burden would become untenable. Therefore, patients accepted treatment (*see quote 3, table 3).*

Burden only became decisive if different treatment options were considered to have the same effect on survival. Then patients generally choose the treatment with the least expected burden. As an exception, for one patient who considered accepting adjuvant treatment, the potential gain in survival was overruled by the potential burden of treatment (i.e. side effects). The burden was considered unacceptable, which resulted in abstaining from treatment.

Theme: Feeling safe because cancer will be removed

Some patients who actively made a treatment choice expressed that treatment should give them a feeling of safety. Patients expressed a preference for a treatment that physically removed the cancer as this was felt to be the safest option. They preferred surgery over radiotherapy or ablation over breast conserving treatment for a higher feeling of safety (*see quote 4, table 3)*.

Theme: Treatment option as plan B

For some patients, the fact that they had a ‘plan B’ influenced decision making. Patients described a ‘plan B’ as a safety net to ensure survival if needed, in case primary treatment fails. One patient reasoned that if surgery was unsuccessful, radiotherapy could be an option. As surgery was not a consecutive option if radiotherapy was unsuccessful, this patient preferred to have surgery first. Another patient explained that she was told that the adjuvant therapy would remain available in case of a recurrence. She therefore refused adjuvant treatment initially and considered this treatment as plan B for the future.

Theme: Expectations from previous experiences with treatment

Previous experiences of the patient or others with treatment and side-effects, such as previous operations, radiotherapy for previous disease or flushes caused by menopause, influenced the expectations of treatment. They could either increase the expected burden or provide trust that it was going to be all right. These experiences were part of the considerations, but were not decisive in treatment decision *(see quote 5, table 3)*.

The added value of the GP shortly after diagnosis

All patients experienced contact with the GP shortly after diagnosis as pleasant. Patients described their GP as “easily accessible”, “independent”, “a trusted person”, “familiar to the patient”, and “has time for the patient.” The themes concerning the added value of the GP during the decision making process were “*the GP is up to date with my situation”*, “*experienced support to cope with diagnosis”* and *“experienced support for decision making.”*

Theme: The GP is up to date about my situation

The majority of the patients mentioned that it is important that the GP was aware of their diagnosis. They explained that in case of future health problems for which they expect to visit their GP, it is important for the GP to be fully up to date with their health status. In addition, patients expressed a feeling of trust, knowing that the GP was up to date.

Theme: Experienced support to cope with diagnosis

The majority of the patients experienced support from their GP in discussing the impact of the diagnosis, discussing their feelings and for reflecting on what was about to happen *(see quote 6, table 3)*. Patients expressed "being heard" by the GP. Knowing that the GP was willing to involve other healthcare professionals for additional support if necessary, strengthened this feeling. Most patients considered the psychological support of the GP as of added value in the process of coping with the diagnosis *(see quote 7, table 3).* Some patients however did not express a need for reflection on the diagnosis with the GP, as they reasoned that they had sufficient support in the hospital and therefore felt well prepared, or because they experienced enough support from their significant others.

Theme: Experienced support for decision making

When reflecting on their TOC with the GP, a minority of the patients experienced GP support in their actual treatment decision making process. If SDM support was present, patients mentioned that the GP helped them to understand the information as given by the treating physician. Patients also indicated that their GP answered the remaining questions or provided questions which the patient could ask during the next consultation with the treating physician. Finally, patients said that the GP created awareness of having a choice or confirmed patient's choice for treatment, if it had already been made by the patient *(see quote 8, table 3).*

Some patients did not experience added value of the GP for decision making. For them, the information provided in the hospital was enough to make a decision since they had trust in the expertise of the treating physician. They explained that in their view the GP does not have sufficient knowledge about treatment options. They also wanted to prevent confusion if the GP would suggest a different treatment.

Table 3. Illustrative quotes of the participants.

	Theme	**Quote**
1	Safeguarding survival	“Then I thought again, yes, but I once started this treatment thinking, well…, please stay away (cancer) as long as possible. So, let’s accept everything then.” (PT13)
2	Trust in the physician	“Even if he (treating physician) had offered me a choice, I would have said to him, doctor: ‘What do you think is the best option?’ Because I don’t know. If I should make a choice, I would start guessing, but I can’t judge what’s best. I do not have the expertise and to go back to school is not an option either. So I trust on the doctor’s profession.” (PT03)
3	Burden of treatment	“So, I let him (treating physician) calculate exactly what that meant for me in terms of survival, 5% I found….well significant. But I thought yes, 5 years of feeling bad…look I’ve been feeling bad from the chemotherapy, operation and radiotherapy let’s say three quarters of a year. Okay, that’s what I’m willing to do. Five years is too long for me. So, I thought I’d get started, but if it’s too much of a burden, then I’ll stop.” (PT13)
4	Feeling safe because cancer will be removed	“In the end I chose for ablation, as it felt safer. That wasn’t supported by evidence, but I thought, I really don’t want anything to ever happen in the remaining breast or to be afraid that anything could happen.” (PT12)
5	Previous experiences with treatment	“Well okay, but I also talked to a friend who is a couple of years younger and she said: “I took it (hormonal treatment) for a couple of months and I've had flushes. I was really in the bathroom at night with my wrists under cold water and thinking, ah I feel so miserable.” But yes, well I thought I've had the menopause and the related issues, but well that's over and well if it comes back, than it will never be as bad as it was then. No." (PT08)
6	Experienced support to cope with diagnosis	“Then they say yes you should be able to discuss it with your family, but there are certain things that you think would burden your partner too much and I would like to discuss these with my GP. Look, one day you can handle it very well, but the other day you feel a sort of sad and you think who should I talk to, so that are moments I think my GP should take care of that.” (PT02)
7	Experienced support to cope with diagnosis	“Well, it does make you feel like they're fighting for you. That you're important. I had that feeling, and I still do, that they are not letting you go.” (PT13)
8	Experienced support for decision making	“She (GP) remarked to ask (to the treating physician), “If I do nothing, no radiotherapy, what would be the consequences?” That was a useful suggestion and made it clear to me that I was not offered by my treating gynaecologist with the choice to accept radiotherapy or not. While that was very important to be able to make an informed choice and not to wait and see what I was told to do.” (PT18)

Discussion

This qualitative study aimed to explore the treatment decision making process for cancer patients treated with a curative intent and the patients' experienced added value of the GP in this process. In this curative setting, the process of decision making was dominated by a focus on safeguarding survival. This resulted in accepting (at least part of) the proposed treatment plan. To ensure survival, patients relied on the physician's expertise to guide the treatment decision. Part of the patients did not perceive having a choice in the treatment decision. Only when treatment options had a comparable influence on survival or when adjuvant treatment was discussed, other considerations could become decisive. The GP was generally experienced as of added value for providing psychosocial support, particularly for coping with the diagnosis. In addition, patients appreciated being able to discuss the impact of the diagnosis with a trusted professional who is up to date with their context. Added value, of the GP in the decision making process was confirmed by some, mainly because of the opportunity for reflection and awareness of choice, but opposed by others.

Strengths and limitations

A strength of this study is data saturation we reached for the main themes. In addition, the chance of interpretation bias was reduced by verbatim transcription of the interviews, coding by two researchers, followed by peer review. The main limitation is the potential recall bias in the interviews since some patients were interviewed after substantial time after the diagnosis. Also, we did not check patients' treatment plan in their electronic health record. Therefore, we do not know whether the treatment option(s) as perceived by the patients, corresponds with those as proposed by the treating physician. In addition, we had difficulties with reaching maximum variation in our sample as patients with breast cancer were overrepresented in the GRIP study. This might have limited diversity in our data and therefore potentially limits transferability of the outcomes. Finally, potential selective participation may have occurred, since reasons for non-participation included "too much of a burden" and since our population was of a relatively high education level. This may lead to a group of participants which is relatively fit and well-equipped for a more active approach to cancer treatment decision making. However, since the strong urge for survival was present in all patients, it seems highly plausible that this is the decisive factor among patients with all cancer types treated with curative intent.

Comparison with existing literature

The literature describes that, as the number of treatment options increases, treatment decisions become more complex. Additionally, professionally dominated decision making processes seem to primarily focus on gaining survival, leaving little room for personal preferences.[4-5, 10, 17-21] Our study shows that from the perspective of cancer patients, the decision making process is dominated by a strong focus on survival. It also shows that this focus on survival in a turbulent phase impedes the perception of choice and leads to a tendency to follow the physician's advice without consideration. This paternalistic approach is the opposite of what is advocated for in recent literature, since it may reduce the room for involving personal preference in decision making.

The perception of not having a choice could be due to inadequate communication (initially proposed treatment plan is not presented as an option), a lack of awareness of having a choice (options presented, but not perceived as options), or a lack of awareness to be involved in a critical decision in the short and turbulent time between diagnosis and treatment decision. This confirms earlier reports. Brom et al. (2017) reported that patients' unawareness of having a treatment choice might be the result of insufficient awareness creation by physicians.[4] Jansen et al. (2006) found that one predictor for not experiencing a treatment choice was the patients' preference for a passive role in decision making.[3] The effect of patients' perceived involvement and the perception of having a choice on patient reported outcomes are relevant, but studies assessing these effects show contradictory results.[22-24]

A review by Puts et al. (2015) concluded that, although the reasons of older adults to accept or decline cancer treatment varied considerably between studies, the physician's recommendation is the most consistent decisive factor.[10] Our results confirm that most patients follow the physician's recommendation, with the underlying explanation that patients want to safeguard their survival and that they trust their physician's expertise to achieve this aim. Both our results as well as the review report that the potential burden of treatment is mentioned as a potential reason to decline treatment.[10]

Regarding the role of the GP, Wallner et al. (2016) concluded that increased GP support in decision making was associated with higher decision satisfaction.[25] In 2019, we showed that palliative cancer patients and their healthcare providers appreciated increased GP involvement in SDM, such as for reflection on and preparation for treatment decision.[9] Our more recent study showed that patients often perceive psychosocial support after a cancer diagnosis, but that the need to be supported by the GP in SDM remains generally unanswered (accepted for publication in *British Journal of General Practice*

Open, June 2020). In this current study, among those treated with curative intent, we found that the added value for GP involvement was mostly ascribed to psychological support and only modestly for supporting the treatment decision. Therefore, the added value of psychological GP support seems universally confirmed, but the experienced added value for SDM support, may be more subject to preference and disease and treatment characteristics.

Implications for practice

The results guide GPs on how to support their patients after a cancer diagnosis. The key added value of the GP is in offering psychological support, to help patients to deal with the impact of the cancer diagnosis. Treating physicians and GPs should actively explore patients' preferences for GP involvement in the decision making process. Also, they should be aware that patients do not always perceive having a choice, are focussed on survival and are inclined to follow the treating physicians' advice. Patients should be actively made aware of their share in decision making, as well as the potential role of the GP in the decision making process.

Conclusion

The treatment decision making process of cancer patients treated with curative intent is dominated by the urge to "safeguard survival." As a result there is a strong tendency to accept the treatment plan as offered by the physician. GPs should be aware of their added value in providing psychological support and their potential role to support SDM following a cancer diagnosis.

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Chapter 7

General discussion

Aim of this thesis

The main aim of this thesis was to explore the role of the general practitioner (GP) in shared decision making (SDM) for cancer treatment. In *Part I* we explored patients' preferred and perceived level of involvement in decision making for cancer treatment and patients preferences for-, and the occurrence of GP involvement following a cancer diagnosis. In *Part II* we explored the effects of a Time Out Consultation (TOC) in primary care between a cancer diagnosis and treatment decision in the hospital, for palliatively treated patients (in a pilot study) and for patients treated with curative intent (in the GRIP randomized controlled trial).[1] Finally, we aimed to improve understanding of our findings through qualitative exploration of the treatment decision making process and the added value of the GP in this process.

In this chapter, we reflect on the main findings of this thesis. Subsequently, we discuss the opportunities and challenges we encountered. Hereafter, we provide recommendations to address these challenges and grasp the opportunities, to improve decision making for cancer patients. The chapter ends with considerations for the future and the final conclusions.

Main findings

Part I: Patient and GP involvement in treatment decision making

Chapter 2 showed that patients' preferences for involvement in decision making for cancer treatment vary, but a large majority prefers to be involved in decision making. The concordance between patients' preferred and perceived role needs to be improved, as a significant number of patients perceived a role other than preferred, especially those who preferred a shared role.

In *Chapter 3* we observed a mismatch between patients' needs for GP involvement and the actual involvement of the GP in decision making for cancer treatment. Whereas GPs do discuss patients' worries and considerations, patients' needs to address other SDM related topics (e.g. checking understanding of information, discuss what is important in patient's life and explaining the importance of patient's opinion in treatment decision making) remained largely unanswered. GP care was evaluated significantly better if the GP was the initiator of contact.

Part II: Effects of a Time Out Consultation with the GP

Chapter 4 & 5 showed that, if a TOC in primary care between cancer diagnosis and treatment decision is offered, it is accepted by the large majority of the patients (78% of the palliative patients and 80.5% of curatively treated patients). A TOC for palliatively treated patients was considered of added value for SDM by patients, GPs and treating physicians, for reasons including improved reflection on- and preparation for treatment choice.[2] Even though acceptance of the TOC among curatively treated patients was high in the "GRIP" trial, the observed effects were unsatisfactory. The perceived level of SDM was lower in the intervention group as compared to the control group. No effect on secondary outcomes, such as information provision and self-efficacy was observed. This inverse effect can probably be explained by the fact that the majority of the TOCs (82%) were planned after treatment decision, most likely as a result of the 'fast-track' cancer care path that is currently applied in the majority of hospitals. Consequently, we could not assess the effects of a timely TOC for patients receiving cancer treatment with curative intent.

Chapter 6 revealed that the treatment decision making process of cancer patients was dominated by a focus on safeguarding survival. Most patients followed the treatment plan as presented by their treating physician, which was encouraged by patient's trust in the treating physician in the hospital. Some of the patients did not experience having a treatment choice. Only if survival was considered equal between different treatments options or when adjuvant treatment was discussed, other considerations became subject of discussion in treatment decision making. The main added value of GP involvement was considered to be the creation of a moment of reflection after the cancer diagnosis and the fact that the GP provided psychological support. A GP who is well-informed and up-to-date on patient's medical situation was well appreciated.

SDM in cancer: *opportunities and challenges*

This thesis revealed several opportunities and challenges for the improvement of SDM for cancer treatment.

Patient involvement in SDM

Our finding that the majority of the patients prefers to be involved in decision making for cancer treatment provides a major opportunity to improve treatment- and patient related outcomes. It has been previously shown that patient involvement improves quality of life[3] and satisfaction with treatment decision.[4] Concordance between patients' preferred and perceived involvement also leads to higher quality of life[5], reduced decision regret[6-7] and higher treatment adherence.[8] However, tailoring patient involvement appears to be challenging, given the disconcordance we demonstrated between patients' preferred and perceived level of involvement.

Several challenges obstruct patient involvement, which, if overcome, provide opportunities for improvement. First of all, patients might not always realise the potential value of being actively involved in the decision making process. They tend to underestimate their potential role in decision making, since they are not always aware of the fact that they actually do have a choice. Previous research showed that the creation of awareness of choice by physicians among patients is limited and needs improvement.[9] Also, physicians might think they know the preferred level of involvement of their patient, and thus insufficiently explore patient's preferences.[10] This could lead to disconcordance, as patients' and physicians' perception of the concept of "patient involvement" can differ.[11] It is shown that patients feel more involved if they are better informed and if their preferences for treatment are explored by physicians.[12-13] However, it is also reported that even if a choice is actively offered by physicians, patients might not always experience having a choice.[14] In the rollercoaster following a cancer diagnosis, as pointed out in our and previous research, this is understandable.[9] Also, patients' strong focus on survival, as expressed in our interview study, might impede the wish for involvement in decision making.

The second challenge is the current 'fast-track' cancer care path, which hardly allows any time for reflection on diagnosis and choice of treatment. The haste after diagnosis seems to be based on the general perception that any delay in start of treatment will compromise outcome. Although the current evidence on the effect of postponing treatment on prognosis does not provides us with a conclusive answer[15-20], it seems unlikely that adding a few days to enable adequate treatment decision making does any harm. Added to this, lack of time in consultations may also decrease patient involvement directly.[21] It has been shown that patients who perceive a lack of time are more likely to experience disconcordance between their preferred and perceived level of involvement.[22]

GP involvement in SDM

This thesis revealed that there is a major opportunity for more GP involvement shortly after a cancer diagnosis. Previous research demonstrated that more GP involvement was welcomed by both patients and healthcare providers.[23-28] Also, patients who had contact with their GP reported increased decision satisfaction[29] and added value for SDM.[30] In our study the majority of the patients preferred a TOC between diagnosis and treatment decision, mainly because they welcomed psychological support provided by the GP. However, we also showed that it is challenging for GPs to provide SDM support according to patients' needs, potentially because of GPs' unawareness of their patients' needs.

Timely involvement of the GP also proved to be challenging. In our trial, the time interval between diagnosis and treatment decision, was often too short to plan a TOC. Moreover, in the trial, we left the responsibility to schedule a TOC with the patient, reflecting current daily care practice. This might have caused delay in the planning of the TOC, as patients might be hesitant to consult their GP.[31] In the pilot study, where the planning of TOC in primary care was the responsibility of the treating hospital, planning a TOC in primary care between diagnosis and treatment choice was much more successful. Moreover, for a GP to be adequately involved, timely and sufficient information exchange between the hospital and primary care is essential. This also appeared to be challenging.

GPs experienced lack of knowledge around the biomedical and clinical aspects of the suggested cancer treatment plan, which can add to their suboptimal involvement in decision making for cancer treatment. This was reported previously, and confirmed in our research as a barrier by both patients and healthcare providers.[24, 32] This barrier seems to be based on an incorrect assumption; the role of the GP in decision making is to support the patient in the elucidation of preferences and in answering questions, rather than to compare or to question the medical details of the treatment options.

Table 1. Opportunities, challenges and recommendations for patient and GP involvement in decision making for cancer treatment.

Opportunities	Challenges	Recommendations
Patient involvement The majority of cancer patients prefers to be involved in decision making. There is room for improvement in meeting these preferences.	Lack of time and space for deliberation between cancer diagnosis and treatment decision.	Treating physicians should emphasize the importance of SDM, stimulate deliberation between diagnosis and choice and cancer pathways should facilitate time accordingly.
	Lack of awareness of having a choice among cancer patients – patients' experience of being in a rollercoaster & focus on survival.	Physicians should create awareness of having a choice.
	Insufficient exploration of cancer patients' preferences for involvement.	Physicians should explore cancer patients' preferences for involvement in decision making.
GP involvement Cancer patients appreciate and see added value for GP involvement in decision making - GPs are well equipped to meet these needs, but need to be facilitated to take this role.	Mismatch between cancer patients' needs for and the occurrence of GP involvement.	Physicians should explore cancer patients' preferences for GP involvement.
	Time between cancer diagnosis and treatment decision is too short for timely involvement of the GP and implementation of a TOC.	GPs should be enabled to support their cancer patients in treatment decision making - a collaborative effort between primary and secondary care is required to create time for GP involvement, including guidelines, clear responsibilities, improved information exchange and tools (such as TOC).

GP = general practitioner. Physicians = includes both treating physicians in secondary care and GPs. TOC = Time Out Consultation.

SDM in cancer: *recommendations to improve patient and GP involvement*

Based on these opportunities and challenges we formulated recommendations to improve patient and GP involvement in the decision making process (Table 1).

First, the key to true personalized cancer care is to tailor patient and GP involvement to patients' individual preferences.[33] Therefore, patients should be acknowledged as an equal partner in the decision making process and their preferences should be actively explored and endorsed by treating physicians and GPs. To facilitate and support physicians in exploring patients' preferences, large scale implementation of tools, such as the TOC, is needed.

Second, we recommend that GPs and treating physicians create the opportunity for reflection between diagnosis and treatment decision. Both should stimulate involvement in SDM and recommend patients to actively explore and share their preferences. To overcome fear of delay among patients, treating physicians should emphasize that a short ‘time out’ interval will not negatively affect prognosis. Furthermore, clear and open communication and a feeling of a shared responsibility between primary and secondary care are necessary to enable the GP to play an active role. This includes actively promoting GP involvement by the specialist in the hospital and timely provision of the required information to the GP. The challenge of organising a timely TOC can be countered if written correspondence is supplemented by telephone contact between the primary and secondary care team.[34] It also requires that primary and secondary care should actively align their planning, to enable integration of a time out in primary care in the daily work flow. We recommend that regional healthcare providers make agreements to arrange this.

We recommend further research on the effect of interventions aimed at improving patient involvement. It has been shown that patient involvement is a difficult concept to measure, subjective reflection by patients in surveys might indicate another level of involvement than through direct observation of consultations.[35-36] Also, patients’ wish for involvement is dynamic, preferences might shift over time[37-38], and can differ between stages of cancer.[39] Thus, longitudinal exploration of patients’ preferences and perceptions of involvement is needed. This includes exploring patients’ perceived involvement shortly after the treatment decision to prevent potential recall bias.

We also recommend further research on organisational aspects of timely GP involvement and barriers and facilitators of SDM for cancer treatment. Finally, a limitation in our studies was the overrepresentation of breast cancer patients. Although this is a well-known phenomenon in cancer research[40-41], further research should also include patients with other types of cancer.

SDM in cancer: *the way forward*

This thesis revealed that for better involvement of both the patient and the GP in SDM for cancer treatment, a “one size fits all approach“ is unlikely to be successful. We think three discussions are important for future SDM in cancer care.

The first one is about the ‘right not to be involved’ Although active patient involvement in decision making is required for optimal personalized cancer care, a minority of cancer patients prefers to leave the treatment decision up to the physician. This raises the question what personalized cancer care really is. Does every patient need to be involved in his or her cancer care decisions or does personalised care also imply respecting patients’ preference to leave the decision up to the physician? We think it is important to respect patients’ preferences, provided that the patient is aware of the potential added value of their involvement in decision making. In case patients do not want to be actively involved in the actual decision, physicians do need to actively explore patient’s preferences and priorities in life in order to incorporate these in patient’s treatment plan. This should also include exploring the potential role of relatives or care takers in decision making.

The second discussion is about the benefits of the ‘fast-track’ cancer care pathway. The current trend to shorten the time interval between diagnosis and treatment needs reconsideration, because short delays in treatment are unlikely to affect survival. As adequate SDM requires time, the public and professional assumption that in cancer care “faster is better” should be countered.

Third, we need to rethink the concept of “best treatment choice.” Optimal treatment should consider short term as well as long term effects, in the light of both the individual medical context as well as the personal preferences. Patients have to live longer with both the benefits and burdens of treatment choice, so finding the optimal balance should be the new adage.

After reconsidering the cancer care pathway, it is essential that this pathway is optimally embedded in current regional practice. This is a continuous and iterative process. Within the context of this thesis we implemented a care path including a TOC in three regions in the Netherlands: Utrecht, Helmond and Harderwijk. The implementation was successful, and in one of the regions, the regional multidisciplinary practice guideline now includes that the possibility of a TOC with the GP is offered to every new patient diagnosed with cancer. The implementation in these regions provided us with insights into the best practices. To successfully embed this care path in practice, it was of great importance to use existing regional care structures and communication lines. Besides, resources, time and education for physicians are essential.[42] First, a tool to perform a TOC should be available for GPs. Second, GPs’ “time to talk” with the patient should be reimbursed by healthcare insurances. Third, education about what SDM entails and the potential role of the GP in SDM is needed. For example, the misconceptions about SDM need to be discussed, such as that implementing SDM takes too much time and that GPs lack the required knowledge about cancer treatment.[42-44] These topics should be included in the medical school curriculum and in E-learnings for healthcare providers.

Besides, it is important to educate patients to participate in decision making and empower them to express their preferences for decision making.[43] Cancer patient advocacy organizations can play a role in raise awareness of the potential role of the GP as well as of the patients’ own role in decision making and in activating cancer patients to choose whoever they want to be involved. One example of a successful campaign is the “Ask 3 questions” campaign, in which the patient is provided with 3 questions regarding his/her treatment choice[45] to empower them to be involved in a tailored decision making process.[46]

Future perspectives

The ongoing developments in cancer diagnostics, treatment and follow-up care will continuously influence the care path of the cancer patient. A quick glance into the future shows us that the developments we outlined in this thesis are only the beginning. Providing patient centered cancer care, at the right place at the right time, will become even more important. This care will be provided by a medical team that transcends current “primary and secondary care” boundaries. The patient will become an acknowledged member of this team. Therefore, patients as well as healthcare professionals should get used to the fact of being a team player. Within this team, the role of the GP as coordinator of care will be more prominent.

In this process, the shift from a paternalistic approach with “doctor knows best” to a patient centered approach with “together with the patient we know best” will continue. The role of the physician will shift from “god to guide”, in which physicians no longer decide about the future of the patient, but rather guide the patient in making the optimal decision. Patients’ empowerment to decide about what care is best for them will continue to grow. In this process, transparency and access to medical information will become even more important. The new generation of active patients will grow up in a fully digital world, with access to their medical records and (online) information everywhere and always. Patients will need support to use this information to their benefit, without being harmed by the abundance of complicated medical information. The importance of E-health will grow, as recent studies show the beneficial role of E-health on outcomes such as experienced support.[47] Although these developments can be beneficial for cancer care, we have to be cautious and bear in mind that patients’ preferences cannot yet be fully predicted by algorithms.

Final conclusion

To conclude, cancer care needs to be tailored to patients’ preferences. The mismatch between patients’ preferred and perceived level of involvement and their unanswered call for more GP involvement in SDM demand improvement. Active patient participation in SDM and timely involvement of the GP are challenging, but if more awareness of its importance is created by- and among both treating physicians and GPs, this can be achieved.

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