University of Groningen

Communication in oncology

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DOI:
[10.33612/diss.168493812](https://doi.org/10.33612/diss.168493812)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2021

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):
Stegmann, M. (2021). *Communication in oncology: positioning the general practitioner in shared decision making for patients with cancer*. [Thesis fully internal (DIV), University of Groningen]. University of Groningen. <https://doi.org/10.33612/diss.168493812>

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Communication in oncology

**Positioning the general practitioner in shared
decision making for patients with cancer**

Mariken Stegmann

De studies die worden beschreven in dit proefschrift zijn gefinancierd door KWF Kankerbestrijding en Stichting Stoffels-Hornstra.

Stichting Stoffels-Hornstra

De publicatie van dit proefschrift werd financieel ondersteund door de SBOH, het Universitair Medisch Centrum Groningen, De Rijksuniversiteit Groningen en onderzoeksschool SHARE.

De omslag en hoofdstukafbeeldingen zijn ontworpen door Maartje de Goede.
Print: Ridderprint | www.ridderprint.nl

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Communication in oncology

Positioning the general practitioner in shared decision making
for patients with cancer

Proefschrift

ter verkrijging van de graad van doctor
aan de Rijksuniversiteit Groningen
op gezag van de
rector magnificus prof. dr. C. Wijmenga
en volgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op

woensdag 2 juni 2021 om 14.30 uur

door

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geboren op 19 april 1986
te Graafstroom

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Chapter 1

General introduction

Introduction

The objective of this thesis is to analyse communication with, and about, patients who have cancer, focusing on the role of the general practitioner (GP). It was anticipated that the findings of this analysis would then allow me to make suggestions to improve the communication process. The results of two studies form the basis of this analysis: 1) OPTION, which focused on shared decision-making (SDM); and 2) PION which focused on information exchange between doctors. In this first chapter I will give an introduction to the topic. After describing the epidemiology of cancer and the effects of cancer treatment, I will outline the basics of shared decision making and the role of the different healthcare providers in the oncological care at this moment. Thereafter I will shortly describe the research projects that form this thesis.

In chapter 2-7 the research projects will be presented more extensively and in chapter 8 I will summarise all findings and present the implications of this thesis for the communication process.

Epidemiology of cancer

In recent years, cancer has become the leading cause of death in high income countries and it is now Globally the incidence of cancer is estimated to be 18.1 million cases in 2018, with 9.6 million cancer deaths.¹ In European countries, these numbers are 3.9 million and 1.9 million respectively.² For an individual, this means that there is a lifetime risk of about one in three for getting cancer and one in six for dying from cancer, responsible for approximately 55% of deaths.³ The most common cancer sites in European countries, excluding non-melanoma skin cancer, are breast cancer, colorectal cancer and lung cancer.² The epidemiology of these cancer types is described in the appendix. Like almost all other types of cancer, these cancers are more common among older people (>65 years). The overall cancer incidence is 11-fold higher in these persons than in younger people.⁴ Approximately 60% of all cancers and 70% of all cancer deaths occur in people older than 65 years.⁴ This proportion is expected to increase even more in the coming years because of an ageing population.¹ Cancer may cause several physical symptoms depending on the localisation of the tumour as well as side-effects like fatigue. Furthermore, cancer is also associated with problems like anxiety, depression and distress. More information about the symptoms of breast cancer, colorectal cancer and lung cancer is provided in the appendix. Both physical and psychosocial symptoms can have important effects on the quality of life of patients with cancer. However, not only the disease itself, but also cancer treatment can have a major impact on patients, both in a positive and a negative way.

Effects of cancer treatment

The main aim of anticancer related treatment is to extend life. For curative treatment, the aim is to give patients the same life expectancy as non-cancer patients. For palliative treatment, extending life means improving survival compared to patients without treatment, which can be expressed as a higher median survival time or a higher 1-year survival rate. However, cancer treatments may also have other positive effects through the reduction of physical symptoms such as reducing dyspnoea by chemotherapy in lung cancer. Cancer treatment can also have negative effects. Common side effects include fatigue (all treatments), pain (surgery, chemotherapy) and other physical symptoms (e.g. nausea due to chemotherapy; early menopause due to hormonal therapy; diarrhoea due to chemotherapy, targeted therapy and immunotherapy; infection due to surgery and immunotherapy).^{5,6} In

addition to having cancer, therapies can also cause or increase symptoms of depression and/or anxiety. Furthermore, cancer treatment has a social impact through reducing independence, e.g. by being hospitalised or being temporarily bedridden. These problems can be of great importance, in particular for older patients.

As it is impossible to predict which patients will benefit from cancer treatment, international guidelines suggest discussing adjuvant systemic treatment with patients if that particular treatment yields at least 3-5% absolute benefit in terms of overall mortality. However, this also implies 95-97% overtreatment.⁷ When the potential risks of a treatment are severe or highly unwanted, this can influence the risk/benefit assessment for treatment. This may explain why older patients are sometimes not treated according to the recommended regimes.⁸

Shared decision making

Because cancer treatment has both positive and negative effects, decisions about cancer treatment often strongly depend on patients' preferences, and are therefore preference sensitive. Preference sensitive decisions are decisions for which there is no obvious 'best' treatment. Treatment choice then depends on a necessarily subjective trade-off between the benefits and side-effects of treatment alternatives.^{7,9}

For older patients, treatment decisions are more preference sensitive because the positive effects of treatment can be smaller and the negative effects may be greater than in younger patients. For older patients the effects of a specific cancer treatment on survival are often not known, because older patients are generally excluded from clinical trials of new treatments. Even if the effect on survival would be the same as in younger patients, this can be of less consequence because older patients have a shorter life-expectancy. Negative treatment effects, on the other hand, can be more serious due to pre-existing frailty caused by aging itself and/or comorbidity.¹⁰ A systematic review showed that treatment complications are more common in frail patients, including intolerance to cancer treatment because of side effects and postoperative complications.¹⁰ Older patients might therefore value the importance of positive and negative effects differently than younger patients. However, there is no literature about this topic, nor on how these considerations may change as the illness progresses. Research in older non-cancer patients has shown that for many older patients maintaining independence is more important than extending life.^{11,12}

Decisions and empowerment

For all preference sensitive decisions, it is advised that both healthcare provider and patient decide on the most appropriate treatment option. This process is called shared decision making (SDM). Emanuel & Emanuel already stated that there are four models of patient-healthcare provider interaction (paternalistic, informative, interpretive and deliberative).¹³ Each model has a different concept of the patient's autonomy and the role of the healthcare provider. They concluded that although different models may be suitable in different settings, the deliberative model is generally the ideal model. The aim of the interaction between healthcare provider and patient in this model is to help the patient determine and choose the best health-related values that can be realised in the clinical situation. The patient should be empowered to consider, through dialogue, all health-related values, their worthiness and their implications for treatment.¹³

In line with this, recent research has shown that most patients prefer to be involved in treatment decisions.^{14,15} Patients with cancer express a higher preference for active

participation in this process than other patient groups, especially when decisions are related to quality of life.^{14,16}

Patients can only fulfil their role in a deliberative model and thus be part of a shared decision-making process when they can act as an equal conversation partner with the healthcare provider. Typically, a shared decision-making procedure consists of several steps (box 1).¹⁷ First, the doctor announces that a decision has to be made. It should be explained that doing nothing or keeping the status quo is also an option. In the second step, the options are described, as well as their benefits and potential side-effects. The third step is to discuss the patient's preferences and finally, in the fourth step, the decision is made. In the second step the main task of the healthcare provider is to provide information, while in the third step active listening is important.¹⁸ In particular in this third step the input of the patient is essential for the quality of the process. This requires patient empowerment.^{19,20} In the context of shared decision making, empowered patients are confident to be able to have a role in the decision making process, which is called decision self-efficacy.¹⁹ Although there is ample evidence for interventions to promote empowerment of patients with chronic diseases,²¹ there exists a scarcity of literature on patients with cancer facing a treatment decision.

Shared Decision Making (SDM) procedure

- 1) Announcement decision has to be made
- 2) Explanation of options
- 3) Discussion of patient's preferences
- 4) Shared decision is made

Box 1. Steps of shared decision making (SDM) procedure

Decision aids

To support the second and third step of SDM, decision aids may be implemented. Most decision aids are disease-specific and focus mainly on providing clear information about the benefits and side-effects of different treatment options. To explore patients' preferences in an encompassing non-disease specific way, the Outcome Prioritisation Tool (OPT) can be used. The OPT was first described in 2011 and is an instrument consisting of four visual analogue scales.²² Each scale represents an universal health outcome (Figure 1). These outcomes have been defined as: extending life, maintaining independence, reducing pain and reducing other symptoms. The healthcare provider invites the patient to value and prioritise the different outcomes. Each outcome can be rated 0-100, with a higher score meaning higher importance. Although the instrument is widely used in practice, literature regarding validity, feasibility, and effects is scarce.

Between the third and fourth step, there is often a need for reflection and deliberation.¹⁸ For patients with a serious disease, this need may conflict with their concurrent sense of urgency to start treatment. Furthermore, logistic processes at hospitals can make it difficult to realise such a 'time out period'. However, recently there has been a call from the government, insurances and patient organisations to facilitate time out consultations.²³ These conversations, aimed at reflection and deliberation, can be conducted with loved ones and/or different healthcare providers, in particular the general practitioner (GP).

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

Healthcare providers

Patients with cancer often interact with several healthcare providers. After referral to the hospital, all patients have an attending medical specialist who is responsible for diagnosis and treatment plan (e.g. a pulmonary oncologist). During both the diagnostic process and the treatment phase, other medical specialists may be involved (e.g. surgeon, radiotherapist, medical oncologist). Furthermore, most patients have a case-manager (e.g. nurse practitioner) who is the accessible key person during treatment. In the case of specific patients, other healthcare providers (e.g. dieticians, nurses, physiotherapists) may be involved.

Role of the GP in the Dutch healthcare system

As in several other Western countries, all patients in the Netherlands are registered with a GP. Dutch GPs provide near and accessible primary health care and offer a 24/7 care service. They often have a long and invested relationship with their patients, in particular with older patients. The GP also acts as a care coordinator, being responsible for managing all their patients' medical data and for liaising with specialists from different services.

Because of this central position in the healthcare system, Dutch GPs also play an important role for patients with cancer throughout the cancer trajectory. After their role in screening and early diagnosis,²⁴ most GPs have contact with their patient shortly after diagnosis. Therefore they are sometimes mentioned as the best positioned health care provider for a time out consultation during the deliberation phase between the third and fourth step of the shared decision making process in the hospital.²⁵ Because of their longstanding relationship with the patient, GPs are often optimally informed about the patient's medical and psychosocial history, personal preferences and individual coping and communication style. In this way they can help patients to weigh the pros and cons of a specific treatment.^{25,26} However, literature about the feasibility and effects of these consultations is scarce as is information about actual use of these consultations.

After diagnosis, GPs aim to provide continuity of care during cancer treatment. Patients with cancer who are treated with a curative intent have more frequent contact with their GP compared to patients without cancer in the first year after diagnosis.^{27,28} The GP is the first contact for new physical problems, but can also provide emotional support for patients and family members.^{24,26} Similar studies are not available for patients with cancer treated with a palliative intent, but it is likely that those patients will also have frequent contact with their GP during treatment. Due to parallel contacts of patients with both the GP and the medical specialist, communication between primary and secondary care is important.

Communication between medical specialist and GP

Communication between GPs and medical specialists often happens through written digitalised correspondence. A special guideline for both GPs and medical specialists, provides suggestions for adequate communication.²⁹ Unfortunately, studies have shown that both GPs and medical specialists are not very satisfied about their mutual communication.^{30,31} It is unknown which information is shared or not shared and which information is deemed essential by the different healthcare providers. However, according to both patients, GPs and medical specialists, inadequate communication can lead to discontinuity and suboptimal quality of care.³²⁻³⁴ This makes mutual communication and collaboration of healthcare providers an important opportunity to improve healthcare for patients with cancer.

Thesis outline

The objective of this thesis is to analyse the communication around cancer patients and the role of the general practitioner (GP) in this process,. We studied two types of communication: GP-patient and GP-medical specialist. Concerning the first type, we aimed to analyse the added value of a conversation about treatment goals with the GP in the process of shared decision making for patients with cancer. The second aim was to analyse the communication between GPs and medical specialists about patients with cancer.

Therefore, in this thesis I will present the results of two research projects: 1) The OPTion project which focuses at shared decision making and 2) PION which focuses at information exchange between doctors. The ultimate aim is to make suggestions for improvements in different types of communication.

In chapter 2, I will describe the protocol of the OPTion-study, a randomised controlled trial (RCT). In this study older patients with a palliative cancer diagnosis were randomly assigned to either a care as usual group or an intervention group. The intervention was an OPT-conversation with their GP, using the Outcome Prioritisation Tool to discuss treatment goals. In chapter 3, the instrument OPT and its use are described in detail, as well as a review of the existing literature about this instrument. In chapter 4, I will report the results of the OPTion-RCT: the effect of the aforementioned OPT-conversation on patient empowerment and on symptoms of anxiety, depression and fatigue. In chapter 5, I will describe treatment goals of older patients with non-curable cancer, whether they changed over time, and what triggered these changes..

In chapter 6, I will present the first part of the PION-study (Patient Information exchange in ONcology). In this qualitative study we analysed medical files containing referral and specialist letters of patients with lung, breast or colorectal cancer. We examined what information was shared and what information was not shared between primary and secondary care during diagnosis and the initial therapy phase. In chapter 7, the second part of the PION-study, I will describe a Delphi study with panels of specialists, GPs and patients in which they decided which items are essential and which items are redundant in their correspondence.

In the last chapter, chapter 8, I will provide a summary and discuss the findings and their implications.

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Chapter 2

Study protocol for the OPTion randomised controlled trial on the effect of prioritising treatment goals among older patients with cancer in a palliative setting

Adapted from Stegmann ME, Schuling J, Hiltermann TJ, Reyners AK, Burger H, Berger MY, Berendsen AJ. Study protocol for the OPTion randomised controlled trial on the effect of prioritising treatment goals among older patients with cancer in a palliative setting. *Maturitas*. 2017 Feb;96:84-88.

Text based on this chapter was also published as: Mariken Stegmann, J. Schuling, Annette Berendsen. Welke behandeling willen ouderen met kanker? *Huisarts en Wetenschap*, 31 maart 2016.

Abstract

Purpose: Traditionally, general practitioners (GPs) are not involved in cancer-related treatment decisions, despite their often long relationship with patients, and their unique position to explore patients' values, especially with older patients. Therefore, we designed a randomised controlled trial to study the effect, on self-efficacy related to treatment decisions, of a conversation about treatment goals between GPs and patients with cancer in a palliative setting.

Methods: We aim to include 168 patients aged ≥ 70 years with a diagnosis of non-curable cancer, due to consult their oncologist about treatment options. In the intervention group, patients will consult their GP using an Outcome Prioritisation Tool (OPT). The control group will receive care as usual. The primary outcome will be the score on a decision self-efficacy scale after the consultation with the oncologist. Secondary outcomes will be symptoms of depression, anxiety, or fatigue. In an embedded observational study of the intervention group, we aim to assess the prioritisation of treatment goals (i.e., OPT scores), and their determinants, over a six-month period.

Conclusions: The OPTion study should provide relevant information about the effect on self-efficacy of a consultation between GPs and older patients with cancer, concerning preferred treatment goals in a palliative setting.

Dutch Trial Register NTR5419

Decision making in cancer

Illustrative case

Consider the case of Mrs. Johnson, a 79-year old widow who valued her independency and loved the outdoor lifestyle, who despite having sold her field, continued to live at her old farm. When she presented to her general practitioner (GP) with persistent dyspnoea, this led to a standard sequence of events. She was sent to the pulmonologist for further assessment, at which point an x-ray showed features suggestive of lung cancer. This, in turn, prompted additional diagnostic tests that confirmed stage IV lung cancer and led to medical intervention with chemotherapy. Although her initial response was favourable, fever developed after the second round of chemotherapy. Per the medical care plan, this prompted contact with an oncologist who admitted her to hospital, and she died two days later. In this case, all aspects of her care were appropriate and consistent with current standards of care, and her family was content with the care provided. However, the question was raised: did this patient truly want to receive chemotherapy?

Healthcare providers in cancer care

Worldwide, an estimated 14.1 million new cancer cases and 8.2 million cancer deaths occurred in 2012, and the incidence is expected to increase as a result of population aging.¹ The percentage of patients with cancer who are aged 65 years or older is, therefore, expected to increase to as high as 70% by 2030.²

The care of patients with cancer is complex and involves many different healthcare providers.³ At present, GPs are formally involved before referral to specialist oncology services and during end-of-life care,⁴ while in the other phases the role of the GP is not well defined.^{3,5} Nevertheless, it is now increasingly recognised that GP involvement is essential at all stages of cancer treatment to optimise patient outcomes, not only through their role in coordinating care but also through their ability to help when making complex treatment decisions and providing psychological support.^{5,6}

Treatment decisions in older people

Complex treatment decisions are often necessary for older patients with cancer because they frequently have multiple comorbidities and shorter life expectancies. These factors may unfavourably influence the risk/benefit assessment before treatment, and could explain why older patients are sometimes not treated according to the recommended standards of care.⁷ Multiple studies have shown that reduction of mortality was less important for older patients with cancer than improvement or maintenance of function.^{8,9} Medical doctors play a very important role in treatment decisions made by older patients.¹⁰ The process of shared decision making (SDM) involves the patient and a medical doctor coming together, recognizing that a decision has to be made, discussing the available options, discussing the patient's preferences, and ultimately, making or deferring a decision.¹¹ Patients with cancer express a higher preference for active participation in this process than other patient groups,¹² especially when decisions are related to quality of life.¹³

There is sufficient evidence that SDM improves knowledge of the options and outcomes among patients, and can lead to more accurate expectations.¹⁴ Besides, SDM may improve patient confidence and empowerment, which can be measured by decision self-efficacy.¹⁴ This is, the confidence or belief in one's ability to make decisions, including the ability to

participate in SDM.¹⁵ Self-efficacy is increasingly viewed as being central to the way patients with cancer cope with their disease, its treatment, and the decisions they make.^{16,17}

The OPTion study

Rationale

Oncologists often lack prior knowledge of the patient and have only limited time to discuss treatment options, making SDM difficult to implement. The GP, by contrast, is better placed to talk about treatment with patients because they share a longer relationship, with a greater understanding of both the patient and his or her context. We therefore reasoned that the SDM process would benefit from GPs helping to prepare patients for conversations with their oncologist. In palliative settings, we think this might increase patient self-efficacy and facilitate personalised treatment decisions when used in collaboration with routine oncology consultations. Therefore, we aim to develop a randomised controlled trial of the effect on decision self-efficacy of structured conversations between GPs and older patients with cancer in palliative settings. We propose that these conversations will focus on generic treatment goals just before a treatment decision needs to be made, and that they should be performed using a standardised format.

Figure 1. Graph showing the proposed measurements at the various time points.

Setting and study design

As in several other Western countries, Dutch GPs have a long relationship with their patients and they provide 24/7 primary care service. The GP also acts as a care coordinator, being responsible for managing all of their patients' medical data and for liaising with specialists from different services.

This study is designed according to the SPIRIT guidelines¹⁸ and planned to be a two-armed parallel group pragmatic randomised trial.¹⁹ We will study the effects of GPs eliciting preferred treatment goals on patient self-efficacy, among older patients with cancer in a palliative setting, in comparison to care as usual. The primary endpoint is the perceived self-efficacy directly after consultation with an oncologist during which the choice for a specific treatment has been made (Fig. 1).

Participants

Recruitment

Eligible patients will be recruited by oncologists from eight locations of five hospitals (one academic and four non-academic) in the north of the Netherlands when a new treatment decision is to be made (e.g. at the moment of diagnosis). The oncologist will then check the inclusion and exclusion criteria, and if suitable, will provide interested patients with written information about the study and ask for permission to send their contact details to the researchers.

Inclusion and exclusion criteria

Participants will be required to be aged 70 years or older, have non-curable cancer, and be in a position requiring them to make a new treatment decision. We will exclude patients if they have a life expectancy of less than three months, have a severe psychiatric disorder; are unable to fill out questionnaires; or have a hematologic malignancy (because the course of these diseases differ from solid tumours²⁰). Patients formerly treated curatively will not be excluded, neither will patients with other comorbidities.

Randomisation

After receiving informed consent, patients will be consecutively allocated to the intervention or care as usual groups. The 1:1 allocation sequence will be produced by a web-based randomisation application using random permuted blocks with randomly varying block sizes stratified by hospital. Allocations will then be kept in a locked file on a computer system, inaccessible to the recruiting oncologists and the researchers.

Intervention

Care in intervention group

When patients are randomised to the intervention group, they will be asked to arrange an appointment with their GP before the next scheduled consultation with their oncologist. During this appointment with the GP the diagnosis of cancer in a palliative setting, and its consequences will be discussed. Using a specifically designed "Outcome Prioritisation Tool" (OPT), also called the "preference slider," preferred treatment goals will then be explored.^{9,21} This OPT is a card with four visual analogue scales, each representing a generic treatment goal (Fig. 2): life extension, preserving independence, reducing pain, and reducing

other symptoms. The GP will invite the patient to value and rank the different goals according to the trade-off principle: that is, that goals can- not be of equal importance. The four values, each representing the importance of a goal, then form the “OPT score.”

Afterwards, the patient and oncologist can then take these preferences into account when discussing treatment options.

Bias in the GP might occur because randomisation will only be performed at the patient level. To compensate for this, each GP will be asked to use the OPT only in patients from the intervention group. We also think that, because patient recruitment will be from eight different locations, there is only a small chance that a GP will have more than one patient included in this study.

Figure 2. Example of the Outcome Prioritisation (OPT) Tool. Note that in this example of the OPT, the most important goal for this patient was to maintain independence.

Training of GPs

When a patient is included and allocated to the intervention group, the researcher will contact the patients’ GP to give extensive information about the study and to request participation. After agreement, the GP will receive the OPT together with written information and a link to the OPT-website (optool.nl) where, among other information, a

short instructional video is available. As the OPT is very easy to use, as shown in earlier research,^{9,21} we believe that more training will be unnecessary.

When a GP will be unable to participate in the study temporarily, another GP from the project group will perform the OPT conversation. When a GP will not want to participate at all, patients will complete their questionnaires as if they had been randomised to the control group. Analysis in the intervention group will be on an intention-to-treat basis, while analysis in the control-group will be on a per-protocol basis.

Care as usual

Patients in the care as usual group will not be asked to contact their GP, but will be allowed to seek the care of their GP at their own discretion without being subject to the OPT-based consultation. These contacts will be recorded to study potential bias.

Outcomes

Baseline characteristics

Patients will be asked to provide their age, gender, education, living situation, social network, and dependency in activities of daily living. Furthermore, information about tumour type, tumour size, tumour location, tumour stage, performance score, comorbidities, and treatments will be extracted from hospital and GP records.

Primary outcome

The primary outcome is patient empowerment, as measured by the decision self-efficacy (D-SE) scale directly after consultations with oncologists when treatment choices have been made. Decision self-efficacy is described as self-confidence or belief in one's ability to make decisions, including participating in SDM. The scale was originally developed in Ottawa, Canada, in 1996,^{22,23} and has been validated in patients with cancer in Denmark.²³ It consists of 11 items that can be scored on 0–4 point scales. Prior to the study, the questionnaire was translated into Dutch, and the translation was validated by back-translation into English.

Secondary outcomes

The presence of anxiety and depression symptoms will be measured using the Hospital Anxiety and Depression Scale (HADS).²⁴ The HADS is used in research for patients with cancer, and has shown adequate psychometric properties in this specific group.²⁵ Fatigue will be measured by the multidimensional fatigue inventory (MFI-20).²⁶ This self-report scale consists of 20 items in five dimensions: general fatigue, physical fatigue, mental fatigue, reduced motivation, and reduced activity. It was developed in Dutch in 1995 and has been validated in patients with cancer.²⁷ In patients with cancer, a subscale difference of two points is usually considered the minimally clinically important difference in change over time.²⁸

During the study, scores for both secondary outcomes (HADS and MFI-20) will be made available to the oncologists and GPs of all participants.

Blinding

We cannot blind patients, GPs, or researchers because of the nature of the intervention and because patients from the intervention group will report OPT scores. However, data analysis will be performed by researchers blinded to patient allocation.

Sample size

In previous research in patients with cancer, a mean of 36 points (standard deviation 9 points) was found on the D-SE scale, the primary outcome of the study.²³ Given that half a standard deviation is considered clinically relevant in health-related quality of life studies, we aim to detect an effect of at least 4 points (effect size 0.44) on this scale.²⁹ Concerning two sided testing, with an alpha of 0.05 and a beta of 0.2 (power 0.8); we would therefore require 80 persons in each group. Because comparison between groups is to be done immediately after consultations, we expect a low rate of loss to follow up. Accounting for a 5% loss, we aim to include 168 patients in total, or 84 per group. To ensure adequate participation, we will recruit participants from five hospitals (eight locations). Both the doctors and participants will receive a newsletter regularly.

Statistical analysis

All data will be entered in a secured digital data management system. When data collection will be completed, all data will be extracted into a statistical software package. Descriptive statistics will be used to compare groups at baseline. The effect of using the OPT on decision self-efficacy will be primarily by comparison of the mean D-SE values, using an independent t-test. The analysis of treatment effects will be on an intention- to-treat principle; that is, participants will be analysed by their randomisation, regardless of the actual intervention received. Per- protocol analyses (based on completion of the intervention) will be conducted to investigate whether deviations from the protocol influence the effect estimates. If baseline differences appear in the per-protocol analyses, they will be adjusted for by linear regression modelling. In this model treatment arm, the hospital site and the unequally distributed baseline variables will be included as independent variables and self-efficacy as the dependent variable. Linear regression will additionally be used to explore the modifying effects of gender, age, anxiety, depression, fatigue, tumour type, educational level, performance score, and social network, by including and testing their respective interactions with the treatment group.

Embedded observational study

An observational prospective cohort study of the patients in the OPT group will be performed to explore the changes in preferences for treatment goals. The first OPT scores will be considered the baseline assessment, and patients will contact their GPs again at 4 weeks, 3 months, and 6 months thereafter to reassess their OPT scores. As secondary outcomes, the D-SE scale, HADS, and MFI- 20 will be completed at each time point (Fig. 1). OPT scores and changes over time will be described, and the association of the OPT scores with gender, age, anxiety, depression, fatigue, tumour type, disease course, educational level, performance score, and social network will be explored in a hypothesis-generating manner. Finally, the experiences with the OPT of both patients and GPs will be assessed using a short questionnaire. Because of an expected survival rate of around 60%, we expect the number of patients that will complete this observational study to be around 50.

Discussion

Particularly when applied to older patients in a palliative care setting, it is important that patients be empowered to make decisions in collaboration with a medical doctor. In the past, some research was conducted into SDM and related tools. However, to our knowledge, this will be the first study in this setting to include the GP in preparing the patient for SDM.

In our intervention, the GP has a conversation with the patient about his or her preferences for generic treatment goals before making a treatment decision in collaboration with the oncologist. The GP's knowledge of the patient's coping with former episodes of sickness may help in eliciting his actual priorities. Besides, patients value the fact that the GP often has a long-term relationship with the patient and has a practice that can be accessed in their own neighborhood.³⁰ An OPT-based conversation can serve as a first step in the end-of-life process that will often be coordinated by the GP. Furthermore, the conversation can facilitate improved communication and collaboration between primary and secondary care, which is important to patient care.³ We anticipate that this study will add to the limited evidence about the use of SDM among older patients with cancer in the palliative setting. This topic is considered highly relevant because of the aging of the population and rapid expansion of treatment possibilities in cancer care.

Additional information*Conflict of interest*

The authors declare that they have no conflict of interest.

Funding

This work is supported by a grant from the Dutch Cancer Society Fund (KWF Kankerbestrijding) (RUG 2014-7273). The sponsor had or has no role in the study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication.

Ethical approval

The Institutional Review Board of the University Medical Centre Groningen (UMCG) reviewed the protocol and informed consent will be obtained from participants.

Acknowledgment

We thank dr. Robert Sykes (www.doctored.org.uk) for providing editorial services.

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Chapter 3

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

Adapted from: Stegmann ME, Festen S, Brandenburg D, Schuling J, van Leeuwen B, de Graeff P, Berendsen AJ. Using the Outcome Prioritization Tool (OPT) to assess the preferences of older patients in clinical decision-making: A review. *Maturitas*. 2019 Oct;128:49-52.

Abstract

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

Introduction

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

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

The Outcome Prioritisation Tool (OPT)

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

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

1. Introduce the instrument and explain the reason for using the instrument.
2. Explain the different health outcomes to the patient.
 - Extending life.
 - Maintaining independence.
 - Reducing or eliminating pain.
 - Reducing or eliminating other symptoms, such as dyspnoea, nausea or itching.
3. Explain the trade-off principle: outcomes have to be prioritised in order of importance, if a patient prioritises one outcome (for example extending life), this means that they are willing to give up something on another outcome (e.g. maintaining independence).
4. Invite the patient to prioritise the health outcomes. During this process, patients are invited to explain what is important to them and why specific choices are made.
5. Check whether the results actually describe the patient’s preferences.

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

Literature review

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

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

In PubMed the search terms *Outcome priorit* tool* and *Health Outcome prior** were used and in Web of Science we searched for articles that cited one of the development articles.^{11,14} The inclusion criterion was the use of the OPT.

Table 1. Characteristics of the included studies

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

We have not applied exclusion criteria. For all included studies, we extracted the following characteristics: design and aim, setting, characteristics of participants, the primary outcomes, how OPT outcomes were prioritised, and information about experiences. The search, performed on November 6 2018, yielded four manuscripts describing three studies,^{15–18} and a protocol article¹⁹ which we will not describe. Two authors (MES and SF) assessed the quality of the studies as moderate using the GRADE-system.²⁰ Characteristics of all studies are shown in Table 1.

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

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

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

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

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

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

Summary

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

Practice points

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

Research agenda

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

Highlights

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

Additional information

Acknowledgements

The authors would like to thank Daniël Bosold (djText) for textual editing.

Contributors

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

Conflict of interest

The authors declare that they have no conflict of interest.

Funding

No funding was received specifically for the preparation of this review.

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Chapter 4

Prioritisation of treatment goals among older patients with non-curable cancer: the OPTion randomised controlled trial in Dutch primary care

Adapted from: Stegmann ME, Brandenburg D, Reyners AK, van Geffen WH, Hiltermann TJN, Berendsen AJ. Prioritisation of treatment goals among older patients with non-curable cancer: the OPTion randomised controlled trial in Dutch primary care. *Br J Gen Pract.* 2020 Jun 1:bjgp20X710405.

Abstract

Background: Older patients with cancer often find it difficult to take part in shared decision making.

Aim: To assess the utility of the Outcome Prioritisation Tool (OPT), designed to aid discussion with a patient in regards to their treatment goals, to empower patients with cancer through structured conversations about generic treatment goals with GPs.

Design and setting: A randomised controlled trial of 114 Dutch participants recruited between November 2015 and January 2019, aged ≥ 60 years with non- curable cancer who had to make a treatment decision with an oncologist. The intervention group used the OPT while the control group received care as usual.

Method: The primary outcome was patient empowerment using the score on the decision self-efficacy (DSE) scale. Secondary outcomes were symptoms measures of fatigue, anxiety, and depression. The experiences of participants were also explored.

Results: No effect was found on patient empowerment between the OPT group ($n = 48$; DSE 86.8; standard deviation [SD] = 18.2) and the control group ($n = 58$; DSE 84.2; SD = 17.6; $P = 0.47$). In the OPT group, although statistically non- significant, fewer patients had low empowerment (18.8%, $n = 9$ versus 24.1%, $n = 14$; $P = 0.50$), but they did have statistically significant lower mean anxiety scores (6.0, SD = 4.6 versus 7.6, SD = 4.4; $P < 0.05$) and less mild fatigue (58.8%, $n = 30$ versus 77.2%, $n = 44$; $P = 0.05$). Overall, 44.8% ($n = 13$) of patients indicated that the OPT- facilitated conversation helped them make a treatment decision, and 31.1% ($n = 14$) of the GPs reported that they gained new insights from the conversation.

Conclusion: An OPT-facilitated conversation about generic treatment goals between patients and their GPs is associated with less anxiety and fatigue, but did not show statistically significant improvements in patient empowerment. Adding the OPT to routine care might ensure more patient-tailored care.

Introduction

Of the estimated 3.9 million new cases of cancer in Europe in 2018,¹ about 75% were in patients aged ≥60 years.² Treatment decisions for such older patients often involve a complex trade-off between risks and benefits. This reflects their limited life expectancy, increased frailty, and greater number of comorbidities, which increase the risk of complications and functional decline after treatment.³

Tailored decisions require that a patient’s preferences and goals should be taken into account.⁴ Though most patients with cancer consider shared decision making to be important,⁵ older patients often find this approach difficult.⁶ A perceived barrier is that the expert position of the oncologist leads to a power imbalance in the doctor–patient relationship.⁷ This can lead to feelings of low empowerment in the patient, which makes it difficult for doctors to estimate the health goals of a given patient.⁸ Consequently, personal preferences may not always be taken into account.⁹ Several decision aids have been developed to rectify this problem,¹⁰ with most being designed to clarify the risks and benefits of specific diseases and their associated treatments. The non-specific Outcome Prioritisation Tool (OPT) has been validated for discussing generic treatment goals, such as extending life (Figure 1).^{11,12}

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

Traditionally, cancer management is provided by oncologists and in the Netherlands most patients also visit their GP during diagnosis and treatment.^{13,14} In countries where the GP functions as a gatekeeper to secondary care, older patients often have a long-term relationship with their GP and consider them a trusted healthcare adviser.^{15,16} This makes the GP well placed to support patients in exploring generic treatment goals and in empowering them for shared decision making with an oncologist.

The authors designed an intervention in which GPs used the OPT to facilitate a conversation with older patients in the period between a diagnosis of non- curable cancer and treatment decisions,¹⁷ focusing on identifying the patients' generic treatment goals. The primary aim of this study was to analyse the effects of these OPT-facilitated conversations on patient empowerment.

Method

This randomised controlled trial was registered in the Dutch trial register (ref: NTR5419), and the study design is published in detail elsewhere.¹⁷

Participants

Participants were recruited from nine locations in six hospitals (one academic) between November 2015 and January 2019. Patients were eligible if they were aged ≥ 60 years, had cancer that had no curative treatment options, and had to make a treatment decision with an oncologist. Patients were excluded if they had a life expectancy of < 3 months or were unable to complete the questionnaires. Patients with haematological cancers were also excluded because they are known to have a different disease course.¹⁸

After providing informed consent, patients were randomised to an intervention group (OPT-facilitated conversation) or control group (care as usual) on a one-to-one basis, stratified by hospital. Allocation was determined by a web-based application (ALEA) that used random permuted blocks with randomly varying block sizes.

Intervention

The intervention consisted of a conversation with the GP during which treatment goals were explored with the aid of the OPT.^{11,12} The OPT is a decision aid with four visual analogue scales, each representing a generic treatment goal: extending life, maintaining independence, reducing pain, and reducing other symptoms (Figure 1). The tool was developed in the US and designed to discuss, with patients, which (treatment) goal was most important to them.^{11,12} GPs were contacted via telephone by the research team. After their consent, the OPT was sent to them with a short user manual that also contained a hyperlink with a video example of an OPT-facilitated conversation. GPs invited patients to value and rank the different goals according to the trade-off principle that the goals cannot be equally important. Patients received no instructions about what to tell their oncologist. The control group received care as usual and could consult their GP at their own discretion. Blinding was not possible owing to the nature of the intervention. Immediately after their follow-up consultations with oncologists, during which the treatment decision was made, patients from both groups completed questionnaires (Figure 2). Oncologists did not receive any training as they played no role in the intervention.

Figure 2. Study timeline. In most cases the time between both consultations was 1 week. Questionnaires were mostly completed directly after the second consultation. OPT = Outcome Prioritisation Tool.

Outcomes

Patient-reported age, sex, education level, and social network data were recorded. Data on the tumour type, performance score (Eastern Cooperative Oncology Group classification¹⁹), and comorbidities (Charlson score²⁰) were extracted from hospital records.

The primary outcome was patient empowerment, as measured by the decision self-efficacy (DSE) scale. The DSE scale comprises 11 items that are scored 0–4.²¹ The scores were transformed to a scale ranging from 0 (no self-efficacy) to 100 (high self-efficacy).²² No cut-off value is described in the literature, but a score of <75 was defined as low empowerment and <50 defined as very low empowerment, based on consensus in the research group.

Secondary outcomes focused on symptoms of fatigue, anxiety, and depression. These outcomes were chosen based on their high prevalence in patients with cancer and their major impact on their lives. It has also been suggested that these outcomes are associated with patient empowerment.^{23,24} Fatigue was measured using the multidimensional fatigue inventory (MFI-20), which ranges from 0 to 80.^{25,26} Based on earlier research in older populations, the authors defined cut off scores of 58 and 73 to represent mild and severe fatigue, respectively.^{27–29} Symptoms of anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS-A and HADS-D). These subscales each include seven questions, resulting in a total score that ranges from 0 to 21.³⁰ Subscale cut-off scores of ≥8 and ≥11 represent mild and severe symptoms, respectively.³¹ Finally, the experiences of patients and GPs with the OPT were explored using questions based on former evaluations of this instrument.³²

Sample size

The authors aimed to include 80 patients in each group based on a difference of at least four points on the DSE (effect size or Cohen's $d = 0.44$),²² two-sided testing, an α of 0.05, and a β of 0.20 ($P = 0.80$). A low rate of loss to follow up was expected because comparison between groups was performed immediately after consultations. Therefore, the authors aimed to include 84 patients per group to allow for a 5% loss.

Statistical methods

All data were entered in a secured digital data management system, pseudonymised, and extracted to IBM SPSS Statistics (version 25) and STATA/SE (version 15). Descriptive statistics were used to describe the participants and to compare groups at baseline. The effects of the intervention on the DSE, MFI-20, and HADS scores were tested by linear regression for continuous measures, and by logistic regression for dichotomous measures. Odds ratios (ORs) and 95% confidence intervals (CIs)

are reported. If scores showed a ceiling effect with censoring from above, that is 100,³³ a Tobit model was used.^{34,35} In all models, adjustments were made where necessary for baseline differences between the groups. A P-value ≤ 0.05 was considered statistically significant for all analyses. Finally, the experiences of GPs and patients were reported descriptively.

Results

Participants

During the study period, the contact details of 268 patients were sent to the research team by oncologists and were screened for eligibility. Of these, 223 were eligible and 145 (65%) agreed to participate. Finally, 53 and 61 patients completed the assessment in the OPT and control groups, respectively (Figure 3). The mean age of participants was 74.0 years (standard deviation [SD] = 6.4 years), 70.2% (n = 80) were male, and 71.9% (n = 82) had lung cancer (Table 1). In the intervention group, both the OPT scores and/or a GP evaluation were available for 47 patients (88.7%). There were no apparent differences in the baseline characteristics between groups (Table 1).

Figure 3. CONSORT diagram of the study. CONSORT = Consolidated Standards of Reporting Trials. OPT = Outcome Prioritisation Tool.

Patient empowerment

Continuous scores. For both groups, high DSE scores were observed (ceiling effect).³³ Correcting for this, the adjusted mean scores were 86.8 (SD = 18.2) for the OPT group and

84.2 (SD = 17.6) for the control group, resulting in an estimated β of 2.54 (95% CI = -4.46 to 9.54; $P = 0.47$) for the effect of the intervention (Table 2).

Dichotomised scores. Between the two groups, 18.8% of patients in the OPT group had low empowerment compared with 24.1% in the control group, but the difference was not statistically significant (OR 0.73; 95% CI = 0.28 to 1.86; $P = 0.50$). Two patients scored very low empowerment in the control group and no patients scored very low empowerment in the OPT group.

Table 1. Baseline characteristics of the OPT group and the control group

	OPT		Control		Total	
	N = 53		N = 61		N = 114	
	N	(%)	N	(%)	N	(%)
Age Mean $\pm$ SD	75.3	± 6.8	72.9	± 5.9	74.0	± 6.4
Sex: male	38	(71.7)	42	(68.9)	80	(70.2)
Education ^a						
Primary school/GCSE	29	(56.9)	40	(69.0)	69	(63.3)
A-levels	16	(31.4)	10	(17.2)	26	(23.9)
College/university	6	(11.8)	8	(13.8)	14	(12.8)
Social support ^a						
None	0		1	(1.7)	1	(0.9)
A bit	4	(7.8)	4	(6.9)	8	(7.3)
Much	34	(66.7)	41	(70.7)	75	(68.8)
Very much	13	(25.5)	12	(20.7)	25	(22.9)
Localisation						
Lung	34	(64.2)	48	(78.7)	82	(71.9)
Urogenital	8	(15.1)	5	(8.2)	13	(11.4)
Gastrointestinal	9	(17.0)	5	(8.2)	14	(12.3)
Other	2	(3.8)	3	(4.9)	5	(4.4)
Symptoms ^a						
Pain	22	(43.1)	24	(40.1)	46	(41.8)
Other symptoms	25	(49.0)	24	(40.1)	49	(44.5)
CCI Mean ^b $\pm$ SD	10.3	± 1.4	9.8	± 1.4	10.0	± 1.4
ECOG Performance ^c						
0	22	(41.5)	29	(47.5)	51	(44.7)
1	24	(45.3)	24	(39.3)	48	(42.1)
2	7	(13.2)	8	(13.1)	15	(13.2)

Abbreviations: CCI, Charlson Comorbidity Index; ECOG, Eastern Cooperative Oncology Group; GCSE, General Certificate of Secondary Education; OPT, Outcome Prioritisation Tool; SD, standard deviation. ^a This variable was not complete for all cases: N = 51, 58, 110, and 39, respectively. ^b CCI, ranging from 0 (healthy) to 37 (all possible comorbidities). ^c ECOG Performance Score, ranging from 0 (fit) to 5 (death).

Symptoms of fatigue, anxiety, and depression

Continuous scores. The mean fatigue scores were 62.9 (SD = 21.2) in the OPT group and 67.1 (SD = 18.6) in the control group (95% CI = -11.28 to 3.8; $P = 0.33$). The mean anxiety score was 6.0 (SD = 4.6) in the OPT group and 7.6 (SD = 4.4) in the control group, a statistically significant difference of -1.67 (95%CI = -3.33 to -0.01; $P < 0.05$). The mean depression score was 5.9 (SD = 4.8) in the OPT group and 6.4 (SD = 4.1) in the control group (95%CI = -2.02 to 1.28; $P = 0.66$).

Dichotomised scores. The proportion of patients with mild fatigue was statistically significantly lower in the OPT group than in the control group (58.8%, $n = 30$ versus 77.2%, $n = 44$; $P = 0.05$), while this was not the case for the proportion of patients with severe fatigue (33.3%, $n = 17$ versus 40.4%, $n = 23$; $P = 0.32$). Fewer patients in the OPT group had either mild anxiety (30.6%, $n = 15$ versus 40.7%, $n = 24$; $P = 0.28$) or severe anxiety (12.2%, $n = 6$ versus 20.3%, $n = 12$; $P = 0.55$). In the OPT group, there were fewer patients with mild depression (28.6%, $n = 14$ versus 37.3%, $n = 22$; $P = 0.34$) or severe depression (16.3%, $n = 8$ versus 18.6%, $n = 11$; $P = 0.75$) (see Table 2).

Table 2. Comparison of outcomes between intervention group and control group

	OPT N = 53		Control N = 61		OPT versus Control	
Continuous outcomes	Mean	±SD	Mean	±SD	Difference	(95% CI)
Patient empowerment: DSE ^{a, b}	86.8	18.2	84.2	17.6	2.54	(-4.46 to 9.54)
Fatigue: MFI ^a	62.9	±21.2	67.1	±18.6	-3.72	(-11.28 to 3.83)
Anxiety: HADS-A ^a	6.0	±4.6	7.6	±4.4	-1.67	(-3.33 to -0.01)*
Depression: HADS-D ^a	5.9	±4.8	6.4	±4.1	-0.37	(-2.02 to 1.28)
Dichotomous outcomes	N	(%)	N	(%)	OR	(95% CI)
Patient empowerment ^a						
DSE < 75	9	(18.8)	14	(24.1)	0.73	(0.28–1.86)
Fatigue ^a						
MFI ≥ 58	30	(58.8)	44	(77.2)	0.44	(0.19–1.00)
MFI ≥ 73	17	(33.3)	23	(40.4)	0.67	(0.30–1.47)
Anxiety ^a						
HADS-A ≥ 8	15	(30.6)	24	(40.7)	0.64	(0.29–1.43)
HADS-A ≥ 11	6	(12.2)	12	(20.3)	0.55	(0.19–1.58)
Depression ^a						
HADS-D ≥ 8	14	(28.6)	22	(37.3)	0.67	(0.30–1.52)
HADS-D ≥ 11	8	(16.3)	11	(18.6)	0.85	(0.31–2.32)

Abbreviations: DSE, decision self-efficacy; HADS-A, Hospital Anxiety and Depression Scale (anxiety subscale); HADS-D, Hospital Anxiety and Depression Scale (depression subscale); IQR, interquartile range; MFI, multidimensional fatigue inventory; OPT, Outcome Prioritisation Tool; SD, standard deviation.

* $p < 0.05$ ^a Due to incomplete questionnaires, the numbers of analysed cases in the OPT group were 48 for DSE, 51 for MFI, 49 for HADS-A, and 49 for HADS-D; the corresponding numbers in the control group were 58, 57, 59, and 59, respectively. ^b Adjusted means and estimated β (95% confidence interval) for the intervention compared to the control group by Tobit regression analysis.

Patients' goals and experiences of GPs and patients

Of the 38 patients who noted their favoured goal, most rated either maintaining independence (31.6%, $n = 12$) or extending life (28.9%, $n = 11$) as their most important goal, while six (15.8%) chose ≥ 1 goal as most important (Table 3).

Of the 29 patients who evaluated the OPT conversation, 13 (44.8%) reported that it helped them make a decision, 15 (51.7%) reported that it had improved their relationship with the GP, and 18 (62.1%) said they would recommend it to other patients (Table 3). None of the patients had negative remarks.

Among the 45 GP responders, most (71.1%, $n = 32$) found it easy to explain the four goals and the concept of prioritisation. One-third ($n = 14$) reported they had gained new insights from the OPT conversations (Table 3). In free-text responses, four GPs mentioned that the OPT conversation was a good basis for advance care planning (more information available from the authors on request).

Table 3. Patients' goals and GPs' and patients' experiences of the OPT-facilitated conversation

	N	(%)
Most important goal	38	
Extending life	11	(28.9)
Maintaining independence	12	(31.6)
Reducing pain	8	(21.1)
Reducing other symptoms	1	(2.6)
Chose more than one goal as most important	6	(15.8)
Patient evaluations	29	
I discussed my OPT-score with my oncologist	14	(48.2)
The OPT conversation:		
is time-consuming	2	(6.9)
helped me to prepare for the conversation in the hospital	8	(27.6)
helped me to make a treatment decision	13	(44.8)
helped me to improve the relationship with my GP	15	(51.7)
made me contemplate	9	(31.0)
I would recommend the OPT conversation to others	18	(62.1)
GP evaluations	45	
I was able to explain:		
'extending life'	42	(93.3)
'maintaining independence'	40	(88.9)
'reducing pain'	43	(95.6)
'reducing other symptoms'	36	(80.0)
I was able to explain the concept of prioritising	32	(71.1)
The patient could easily prioritise the goals	29	(64.4)
I gained new insights	14	(33.3)

Abbreviations: GP, general practitioner; OPT, Outcome Prioritisation Tool.

Discussion

Summary

A structured OPT-facilitated conversation about generic treatment goals with the GP had no statistically significant effect on empowering older patients with non-curable cancer compared with care as usual. However, there were more patients with low empowerment scores in the control group. This study also found that patients in the intervention group had statistically significantly lower mean anxiety scores and less mild fatigue. Furthermore, half of the participating patients in the intervention group reported that it helped them make a decision and that it had improved their relationship with the GP. One-third of the GPs reported they had gained new insights from the OPT conversations.

Strengths and limitations

Though the OPT has been used in other settings,¹² the authors believe this was the first application by GPs for patients with cancer and it was well received. Despite the small differences in empowerment between groups, the OPT conversation was considered to support treatment decisions by about half of the patients, suggesting that the OPT may have an added value to usual care.

Despite the small sample size, the authors argue that the results of the present analyses have clinical relevance. Furthermore, the study sample mainly included older patients with less education and with lung cancer. The authors believe it is very important to gain data from this vulnerable group as this group can be difficult to include in studies, making these data informative and useful in an otherwise scarce research landscape.

The main limitation of the present study was the failure to meet the pre-specified sample size requirements; including older patients with non-curable cancer appeared to be difficult for various reasons. Oncologists did not ask all eligible patients whether they could be contacted by the researchers because they forgot or because they thought it too difficult to combine delivering 'bad news' with a request to participate in a study. The interval between diagnosis and treatment decision was often surprisingly short (1–2 days). Sometimes the decision had already been made when the researchers contacted the patient or the interval was too short a time for the intervention to take place. The short interval appears to be a frequently encountered phenomenon, which is exemplified by the current discussion in the Netherlands that patients should be given multiple treatment options and a 'time-out' interval to allow non-rushed decision making.³⁶ Further, dropout rates were higher than expected. Despite requiring that patients should have a life expectancy of >3 months, many patients died or became too ill before they could complete questionnaires. Various methods were employed, such as weekly personal contact between researchers and oncologists, to improve accrual and the changing of the original inclusion criterion from age >70 years to ≥60 years.

Finally, it is important to realise that the effects of an OPT-facilitated conversation can be partly determined by other topics of a conversation with the GP, such as attention to symptoms, and words of reassurance and support. Though the authors have no information about the conversations in the usual care group, earlier research showed that many patients have contact with their doctor immediately after a cancer diagnosis.¹³

Comparison with existing literature

Other studies using the same questionnaire have described comparably high mean scores,^{22,37,38} indicating that patients might generally be confident in their ability to participate in shared decision making.³⁹ It may also be that the outcome measure is not robust enough. Finding robust outcome measures has proven to be a problem in research on improving health care.⁴⁰

Any healthcare provider can use the OPT, but the authors deliberately chose the GP because of their often longstanding relationship with older patients. Interestingly, one-third of the GPs reported that they still gained new insights about the treatment goals of their patients during the conversations, consistent with earlier research showing that healthcare providers often incorrectly assume their patients' priorities.⁸ GPs also reported that the OPT helped them to start a conversation about advance care planning. This is particularly important because research indicates that most patients would not only like to talk with their GP about this topic but also that they would like GPs to take the initiative.⁴¹ It has been argued that GPs lack the expertise to discuss different treatment options and could increase confusion and anxiety.³⁶ However, treatment options are irrelevant to the OPT-facilitated conversation, which only considers the generic goals of patients. Moreover, in the present study sample, the OPT-facilitated conversation was associated with statistically significant lower anxiety compared with care as usual.

Implications for research and practice

In conclusion, the results presented here indicate that an OPT-facilitated conversation with a GP about generic treatment goals may lead to less anxiety and fatigue. This conversation might affect empowerment for subgroups of patients with low baseline empowerment scores, yet the present results remain inconclusive. Further research is needed into the effect of these conversations, but in view of the positive evaluations, healthcare providers might consider adding the OPT to facilitate conversations that seek to improve patient-tailored care.

Additional information*Funding*

This study was supported by a grant from the Dutch Cancer Society Fund (KWF Kankerbestrijding) (ref: RUG 2014-7273). The sponsor had no role in the study design, collection, analysis, interpretation of data, the writing of the report, or in the decision to submit the article for publication.

Ethical approval

The trial was assessed by the Medical Ethics Committee of the University Medical Centre Groningen (ref: 2015/275).

Provenance

Freely submitted; externally peer reviewed.

Competing interests

The authors have declared no competing interests.

Acknowledgements

The authors would like to thank the participating hospitals (Universitair Medisch Centrum Groningen, Ommelander ZorgGroep, Treant Zorggroep, Martini Ziekenhuis, Wilhelmina Ziekenhuis Assen, and Medisch Centrum Leeuwarden) and all participating GPs for their efforts. They would like to thank Jan Schuling for his advice and support, and Vera Bouwknecht, Mechteld Jansen, Eva Postma, Bren Hartjes, and especially Lisa Louer and Pim Brandenburg for their help with data collection. Finally, they thank Robert Sykes for providing editorial services (www.doctored.org.uk).

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Chapter 5

Treatment goals and changes over time in older patients with non-curable cancer

Adapted from: Stegmann ME, Brandenburg D, Reyners AK, van Geffen WH, Hiltermann TJN, Berendsen AJ. Treatment goals and changes over time in older patients with non-curable cancer. Accepted by Supportive Care in Cancer, Dec 2020.

Abstract

Purpose. To investigate treatment goals of older patients with non-curable cancer, whether those goals changed over time, and if so, what triggered those changes.

Methods. We performed a descriptive and qualitative analysis, using the Outcome Prioritisation Tool (OPT) to assess patient goals across four conversations with general practitioners (GPs) over 6 months. Text entries from electronic patient records (hospital and general practice) were then analysed qualitatively for this period.

Results. Of the 29 included patients, 10 (34%) rated extending life and 9 (31%) rated maintaining independence as their most important goals. Patients in the last year before death (late phase) prioritised extending life less often (3 patients; 21%) than those in the early phase (7 patients; 47%). Goals changed for 16 patients during follow-up (12 in the late phase). Qualitative analysis revealed three themes that explained the baseline OPT scores (prioritising a specific goal, rating a goal as unimportant, and treatment choices related to goals) Another three themes related to changes in OPT scores (symptoms, disease course, and life events) and stability of OPT scores (stable situation, disease-unrelated motivation, and stability despite symptoms).

Conclusion. Patients most often prioritised extending life as the most important goal. However, priorities differed in the late phase of disease, leading to changed goals. Triggers for change related to both the disease (e.g., symptoms and course) and to other life events. We therefore recommend that goals should be discussed repeatedly, especially near the end of life.

Trial registration: Based on the OPTion study (NTR5419)

Introduction

Treatment decisions are often complex for older patients with cancer. The expected positive effects of treatment are unclear in this group because most studies of therapeutic efficacy are performed in younger patients.^{1,2} Older patients also tend to be more frail or to have comorbidities that increase the negative effects of treatment.³ It is therefore advised that health care providers discuss the benefits and harms of available treatment options comprehensively, making efforts to involve patients in treatment decisions and to respect their preferences whenever possible.⁴ This is important because treatment guidelines are generally based on optimal survival, whereas not all older patients will value extending life as the main treatment goal.⁵ Indeed, other goals are more important for about half of these patients, such as maintaining independence.⁵ The importance of explicitly discussing patients' treatment goals is exemplified by research showing that health care professionals often make incorrect assumptions about these goals.⁶ Furthermore, goals may be dynamic and change as illness progresses, particularly for incurable disease where treatment priorities often change gradually from extending life to optimising comfort.⁷ In a study of patients with non-curable cancer, most patients said they would like to talk to their health care provider about end-of-life care when their health deteriorated.⁸ Although this suggests that health deterioration may trigger a change in treatment preference, we are aware of no literature on this topic. In the present study, we therefore aimed to investigate the treatment goals of older patients with non-curable cancer, to determine if those goals changed over time, and if they did change, what triggered that change.

Methods

This was a descriptive qualitative study of patients included in the intervention group of the OPTion study (NTR5419), which was conducted between November 2015 and January 2019. The protocol and outcomes of the original randomised controlled trial (RCT) have been published elsewhere.^{9,10} The Institutional Review Board of the University Medical Center Groningen assessed the protocol and we obtained informed consent from all participants.

The OPTion RCT

The original OPTion RCT was designed to assess how patient self-efficacy was affected by a structured conversation about goals with a general practitioner prior to making a decision about treatment. Older patients (age ≥ 60 years) with non-curable cancer were included in the period between their diagnosis and treatment decision, and they were excluded if they had haematological cancers, a life expectancy of < 3 months, or could not complete the questionnaires. After the treatment decision (baseline), patients completed questionnaires about demographic characteristics and decision self-efficacy (primary outcome), as well as symptoms of fatigue, depression, and anxiety.¹⁰

The Outcome Prioritisation Tool (OPT; Figure 1) was used during the conversation with a GP. This instrument can be used to discuss and prioritise four generic treatment goals: extending life, maintaining independence, reducing pain, and reducing other symptoms.^{5,11} Each goal is valued from 0 to 100, resulting in four OPT scores. In the OPTion RCT, patients received either an OPT-facilitated conversation (n=53) or care as usual (n=61). Prioritisation discussions in the intervention arm could be facilitated using moveable sliders (0–100). They were provided on a card or were available online (www.optool.nl).

Current study

In this study, we followed-up on the patients included in the intervention group of the OPTion RCT. We repeated the OPT-facilitated GP conversations at 4 weeks, 3 months, and 6 months after baseline and noted the OPT scores. All patients did the follow-up conversations with the same GP as the baseline conversation. Whether former OPT-scores were mentioned as reference was decided by the GP. Text entries made by health care providers were examined in the electronic patient records of hospitals and GP practices from baseline to 6 months. This included both documentation about routine visits and about OPT-conversations. In the Netherlands, GP function as care coordinators and gatekeepers to specialist hospital care. Between hospital visits, most patients also have contact with their GP.

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

Data analysis

We descriptively analysed the OPT scores and their changes over time. In the patient records, we checked if a patient had died, and if so, extracted the date of death. Patients were categorised by their disease phase (early/late) and goal pattern (change/stable). We defined patients as being in the late phase of disease if they died within 1 year of their last follow-up conversation. We defined goals as having changed when the most important treatment goal changed or when at least one value changed by ≥ 20 points (scale 0–100 points) at two consecutive OPT conversations. Thereafter, we analysed the text entries from patient records in a qualitative hypothesis-generating manner. Two researchers (MES and DB) independently analysed all text entries using an open coding system, with codes grouped into themes in an axial way. The two researchers discussed and compared their findings until consensus was reached, and a third researcher (AJB) was consulted if disagreement persisted. Representative quotations (*Q*) are presented and identified by a patient number in the results. Each quotation is accompanied by the corresponding *OPT* scores, which are displayed as the four scores for extending life, maintaining independence,

reducing pain, and reducing other symptoms (i.e., *extending, independence, pain, and other*, respectively).

Results

Participants

Of the 47 patients who participated in an OPT conversation at baseline, 29 (62%) had one or more follow-up OPT conversations and could be included in the current study. Among these, the mean age was 75.3 years (standard deviation [SD] = 6.4 years), 24 (83%) were male, 13 (45%) had low education levels, and 17 (61%) had lung cancer (Table 1). About half of the participants (52%; $n=15$) were in the early phase of disease. The main reasons for dropout before follow-up were increased illness severity and death. Only 16 patients (55%) attended all three follow-up OPT conversations.

Table 1. Patient characteristics, most important goals, and goal patterns

	Total sample (N = 29)	Early phase (N = 15)	Late phase (N = 14)
	N (%)	N (%)	N (%)
Age (mean, SD)	75.3 (6.4)	76.4 (6.4)	74.2 (6.3)
Gender: male	24 (83)	12 (80)	12 (86)
Education			
Primary school/GCSE	13 (45)	7 (47)	6 (43)
A-levels	10 (35)	5 (33)	5 (36)
College/University	4 (14)	3 (20)	1 (7)
Not known	1 (10)	0	2 (14)
Cancer type			
Lung	17 (59)	8 (53)	9 (64)
Prostate	4 (14)	1 (7)	3 (21)
Gastrointestinal	6 (21)	4 (27)	2 (14)
Other	2 (7)	2 (13)	0
Hospital			
University hospital	16 (55)	9 (60)	7 (50)
Teaching hospital	5 (17)	2 (13)	3 (21)
Community hospital	8 (28)	4 (27)	4 (29)
Most important goal at baseline			
Extending life	10 (34)	7 (47)	3 (21)
Maintaining independence	9 (31)	4 (27)	5 (36)
Reducing pain	4 (14)	1 (7)	3 (21)
Reducing other symptoms	1 (3)	0	1 (7)
Chose ≥ 1 goal as most important	5 (17)	3 (20)	2 (14)
Goal pattern			
Changed goals after baseline	16 (55)	4 (27)	12 (86)
Stable goals after baseline	13 (45)	11 (73)	2 (14)

Late phase: death within one year of the last follow-up conversation. Changed goal: most important treatment goal changed or ≥ 1 item changed by ≥ 20 points (scale, 0–100) between consecutive OPT-based conversations.

OPT scores

Most patients rated extending life (34%; n=10) or maintaining independence (31%; n=9) as the most important goal at baseline. Patients in the late phase less often rated extending life as most important goal compared with those in the early phase (3/14 vs 7/15), more often prioritising the reduction of pain or other symptoms (28% vs 7%) (Table 1). Five patients chose >1 goal as most important, despite the OPT guideline explicitly stating that only one should be prioritised. Goals changed during the follow-up period for 16 patients (55%): 4 in the early phase (27%) and 12 in the late phase (86%). For all goals, we observed both increases and decreases in the scores. The most frequently observed change was that extending life became less important in the month before death (21%). However, goals did not change during the follow-up period for 13 patients (45%): 11 in the early phase (73%) and 2 in the late phase (14%).

Qualitative analysis of electronic patient records

In the qualitative analysis, we reached saturation after reviewing 26 of the 29 records, (i.e. no new codes were used for the last three patients)¹². We deducted three topics: 1) *reasons for a specific baseline OPT score*; 2) *reasons for an OPT score change*; and 3) *reasons for OPT score stability*. For each topic, several themes were identified (Table 2; discussed in the following paragraphs). There were also some differences between GP and specialist records, with the latter having a tendency to report patients' conditions more positively (Q1).

Q1a: *Patient says he is feeling pretty good* (078, hospital record)

Q1b: *It is not going well. Chemotherapy has much effect on patient* (078, GP record, 1 day later)

OPT scores: 80-80-80-80 (extending-independence-pain-other)

Table 2. Topics and themes from the qualitative analysis

Topic	Themes
Reasons for a specific baseline OPT score	Prioritising a specific goal Rating a goal as unimportant Treatment choices related to goals
Reasons for goal changes during follow-up	Change related to symptoms Change related to disease course Change related to life events
Reasons for goal stability during follow-up	Stability related to stable situation Stability related to disease-unrelated motivation Stability despite symptoms

Changed goal: most important treatment goal changed or ≥1 item changed by ≥20 points (scale, 0–100) between OPT-based conversations.

Reasons for a specific baseline OPT score

We found three themes regarding the choice of initial goals: *prioritising a specific goal*, *rating a goal as unimportant*, and *treatment choices related to goals* (Table 2). Some patients *prioritised a specific goal* consciously. In their text entries, health care providers described that some patients with a high score for extending life and/or maintaining independence were feeling healthy and wanted to preserve the feeling (Q2).

Furthermore, some patients who prioritised maintaining independence explicitly indicated that quality of life was very important to them. This also applied to patients who, according to their patient record, lived very independently with a small social network. Patients with a high OPT score for reducing pain were often those recorded as experiencing pain in their medical records. *Rating a goal as unimportant* was found for one patient in the early phase and one in the late phase patient, with these explicitly stating that extending life was no longer important, consistent with giving low scores in this domain (Q3).

Six patients had several treatment options described in the patient record, and the considerations for the *treatment choice related to goals* were described explicitly for two of them. In both cases, the patient opted to refrain from active treatment after ample consideration of the risks and benefits, as reflected by low scores for extending life (Q4). Both patients also explicitly discussed their treatment options with their GP. In one of these two cases, as well as in another two cases, the medical specialist and GP discussed treatment options and/or goals by phone contact. For most patients, the goal of the chosen treatment matched the goal prioritised by the patients during the OPT conversation. For two patients, however, the goals and chosen treatment did not match: both scored low on extending life, but they chose a life-extending treatment.

Q2: *Patient is down to earth and has a clear opinion during the conversation. She feels vital and would very much like to try treatment in order to live longer.* (065, GP record)

OPT scores: 100-90-0-0 (extending-independence-pain-other)

Q3: *Patient lives alone, does have domestic help, still cooks for himself, does his own grocery shopping, otherwise he spends a large part of the day sitting in a chair. His hips are painful, sagging leg, hasn't yet received radiotherapy, doesn't want to (...). Doesn't want chemotherapy either. (...) "I am 84, what more do you want?"* (266, hospital record)

OPT scores: 60-90-80-30 (extending-independence-pain-other)

Q4: *Patient is concerned about the side-effects of treatment and their impact on his daily routine. After joint consultation with the geriatrician and me, patient refrains from treatment. He realises that if we don't treat the tumour now, he will develop symptoms and will probably die due to tumour progression.* (238, hospital record)

OPT scores: 30-50-60-60 (extending-independence-pain-other)

Reasons for goal changes during follow-up

We deducted three themes in relation to changing goals: *symptoms*, the *disease course*, or *life events* (Table 2).

Changes related to *symptoms* were observed most often. For patients who lowered their score on maintaining independence, a deterioration in their overall condition was described. According to the text entries, patients who experienced more pain over the course of their treatment changed their goals to give more importance to reducing pain during subsequent follow-up (Q5). Similar explanations were observed for changes in the goal of reducing other symptoms. When patients started to experience fatigue, or when this was aggravated, their goal to reduce other symptoms changed accordingly. One patient changed several goals

after having a conversation with his GP, concluding that chemotherapy had several unwanted negative side-effects. For changes related to the *disease course*, we observed a decrease in the value of extending life after patients had heard that their disease had progressed despite treatment (Q6). On the contrary, patients tended to give a higher value to extending life if they had recently started a new treatment. Changes related to *life events* were observed for three patients. One was in response to celebrating the birthday of his 102-year-old mother, which resulted in him also wanting to live longer, as reflected by a higher value on this domain (Q7). However, two other patients reported that the death of a close relative lowered their desire to extend life.

Q5: *Conversation about the course of events. Patient complains about more fatigue and more pain.* (180, GP record)

OPT scores: 30-70-50-50 from 30-80-30-60 (extending-independence-pain-other)

Q6: *The CT scan shows progression of the primary tumour (mediastinal, hilar) and progression of the bone metastases. Patient opts for supportive care. The option for another chemotherapy exists, but she has so much pain and has deteriorated so rapidly, that she doesn't want to continue chemotherapy to possibly slow down the illness, but then probably with so much back pain.* (216 hospital record)

OPT scores: 10-60-80-70 from 50-90-80-70 (extending-independence-pain-other)

Q7: *Besides short of breath on exertion, he feels very well. His mother just turned 102, he wants that too.* (012 GP record)

OPT scores: 80-80-20-20 from 30-30-80-80 (extending-independence-pain-other)

Reasons for goal stability during follow-up

Three themes related to stability: *stable situation*, *disease-unrelated motivation*, and *stability despite symptom increases* (Table 2).

For all patients in a *stable situation*, text entries described that they did not experience changes in disease symptoms, that their condition was generally stable, and that they had few or no treatment-related side-effects. As such, there seemed no reason to adjust their goals (Q8). Some (n=2) patients appeared to determine their goals based on some *disease-unrelated motivation* that did not change during follow-up. For example, a patient who valued extending life highly said that this was important because of his religion (Q9). In seven patients, we observed *stability despite symptom increases*. According to their medical records, these patients had an increase in disease-related symptoms and/or experienced substantial side-effects from therapy. However, they did not adjust their goals or scores related to reducing pain or other symptoms (Q10). No reasons were identified.

Q8: *No new complaints or insights. Wants to leave the OPT scores as they are.* (036, GP record)

OPT scores : 40-60-20-10 (extending-independence-pain-other)

Q9: *She [spouse] says that her husband will die when it's his time. She wants to keep him with her for as long as possible. They won't just "throw in the towel."* (203 hospital record)

OPT scores (extending-independence-pain-other): 90-10-70-40

Q10: *Severe back pain (...) Stop chemotherapy, start symptom-oriented palliation.*
(265 hospital record)

OPT scores: 80-70-30-50 (extending-independence-pain-other)

Discussion

Summary

Extending life was most often (n=10, 34%) prioritised as the most important goal. However, compared with patients in the early phase of their disease, those in the late phase not only prioritised extending life less often (n=3, 21% vs n=7, 47%) but also changed their goals more often (n=12, 86% vs n=4, 27%). Triggers for these changes appeared related to both the disease (e.g., symptoms, disease course) and to other life events (e.g. death of a close relative). Goal stability was most often observed in patients without changes in disease symptoms or without side-effects from treatment.

Strengths and limitations

As far as we know, this is the first study exploring changes over time in the generic treatment goals of patients with non-curable cancer. The qualitative design meant that we could generate hypotheses about which patients change their goals and what might trigger those changes, although these hypotheses must now be validated in further research. An important limitation of the study is that we did not use a purposive sample, which is recommended to achieve a wide variety of participants in qualitative research.¹³ Instead, we used the intervention group of the OPTion RCT in which more than half of the participants were men with lung cancer treated in an academic hospital. However, older patients with lung cancer are often less well educated and are generally more difficult to recruit, making this an interesting sample.

Another limitation is that we used text entries from the patient records of health care providers. This is important because these reflect the health care provider's perception of the consultation, and there will have been incomplete details of what was discussed. For example, although we found few entries concerning the benefits and harms of different treatment options, these may have been discussed but not recorded. Similarly, we could not discuss prior treatment experiences because we lacked that information.

Comparison with existing literature

Most patients in this study indicated that extending life (34%) or maintaining independence (31%) was their most important goal. Although other studies among older patients have shown similar percentages for extending life (31%–35%), they have also shown that maintaining independence was more often prioritised as the most important outcome (35%–49%).^{5,14} This might be explained by patients in our sample having non-curable cancer, in whom there was a notable difference between the early phase (47% and 27% for extending life and maintaining independence, respectively) and the late phase (21% and 36% for extending life and maintaining independence, respectively). The relatively high proportion of patients who prioritised extending life in our early phase group could be explained not only by the longer life expectancy of this group but also the high proportion of patients receiving care in a university hospital (60%). Patients can be referred to this centre for new (targeted) therapies in a research context, which may have led to a more select

population with a strong wish for treatment.

Our study suggests that patients' goals become less stable when they enter the late phase of their disease. In practice, it is a challenge for health care providers to determine when patients have entered this phase. The surprise question ("Would I be surprised if this patient died in the next year?") has been shown to be a simple and effective tool for identifying patients with cancer who have a greatly increased 1-year mortality risk.¹⁵ Recently, it was suggested that a double surprise question, adding "Would it surprise me if this patient is still alive after 12 months?" had even better predictive values.¹⁶ Our research also showed that non-disease-related life events may be a trigger for change, though it remains a challenge to identify such patients who are about to change their goals and may want to adjust their treatment accordingly. This is in line with the widely supported suggestion that health care professionals in the field of palliative care should discuss not only physical issues but also psychological, social, and existential issues.¹⁷

Finally, the GP was asked to perform the OPT conversations in the current study. This was a deliberate choice based on the often longstanding relationship between GPs and older patients in the Netherlands.^{10,18,19} In a recent survey, more than two-thirds of responding cancer patients indicated a need to discuss their treatment decision with the GP.²⁰ During this conversation, the GP must explain information, check understanding, and discuss priorities.²⁰ However, it is important that this supplements, rather than replaces, the discussions that patients have about goals and preferences with medical specialists and/or specialist nurses.⁵

Conclusion

We showed that the treatment goals of older patients with non-curable cancer can change over time, and that these changes may be related to the primary disease or to other life events. Future research may benefit from analysing the audio recordings of consultations or from interviewing patients about their goals and the reasons for changes. In the meantime, however, health care providers should endeavour to discuss goals regularly with their patients. This enables the health care provider to more directly assist the patient in making choices, by linking the discussed goals to the different treatment options. This should certainly occur when there is a change in the disease, but we contend that it may be more prudent to perform this as part of a regular and more comprehensive multidomain assessment. Correctly and regularly identifying patient goals, as well as communicating them with other health care providers, can help ensure that therapy remains appropriate and evolves with the needs of patients.

Additional information

Funding

This study was supported by a grant from the Dutch Cancer Society Fund (KWF Kankerbestrijding) (ref: RUG 2014-7273). The sponsor has no role in the study design, collection, analysis, interpretation of data, the writing of the report, or in the decision to submit the article for publication.

Conflicts of interest

The authors have declared no competing interests.

Ethics approval

The trial was assessed by the Medical Ethics Committee of the University Medical Centre Groningen (ref: 2015/275)

Consent to participate

All participants provided informed consent

Authors' contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by MES and DB. The first draft of the manuscript was written by MES, DB and AJB and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Acknowledgments

The authors would like to thank the participating hospitals (Universitair Medisch Centrum Groningen, Wilhelmina Ziekenhuis Assen, Ommelander ZorgGroep, Trant Zorggroep and Medisch Centrum Leeuwarden) and all participating GPs for their efforts. They would like to thank Lisa Louer, Pim Brandenburg and Loes Overeem for their help with data collection. Finally, they thank Robert Sykes for providing editorial services (www.doctored.org.uk)

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Chapter 6

Correspondence between primary and secondary care about patients with cancer: A qualitative mixed-methods analysis

Adapted from: Stegmann ME, Meijer JM, Nuver J, Havenga K, Hiltermann TJN, Maduro JH, Schuling J, Berendsen AJ. Correspondence between primary and secondary care about patients with cancer: A qualitative mixed-methods analysis. *Eur J Cancer Care (Engl)*. 2018 Aug 23:e12903.

Text based on this chapter was also published as: Stegmann ME, Meijer JM, Nuver J, Havenga K, Hiltermann TJN, Maduro JH, Berendsen AJ. Correspondentie tussen de eerste en tweede lijn over patiënten met kanker. Hoe kan het beter? *Ned Tijdschr Geneeskd*. 2019 May 31;163. pii: D3616. And as: Mariken Stegmann, Jiska Meijer, Annette Berendsen. Maak van je verwijsbrief geen troebele SOEP. *Huisarts en Wetenschap*. 10 juli 2019 .

Abstract

Cancer care is complex and involves many different healthcare providers, especially during diagnosis and initial treatment, and it has been reported that both general practitioners and oncology specialists experience difficulties with interdisciplinary communication. The aim of this qualitative study was to explore information sharing between primary and secondary care for patients with lung, breast or colorectal cancer. A qualitative content analysis of 50 medical files (419 documents) was performed, which identified 70 correspondence-related items. Six main topics were identified in most referral letters from primary to secondary care, but it was particularly notable that highly relevant information regarding the past medical history was often mixed with less relevant information. To lesser extents, the same held true for the medication list and presenting history. In the letters from specialists, nine topics were identified in most letters. Although information about actual treatment was always present, only limited detail, if any, was given about the intent of the treatment (curative or palliative) or the treatment alternatives. Interviews with nine healthcare providers confirmed these issues. These findings indicate that neither the initial referral nor the specialist correspondence is tailored to the needs of the recipient.

Introduction

An estimated 14.1 million new cases of cancer were reported worldwide in 2012, and this incidence is increasing, with cancer now being the second leading cause of death worldwide.^{1,2} The three most common types of cancer are lung, breast and colorectal cancer.² Cancer care is complex and involves a range of healthcare providers both inside and outside hospitals,³ and patients find it important that these providers exchange relevant information appropriately to ensure smooth continuity of care.^{4,5} In countries where general practitioners (GPs) provide that continuity of care and function as gatekeepers, communication between primary and secondary care is particularly relevant and especially for patients in complex situations such as cancer.^{6–8} In the Netherlands and other countries with a similar system, all patients do have a GP and they often see their GP also during specialist treatment, not only for other health problems but also for explanation and for emotional support.

Formal communication between different healthcare providers in these countries is mostly by written correspondence, which is often sent digitally. When a GP refers a patient to a hospital specialist, they must write a “referral letter” that mentions the reason for referral. Then, when the hospital specialist has seen a patient, a “specialist letter” should be returned to the GP detailing the findings, treatment and follow-up plans. Because of the coordinating role of the GP, this letter should be sent within 5 days and sooner if needed to ensure continuity of care.⁹

However, primary and secondary care each have their own needs and expectations, which can lead to communication difficulties.^{10–14} Moreover, each party typically reports the quality of correspondence as being low from the other party, with disagreement cited about the precise issues.^{11,14} Referral letters are often said to lack relevant clinical information or a specific request,^{14,15} whereas specialist letters are reported to lack information about what the GP needs to know,^{16,17} and can arrive late after a consultation.^{12,16} According to both patients and physicians, inadequate communication between healthcare providers can lead to suboptimal quality, poor coordination, discontinuity and suboptimal quality of care.^{18,19}

The aim of this qualitative study was to explore the information that is shared in referral letters and specialist letters between primary and secondary care during the process of diagnosis and initial treatment of patients with lung, breast or colorectal cancer.

Methods

Design and setting

In this study, we performed a qualitative analysis of correspondence because of the explanatory nature of the research question. The medical records of patients diagnosed with lung, breast and colorectal cancer in the north of the Netherlands in 2014 or 2015 were assessed. These tumours were chosen because they are the most common types² and because both oncology specialists and GPs are frequently consulted about them during treatment.^{6,20} To provide a comprehensive overview and confirmation of our findings, we performed data triangulation (i.e., cross verification with other sources) was performed²¹ through semi-structured interviews with GPs and oncology healthcare providers. The

Institutional Review Board of the University Medical Centre Groningen reviewed the protocol and informed consent was obtained from all interviewees. We report this research based on the Consolidated Criteria for Reporting Qualitative Research.²²

Data collection of medical files

Medical hospital files were selected by purposive sampling. We aimed to include patients of different age, gender and tumour stage who were treated by oncology specialists and GPs of different experience levels, ages and genders.

We extracted all referral letters from medical files, including those sent by mail or fax, and those sent digitally using ZorgDomein (Care Domain).²³ The ZorgDomein system provides GPs with a predefined format that automatically imports some key information (e.g. prescriptions or past history) from the GP's file into the referral letter. This system has become widely used in the Netherlands over the last decade. The precise format differs slightly by the reason for referral and by department, as all formats are composed at a regional level by collaboration between specialists and GPs.²³

Next, we extracted the specialist letters written from the time of referral to the end of the initial phase of treatment (which was defined as the first three months after diagnosis and the start of any other treatment thereafter, if described in the initial treatment plan). Notes were also extracted regarding outpatient visits, allied health professional (e.g. psychotherapists, social workers and dieticians) visits, telephone calls and multidisciplinary meetings. In the multidisciplinary meetings, all patients diagnosed with a specific type of cancer were discussed by specialists of different relevant departments (e.g. surgeons, medical oncology specialists, radiologists, pathologists, pulmonologists and radiation oncology specialists), but without input from GPs. However, sometimes reports of these meetings were sent to GPs. We excluded documents used to exchange information between in-house healthcare providers.

Data collection of interviews

To confirm our data, healthcare providers were recruited for the interviews by purposive sampling. We aimed to include GPs and oncology specialists from different departments, age and gender. Discussed topics were the content and quality of any referral letters, specialist letters, other ways of communication and non-shared information. All interviews were recorded, five were fully transcribed, and for the others, all relevant quotations were written down.

Data analysis

Descriptive statistical analyses are given about the number of pages of correspondence and the time interval between consultation and correspondence. To illustrate the findings of the medical files and interviews, quotations (Q) are presented and identified by a department and a document number.

During a pilot study of five files of patients with breast cancer, a preliminary code list was produced, and checked by two other researchers, which was used when analysing the patient files. Relevant text fragments were identified and coded, before the coded text fragments were analysed thematically, all supervised by experienced researchers.^{24–26}

Codes concerning the same topic were grouped into a theme. For each tumour site (lung, breast or colorectal), a second researcher independently analysed random samples of the documents. Agreement between the researchers was calculated as the percentage of exactly corresponding codes. Any discrepancies were discussed until consensus was reached, and if necessary, the coding list was refined in an iterative process. In the interviews, two researchers independently identified relevant text fragments.

Sampling was continued until saturation, which was defined as the moment that no new codes were identified. When saturation was reached for one tumour type in one hospital, we analysed two more medical files to ensure saturation. All documents and notes were anonymously uploaded in Atlas.ti (version 7.15.12). Any discrepancies were discussed with a third member of the research team until consensus was reached. Finally, the results were discussed in a multidisciplinary meeting with all co-authors.

Results

Sample characteristics

All six departments that we approached agreed to collaborate. In total, 50 patient files containing 419 documents were analysed and nine healthcare professionals were interviewed. The purposive sample of interviewees consisted of four GPs, four oncology specialists and one specialist oncology nurse. The characteristics of the included patients and the interviewed healthcare providers are detailed in Table 1.

Table 1. Sample Characteristics

		Patient files (%) n = 50	Interviews (%) n = 9
Patients	Gender		
	Male	19 (38%)	
	Tumour site		
	Lung	20 (40%)	4 (44%)
	Mamma	16 (32%)	3 (33%)
	Colorectal	14 (28%)	2 (22%)
	Age (mean, SD)	65 (10)	
	Tumour stage		
	Stage I	9 (18%)	
	Stage II	11 (22%)	
	Stage III	16 (32%)	
	Stage IV	14 (28%)	
Oncological healthcare providers	Gender		
	Male		3 (60%)
General practitioners	Gender		
	Male		3 (75%)

Coding

First, the files of three departments in an academic hospital were analysed, and saturation was reached for lung, breast and colorectal cancer after 19, 15 and 11 files respectively. Thereafter, we analysed the files of two non-academic hospitals until saturation was reached. The final code list contained 70 codes in 13 themes (Supporting Information Table S1). Agreement between the coding researchers was 90% on average. No additional codes were identified from interviewing the healthcare professionals.

Referral letters from GPs

In total, 50 referral letters were analysed; 96% of these were written using ZorgDomein, the others were written without a program. The referral letters were one to two pages long, although a medication list was sometimes attached on a separate page. Box 1 contains a summary of the information provided in most referral letters.

The following information was given in most referral letters

- Reason of referral/specific request
- Past medical history and current use of medication
- History, family history and intoxications
- Physical examination
- Additional diagnostic information

Box 1. Common topics in Referral Letters

In general, the referral letters tended to contain relevant information for the oncology healthcare provider mixed with information less relevant for the current problem. This was most notable in the past medical history, where major and minor health problems were often detailed in one list without prioritisation (Q1), and sometimes without a chronological order. To a lesser extent, the same held true for the medication list and history of the presenting complaint. In the latter case, information about different aspects of the patient's history was mixed, often with information about the physical examination. This mixed presentation of data was also mentioned in the interviews. An example of this problem can be seen in Q1.

- Q1:
- 16-07-2010 Proximal phalanx left 5th digit fracture
 - 30-11-2009 Osteoporosis
 - 02-07-2009 Diabetes Mellitus type 2
 - 02-03-2008 Rib # right, liver contusion (dd rupture) after fall
 - 01-01-2005 Polyarthralgia based on arthrosis
 - 01-01-2000 Morton's neuroma
 - 01-01-1999 Mamma reduction
 - 01-01-1987 Rotator cuff syndrome
 - 01-01-1963 Adenomyosis of gallbladder, because of which cholecystectomy
 - 01-01-1980 Sterilisation
 - 01-01-1973 Appendectomy
 - 15-10-2013 Coughing

Referral letter – past medical history. (Lung cancer, doc90). This quotation shows a non-chronological order and a mix of information that is (e.g. diabetes mellitus) and

is not (e.g. sterilisation) relevant for the current health problem.

Specialist letters

In total, 369 specialist letters were analysed. A structured format was used in all letters, but these formats differed between departments and hospitals. The lengths of the letters ranged from 1 to 4 pages, and the interval between date of consultation and date of sending the letter ranged from 0 to 40 days (median 3 days, inter-quartile range 1–9 days). In a few cases, treatment was started before the GP had received written information about diagnosis and treatment. The information provided in most specialist letters is summarised in Box 2.

The following information was given in most specialist letters:

- Date of consultation or hospitalisation
- Relevant past medical history, including, if applicable, current diagnosis and recent treatment
- History paragraph (e.g. which symptoms does the patient have)
- Physical examination, often restricted to abnormal findings
- Results from additional diagnostic tests (e.g. blood results)
- (Preliminary) diagnosis
- Policy (e.g. additional diagnostic test, new treatment, next visit)
- Meta-communication (what does the patient know)

Box 2. Common topics in Specialists' Letters

All these letters contained information about actual treatment. Often this information was comprehensive and provided details about the exact type of surgery, chemotherapy or radiotherapy, together with the dose, frequency and period of treatment. However, an explicit statement about whether the treatment was given with curative or palliative intent was rare. Treatment alternatives and patient preferences were also seldom written down. If they were mentioned, it was mostly because an alternative had been chosen for medical reasons, such as for severe comorbidity or certain tumour characteristics (e.g. a specific mutation; see Q2). In the interviews, GPs also mentioned a lack of specific information about the curative or palliative intent of a treatment.

Q2: Wait for mutation analysis. To choose either a TKI-inhibitor or chemotherapy with cisplatin-pemetrexed

Specialist letter - policy (Large non-academic hospital, lung cancer, Doc19)

Plain language: Wait for a specific genetic test, based on which we will choose for either immunotherapy or chemotherapy.

All specialist letters contained details of the patient's history, but often provided other information too; in some cases, no history was provided at all. A typical example (e.g. Q3) included information about what was discussed with the patient during the consultation.

Q3: History: Patient visited our outpatient clinic together with four children. Results discussed.

Specialist letter - history. (Academic hospital, lung cancer, Doc49)

Additional diagnostic tests were reported in detail. In most cases, the report of the

radiologist or pathologist was given without description of their implications for diagnosis or treatment. Many letters also mentioned the potential side effects of proposed or given treatment. In some letters, specific recommendations were given to the GP about how to handle side effects, but in others, either a simple reference to a protocol or guideline was provided, or no recommendations were mentioned (e.g. Q4). Late effects were almost never mentioned.

Q4: The surgical operation, the expected course, but also the complications related to the treatment, were discussed with her.

Specialist letter – policy. (Small non-academic hospital, colorectal cancer, Doc6)

Although many letters reported that information was shared with the patient, this was not very specific in most cases. The emotional reaction of the patient to receiving specific information was seldom reported (e.g. Q5). In the interviews, GPs mentioned that they would like to receive information about what was discussed with the patient regarding treatment and prognosis.

Q5: Patient and daughter are very relieved that we did not opt for chemotherapy; they agree with the therapy proposed.

Specialist letter - policy. (Academic hospital, breast cancer, Doc50)

Both referral and specialists' letters

Abbreviations were used in all letters. Most were common medical abbreviations (e.g. Q6), but some were department-specific (e.g. Q7). In the interviews, GPs mentioned that they did not understand all abbreviations that were used, and some medical specialists stated that they tried to avoid abbreviations and department-specific terms whenever possible (e.g. Q8).

Q6: Cor ne, pulm vbs, abd nca, shoulder limited mobility. Full version: Cor normal examination, pulmones vesicular breathing sounds, abdomen no clear abnormalities, shoulder limited mobility.

Referral letter – physical examination. (Lung cancer, Doc17)

Q7: During positioning of PCEA, patient developed AF, for possible post-surgical anticoagulation PCEA abandoned. After resection ICG-clearance 8%.

Specialist letter – surgery report (Academic hospital, colorectal cancer, Doc6)

Full version: During positioning of patient-controlled epidural analgesia, the patient developed atrial fibrillation. For possible post-surgical anticoagulation, patient-controlled epidural analgesia was abandoned. After resection, the indocyanine-green clearance was 8%.

Q8: I really try to avoid using abbreviations, since knowing all different abbreviations by all different specialisations is not doable for a general practitioner.

Interview of specialist nurse (Academic hospital, breast cancer, I3)

Rarely used codes

Almost no remarks were found about advance directives (e.g. do not resuscitate) in either referral letters or specialist letters. In some letters, a special heading regarding this subject was available, but was often not completed. In addition, psychosocial information was only very rarely found in either referral or specialist letters. One GP mentioned that psychosocial information was almost never provided in letters, but that it was often shared during telephone contact (e.g. Q9). Some specialist letters presented a summary of complaints in organ systems other than the one of primary interest, but this was rare. Equally, it was rare to receive a differential diagnosis of the other possible explanations for the complaints.

Q9: In case of malignancies, I always have contact by telephone with the treating specialist in between his consultations. This provides me with relevant information on how a patient is coping.

Interview with GP1. (Rural general practice, I1)

Reports

All patients were discussed at least once in a multidisciplinary meeting/ setting. In some departments, the comprehensive reports of these meetings were sent to the GP. In other departments, the report was available in the hospital file, but was not shared with the GP. In those cases, the conclusions of the multidisciplinary meetings were often summarised in the specialist letters. Some of these reports contained more information about alternative treatment options and the choices made compared with the specialist letters (see Q10 and Q11 for examples). Some GPs mentioned they would prefer to receive these reports, since they often provide a summary of diagnoses and planned treatment. Other GPs thought these reports did not add any value to the specialist letters.

Q10: Treatment plan: in case the patient prefers a breast saving treatment, there is an indication for neo-adjuvant chemotherapy. Otherwise mamma ablation and axillary lymph node dissection.

Multidisciplinary meeting report. (Academic hospital, breast cancer, Doc101)

Q11: Treatment plan: modified radical mastectomy

Specialist letter. (Academic hospital, breast cancer, Doc12)

Q10 and Q11 are about the same patient at the same moment.

Reports of invasive diagnostic procedures (e.g. colonoscopy or bronchoscopy) were almost always sent to the GP, either separately or integrated in a specialist letter. The same held true for surgery reports. Reports from consultations with allied health professionals and medical consultants were available in the patient's file, but were not usually detailed in the letter sent to the GP.

Telephone calls

Both GPs and oncology specialists mentioned that they preferred telephone contact when dealing with oncological diagnoses. However, telephone calls to other healthcare providers were rarely mentioned in either referral or specialist letters or somewhere else in the patient file. In addition, both groups of healthcare providers mentioned that it was often difficult to contact each other by telephone because of limited availability. Some GPs

preferred regional hospitals because, compared to university hospitals, it was considered easier to contact specialists (Q12).

Q12: But, talking about [the university hospital]; yes, I prefer not to work with them [...] yes, I often find it difficult to contact them.

Interview with GP1. (Rural general practice, I1)

Discussion

Key findings

We identified 70 items of correspondence between primary and secondary care. Six topics were identified in almost all referral letters (Box 1), but it was most notable that highly relevant information was often mixed with less relevant information in the past medical history, medication list and history of the presenting complaint. By contrast, specialist letters included nine common topics (Box 2), and although information about actual treatment was always presented, it was rare for the letters to include information about the intent of the treatment (curative or palliative), whether there had been any discussion about treatment alternatives or about how the patient had reacted to the information received.

Comparison with the literature

This study adds to the small body of evidence about written communication between healthcare providers, especially that concerning patients with cancer. We note two features that we believe reflect use of the ZorgDomein system. Firstly, in contrast to existing results in the literature,^{14,15} referral letters in our sample typically mentioned the reason for referral. This could be explained by the fact that most GPs in the Netherlands refer patients using ZorgDomein, which pre-specifies the information required.²³ Secondly, the lack of discrimination between relevant and less relevant information has not been mentioned in the literature before. This finding can also be explained using the ZorgDomein system that automatically exports information from the electronic patient file into the referral letter. Apparently, GPs fail to adjust the exported information.

Concerning specialist letters, and consistent with the existing literature, we found that the treatment goal and prognosis were seldom mentioned.^{16,27} By contrast, current medication details were almost always mentioned, despite this not being the case in previous research.¹⁷ Also consistent with previous research, technical information about radiation therapy was included in all letters, even though only a minority of the GPs wanted the information.²⁸ These findings suggest that letters are sometimes meant to provide a means of storing rather than exchanging information, which may explain why they are poorly tailored to the needs of the recipient.^{16,17}

Overall, the findings of our study indicate that both referral and specialist letters were not always written with the primary aim of mutual communication. This aim could be defined as providing the information needed to ensure continuity of care, between hospital and primary care, without giving redundant information.²⁹ To improve communication, it would be interesting to explore the information different healthcare providers find essential or desirable in communication.

Strengths and limitations

To the best of our knowledge, this is the first study not to use pre-specified quality criteria when analysing the content of letters concerning patients with cancer. We gathered information in a very open and explorative way, as is needed in qualitative research,²⁵ and much attention was paid to the sample composition. Indeed, we generated a purposive sample of patients by different hospital types, different cancer types and different tumour stages, and we included both GPs and oncology specialists of different ages and genders. Interviews were also included to ensure data triangulation. Despite the fact that our research was aimed at correspondence about patients with cancer, the findings seem to be not very disease specific and may be generalisable to other diseases.

However, several limitations do exist. First, all researchers who analysed the data for coding were associated with our Department of General Practice, and this might hamper objectivity. To combat this, however, a value-free code list was used and all results were discussed extensively with co-authors working in different hospital departments. Second, only written information was used because of the nature of the content analysis. Non-recorded phone calls between healthcare providers were, therefore, not included. Although this does not mean that none occurred, we assume that transparency and continuity of care, as well as medico legal considerations, would mean that notes would have been made of these contacts. Related to this point, our sample only contained letters from the initial treatment period. This may be relevant to items such as late side effects, which often were not mentioned in the present sample, but which might have been mentioned in specialist letters at the end of treatment.

Considerations

In the Netherlands, as in other countries, hospitals are now developing a patient record file that cannot only be used by specialists but also by other healthcare providers, such as GPs, and by patients. Consequently, it can be expected that such files will comprise a lot of information, of varying relevance, and that will contain notes from different healthcare providers. This growth in information may make it increasingly difficult to identify the most relevant data; therefore, exchanging summaries of relevant information would appear to be of critical importance.

Conclusion

General practitioners and oncology specialists exchange a lot of information in correspondence. In this study, we identified certain problems that were specific to referral letters and others that were specific to specialist letters. Notably, referral letters suffered from a lack of focus, which probably reflected a failure to use referral templates correctly. By contrast, although specialist letters included information about actual treatment, other information relevant to primary care was often missing; this included the intent of the treatment (curative or palliative), the alternative treatment options and the details of any discussion with patients. Our findings indicate that neither referral nor specialist letters are tailored to the needs of the recipient. Further re- search should focus on the information different healthcare providers would like to receive. In the meantime, however, it seems prudent to recommend that all correspondence should be written with the receiver in mind and that summaries of relevant information be included in a prominent position in all correspondence.

Additional information

Funding

This study was supported by a grant from the Stichting Stoffels-Hornstra. The sponsor has no role in the study design, collection, analysis, interpretation of data, the writing of the report, or in the decision to submit the article for publication.

Conflicts of interest

The authors have declared no competing interests.

Acknowledgements

We would like to thank C. Roorda, F. Gaster, A. Stilma and R. Dik for their help with coding documents. We would like to thank the participating hospitals: University Medical Centre Groningen, Treant Zorggroep locatie Scheperziekenhuis Emmen, and Antonius Ziekenhuis Sneek. Dr Robert Sykes (www.doctored.org.uk) provided technical editing and writing services for the final draft of the manuscript.

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Supplementary Table 1. Codes and Themes

Themes	Codes
Administrative details	
Purpose	Reason of consultation or letter
Background information	Allergies Cardiopulmonary resuscitation policy Past medical history in general Past medical history concerning this cancer Smoking status Packyears Alcohol use Hard drugs/soft drugs use Actual medication
History	Summary of complaints Interval history (what happened between the last consultation and now) Family history Tractus history Psychosocial status (relation, work)
Inpatient episode	General report Report of surgery or procedure
Physical examination	Overall impression (for example 'ill') Performance status Clinical findings
Diagnostic tests	Blood results Pathological results Genetical results Imaging results Endoscopy results Lung function test results Results of population survey Results of diagnostic test will follow later Results of discussion with medical experts Results of a multidisciplinary meeting
Diagnosis	Diagnosis or final diagnosis Differential diagnosis (other options) TNM classification
Policy	To do further diagnostic tests To be discussed in multidisciplinary meeting To have a consultation with another medical doctor Lifestyle advices Participation in a scientific research project Start or change in medication Removed materials (for example drains) Reassurance / expectative policy

	<ul style="list-style-type: none">Going to have radiotherapyGoing to have surgeryGoing to have chemotherapyGoing to have hormonal therapyGoing to have immune /targeted therapyDoseFrequency / durationDate for start of the therapy
Considerations	<ul style="list-style-type: none">Treatment goal (palliative or curative)Other options for treatmentMotivation for treatment from patientMotivation for treatment medicalPrognosis
Expected effects	<ul style="list-style-type: none">Prognosis with / without treatmentProbability of response to therapyExpected side effects or adverse effectsAdvice concerning side effects or adverse effectsLate effectsLater treatment options
What's next	<ul style="list-style-type: none">Materials still to be removed (for example drains)Date for next consultationWho can the patient contact when problems ariseRecommendations for the general practitionerGP/oncologic specialist was already contacted by phoneQuestion for someone in CC
Summary	<ul style="list-style-type: none">Summary or conclusion of the letterWhich information was or was not shared with the patientWhat was the emotional reaction of the patient

Chapter 7

Correspondence between primary and secondary care about patients with cancer: a Delphi consensus study

Adapted from: Stegmann ME, Homburg TM, Meijer JM, Nuver J, Havenga K, Hiltermann TJN, Maduro JH, Schuling J, Brandenburg D, Berendsen AJ. Correspondence between primary and secondary care about patients with cancer: a Delphi consensus study. *Supportive Care in Cancer*. 2019 Nov;27(11):4199-4205.

Text based on this chapter was also published as: Mariken Stegmann, Daan Brandenburg, Maarten Homburg en Annette Berendsen. Welke informatie moeten brieven over patiënten met kanker bevatten? *Huisarts en Wetenschap*. 31 januari 2020.

Abstract

Introduction: To provide optimal care for patients with cancer, timely and efficient communication between healthcare providers is essential. In this study, we aimed to achieve consensus regarding the desired content of communication between general practitioners (GPs) and oncology specialists before and during the initial treatment of cancer.

Methods: In a two-round Delphi procedure, three expert panels reviewed items recommended for inclusion on referral and specialist letters.

Results: The three panels comprised 39 GPs (42%), 42 oncology specialists (41%) (i.e., oncologists, radiotherapists, urologists and surgeons) and 18 patients or patient representatives (69%). Final agreement was by consensus, with 12 and 35 items included in the GP referral and the specialist letters, respectively. The key requirements of GP referral letters were that they should be limited to medical facts, a short summary of symptoms and abnormal findings, and the reason for referral. There was a similar requirement for letters from specialists to include these same medical facts, but detailed information was also required about the diagnosis, treatment options and chosen treatment. After two rounds, the overall Content Validity Index (CVI) for both letters was 71%, indicating that a third round was not necessary.

Discussion: This is the first study to differentiate between essential and redundant information in GP referral and specialist letters, and the findings could be used to improve communication between primary and secondary care.

Introduction

The incidence of cancer is rising in Europe [1,2]. Cancer care is complex in most instances, requiring the involvement of multiple healthcare providers for diagnosis and treatment [3–5]. Consequently, a patient may visit many different healthcare providers over a relatively short and intense period.

In the Netherlands and other countries with a similar system, all inhabitants are registered with a general practitioner (GP). This GP functions as gatekeeper and coordinator of healthcare. In countries with such a system, patients often consult their GP for support [6,7]. To provide this care in an optimal manner, timely and efficient information exchange is essential, both at time of diagnosis and during therapy [5,8,9]. As the electronic patient records of GPs and medical specialists are separate, the most common way of communication is the digital exchange of letters between GP (i.e., referral letters) and specialists (i.e., consultation and treatment) [10]. These must be relevant and complete, particularly with regards to the specific needs of the recipient party. Inadequate correspondence by GPs may lead to unnecessary repetition of diagnostic tests, patient anxiety and low patient satisfaction [4,11]. Timely and relevant information from specialists can enable GPs to support their patient to make treatment decisions, give moral support during treatment, and monitor and treat side-effects and complications [10]. Despite all parties agreeing that adequate correspondence is important, it is equally agreed that the current situation could be improved [8,12].

We aimed to find consensus among GPs, oncology specialists (i.e., oncologists, radiotherapists, urologists and surgeons) and patients regarding the content of referral and specialist letters before and during the initial treatment (i.e. until start of treatment as described in the original treatment plan) of cancer.

Methods

Study design

We used the Delphi procedure to reach consensus about the required content [13]. According to our institutional review board, no approval was needed because this study was not subject to the Dutch Medical Research Involving Human Subjects Act. All participants were informed about the aims of the study and agreed to participate.

Composition of the item list

The initial list of items was based on two sources: the code list of an earlier qualitative study [14] and the results of a literature search. The literature search was performed in Medline and Web of Science (Supplement 1, Figure S1a). The items derived from the qualitative study and the literature search were discussed until consensus on every item was reached among four members of the research group (MH, MS, JS and AB). To test the applicability, the item list was presented to two GPs and two medical specialists in individual sessions.

Composition of the expert panels

The following three expert panels were formed by purposive sampling to optimise diversity: a GP panel, an oncology specialist panel (i.e., oncologists, radiotherapists, urologists and surgeons) and a patient panel (patients or close relatives). Potential participants were

invited from different fields, ensuring variety in characteristics such as age, gender, academic qualification and place of employment. Patient associations in the Netherlands were approached to identify patients. Given the number of sample characteristics, we aimed to include 20 GPs, 20 oncology specialists and 15 patients after the final round.

Data collection and analysis

The Delphi procedure was performed over at least two rounds, with participants using the online Qualtrics tool, version 2005, to complete questionnaires (Qualtrics, Provo, Utah, USA). The patient panel received a list of definitions for the items used in the questionnaire. During Round 1, we also sent a short questionnaire about demographic characteristics and preferences for the layout and writing style of the respective letters. Descriptive statistics were applied to the answers of these questions. All data were analysed using IBM SPSS for Windows, version 22.0 (IBM Corp., Armonk, NY, USA).

Delphi procedure

Round 1

Participants were asked to rate each list item on four-point Likert-type scales (not relevant = 1 point; moderately relevant = 2 points; relevant = 3 points; and highly relevant = 4 points), with a fifth “no opinion” option (0 points). Participants were provided with a free text area at the end of the questionnaire in which they could propose additional items. The median scores for each item were calculated for the panels combined and for each panel individually. If the difference between the median scores of the GPs and the specialists was ≥ 2 points, the item score of the receiving party was weighed more heavily (weight factor 1:2). Items with median scores < 2.5 were considered not relevant. Items with median scores ≥ 2.5 were included in the concept consensus list: those with scores ≥ 2.5 but < 3.5 were considered less relevant and those with scores ≥ 3.5 were defined as highly relevant. Additional items were added to the concept consensus list if more than one participant suggested the same item.

Round 2

Participants were asked to indicate whether they agreed (yes/no) with inclusion of the highly relevant items on the consensus list. Based on the content validity index (CVI, which is the proportion of respondents who agree with the proposed relevance of the item), if $\geq 70\%$ of respondents disagreed with a proposed item, it was excluded from the final list [13,15]. For all items scored as less relevant in the first round, participants were asked to indicate whether they agreed (yes/no) with their exclusion from the consensus list; if $\geq 70\%$ of respondents disagreed with this proposal, the item was included in the final consensus list [12,13]. Participants were not asked to review items with low relevance a second time. If $\geq 70\%$ of the items included in round two reached a CVI of ≥ 0.70 , an additional (third) round was not deemed necessary. Agreement (CVI) between the panels was calculated as the percentage of items in which the different panels separately reached the same decision.

Results

Composition of the expert panels

In both rounds, GPs ($n = 39$; 42%), medical specialists ($n = 42$; 41%) and patient

representatives (n = 18; 69%) completed the whole questionnaire or at least 70% of the questions. The respondents' characteristics met the inclusion requirements (Table 1). Members of the panels were more mostly experienced clinicians and older patients.

Composition of the item list

The process for composing the original item list for panel review is shown in the supplementary material (Supplement 1, Figure S1 b–c). In round one, the differences between the median scores of GPs and specialists were never ≥ 2 points, so no weighting was applied. In round two, the overall CVI for both letters was 71%, indicating that a third round was not necessary. For those items for which no agreement was reached, the patient panel was usually inclined to include the item, while the GPs and medical specialists were not.

Delphi procedure: Referral letters

For referral letter content, 72 items were included in the original list. The participants rated 12 items (17%) as highly relevant, 45 items (63%) as less relevant and 15 items (21%) as not relevant (Supplement 2). Thus, the consensus list for referral letters consisted of 57 items after the first round. All 12 highly relevant items from round one remained after round two, but consensus did not reach the required level for any of the 45 less relevant items. Therefore, only 12 items were included in the final consensus list for the referral letters (Table 2). These items mainly concerned medical facts (e.g., past medical history, resuscitation policy and medication details [names, doses and allergies]). Besides requiring the reason for referral and the level of urgency, information was also required about the presenting symptoms and the history of symptoms, as well as any aberrant findings on both physical examination and investigation. Regarding psychosocial information, the only retained item was the need for an interpreter when a language barrier was present. However, there was no requirement for a provisional diagnosis or for treatment, contextual or psychosocial information.

Delphi procedure: specialist letters

Of the original 108 items, 32 (30%) were rated as highly relevant, 51 (47%) as less relevant and 25 (23%) as not relevant (Supplement 2). After the second round, all 32 highly relevant items remained on the list and 3 less relevant items were included. Therefore, the final consensus list for specialist letters contained 35 items (Table 2). Three new items were proposed in round one, but each was only suggested once (Supplement 2). In the final consensus list for specialist letters, the requirements were for the purpose of the letter to be stated, for the corresponding medical facts to be included from the referral letters (e.g., history, resuscitation policy, and medication details) and for details of any trial enrolment. The requirement for information about the diagnostic process was limited to details about presenting symptoms, physical examination (abnormal findings relevant to the current problem) and investigation results (aberrant findings relevant to the current problem). Concerning the diagnosis, it was agreed that the following six items should be included: provisional diagnosis/diagnosis, whether the tumour is localised or metastasised, a description of the size and local invasion of the primary tumour, whether there is spread to regional lymph nodes, and whether there is distant metastasis.

Table 1. Panel characteristics

Characteristics	GPs (n=39)	Medical specialists (n=42)	Patients (n=18)
Age (years)	Mean 50.5, SD 8.8	Mean 47.6, SD 7.9	mean 64.8, SD 8.2
Male, n (%)	20 (51%)	28 (67%)	12 (67%)
Academic title MD PhD, n (%)	11 (28%)	26 (62%)	
Involved in training GPs/medical specialists, n (%)	22 (56%)	25 (60%)	
Active/board member of (scientific) union/patient association n (%)	22 (56%)	20 (48%)	9 (50%)
Employed, n (%)			
City area	14 (36%)		
Semi-urban area	14 (36%)		
Rural area	11 (28%)		
University hospital		17 (40%)	
Leading general hospital		9 (21%)	
Peripheral hospital		16 (38%)	
Type of employment, n (%)			
Self-employed	34 (87%)	16 (38%)	
Paid employment	5 (13%)	26 (62%)	
Type of practice, n (%)			
Solo practice	5 (13%)		
Duo practice	12 (31%)		
Group practice	14 (36%)		
Family practice centre	8 (21%)		
Discipline, n (%)			
Medical Oncologist		11 (26%)	
Surgeon		7 (17%)	
Radiation oncologist		3 (7%)	
Pulmonologist		12 (29%)	
Urologist		2 (5%)	
Gynaecologist		2 (5%)	
Gastroenterologist		2 (5%)	
Other		3 (7%)	
Situation, n (%)			
Patient representatives			17 (94%)
Close contact of patient			1 (6%)
Type of cancer, n (%)			
Breast			2 (11%)
Lung			5 (28%)
Prostate			10 (56%)
Colorectal			1 (6%)

Table 2. Desired content of referral letter and specialist letter

Category	Referral letter	Specialist letter
Purpose	Reason for referral Level of urgency	Purpose of the letter
Medical facts	Active diagnoses/history Resuscitation policy Medication allergies Medication names Medication doses and frequencies	Active diagnoses/history Resuscitation policy Medication allergies Medication names Medication doses and frequencies Any clinical trial the patient is involved in*
History	Presenting symptoms History of symptoms	Presenting symptoms
Psychosocial information	Need for an interpreter	
Diagnostic pathway	Physical examination: Aberrant findings, relevant for current problem Investigations: Aberrant findings, relevant for current problem	Physical examination: Aberrant findings, relevant for current problem Investigations: Aberrant findings, relevant for current problem
Diagnosis		Provisional diagnosis/diagnosis Whether tumour is localised or metastasised Description of size and direct expansion of primary tumour** Description of expansion to regional lymph nodes Description of distant metastasis
Treatment		Treatment options Selected treatment (e.g. watchful waiting or surgery) Explanations for chosen treatment Aim of treatment: curative or palliative Summary/conclusion of multidisciplinary consultation Prognosis with treatment Short-term side-effects of treatment* Effective initiated treatment Response on initiated treatment
Completion		Summary/conclusion What the patient has been told For what problems should the patient contact the medical specialist? Whom should the patient contact Specific request to the GP
Hospitalisation		Discharge destination Complications Medication changes Complete medication list Active medical problems at discharge Intentions regarding residual medical materials (e.g., drains or stitches)

* Less relevant in round 1. ** Less relevant in round 1 and also overall score < 70% in round 2 (62.7%), but included because 71.4% for GPs in round 2.

Concerning treatment, the following eight items were desired: the option(s), the selected option(s), the explanation(s) given, the aims (curative or palliative), a summary/conclusion of any multidisciplinary meeting, the prognosis, the short-term side-effects, the expected effectiveness, and the response to date. There were also a few other requirements of the included information. Five completion-related items were included, such as the provision of a summary/conclusion, details of what the patient has been told and whom the patient should contact. When a patient was hospitalised, six additional items were requested, such as the discharge destination.

Layout and writing preferences

All parties preferred referral letters to be short (mean 1.36 pages) and specialist letters to be longer (mean 1.76 pages). However, the panels did not agree about the preferred structure or writing style (Table 3). The oncologists preferred a structured format, unlike the other two panels, which preferred an unstructured format with no predefined sections. Moreover, most patient representatives thought the information could be best communicated in a short-hand or abbreviated medical style (e.g., “chemotherapy delayed because of cough, whereas half of the doctors was in favour of full phrases (e.g., “We delayed chemotherapy for one week because the patient developed a cough”). Most respondents thought that correspondence from specialists should not include all information available in the hospital records, and only a minority advocated using jargon (specialism-specific abbreviations; e.g., “hipec” for “hyperthermic intra peritoneal chemotherapy”). However, all parties agreed that it was appropriate to use abbreviations that are in common use (“e.g.” for exempli gratia) and most GPs thought that common medical abbreviations (e.g., BP for blood pressure) were appropriate (Table 3).

Table 3. Layout and writing preferences

	Referral letters				Specialist letters			
	GPs (%)	MSs (%)	Ps (%)	Overall (%)	GPs (%)	MSs (%)	Ps (%)	Overall (%)
Format and writing style								
A structured format is important	54.0	61.8	61.1	58.5	43.2	71.8	66.6	59.6
I prefer phrases above short-hand or abbreviated medical style	45.9	46.2	22.2	41.8	54.1	64.1	22.2	52.1
The specialist letter should contain all information available in hospital records					25.6	35.7	72.2	38.4
Use of abbreviations								
No abbreviations	2.7	2.6	11.1	4.3	2.7	5.1	11.1	5.3
Only general abbreviations	35.1	46.2	77.8	47.9	35.1	46.2	72.2	46.8
Also medical abbreviations	54.1	38.5	5.6	38.3	59.5	35.9	11.1	40.4
Also jargon abbreviations	8.1	12.8	5.6	9.6	2.7	12.8	5.6	7.4

GPs = General Practitioners, MSs = medical specialists, Ps = patients

Discussion

In the two-round Delphi process, GPs, medical specialists, and patient representatives reached consensus on lists for the most relevant items in correspondence between primary and secondary care.

It was agreed that referral letters should contain medical facts and information about the current problem, but that a detailed description of the physical examination and investigation findings was not necessary. Information about social context, diagnosis and treatment to date was considered unnecessary. It was considered that the specialist letters should contain the same medical facts as the referral letters. Also, it was agreed that diagnosis and treatment should be described in detail, and that items such as "what the patient has been told" and "whom the patient should contact" should be mentioned in the conclusion of the letter.

Interestingly, the panels considered that it was important to share information about resuscitation plans in both the referral and specialist letters. Recent studies have indicated that timely discussion of preferences for end-of-life care is important to improve quality of life and care in this phase [16]. Our findings are in line with earlier research that doctors take these discussions seriously and need to have clear information to do this effectively [17]. Although outside the scope of this study, it would be interesting to elaborate on the responsibilities in this matter as perceived by GPs, oncology specialists and patients. Concerning the content of specialists' letters, the most striking requirement was for the inclusion of detailed information, including the rationale, about diagnosis and treatment. Earlier research by our group showed that detailed information about diagnosis is often available in correspondence, but that key information about possible treatment options and the justification is often lacking [14]. Similarly, it is typically the case that no explicit information is given about whether the treatment is being done with palliative or curative intent [14]. This is important because GPs are not only involved in providing care for patients during and after cancer treatment [6,7] but also because they are expected to be formally involved in that care [9]. After a patient has visited an oncology specialist, the GP is able to answer questions that arise and to discuss the diagnosis and the treatment options after the patient has digested the initial information. In this way, GPs can bridge the gap between the patient and specialist by delivering care close to home, potentially allaying patient distress and possibly even reducing the burden on secondary care.

In this study, we also asked the panels to indicate their preferences regarding the use of undefined abbreviations in correspondence. We previously reported that abbreviations are common in medical practice (e.g., "BP" for "blood pressure" or "abd." for "abdomen") [14]. However, some medical abbreviations can have different meanings depending on the context and specialism (e.g., "OAC" for both "oral anti-conceptive" and "oral anti-coagulant") and may cause confusion [18]. To ensure mutual understanding, abbreviations should be avoided, even if their meaning is customary and obvious to the writer. Although the study was performed in the Netherlands, we think that the results may also be of interest to doctors in other healthcare systems. The care for cancer patients often involves several doctors and it is important for them to share all important information. Besides, our results have the potential to inform medical training, they can be used to develop guidelines and they can help develop formats for letters generated from electronic patient files.

A major strength of this study is that it provides important information that can be used by all doctors to improve communication. Another strength is the quality of the item list, which had large content validity because it combined data from a previous study and an extensive literature search, and because participants were asked to suggest additional items. To ensure comprehensibility of the item list, all items were discussed in several meetings, the list was assessed among GPs and oncology specialists, and explanations of all items were provided in writing to participants from the patient panel.

The panel quality was key to producing valid outcomes from this study, so we composed each panel with great care by purposive sampling. This was both a strength and a limitation. On the one hand, participants were recruited from across the Netherlands and sampled based on a list of desired characteristics, with the experts showing a high level of consensus, indicating a high probability that the study results could be generalised to cancer care in the Netherlands and in countries with comparable healthcare systems. On the other hand, it is possible that our cohort was not representative of all healthcare providers, given the response rates of 42% and 41% respectively for GPs and medical specialists.

This study is the first to use an iterative approach to identify what information is perceived as relevant and what is perceived as redundant in communication between primary and secondary care. Given that administration, including writing letters, is a time-consuming task for doctors [19], it is important that the focus is on providing only that information considered relevant to the recipient. Such an approach can enhance the effectiveness of communication, lessen administrative burdens and potentially result in cost-saving.

Conclusion

Our research focused on communication between primary and secondary care before and during the initial treatment of cancer in the Netherlands. Using a consensus approach with panels of GPs, oncology specialists and patients, we obtained a set of items that were deemed relevant for inclusion in referral letters and specialist letters by all groups. The recommendations of this study can be used to develop guidelines for the correct composition of these letters and could be incorporated in computerised systems in both primary and secondary care that generate letters from electronic patient records.

Additional information

Funding information

This study was supported by a grant from the Stoffels-Hornstra Foundation, Coevorden, the Netherlands.

Role of the funding source

This funding source had no role in the design of this study nor had it any role during its execution, analyses, interpretation of the data, or decision to submit results.

Conflict of interest

The authors declare that they have no conflict of interest.

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Supplement 1: Literature search

We used four different MeSH and key term strings covering primary care, secondary care, written information exchange and grading parameter (quality, opinion).

Search strategy MEDLINE:

```
((((Primary Care[Title/Abstract] OR GP[Title/Abstract] OR primary health care[MeSH Terms] OR family practice[MeSH Terms] OR family practice[Title/Abstract] OR family physician[Title/Abstract] OR family physicians[Title/Abstract] OR general practitioners[MeSH Terms] OR general practitioner[Title/Abstract] OR general practitioners[Title/Abstract] OR primary[Title/Abstract] OR general practice[MeSH Terms] OR general practice[Title/Abstract])))
```

AND

```
(secondary care[MeSH Terms] OR hospital-based[Title/Abstract] OR hospital care[Title/Abstract] OR secondary care centers[MeSH Terms] OR secondary care[Title/Abstract] OR specialist*[Title/Abstract] OR specialized[Title/Abstract] OR specialised[Title/Abstract] OR consultants[MeSH Terms] OR consultant*[Title/Abstract])) AND
```

```
(correspondence as topic[MeSH Terms] OR correspondence[Title/Abstract] OR written communication[Title/Abstract] OR writing[Title/Abstract] OR patient discharge summaries[MeSH Terms] OR health information exchange[MeSH Terms] OR information exchange[Title/Abstract] OR discharge summaries[Title/Abstract] OR discharge summary[Title/Abstract] OR information transfer[Title/Abstract] OR letter*[Title/Abstract]))
```

AND

```
(Quality[Title/Abstract] OR content[Title/Abstract] OR deficit*[Title/Abstract] OR deficienc*[Title/Abstract] OR Value[Title/Abstract] OR contain[Title/Abstract] OR view[Title/Abstract] OR perspective*[Title/Abstract] OR opinion*[Title/Abstract] OR assessment[Title/Abstract])
```

AND

```
(Journal Article[ptyp] AND full text[isb] AND ("1990/01/01"[PDat] : "3000/12/31"[PDat]) AND English[lang])
```

Search strategy Web Of Science:

TOPIC: ("Primary Care" OR "GP" OR "primary health care" OR "family practice" OR "family physician" OR "family physicians" OR "general practitioner" OR "general practitioners" OR "primary" OR "general practice")

AND

TOPIC: ("secondary care" OR "hospital-based" OR "hospital care" OR "specialist" OR "specialists" OR "specialized" OR "specialised" OR "consultant" OR "consultants")

AND

TOPIC: ("correspondence" OR "written communication" OR "writing" OR "information exchange" OR "discharge summaries" OR "discharge summary" OR "information transfer" OR "letter" OR "letters")

AND TOPIC: ("Quality" OR "content" OR "deficit" OR "deficits" OR "deficiency" OR "deficiencies" OR "Value" OR "contain" OR "view" OR "views" OR "perspective" OR "perspectives" OR "opinion" OR "opinions" OR "assessment")

Refined by: DOCUMENT TYPES: (ARTICLE OR REVIEW) AND LANGUAGES: (ENGLISH)

Timespan: 1990-2016. Indexes: SCI-EXPANDED, SSCI, A&HCI, ESCI.

The following inclusion criteria were defined:

- original research, systematic-review or meta-analysis;
- published after 1990 in peer-reviewed journal;
- English language;
- concerned medical correspondence in general or correspondence in cancer care.

Figure S1a: Search strategy

Figure S1b: Flow diagram for the literature search

Figure S1c: Flow diagram for composing the original item list for panel review

Supplement 2: Complete item list and results of both Delphi rounds

Category	Item	Round one (median score)				Round two (agreement %)*				Status
Referral letter										
		Overall	GPs	MSs	Ps	Overall	GPs	MSs	Ps	
Background	Reason for referral/referral question	4	4	4	4	99	100	100	93	Included
	New referral or re-referral	3	3	3	3	82	82	85	73	Excluded R2
	Level of urgency	4	3.5	4	4	87	82	91	87	Included
	Reanimation policy	4	4	4	4	54	57	55	47	Included
	Active diagnoses/relevant past medical history	4	4	4	4	97	100	100	87	Included
	Other/miscellaneous past medical history	3	3	4	3	67	86	49	73	Excluded R2
	Smoking habits	3	3	3	3	75	64	76	93	Excluded R2
	Number of pack years	3	3	3	3	88	89	85	93	Excluded R2
	Alcohol habits	3	3	3	3	74	61	79	87	Excluded R2
	Number of alcoholic intakes per day	3	2	3	3	83	79	85	87	Excluded R2
	Soft/hard drug habits	3	3	3	3	72	64	76	80	Excluded R2
	Frequency and dosage of drugs	3	3	3	3	83	82	82	87	Excluded R2
	Diet habits	2	2.5	2	3	-				Excluded R1
	Statement of level of involvement of the patient with the referral	2	2.5	2	3	-				Excluded R1
	Expectations of the patient regarding the referral	3	3	3	3	78	71	79	87	Excluded R2
	Expectations of family regarding the referral	2	2	2	2	-				Excluded R1
	Information about desired level of involvement of the patient in the care process	3	3	3	4	78	79	94	40	Excluded R2
Allergies and medication	Medication allergies	4	4	4	4	90	96	88	80	Included
	Non-medication allergies	3	3	4	4	72	68	76	73	Excluded R2
	Symptoms during allergic reaction	3	3	4	4	82	79	88	73	Excluded R2

List of active medication												
		4	4	4	4	3	84	100	88	47	Included	
History and symptoms	Dose and frequency of active medication	4	4	4	4	3	74	89	70	53	Included	
	Presenting symptoms	4	4	4	4	4	95	96	94	93	Included	
	History of symptoms	4	3.5	4	4	4	75	82	70	73	Included	
	Symptoms in other tract	2	3	2	3	3	-				Excluded R1	
	Psychological wellbeing	3	3	3	3	3	63	71	70	33	Excluded R2	
	Oncological family history	3	3	3	3	3	70	64	82	53	Excluded R2	
	Non-oncological family history	2	2	2	2	2	-				Excluded R1	
	Psychosocial information	Living conditions	3	3	3	3	2	84	86	85	80	Excluded R2
		Home care	3	3	3	3	3	84	89	88	67	Excluded R2
		Mobility (e.g. car/use of public traffic services)	2	2	2	2	3	-				Excluded R1
Hobbies		2	2	2	2	2	-				Excluded R1	
Employment		2	2	2	2	2	-				Excluded R1	
Impact of disease and treatment on employment		3	3	2	3	3	92	96	91	87	Excluded R2	
Impact of disease and treatment on direct environment		2	3	2	2	2	-				Excluded R1	
Understanding/awareness of illness		3	3	3	3	3	78	79	79	73	Excluded R2	
Coping and coping habits		3	3	3	3	3	83	82	85	80	Excluded R2	
Level of social support		3	3	3	3	3	86	86	91	73	Excluded R2	
Religious and cultural beliefs about disease and death	Level of adherence to therapy	3	3	3	3	3	76	75	85	60	Excluded R2	
	Religious and cultural beliefs about disease and death	3	2	3	3	3	84	93	88	60	Excluded R2	
	Need for an interpreter	4	4	4	4	3	70	61	85	53	Included	
	Complementary healthcare methods used by this patient	2	2	3	2	2	-				Excluded R1	

Physical examination	First impression (e.g. healthy or really ill)	3	3	3	3	3	76	79	79	67	Excluded R2
	Abnormal findings, relevant for the current problem	4	4	3	4	3	91	100	85	87	Included
	Normal findings, relevant for the current problem	3	3	3	3	3	76	86	79	53	Excluded R2
	Abnormal findings, not relevant for the current problem	2	3	2	3	-					Excluded R1
	Normal findings, not relevant for the current problem	2	2	2	2	-					Excluded R1
	Performance status (level of functioning 0-100%)	3	2	3	3	3	72	89	61	67	Excluded R2
	Abnormal findings, relevant for the current problem	4	4	4	4	4	95	100	97	80	Included
	Normal findings, relevant for the current problem	3	3	3	3	3	78	75	91	53	Excluded R2
	Abnormal findings, not relevant for the current problem	3	3	2	3	3	74	71	76	73	Excluded R2
	Normal findings, not relevant for the current problem	2	2	2	2	-					Excluded R1
Investigations	Upcoming results (investigation already finished)	3	3	3	4	4	67	54	76	73	Excluded R2
	Abnormal findings, relevant for the current problem	4	4	4	4	4	95	100	97	80	Included
	Normal findings, relevant for the current problem	3	3	3	3	3	78	75	91	53	Excluded R2
	Abnormal findings, not relevant for the current problem	3	3	2	3	3	74	71	76	73	Excluded R2
	Normal findings, not relevant for the current problem	2	2	2	2	-					Excluded R1
	Upcoming results (investigation already finished)	3	3	3	4	4	67	54	76	73	Excluded R2
	Abnormal findings, relevant for the current problem	4	4	4	4	4	95	100	97	80	Included
	Normal findings, relevant for the current problem	3	3	3	3	3	78	75	91	53	Excluded R2
	Abnormal findings, not relevant for the current problem	3	3	2	3	3	74	71	76	73	Excluded R2
	Normal findings, not relevant for the current problem	2	2	2	2	-					Excluded R1
Policy and treatment	Diagnosis/provisional diagnosis	3	4	3	4	4	51	32	61	67	Excluded R2
	Other possible diagnoses	3	3	3	4	4	84	79	88	87	Excluded R2
	Argumentation for chosen treatment	3	3	3	3	3	86	86	91	73	Excluded R2
	Used treatments, with effect	3	3	3	3	3	50	61	52	27	Excluded R2
	Used treatments, without effect	3	3	3	3	3	61	68	58	53	Excluded R2
	Reaction to former treatments	3	3	3	3	3	55	64	58	33	Excluded R2
	Factors influencing treatment effect	3	3	4	4	4	55	50	64	47	Excluded R2
	Ideas from the GP regarding what could be a good treatment	3	3	3	3	3	81	89	79	67	Excluded R2
	Ideas from the GP regarding his/her own role in the future care for this disease	3	3	3	4	4	67	71	7	33	Excluded R2
	Lifestyle advices given to the patient	3	3	3	3	3	87	82	91	87	Excluded R2

Summary and closure	Summary/conclusion	3	4	3	4	47	61	42	33	Excluded R2
	What is told to the patient	3	3	3	4	63	64	67	53	Excluded R2
	Reaction from the patient regarding the given information	3	3	3	3	82	86	88	60	Excluded R2
	Involvement of other medical doctors	3	3	3	3	59	50	67	60	Excluded R2
	Care that is arranged for at home	3	3	3	2	90	93	94	73	Excluded R2
	Scientific studies patient is eligible for	1	1	1	2	-				Excluded R1
	Scientific studies patient is participating in	3	3	3	3	58	64	58	47	Excluded R2
	Is the medical specialist called before sending the letter	3	3	2	3	76	75	79	73	Excluded R2
	Has the patient received a copy of the letter	2	2	2	3	-				Excluded R1
Specialist letter										
Background	Reason/purpose of the letter	4	3	4	3	96	92	100	93	Included
	Reanimation policy	4	4	4	4	75	79	81	53	Included
	Active diagnoses/relevant past medical history	4	4	4	4	96	89	100	100	Included
	Other/miscellaneous past medical history	3	2.5	4	2	73	92	60	67	Excluded R2
	Smoking habits	3	3	3	2	81	97	72	73	Excluded R2
	Number of packyears	2	2	3	2	-				Excluded R1
	Alcohol habits	2	2	3	2	-				Excluded R1
	Number of alcoholic intakes per day	2	2	3	2	-				Excluded R1
	Soft/hard drug habits	3	3	3	2	80	93	78	60	Excluded R2
	Frequency and dosage of drugs	3	3	3	2	85	96	84	67	Excluded R2
	Diet habits	2	3	3	2	-				Excluded R1
	Information about desired level of involvement of the patient in the care process	3	3	3	4	75	86	81	40	Excluded R2

Allergies and medication	Medication allergies	4	4	4	4	3	90	89	94	80	Included
History and symptoms	Non-medication allergies	3	3	3	3	3	77	86	72	73	Excluded R2
	Symptoms during allergic reaction	3	3	3	3	3	76	86	72	67	Excluded R2
	List of active medication	4	4	4	4	3	92	96	97	73	Included
	Dose and frequency of active medication	4	4	4	4	4	89	93	84	73	Included
	Presenting symptoms	4	3	4	4	4	95	89	100	93	Included
Psychosocial information	History of symptoms	3	3	4	3	3	75	82	72	67	Excluded R2
	Symptoms in other tract	2	2.5	2	2	2	-	-	-	-	Excluded R1
	Psychological wellbeing	3	3	3	3	3	71	71	81	47	Excluded R2
	Oncological family history	3	3	3	3	3	64	75	63	47	Excluded R2
	Non-oncological family history	2	2	2	2	2	-	-	-	-	Excluded R1
Allergies and medication	Living conditions	2	2	2	2	2	-	-	-	-	Excluded R1
	Home care	2	3	2	2	2	-	-	-	-	Excluded R1
	Mobility (e.g. car/use of public traffic services)	2	2	2	2	2	-	-	-	-	Excluded R1
	Hobbies	2	2	2	2	1	-	-	-	-	Excluded R1
	Employment	2	2	2	2	2	-	-	-	-	Excluded R1
	Impact of disease and treatment on employment	2	2.5	2	2	2	-	-	-	-	Excluded R1
	Impact of disease and treatment on direct environment	2	2	2	2	2	-	-	-	-	Excluded R1
	Understanding/awareness of illness	3	3	3	3	3	73	75	78	60	Excluded R2
	Coping and coping habits	3	3	2	3	3	81	89	81	67	Excluded R2
	Level of social support	2	2	2	2	2	-	-	-	-	Excluded R1
	Level of adherence to therapy	3	3	3	3	3	75	82	75	60	Excluded R2

	Religious and cultural beliefs about disease and death	2	2	2	3	-	Excluded R1
	Need for an interpreter	2	2	2	3	-	Excluded R1
	Complementary healthcare methods used by this patient	2	2	2	2	-	Excluded R1
Physical examination	First impression (e.g. healthy or really ill)	3	3	4	3	65	Excluded R2
	Abnormal findings, relevant for the current problem	4	4	4	4	93	Included
	Normal findings, relevant for the current problem	3	2	3	3	72	Excluded R2
	Abnormal findings, not relevant for the current problem	3	3	3	2	63	Excluded R2
	Normal findings, not relevant for the current problem	2	2	2	3	-	Excluded R1
	Performance status (level of functioning 0-100%)	3	2.5	4	3	61	Excluded R2
	Abnormal findings, relevant for the current problem	4	4	4	4	99	Included
Investigations	Normal findings, relevant for the current problem	3	3	3	3	76	Excluded R2
	Abnormal findings, not relevant for the current problem	3	3	3	3	57	Excluded R2
	Normal findings, not relevant for the current problem	2	2	2	3	-	Excluded R1
	Upcoming results (investigation already finished)	3	3	3	4	61	Excluded R2
	Diagnosis/provisional diagnosis	4	4	4	4	99	Included
	Other possible diagnoses	3	3	3	4	55	Excluded R2
Diagnosis	TNM classification	3	3	4	4	37	Excluded R2
	Whether the tumour is localised or metastasised.	4	4	4	4	100	Included
	Size and local extension of the primary tumour (T)**	3	3	3	4	37**	Included
	Level of metastases tot regional lymph nodes (N)	4	3.5	3	4	95	Included
	Description of metastases (M)	4	4	3	4	93	Included

Results of intercollegiate consultations		3	3	3	4	43	50	44	27	Excluded R2
Summary/conclusion of multidisciplinary tumour board meeting		4	4	4	4	96	100	91	100	Included
Full report of multidisciplinary tumour board meeting		2	2	2	2	-				Excluded R1
Actions/treatments done by other medical specialists		3	3	3	4	76	86	75	60	Excluded R2
Policy and treatment	Possible treatment options	4	3	4	4	93	100	88	93	Included
	Chosen treatment (e.g. watchful waiting, surgery)	4	4	4	4	100	100	100	100	Included
	Argument for chosen treatment	4	4	4	3	95	100	94	87	Included
	Alternative treatment options in case of failure of first choice	3	3	3	3	73	64	91	53	Excluded R2
	Whether the intent of treatment is curative of palliative	4	4	4	4	99	100	100	93	Included
	Prognosis with treatment	4	3.5	3	4	85	93	78	87	Included
	Prognosis without treatment	3	3	3	4	51	43	72	20	Excluded R2
	Former treatments with positive effects	4	4	4	4	96	100	91	100	Included
	Former treatments without positive effects	3	3	4	4	53	46	59	53	Excluded R2
	Response on former treatments	4	3.5	4	4	96	100	91	100	Included
	Lifestyle advices given to the patient	3	3	3	3	61	75	56	73	Excluded R2
	Treatment schedule chemotherapy	3	3	3	3	44	46	41	47	Excluded R2
	Treatment schedule radiotherapy	3	3	3	3	47	46	47	47	Excluded R2
	Short-term side-effects**	3	3	3	3	24	25	25	20	Included
	Treatment recommendations for short-term side-effects	3	3	3	3	39	32	53	20	Excluded R2
	Expected course of the disease	3	3	3	4	57	57	72	27	Excluded R2
Treatment recommendations for future symptoms of the disease		3	3	3	4	59	61	75	20	Excluded R2
Nutritional advices given to the patient		3	2.5	3	4	72	75	81	47	Excluded R2

Hospitalisation	Psycho-social care agreed on	3	3	3	3	61	64	72	33	Excluded R2
	Needed care at home	3	3	3	3	72	71	78	60	Excluded R2
	Discharge destination	4	4	4	3	85	93	84	73	Included
	Course (what happened) during hospitalisation	3	3	4	3	48	50	41	60	Excluded R2
	Complications	4	4	4	3	95	96	97	87	Included
	Summary/conclusion of surgical procedure	3	3	3	3	41	46	41	33	Excluded R2
	Full report of surgical procedure	2	2	2	2	-				Excluded R1
	Medication changes	4	4	4	4	89	96	88	80	Included
	Actual list of medication	4	4	4	3	89	89	91	87	Included
	Active medical problems at discharge	4	4	4	4	99	100	97	100	Included
	Care that is arranged for at home	3	3	3	3	51	50	50	53	Excluded R2
	Intentions regarding residual medical materials (e.g., drains or stitches)	4	4	4	4	96	100	100	80	Included
Summary and closure	Summary/conclusion	4	4	4	4	100	100	100	100	Included
	What the patient has been told	4	4	4	4	95	100	91	93	Included
	Reaction from the patient regarding the given information	3	3	3	4	69	68	72	67	Excluded R2
	Involvement of other medical doctors	3	3	3	4	51	50	59	33	Excluded R2
	Scientific studies patient is eligible for	3	3	3	3	80	89	81	60	Excluded R2
	Scientific studies patient is participating in**	3	3	4	4	21**	14	16	47	Excluded R2
	Is the medical specialist called before sending the letter	3	3	3	3	80	75	88	73	Excluded R2
	Has the patient received a copy of the letter?	2	2.5	2	3	-				Excluded R1
	For what problems should the patient contact the medical specialist?	4	4	3	4	87	93	78	93	Included
	Whom the patient should contact	4	4	3	4	85	96	72	93	Included

With whom (which specialism) has the patient appointments during the upcoming period?		3	3	3	3	3	3	60	61	63	53	Excluded R2
Frequency of appointments	Frequency of appointments	2	2	2	2	3	3	-				Excluded R1
	Date and time of appointments	2	2	3	3	2	2	-				Excluded R1
	Request to the GP	4	4	4	4	3	3	95	96	97	87	Included
	Requests to other medical specialists	3	3	3	3	3	3	67	68	63	73	Excluded R2
Closure of treatment	Known late effects of treatment	3	3	3	3	4	4	51	50	63	27	Excluded R2
	Given cumulative dose of a treatment	2	2	2	2	3	3	-				Excluded R1
	Follow-up procedure, which specialism	3	3	3	3	3	3	43	54	34	40	Excluded R2
	Follow-up procedure, frequency	3	3	3	3	3	3	60	68	63	40	Excluded R2

*: items with overall median scores of four: percentage agreed with including, for item with overall median scores of three: percentage agreed with excluding. **: items with overall median scores of three but included on the ultimate consensus list after round two. -: item excluded after round one, so agreement round 2 is not applicable. R1: after Round 1; R2: after Round 2.

Chapter 8

Summary and General discussion

Introduction

The objective of this thesis was to analyse communication with, and about, patients who have cancer, focusing on the role of the general practitioner (GP). It was anticipated that the findings of this analysis would then allow me to make suggestions to improve the communication process. The results of two studies form the basis of this analysis: 1) *OPTion*, which focused on shared decision-making (SDM); and 2) *PION* which focused on information exchange between doctors. In this chapter, I will first summarise the main findings of these studies, before highlighting their relevance in the context of SDM and discussing how they relate to the findings of other researchers. Finally, I will describe some important methodological challenges inherent to research into communication in oncology and outline the implications of the present results for health care, education, and further research.

Summary of Main Findings

The protocol for the *OPTion* randomised controlled trial (RCT) was described in Chapter 2, the Outcome Prioritisation Tool (OPT) itself was described in Chapter 3, and the results of the RCT were presented in Chapters 4 and 5. The *PION* study is then summarised in Chapters 6 and 7.

In Chapter 3, the OPT instrument and its use were described in detail with a review of the existing literature about the instrument. The OPT was developed to facilitate the discussion of goals and preferences in an encompassing, non-disease-specific way. The OPT is used in both primary and secondary care to facilitate treatment decisions in different health care settings. However, the available scientific literature about the tool was limited, with the review yielding only a study protocol, two articles about its development, and four articles describing its use. All studies were performed among older patients, and most of the included patients rated maintaining independence as their most important goal. Nevertheless, the tool had been shown to be feasible for both patients and health care providers.

We reported the results of the *OPTion* RCT in Chapter 4. We randomly assigned older patients with non-curable cancer to either care as usual or the OPT-based intervention, which involved an OPT-facilitated conversation with the GP at some point between diagnosis and treatment decision. The score on a decision self-efficacy (DSE) scale, which ranged from 1 (no empowerment) to 100 (full empowerment), was used as the primary outcome measure. All questionnaires were completed at home, after the consultation with an oncologist during which a treatment decision was made. Symptoms of fatigue, depression, or anxiety were also measured as secondary outcomes. Of interest, although there was no difference in patient empowerment between the OPT ($n = 48$; $DSE\ 86.8 \pm 18.2$) and control ($n = 58$; $DSE\ 84.2 \pm 17.6$; $p = 0.47$) groups, non-significantly fewer patients in the OPT group had low empowerment (17.0% vs 23.0%; $p = 0.50$). However, patients in the OPT group did have significantly lower mean anxiety scores (6.0 ± 4.6 vs 7.6 ± 4.4 ; $p < 0.05$) and less fatigue rated as mild (57.6% vs 72.1%; $p = 0.05$). Overall, 44.8% of patients indicated that the OPT-facilitated conversation helped them make a treatment decision and that 33.3% of GPs indicated that they gained new insights from the conversation.

In Chapter 5 we presented the results of *OPTion2*, a follow-up study of 29 patients from the intervention group of the *OPTion* study. We descriptively analysed goals discussed by them

during four OPT-facilitated conversations with the GP over a 6-month period. Most participants rated either extending life (n = 10; 34%) or maintaining independence (n = 9; 31%) as their most important goal. Patients in the last year before death (late phase) less frequently prioritised extending life (n = 3; 21%) than those in an earlier phase (n = 7; 47%). Goals also changed during follow-up in 16 patients, typically during the late phase (n = 12; 75%). In the qualitative analysis of text entries from patients records, we deduced three broad themes for a specific baseline OPT score: Prioritising a specific goal, rating a goal as unimportant, and making treatment choices related to goals. Goal changes during follow-up were then shown to be related to symptoms, the disease course, or life events. By contrast, goal stability during follow-up was related to being in a stable situation, having a motivation unrelated to the disease, and retaining stable goals despite symptoms.

Chapter 6 details the first part of the patient information exchange in oncology study (PION1). In this study, we performed a qualitative content analysis of the medical files of 50 patients with colorectal, breast, or lung cancer who were treated with a curative intent. The files contained 419 documents that included referral letters from GPs and specialist letters. For data-triangulation, we also performed interviews with nine health care providers. A total of 70 items related to correspondence were identified, with six main topics identified in most referral letters from primary to secondary care. It was particularly notable that highly relevant information regarding the past medical history was often mixed with less relevant information (e.g., heart failure and broken finger). To a lesser extent, the same held true for the presenting history and medication list. In the specialist letters, nine topics were identified in most letters. Although information about the actual treatment was always present, only limited detail was given about treatment intent (curative or palliative) or treatment alternatives. The interviews with nine health care providers confirmed these issues.

Chapter 7 outlines the results of PION2, a Delphi consensus study that sought to construct a list of items that are essential for referral letters from GPs and specialist letters. We formed three panels that comprised 39 GPs, 42 oncology specialists (i.e., oncologists, radiotherapists, urologists, and surgeons), and 18 patients or patient representatives. After two rounds, the overall content validity for both letters was 71%, indicating that a third round was not necessary. The final consensus list included 12 and 35 items for the referral and specialist letters, respectively. The key requirements of GP referral letters were that they should be limited to medical facts, a brief summary of symptoms and abnormal findings, and the reason for referral. There was a similar requirement for letters from specialists to include these medical facts, but with the addition of detailed information about the diagnosis, treatment options, chosen treatment, and whether treatment was curative or palliative.

Reflection on the Findings

Emanuel and Emanuel argued in 1992 that the deliberative model is the most appropriate approach to use when assessing the interaction between patient and health care provider.¹ This model advocates that health care providers “engage the patient in dialog on what course of action would be best,”¹ a process that is currently termed SDM. Although this approach has numerous beneficial effects, such as reducing regret about decisions,² SDM is not often used in practice.^{3–5} In the following sections, I will discuss several key aspects of

SDM, including the people who should be involved, the method, and the effects, highlighting areas in which this thesis may add to the existing literature.

Shared decision making as a team

To have a good SDM process, it is important to involve appropriate partners. Thus, I will first discuss the roles of the patient and health care providers in primary and secondary care, before taking a look at the collaboration between those professionals.

Patients and loved ones

Although it is accepted that patients should feel empowered to participate in SDM, the available literature indicates that older patients often feel no empowerment.^{6,7} However, the OPTion study (Chapter 4) showed that DSE was high in older Dutch patients with non-curable cancer, possibly due to the generally high satisfaction with care reported in the Netherlands.⁸ Most patients also reported a high level of social support and visited medical specialists or GPs with a partner or another close relative, which may have further contributed to a sense of empowerment. Research by the Dutch Federation of Cancer Patient Organisations (NFK) has supported the importance of social support. In an online survey of 1,104 patients with non-curable cancer, they showed that most respondents preferred to talk about end of life issues not only with their GP (76%) and specialist (63%) but also with their partner (80%) and children (65%).⁹

Secondary care

In most cases, the medical specialist is responsible for both diagnosing the patient with cancer and initiating treatment, and in some instances, several specialists may need to be involved (e.g., an oncologist and a radiotherapist). Fortunately, patients in the Netherlands are generally very satisfied with this care.^{8,10} However, when told that their cancer was incurable, patients in the NFK survey indicated that emotional support was mediocre (mean score 6.5 ± 2.64 on a scale from 1 to 10). Among the patients who did not receive further support from the hospital (37%), most (59%) expressed a clear need for support. This was stated as a need for one key contact (55%; typically a specialist nurse), support for family and loved ones (43%), or information or advice regarding psychological symptoms (43%).⁹ In another NFK survey, seeking the opinions 4,763 Dutch patients with cancer had of specialist oncology nurses, most patients (77%) had required contact, and when received, rated the care with a mean score of 8.0 on a scale from 1 to 10).¹¹

Primary care

GPs have an important role in the Dutch health care system. Traditionally, the GP offers long-term accessible care with greater focus on context, but demographical shifts in recent decades may have influenced the closeness of this relationship. On the one hand, GPs are working part-time more often, which can decrease the continuity of care; on the other hand, patients tend to move and switch GPs more often. In 2019, The Dutch College of General Practitioners (NHG) redefined the core values of the GP to continuity of care, generalism, and person-centeredness,¹² adding collaboration as a fourth value,¹² consistent with the wishes of patients.^{9,13} In an NFK survey, 59% of respondents indicated they had a need for GP contact and rated the care they received with a mean score of 7.4 on a scale from 1 to 10.^{11,14} A position paper by the NHG about the role of primary care in oncology emphasised that GPs are often concerned with the care of patients with cancer, but it was stated that

this role should be formalised.¹⁵ In some GP practices, the practice nurse may provide some of the care for older patients, and more rarely, to oncological patients. This role has not been described in the literature.

Collaboration between primary and secondary care

To establish effective collaboration between primary and secondary care, it is essential that important information is shared. GPs refer patients to the hospital with a referral letter, and after consultation, medical specialists provide the GP with diagnostic and treatment information in a specialist letter. The results in Chapters 6 and 7 show that the information desired by each party is often not shared. In both instances, there is a need to write the letter to the needs of the receiver, and both medical specialists and GPs preferred to receive telephone calls and letters (Chapter 6). Although this has been mentioned in other research,^{16,17} phone calls can be difficult to realise because the receiver is not always available when a call needs to be made. However, the growth in mobile phones and apps raise the possibility of new opportunities. Hospital call centres, for example, often have access to the mobile phone numbers of specialists and occasionally of GPs. Some medical specialists also include their personal phone numbers in specialist letters or communicate with GPs via new chat platforms.

The shared decision-making method

SDM should only occur when all key stakeholders are involved and if all essential steps are taken. These steps are described in more detail in the introduction, but they are summarised in Box 1. Hereafter, I discuss what new knowledge this thesis adds to each step.

Procedure for Shared Decision-making

- 1) Announcement of decision
- 2) Explanation of options
- 3) Discussion of patient preference
- 4) Shared decision is made

Box 1. Steps of the shared decision-making procedure

Steps 1 and 2 of SDM: Announcement of decision and explanation of options

In Chapter 7 we showed that the chosen treatment is described in most specialist letters, but without mentioning other treatment options. This is consistent with recent literature showing that treatment options are often not discussed with patients.^{4,18,19} In the OPTION RCT (Chapter 4), we did not explicitly study this topic, but both patients and GPs often reported that there was only one treatment option. Also, in OPTion2 (Chapter 5; n = 29), several treatment options were described in the patient record for only six patients, and the considerations for the treatment choice were only described explicitly for two cases. However, our findings in Chapter 7 indicated that patients, GPs, and medical specialists agree that information about the various treatment options is relevant in the specialist letter. This supports the position paper of the NHG, which states that GPs should be able to discuss available treatment options with their patient. In the NFK GP/nurse survey, 67% of respondents wanted the GP to explain the importance of the patient's opinion in decisions and 69% wanted them to check that information about diagnosis and treatment options had been understood.¹⁴

To promote discussion of treatment options, the "Ask 3 Questions" campaign has been launched worldwide (Dutch: *3 goede vragen*), in which patients are encouraged to ask health

care providers three important questions (Box 2). SDM should then be stimulated by discussing these; however, research has recently shown that an SDM intervention aimed at patients was ineffective, whereas training health care providers significantly increased the use of SDM.²⁰

Ask 3 Questions

International version

1. What are my options?
2. What are the possible benefits and risks of these options?
3. How likely are the possible benefits and risks of each option to occur?

Dutch version (translated)

1. What are my options?
2. What are the possible benefits and risks of those options and how likely are they to occur?
3. What does this mean for me?

Box 2. The “Ask 3 Questions” campaign

Step 3 of SDM: Discussing patients’ preferences

Discussing goals and preferences is not included in the original version of Ask 3 Questions. The Dutch version merges the second and third questions, and adds a new question “What does this mean for me?” (Box 2). This last question is exemplified with the text “Your personal situation is important for your choice: what is your living situation, what is your job, how old are you, and what are your needs and goals?” Discussing this question might lead to a better understanding of patient preference. To the best of my knowledge, no literature has described if this question works and which health care provider is best placed to discuss this question.

Patients are often left believing that there is only one viable treatment option, but in most cases, multiple treatment options are available. In these settings, the presented option is often that described as standard care in guidelines, typically offering the highest survival. However, in the OPTion study, we showed that only 29% the older patients with a non-curable malignancy chose extending life as the most important goal (Chapter 4), consistent with other research using the same instrument (Chapter 3). Although research has shown that the main reason for non-adherence is patients preference,^{21,22} guidelines often pay little attention to alternative treatment options or patient preferences.²³

Older patients often find it difficult to express their preferences explicitly.^{6,7} Sometimes they ask their health care provider to “do what is best for me,” yet as has been shown, health care providers are poor at estimating a patient’s goals.²⁴ In a recent study, it was shown that agreement was poor between the most important goal according to the health care provider and the most important goal according to the patient, at only 42% for GPs (weighted kappa 0.067; $p = 0.39$) and 40% for medical specialists (weighted kappa 0.074; $p = 0.33$).²⁴ This is consistent with other studies^{25,26} and emphasises the importance of explicitly discussing preferences. The OPT can be used to clarify patient goals based on non-disease-specific goals, such as extending life and reducing pain.

GPs often have a longstanding relationship with older patients and can be well placed to discuss needs and goals.¹⁵ In the NFK survey, most patients (66%) indicated they thought the GP should discuss the priorities of patients in life and how these affect treatment options when a patients is about to make a treatment decision.¹⁴ Furthermore, as shown in OPTion2

(Chapter 5), more than half of the patients (16/29) changed their goals during follow-up. This suggests that it is essential to discuss treatment goals not only directly after diagnosis but also regularly as the disease and treatment progresses. It was also relevant that patients in the late stage of their disease (47%, $n = 7$) changed goals more often than those in the early phase of their disease (21%, $n = 3$).

Step 4: Time-out and decision

After discussing preferences, some models of SDM suggest that patients should take time to reflect before making a decision.²⁷ However, time is rarely put aside for this in practice.^{18,28,29} The findings in Chapter 4 indicate that it is possible to have a meaningful and deliberative conversation with a GP at some point between diagnosis and starting treatment. That said, many patients were excluded (39/268) because they had already started treatment when contacted. The same problem has been reported elsewhere,³⁰ reflecting the short window between diagnosis and treatment. Addressing factors at both the patient and the hospital level may help to correct this issue.

Patients who have just received a cancer diagnosis often want to start treatment immediately in the hope of achieving maximum benefits. This is an understandable urge, but given that most tumours grow slowly, treatment outcomes are frequently unaffected by having a time-out period to consider options. Indeed, a systematic review has produced contradictory evidence for the relationship between time to treatment and cancer outcomes,³¹ and literature shows that patients are usually more satisfied when they have more than one conversation about their treatment decision.³² Urgency can be felt in hospitals because of waiting time requirements. Multidisciplinary oncological care standards state that the time between the first visit to the medical specialist and start of treatment should not exceed 6 weeks.³³ This time frame includes any diagnostic activities and necessary precautions for treatment to start, leaving only a short period between diagnosis and the possibility of making a treatment choice. In the OPTion study (Chapter 4), this period was ≤ 1 week for most patients. The Dutch Cancer Federation (*KWF Kankerbestrijding*) has mentioned even stricter time frames. Although these standards are meant to ensure a good quality of care, we should consider whether they are counterproductive to patient-centered care and require adjusting to allow for a time-out period. For example, it may be wise to apply separate waiting time requirements to the time between referral and diagnosis, time between diagnosis and treatment decision and time between treatment decision and starting that treatment. The second one should than be wide enough (e.g. 3 weeks) to provide time for deliberation and a conversation with the GP. It is important to note that not all patients want to make a decision themselves: some prefer to delegate the decision to their health care provider.³⁴ However, for the health care provider to make the right decision in these cases, it remains important that they follow the SDM procedure through the first three steps, before departing in step 4, where they should summarise the detail of the preceding steps and make a decision that reflects what they have ascertained.

Effects of shared decision making

SDM can have positive effects when all relevant persons are involved and all essential steps have been taken. A systematic review showed that SDM using decision aids can lead to increased knowledge, fewer decision-related conflicts, and fewer people being passive when

making a decision.² Most research concerning SDM in patients with cancer has focused on improving advanced care planning and documentation.³⁵ However, evidence about clinical outcomes in this patient group is scarce. In a systematic review summarising the effects of SDM on distress and health care utilisation for patients with lung cancer,³⁶ studies were only found in which SDM was part of broader supportive care interventions. This made it impossible to draw conclusions about the effect of SDM alone. Nevertheless, positive effects were reported in favour of the intervention groups in studies using anxiety-specific measures or depression-specific measures.³⁶ Evidence for reductions in health care utilisation were also found in five studies.³⁶

SDM in primary care

To date, most research into the effects of SDM for patients with cancer has been performed in secondary care. The OPTion study (Chapters 2 to 5), which was based in primary care, therefore adds valuable information. For example, we showed that an OPT conversation with the GP had no significant effect on patient empowerment, but that it did improve symptoms of anxiety. This may have occurred because patients who are more engaged in the treatment decision felt more in control and less anxious. It is also possible that the conversation itself helped to reduce anxiety by giving the patient an opportunity to share feelings and receive emotional support from the GP. This is consistent with the observation in NFK GP/nurse survey that 82% of patients wanted their GP to listen to their worries and fears.¹⁴

No negative effects of SDM were identified in the OPTion study (Chapter 4). However, a recent study in primary care detected that there was less perceived SDM in the intervention group after a time-out consultation with the GP in which treatment goals were discussed.³⁰ According to the authors, this could be explained by the timing of the conversation, which due to logistical problems, was typically after the treatment decision had made.

Literature about the effects of SDM on health care professionals is scarce. One systematic review concluded that decision aids can improve a health care provider's satisfaction with medical decision-making and provide helpful information.³⁷ In the OPTion study (Chapter 4), one-third of participating GPs indicated that the OPT conversation had given them new insights into the patient, including their treatment goals and preferences for end-of-life care (advance care planning). In another study with a similar intervention, GPs experienced more appreciation and information from the hospital, leading to greater involvement in guiding the patient.²⁹

Methodological Challenges

Although the strengths and limitations specific to the study are presented in each Chapter, I would like to draw the reader's attention to some important methodological challenges that should be considered in greater detail. Chief among these are the challenges in research among patients with non-curable cancer, as well as the challenges specific to research about medical communication.

Research among patients with non-curable cancer

Patients with non-curable cancer will probably die because of their cancer, but new therapies mean that some patients can survive for many years. Nevertheless, as shown in the OPTion study (Chapter 4), many of the 145 included patients deteriorated ($n = 12$) or died ($n = 8$) within only a few weeks. It is therefore unsurprising that 44 of the 268 patients

we approached refused to participate because they felt too ill. The OPTion study mainly included patients with lung cancer, known to have a poor prognosis, and these were not only included directly after diagnosis but also at the moment of a later treatment decision. These factors may have increased the recruitment problems in our study. However, it should be realised that these issues can be expected, to some extent, in all research among patients with non-curable cancer.

Ethics

The high dropout rate because of health deterioration raises the ethical question as to whether we should perform research in patients with non-curable cancer. However, some patients in the OPTion study explicitly stated that participation made them feel valuable and that they wanted to help future patients in the same situation. Furthermore, greater attention has been paid to aggressive end-of-life care in recent years, with disease-oriented treatment continued to shortly before death.³⁸ SDM allows patients to discuss the benefits and negative effects and make informed choices that meet their needs. One may argue that health care should be particularly optimised in this highly vulnerable population. However, achieving this goal will involve further research that will come with important responsibilities to use sound methodology and to recruit adequate samples. Both topics are discussed more extensively in the following sections. There must also be an adequate dissemination strategy that reaches the involved stakeholders. Studies should therefore be published not only in international journals but also in Dutch journals that are read by practicing health care professionals and shared during training sessions.

Outcome measures

The ultimate outcome measure in medical research is traditionally survival, yet this is not always the most important outcome for patients, particularly those with non-curable cancer. Quality of life has therefore been suggested as a valuable patient reported outcome measure in SDM research, but for patients with non-curable cancer, this is affected by physical symptoms, knowledge of impending death, and other contextual factors. This makes it almost impossible to influence quality of life or other general outcome measures by changes in health care organisation. Consequently, we chose DSE, which is a very specific outcome measure (Chapter 2). However, using this had a ceiling effect, with most patients in both groups scoring so high on DSE that the questionnaire was unable to detect differences. Other studies have also reported high scores for DSE, but without explicitly mentioning the ceiling effect.^{39–41} A similar problem has been described when using patient satisfaction as the outcome measure.⁴² Researchers should be aware of the problems inherent to using outcome measures that are too general or unresponsive. Conducting a pilot study in the target population can be sufficient to see how the proposed outcome measure performs.

Recruitment

A pilot study can also yield valuable information about recruitment, identifying potential factors related to the patient, health care professional, and researcher. As mentioned above, health deterioration is a common reason for patients to refrain from participation. To minimise this problem, it is important that the commitments for the questionnaires and other burdens are limited as much as possible. This minimal impact for the participant should then be made clear in any patient information material. In the Netherlands, there are strict regulations on research where patients are subject to new treatments or activities with

potential risk. This legislation (WMO) obliges researchers to supply participants with extensive information about all procedures and their risks. Although this law does not apply to research projects with only low risk, such as those presented in this thesis, there is a tendency to impose the same rules and regulations, leading to lengthy and irrelevant information for patients that can demotivate them and act as a barrier to participation. At the same time, researchers have a responsibility to consider how they can keep the burden of the study as low as possible for patients (e.g., performing interviews at home, using online questionnaires, or involving informal caregivers).

Regarding the factors related to health care professionals, I was both positively and negatively surprised. In the study of the desired content of correspondence between professionals (Chapter 7), about 40% of the health care providers we approached engaged in the panels and almost all of them answered at least 70% of the questions in both rounds. For the OPTion study, medical specialists at nine locations in six hospitals were willing to participate, but the numbers of patients approached differed substantially between departments, with some failing to meet our stated expectations. During the first months of the trial, one of our students analysed the reasons for poor performance and showed that the most important factors for non-academic specialists were feeling a barrier to asking patients and forgetting to ask because of the low frequency of eligible patients. For academic specialists, competition with other studies and having concerns about the desirability or feasibility of the intervention were the main reasons for non-compliance. This is in line with existing literature about this topic.⁴³

It might be advisable for researchers to ask explicitly about potential barriers at an early stage of the research project. During a study, researchers can improve recruitment by maintaining regular contact with specialists. In the OPTion study, for example, we were able to double the inclusion rate by intensifying this contact, even though the specialists often argued this was unnecessary. To ensure that these contacts do not place additional burdens on specialists, however, it is advisable for researchers to attend their regular meetings and stay connected by e-mail. Intensifying the contact was highly effective in our study, and had a greater impact than our earlier efforts at distributing posters, pocket cards, and sweets, as suggested in the literature.⁴⁴ Providing additional training for clinicians on patient recruitment could also improve patient uptake. This could be delivered both routinely during postgraduate training and specifically for the purposes of the study.

Research about medical communication

Qualitative versus quantitative research

Research into medical communication often involves qualitative research. Although this research has a low position in the pyramid of evidence, which may imply inferiority to other methods, it can also be the most appropriate design. The open and broad way of data analysing data in qualitative research means that new patterns can be discovered and new hypotheses formulated. This is exemplified by the findings in Chapter 5 about the change of treatment goals, and by the findings in Chapter 7 about the desired content in correspondence. Qualitative data are also much richer than quantitative data. Indeed, the open evaluation questions for GPs participating in the OPTion study (Chapter 4) provided important data about the added value of the intervention for GPs. By contrast, when solid

hypotheses exist and an intervention is known to be feasible, an RCT is appropriate to deliver more robust data about the effect of the intervention in comparison with a control group. However, the above-mentioned suggestions about recruitment and outcome measures still apply.

Researchers tend to reach for the highest level of evidence, the RCT, whenever possible, even where this does not suit the research question. Where research focuses on exploring opinions, developing hypotheses, and/or assessing the feasibility of interventions, qualitative research has an important role to play, either alone or in a mixed-methods design. In retrospect, for the OPTion RCT (Chapters 2 and 4), we were too eager to perform an RCT and should have performed a pilot study before progressing.

Generalisation

A last point to consider is the generalisability of the findings concerning medical communication. Because the organisation of health care differs substantially between countries it can be difficult to extrapolate findings. The role of primary care, for example, is very different among European countries. To help health care providers interpret findings, the research setting should be always be described, preferably with a concise description of the health care system. Furthermore, we must acknowledge that all patients and medical doctors are unique, and that a one-size-fits-all solution to the existing problems with medical communication probably does not exist.

Implications of our findings

Further research

Answering one research question rarely fails to uncover new questions. Based on the current research, the following topics would be worth pursuing in the future:

- Can a conversation with the GP about treatment goals reduce anxiety, as shown in Chapter 4, when measured as the primary outcome? Is our finding reproducible, and does it add clinical value for patients? What is the most appropriate outcome measure for SDM interventions?
- Can we reproduce the findings of Chapter 6 regarding goals changing or remaining stable among patients with non-curative cancer and explore this topic further? Specifically, it would be interesting to analyse the audio files of consultations and/or to use patient interviews.
- Is it feasible to implement changes to the format of correspondence between primary and secondary care, as suggested in Chapters 6 and 7? (i.e., a short and well-organised referral letter and a specialist letter with information about all treatment options.) What effects would these changes have in practice? What is the most appropriate outcome measure for these effects? What are the potential barriers to, and facilitators of, such implementation?
- Based on the findings in Chapters 4 to 7, can improved communication between primary and secondary care about a patient's treatment goals lead to patients making better treatment decisions and altering those decisions if their goals change?

Methodological advice

- When performing an RCT, it is prudent to perform a pilot study first to explore potential problems with recruitment and to check the performance of the outcome measure.

- Consider adding a qualitative component when performing an RCT or other quantitative research.
- Ask the recruiting health care professionals about barriers to recruitment, and explicitly discuss several key issues: (1) if they will perceive a barrier to asking their patients to participate in research; (2) the risk of forgetting the research project because of the low frequency of eligible patients; (3) competition with other research projects; and (4) concerns about the desirability or feasibility of the intervention.
- Be proactive and engage in regular contact with health care providers, even if they do not think this is necessary. Try to avoid creating extra meetings by joining routine ones that the clinician already attends.

Care practice

- To ensure patient-centered care, primary and secondary care must work closely together. Health care providers in both areas should therefore write any correspondence with the needs of the receiver in mind. Regular contact can also ensure that each party remains aware of the patient's goals and treatments.
- Treatment goals should be explicitly discussed with all patients and documented in the patient record and correspondence. Discussions should occur not only after diagnosis but also repeatedly as the disease evolves and new decisions need to be made.
- Before making a treatment decision, the patient should be afforded a time-out period for reflection. This could be achieved by adjusting the waiting time standards of hospitals. In this period, the GP should be informed and empowered to support the patient.

Education

- This thesis has generated new knowledge about the desired content of correspondence for patients with cancer. It is advisable that these findings be implemented in the vocational training of new health care providers.
- Other research has shown that training oncologists in SDM improved its practice.²⁰ Such training should be added to all vocational training in primary and secondary care. Delivering the training as an educational program in a multidisciplinary setting could also teach new health care providers to collaborate better in the SDM process.
- Patient recruitment for research should be implemented as an educational topic to the vocational training courses of newly qualified health care providers in both primary and secondary care.

Conclusion

This thesis has outlined and presented the results for two studies. The OPTion study showed that an OPT-guided conversation did not increase patient empowerment. However, we did show the importance of talking about treatment goals to help patients make treatment decisions and of discussing goals repeatedly over time because they can change. In the PION study, we showed that referral letters should be very concise, but that specialist letters should contain more detail about the full range of treatment options. This can enable the GP to talk with their patients about treatment choices. Thus, the results of both studies add valuable knowledge that can be used to facilitate SDM and deliver health care that is truly patient-centered.

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Appendices

Epidemiology of frequent types of cancer and cancer symptoms

Epidemiology of common cancer types

Breast cancer

Breast cancer is the most common cancer type in Europe, responsible for 13.4% of all cancer cases.¹ In the Netherlands, one out of seven women will have breast cancer during her life.² The mean age at diagnosis is 61 years; 80% is 50 years or older at diagnosis and 27% is 70 years or older.^{2,3} The most common symptoms of breast cancer are a lump in the breast and / or changes of the skin of the breast. In the Netherlands there is a breast screening program for women aged 50-74. In this age-group, 53% of breast cancer cases are diagnosed by the screening program.² About 5% of all breast cancer cases are diagnosed with stage IV.⁴ Most patients with breast cancer are surgically treated (90%). Nowadays in most cases (57% of all surgeries) this is a breast conserving therapy.² Most patients also receive radiotherapy (65%) and/or hormonal therapy (55%).² Chemotherapy is being used in 30% of patients, half of them in a neo-adjuvant setting, i.e. before surgery.² Targeted therapy for breast cancer was introduced in the Netherlands in 2005, and in 2017 about 10% of all women with breast cancer received this form of therapy, half of them in a neo-adjuvant setting.² Despite being the most frequent diagnosed form of cancer, breast cancer is third cause (7.1%) of cancer caused mortality in Europe.¹ In the Netherlands, the five years survival rate after diagnosis is 87%.² For women the life time risk of dying because of breast cancer is 1 out of 27.²

Colorectal cancer

Colorectal cancer is the second most common type of cancer in Europe, responsible for 12.8% of all cancer cases.¹ This cancer type is common both in men (13.2% of cancer cases in men) and in women (12.3% of cancer cases in women).¹ Cancer of the colon is twice as common as cancer of the rectum.⁴ About 80% of all patients with colorectal cancer is 60 years or older.⁴ The most common symptoms of colorectal cancer are change in bowel habits, rectal bleeding and abdominal discomfort. In the Netherlands there is a colorectal cancer screening program for men and women in the age of 55-75 since 2014. Of the patients aged 60-75, 38.5% of the colorectal cancer cases were detected by screening.⁵ For all cases of colorectal cancer, about one in five are diagnosed with stage IV.⁴ Most patients with colorectal cancer are surgically treated.⁴ Patients with rectal cancer are most often also treated by neo-adjuvant radiotherapy and patients with stage III and IV disease often receive adjuvant chemotherapy.⁴ Colorectal cancer is the second leading cause of cancer death in men and the third in women in Europe.¹ In the Netherlands, the five years survival rate after diagnosis is 65%.⁶ Survival rates are much better for disease detected at an early stage (stage I: 95%) compared to a later stage (stage IV: 11%).⁶

Lung cancer

Lung cancer is the third most common cancer type in Europe, responsible for 12.0% of all cancer cases.¹ This cancer type is common both in men (15.1% of cancer cases in men) and in women (8.5% of cancer cases in women).¹ The most common type of lung cancer is non-small cell lung cancer (85%).⁴ About 90% of all lung cancer cases is caused by smoking.⁷ The mean age at diagnosis is 70 years; 81% is 65 years or older at diagnosis and 52% is 75 years or older.⁸ The most common symptoms of lung cancer is persistent cough. In the

Netherlands there is no lung cancer screening program. Treatment of lung cancer is highly dependent on the cancer stage at diagnosis. Most patients with early stage lung cancer are surgically treated (73% stage I; 55% stage II).⁴ Most patients in stage III are treated with chemotherapy (47% stage III, 44% stage IV), sometimes combined with radiotherapy. Targeted therapy and immunotherapy are fast growing treatment modalities for patients with stage III or IV lung cancer.⁹ Lung cancer is the most frequent cause of death from cancer in Europe (20% of the total).¹ In the Netherlands, the five years survival rate after diagnosis is 20%.⁸

Symptoms during diagnosis and treatment

A cancer diagnosis often has a lot of impact, both physical and psychosocial. Almost all patients with cancer experience physical symptoms.¹⁰ Apart from the above mentioned disease specific diagnostic symptoms (e.g. rectal bleeding), most patients during therapy and living with cancer experience general symptoms like fatigue and pain. Cancer not only leads to physical symptoms, but often also causes distress. The American national comprehensive cancer network defines distress as “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature.”¹¹ Of all cancer patients, 20-50% shows a significant level of distress.¹¹ Symptoms of anxiety and depression are the most commonly reported forms of distress. Unfortunately, the prevalences of both physical and distress symptoms in older palliative patients are often unknown.

Physical symptoms

Fatigue is the most frequent symptom during medical treatment.¹² Depending on the definition and method of measurement, 40 to 100 percent of all patients with cancer are estimated to experience fatigue.¹⁰ For patients with incurable cancer a systematic review calculated a pooled prevalence of 74% (95% CI 63-83).¹³ Other studies reported lack of energy (pooled prevalence 69%) or weakness (pooled prevalence 60%), which can be seen as variants of fatigue. The cause of cancer related fatigue is thought to be multifactorial.¹⁰ Part of the etiology are tumour-related factors like anemia, electrolyte abnormalities, anorexia, hypoxia and fever.¹⁰ Comorbid conditions, e.g. heart failure, and side effects of medication, e.g. beta blockers, can also cause or increase fatigue. Lastly, anxiety, depression and sleep disorders, also common in patients with cancer, are associated with fatigue.¹⁰ Cancer related fatigue is difficult to manage and mainly consists of treatment of the underlying factors.¹⁰ Many patients with cancer experience pain. The pooled prevalence of pain for patients during cancer treatment was calculated as 55% (95% CI 45.9-64.2)¹⁴ and 66-71% for patients with incurable cancer.^{13,14} Cancer related pain is mostly (70%) caused by tumour growth at the primary site or in metastases.¹⁵ However, problems like obstipation and decubitus can also cause pain.¹⁵ Psychosocial factors are thought to influence pain experience as well.¹⁴ Most cancer related pain can be treated effectively with pain killers or radiotherapy.¹⁵ Patients with cancer can experience a wide range of other physical symptoms. Frequently reported ones are weight loss, dry mouth, dyspnea, nausea, bloating, cough, cognitive symptoms, taste changes, sore mouth, vomiting and drowsiness.¹³

Symptoms of anxiety and depression

The main symptoms of depression are continuous low mood or sadness and loss motivation or interest in things. These symptoms occur in almost all patients with a life-threatening disease shortly after diagnosis as normal reaction to the bad news. However, in some patients these symptoms are more severe and/or are persistent. Prevalence's are difficult to obtain because they depend strongly on the diagnostic instrument or screening questionnaire. A formal depression, diagnosed using the DSM criteria (Diagnostic and Statistical Manual of Mental Disorders) occurs in about 15% of all patients with cancer,¹⁶ whereas depressive symptoms occur in about 30-35% of all patients with cancer.^{16,17} For patients in a palliative care setting, the same percentages apply.^{13,16} Depressive symptoms for patients with cancer are often treated with supporting conversations. Cognitive therapy and antidepressant medication are sometimes used as well.¹⁷ Feelings of anxiety are a normal reaction to a life-threatening disease as well. Again, prevalence's are difficult to obtain because they depend strongly on the diagnostic instrument or screening questionnaire. The prevalence of a formal anxiety disorder is about 10% for patients with cancer.¹⁶ Symptoms of anxiety are however frequently present, a review in patients with incurable cancer showed a prevalence of 30%.¹³ Symptoms of anxiety for patients with cancer are often treated with supporting conversations. Cognitive therapy and anti-anxiolytic medication are sometimes used as well.¹⁸

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Nederlandse samenvatting

Het doel van dit proefschrift was het analyseren van de communicatie met, en over, patiënten met kanker, met een focus op de rol van de huisarts. De bevindingen van de analyse zouden moeten leiden tot aanbevelingen om de communicatie te verbeteren. De resultaten van twee verschillende studies vormden de basis van deze analyse, 1) OPTion, een studie die zich richtte op gezamenlijke besluitvorming en 2) PION, een studie over informatie-uitwisseling tussen artsen onderling.

Hoofdstuk 1 vormt een introductie. Hierbij wordt het proces van gezamenlijke besluitvorming beschreven en wordt toegelicht wat de rol van verschillende zorgverleners in het Nederlandse zorgsysteem is.

In hoofdstuk 2 beschreef ik het protocol voor de OPTion-studie, een gerandomiseerd onderzoek waarbij gebruik werd gemaakt van de OPT (outcome prioritisation tool). Dit instrument beschreven we meer uitgebreid in hoofdstuk 3, en in hoofdstuk 4 en 5 beschreven we de resultaten van de studie. De PION-studie werd beschreven in hoofdstuk 6 en 7.

In hoofdstuk 3 beschreven we de OPT en het gebruik ervan in detail, waarbij we ook een overzicht gaven van de literatuur over het instrument. De OPT werd ontwikkeld om gesprekken over patiëntendoelen en -voorkeuren te faciliteren, waarbij gebruik wordt gemaakt van overkoepelende, niet ziekte-specifieke doelen. De OPT wordt in zowel de eerste als de tweede lijn gebruikt om behandelbeslissingen in verschillende situaties te ondersteunen. Er is echter weinig beschikbare literatuur over het instrument. Ons literatuuronderzoek leverde slechts een protocolartikel, twee artikelen over de ontwikkelen van het instrument en vier artikelen waarin het gebruik werd beschreven op. Alle studies werden uitgevoerd bij oudere patiënten. De meeste patiënten prioriteerden 'onafhankelijkheid bewaren' als hun meest belangrijke doel. Zowel patiënten als zorgverleners gaven aan dat het instrument goed bruikbaar was.

In hoofdstuk 4 rapporteerden we de primaire resultaten van de OPTion-studie. We verdeelden oudere patiënten met niet te genezen kanker willekeurig over de groep met reguliere zorg of de groep met de OPT-interventie. Deze interventie bestond uit een OPT-gefaciliteerd gesprek met de huisarts tussen diagnose en de behandelbeslissing. De score op de DSE-vragenlijst (*decision self efficacy*, het vertrouwen in het vermogen om mee te beslissen was de primaire uitkomstmaat. De vragenlijst loopt van 0 (geen vertrouwen) tot 100 (volledig vertrouwen). De vragenlijst werd ingevuld direct na het consult met de specialist waarin de behandelbeslissing werd genomen. Symptomen van vermoeidheid, somberheid en angst werden gemeten als secundaire uitkomsten. Er was geen verschil in vertrouwen tussen de OPT-groep ($n = 48$; DSE 86.8 ± 18.2) en de controlegroep ($n = 58$; DSE 84.2 ± 17.6 ; $p = 0.47$). Desondanks bleken er in de OPT-groep wel niet-significant minder patiënten met laag vertrouwen (17.0% vs 23.0% ; $p = 0.50$). Daarnaast hadden patiënten in de OPT-groep gemiddeld een significant lagere angstscores (6.0 ± 4.6 vs 7.6 ± 4.4 ; $p < 0.05$) en minder milde vermoeidheidsklachten (57.6% vs 72.1% ; $p = 0.05$). Verder gaf 45% van de patiënten aan dat het OPT-gefaciliteerde gesprek had geholpen bij de behandelbeslissing en rapporteerde 33% van de huisartsen dat het gesprek nieuwe inzichten had opgeleverd.

In hoofdstuk 5 presenteerden we de resultaten van OPTion2, een vervolgstudie van 29 patiënten van de interventiegroep van de OPTion-studie. We analyseerden de doelen die zij aangaven tijdens vier OPT-gesprekken met de huisarts in een periode van zes maanden. De meeste deelnemers prioriteerden ofwel levensverlenging (n=10, 34%) ofwel onafhankelijkheid bewaren (n=9, 31%) als belangrijkste doel tijdens het eerste OPT-gesprek. Patiënten in het laatste jaar voor hun dood (late fase) prioriteerden levensverlenging minder vaak (n=3, 21%), dan die in de vroege fase (n=7, 47%). Bij 16 patiënten (55%) veranderde het meest belangrijke doel tijdens de studie, dit kwam vooral voor bij patiënten in de late fase (n=12, 75%). Vervolgens deden we een kwalitatieve analyse van de teksten uit het ziekenhuisdossier en huisartsendossier. We ontdekten drie thema's voor OPT-scores bij het eerste gesprek: een specifiek doel prioriteren, een doel als onbelangrijk waarderen, en behandelbeslissingen nemen gerelateerd aan doelen. Veranderingen in OPT-scores waren gerelateerd aan symptomen, het ziektebeloop, of life-events. Stabiele OPT-scores waren juist gerelateerd aan een stabiele situatie, een niet-ziekte gerelateerde motivatie of stabiele doelen ondanks symptomen.

In hoofdstuk 6 beschreven we het eerste deel van de PION-studie (PION1, patient information exchange in oncology). Deze studie was een kwalitatieve inhoudsanalyse van de correspondentie in de medische dossiers van 50 patiënten met darm-, borst- of longkanker die in opzet curatief werden behandeld. De dossiers bevatten 419 documenten waaronder zowel verwijsbrieven als specialistenbrieven. In verband met data-triangulatie, deden we ook interviews met zorgverleners. In totaal identificeerden we 70 items. In de verwijsbrief vonden we zes thema's die vrijwel altijd aan bod kwamen. Het was opvallend dat zeer relevante informatie uit de medische voorgeschiedenis vaak was vermengd met minder relevante informatie (bv hartfalen en gebroken vinger). In mindere mate gold dit ook voor de anamnese en medicatielijst. De specialistenbrieven bevatten in het algemeen informatie over negen thema's. Hoewel informatie over de actuele behandeling altijd aanwezig was, werden vaak weinig details gegeven over de opzet van de behandeling (curatief of palliatief) en over alternatieve behandelkeuzes. De interviews met negen zorgverleners bevestigden onze bevindingen.

In hoofdstuk 7 beschreven we de resultaten van PION2, een Delphi consensus studie die als doel had een lijst te maken met items die essentieel zijn voor verwijsbrieven en specialistenbrieven. We stelden drie panels samen, die bestonden uit 39 huisartsen, 42 oncologisch specialisten (oncologen, radiotherapeuten, urologen en chirurgen) en 18 patiënten en patiëntvertegenwoordigers. Na twee rondes was de *content validity index* voor beide brieven 71%, waaruit bleek dat een derde ronde niet nodig was. De belangrijkste eisen voor verwijsbrieven waren dat deze beperkt moeten zijn tot medische feiten, een korte samenvatting van symptomen en abnormale bevindingen, en de reden voor verwijzing. In de specialistenbrief moeten dezelfde medische feiten worden vermeld, met daarbij gedetailleerde informatie over diagnose, behandelopties en gekozen behandeling, inclusief de intentie daarvan (curatief of palliatief).

In hoofdstuk 8 vatte ik alle resultaten samen en besprak ik wat dit betekent voor degenen die betrokken zijn bij het proces van gezamenlijke besluitvorming en voor dit proces zelf. Tot slot presenteerde ik de volgende aanbevelingen voor de zorg:

- Om zorg rondom de patiënt te realiseren, moeten de eerste en tweede lijn nauw

samenwerken. Zorgverleners uit beide vakgebieden moeten brieven schrijven met de behoeften van de ontvanger in gedachten. Regelmatig contact kan bijdragen aan bewustzijn van beide partijen over de doelen van de patiënt.

- Behandeldoelen moeten expliciet worden besproken met alle patiënten en worden gedocumenteerd in het dossier en in correspondentie. Deze gesprekken moeten niet alleen plaatsvinden direct na diagnose maar ook worden herhaald als de ziekte zich ontwikkelt en nieuwe beslissingen moeten worden genomen.
- Voordat een patiënt een behandelbeslissing neemt, moet een time-out periode voor reflectie in acht worden genomen. In deze periode moet de huisarts worden geïnformeerd en in staat worden gesteld om de patiënt te ondersteunen.

Dankwoord

Er zijn de afgelopen jaren ontzettend veel mensen om me heen geweest die hebben bijgedragen aan dit proefschrift. In dit dankwoord wil ik aandacht besteden aan hen zonder wie dit proefschrift niet tot stand gekomen was. Maar er waren ook vele inspirerende anderen. Vrienden, familie, collega's, bekenden en onbekenden. Van sommigen weet ik niet eens de namen, zoals van diegenen met wie ik op congressen onverwachte gesprekjes voerde. Anderen waren juist belangrijk doordat we samen iets leuks deden (bijvoorbeeld roeien of dansen) waardoor mijn gedachten even helemaal bij het onderzoek weg waren. Weet dat ik jullie allemaal erg dankbaar ben voor jullie bijdragen!

Voor de uitvoering van onderzoek zijn natuurlijk de deelnemers onmisbaar. Vooral dus heel veel dank aan de **patiënten** en hun naasten die bereid waren hun ervaringen te delen. Ik realiseer me dat ik jullie op een moeilijk moment in jullie leven heb gevraagd om mee te doen aan mijn onderzoek en ik vind het bijna niet te geloven dat jullie daartoe bereid waren. Ik ben ervan overtuigd dat we kunnen leren van wat jullie vertelden en ik weet zeker dat het kan helpen de zorg te verbeteren. Zonder jullie was dat niet gelukt.

Lieve **Annette**, toen ik in november 2014 contact met jou opnam, omdat ik graag meer informatie wilde over het aioto-traject had ik nog geen idee dat ik zes jaar later zou promoveren met jou als copromotor. Ik ben je dankbaar voor de manier waarop je me onder je hoede hebt genomen. Je was laagdrempelig bereikbaar en altijd bereid tot overleg, of het nu ging om grote lijnen of om details zoals woordvolgorde in een titel. Je stimuleerde me om nieuwe dingen te leren maar hield ook altijd het einddoel en de planning in de gaten. In de loop van de jaren heb je me steeds zelfstandiger laten worden waarbij je altijd geïnteresseerd en betrokken bleef. Je hebt me honderden keren verteld dat het goed zou komen en je hebt volledig gelijk gekregen.

Lieve **Marjolein**, als promotor was jij vanaf het begin op afstand betrokken. Hoewel we elkaar niet vaak spraken, waren de gesprekken die we voerden altijd de moeite waard. Je stelde vragen over klinische relevantie van onderzoeksideeën, inspirerende casuïstiek en implicaties van resultaten op de praktijk. Daarnaast had je een scherp oog voor hoe ik me voelde. Je verstaat de kunst om te luisteren zonder oplossingen aan te dragen en daarvoor ben ik je heel erg dankbaar.

Graag bedank ik ook de leden van de beoordelingscommissie, **prof. Niek de Wit**, **prof. Trudy van der Weijden** en **prof. Marian Mourits** voor hun bereidheid om mijn proefschrift te lezen en te beoordelen. Jullie krijgen vast zeer regelmatig dit soort verzoeken en het moet ontzettend veel tijd kosten. Dat jullie desondanks enthousiast reageerden, vond ik heel bijzonder.

Ook de projectteams wil ik hartelijk bedanken. Allereerst natuurlijk **Jan Schuling**. Jij was aan het begin van mijn traject zeer nauw betrokken bij alles wat ik deed. Ik heb je bedachtzame, praktische manier van meedenken erg gewaardeerd. Later nam je wat meer afstand, maar je bleef steeds op de achtergrond aanwezig en bent altijd benieuwd naar de onderzoeksresultaten en nieuwe plannen. **An Reyners, Jeroen Hiltermann en Wouter van Geffen**, als OPTion-projectteam hebben jullie meegeleefd met de moeizame inclusie en telkens nieuwe ideeën helpen bedenken. Ik ben trots en dankbaar dat mede met jullie hulp we het project uiteindelijk toch af hebben kunnen ronden. **Janine Nuver, John Maduro, Klaas Havenga, Jeroen Hiltermann en Jiska Meijer**, jullie voorzagen me als PION-projectteam van waardevolle inzichten vanuit verschillende perspectieven en waren altijd bereid om mee te denken. Mede onder jullie leiding ben ik gegroeid van een onervaren onderzoeker tot waar ik nu sta. **Suzanne Festen, Pauline de Graeff en Barbara van Leeuwen**, ik heb genoten van onze samenwerking in verschillende onderzoeksprojecten rondom de OPT en hoop dat er nog veel zullen volgen.

Veel dank ook aan de artsen die het mogelijk maakten mijn studies uit te voeren. Voor PION1 mochten we gebruik maken van dossiers uit het **UMCG** (Groningen), **Treant locatie Scheper** (Emmen) en **Sint Antonius Ziekenhuis** (Sneek), waarvoor veel dank. Voor PION2 vonden we huisartsen en specialisten uit het hele land bereid om deel te nemen aan een panel. En voor de OPTion-studie hebben de medisch oncologen, longartsen en verpleegkundig specialisten in het **UMCG** (Groningen), **Martiniziekenhuis** (Groningen), **OZG** (Scheemda), **Treant** (Emmen, Hogeveen en Stadskanaal), **WZA** (Assen) en **MCL** (Leeuwarden) hard gewerkt om zoveel mogelijk patiënten te benaderen. Zonder jullie inzet was het niet gelukt.

Dank ook aan mijn collega's van de **afdeling Huisartsgeneeskunde en Ouderengeneeskunde**. Van jullie leerde ik dat onderzoek doen ontzettend leuk is als je het samen deelt. In deze thuiswerkperiode mis ik vooral de gezellige koffiepauzes en het gevoel dat we allemaal bezig zijn met ons eigen project maar toch samen één geheel vormen. Ik hoop dat het snel mogelijk is om jullie allemaal weer te zien en ben ontzettend blij dat ik als postdoc verder mag zodat we collega's blijven.

Bovenstaande geldt natuurlijk in het bijzonder voor *de onco's*, mijn collega's van het programma Oncologie in de Huisartsenpraktijk. **Saskia, Geertje, Famke, Niek en Marijke**, ik ben blij met onze supergezellige groep. **Daan**, jou wil ik niet alleen voor de gezelligheid van afgelopen jaren bedanken, maar ook voor je kritische en constructieve blik bij een aantal van mijn artikelen. En vooral ook voor de vele inspirerende brainstormsessies over nieuwe projecten en de persoonlijke gesprekken tussendoor. **Olaf**, wij hebben een aantal ontzettend leuke projecten samen gedaan en ik vond het bijzonder plezierig samenwerken. Jammer dat je geen directe collega meer bent, maar ik hoop dat we desondanks nog veel leuke projecten samen zullen doen.

Ook Pim en Lisa wil ik een eigen plek geven in dit dankwoord. Jullie waren onmisbaar bij de uitvoering van de OPTion-studie. Contacten met patiënten, huisartsen, specialisten, jullie draaiden er je hand niet voor om. **Lisa**, jij was naast onderzoeksmedewerker ook mijn kamergenoot en maatje. Ik denk met ontzettend veel plezier terug aan alle gezellige gesprekjes, alle bak- en knutselprojecten en alle keren thee en taart bij Britta. Ons 'feel good boek' waarin we positieve onderzoekservaringen verzamelden tijdens de start van de OPTion-studie, heeft me regelmatig opgepept en is nu een dierbaar bezit. **Pim**, jij deed alle taken grotendeels in mijn afwezigheid, omdat ik op dat moment het grootste deel van de week in de huisartsenpraktijk aan het werk was. Dank voor je zelfstandigheid en doorzettingsvermogen, door jou hebben we de eindstreep gehaald.

De verschillende studenten die hun stage wetenschap deden bij PION en OPTion hebben een belangrijke bijdrage geleverd aan de studies. **Vera, Annie, Raoul, Maarten, Mechteld, Bren, Annemiek en Hilda**, ik heb genoten van jullie nieuwe perspectieven en ben jullie dankbaar voor alle praktische hulp die jullie leverden.

KWF Kankerbestrijding en **Stichting Stoffels-Hornstra** wil ik graag bedanken voor de subsidie waardoor ik dit onderzoek uit kon voeren. Ik vond het prettig om met jullie samen te werken door de fijne manier waarop jullie tijdens de studies steeds interesse hadden in de voortgang en resultaten.

Graag wil ik ook mijn huisartsopleiders bedanken. In het eerste jaar **Jan en Mariska**. Jullie lieten me ervaren hoe leuk het is om huisarts te zijn en samen met **Geertje, Dorine, Marjan en Baukje** zorgden jullie ervoor dat de sfeer in Huisartsenpraktijk Niekerk super was en dat ik me ontzettend thuis voelde. Bovendien waren jullie altijd geïnteresseerd in mijn onderzoek. Jullie vertrouwen aan het eind van dat jaar dat het met mijn promotie zeker goed ging komen vond ik heel bijzonder en ik ben heel blij dat de inscriptie die jullie destijds in mijn afscheidscadeau lieten zetten vanaf nu volledig terecht is!

En in mijn derde jaar **Johan**. Jij bent voor mij een rolmodel in hoe je als praktiserend huisarts om kunt gaan met wetenschap. We voerden oneindig veel gesprekken over vragen die bij ons opkwamen naar aanleiding van dingen die we tegenkwamen in de praktijk en over hoe je die vragen zou kunnen beantwoorden. En even zo vaak hadden we het over hoe je conclusies van recent gepubliceerde onderzoeken zou kunnen toepassen in de spreekkamer. Ik heb genoten van deze en alle andere gesprekjes en ook van de tochtjes op de racefiets in het coronavoorjaar. **Annemiek, Roeline, Barbara, Monica, Jeanine en Rianne**, ook jullie hebben ervoor gezorgd dat de Hunzepraktijk een plek is waar ik nog graag afentoe even langskom!

Ook mijn **groepsbegeleiders Jan, Donald, Erna, Anne en Jan Willem** en mijn **groepsgenoten** van de huisartsopleiding wil ik hartelijk bedanken voor hun bereidheid om me de ruimte te geven om praktijk en onderzoek te combineren. Jullie hebben me geholpen om me tegelijkertijd op beide gebieden te ontwikkelen. En het komt zeker mede door jullie dat ik de keuze heb durven maken om nu als zowel huisarts als onderzoeker aan het werk te zijn.

Mijn ouders **Luuk en Annelies** hebben me altijd gestimuleerd om op zoek te blijven gaan naar uitdaging en inspiratie. Erg leuk ook dat jullie meegedacht hebben over mijn stellingen en de Nederlandstalige folder.

Roelant, ik vind het erg leuk om samen te zeilen en gezellig dat je afentoe zomaar even belt om bij te praten. Je bent van mijn kleine broertje een ontzettend leuke man geworden met wie ik ook prima kan discussiëren over van alles en nog wat. **Karlijn**, ondanks de afstand gaat er geen dag voorbij dat wij geen contact hebben. Wij kunnen lachen om dingen die verder niemand grappig vindt en het is heel leuk om samen creatief bezig te zijn. Ik ben blij dat je mij als ceremoniemeester bij wilt staan. Jullie zijn een fantastische broer en zus en ik baal er regelmatig van dat ik niet wat dichterbij jullie woon!

Bonmam, jij volgt mijn avonturen altijd op de voet en ik voel me echt extra blij als jij me appt dat je een trotse grootmoeder bent. Bonpap en jij hebben altijd gezegd dat Engels belangrijk voor me zou worden en me gestimuleerd toch wat van het middelbare schoolvak te maken. En jullie hebben helemaal gelijk gekregen, zoals dit proefschrift laat zien. 33 knuffels voor jou lieve bonmam. **Opa en Oma Schepel**, jullie hebben me als aangetrouwd kleinkind direct opgenomen in de familie en ik denk niet dat ik overdrijf als ik zeg dat van allemaal opa degene is die mijn artikelen het meest zorgvuldig en geïnteresseerd heeft gelezen.

Ernst, dankjewel voor alle uren samen roeien. Jij bent degene die me leerde dat ideeën die op het eerste gezicht knettergek en onhaalbaar lijken soms toch uitvoerbaar zijn. En je leerde me ook dat je niet elke dag bovengemiddeld kunt presteren. We zijn de afgelopen jaren niet alleen roeimaatjes, maar ook goede vrienden geworden en we hebben heel wat vrolijke en minder vrolijke momenten met elkaar gedeeld. Er zijn weinig mensen die ik zozeer vertrouw als jou.

Nynke, dankjewel voor alle goede gesprekken van de afgelopen jaren. Met jou kan ik letterlijk uren kletsen over van alles en nog wat. Ik heb kostbare herinneringen aan de momenten waarop we deelden wat ons opvalt, raakt en verwondert. Van het begin tot het einde was je heel geïnteresseerd in hoe het ging met mijn onderzoek en wat ik van het promotietraject zelf vond. En ik vind het heel bijzonder om met jou samen te genieten van muziek die we allebei prachtig vinden. Ik ben dan ook ontzettend blij dat jullie mijn paranimfen willen zijn.

En tot slot natuurlijk Wim. Jij stond erop dat ik ook onze katten zou noemen in dit dankwoord. En je hebt gelijk. Lieve **Hephaistos en Artemis**, al jullie uren spinnen op mijn schoot hebben absoluut een belangrijke bijdrage geleverd aan dit proefschrift. Lieve **Wim**, ik ben onbeschrijfelijk blij met jou. Jij had er altijd vertrouwen in dat dit traject tot een succesvol einde zou komen. Je hebt me onvoorwaardelijk gesteund bij elke beslissing die ik nam en je hebt me met een enorme vanzelfsprekendheid steeds de ruimte gegeven om mezelf te zijn. Kusje kopje schnurr. Ik houd van je!

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Curriculum vitae

Mariken Stegmann werd geboren op 19 april 1986 in Bleskensgraaf. In 2004 deed ze eindexamen aan het gymnasium Camphusianum in Gorinchem. Vervolgens studeerde ze Geneeskunde aan de Rijksuniversiteit Groningen, waar zij in 2011 haar masterdiploma haalde. Gelijktijdig aan deze studie volgde ze vakken bij Griekse en Latijnse Talen en Culturen, wat in 2012 leidde tot een bachelordiploma. Na het behalen van haar artsdiploma werkte Mariken als arts-assistent niet in opleiding bij achtereenvolgens de Crisisdienst van GGZ-instelling Lentis in Groningen, de Spoedeisende Hulp van het Ommelander Ziekenhuis locatie Delfzijl, de afdeling Chirurgie van het Martiniziekenhuis in Groningen en de afdeling Intensive Care van hetzelfde ziekenhuis. In 2015 begon zij aan de opleiding Huisartsgeneeskunde in Groningen. Als aioto (arts in opleiding tot onderzoeker) combineerde zij deze opleiding met een promotietraject. De resultaten van de studies die zij hiervoor uitvoerde, zijn weergegeven in dit proefschrift. Op dit moment werkt Mariken als huisarts bij Huisartsenpraktijk Veen in Uithuizen. Daarnaast werkt zij als postdoc-onderzoeker op de afdeling Huisartsgeneeskunde en Ouderengeneeskunde van het Universitair Medisch Centrum Groningen.