

Prevalence and Predictors of Physician-Patient Discordance in Prognostic Perceptions in Advanced Cancer

Naomi Cornelia Anna van der Velden^{*,1,2,3}, Paul K.J. Han⁴, Hanneke W.M. van Laarhoven^{3,5}, Filip Y.F.L. de Vos⁶, Lizza E.L. Hendriks⁷, Sjaak A. Burgers⁸, Anne-Marie C. Dingemans⁹, Jan Maarten W. van Haarst¹⁰, Joyce Dits¹¹, Ellen M.A. Smets^{1,2,3}, Inge Henselmans^{1,2,3}

¹Department of Medical Psychology, Amsterdam UMC Location University of Amsterdam, Amsterdam, The Netherlands

²Quality of Care, Amsterdam Public Health, Amsterdam, The Netherlands

³Cancer Treatment and Quality of Life, Cancer Center Amsterdam, Amsterdam, The Netherlands

⁴Behavioral Research Program, National Cancer Institute, Bethesda, MD, USA

⁵Department of Medical Oncology, Amsterdam UMC Location University of Amsterdam, Amsterdam, The Netherlands

⁶Department of Medical Oncology, University Medical Center Utrecht, Utrecht University, Utrecht, The Netherlands

⁷Department of Pulmonary Diseases, GROW School for Oncology and Reproduction, Maastricht University Medical Center+, Maastricht, The Netherlands

⁸Department of Thoracic Oncology, Netherlands Cancer Institute, Antoni van Leeuwenhoek Ziekenhuis, Amsterdam, The Netherlands

⁹Department of Pulmonary Diseases, Erasmus MC Cancer Institute, Erasmus University Medical Center, Rotterdam, The Netherlands

¹⁰Department of Respiratory Medicine, Tergooi Medical Center, Hilversum, The Netherlands

¹¹Department of Pulmonology, Franciscus Gasthuis en Vlietland, Rotterdam, The Netherlands

*Corresponding author: Naomi C.A. van der Velden, MSc, Department of Medical Psychology, Amsterdam UMC Location University of Amsterdam, Meibergdreef 9, 1105 AZ Amsterdam, The Netherlands. Tel: +31642871719; Email: n.c.vandervelden@amsterdamumc.nl

Abstract

Background: Discordance between physicians' and patients' prognostic perceptions in advanced cancer care threatens informed medical decision-making and end-of-life preparation, yet this phenomenon is poorly understood. We sought to: (1) describe the extent and direction of prognostic discordance, patients' prognostic information preferences in cases of prognostic discordance, and physicians' awareness of prognostic discordance; and (2) examine which patient, physician, and caregiver factors predict prognostic discordance.

Materials and Methods: Oncologists and advanced cancer patients (median survival ≤ 12 months; $n = 515$) from 7 Dutch hospitals completed structured surveys in a cross-sectional study. Prognostic discordance was operationalized by comparing physicians' and patients' perceptions of the likelihood of cure, 2-year mortality risk, and 1-year mortality risk.

Results: Prognostic discordance occurred in 20% (likelihood of cure), 24%, and 35% (2-year and 1-year mortality risk) of physician-patient dyads, most often involving patients with more optimistic perceptions than their physician. Among patients demonstrating prognostic discordance, the proportion who preferred not knowing prognosis varied from 7% (likelihood of cure) to 37% (1-year mortality risk), and 45% (2-year mortality risk). Agreement between physician-perceived and observed prognostic discordance or concordance was poor ($\kappa = 0.186$). Prognostic discordance was associated with several patient factors (stronger fighting spirit, self-reported absence of prognostic discussions, an information source other than the healthcare provider), and greater physician-reported uncertainty about prognosis.

Conclusion: Up to one-third of the patients perceive prognosis discordantly from their physician, among whom a substantial proportion prefers not knowing prognosis. Most physicians lack awareness of prognostic discordance, raising the need to explore patients' prognostic information preferences and perceptions, and to tailor prognostic communication.

Keywords: health communication; physician-patient relations; truth disclosure; prognosis; life expectancy; neoplasm metastases.

Implications for Practice

Up to 35% of patients with advanced cancer have perceptions of prognosis that are discordant (often more optimistic) from those of their physician. A substantial group of patients perceiving prognosis discordantly from their physician actually prefer not knowing their prognosis. Patients with stronger fighting spirit, who report absence of prognostic discussions, who use an information source other than the healthcare provider, and whose physician reports greater uncertainty about prognosis are more likely to perceive prognosis discordantly from their physician. Still, physicians are often unaware of prognostic discordance. Hence, physicians should explore patients' prognostic information preferences and prognostic perceptions to tailor their prognostic communication.

Introduction

Prognostic information enables patients with advanced cancer to make informed medical decisions and prepare for the end of life practically, psychologically, and socially.¹⁻¹² Nevertheless, evidence suggests that between 25% and 100% of patients hold inaccurate perceptions of their prognosis, depending on the specific study sample and definition of (accurate) prognostic perceptions.^{4,13-16}

Patients' perceptions of prognosis are often optimistically biased.^{2,3,9,17-23} A previous study showed that nearly half of patients with metastatic cancer overestimated their life expectancy by >2 years compared with their actual survival, and nearly one-third did so by >5 years.¹⁷ Not uncommonly, patients believe that palliative chemotherapy will cure their disease.¹⁹ Overly optimistic prognostic perceptions may lead patients to forego advance care planning and choose aggressive treatments near death, possibly lowering their quality of life.^{17,18,20,23-31} Conversely, overly pessimistic prognostic perceptions—although less common—may induce symptoms of anxiety or depression.^{3,32} Both optimistic and pessimistic prognostic perceptions among patients could be discordant from physician's estimates, which might result in physician-patient disagreement about goals of care and medical decisions.³ Importantly, patients rarely know that their prognostic estimates differ from those of the physician.²

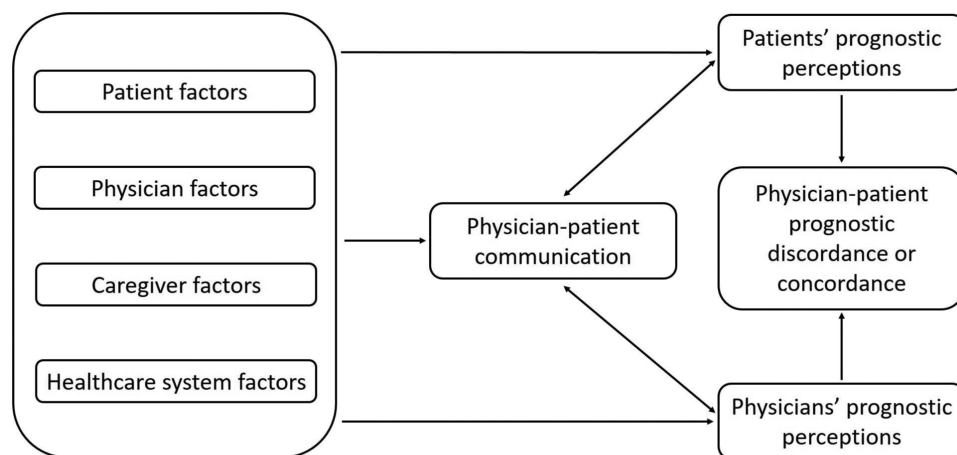
Hence, it is essential to understand not only the extent of discordance between physicians' and patients' prognostic perceptions—hereafter referred to as prognostic discordance—but its causes also. To facilitate further investigation of this problem, we developed an overarching conceptual model. **Figure 1** illustrates factors (ie, patient, physician, caregiver, and healthcare system factors) that may influence physicians' and patients' prognostic perceptions and the discordance between them directly, or else indirectly by influencing physician-patient prognostic communication.

This study investigated various *patient* factors that may promote prognostic discordance. These include background factors that have previously been associated with inaccurate prognostic perceptions (eg, older age, male sex, non-white race, and lower education).^{1,2,14,15,33,34} Also, patients'

prognostic information preferences potentially affect information seeking and exposure, and limited health literacy and numeracy may cause difficulties with understanding prognostic information.^{9-11,35-45} Clinical factors could contribute to prognostic discordance too; patients who feel relatively well or who have fallen ill recently often overestimate their survival.^{34,46,47} Furthermore, personal factors like traits (eg, dispositional optimism or pessimism) and affective states (eg, anxiety or depression) possibly shape patients' prognostic perceptions, as may coping strategies (eg, regarding cancer or uncertainty).^{8,10,22,33,46} Adopting a fighting spirit to “beat the odds,” for example, could promote optimistic prognostic perceptions.^{1,4,10,48} Furthermore, it is hypothesized that relational factors, such as patients' trust in their physicians' expertise, influence divergence in prognostic perceptions.³⁴

This study additionally examined various *physician* and *caregiver* factors (ie, primary informal caregiver) that may influence prognostic discordance either directly or indirectly. Hypothetically, physicians' experience in oncology practice and certainty about prognostic estimates affect their prognostication skills, prognostic perceptions, and prognostic communication.^{49,50} Also, certain communication strategies (eg, prognostic non-disclosure; ambiguous, or optimistic framing of estimates) are known to promote prognostic discordance.^{10,17,21,33,47,51-61} Potentially influential caregiver factors include a preference for not knowing prognosis and protective buffering (ie, efforts to prevent patient burden), as these could limit patients' exposure to prognostic information.^{38,61-64}

Although research on prognostic discordance has expanded, evidence on the hypothesized predictors remains either scarce or inconclusive.^{3,10,34} Moreover, studies reporting rates of prognostic discordance often disregard that some patients simply do not want prognostic information and might therefore, by choice, not know their prognosis. This dearth of research clouds insight into the nature of prognostic discordance, which also obscures understanding of the magnitude of the problem and the avenues to act on it. Hence, it is important to investigate how prognostic discordance varies according to patients' prognostic information preferences.^{4,9,15} Furthermore, prognostic discordance seems less addressable if



^aPROSPECT included patient, physician and caregiver factors, yet did not measure healthcare system factors.

Figure 1. Overarching conceptual model illustrating the potential predictors of physician-patient prognostic discordance. ^aPROSPECT included patient, physician, and caregiver factors, yet did not measure healthcare system factors.

physicians are unaware of it. Therefore, we need insight into physicians' awareness of prognostic discordance.¹⁴ To address these knowledge gaps, we conducted a study with the following aims:

1. Describe physician-patient prognostic discordance, namely:
 - 1.1. The extent and direction of prognostic discordance.
 - 1.2. Patients' prognostic information preferences in cases of prognostic discordance.
 - 1.3. Physicians' awareness of prognostic discordance.
2. Explore which factors predict physician-patient prognostic discordance, focusing on factors suggested by past research, pertaining to: patients (age, sex, nationality, religiosity, education, health literacy, numeracy, time since diagnosis, line of systemic treatment, health-related quality of life, trait optimism, trait anxiety, fighting spirit, avoidance coping, uncertainty tolerance, trust in the physician, prognostic information preference, perceived discussions of life expectancy, main source of prognostic perceptions), physicians, (experience in oncology practice, certainty about prognosis) and caregivers (prognostic information preferences, protective buffering).

Materials and Methods

Study Design

We conducted a cross-sectional survey study among physician-patient-caregiver triads in the advanced cancer setting (PROSPECT, September 2019–June 2021), aiming to examine prognostic perceptions and information preferences. This paper presents our primary analyses, using physician-patient prognostic discordance as the primary outcome. Primary analyses on prognostic information preferences and secondary analyses on patient-caregiver prognostic discordance are reported elsewhere.^{65,66}

Sample and Procedure

Medical and pulmonary oncologists from seven Dutch academic and non-academic hospitals were invited. Consenting physicians selected eligible patients from their outpatient clinics. Eligible patients had incurable metastatic/inoperable cancer (≥ 2 months after diagnosis), were ≥ 18 years and proficient in Dutch. Patients' expected median overall survival was ≤ 12 months at group level (with or without anticancer treatment), at diagnosis of metastatic disease or after disease progression. Physicians received an overview of all inclusion criteria, also specifying when the median overall survival of ≤ 12 months at group level was expected per tumor type (ie, for which type and line of anticancer treatment; see [Supplementary Table S1](#)), based on clinical trials. Naturally, patient's life expectancy at the *individual*-level could deviate from this *group*-level estimate.

The research team orally informed patients about the study focus in general terms (ie, patients' views on illness, treatment, and prospects) and the favored (yet not required) participation of a primary informal caregiver. Patients could invite a caregiver (≥ 18 years, proficient in Dutch) who was closely involved in the disease trajectory. Interested patients

received a patient information letter and (if applicable) a tailored caregiver version, by e-mail or postal mail. Both were blinded to prognostic eligibility criteria. Patients and caregivers each provided written informed consent and completed one structured survey online or on paper. Procedures conformed to the Helsinki Declaration. All medical ethics review boards waived formal approval (W19_051#19.073).

We conducted a priori power calculations (independent *t*-test; $\alpha = 0.05$, power = 0.80, Cohen's $d = 0.5$) to establish relationships between prognostic discordance (categorical) and patient, physician and caregiver factors (mostly continuous).^{40,42,44} We adopted an average cluster size of 10 (patients per physician) and an intraclass correlation (ICC) of 0.15, as prognostic discordance could vary by physician. We included more patients than the required sample of $n = 375$ to reach a sufficient number of patients with a participating caregiver.

Measures

Surveys were composed by the research team and consisted mostly of standardized instruments. In absence of standardized instruments, we used self-developed items, building on previous literature. All surveys, and self-developed items especially, were pilot-tested among the target population ($n = 8$ patients; $n = 8$ caregivers) to assess comprehensibility, emotional impact, and length.

Outcome Variables

[Table 1](#) presents measures for 3 types of *prognostic perceptions* among physicians and patients: likelihood of cure, 2-year mortality risk, and 1-year mortality risk. Items were introduced by the phrase: "Based on your understanding about your (this patient's) illness, your (his/her) health in general, and the treatments you are (he/she is) receiving, how likely is it that" followed by, for example, "you (this patient) will die from your (his/her) cancer within 1 year from now?" Items were scored on a 7-point scale ("extremely unlikely, 0%-10%/very unlikely, 10%-25%/unlikely, 25%-40%/possible, 40%-60%/likely, 60%-75%/very likely, 75%-90%/extremely likely, 90%-100%").⁶⁷ Estimates were reported at the level of individual patients (not group-level). To operationalize *physician-patient prognostic discordance* ([Table 1](#)), we dichotomized the 7-point scales for prognostic perceptions and compared physicians' and patients' answers. This method allows classification of overall physician-patient prognostic discordance, yet implies that detailed information is obscured and the degree of discordance may vary within dyads (ie, how far apart physicians' and patients' estimates actually are). We distinguished between *optimistic prognostic discordance* and *pessimistic prognostic discordance* to describe the direction of patients' estimates in relation to physicians' estimates (ie, patient holds more optimistic or, respectively, pessimistic perceptions than the physician). We also distinguished between *optimistic prognostic concordance* and *pessimistic prognostic concordance* (ie, physicians and patients both hold optimistic or, respectively, pessimistic perceptions).

Predictor Variables

[Supplementary Table S2](#) presents details about our measures for patient, physician, and caregiver factors, including Cronbach's alphas and example items.

Table 1. Items for prognostic perceptions and operationalization of physician-patient prognostic discordance.

| Type of prognostic perception | Items for prognostic perceptions ^a | Operationalization of physician-patient prognostic discordance ^b |
|-------------------------------|---|---|
| Likelihood of cure | <p>“How likely is it that your (this patient’s) cancer will be cured?”</p> <ol style="list-style-type: none"> (1) Extremely likely (100%-90%) (2) Very likely (90%-75%) (3) Likely (75%-60%) (4) Possible (60%-40%) (5) Unlikely (40%-25%) (6) Very unlikely (25%-10%) (7) Extremely unlikely (10%-0%) | <p><i>Optimistic prognostic discordance:</i> Patient responds ≤4; physician responds ≥5.</p> <p><i>Pessimistic prognostic discordance:</i> Patient responds ≥5; physician responds ≤4.^c</p> <p><i>Optimistic prognostic concordance:</i> Patient and physician respond ≤4.^c</p> <p><i>Pessimistic prognostic concordance:</i> Patient and physician respond ≥5.</p> |
| 2-Year mortality risk | <p>“How likely is it that you (this patient) will die from your (his/her) cancer within 2 years from now?”</p> <ol style="list-style-type: none"> (1) Extremely unlikely (0%-10%) (2) Very unlikely (10%-25%) (3) Unlikely (25%-40%) (4) Possible (40%-60%) (5) Likely (60%-75%) (6) Very likely (75%-90%) (7) Extremely likely (90%-100%) | <p><i>Optimistic prognostic discordance:</i> Patient responds ≤3; physician responds ≥4.</p> <p><i>Pessimistic prognostic discordance:</i> Patient responds ≥4; physician responds ≤3.</p> <p><i>Optimistic prognostic concordance:</i> Patient and physician respond ≤3.</p> <p><i>Pessimistic prognostic concordance:</i> Patient and physician respond ≥4.</p> |
| 1-Year mortality risk | <p>“How likely is it that you (this patient) will die from your (his/her) cancer within 1 year from now?”</p> <ol style="list-style-type: none"> (1) Extremely unlikely (0%-10%) (2) Very unlikely (10%-25%) (3) Unlikely (25%-40%) (4) Possible (40%-60%) (5) Likely (60%-75%) (6) Very likely (75%-90%) (7) Extremely likely (90%-100%) | <p><i>Optimistic prognostic discordance:</i> Patient responds ≤3; physician responds ≥4.</p> <p><i>Pessimistic prognostic discordance:</i> Patient responds ≥4; physician responds ≤3.</p> <p><i>Optimistic prognostic concordance:</i> Patient and physician respond ≤3.</p> <p><i>Pessimistic prognostic concordance:</i> Patient and physician respond ≥4.</p> |

^aItems were adopted from prior research and adjusted for the current analysis. Items for patients were preceded by the following introduction: “Based on your understanding about your illness, your health in general, and the treatments you are receiving, how likely is it that...”.⁴⁵

^bPrognostic perceptions were measured at verbatim-level (ie, precise, detailed information) using 7-point scales. Physician-patient prognostic discordance was measured at gist-level (ie, essential meaning of information) through dichotomization of the 7-point scales for prognostic perceptions.⁶⁶

^cPhysicians were instructed to include patients with an inoperable/metastatic tumor, for which treatment with curative intent was no longer possible. Our data however revealed that a few physicians perceived patients’ likelihood of cure as “possible.” Records were kept if compliance with the inclusion criteria was verified by the treating physician and the electronic patient file. Previous research similarly found that physicians may report “cure” as a treatment goal in the metastatic cancer setting.⁶⁷

Patient Factors

We assessed patients' background factors (age, sex, nationality, religiosity, education, health literacy [Set of Brief Screening Questions],^{68,69} and numeracy [Subjective Numeracy-Scale]⁷⁰). Regarding clinical factors, physicians registered patients' date of diagnosis of metastatic/inoperable cancer (to calculate time since diagnosis), line of systemic treatment during study participation, and tumor type. Patients reported their health-related quality of life (Global Health Status-subscale, EORTC Quality-of-Life Questionnaire).⁷¹ Additionally, we measured personal factors: trait optimism (life orientation test-revised),⁷² trait anxiety [Spielberger State and Trait Anxiety-Inventory],⁷³ fighting spirit [Mini Mental Adjustment to Cancer-scale],⁷⁴ avoidance coping [Utrecht Coping-List],⁷⁵ uncertainty tolerance [Tolerance for Ambiguity]⁷⁶). We also assessed relational factors: trust in the physician [Trust in Oncologist Scale-Short Form]⁷⁷ and prognostic information-related factors. The latter included prognostic information preferences⁴⁰ (eg, "Are you a person who wants to know the likelihood of dying from your cancer within 1 year from now?" Yes/No), self-reported prognostic discussions (eg, "Did the physician inform you about your life expectancy?" Yes/No/I don't know), main source of prognostic perceptions (ie, "On what do you base your perceptions of prognosis primarily?" Healthcare provider/Family or friends/Support group/Internet/Books/Personal beliefs), perceived adequacy of prognostic information (ie, "What do you think of the amount of prognostic information provided by your physician?" 1-5, Far too much-Far too little) and perceived quality of prognostic communication (ie, "What do you think of the way in which prognostic information was provided by your physician?" 1-5, Bad-Very good).

Physician Factors

We assessed physicians' background factors (age, sex, medical specialty, certification, and experience in oncology practice) and prognostic information-related factors. The latter included items on physicians' perceived importance of communicating prognosis and attitudes toward early prognostic communication,²¹ introduced by the phrase: "Assume you are caring for a patient who is newly diagnosed with metastatic cancer and you estimate that the patient has 12 months to live" followed by, for example, "how (un)important do you believe providing information about life expectancy to the described patient is?" (1-5, Not important at all-Very important) and "when in the course of the typical patient's illness are you most likely to discuss life expectancy for the first time?" (1-7, Now-Never). Physicians responding "Now" were defined as having a positive attitude towards early prognostic communication. Additionally, we assessed self-reported prognostic discussions (eg, "Did you inform the patient about his/her life expectancy?" Yes/No/I don't know), certainty about prognosis (ie, "How certain are you about this patient's prognosis?" 1-5, Not at all certain-Very certain) and awareness of physician-patient prognostic discordance (ie, "Does this patient know what the likelihood is of dying from his/her cancer within 1 year?" Yes/No).

Caregiver Factors

We assessed caregivers' background factors (age, sex, relationship with the patient), relational factors (protective buffering [Active Engagement, Protective Buffering,

and Overprotection-Questionnaire]⁶²) and prognostic information-related factors (prognostic information preference: "Are you a person who wants to know the likelihood of your loved one dying from his/her cancer within 1 year from now?" Yes/No).⁴⁰

Statistical Analysis

Analyses were performed with IBM-SPSS-Statistics 26. Missing data were reported, not imputed. Patients missing responses to all items on prognostic perceptions were excluded from the analyses (Supplementary Fig. S1).

Physician-Patient prognostic Discordance, Patients' Prognostic Information Preferences, and Physicians' Awareness of Prognostic Discordance (Aim 1)

We used frequencies to present the extent and direction of prognostic discordance regarding the likelihood of cure, 2-year and 1-year mortality risk (optimistic prognostic discordance, pessimistic prognostic discordance, optimistic prognostic concordance, and pessimistic prognostic concordance; Table 1) and the proportion of patients who preferred (not) to know prognosis. For subsequent analyses, we focused on prognostic discordance regarding the 1-year mortality risk, as this estimate was considered most relevant to prepare for the end of life.⁷⁸ We calculated frequencies to assess the agreement between physician-perceived and observed prognostic discordance or concordance, as well as a kappa-value, which corrects for agreement that occurs by chance (kappa < 0.20 poor; 0.21-0.40 fair; 0.41-0.60 moderate; 0.61-0.80 good; or 0.81-1.00 very good agreement).⁷⁹

Patient, Physician, and Caregiver Factors Predicting Physician-Patient Prognostic Discordance (Aim 2)

First, we tested significant differences in the hypothesized predictors (based on theory) between patients demonstrating optimistic prognostic discordance, pessimistic prognostic discordance, and prognostic concordance (one-way ANOVA, Welch, Kurskal-Wallis, Chi² tests; post hoc Tukey, Games-Howell tests). Next, we tested the need for mixed-effects multinomial logistic regression analyses (data clustering within physicians, ICC ≥ 10%).⁸⁰⁻⁸² This method performs maximum likelihood estimation to deal with missing data and uses partial pooling to adjust for multiple testing. Partial pooling moves point estimates and their corresponding intervals toward each other, which makes comparisons appropriately more conservative, while classical procedures adjust *P*-values.^{83,84} We constructed unconditional models (ie, without predictors) including the outcome variable only (ie, optimistic prognostic discordance = 2, pessimistic prognostic discordance = 1, prognostic concordance = 0). We tested random intercepts of patients (level 1) and physicians (level 2). Levels were kept if likelihood-ratio Chi²-tests were significant ($\alpha = 0.05$) and ICC ≥ 10%.⁸⁰⁻⁸² Subsequently, we constructed conditional models by adding fixed factors (ie, predictors that were significant in univariate tests; intercorrelations $r < 0.80$). We added patient factors one by one first (eg, age, sex, nationality, religiosity, education, health literacy, numeracy, time since diagnosis, line of systemic treatment, health-related quality of life, trait optimism, trait anxiety, fighting spirit, avoidance coping, uncertainty tolerance, trust in the physician, prognostic information preference, patient-perceived discussions of life expectancy, and main source of prognostic perceptions), followed

by physician and caregiver factors (eg, physicians' experience in oncology practice, certainty about prognosis; caregivers' prognostic information preference, and protective buffering). During model building, we tested variables at a liberal significance level ($\alpha = 0.20$) to prevent elimination because of confounding or modification effects. We tested resultant models at $\alpha = 0.05$ and eliminated non-significant variables one by one to simplify the final model.

Results

PROSPECT included 540 patients and/or caregivers (response rate 62%; [Supplementary Fig. S1](#)). For this paper, we included 515 patients who reported their prognostic perceptions (likelihood of cure, 2-year or 1-year mortality risk), of whom 409 had a participating caregiver. Most participating caregivers were patients' partners (76%). Patients (54% male; aged 19-90 years) were consulted by $n = 32$ medical oncologists and $n = 21$ pulmonary oncologists. Most physicians had a positive attitude towards early communication of the likelihood of cure (98%, $n = 52/53$) and life expectancy (79%, $n = 42/53$). They reported discussing such information with 93% ($n = 480/515$) and, respectively, 58% ($n = 298/515$) of patients. About one-sixth of patients (17.3%, $n = 89/515$) felt they received (far) too little prognostic information ([Table 2](#)).

Physician-Patient Prognostic Discordance, Patients' Prognostic Information Preferences, and Physicians' Awareness of Prognostic Discordance (Aim 1)

Twenty percent of patients perceived the *likelihood of cure* discordantly from their physician ($n = 98/502$). Among those patients, 93% preferred knowing the *likelihood of cure* and 7% did not ($n = 90/97$ vs. $7/97$). Twenty-four percent of patients perceived the *2-year mortality risk* discordantly from their physician ($n = 121/512$). Among those patients, 55% preferred knowing the *2-year mortality risk* and 45% did not ($n = 67/121$ vs. $54/121$). Thirty-five percent of patients perceived the *1-year mortality risk* discordantly from their physician ($n = 179/512$). Among those patients, 63% preferred knowing the *1-year mortality risk* and 37% did not ($n = 112/179$ vs. $67/179$).

Generally, patients' discordant prognostic perceptions were more often optimistically than pessimistically biased compared to physicians' estimates ([Table 3](#)). Regarding the *likelihood of cure*, 19% demonstrated *optimistic prognostic discordance* versus less than 1% with *pessimistic prognostic discordance*. Regarding the *2-year mortality risk*, 21% of patients demonstrated *optimistic prognostic discordance* versus 2% with *pessimistic prognostic discordance*; this was 28% versus 7% for the 1-year mortality risk.

[Supplementary Figs. S2–S5](#) illustrate—in detail—how physicians' and patients' estimates related to one another, suggesting that patients' *pessimistic prognostic discordance* was relatively more likely to occur regarding the 1-year mortality risk, compared to the 2-year mortality risk and the likelihood of cure. Also, compared to the 2-year mortality risk and the likelihood of cure, physicians' estimates regarding the likelihood of patients' death within one year seemed to move away from "extremely likely/unlikely" toward "possible."

Physicians were correct about the (mis)match between patients' perceptions of the *1-year mortality risk* and their own estimates in 59% of all cases ($n = 303/512$; [Table 4](#)). Among patients perceiving the *1-year mortality risk* discordantly from their physician, 64% had a physician who was aware of such discordance ($n = 114/179$). Among patients perceiving the *1-year mortality risk* concordantly with their physician, 57% had a physician who was aware of such concordance ($n = 189/333$). Overall, accounting for chance, a kappa-value of 0.186 indicated that agreement between physician-perceived and observed prognostic discordance or concordance was poor.

Patient, Physician, and Caregiver Factors Predicting Physician-Patient Prognostic Discordance (Aim 2)

Univariate test results ([Table 5](#)) show that among patients with optimistic discordant perceptions, pessimistic discordant perceptions or concordant perceptions of the *1-year mortality risk*, there were significant differences in patients' health-related quality of life, trait anxiety, fighting spirit, perceived discussions of life expectancy, main source of prognostic perceptions ($P < .001$) and prognostic information preference ($P < .01$), and in physicians' certainty about prognosis ($P < .001$).

[Table 6](#) shows the multivariate results. *Patient* factors associated with *optimistic discordant* perceptions of the *1-year mortality risk* included a stronger fighting spirit (OR = 1.20, 95%CI [1.10; 1.31], $P < .001$), self-reported absence of discussions of life expectancy (OR = 2.02, 95%CI [1.29; 3.15], $P = .002$), and using a source other than the healthcare provider for one's prognostic perceptions (OR = 1.67, 95%CI [1.07; 2.61], $P = .025$). Regarding *physician* factors, *optimistic*, and *pessimistic prognostic discordance* were associated with greater uncertainty about prognosis (OR_{optimistic} = 0.70, 95%CI [0.55; 0.90], $P = .006$; OR_{pessimistic} = 0.40, 95%CI [0.24; 0.67], $P = .001$).

Discussion

This study shows that a substantial group of patients with advanced cancer have prognostic perceptions that are discordant with physicians' estimates, ranging from 20% for the likelihood of cure to 24% and 35% for the 2-year and 1-year mortality risk, respectively. In most cases, patients were more optimistic about prognosis than their physician. This study furthermore demonstrates that 7%-45% of patients who perceive prognosis discordantly from their physician do not want prognostic information. This finding underlines the importance of assessing patients' prognostic information preferences. Additionally, this study shows that physicians are often unaware of the discordance between patients' and their own estimates. This suggests that prognostic discordance may be overlooked, which could hamper patients' informed treatment and end-of-life decision-making.^{16,53,85,86}

Our research corroborates most studies demonstrating patients' optimistically biased prognostic perceptions, yet also exposes a potential blind spot, as we observed a small subgroup of pessimistic patients. Physicians should be mindful of patients who unrealistically believe that death is looming since they might experience emotional burden and prematurely withdraw from medical interventions and/or daily life

Table 2. Background, clinical, personal, relational, and prognostic information-related factors of patients, physicians and caregivers.

| Patient factors | Total sample <i>n</i> _{patients} = 515 |
|---|--|
| Age (years), mean ± SD | 63.87 ± 11.00 |
| Sex (male), % (<i>n</i>) | 54.2 (279) |
| Nationality (Dutch), % (<i>n</i>) | 95.3 (491) |
| Religiosity (yes), % (<i>n</i>) ^a | 40.8 (210) |
| Education, % (<i>n</i>) ^b | |
| Low | 37.9 (195) |
| Medium | 26.6 (137) |
| High | 35.5 (183) |
| Health literacy (SBSQ-D, 0-4), mean ± SD ^c | 3.24 ± 0.79 |
| Numeracy (SNS, 1-6), mean ± SD | 4.18 ± 1.17 |
| Time since diagnosis (months), mean ± SD ^c | 16.95 ± 17.65 |
| Line of systemic treatment during study participation, % (<i>n</i>) ^d | |
| None ^e | 23.5 (120) |
| First line | 43.3 (221) |
| Second line | 20.2 (103) |
| ≥Third line | 12.9 (66) |
| Tumor type, % (<i>n</i>) | |
| Lung | 23.9 (123) |
| Pleura | 6.0 (31) |
| Esophagogastric | 13.8 (71) |
| Pancreatic | 6.8 (35) |
| Other gastrointestinal | 15.0 (77) |
| Colorectal | 2.9 (15) |
| Brain | 11.8 (61) |
| Gynaecological | 9.5 (49) |
| Soft tissue | 2.7 (14) |
| Other (each type <i>n</i> <10) ^f | 7.6 (39) |
| Health-related quality of life (GHS-subscale of EORTC-QLQ-C30, 0-100), mean ± SD ^g | 63.15 ± 20.98 |
| Trait optimism (LOT-R, 0-24), mean ± SD ^g | 14.64 ± 3.91 |
| Trait anxiety (subscale of STAI, 20-80), mean ± SD ^g | 39.64 ± 10.64 |
| Fighting spirit (subscale of Mini-MAC, 4-16), mean ± SD ^h | 11.48 ± 2.70 |
| Avoidance coping (subscale of UCL, 8-32), mean ± SD ⁱ | 15.52 ± 3.29 |
| Uncertainty tolerance (TFA, 7-42), mean ± SD ⁱ | 25.85 ± 5.92 |
| Trust in the physician (TiOS-SF, 1-5), mean ± SD ^g | 4.31 ± 0.69 |
| Preference to know likelihood of cure (yes), % (<i>n</i>) ^c | 93.4 (478) |
| Preference to know 2-year mortality risk (yes), % (<i>n</i>) ^g | 70.2 (361) |
| Preference to know 1-year mortality risk (yes), % (<i>n</i>) | 68.7 (354) |
| Patient-reported prognostic discussions (yes), % (<i>n</i>) | |
| Likelihood of cure ^d | 86.9 (443) |
| Life expectancy ^c | 57.2 (293) |
| Main source of prognostic perceptions (healthcare provider), % (<i>n</i>) ^{i, j} | 62.2 (319) |
| Perceived adequacy of prognostic information, % (<i>n</i>) ^c | |
| Far too little information | 2.1 (11) |
| Too little information | 15.2 (78) |
| Exactly right | 79.9 (409) |
| Too much information | 2.1 (11) |
| Far too much information | 0.6 (3) |
| Perceived quality of prognostic communication, % (<i>n</i>) ^k | |
| Bad | 2.7 (14) |
| Mediocre | 8.6 (44) |
| Sufficient | 22.3 (114) |
| Good | 38.6 (197) |
| Very good | 27.8 (142) |

Table 2. Continued

| Physician factors | Total sample |
|--|---|
| <i>Physician level</i> | <i>n</i> _{physicians} = 53 |
| Age (years), mean ± SD | 42.25 ± 9.93 |
| Sex (male), % (<i>n</i>) | 35.8 (19) |
| Medical specialty (medical oncologist), % (<i>n</i>) | 60.4 (32) |
| Certification (fellow), % (<i>n</i>) | 34.0 (18) |
| Experience in oncology practice (years), mean ± SD | 9.61 ± 9.97 |
| Positive attitude towards early prognostic communication (yes), % (<i>n</i>) | |
| Likelihood of cure | 98.1 (52) |
| Life expectancy | 79.2 (42) |
| Perceived importance of communicating likelihood of cure, % (<i>n</i>) | |
| Not important at all | 0.0 (0) |
| Not very important | 0.0 (0) |
| Somewhat important | 0.0 (0) |
| Important | 34.0 (18) |
| Very important | 66.0 (35) |
| Perceived importance of communicating life expectancy, % (<i>n</i>) | |
| Not important at all | 1.9 (1) |
| Not very important | 5.7 (3) |
| Somewhat important | 39.6 (21) |
| Important | 32.1 (17) |
| Very important | 20.8 (11) |
| <i>Patient level</i> | <i>n</i> _{patients} = 515 |
| Physician-reported prognostic discussions (yes), % (<i>n</i>) | |
| Likelihood of cure | 93.2 (480) |
| Life expectancy | 57.9 (298) |
| Certainty about prognosis (1-5), mean ± SD | 3.61 ± 0.95 |
| <i>Caregiver factors</i> | <i>n</i> _{caregivers} = 409 ^l |
| Age (years), mean ± SD ^m | 58.34 ± 12.97 |
| Sex (male), % (<i>n</i>) | 39.1 (160) |
| Relation with patient, % (<i>n</i>) | |
| Caregiver is patient's partner | 76.3 (312) |
| Caregiver is patient's child | 13.7 (56) |
| Other ⁿ | 10.0 (41) |
| Protective buffering (subscale of ABO, 1-5), mean ± SD ^d | 2.44 ± 0.54 |
| Preference to know 1-year mortality risk (yes), % (<i>n</i>) | 85.3 (349) |

^aIncluding Christianity, Islam, Buddhism, Hinduism, Judaism, Humanism, spirituality, and "own belief."

^bLow: elementary to low vocational education. Medium: up till medium level vocational education. High: high vocational or academic education.

^cThree missing (*n* = 512/515 among the total sample of patients).

^dFive missing (*n* = 510/515 among the total sample of patients; or *n* = 404/409 among the total sample of caregivers).

^ePatients in the category "None" could have received systemic treatment before participation, receive non-systemic treatment during participation (eg, radiotherapy), and/or receive (non-)systemic treatment in the future. Yet, this was not reported.

^fIncluding melanoma, head and neck, thyroid, breast, vagina, prostate, bladder, kidney, adrenal cortex, bone, carcinoid and unknown primary tumors.

^gOne missing (*n* = 514/515 among the total sample of patients).

^hSix missing (*n* = 509/515 among the total sample of patients).

ⁱTwo missing (*n* = 513/515 among the total sample of patients).

^jIncluding treating physicians, second opinion physicians, nurses, general practitioners and other healthcare providers. Patients who did not indicate a healthcare provider as the main source of their prognostic perceptions, were categorized as "other." "Other" included family, friends, colleagues, support group, patient advocate groups, internet, books and personal beliefs.

^kFour missing (*n* = 511/515 among the total sample of patients).

^lBased on the sample of caregivers in the mixed-effects multinomial logistic regression models (*n* = 409/411).

^mTen missing (*n* = 399/409 among the total sample of caregivers).

ⁿIncluding caregivers who were patient's parent, sibling, aunt, uncle, cousin, friend, neighbor, or other.

Abbreviations: ABO, Active Engagement, Protective Buffering and Overprotection EORTC-QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Cancer; GHS, Global Health Status; LOT-R, Life Orientation Test-Revised; MAC, Mental Adjustment to Cancer; *n*, sample size; SBSQ-D, Set of Brief Screening Questions-Dutch; SNS, Subjective Numeracy Scale; STAI, Spielberger State and Trait Anxiety Inventory; TFA, tolerance for ambiguity; TiOS-SF, Trust in Oncologist Scale-Short Form UCL, Utrecht Coping List.

Table 3. Physician-patient prognostic discordance and concordance (optimistic and pessimistic).

| Prognostic perceptions | Likelihood of cure <i>n</i> = 502 ^a | 2-Year mortality risk <i>n</i> = 512 ^b | 1-Year mortality risk <i>n</i> = 512 ^b |
|---|---|--|--|
| Prognostic discordance, % (<i>n</i>) | 19.5 (98) | 23.6 (121) | 35.0 (179) |
| Patient is optimistic, physician is pessimistic, % (<i>n</i>) | 19.1 (96) | 21.3 (109) | 28.3 (145) |
| Patient is pessimistic, physician is optimistic, % (<i>n</i>) | 0.4 (2) ^c | 2.3 (12) | 6.6 (34) |
| Prognostic concordance, % (<i>n</i>) | 80.5 (404) | 76.4 (391) | 65.0 (333) |
| Patient and physician are pessimistic, % (<i>n</i>) | 80.5 (404) | 75.4 (386) | 58.8 (301) |
| Patient and physician are optimistic, % (<i>n</i>) | 0.0 (0) | 1.0 (5) | 6.3 (32) |

^aThirteen missing (*n* = 502/515 among the total sample of patients).

^bThree missing (*n* = 512/515 among the total sample of patients).

^cPhysicians were instructed to include patients with an inoperable/metastatic tumor, for which treatment with curative intent was no longer possible. Our data however revealed that a few physicians perceived patients' likelihood of cure as "possible." Records were kept if compliance with the inclusion criteria was verified by the treating physician and the electronic patient file. Previous research similarly found that physicians may report "cure" as a treatment goal in the metastatic cancer setting.⁶⁷

Abbreviation: *n*: sample size.

Table 4. Physicians' awareness of physician-patient prognostic discordance regarding the 1-year mortality risk.

| Physician-perceived ^a | Observed | | Total |
|--|--|--|-------|
| | Physician-patient prognostic discordance % (<i>n</i>) | Physician-patient prognostic concordance % (<i>n</i>) | |
| Physician-patient prognostic discordance | 63.7 (114) [†] | 43.2 (144) ^{††} | 254 |
| Physician-patient prognostic concordance | 36.3 (65) ^{††} | 56.8 (189) [†] | 258 |
| Total | 100 (179) | 100 (333) | 512 |

^aThree missing (*n* = 512/515 among the total sample of patients).

[†]Physician is aware of physician-patient prognostic discordance or concordance.

^{††}Physician is unaware of physician-patient prognostic discordance or concordance.

Abbreviations: *n*: sample size.

(eg, career, relationships).^{87,88} Additionally, we found that prognostic discordance is less likely when estimating the likelihood of cure versus the 2-year or 1-year mortality risk. Most physician-patient dyads acknowledged the absence of cure and often agreed that surviving 2 years is rather unlikely. Hypothetically, estimating the likelihood of dying within one year was most difficult for both patients and physicians, introducing variability in their estimates. That is, contemplating the 1-year mortality risk may have been most threatening for patients, perhaps leading them to avoid drawing definitive conclusions about their prospects. The 1-year mortality risk may not have been threatening for physicians, yet physicians possibly were more uncertain about making this estimate for individual patients, given the inclusion criterion of a 50-50 chance of death within 12 months at group-level. Hence, the 1-year mortality risk potentially left most room for a mismatch between physicians' and patients' responses.

The impact of physicians' uncertainty about prognosis seems substantial, as it was the only factor associated with patients' both overly optimistic and overly pessimistic prognostic perceptions. Literature suggests that physicians regularly use ambiguous prognostic language or state they "don't know," out of fear that patients will hold onto explicit estimates that might turn out wrong.^{53,54,89,90} Hypothetically, physicians' uncertainty "opens the door" to a wider variety

of interpretations of prognosis. Some patients may react frightfully in the absence of explicit information and expect the worst, while other patients see an opportunity for hope, potentially depending on personality or past experiences.⁹¹ Physicians' personal discomfort with prognostic communication may also lead to non-disclosure.^{85,92,93} Like previous studies, we noted an intention-behavior gap between physicians' overall positive attitude (79%) toward early communication of life expectancy and their self-reported discussions (58%) of life expectancy patients' overly optimistic prognostic perceptions.

Our study additionally demonstrates that prognostic (Table 2).^{21,94} Our results show that a lack of prognostic discussions, too, contributes to discordance is associated with factors other than the extent of physicians' prognostic discussions. Patients who identified the internet, books, friends, family, support groups, or personal beliefs as a source of their prognostic perceptions—rather than the physician—were more likely to be overly optimistic about their prospects. This matches research indicating that patients who do not base life expectancy estimates on a medical provider, but instead rely on personal beliefs, more often report inaccurate estimates.⁵⁹ Possibly, these patients hold on to positive beliefs to allow hope. Past research suggests that wanting to stay optimistic motivates patients to avoid prognostic information, and that

Table 5. (Non)significant differences in patient, physician and caregiver factors between optimistic prognostic discordance, pessimistic prognostic discordance, and prognostic concordance.^a

| Patient factors | Optimistic prognostic discordance (1-year mortality risk) <i>n</i> _{patients} = 145 | Pessimistic prognostic discordance (1-year mortality risk) <i>n</i> _{patients} = 34 | Prognostic concordance (1-year mortality risk) <i>n</i> _{patients} = 333 |
|--|--|--|---|
| Age (years), mean ± SD | 64.04 ± 10.79 | 66.65 ± 10.39 | 63.50 ± 11.17 |
| Sex (male), % (<i>n</i>) | 59.3 (86) | 44.1 (15) | 53.5 (178) |
| Nationality (Dutch), % (<i>n</i>) | 93.1 (135) | 97.1 (33) | 96.1 (320) |
| Religiosity (yes), % (<i>n</i>) ^b | 42.8 (62) | 47.1 (16) | 39.0 (130) |
| Education, % (<i>n</i>) ^c | | | |
| Low | 44.1 (64) | 35.3 (12) | 34.8 (116) |
| Medium | 20.0 (29) | 32.4 (11) | 29.1 (97) |
| High | 35.9 (52) | 32.4 (11) | 36.0 (120) |
| Health literacy (SBSQ-D, 0-4), mean ± SD | 3.18 ± 0.87 ^d | 3.37 ± 0.62 | 3.26 ± 0.77 ^e |
| Numeracy (SNS, 1-6), mean ± SD | 4.17 ± 1.12 | 4.36 ± 1.11 | 4.17 ± 1.19 |
| Time since diagnosis (months), mean ± SD | 16.96 ± 17.64 | 22.95 ± 19.73 | 16.33 ± 17.43 ^f |
| Line of systemic treatment during study participation, % (<i>n</i>) | ^d | | ^g |
| None | 19.4 (28) | 35.3 (12) | 24.3 (80) |
| First line | 50.0 (72) | 41.2 (14) | 40.4 (133) |
| Second line | 15.3 (22) | 20.6 (7) | 22.2 (73) |
| ≥Third line | 15.3 (22) | 2.9 (1) | 13.1 (43) |
| Health-related quality of life (GHS-subscale of EORTC-QLQ-C30, 0-100), mean ± SD *** | 68.06 ± 19.61 ^{d,1} | 67.65 ± 18.89 ^{1,2} | 60.54 ± 21.40 ² |
| Trait optimism (LOT-R, 0-24), mean ± SD | 15.09 ± 3.77 | 14.71 ± 4.17 | 14.45 ± 3.93 ^d |
| Trait anxiety (subscale of STAI, 20-80), mean ± SD *** | 36.96 ± 9.85 ¹ | 39.00 ± 11.51 ^{1,2} | 40.81 ± 10.69 ^{d,2} |
| Fighting spirit (subscale of Mini-MAC, 4-16), mean ± SD *** | 12.48 ± 2.47 ^{d,1} | 11.40 ± 2.43 ^{d,1,2} | 11.04 ± 2.72 ^{g,2} |
| Avoidance coping (subscale of UCL, 8-32), mean ± SD | 15.58 ± 3.53 | 15.35 ± 3.39 | 15.53 ± 3.18 ^e |
| Uncertainty tolerance (TFA, 7-42), mean ± SD | 25.12 ± 6.07 | 25.53 ± 6.29 | 26.26 ± 5.77 ^e |
| Trust in the physician (TiOS-SF, 1-5), mean ± SD | 4.26 ± 0.79 | 4.38 ± 0.53 | 4.33 ± 0.66 ^d |
| Preference to know 1-year mortality risk (yes), % (<i>n</i>) ** | 59.3 (86) ¹ | 76.5 (26) ^{1,2} | 72.7 (242) ² |
| Patient-reported discussions of life expectancy (yes), % (<i>n</i>) *** | 44.1 (63) ^{e,1} | 57.6 (19) ^{d,1,2} | 63.4 (211) ² |
| Main source of prognostic perceptions (healthcare provider), % (<i>n</i>) ^h *** | 48.6 (70) ^{d,1} | 50.0 (17) ¹ | 69.0 (229) ^{d,2} |
| Physician factors | Optimistic prognostic discordance (1-year mortality risk) | Pessimistic prognostic discordance (1-year mortality risk) | Prognostic concordance (1-year mortality risk) |
| <i>Physician level</i> | <i>n</i> _{patients} = 145 | <i>n</i> _{patients} = 34 | <i>n</i> _{patients} = 333 |
| Experience in oncology practice (years), mean ± SD | 12.04 ± 9.56 | 12.77 ± 10.52 | 10.09 ± 8.39 |
| <i>Patient level</i> | <i>n</i> _{patients} = 145 | <i>n</i> _{patients} = 34 | <i>n</i> _{patients} = 333 |
| Certainty about prognosis (1-5), mean ± SD *** | 3.42 ± 0.95 ¹ | 2.94 ± 0.78 ² | 3.76 ± 0.92 ³ |

Table 5. Continued

| Caregiver factors | Optimistic prognostic discordance (1-year mortality risk) <i>n</i> _{caregivers} = 121 ⁱ | Pessimistic prognostic discordance (1-year mortality risk) <i>n</i> _{caregivers} = 28 ⁱ | Prognostic concordance (1-year mortality risk) <i>n</i> _{caregivers} = 257 ⁱ |
|--|---|---|--|
| Protective buffering (subscale of ABO, 1-5), mean ± SD | 2.46 ± 0.61 ^f | 2.40 ± 0.61 | 2.44 ± 0.50 ^e |
| Preference to know 1-year mortality risk (yes), % (<i>n</i>) | 83.5 (101) | 89.3 (25) | 86.0 (221) |

^aWe tested a subset of background, clinical, personal, relational and prognostic information-related factors of patients, physicians and caregivers in univariate tests, which were selected as potential predictors based on predefined, theory-driven hypotheses.

^bIncluding Christianity, Islam, Buddhism, Hinduism, Judaism, Humanism, spirituality, and “own belief.”

^cLow: elementary to low vocational education. Medium: up till medium level vocational education. High: high vocational or academic education.

^dOne missing (*n* = 144/145 among patients demonstrating optimistic prognostic discordance; *n* = 33/34 among patients demonstrating pessimistic prognostic discordance; or *n* = 332/333 among patients demonstrating prognostic concordance).

^eTwo missing (*n* = 143/145 among patients demonstrating optimistic prognostic discordance; *n* = 331/333 among patients demonstrating prognostic concordance; or *n* = 255/257 among caregivers of patients demonstrating prognostic concordance).

^fThree missing (*n* = 330/333 among patients demonstrating prognostic concordance; or *n* = 118/121 among caregivers of patients demonstrating optimistic prognostic discordance).

^gFour missing (*n* = 329/333 among patients demonstrating prognostic concordance).

^hIncluding treating physicians, second opinion physicians, nurses, general practitioners, and other healthcare providers. Patients who did not indicate a healthcare provider as the main source of their prognostic perceptions, were categorized as “other.” “Other” included family, friends, colleagues, support group, patient advocate groups, internet, books and personal beliefs.

ⁱBased on the sample of caregivers in the mixed-effects multinomial logistic regression models (*n* = 409/411).

P* < .05, *P* < .01, ****P* ≤ .001.

Abbreviations: ABO, Active Engagement, Protective Buffering and Overprotection EORTC-QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Cancer; LOT-R, Life Orientation Test-Revised; MAC, Mental Adjustment to Cancer; *n*, sample size; SBSQ-D, Set of Brief Screening Questions-Dutch; SNS, Subjective Numeracy Scale; GHS, Global Health Status; STAI, Spielberger State and Trait Anxiety Inventory; TFA, tolerance for ambiguity; TiOS-SF, Trust in Oncologist Scale-Short Form; UCL, Utrecht Coping List.

keeping a positive attitude characterizes patients who adopt a fighting spirit to cope with cancer.^{66,95} These insights may support our data that patients with a strong fighting spirit are more likely to hold optimistically discordant prognostic perceptions. Fighting spirit may enable patients to deal with their disease by seeing cancer as a challenge, but could also be maladaptive when the end of life is near.^{95,96}

We believe our findings have implications for how prognostic discordance might be addressed in clinical practice. First, given patients’ observed optimistic discordance regarding the likelihood of cure, we argue that the non-curative intent of treatment should be made clear to all patients. Of note, this recommendation does not imply that physicians in our study omitted communication of the absence of cure or that such communication precludes patients’ optimistically biased perceptions. Second, our study indicates that we can intervene on discordance regarding the 1-year mortality risk, considering that it is partly associated with modifiable factors (eg, prognostic discussions), and physicians show positive attitudes towards prognostic communication. Our results suggest the value of explicitly exploring patients’ prognostic information preferences and prognostic perceptions, and assessing the presence, extent, and direction of prognostic discordance. Physicians should engage in such assessments regularly, since patients’ prognostic information preferences and perceptions may evolve over time.^{33,44} If patients want life expectancy estimates, physicians can offer tailored information to complement or adjust patients’ prognostic perceptions, thereby reducing prognostic discordance.⁵³ Moreover, physicians could explain their uncertainty about the applicability of group-level estimates to individuals, and discuss multiple scenarios to allow patients to hope for the best, yet prepare for the worst.⁹⁷ If patients prefer not knowing life expectancy, physicians should explore whether prognostic discordance undermines goal-concordant care.⁴¹ Training physicians to tailor prognostic communication, address

emotions, and manage prognostic uncertainty seems highly relevant.¹ Perhaps, enhanced tools for personalized prognostic information may help physicians in managing prognostic uncertainty, as literature suggests that availability of prognostic models can increase physicians’ prognostic communication intentions, especially when these models are perceived as credible.⁹⁸

Our research has limitations. First, physicians selected patients, which may have led to a biased sample, perhaps predominantly including dyads with a positive rapport. Second, it remains uncertain if patients’ self-reported prognostic perceptions reflected their prognostic understanding per se, as opposed to psychological processes (eg, coping and emotions). Our operationalization of prognostic discordance established if patients had a *gist* understanding of their prognosis (ie, essential meaning), preventing overestimation of discordance rates. Yet, this implies that patients who believe death is “extremely unlikely,” while it is “extremely likely” according to the physician, are equally discordant as patients perceiving death as “unlikely,” while dying is considered “possible” by the physician. Regarding prognostic concordance, it is questionable if knowing that dying is “possible,” while it is “extremely likely,” is sufficient for patients to anticipate the end of life. Furthermore, our measures for self-reported prognostic discussions were potentially influenced by recall and the extent of physician-patient contact, as timing of participation within the disease trajectory varied per patient. Also, some patients consulted several physicians, implying that participating physicians did not necessarily discuss treatment options or the associated prospects with patients. Third, associations with pessimistic prognostic discordance may have been undetected because of limited cases, which is a common issue.⁸⁷ Finally, we cannot draw conclusions about causality, nor make generalizations about non-Western cultures. Past evidence of unrealistic optimism among cancer

Table 6. Mixed-effects multinomial logistic regression model with predictors of physician-patient prognostic discordance regarding the 1-year mortality risk.^a

| Final model ^b n = 502 ^c | | | | | | | |
|--|--------|-------|--------|---------|--------|-----------------|-----------------|
| | B | SE | t | P | Exp(b) | Lower CI Exp(b) | Upper CI Exp(b) |
| Prognostic discordance (patient is more optimistic than physician) | | | | | | | |
| Intercept | -2.233 | 0.725 | -3.079 | .002** | 0.107 | .026 | .446 |
| Patient factors | | | | | | | |
| Fighting spirit (Mini-MAC) | 0.180 | 0.044 | 4.099 | .000*** | 1.197 | 1.098 | 1.305 |
| Patient-perceived discussions of life expectancy (ref = yes) | 0.701 | 0.227 | 3.088 | .002** | 2.015 | 1.290 | 3.147 |
| Main source of prognostic perceptions (ref = healthcare provider) | 0.513 | 0.228 | 2.254 | .025* | 1.671 | 1.068 | 2.614 |
| Physician factors | | | | | | | |
| Certainty about prognosis | -0.355 | 0.128 | -2.774 | .006** | 0.701 | .545 | .902 |
| Prognostic discordance (patient is more pessimistic than physician) | | | | | | | |
| Intercept | 0.272 | 1.317 | 0.207 | .836 | 1.313 | 0.099 | 17.451 |
| Patient factors | | | | | | | |
| Fighting spirit (Mini-MAC) | -0.001 | 0.078 | -0.008 | .993 | 0.999 | 0.857 | 1.165 |
| Patient-perceived discussions of life expectancy (ref = yes) | 0.057 | 0.429 | 0.133 | .894 | 1.059 | 0.456 | 2.460 |
| Main source of prognostic perceptions (ref = healthcare provider) | 0.774 | 0.420 | 1.846 | .066 | 2.169 | 0.951 | 4.948 |
| Physician factors | | | | | | | |
| Certainty about prognosis | -0.921 | 0.267 | -3.454 | .001*** | 0.398 | 0.236 | 0.672 |

^aOptimistic prognostic discordance = 2, pessimistic prognostic discordance = 1, prognostic concordance = 0.

^bWe included patient, physician, caregiver factors that were significant in univariate tests in mixed-effects multinomial logistic regression models with two levels (ICC > 10%). Intercorrelations between included factors were < .52 (ie, patients' health-related quality of life, trait anxiety, fighting spirit, prognostic information preference, perceived discussions of life expectancy, main source of prognostic perceptions; physicians' certainty about prognosis). During model building, patients' trait anxiety and prognostic information preference (P > .20) were eliminated. To simplify the final model, patients' health-related quality of life (P > .05) was eliminated. Results remained stable when using different variable entry methods and controlling for background variables, indicating robustness.

^cThirteen missing (n = 502/515 among the total sample of patients).

^dSignificant at P < .05. ** Significant at P < .01. *** Significant at P < .001.

Abbreviations: B, unstandardized coefficient; CI Exp(b), 95% CI of exponentiation of the B coefficient; Exp(b), exponentiation of the B coefficient, which is an odds ratio; ICC, intraclass correlation; MAC, Mental Adjustment to Cancer; n, sample size; P, significance; ref, reference category; t, test statistic.

patients and the general population however suggests that this phenomenon—and possibly its predictors—could be universal.⁸⁷

Strengths include the study's predefined conceptual model, pilot-tests of measures with various stakeholders, large sample of physician-patient-caregiver triads in the palliative setting, and robustness of results independent of statistical choices. Opposite to most studies, we assessed multiple types of prognostic perceptions, distinguished between patients with and without a preference to know prognosis, and explored multiple predictors of both optimistic and pessimistic prognostic discordance.

Still, further analyses should test unexplored relationships with prognostic discordance (Fig. 1). Future research might also study the unique predictors of patients' optimistic and pessimistic prognostic perceptions, and explore moderators of the effect of physicians' uncertainty about prognosis on these perceptions (eg, physicians' uncertainty tolerance). Aligning conceptualization and measurement of (accurate) prognostic perceptions is paramount. Lastly, to provide evidence-based guidance for physicians, we need insight into how different prognostic communication strategies impact individual patients.

Conclusion

Up to one-third of patients with advanced cancer perceive prognosis discordantly from their physician, among whom a substantial group prefers not knowing. Considering that most physicians lack awareness of prognostic discordance, we encourage them to explore patients' prognostic information preferences and prognostic perceptions, and tailor prognostic communication accordingly. Interventions may be helpful to resolve prognostic discordance and ultimately safeguard high-quality care in the last phase of life.

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Conflict of Interest

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Amgen, and Janssen (all institutional) and Roche (one-time, self); speaker for MSD and Lilly (institution); travel/conference reimbursement from Roche Genentech (self); and other: mentorship program with key opinion leaders: funded by AstraZeneca; fees for educational webinars: Benecke, Medtalks, VJ Oncology (self), high5oncology (institution); interview sessions funded by Roche Genentech, Bayer, Lilly (institution); and local PI of clinical trials: AstraZeneca, Novartis, BMS, MSD, Merck, GSK, Takeda, Blueprint Medicines, Roche Genentech, Janssen Pharmaceuticals, Mirati, Abbvie, and Gilead, all outside of current manuscript. The other authors indicated no financial relationships.

Ethics Statement

The study was granted exemption from formal approval by the Amsterdam University Medical Centers Institutional Medical Ethics Review Board (W19_051#19.073, February 14, 2019), the Medical Research Ethics Committee academisch ziekenhuis Maastricht, Maastricht University (METC 2019-1146, May 8, 2019), the Institutional Review Board of the Netherlands Cancer Institute-Antoni van Leeuwenhoek hospital (19.228/IRBd19152-M19PCC, 19th of July 2019), the Hospital Board of Tergooi Ziekenhuis (Kv/19.035, August 1, 2019), the Medical Research Ethics Committee Utrecht (WAG/mb/19/027709, August 7, 2019), the Daily Board of the Medical Ethics Committee Erasmus MC (MEC-2020-0529, July 9, 2020) and the Hospital Board of Franciscus Gasthuis & Vlietland Ziekenhuis (T110/2020-084, July 15, 2020). All methods adhered to the Helsinki Declaration. All study participants provided written informed consent on voluntary basis only. Study data are kept confidential and all identifiers have been removed prior to submission for publication.

Author Contributions

Conception/design: N.C.A.v.d.V., P.K.J.H., H.W.M.v.L., E.M.A.S., I.H. Provision of study material or patients: N.C.A.v.d.V., H.W.M.v.L., F.Y.F.L.d.V., L.E.L.H., J.A.B., A.M.C.D., J.M.W.v.H., J.D., E.M.A.S., I.H. Collection and/or assembly of data: N.C.A.v.d.V., H.W.M.v.L., F.Y.F.L.d.V., L.E.L.H., J.A.B., A.M.C.D., J.M.W.v.H., J.D. Data analysis and interpretation: N.C.A.v.d.V., P.K.J.H., H.W.M.v.L., E.M.A.S., I.H. Manuscript writing: N.C.A.v.d.V., P.K.J.H., H.W.M.v.L., E.M.A.S., I.H. Final approval of manuscript: All authors.

Data Availability

The datasets analyzed during the current study are not publicly available due to ethical considerations but are available from the corresponding author on reasonable request.

Supplementary Material

Supplementary material is available at *The Oncologist* online.

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