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**Original Article**

# Patient-Caregiver Dyads' Prognostic Information Preferences and Perceptions in Advanced Cancer



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**Abstract**

**Context.** Prognostic information is considered important for advanced cancer patients and primary informal caregivers to prepare for the end of life. Little is known about discordance in patients' and caregivers' prognostic information preferences and prognostic perceptions, while such discordance complicates adaptive dyadic coping, clinical interactions and care plans.

**Objectives.** To investigate the extent of patient-caregiver discordance in prognostic information preferences and perceptions, and the factors associated with discordant prognostic perceptions.

**Methods.** We conducted secondary analyses of a cross-sectional study (PROSPECT, 2019–2021). Advanced cancer patients (median overall survival  $\leq 12$  months) from seven Dutch hospitals and caregivers completed structured surveys ( $n = 412$  dyads).

**Results.** Seven percent of patient-caregiver dyads had discordant information preferences regarding the likelihood of cure; 24%–25% had discordant information preferences regarding mortality risk (5/2/1 year). Seventeen percent of dyads had discordant perceptions of the likelihood of cure; 12%–25% had discordant perceptions of mortality risk (5/2/1 year). Dyads with discordant prognostic information preferences ( $P < 0.05$ ) and dyads in which patients reported better physical functioning ( $P < 0.01$ ) were significantly more likely to perceive the one-year mortality risk discordantly.

**Conclusion.** Physicians should be sensitive to discordant prognostic information preferences and prognostic perceptions among patient-caregiver dyads in advanced cancer care. *J Pain Symptom Manage* 2023;65:442–455. © 2023 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>)

**Key Words**

*Health communication, Informal caregivers, Interpersonal relations, Truth disclosure, Prognosis, Neoplasm metastases*

**Key Message**

This cross-sectional survey study in advanced cancer care shows that up to one-quarter of patient-caregiver dyads have discordant prognostic information preferences,

and similarly up to one-quarter perceive patients' prognosis discordantly. Hence, physicians should explore patients' and caregivers' prognostic information preferences and prognostic perceptions, and be sensitive to potential discordance.

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## Introduction

Advanced cancer threatens patients' physical and psychological well-being, and interferes with social relationships. Primary informal caregivers (e.g., intimate partner, family member) need to adapt to patients' disease and are confronted with an uncertain future.<sup>1,2</sup> Besides facing cancer-related distress individually, patients and caregivers experience the disease as a shared stressor.<sup>3,4</sup> They may cope with cancer as a unit (i.e., dyadic coping), which can ameliorate psychological and relationship functioning.<sup>1,2</sup> Open communication is essential in dyadic coping, as it enables a shared understanding of treatment risks, benefits, and future care goals.<sup>2,5-8</sup> Apart from emotional support, caregivers assist patients in daily tasks, symptom management, and medical decisions.<sup>1,2,5,7,9-11</sup> Caregivers' role in patient care commonly intensifies when cancer advances.<sup>6,9</sup>

Information about prognosis (e.g., likelihood of cure, life expectancy) is important for treatment decision-making and practical preparation for the end of life.<sup>3,9,10,12-17</sup> Prognostic information additionally facilitates psychological and social adjustment to death, and stimulates patient-caregiver support.<sup>12,13,15,16,18</sup> As individual prognostic perceptions are impacted by complex interpersonal processes (e.g., interpretation of physicians' information), patient-caregiver dyads may not have a shared understanding of prognosis.<sup>7,10,19</sup> Generally, it is suggested that patients view prognosis more optimistically than caregivers.<sup>9-11,14,20,21</sup> One study among dyads of older patients with advanced cancer and caregivers showed that almost one-half had discordant perceptions of patients' survival.<sup>6</sup> Discordance in prognostic perceptions may induce anxiety, depression, and caregiver burden; impede patient-caregiver communication, adaptive dyadic coping and relational satisfaction; and complicate clinical interactions, goal-concordant medical decision-making, and (planning of) patients' care.<sup>2,5-7,10,11,14,19,22</sup>

Patient-caregiver discordance in prognostic perceptions possibly arises from conflicting information preferences.<sup>13</sup> Research suggests that caregivers are more likely to want prognostic information than patients, particularly in later disease stages.<sup>13,15,23,24</sup> Also, dyads may base their prognostic perceptions on different data sources, especially since individuals often seek information outside of the physician.<sup>18,25</sup> Furthermore, families in non-Western cultures commonly request physicians to limit prognostic communication to patients.<sup>26,27</sup> Caregivers who want to hide concerns and negative information (i.e., protective buffering) or take control over patients' care to mitigate patient burden (i.e., overprotection) may limit patients' exposure to prognostic information and conceal discordant perceptions.<sup>28</sup> Contrastingly, caregivers who deliberate patients' emotions and information needs regarding cancer (i.e.,

active engagement) may facilitate concordant prognostic perceptions.<sup>28</sup> Additionally, conflicting personal coping styles potentially contribute to discordance in prognostic perceptions; some people may avert confrontational stimuli like prognosis (i.e., avoidance coping) while others seek information to handle stressors (i.e., active coping).<sup>12</sup> Lastly, patients' physical condition is integral in estimating prognosis, and caregivers rely on patients' appearance. When patients exhibit few symptoms, prognostication could be more complicated, leaving room for diverging prognostic perceptions.<sup>29</sup>

While knowledge of patients' and caregivers' *individual* prognostic information preferences and perceptions is increasing, the *agreement* of prognostic information preferences among dyads is largely unstudied. The limited number of dyadic studies on prognostic perceptions paint a confined picture by isolating one aspect of prognosis (i.e., likelihood of cure or life expectancy) and focusing on the consequences of discordance<sup>10,14,22</sup>; the only paper including predictors lacked assessment of *dyadic* drivers.<sup>6</sup> To address these knowledge gaps, our study in the advanced cancer setting sought to:<sup>1</sup> describe the extent of patient-caregiver discordance in prognostic information preferences and<sup>2</sup> prognostic perceptions (i.e., likelihood of cure; 5/2/1 year mortality risk); and<sup>3</sup> explore the (primarily dyadic) factors associated with patient-caregiver discordance in prognostic perceptions (i.e., one-year mortality risk).

## Methods

### Design

This is a secondary analysis of a cross-sectional survey study on prognostic information preferences and prognostic perceptions among patients with advanced cancer, caregivers and physicians (PROSPECT, September 2019–June 2021). As the primary outcomes of this paper are patient-caregiver discordance in prognostic information preferences and perceptions, we only included patients from the original sample with a participating caregiver.

### Sample and Procedure

Medical and pulmonary oncologists from seven Dutch (non)academic hospitals selected eligible patients from their outpatient clinic. Eligible patients ( $\geq 18$  years old, proficient in Dutch) had incurable metastatic/inoperable cancer with an estimated median overall survival of  $\leq 12$  months at group-level (at diagnosis of advanced disease or after disease progression; with or without anticancer treatment). Physicians received an overview of all inclusion criteria, which additionally specified when a median overall survival of

≤12 months at group-level was expected per tumor type (i.e., for which type and line of anticancer treatment) based on clinical trials (Table S1, Supplemental files). Eligible patients were orally informed about the study's focus in general terms (i.e., views on illness, treatment, and prospects) and the preferred participation of a primary informal caregiver (≥18 years, proficient in Dutch). Patients were asked to invite a caregiver who was closely involved in the disease trajectory. This could be their intimate partner or, if patients did not have an intimate partner or he/she was unable or unwilling to participate, someone with whom they had a close relationship (regardless of relationship type). Interested patients received a patient information letter by e-mail or postal mail and, if applicable, a tailored version for their caregiver. Both were blinded to prognostic eligibility criteria. After providing written informed consent, patients and caregivers each completed one survey, which was sent by e-mail or postal mail. The research team instructed patients and caregivers to complete the surveys separately from each other. Study invitation was not linked to a specific moment in the disease trajectory; timing of participation could therefore vary. Procedures adhered to the Helsinki Declaration. All medical ethics review boards granted exemption from formal approval (W19\_051#19.073). The predetermined sample size met general rules of thumb (≥10 observations per independent variable) and was sufficiently large to establish proportions of discordance.<sup>30</sup>

### Measures

Surveys were composed by the research team (i.e., medical oncologists and communication researchers) and pilot tested among  $n = 8$  patients and  $n = 8$  caregivers from the target population to optimize comprehensibility, emotional load, and length.

**Descriptive Variables.** Patients and caregivers reported their sex (male/female), age, education (low/medium/high), nationality (Dutch/other) and religiosity (yes/no). Physicians reported patients' date of diagnosis of metastatic/inoperable cancer to calculate time since diagnosis, tumor type and line of systemic treatment during study participation (none/first/second/≥third). The category "none" included patients who previously received systemic treatment, and/or received nonsystemic treatment (e.g., radiotherapy) during study participation, and/or would receive (non)systemic treatment in the future.

**Dependent Variables.** We assessed patients' and caregivers' prognostic information preferences regarding the likelihood of cure and mortality risk (5/2/1 year) with four items on a binary scale (yes/no). We introduced these items with the phrase: "Are you a person who

wants to know?" followed by, for example, "the likelihood of (the patient) dying from your (his/her) cancer within one year from now." Items were self-developed, in absence of standardized instruments, yet inspired by prior Australian studies.<sup>31,32</sup> Patient-caregiver discordance in prognostic information preferences was operationalized by comparing patients' and caregivers' preferences (Table 1).

We measured patients' and caregivers' prognostic perceptions of the likelihood of cure and mortality risk (5/2/1 year) with four items. We introduced these items with the phrase: "Based on your understanding about your (the 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 (the patient) will die from your (his/her) cancer within one year from now." Scores ranged from 1–7 (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%). Items were self-developed, in absence of standardized instruments, yet inspired by Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) studies.<sup>33–37</sup> Patient-caregiver discordance in prognostic perceptions was operationalized by comparing patients' and caregivers' perceptions (Table 1).

**Independent Variables.** In response to literature gaps, we used a dyadic perspective to predict patient-caregiver discordance in prognostic perceptions. Hence, as independent variables, we selected factors that provided information about how people experience and deal with cancer and the associated prognosis within dyads.

We assessed patients' and caregivers' main source of prognostic perceptions (healthcare provider/family or friends/support group/internet/books/feeling or personal beliefs), and compared answers within dyads to operationalize patient-caregiver discordance in main source of prognostic perceptions (Table 1).

We measured patients' and caregivers' avoidance coping and active coping with the eight-item avoidance-subscale (e.g., "Avoiding difficult situations") and the seven-item active tackling-subscale (e.g., "Using a direct approach to solve the problem") of the Utrecht Coping List (UCL).<sup>38</sup> Items were scored (1–4, "never" to "very often") and summed per subscale. Sum scores were classified as (very) low, average, or (very) high based on normative scores among the general population (18–65 years), specified by gender.<sup>38</sup> We operationalized patient-caregiver discordance in avoidance coping and active coping by comparing patients' and caregivers' classifications (Table 1).

Patients reported their health-related quality of life (HR-QL) with the two-item Global Health Status-subscale of the EORTC-Quality-of-Life-Questionnaire

*Table 1*  
**Operationalization of Dyadic Variables (Patient-Caregiver Discordance in Prognostic Information Preferences, Prognostic Perceptions, Main Source of Prognostic Perceptions, Avoidance Coping and Active Coping)**

			Patient	Caregiver	
<b>Prognostic information preferences</b> <i>Likelihood of cure</i> One item: "Are you a person who wants to know the likelihood of (the patient) being cured from your (his/her) cancer?" <i>Mortality risk (5/2/1 yr)</i> Three items: "Are you a person who wants to know the likelihood of (the patient) dying from your (his/her) cancer within 5/2/1 yr(s) from now?"	<b>Discordance</b>	<b>Patient prefers prognostic information, caregiver does not</b>	<i>Likelihood of cure and five-, two-, one-year mortality risk</i> Answer: "Yes, I prefer to know."	<i>Likelihood of cure and five-, two-, one-year mortality risk</i> Answer: "No, I prefer not to know."	
	<b>Concordance</b>	<b>Caregiver prefers prognostic information, patient does not</b>	<i>Likelihood of cure and five-, two-, one-year mortality risk</i> Answer: "No, I prefer not to know."	<i>Likelihood of cure and five-, two-, one-year mortality risk</i> Answer: "Yes, I prefer to know."	
		<b>Patient and caregiver prefer prognostic information</b>	<i>Likelihood of cure and five-, two-, one-year mortality risk</i> Answer: "Yes, I prefer to know."	<i>Likelihood of cure and five-, two-, one-year mortality risk</i> Answer: "Yes, I prefer to know."	
		<b>Patient and caregiver do not prefer prognostic information</b>	<i>Likelihood of cure and five-, two-, one-year mortality risk</i> Answer: "No, I prefer not to know."	<i>Likelihood of cure and five-, two-, one-year mortality risk</i> Answer: "No, I prefer not to know."	
<b>Prognostic perceptions</b> <i>Likelihood of cure</i> One item: "Based on your understanding about your (the patient's) illness, your (his/her) health in general and the treatments you are (he/she is) receiving, how likely is it that your (the patient's) cancer will be cured?" <i>Mortality risk (5/2/1 yr)</i> Three items: "Based on your understanding about your (the patient's) illness, your (his/her) health in general and the treatments you are (he/she is) receiving, how likely is it that you (the patient) will die from your (his/her) cancer within 5/2/1 yr(s) from now?"	<b>Discordance</b>	<b>Patient is optimistic, caregiver is pessimistic</b>	<i>Likelihood of cure</i> Answer: "Possible (60%–40%)," "Likely (75%–60%)," "Very likely (90%–75%)," or "Extremely likely (100%–90%)." <i>Five-, two-, one-year mortality risk</i> Answer: "Unlikely (25%–40%)," "Very unlikely (10%–25%)," or "Extremely unlikely (0%–10%)."	<i>Likelihood of cure</i> Answer: "Unlikely (40%–25%)," "Very unlikely (25%–10%)," or "Extremely unlikely (10%–0%)." <i>Five-, two-, one-year mortality risk</i> Answer: "Possible (40%–60%)," "Likely (60%–75%)," "Very likely (75%–90%)," or "Extremely likely (90%–100%)."	
		<b>Caregiver is optimistic, patient is pessimistic</b>	<i>Likelihood of cure</i> Answer: "Unlikely (40%–25%)," "Very unlikely (25%–10%)," or "Extremely unlikely (10%–0%)." <i>Five-, two-, one-year mortality risk</i> Answer: "Possible (40%–60%)," "Likely (60%–75%)," "Very likely (75%–90%)," or "Extremely likely (90%–100%)."	<i>Likelihood of cure</i> Answer: "Possible (60%–40%)," "Likely (75%–60%)," "Very likely (90%–75%)," or "Extremely likely (100%–90%)." <i>Five-, two-, one-year mortality risk</i> Answer: "Unlikely (25%–40%)," "Very unlikely (10%–25%)," or "Extremely unlikely (0%–10%)."	
	<b>Concordance</b>	<b>Patient and caregiver are pessimistic</b>	<i>Likelihood of cure</i> Answer: "Unlikely (40%–25%)," "Very unlikely (25%–10%)," or "Extremely unlikely (10%–0%)." <i>Five-, two-, one-year mortality risk</i> Answer: "Possible (40%–60%)," "Likely (60%–75%)," "Very likely (75%–90%)," or "Extremely likely (90%–100%)."	<i>Likelihood of cure</i> Answer: "Unlikely (40%–25%)," "Very unlikely (25%–10%)," or "Extremely unlikely (10%–0%)." <i>Five-, two-, one-year mortality risk</i> Answer: "Possible (40%–60%)," "Likely (60%–75%)," "Very likely (75%–90%)," or "Extremely likely (90%–100%)."	
		<b>Patient and caregiver are optimistic</b>	<i>Likelihood of cure</i> Answer: "Possible (60%–40%)," "Likely (75%–60%)," "Very likely (90%–75%)," or "Extremely likely (100%–90%)." <i>Five-, two-, one-year mortality risk</i> Answer: "Unlikely (25%–40%)," "Very unlikely (10%–25%)," or "Extremely unlikely (0%–10%)."	<i>Likelihood of cure</i> Answer: "Possible (60%–40%)," "Likely (75%–60%)," "Very likely (90%–75%)," or "Extremely likely (100%–90%)." <i>Five-, two-, one-year mortality risk</i> Answer: "Unlikely (25%–40%)," "Very unlikely (10%–25%)," or "Extremely unlikely (0%–10%)."	

(Continued)

Table 1  
Continued

	Patient	Caregiver
<b>Main source of prognostic perceptions</b> One item: "On what information source do you base your answers to the questions about your (the patient's) prognosis mainly?"	<b>Discordance</b>	Patients and caregivers choose a <i>different</i> answer: "healthcare provider," "family or friends," "support group," "internet," "books," or "feeling or personal beliefs."
	<b>Concordance</b>	Patients and caregivers choose the <i>same</i> answer: "healthcare provider," "family or friends," "support group," "internet," "books," or "feeling or personal beliefs."
<b>Avoidance coping</b> Example item: "Avoiding difficult situations."	<b>Discordance<sup>a</sup></b>	(Very) low scores (males, $\leq 11$ ; females, $\leq 11$ ). (Very) low scores (males, $\leq 11$ ; females, $\leq 11$ ). Average scores (males, 12–17; females, 12–16). Average scores (males, 12–17; females, 12–16). (Very) high scores (males, $\geq 18$ ; females, $\geq 17$ ). (Very) high scores (males, $\geq 18$ ; females, $\geq 17$ ). (Very) low scores (males, $\leq 11$ ; females, $\leq 11$ ). Average scores (males, 12–17; females, 12–16). (Very) low scores (males, $\leq 11$ ; females, $\leq 11$ ). Average scores (males, 12–17; females, 12–16). (Very) high scores (males, $\geq 18$ ; females, $\geq 17$ ). Average scores (males, 15–20; females, 16–20).
	<b>Concordance<sup>a</sup></b>	(Very) low scores (males, $\leq 11$ ; females, $\leq 11$ ). Average scores (males, 12–17; females, 12–16). (Very) high scores (males, $\geq 18$ ; females, $\geq 17$ ). Average scores (males, 12–17; females, 12–16). (Very) high scores (males, $\geq 18$ ; females, $\geq 17$ ). Average scores (males, 15–20; females, 16–20).
<b>Active coping</b> Example item: "Using a direct approach to solve the problem."	<b>Discordance<sup>a</sup></b>	(Very) low scores (males, $\leq 14$ ; females, $\leq 15$ ). Average scores (males, 15–20; females, 16–20). Average scores (males, 15–20; females, 16–20). (Very) high scores (males, $\geq 21$ ; females, $\geq 21$ ). (Very) high scores (males, $\geq 21$ ; females, $\geq 21$ ). (Very) low scores (males, $\leq 14$ ; females, $\leq 15$ ). Average scores (males, 15–20; females, 16–20). (Very) high scores (males, $\geq 21$ ; females, $\geq 21$ ). Average scores (males, 15–20; females, 16–20).
	<b>Concordance<sup>a</sup></b>	(Very) low scores (males, $\leq 14$ ; females, $\leq 15$ ). Average scores (males, 15–20; females, 16–20). (Very) high scores (males, $\geq 21$ ; females, $\geq 21$ ). Average scores (males, 15–20; females, 16–20). (Very) high scores (males, $\geq 21$ ; females, $\geq 21$ ).

<sup>a</sup>Based on normative scores of the general population (18–65 years) on the avoidance-and active tackling-subcales of the Utrecht Coping List (UCL), specified by gender.<sup>38</sup>

(EORTC-QLQ-C30). Items (i.e., “How would you rate your overall<sup>1</sup> health and<sup>2</sup> quality of life during the past week?”) were scored from 1–7 (“very poor” to “excellent”). We assessed patients’ *physical functioning* with the five-item physical functioning-subscale of the EORTC-QLQ-C30. Items (i.e., “Do you need help with eating, dressing, washing yourself, or using the toilet?”) were scored from 1–4 (“not at all” to “very much”). All EORTC-QLQ-C30 scores were transformed to a 0–100 scale.<sup>39</sup>

Caregivers reported their *relationship with the patient* (being a partner/parent/child/sibling/uncle/aunt/cousin/friend/neighbor/other), yet we clustered answers (partner/child/other) to limit the number of statistical comparisons. We measured caregivers’ style of providing support with three subscales of the 19-item Active Engagement, Protective Buffering, and Overprotection-Questionnaire (ABO): *active engagement* (five items, e.g., “I ask the patient how he or she feels”), *protective buffering* (eight items, e.g., “I try to hide my worries about the patient”) and *overprotection* (six items, e.g., “When it comes down to it, I think that the patient does not know what’s right for him or her”).<sup>40</sup> Items were scored (1–5, “I do not think that” to “I very strongly think that”), summed and averaged per subscale.

### Statistical Analysis

We calculated frequencies to present the extent of patient-caregiver discordance (four categories; Table 1) in information preferences and perceptions regarding the likelihood of cure and five-, one- and one-year mortality risk (aim 1 and 2).

We calculated descriptive statistics for factors that were hypothesized to relate to patient-caregiver discordance in prognostic perceptions, distinguished by concordant and discordant dyads. To explore which factors were significantly associated with patient-caregiver discordance in prognostic perceptions (aim 3), we first tested the need for multilevel binomial logistic regression analyses (intraclass correlations  $\geq 10\%$ ).<sup>41</sup> Multilevel analyses deal with clustered observations, missing data (using maximum likelihood estimation), and multiple testing problems.<sup>42</sup> Next, we built an unconditional model (i.e., without predictors) with patient-caregiver discordance in prognostic perceptions as the dependent variable (0 = concordance, 1 = discordance). Level one (dyads) and level two (physicians) were kept if likelihood-ratio chi-square tests were significant ( $\alpha = .05$ ) and intraclass correlations were  $\geq 10\%$ .<sup>41</sup> Subsequently, we built conditional models (i.e., with predictors) by adding fixed factors one by one, which were selected on theoretical grounds (patient-caregiver discordance in prognostic information preferences, main source of prognostic perceptions, avoidance coping and active coping;

patients’ HR-QL and physical functioning; caregivers’ relationship with the patient, active engagement, protective buffering and overprotection; intercorrelations  $r < .80$ ). During model building, we tested variables at a liberal  $\alpha$ -level of 20%, preventing elimination because of confounding or modification effects. We tested the resultant model at an  $\alpha$ -level of 5%, eliminating nonsignificant variables one by one to simplify the final model. Analyses were performed with IBM SPSS Statistics 26.

### Results

PROSPECT included 540 patients and/or caregivers (response rate 62%; Supplemental files, Fig. S1), of whom 412 dyads reported prognostic information preferences and prognostic perceptions. About half of patients was male; the mean age was 64 years (range 26–90 years). Caregivers were more often female (61%;  $n = 250/412$ ) and somewhat younger (mean age 58, range 21–82 years). About three-quarters (77%;  $n = 315/412$ ) of dyads included partner-relationships (Table 2).

#### Patient-Caregiver Discordance in Prognostic Information Preferences (Aim 1)

Few patient-caregiver dyads had discordant information preferences regarding the likelihood of cure (7%;  $n = 29/409$ ); both dyad-members generally wanted to know. In contrast, 24%–25% of dyads had discordant information preferences regarding the five-year ( $n = 104/410$ ), two-year ( $n = 99/409$ ) or one-year ( $n = 102/410$ ) mortality risk (Table 3). Overall, dyads with discordant prognostic information preferences mostly encompassed caregivers with and patients without a wish to know (75%–80%;  $n_{\text{likelihood of cure}} = 23/29$ ,  $n_{5\text{-year mortality}} = 78/104$ ,  $n_{2\text{-year mortality}} = 78/99$ ,  $n_{1\text{-year mortality}} = 82/102$ ). Dyads with concordant preferences mostly encompassed patients and caregivers who both wanted prognostic information (87%–100%;  $n_{\text{likelihood of cure}} = 379/380$ ,  $n_{5\text{-year mortality}} = 270/306$ ,  $n_{2\text{-year mortality}} = 272/310$ ,  $n_{1\text{-year mortality}} = 268/308$ ).

#### Patient-Caregiver Discordance in Prognostic Perceptions (Aim 2)

About 17% of patient-caregiver dyads ( $n = 67/404$ ) had discordant perceptions of the likelihood of cure. Discordance in perceptions of mortality risk varied between 12% and 25% ( $n_{5\text{-year mortality}} = 47/401$ ,  $n_{2\text{-year mortality}} = 76/402$ ,  $n_{1\text{-year mortality}} = 101/401$ ). The shorter the indicated survival time (5/2/1 year), the larger the proportion of dyads with discordant perceptions (Table 4). Overall, dyads with discordant perceptions mostly encompassed patients who were more optimistic about prognosis than caregivers (57%–70%;

Table 2  
Descriptive Factors of Patients and Caregivers

Descriptive Factors	Cronbach's Alpha <sup>a</sup>	Patients	Caregivers
		<i>n</i> = 412	
Sex (male), % ( <i>n</i> )		53.6 (221)	39.3 (162)
Age (yrs), mean ± SD		63.7 ± 11.1	58.3 ± 13.0 <sup>b</sup>
Education, % ( <i>n</i> ) <sup>c</sup>			
Low		38.2 (157) <sup>d</sup>	34.7 (143)
Medium		26.8 (110) <sup>d</sup>	26.9 (111)
High		35.0 (144) <sup>d</sup>	38.3 (158)
Nationality (Dutch), % ( <i>n</i> )		95.9 (395)	96.6 (398)
Religiosity (yes), % ( <i>n</i> ) <sup>e</sup>		40.0 (165)	36.0 (148) <sup>f</sup>
Relationship with the patient, % ( <i>n</i> )			
Caregiver is patient's partner		76.5 (315)	76.5 (315)
Caregiver is patient's child		13.6 (56)	13.6 (56)
Other <sup>g</sup>		10.0 (41)	10.0 (41)
Time since diagnosis (months), mean ± SD		16.9 ± 17.4 <sup>d</sup>	
Line of systemic treatment during study participation			
None		24.0 (98) <sup>h</sup>	
First line		42.9 (175) <sup>h</sup>	
Second line		20.8 (85) <sup>h</sup>	
≥Third line		12.3 (50) <sup>h</sup>	
Tumor type, % ( <i>n</i> )			
Lung		25.5 (105)	
Pleura		6.3 (26)	
Esophagogastric		14.6 (60)	
Pancreatic		7.0 (29)	
Other gastrointestinal		12.1 (50)	
Colorectal		2.7 (11)	
Brain		12.6 (52)	
Gynaecological		10.0 (41)	
Soft tissue		2.7 (11)	
Other (each type <i>n</i> < 10) <sup>i</sup>		6.6 (27)	
Health-related quality of life (EORTC-QLQ-C30 subscale, 0–100), mean ± SD	.88 <sup>d</sup>	63.1 ± 20.9 <sup>d</sup>	
Physical functioning (EORTC-QLQ-C30 subscale, 0–100), mean ± SD	.85 <sup>j</sup>	71.3 ± 22.8 <sup>j</sup>	
Avoidance coping (UCL subscale, 8–32), mean ± SD	.73 <sup>j</sup> –.72 <sup>k</sup>	15.7 ± 3.4 <sup>d</sup>	15.0 ± 3.2 <sup>k</sup>
Active coping (UCL subscale, 7–28), mean ± SD	.82 <sup>l</sup> –.83 <sup>m</sup>	19.8 ± 3.6 <sup>d</sup>	20.6 ± 3.5 <sup>k</sup>
Patient-caregiver discordance in avoidance coping (discordant), % ( <i>n</i> )		54.7 (223) <sup>n</sup>	
Patient-caregiver discordance in active coping (discordant), % ( <i>n</i> )		52.9 (216) <sup>n</sup>	
Active engagement (ABO subscale, 1–5), mean ± SD	.77 <sup>o</sup>		4.3 ± 0.5 <sup>p</sup>
Protective buffering (ABO subscale, 1–5), mean ± SD	.70 <sup>q</sup>		2.5 ± 0.5 <sup>m</sup>
Overprotection (ABO subscale, 1–5), mean ± SD	.77 <sup>b</sup>		2.4 ± 0.7 <sup>o</sup>
Preference to know the likelihood of cure (yes), % ( <i>n</i> )		94.1 (385) <sup>j</sup>	98.3 (405)
Preference to know the five-year mortality risk (yes), % ( <i>n</i> )		72.0 (296) <sup>d</sup>	84.9 (349) <sup>f</sup>
Preference to know the two-year mortality risk (yes), % ( <i>n</i> )		71.3 (293) <sup>d</sup>	85.6 (351) <sup>r</sup>
Preference to know the one-year mortality risk (yes), % ( <i>n</i> )		70.1 (288) <sup>d</sup>	85.4 (351) <sup>f</sup>
Perceived likelihood of cure, % ( <i>n</i> )			
Extremely likely		2.2 (9) <sup>s</sup>	2.9 (12) <sup>r</sup>
Very likely		2.0 (8) <sup>s</sup>	3.2 (13) <sup>r</sup>
Likely		3.0 (12) <sup>s</sup>	2.9 (12) <sup>r</sup>
Possibly		11.8 (48) <sup>s</sup>	7.3 (30) <sup>r</sup>
Unlikely		15.0 (61) <sup>s</sup>	12.9 (53) <sup>r</sup>
Very unlikely		13.1 (53) <sup>s</sup>	16.6 (68) <sup>r</sup>
Extremely unlikely		53.0 (215) <sup>s</sup>	54.1 (222) <sup>r</sup>
Perceived likelihood of dying within five years, % ( <i>n</i> )			
Extremely unlikely		5.4 (22) <sup>t</sup>	2.2 (9) <sup>u</sup>
Very unlikely		2.5 (10) <sup>t</sup>	1.5 (6) <sup>u</sup>
Unlikely		4.4 (18) <sup>t</sup>	3.4 (14) <sup>u</sup>
Possibly		27.3 (111) <sup>t</sup>	27.8 (113) <sup>u</sup>
Likely		11.3 (46) <sup>t</sup>	10.3 (42) <sup>u</sup>
Very likely		15.2 (62) <sup>t</sup>	15.5 (63) <sup>u</sup>
Extremely likely		33.9 (138) <sup>t</sup>	39.2 (159) <sup>u</sup>
Perceived likelihood of dying within two years, % ( <i>n</i> )			
Extremely unlikely		7.4 (30) <sup>t</sup>	3.7 (15) <sup>u</sup>
Very unlikely		6.1 (25) <sup>t</sup>	3.9 (16) <sup>u</sup>
Unlikely		9.3 (38) <sup>t</sup>	7.6 (31) <sup>u</sup>
Possibly		33.7 (137) <sup>t</sup>	36.5 (148) <sup>u</sup>
Likely		9.6 (39) <sup>t</sup>	9.6 (39) <sup>u</sup>
Very likely		14.7 (60) <sup>t</sup>	17.2 (70) <sup>u</sup>
Extremely likely		19.2 (78) <sup>t</sup>	21.4 (87) <sup>u</sup>

(Continued)



Table 2  
Continued

Descriptive Factors	Cronbach's Alpha <sup>a</sup>	Patients	Caregivers
Perceived likelihood of dying within one year, % (n)			
Extremely unlikely		14.0 (57) <sup>f</sup>	8.4 (34) <sup>o</sup>
Very unlikely		11.1 (45) <sup>f</sup>	7.4 (30) <sup>o</sup>
Unlikely		10.6 (43) <sup>f</sup>	12.3 (50) <sup>o</sup>
Possibly		36.6 (149) <sup>f</sup>	41.2 (167) <sup>o</sup>
Likely		7.1 (29) <sup>f</sup>	9.1 (37) <sup>o</sup>
Very likely		8.8 (36) <sup>f</sup>	9.9 (40) <sup>o</sup>
Extremely likely		11.8 (48) <sup>f</sup>	11.6 (47) <sup>o</sup>
Main source of prognostic perceptions, % (n)			
Healthcare provider <sup>v</sup>		63.9 (262) <sup>l</sup>	66.6 (273) <sup>r</sup>
Family or friends		0.2 (1) <sup>l</sup>	1.2 (5) <sup>r</sup>
Support group		1.7 (7) <sup>l</sup>	0.5 (2) <sup>r</sup>
Internet		5.4 (22) <sup>l</sup>	8.5 (35) <sup>r</sup>
Books		0.2 (1) <sup>l</sup>	0.2 (1) <sup>r</sup>
Personal beliefs		28.5 (117) <sup>l</sup>	22.9 (94) <sup>r</sup>
Patient-caregiver discordance in main source of prognostic perceptions (discordant), % (n)		33.1 (135) <sup>n</sup>	

Abbreviations: n, sample size; SD, standard deviation; EORTC-QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Cancer; UCL, Utrecht Coping List; ABO, Active Engagement, Protective Buffering and Overprotection.

<sup>a</sup>Interpretation: <0.50 unacceptable, 0.50–0.60 poor, 0.60–0.70 questionable, 0.70–0.80 acceptable, 0.80–0.90 good, 0.90–1.00 excellent.

<sup>b</sup>Caregivers: n = 401/412 (11 missing).

<sup>c</sup>Low: elementary to low vocational education. Medium: up till medium level vocational education. High: high vocational or academic education.

<sup>d</sup>Patients: n = 411/412 (one missing).

<sup>e</sup>Including Christianity, Islam, Buddhism, Hinduism, Judaism, Humanism, spirituality, and "own belief."

<sup>f</sup>Caregivers: n = 411/412 (one missing).

<sup>g</sup>Including caregivers who are patient's parent, sibling, aunt, uncle, cousin, friend, or neighbour or who have another type of relationship.

<sup>h</sup>Patients: n = 408/412 (four missing).

<sup>i</sup>Including melanoma, head and neck, thyroid, breast, vagina, prostate, bladder, kidney, adrenal cortex, bone, carcinoid, and unknown primary tumors.

<sup>j</sup>Patients: n = 409/412 (three missing).

<sup>k</sup>Caregivers: n = 409/412 (three missing).

<sup>l</sup>Patients: n = 410/412 (two missing).

<sup>m</sup>Caregivers: n = 407/412 (five missing).

<sup>n</sup>Patient-caregiver dyads: n = 408/412 (four missing).

<sup>o</sup>Caregivers: n = 405/412 (seven missing).

<sup>p</sup>Caregivers: n = 408/412 (four missing).

<sup>q</sup>Caregivers: n = 404/412 (eight missing).

<sup>r</sup>Caregivers: n = 410/412 (two missing).

<sup>s</sup>Patients: n = 406/412 (six missing).

<sup>t</sup>Patients: n = 407/412 (five missing).

<sup>u</sup>Caregivers: n = 406/412 (six missing).

<sup>v</sup>Including treating physician, second opinion physician, nurse, general practitioner, or other healthcare provider.

Table 3  
Discordance and Concordance Between Patients' and Caregivers' Information Preferences Regarding Prognosis

Prognostic Information Preferences	Likelihood of Cure % (n)	five-Year mortality Risk % (n)	two-Year Mortality Risk % (n)	One-Year Mortality Risk % (n)
<b>Discordance</b>	<b>7.1 (29/409)</b>	<b>25.4 (104/410)</b>	<b>24.2 (99/409)</b>	<b>24.9 (102/410)</b>
Patient prefers prognostic information, caregiver does not	1.5 (6/409)	6.3 (26/410)	5.1 (21/409)	4.9 (20/410)
Proportion within discordant dyads	20.7 (6/29)	25.0 (26/104)	21.2 (21/99)	19.6 (20/102)
Caregiver prefers prognostic information, patient does not	5.6 (23/409)	19.0 (78/410)	19.1 (78/409)	20.0 (82/410)
Proportion within discordant dyads	79.3 (23/29)	75.0 (78/104)	78.8 (78/99)	80.4 (82/102)
<b>Concordance</b>	<b>92.9 (380/409)</b>	<b>74.6 (306/410)</b>	<b>75.8 (310/409)</b>	<b>75.1 (308/410)</b>
Patient and caregiver prefer prognostic information	92.7 (379/409)	65.9 (270/410)	66.5 (272/409)	65.4 (268/410)
Proportion within concordant dyads	99.7 (379/380)	88.2 (270/306)	87.7 (272/310)	87.0 (268/308)
Patient and caregiver do not prefer prognostic information	0.2 (1/409)	8.8 (36/410)	9.3 (38/409)	9.8 (40/410)
Proportion within concordant dyads	0.3 (1/380)	11.8 (36/306)	12.3 (38/310)	13.0 (40/308)
<b>Total sample</b>	<b>100% (409)</b>	<b>100% (410)</b>	<b>100% (409)</b>	<b>100% (410)</b>

Abbreviation: n, sample size.

Table 4  
Discordance and Concordance Between Patients' and Caregivers' Perceptions of Prognosis

Prognostic Perceptions	Likelihood of Cure % (n)	Five-Year Mortality Risk % (n)	Two-Year Mortality Risk % (n)	One-Year Mortality Risk % (n)
<b>Discordance</b>	<b>16.6 (67/404)</b>	<b>11.7 (47/401)</b>	<b>18.9 (76/402)</b>	<b>25.2 (101/401)</b>
Patient is optimistic, caregiver is pessimistic	9.4 (38/404)	8.2 (33/401)	13.2 (53/402)	16.2 (65/401)
Proportion within discordant dyads	56.7 (38/67)	70.2 (33/47)	69.7 (53/76)	64.4 (65/101)
Caregiver is optimistic, patient is pessimistic	7.2 (29/404)	3.5 (14/401)	5.7 (23/402)	9.0 (36/401)
Proportion within discordant dyads	43.3 (29/67)	29.8 (14/47)	30.3 (23/76)	35.6 (36/101)
<b>Concordance</b>	<b>83.4 (337/404)</b>	<b>88.3 (354/401)</b>	<b>81.1 (326/402)</b>	<b>74.8 (300/401)</b>
Patient and caregiver are pessimistic	74.0 (299/404)	84.8 (340/401)	71.6 (288/402)	56.1 (225/401)
Proportion within concordant dyads	88.7 (299/337)	96.0 (340/354)	88.3 (288/326)	75.0 (225/300)
Patient and caregiver are optimistic	9.4 (38/404)	3.5 (14/401)	9.5 (38/402)	18.7 (75/401)
Proportion within concordant dyads	11.3 (38/337)	4.0 (14/354)	11.7 (38/326)	25.0 (75/300)
<b>Total</b>	<b>100% (404)</b>	<b>100% (401)</b>	<b>100% (402)</b>	<b>100% (401)</b>

Abbreviations: n, sample size.

$n_{\text{likelihood of cure}} = 38/67$ ,  $n_{5\text{-year mortality}} = 33/47$ ,  $n_{2\text{-year mortality}} = 53/76$ ,  $n_{1\text{-year mortality}} = 65/101$ ). Dyads with concordant perceptions mostly encompassed patients and caregivers who both were pessimistic about patients' prognosis (75%–96%;  $n_{\text{likelihood of cure}} = 299/337$ ,  $n_{5\text{-year mortality}} = 340/354$ ,  $n_{2\text{-year mortality}} = 288/326$ ,  $n_{1\text{-year mortality}} = 225/300$ ). Still, our findings on concordance suggest that the proportion of dyads with optimistic perceptions is larger when the indicated survival time is shorter (5/2/1 year).

### Factors Associated With Patient-Caregiver Discordance in Prognostic Perceptions (Aim 3)

Table 5 describes the factors that were hypothesized to relate to patient-caregiver discordance in prognostic perceptions, for concordant and discordant dyads separately. Multilevel analyses showed that patient-caregiver dyads with discordant prognostic information preferences were significantly more likely to have discordant perceptions of the one-year mortality risk than dyads with concordant information preferences (OR = 1.66,

Table 5

### Descriptive Statistics of Factors Potentially Associated With Patient-Caregiver Discordance in Prognostic Perceptions (Included in Multilevel Analyses)

Factor	Patient-Caregiver Dyads With Discordant Perceptions of the One-Year Mortality Risk n = 99	Patient-Caregiver Dyads With Concordant Perceptions of the One-Year Mortality Risk n = 298
Relationship with the patient, % (n)		
Caregiver is patient's partner	77.8 (77)	75.8 (226)
Caregiver is patient's child	12.1 (12)	14.1 (42)
Other <sup>a</sup>	10.1 (10)	10.1 (30)
Health-related quality of life (EORTC-QLQ-C30 subscale, 0–100), mean ± SD	66.3 ± 19.5	61.7 ± 21.5
Physical functioning (EORTC-QLQ-C30 subscale, 0–100), mean ± SD	76.4 ± 17.3	69.9 ± 24.2
Patient-caregiver discordance in avoidance coping (discordant), % (n)	49.0 (48) <sup>b</sup>	56.9 (169) <sup>b</sup>
Patient-caregiver discordance in active coping (discordant), % (n)	46.9 (46) <sup>b</sup>	54.5 (162) <sup>b</sup>
Active engagement (ABO subscale, 1–5), mean ± SD	4.3 ± 0.5 <sup>b</sup>	4.4 ± 0.5 <sup>c</sup>
Protective buffering (ABO subscale, 1–5), mean ± SD	2.5 ± 0.6 <sup>c</sup>	2.4 ± 0.5 <sup>c</sup>
Overprotection (ABO subscale, 1–5), mean ± SD	2.4 ± 0.7 <sup>b</sup>	2.4 ± 0.7 <sup>d</sup>
Patient-caregiver discordance in preference to know the one-year mortality risk (discordant), % (n)	32.3 (32)	22.1 (66)
Patient-caregiver discordance in main source of prognostic perceptions (discordant), % (n)	41.4 (41)	30.6 (91) <sup>b</sup>

Abbreviations: n, sample size; SD, standard deviation; EORTC-QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Cancer; ABO, Active Engagement, Protective Buffering and Overprotection.

<sup>a</sup>Including caregivers who are patient's parent, sibling, aunt, uncle, cousin, friend, or neighbor or who have another type of relationship.

<sup>b</sup>Patient-caregiver dyads with discordant prognostic perceptions: n = 98/99 (one missing). Patient-caregiver dyads with concordant prognostic perceptions: n = 297/298 (one missing).

<sup>c</sup>Patient-caregiver dyads with discordant prognostic perceptions: n = 97/99 (2 missing). Patient-caregiver dyads with concordant prognostic perceptions: n = 296/298 (2 missing).

<sup>d</sup>Patient-caregiver dyads with concordant prognostic perceptions: n = 293/298 (5 missing).

Table 6  
Mixed-Effects Binomial Logistic Regression Model With Predictors of Patient-Caregiver Discordance in Perceptions of the One-Year Mortality Risk<sup>a</sup>

Patient-caregiver discordance in perceptions of the one-year mortality risk	Final Model <sup>b</sup> n = 397 <sup>c</sup>				
	B	P	Exp(b)	Lower CI Exp(b)	Upper CI Exp(b)
Intercept	-2.228	0.000 <sup>g</sup>	0.108	0.050	0.233
Patients' physical functioning (EORTC-QLQ-C30)	0.013	0.008 <sup>f</sup>	1.013	1.003	1.022
Patient-caregiver dyads' information preference for one-year mortality risk (ref = concordant) <sup>d</sup>	0.506	0.040 <sup>e</sup>	1.659	1.022	2.692

Abbreviations: n, sample size; B, unstandardized coefficient; P, significance; Exp(b), exponentiation of the B coefficient, which is an odds ratio; CI Exp(b), 95% confidence interval of exponentiation of the B coefficient; ref, reference category; EORTC-QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Cancer; ICC, intraclass correlation.

<sup>a</sup>0 = Concordance between patients' and caregivers' perceptions of prognosis, 1 = Discordance between patients' and caregivers' perceptions of prognosis.

<sup>b</sup>We used a mixed-effects binomial logistic regression model with two levels, because of an ICC = 9.8%. Intercorrelations between predictors were <.54. Patient-caregiver discordance in active coping and caregivers' relationship with the patient, active engagement, and protective buffering were omitted from the model ( $P > 0.20$ ). To simplify the final model, patients' health-related quality of life, patient-caregiver discordance in avoidance coping, caregivers' overprotection, and patient-caregiver discordance in main source of prognostic perceptions ( $P > 0.05$ ) were eliminated. Associations of patients' physical functioning and patient-caregiver discordance in prognostic information preferences with patient-caregiver discordance in prognostic perceptions remained significant in models that controlled for caregivers' relationship with the patient.

<sup>c</sup>Patient-caregiver dyads: n = 397/412 (11 missing on dependent variable, four missing on independent variables).

<sup>d</sup>0 = Concordance between patients' and caregivers' prognostic information preference, 1 = Discordance between patients' and caregivers' prognostic information preference.

<sup>e</sup>Significant at  $P < 0.05$ .

<sup>f</sup>Significant at  $P < 0.01$ .

<sup>g</sup>Significant at  $P < 0.001$ .

95% CI [1.02; 2.69,  $P < 0.05$ ; Table 6). Additionally, dyads in which patients had better physical functioning were significantly more likely to have discordant perceptions of the one-year mortality risk (OR = 1.01, 95% CI [1.00; 1.02],  $P < 0.01$ ). There were no significant associations of patient-caregiver discordance in prognostic perceptions with discordance in the main source of prognostic perceptions, avoidance coping or active coping, nor with patients' health-related quality of life or caregivers' relationship with the patient (partner/child/other), active engagement, protective buffering, or overprotection.

## Discussion

This is the first study among patient-caregiver dyads to reveal that up to 25% have discordant preferences for information about patients' mortality risk. Like most Western literature on dyad-members' individual information preferences suggests, we observed that patients are less likely to want prognostic information than caregivers.<sup>13,43</sup> According to prior studies, patients', and caregivers' readiness to deal with prognostic information could differ.<sup>44,45</sup> Being confronted with one's own mortality is undeniably confrontational, likely triggering coping mechanisms, and emotions. For some patients, prognostic ignorance is existentially essential to endure sickness and treatment.<sup>46</sup> It is plausible that patients' level of acceptance of the terminal diagnosis affects their desire for prognostic information. Caregivers, however, possibly approach prognostic information more instrumentally, as they are managing patient's care and daily tasks as well as their own future.<sup>23,47</sup>

Up to one-fourth of patient-caregiver dyads had discordant prognostic perceptions. Such discordance was more likely when predicting death within a shorter timeframe (5/2/1 year). Dyad-members potentially felt most uncertain about the one-year mortality risk, leaving room for diverging perceptions. Considering the median survival of  $\leq 12$  months in our sample, death within five years is more plausible and therefore perhaps harder to disagree on. Alternatively, our measures captured psychological processes (e.g., disbelief, hope, sadness) rather than knowledge of prognosis only. These psychological processes—affecting prognostic perceptions—might be most influential when confronted with closer proximity to death. In line with literature, we showed that caregivers are generally more pessimistic about prognosis than patients.<sup>20,21</sup> Caregivers' "outsider" perspective possibly facilitates more objective prognostication. Interestingly, previous research points out that cognitive prognostic understanding does not necessarily imply emotional preparedness for death, and hope can exist alongside recognition of terminal cancer.<sup>9,48,49</sup>

Inspecting both prognostic information preferences and prognostic perceptions, it is remarkable that nearly all dyads agreed on wanting to know the likelihood of cure, yet they relatively often had different understandings of advanced cancers' curability. Potentially, hope for any chance of cure continues to live as long as patients receive treatment.<sup>50,51</sup> Contrarily, one-quarter of dyads disagreed on wanting five-year mortality risk information, yet they relatively often agreed on the likelihood of dying within this timeframe. When contemplating a fairly distant future, patients and caregivers seemingly both adopt a

more realistic perspective, independent of *wanting* prognostic information. These hypotheses are speculative; additional research needs to clarify how and why patients and caregivers differentially perceive various types of prognostic information.

We are the first to demonstrate that discordant prognostic information preferences among patient-caregiver dyads could impede a shared understanding of prognosis. We did not find associations of discordant information sources with discordant prognostic perceptions, suggesting that agreement about *if* dyad-members want prognostic information is more influential than acquiring information from the *same* source. However, causality of the effect of discordant information preferences cannot be inferred. It could also be that dyads who think about patients' prospects differently therefore have different preferences for prognostic information. Associations with discordance in personal coping styles (i.e., active and avoidance coping) or caregivers' styles of support (i.e., active engagement, protective buffering, overprotection) were absent; possibly these were accounted for by the effect of discordant prognostic information preferences. An alternative explanation might be that our measures assessed reactions to problems in general—not cancer or prognosis in particular. Although patients' overall HR-QL had no influence, we showed that patient-caregiver dyads are more likely to perceive the one-year mortality risk discordantly when patient's physical functioning is relatively good. It is conceivable that prognostication is more difficult when indicators of physical deterioration are lacking, and patients still participate in daily activities.<sup>29</sup>

Discordance in prognostic information preferences and perceptions could complicate patient-caregiver communication about the disease and the future (and vice versa). When caregivers who prefer prognostic information cannot discuss prognosis with patients who favor ignorance, it is challenging to prepare emotionally and practically (e.g., planning a funeral) for the end-of-life together.<sup>2,5,6,22</sup> For caregivers specifically, being unprepared for patient's death may contribute to complicated grief during bereavement.<sup>52,53</sup> Also, discordance among patient-caregiver dyads adds complexity to clinical interactions. Physicians may need to navigate conflicting prognostic information needs and balance differing prognostic perceptions. Deliberating discontinuation of aggressive anticancer treatment, for example, seems difficult if one dyad-member perceives prognosis optimistically.<sup>10,14,19</sup>

Open dyadic communication could increase intimacy, satisfaction with the relationship and patient care, and reduce interpersonal conflict.<sup>2,5-8,11</sup> For physicians, it might be helpful to explain that prognostic information preferences and perceptions can differ from person to person. Physicians may explicitly ask

what patients and caregivers (want to) know about prognosis and explore *if* and *why* there are differences. Such communication allows awareness of discordance and deliberation of how this could be handled. While acknowledging both dyad-members' viewpoints, physicians may explicate their primary responsibility for meeting patients' information needs, given the therapeutic relationship.<sup>54</sup> If desired, accurate prognostic estimates should be delivered empathetically; adding multiple survival scenarios (e.g., best- and worstcase) might help balancing realism with hope and allows coexistence of different prognostic perceptions.<sup>24,55</sup> If patients reject prognostic discussions, caregivers could share their thoughts with other supportive people, which is shown to relieve distress in both dyad-members.<sup>8</sup> These complex situations nonetheless raise ethical—and culturally sensitive—questions about the degree to which physicians' responsibility extends beyond the patient.<sup>54</sup> Besides tailoring prognostic information, physicians may highlight that dyadic open communication has emotional and practical benefits. To better understand dyads' communication patterns and ultimately guide them in coping with cancer together, assistance of a nurse or medical psychologist seems advisable.<sup>8</sup> In this regard, policy makers may focus on developing couple-focused interventions to stimulate communication about dyadic coping with cancer, including communication about differences in information needs and prognostic perceptions. Previous work demonstrated that simple tools such as question prompt lists can promote prognostic discussions among advanced cancer patients, caregivers, and physicians.<sup>56</sup>

Our research has limitations. First, our measures of prognostic information preferences and prognostic perceptions were nonvalidated. Second, our operationalization of discordance in prognostic perceptions (i.e., dichotomization of seven-point scales) implies that there is variation regarding how far apart dyad-members' discordant estimates are. Yet, we chose this method to reveal if patient-caregiver dyads agreed about prognosis on a basic, "gist" level, preventing overestimation of discordance rates by incorporating minor differences. Besides, we cannot draw conclusions about the accuracy of prognostic perceptions, as we did not include physicians' estimates or actual survival data in our analyses. Third, our secondary analyses did not include measurements of patient-caregiver communication about prognosis or physicians' prognostic (non)disclosure to dyads, which both may contribute to patient-caregiver discordance in prognostic perceptions in reality. Last, the study's Dutch setting restricts generalizability and its cross-sectional nature cannot determine causality.

Future quantitative research may investigate the unique drivers of patients' or caregivers' more optimistic prognostic perceptions, considering individual coping

styles, fighting spirit, death acceptance, and denial as predictors. Longitudinal survey studies could reveal if, how and why patients' and caregivers' shared understanding of prognosis may change over time. Qualitative research (e.g., ethnography, interviews) may uncover how dyads communicate about prognosis, whether they are aware of possibly discordant prognostic perceptions, and how dyads deal with prognostic discordance. Lastly, while this study did not find associations with relationship type, it would be interesting to explore if prognostic communication is different within dyads who are intimate partners opposed to other loved ones.

Strengths include the investigation of prognostic information preferences and perceptions within patient-caregiver dyads rather than individuals, among a relatively large sample. We gained thorough insight into patients' and caregivers' shared understanding of prognosis by examining multiple aspects of prognosis. Finally, we are the first to study dyadic factors that predict patient-caregiver discordance in prognostic perceptions, which provides entry points for interventions to help dyads deal with advanced cancer.

### Conclusion

A substantial proportion of patient-caregiver dyads in advanced cancer care have discordant preferences for prognostic information. Patient-caregiver dyads with discordant prognostic information preferences and dyads including a patient with better physical functioning are more likely to hold discordant prognostic perceptions. Physicians should gauge patients' and caregivers' prognostic information preferences and prognostic perceptions, and address the potential discordance.

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All authors declare no conflicts of interest.

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### Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:[10.1016/j.jpainsymman.2023.01.012](https://doi.org/10.1016/j.jpainsymman.2023.01.012).

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*Table S1*  
**Overview of Eligible Tumor Types, Specified by Nontreated and Treated Cancer**

<u>Absence of Disease-Oriented Therapy</u>	<u>Presence of Disease-Oriented Therapy, Inclusion in Case of</u>
Stage IV	
Liver cancer	All lines of systemic therapy
Biliary tract cancer	All lines of systemic therapy
Gall bladder cancer	All lines of systemic therapy
Pancreatic cancer	All lines of systemic therapy
Sarcoma	All lines of systemic therapy
Endometrium cancer	All lines of systemic therapy
Cervix cancer	All lines of systemic therapy
Unknown primary	All lines of systemic therapy
Stomach cancer	All lines of systemic therapy, <i>except</i> first line trastuzumab
Oesophagogastric cancer	All lines of systemic therapy, <i>except</i> first line trastuzumab
Ovarian cancer	Platinum resistant disease
Prostate cancer	Second generation anti-androgen resistant disease <i>or</i> progression after the last line cabazitaxel
Breast cancer	Fourth line of systemic therapy <i>or</i> triple negative disease
Bladder cancer	Second line of systemic therapy
Colorectal cancer	Third line of systemic therapy
Anal cancer	Progression after the first line of systemic therapy
Renal cell cancer	Third line of systemic therapy for MSKCC intermediate <i>or</i> poor risk
Neuroendocrine carcinoma	Second line of systemic therapy
Small cell lung cancer	All lines of systemic therapy
Non–small cell lung cancer without driver mutation	Second line of immuno (chemo) therapy <i>or</i> all lines of chemotherapy
Non–small cell lung cancer with driver mutation	Last line of systemic therapy
Mesothelioma	All lines of systemic therapy
Thymoma	Second line of systemic therapy
Grade IV	
Glioblastoma	Progression after chemo-radiation

This overview is not inclusive. Physicians could include patients with other tumor types, for whom the general inclusion criteria were applicable ( $\geq 18$  years, Dutch language proficiency, diagnosis of metastatic or locally inoperable cancer at least two months before participation, not eligible for therapy with curative intent, median survival of 12 months or less on group-level). Patients could participate when receiving anticancer therapy or comfort care.



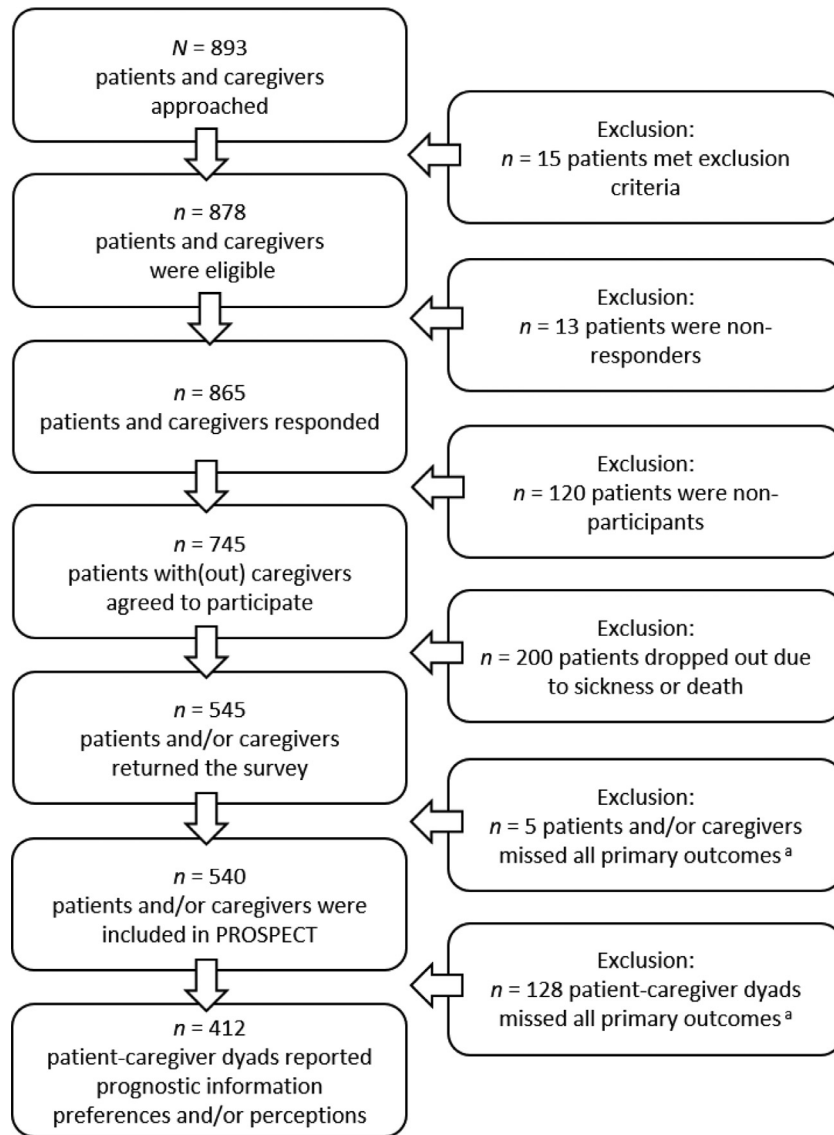


Fig. S1. Flowchart showing inclusion, exclusion and response of the PROSPECT study.

<sup>a</sup>Primary outcomes of PROSPECT were prognostic information preferences and prognostic perceptions.