




# Psychological factors and prognostic communication preferences in advanced cancer: multicentre study

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## ABSTRACT

**Objectives** Communication regarding prognosis to patients with advanced cancer is fundamental for informed medical decision making. Our objective was to analyse (1) the proportion of subjects with advanced cancer who prefer to know their prognosis, (2) the characteristics associated with patients' preference for prognostic information, (3) the psychological factors that impact the preference to know prognosis and (4) the concordance between preference for prognostic information perceived among physicians and patients.

**Methods** A prospective, cross-sectional design was adopted. Data were collected from 748 participants with advanced cancer at 15 tertiary hospitals in Spain. Participants completed the following questionnaires: Mental Adjustment to Cancer; Trust in the Physician; Uncertainty in Illness Scale Patient's Prognostic Preferences.

**Results** Fifty-two per cent of advanced cancer sufferers preferred to know the prognosis of their disease. Compared with participants who preferred not to know, those who did reported more uncertainty, greater satisfaction with their physician and higher scores on positive attitude (all  $p=0.001$ ). Thirty-seven per cent of the physicians believed that patients want to know their prognosis, indicating that they underestimate the number of such patients. No significant differences were found regarding preference to know prognosis as a function of sociodemographic and clinical variables.

**Conclusions** A substantial proportion of individuals with advanced cancer prefer to know the prognosis of their disease. It appears that knowing their prognosis was mainly motivated by a need to maintain a positive attitude, lessen uncertainty and by satisfaction with the physician. It is important to explore patients' preferences for information to offer more personalised communication.

## WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ A clear understanding of prognosis is vital for cancer patients.
- ⇒ Prognostic information aids patients' and families' understanding of illness trajectory.

## WHAT THIS STUDY ADDS

- ⇒ 52% of advanced cancer patients prefer to know their prognosis.
- ⇒ Regarding prognostic information, physicians' perception was aligned with the patients' preference in 37% of the cases.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ Improved disclosure of prognosis leads to better informed decisions for advanced cancer patients.
- ⇒ Personalised communication can improve the quality of care for patients with advanced cancer.

## INTRODUCTION

Increasingly, physicians caring for subjects with advanced cancer are expected both to be up-to-date on the latest diagnostic modalities and staging, treatment regimens and clinical trials, and also to know how to communicate effectively with patients and their families with respect to these issues.<sup>1 2</sup> The physician must translate data that are often inaccurate or contradictory into meaningful, personalised information that enables the patient to make decisions about their life and their body.<sup>1</sup> This requires understanding, compassion, patience and ability.<sup>1 3</sup>

More than 70% of all individuals with advanced cancer want to be informed about their diagnosis and receive detailed prognostic information about their illness,<sup>1 2</sup>

but they would prefer to negotiate the amount, format and timing of the information they receive from their oncologists.<sup>1</sup> Despite wanting to know their prognosis, fewer than 20% have an exact understanding of their disease.<sup>2-4</sup> They tend to underestimate the severity of their diagnosis,<sup>5,6</sup> perceive their prognosis in an overly positive and unrealistic way<sup>7-9</sup> or mistakenly believe that the aim of therapy is to cure their cancer.<sup>8,10</sup>

Prognostic information is important for individuals with advanced cancer because it allows them to make personalised decisions, put the risks and benefits of treatment in the balance,<sup>3,6,10</sup> make future care plans and prepare for the end-of-life.<sup>1,2,11</sup> These subjects' psychological characteristics affect their preference to know the prognosis of their disease.<sup>1,5</sup> Moreover, displaying an avoidant coping style can predispose them to avoiding threatening information.<sup>2</sup> In addition, intolerance of uncertainty can lead them to feel aversion towards uncertain predictions.<sup>12,13</sup> People who score high for positive attitude or who are optimistic prefer not to know their prognosis so as to maintain hope.<sup>12,13</sup> In this regard, the most confident patients may prefer to trust their physician instead of seeking information.<sup>14,15</sup>

Some studies have demonstrated that more accurate prognostic awareness can be associated with less uncertainty of illness and less anxiety and depression, despite a greater feeling of self-perceived burden,<sup>16,17</sup> while others indicate that being aware that their condition is terminal may generate greater psychological distress, diminish quality of life, increase anxiety and depression and even shorten survival.<sup>14,7</sup> These contradictory results may be due to the fact that the available research has used different, often non-standardised methodologies to assess prognostic awareness.<sup>1,18,19</sup> Furthermore, while some studies have reported correlations between prognostic awareness and age, being female, and lower income, there is a paucity of studies that have analysed the sociodemographic and clinical characteristics of those patients who prefer to know their prognosis.<sup>20,21</sup>

Subjects' limited knowledge concerning prognosis may reflect their preference not to know, although it may also attest to the lack of suitable discussion with their physicians regarding prognosis.<sup>8,11</sup> Physicians may disagree widely with respect to their inclination to talk about prognosis with the people with advanced cancer in their care and the timing for such conversations.<sup>1,22</sup> In a survey of 1137 oncologists, 48% reported communicating prognosis only when the patient expresses specific preferences about having this information.<sup>22</sup> Communicating prognosis requires a balance between providing the person with enough information while not furnishing them with unwanted information.<sup>22</sup> Impediments to disclosing and understanding this information exist on both sides of the physician-patient relationship. Conversations concerning prognosis are technically complex and have a psychological, social and spiritual impact for

the patient.<sup>11,22</sup> Likewise, there are studies that suggest that oncologists rarely explore their patients' information preferences and tend to adapt the information poorly,<sup>23,24</sup> pointing towards physicians finding it difficult to judge people's preferences in this regard.<sup>23,24</sup>

So far as we know, most of the studies surrounding this issue have focused on improving prognostic disclosure by means of guidelines, training, lists of questions, etc. Nonetheless, the characteristics and psychological factors that might affect individuals' preference to know their prognosis must be known, thereby fostering more personalised communication with people with advanced cancer. The aims of this work were to examine (1) the proportion of subjects with advanced cancer that prefer to know their prognosis, (2) the sociodemographic or clinical characteristics associated with patients' preference for prognostic information, (3) the psychological factors (coping strategies, uncertainty of illness, trust in oncologist and relation with physician) that impact the preference to know their prognosis and (4) the concordance between physicians' perception of patients' prognostic information preference and the latter's desire for said information.

## MATERIALS AND METHODS

### Participants and procedures

This was a multicentre, prospective (data collection chronology), cross-sectional study. A consecutive sample of advanced cancer patients was recruited at 15 medical oncology departments at different hospitals in Spain between February 2020 and October 2021. Subjects were selected at their first appointment with the medical oncologist during which their diagnosis, stage of disease, incurable disease status and systemic antineoplastic treatment options were explained.

Inclusion criteria comprised being  $\geq 18$  years of age with histologically confirmed advanced cancer that was not eligible for surgery or other therapy with curative intent. Individuals were excluded if they had a physical ailment, comorbidity and/or age that contraindicated antineoplastic treatment in the opinion of the attending oncologist; that is, heart, lung or kidney diseases, which can increase the risk of complications during treatment; if they had received cancer treatment in the previous 2 years for another advanced cancer, or had any underlying personal, family, sociological and/or medical condition that might impede their ability to participate in the study, such as cognitive impairment that would prevent them from comprehending and thinking through what was asked in the questionnaires, or severe deterioration of general status due to cancer or other causes.

This research was conducted in accordance with current ethical principles. The study comprised the completion of several questionnaires and collection of clinical data from the interview and medical records. Data collection procedures were similar at all hospitals

and data relating to the participants were obtained from the institutions where they received treatment. Participation was voluntary, anonymous and in no way affected patient care. All participants signed informed consent prior to inclusion, which was provided by the medical oncologist. Data were collected and updated by the medical oncologist, through a web-based platform (www.neoetic.is).

### Measures

*Demographic characteristics* was collected using a standardised questionnaire (see online supplemental appendix 1). Cancer and treatment information was obtained from patients' medical records and through interviews with attending oncologists. Performance status was assessed using the Eastern Cooperative Oncology Group (ECOG) performance scale, with a range of values from 0 (asymptomatic) to 5 (deceased). Patients completed the questionnaire at home prior to initiating systemic cancer treatment after receiving it during their initial consultation with the oncologist.

*Patient's prognostic preferences (PPP)* were ascertained by asking them to indicate their preferences as to the information they would like their physician to give them concerning their disease. A survey was conducted to determine their preferences in terms of the amount and type of information they would like to receive about their medical prognosis. The survey included five items, such as whether they would like to know their prognosis or if they prefer their physician to communicate any relevant or uncertain findings. Participants rated these items on a 5-point Likert scale, with higher scores indicating a greater desire for detailed information about their disease prognosis. The internal consistency of the global scores in our sample was Cronbach's  $\alpha=0.82$ .

*Uncertainty of Illness* was gauged using the 5-item, Mishel Uncertainty of Illness Scale (MUIS) validated for the Spanish population.<sup>25 26</sup> This questionnaire appraises reactions to uncertainty, ambiguity and the future. Items are scored on a Likert scale ranging from 1 (subject displays none of the characteristics described in the item) to 5 (person exhibits the highest degree of the characteristic described), yielding total scores of 5–25; higher scores correspond to greater uncertainty. Cronbach's  $\alpha$  was 0.83.<sup>25</sup>

Coping strategies were measured using the Mini Mental Adjustment to Cancer (M-MAC) scale comprising 29 items, which classify four coping strategies: anxious preoccupation, helplessness, positive attitude and cognitive avoidance;<sup>27</sup> the version adapted for Spanish cancer patients was used.<sup>28</sup> Items are rated on a 4-point Likert scale; the higher the score, the better the coping strategies. Scores for the Spanish version ( $\omega$ ) range from 0.76 to 0.90.<sup>28</sup>

*Relation with physician* was quantified using the Scale to Assess Therapeutic Relationship (STAR-P). The STAR-P was especially developed to investigate

the therapeutic alliance between patient and physician.<sup>29</sup> STAR consists of 12 items, each one rated on a five-point Likert scale from 0 (never) to 4 (always); the higher the score, the better the relationship between patient and physician. According to Gairing *et al*,<sup>29</sup> the internal consistency of the total scores is high, which was also noted in our sample (Cronbach's  $\alpha=0.85$ ).

*Trust* was evaluated using the short form of the Trust in Oncologist Scale (TiOS-SF). The 5-item TiOS-SF<sup>30</sup> assessed whether the physician was perceived as inspiring trust. Each item was rated on a five-point Likert scale, with higher scores indicating greater trust. Overall, the reliability of the TiOS-SF overall was high ( $\alpha = 0.92$ ).<sup>30</sup>

### Data analysis

Descriptive statistics for demographic and other variables were expressed as mean, SD, number (N) and percentage (%) as appropriate. To identify patients with similar patterns of preference for knowledge regarding prognosis, a cluster analysis was conducted. Clustering variables comprised the PPP items. Given that clustering requires valid values for all variables, subjects with any missing PPP values were eliminated. A final sample of  $n=863$  was used for the cluster analysis. We performed a k-means method using Euclidean distances between observations to estimate clusters and Ward's hierarchical clustering method,<sup>31</sup> where the distance between two clusters is defined as the squared error criterion. In all instances, the distances were computed from the raw data to incorporate the elevation, scatter and shape of the subjects' profiles.<sup>32 33</sup>  $\chi^2$  analyses were performed to evaluate differences in demographic, clinical and psychological characteristics among the prognosis profiles. Analysis of variance appraised differences in psychological characteristics among across profiles. Bonferroni correction was used for post hoc contrast. Eta squared ( $\eta^2$ ) quantified effect size in continuous variables and ranges from 0 to 1, with  $\eta^2 \sim 0.01$  for a small,  $\eta^2 \sim 0.06$  for a medium and  $\eta^2 > 0.14$  for a large effect size.<sup>34</sup> Multivariate logistic regression analysis was executed to examine the effects of psychological variables on patient prognosis preferences, using the forward conditional method. We applied Nagelkerke's  $R^2$  to determine goodness-of-fit of the logistic regression model. Pearson's correlation assesses the association between physicians' perceived and patients' actual preference to know their prognosis. Data were analysed with the Statistical Package for Social Sciences (SPSS) for Windows V.26.0 (SPSS, Chicago, Illinois). A p-value of  $<0.05$  was deemed statistically significant.

## RESULTS

### Patient prognostic information preferences and survival estimation

Data from 863 participants (mean age,  $65 \pm 11$ ) were included in the analysis after excluding missing data

(80% response rate; see online supplemental file 1). Thirty-two physicians from 15 hospitals all over Spain participated in recruitment. Most subjects were male (55%); 67% were married; 48% had completed junior high school and 53% were retired or unemployed. The most common tumours were bronchopulmonary (32%), digestive (15%) and breast (9%). Adenocarcinoma histology was the most prevalent (63%) and most cancers were diagnosed in stage IV (80%). The most frequent treatment was chemotherapy alone or combined with other treatment modalities (88%).

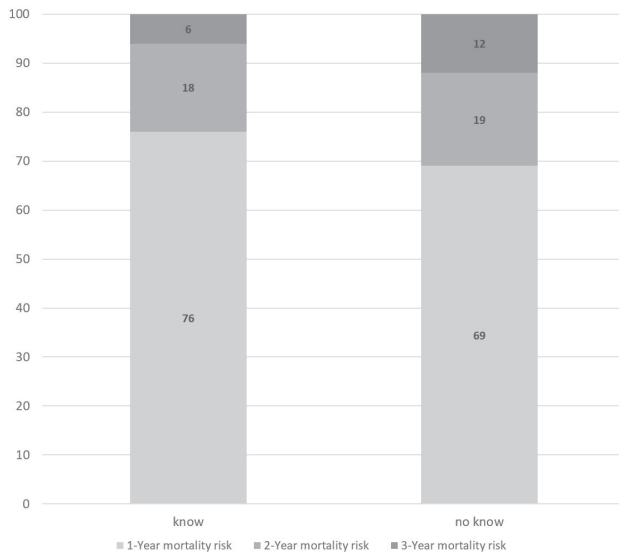
Estimated survival was <18 months for 46% of the sample (see table 1).

Approximately half of the participants (51.8%, n=447/863) preferred to know the general prognosis of their disease. The proportion of patients who preferred to avail themselves of information about their disease prognosis increased numerically as survival lengthened (1/2/3 years) compared with those who preferred not to know ( $\chi^2=7.656$ ,  $p=0.022$ ,  $\lambda=0.006$ ), (see figure 1).

**Table 1** Differences in demographic and clinical characteristics among patients who wanted and those who did not want to know their prognosis (n=863)

Variables	Total sample n (%) 863 (100%)	Patients preferring not to know prognosis, n=416 (48%)	Patients preferring to know prognosis, n=447 (52%)	$\chi^2$	P value
Sex					
Male	473 (55)	219 (53)	254 (57)	1.519	0.218
Female	390 (45)	197 (47)	193 (43)		
Age					
<65 years	378 (44)	179 (43)	199 (45)	0.194	0.659
≥65 years	485 (56)	237 (57)	248 (55)		
Marital status					
Married or partnered	582 (67)	270 (65)	312 (70)	2.351	0.125
Not partnered	281 (33)	146 (35)	135 (30)		
Educational level					
Primary	410 (48)	188 (45)	222 (50)	1.728	0.189
High school or more	453 (53)	228 (55)	225 (50)		
Employment					
Retired	456 (53)	218 (52)	238 (53)	0.061	0.805
Employed	407 (47)	198 (48)	209 (47)		
Tumour site					
Bronchopulmonary	275 (32)	144 (35)	131 (29)	2.817	0.421
Digestive	131 (15)	61 (15)	70 (16)		
Breast	79 (9)	36 (9)	43 (10)		
Others	378 (44)	175 (42)	203 (45)		
Histology					
Adenocarcinoma	544 (63)	254 (61)	290 (65)	1.349	0.245
Others	319 (37)	162 (39)	157 (35)		
Stage					
Locally advanced	174 (20)	85 (20)	89 (20)	0.036	0.848
Metastatic disease (IV)	689 (80)	331 (80)	358 (80)		
Type of treatment					
Chemotherapy	455 (53)	226 (54)	229 (51)	5.947	0.114
Chemo+others	300 (35)	130 (31)	170 (38)		
Immunotherapy	62 (7)	36 (9)	26 (6)		
Targeted drug	46 (5)	24 (6)	22 (5)		
ECOG					
0	316 (37)	142 (34)	174 (39)	2.132	0.144
1 or more	547 (63)	274 (66)	273 (61)		
Survival					
<18 months	392 (46)	192 (46)	200 (45)	0.149	0.699
≥18 months	470 (54)	224 (54)	246 (55)		

ECOG, Eastern Cooperative Oncology Group.



**Figure 1** Patients' preferences to know prognosis and their oncologists' 1-year, 2-year and 3-year survival estimation.

### Characteristics related to patients' prognostic information preference

Univariate analyses detected no significant differences as a function of patients' sociodemographic or clinical characteristics (see table 1). However, differences were observed with respect to psychological variables. Subjects with a more positive attitude were significantly more likely to prefer to know their prognosis versus those who scored lower for positive attitude ( $F=12.025$ ,  $p=0.001$ ,  $\eta^2=0.014$ ). Participants with higher uncertainty scores were more given to preferring to know their prognosis than those with lower uncertainty scores ( $F=10.510$ ,  $p=0.001$ ,  $\eta^2=0.021$ ), while those who scored higher for trust and satisfaction with their physician displayed a greater inclination to prefer to know their prognosis than those who scored lower for this aspect ( $F=5.541$ ,  $p=0.019$ ,  $\eta^2=0.006$  and  $F=32.687$ ,  $p=0.001$ ,  $\eta^2=0.037$ , respectively) (see table 2).

Multivariate analyses revealed that patients with greater uncertainty (OR=1.07; 95% CI (1.30 to 1.10),  $p=0.001$ ), those who were more satisfied with their physician (OR=1.06; 95% CI (1.03 to 1.08),

$p=0.001$ ) and those who scored higher for positive attitude (OR=1.0; 95% CI (1.00 to 1.02),  $p=0.001$ ) were significantly more inclined to prefer to know their prognosis than participants with less uncertainty, less satisfaction with their physician, and less positive attitude (see table 3).

### Concordance between physician-perceived prognostic information preference and patient preference

The concordance between physicians' perception and patients' preference to know their prognosis was 37% ( $n=322/863$ ), suggesting that physicians underestimate the number of patients who want to know their prognosis. The lack of statistical significance in the  $\chi^2$  test ( $\chi^2=0.205$ ,  $p=0.650$ ) indicates that there is not enough evidence to affirm that there is a significant association between patients' and physicians' opinions (see table 4).

## DISCUSSION

This is the first study to examine the association between preferences for prognostic information and certain psychological variables such as coping, uncertainty and trust and satisfaction with one's physician in a large sample of Spanish patients with advanced cancer. Approximately half of the individuals analysed preferred to know the prognosis of their disease. Similar results have been obtained in other studies in which most patients with advanced cancer wish to receive prognostic information about their disease.<sup>1 2</sup> Patients regard having prognostic information as important, particularly for those whose cancer is in advanced stages; furthermore, it is an essential component of informed decision making.<sup>11 19</sup>

In our study, participants who preferred to know their prognosis exhibited higher levels of positive attitude and uncertainty and greater trust and satisfaction with their physician. In a sample of 524 cases of metastatic thoracic cancer, the authors found that up to 31% of the sample preferred not to know their prognosis, primarily to remain optimistic and, to a lesser extent, due to avoidance and their inability to fully grasp the information received.<sup>3</sup> People may prefer to know

**Table 2** Psychosocial characteristics of patients with and without a preference to know their prognosis

Scales	Patients preferring not to know prognosis (n=416)		Patients preferring to know prognosis (n=447)		F	P value	$\eta^2$
	Mean	SD	Mean	SD			
Anxious preoccupation (M-MAC)	49.7	20.9	48.7	22.1	0.487	0.485	–
Hopelessness (M-MAC)	26.1	23.0	25.9	24.0	0.019	0.891	–
Positive attitude (M-MAC)	77.4	18.4	81.6	17.2	12.025	0.001	0.014
Avoidance cognitive (M-MAC)	65.5	24.3	67.1	28.1	2.939	0.087	–
Trust in the oncologist (TIOS-SF)	23.8	2.7	24.2	2.2	5.541	0.019	0.006
Illness uncertainty (IUS)	13.7	3.9	14.6	4.1	10.510	0.001	0.012
Relation with physician (STAR)	30.8	6.6	33.5	7.1	32.687	0.001	0.037

IUS, Uncertainty in Illness Scale; M-MAC, Mental Adjustment to Cancer; STAR, Relation with physician; TIOS-SF, Trust in the oncologist.

**Table 3** Multivariate logistic regression of significant factors with patient preference

Scales	$\beta$	Wald test (z-ratio)	Sig.	OR	95% CI
Relation with physician (STAR)	0.056	24.552	0.001	1.058	1.03 to 1.08
Illness uncertainty (IUS)	0.066	14.158	0.001	1.069	1.31 to 1.10
Positive attitude (M-MAC)	0.012	8.391	0.004	1.012	1.00 to 1.02
Trust in the oncologist (TiOS-SF)	0.001	0.001	0.980	–	–
Constant	–3.652	19.414	0.001	0.001	0.03 to 0.93

IUS, Uncertainty in Illness Scale; M-MAC, Mental Adjustment to Cancer; STAR, Relation with physician; TiOS-SF, Trust in the oncologist.

their prognosis in order to gain a sense of control, lessen their uncertainty, gain autonomy, etc.<sup>16 17</sup> At times, they may even be ambivalent about knowing their prognosis, as they often wrestle between wanting to know and understand, and needing to hold on to hope, so as to continue to fight.<sup>3</sup> This dichotomy might be lessened if physicians disclosed prognosis using different types of information in different formats; for instance, by talking about life expectancy, mortality risk, probability of adverse events, score estimates, multiple scenarios or by providing qualitative and/or quantitative information;<sup>3</sup> in other words, adapting the information to the needs of each individual and to the specific time. It is important for future studies to also have information from caregivers, inasmuch as some studies indicate that they may be more cautious than the patients themselves.<sup>35 36</sup> In one study of 250 individuals with cancer, 66% of the caregivers preferred not to provide full prognostic information to the people in their care,<sup>35</sup> possibly because of the self-fulfilling prophecy effect.

No significant differences in terms of sociodemographic or clinical variables were identified in our study. Some studies have found that women are more likely to want to know their prognosis, talk to their physician and try to understand the stage of their disease,<sup>37</sup> whereas other studies indicate just the opposite, that more females prefer not to know the prognosis of their disease compared with males,<sup>3</sup> which points to the need for further research to analyse whether there are gender differences in the inclination to know the prognosis of one's disease.

Our results indicate that as the estimation of survival increased over the period indicated (1/2/3 years), the proportion of subjects who preferred to know their prognosis also rose. Similar results were found in a sample of metastatic thoracic patients, in which the longer the survival period, the greater the number of participants who preferred to know their prognosis.<sup>3</sup>

Prognosis also informs possible treatment decisions. Individuals having a better prognosis may choose more aggressive treatments, while those whose prognosis is worse may be advised to pursue palliative treatment to alleviate side effects and improve their quality of life.<sup>38</sup> While preferences for the amount or timing of prognostic information may vary between patients and physicians, both groups believe it to be valuable information for patients to have for both planning and decision making.<sup>38 39</sup> In our study, participants were not asked about their reasons for not wanting to know their prognosis. It would be worthwhile in future studies to ascertain these reasons and whether they evolve over time. Thus, the discussion of prognosis might change in the future and physicians may need to explore their patients' preferences with respect to prognostic information several times throughout treatment.<sup>3 18</sup> Whereas patients want a positive prognosis, physicians tend to address prognosis primarily when it is poor and the conversation often includes discussions about end-of-life planning. Gordon and Daughtery found that oncologists provided prognostic information in four scenarios, when (a) treatment decisions needed to be made, (b) therapy was failing, (c) patients were getting worse or in pain or (d) subjects were transitioning to a palliative care programme.<sup>40</sup>

Our study evidenced a 15% discrepancy between the percentage of patients who actually wanted to know their prognosis and the percentage of individuals the physicians estimated preferred to know. This may point towards physicians underestimating the number of subjects who want to know their prognosis. Most research indicates that patients wish to be informed about prognosis,<sup>1 2</sup> however when asked in greater detail, their wish and readiness for explicit prognostic information did not match.<sup>3</sup> Information, decision making and care preferences can fluctuate during the course of a disease and can also differ between patients and their caregivers.<sup>3 19</sup> Half of the participants in our

**Table 4** Concordance between physicians' perception of and patients' actual preference to know prognosis

Physicians' perception of patients' information preference	Patients preferring not to know prognosis % (n)	Patients preferring know prognosis % (n)	Total
Patient prefers not to know	64 (264)	62 (277)	541
Patient prefers to know	37 (152)	38 (170)	322
Total	100 (416)	100 (447)	863

cohort wanted to know their prognosis and the half did not. This may be due to the need that patients have to cling to hope. In the case of the physicians, most believed that their patients were not inclined to want to know about their prognosis. Future studies should inquire about whether the desire not to know is articulated by the patients themselves or by their relatives who often want to protect them from discouraging news.

The strengths of our study include the availability of sociodemographic and clinical data from a large, multiregional, representative sample and the linkage of participant and physician data. Nonetheless, our study contains certain limitations. The first is a potential selection bias in the sense that it is conceivable that individuals who avoid receiving potentially threatening information may be more likely to decline participation in the study, thereby resulting in an underestimation of the proportion of subjects who would prefer not to know their prognosis. Second, most of our study population preferred to fill in the questionnaires and home and bring them to their next appointment. This data collection methodology could introduce a selection bias, given that those individuals who are willing and able to complete the questionnaires may be different from those who fail to do so. Third, participating oncologists may have been biased by their interest in communication issues. This interest could affect how they interact with their patients, potentially creating a patient response bias. Fourth, the study can be generalised solely to the Spanish population, which has moved increasingly towards a greater role for patients in informed decision making, although a degree of paternalism in the patient–physician interaction persists, particularly among older people. Therefore, the desire not to know their prognosis may be more pronounced than in other countries. Finally, future research could examine the changes in prognostic information preferences over time and investigate the impact of prognostic disclosure on subjects who prefer to remain unaware, as well as the preferences of family members accompanying the patient.

## CONCLUSION

In our study, 52% of advanced cancer patients preferred to know their prognosis. Though the underlying reasons may vary from one person to another, it appears that knowing their prognosis was prompted primarily by a need to maintain a positive attitude, decrease uncertainty and by satisfaction with the physician. Physicians' perception substantially matched patients' prognostic information preference. Ascertaining patient information preferences is relevant to providing more personalised communication.

## CLINICAL IMPLICATIONS

Despite potential identifiable trends, demographic or cancer-specific factors are insufficient for predicting

individual information preferences. Thus, physicians should regularly inquire about patients' desired information, including who else should be informed and involved in decision-making, as well as how they prefer to receive such information. These preferences may vary between individuals and even change over time. Evidence-based guidelines are needed for effectively analysing and communicating patients' prognostic information preferences.

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**Patient consent for publication** Consent obtained directly from patient(s)

**Ethics approval** This study involves human participants and was approved by Spanish Agency of Medicines and Health Products (AEMPS; identification code: ES14042015). The study was approved by the Research Ethics Committee of the Principality of Asturias (17 May 2019) and by the Spanish Agency of Medicines and Medical Devices (AEMPS) (identification code: L34LM-MM2GH-Y925U-RJDHQ). Participants gave informed consent to participate in the study before taking part.

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