Changes in perception of prognosis in the last year of life of patients with advanced cancer and its associated factors: longitudinal results of the eQuiPe study

Versluis, M.A.J.; Poll-franse, L.V. van de; Zijlstra, M.; Laarhoven, H.W.M. van; Vreugdenhil, G.; Henselmans, I.; ... ; Raijmakers, N.H.J.

Original Article

PALLIATIVE MEDICINE

Palliative Medicine
1–9

DOI: 10.1177/02692163241301220
journals.sagepub.com/home/pmj
Sage

Changes in perception of prognosis in the last year of life of patients with advanced cancer and its associated factors: Longitudinal results of the eQuiPe study

M.A.J. Versluis[1,2], L.V. van de Poll-Franse[1,3,4], M. Zijlstra[1,5], H.W.M. van Laarhoven[6,7], G. Vreugdenhil[8], I. Henselmans[9], L. Brom[1], E.J.M Kuip[10,11], Y.M. van der Linden[1,12,13] and N.H.J. Raijmakers[1]

Abstract

Background: Many patients with advanced cancer are unaware of their limited prognosis, however little is known about the change in awareness during the last year of their lives.

Aim: To investigate changes in the perception of prognosis in the last year of life of patients with advanced cancer and its associated factors.

Design: Prospective, longitudinal, multicentre, observational study in patients with advanced cancer (eQuiPe). Patients completed 3-monthly follow-up questionnaires until death.

Setting/participants: Adult patients diagnosed with advanced cancer were recruited by their treating physician or self-enrolled in one of the forty Dutch hospitals. Only deceased patients with available prognostic data were included for analysis (n = 801).

Results: Perception of prognosis changes in the last year of life with an increase in the percentage of patients who are aware of their limited prognosis (from 15% to 40%). Especially in the last 6 months of life, most of the changes were towards a more realistic perception of prognosis. Patients who did not want to know their prognosis remained relatively stable in their wish not to know (range: 14%–18%). Time to death was associated with having a perception of prognosis of $<$ 1 year, $>$1 year or not knowing the prognosis, but was not associated with not wanting to know the prognosis.

Conclusion: Becoming aware of their limited prognosis may make patients with advanced cancer more receptive to start end-of-life discussions. Although some patients prefer not to know their prognosis, it remains important to respectfully explore their preferences and wishes for end-of-life care.

Keywords

Prognosis, longitudinal studies, palliative care, terminal care

[1]Research and Development, Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, The Netherlands
[2]Graduate school of Social and behavioral sciences, Tilburg University, Tilburg, The Netherlands
[3]Department of Medical and Clinical Psychology, Center for Research on Psychological and Somatic Diseases (CoRPS), Tilburg University, Tilburg, The Netherlands
[4]Department of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, The Netherlands
[5]Department of Internal Medicine, St. Jans Gasthuis, Weert, The Netherlands
[6]Cancer Center Amsterdam, Cancer Treatment and Quality of Life, Amsterdam, The Netherlands
[7]Department of Medical Oncology, Amsterdam University Medical Centre location Amsterdam University, Amsterdam, The Netherlands
[8]Department of Medical Oncology, Maxima Medical Centre, Veldhoven, The Netherlands
[9]Department of Medical Psychology, Amsterdam University Medical Centre, Amsterdam, The Netherlands
[10]Department of Medical Oncology, Radboud University Medical Centre, Nijmegen, The Netherlands
[11]Department of Anaesthesiology, Pain and Palliative Care, Radboud University Medical Centre, Nijmegen, The Netherlands
[12]Centre of Expertise in Palliative Care, Leiden University Medical Centre, Leiden, the Netherlands
[13]Department of Radiotherapy, Leiden University Medical Centre, Leiden, the Netherlands

Corresponding author:
M.A.J. Versluis, The Netherlands Comprehensive Cancer Organisation (IKNL), PO box 19079, Utrecht, 3501 DB, the Netherlands.
Email: m.versluis@iknl.nl

Key statements

What is already known about the topic:

- Patients who are aware of their limited prognosis are more likely to be actively involved in advance care planning
- Many patients with advanced cancer are unaware of their limited prognosis

What does this paper add:

- More patients with advanced cancer become aware of their limited prognosis during their last year of life
- Some patients do not want to know their prognosis, and their wish to not know their prognosis is persistent during their last year of life

Implications for practice, theory or policy:

- It is important for physicians to recognise that the patients' perception of prognosis may change as the disease progresses and to invite patients to discuss their needs and wishes regularly
- Although some patients may prefer not to know their prognosis, it remains important to respectfully explore their preferences and wishes for end-of-life care

Introduction

Cancer is the leading cause of death worldwide, accounting for almost 10 million deaths in 2022.[1] When the disease progresses and is no longer curable, care will focus on improving and/or maintaining the patients' quality of life. Treatment decisions should preferably take into account patients' wishes and preferences, which requires good and ongoing communication between patients, their families and their clinicians. Patients' wishes and preferences may be influenced by their prognostic awareness. It is known that patients who are aware of their prognosis are more likely to accept their illness and to be actively involved in advance care planning.[2,3] In addition, patients who are aware of their prognosis are less likely to choose life-prolonging treatment at a later stage of their disease.[4]

Several studies have shown low levels of prognostic awareness in patients with advanced cancer and identified specific factors associated with this lack of awareness.[5–13] For example, patients who are aware of their limited prognosis are often better educated and have poorer spiritual well-being scores than those who are unaware of their prognosis.[10] In addition, patients who are aware of their limited prognosis have higher anxiety symptoms, depression symptoms and lower quality of life scores compared to patients who are unaware of their prognosis.[12–15] Another study in patients with advanced cancer showed that prognostic awareness was associated with physicians' explanation of their prognosis, emphasising the importance of excellent communication between patients and physician.[11] Moreover, patient-physician discordance in prognostic awareness is associated with patient-reported absence of prognostic discussions and retrieving information from other sources outside the healthcare providers, and physicians reported uncertainty about the prognosis.[16]

However, the majority of the results originate from cross-sectional studies, and little is known about changes in prognostic awareness over time. A longitudinal study of 225 newly diagnosed Japanese patients with advanced lung cancer showed that 79% of patients remained consistent in their unawareness of their prognosis for 6 months after diagnosis.[17] Furthermore, being aware of the prognosis was associated with lower emotional well-being in this Japanese study. In another longitudinal study, including 134 patients with cancer from the Czech Republic with a life expectancy of $<$ 12 months, prognostic awareness remained stable during follow up (9 months) and no association was found for gender, education, type of cancer or spirituality.[6]

However, the longitudinal results that are available, as described above, often do not include time to death, are based on a specific tumour type, or are based on a relatively small study sample. Towards death, the quality of life decreases, and the symptom burden increases significantly,[18–20] which may force patients to face their limited prognosis. Therefore, we hypothesise that patients become more aware of their prognosis as they approach death, which may influence their wishes and preferences for end-of-life care. If this is the case, physicians should be made aware of these changes and be encouraged to have ongoing discussions about prognostic disclosure and preferences for end-of-life care. Therefore, this study aims to investigate the changes in the perception of prognosis during the last year of life in patients with advanced cancer using longitudinal data from a prospective, multicentre, observational study. In addition, this study will also

explore which factors may be associated with having a specific perception of prognosis.

Methods

Study design

Data were used from the prospective, longitudinal, multicentre, observational eQuiPe study on health-related quality of life and experienced quality of care in patients with advanced cancer in forty Dutch hospitals, details of which have been published elsewhere.[21] After informed consent was signed, patients were asked to complete a baseline questionnaire followed by 3-monthly follow-up questionnaires (on paper or online) via the Patient Reported Outcomes Following Initial Treatment and Long-term Evaluation of Survivorship (PROFILES) registry[22] until death or loss to follow-up. The questionnaires were linked to the Netherlands Cancer Registry (NCR) to obtain clinical data and date of death. The eQuiPe study is registered in the Netherlands Trial Register (NTR6584) and was exempted from medical ethical review by the Medical Research Ethics Committee of the Antoni van Leeuwenhoek Hospital (METC17.1491).

Study population

All patients diagnosed with a solid metastasised tumour (stage IV) and aged $\geqslant$ 18 years were eligible for inclusion. Additional inclusion criteria were defined for patients diagnosed with breast or prostate cancer to reduce the overrepresentation of patients with a relatively good prognosis. Breast cancer patients were eligible if they had metastases in multiple organ systems and prostate cancer patients were eligible if their cancer was castrate resistant. Exclusion criteria included patients with dementia or patients with a history of severe psychiatric illness. Patients were included from November 2017 to March 2020. Patients were recruited by their treating physician or self-enrolled through advertisements, posted on the Dutch online platform for patients who are confronted with cancer. The eQuiPe study included a total of 1108 patients. Only deceased patients (data cut-off January 2023) with available data on perception of prognosis were included in this analysis.

Measurements

Perception of prognosis. Both the baseline and the follow-up questionnaires included the multiple-choice question '*What do you think your life expectancy is?*' to assess the perception of prognosis. The following answers could be given; (A) 'less than one year', (B) 'more than one year', (C) "not life-threatening", (D) 'I was not told or don't know', (E) 'I don't want to know' or (F) 'other, namely'. If a patient chose the option "other, namely", the patient was given the opportunity to further explain their answer. Where possible, this explanation was categorised into one of the pre-defined options.

Quality of life. Health-related quality of life was measured using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30).[23,24] This questionnaire consists of a global quality of life scale, five functional subscales (emotional, physical, cognitive, social and role), three symptom subscales (fatigue, nausea/vomiting, and pain), five single-symptom items (insomnia, dyspnoea, constipation, diarrhoea and loss of appetite) and an item on perceived financial burden. For this study, the recently developed QLQ-C30 summary score was used, which combines all subscales.[25] The summary score was transformed to a scale of 0–100, with a higher score indicating a better overall quality of life.

Socio-demographic and clinical characteristics. Age, gender, education, marital status, number of children and religion were self-reported in the baseline questionnaire. Religion was a single item asking patients to what religion they belonged. This was then dichotomised into being or not being religious. Comorbidity was measured using the Self-administered Comorbidity Questionnaire (SCQ) at baseline.[26] Cancer-related treatments received in the previous 3 months were self-reported in the follow-up questionnaires. Primary tumour type, date of primary cancer diagnosis and date of death were obtained from the Netherlands Cancer Registry (NCR).

Statistical analysis

Descriptive analysis was used to describe the sociodemographic and clinical characteristics of patients. For each questionnaire, time to death was defined as months between completion of the questionnaire and date of death and was categorised into nine groups of 3 months each: $>$ 24 months before death (T0), 22-24 months (T1), 19–21 months (T2), 16–18 months (T3), 13–15 months (T4), 10–12 months (T5), 7–9 months (T6), 4–6 months (T7) and 0-3 months before death (T8). Descriptive analysis was used to describe the distribution of patients by perception of prognosis per time category, and a Sankey plot was used to show changes in perception of prognosis over time. Logistic mixed-effect models were used to explore the association between time until death and having a specific perception. Statistical significance was achieved at $p < 0.05$. All statistical analyses were performed with STATA 17.0.

Results

In total, 801 patients were included for analysis (Figure 1). The mean age at death was 67 (SD 11) years and 50% were female (Table 1). The most common primary tumour types were lung (29%), colorectal (16%) and breast cancer

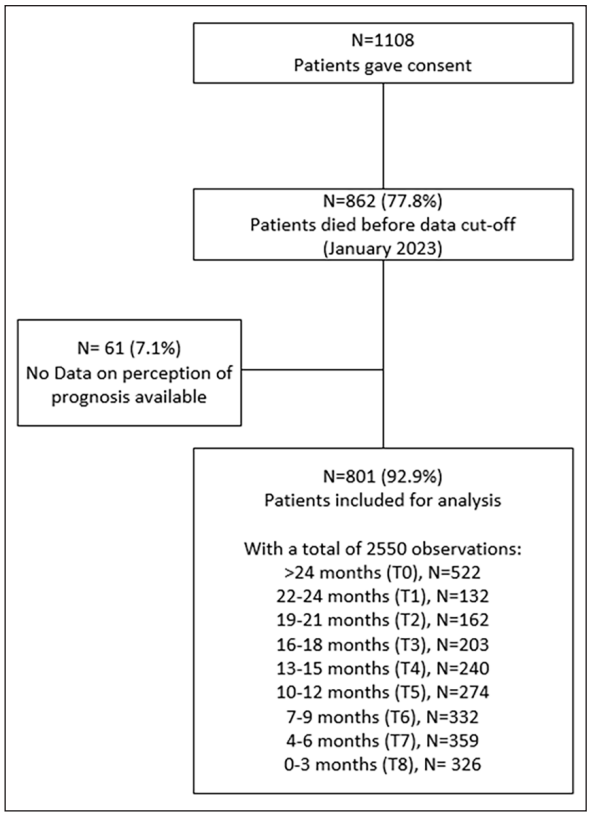

Figure 1. Flowchart of the inclusion and distribution of patients and observations.

(16%). The majority of patients (65%) had a follow-up time of 0–6 months.

Perception of prognosis

Twenty-four–13 months before death, patients with advanced cancer remained relatively stable in their perception of prognosis; between 7% and 12% of patients perceived their prognosis to be less than 1 year, 26-32% perceived their prognosis to be more than 1 year, 40%–46% did not know their prognosis, 13%–19% did not want to know their prognosis and 1%–3% did not perceive their disease to be life-threatening (Figure 2). Twelve months before death, the proportion of patients who perceived their prognosis to be less than 1 year increased from 15% to 40%, and the proportion of patients who perceived their prognosis to be more than 1 year decreased from 26% to 16%. The proportion of patients who did not know their prognosis also decreased (40% to 29%), while the proportion of patients who did not want to know their prognosis (14%–18%) or perceived their disease as non-life-threatening (1%–3%) remained relatively stable.

Changes in perception of prognosis

As shown in the Sankey plot (Figure 3), the majority of patients remained stable in their perception of prognosis during the last 2 years of their life. Patients who changed their perception and originally had perceived their prognosis as being less than 1 year changed their perception of prognosis towards not knowing or to more than one year. Patients who changed their perception and originally perceived their prognosis as being more than 1 year changed their perception towards not knowing their prognosis (6%-19%) until the last 6 months of life. In these remaining 6 months of life, one quarter of patients with a perceived prognosis of more than 1 year did not change

Table 1. Socio-demographic and clinical characteristics of deceased patients (*n* = 801).

Socio-demographic and clinical characteristics	N (%)[a]
Age at death (mean (SD)	67 (11) 27–99
Gender	
Male	402 (50)
Female	399 (50)
Having a Partner	
Yes	657 (82)
No	143 (18)
Having Children	
Yes	655 (83)
No	130 (17)
Religious	
Yes	539 (68)
No	259 (32)
Education[b]	
Low	251 (32)
Medium	327 (41)
High	216 (27)
Primary tumour type	
Lung	227 (29)
Breast	122 (16)
Colorectal	120 (16)
Prostate	92 (12)
Ovary and fallopian tube	30 (4)
Oesophagus	29 (4)
Pancreas	21 (3)
Other	133 (17)
Comorbidity	
One	275 (35)
More than one	245 (32)
None	257 (33)
Time in follow-up	
0–6 months	522 (65)
7–12 months	107 (13)
>12 months	172 (21)

[a]Percentages may not add up to 100 due to rounding. Missings did not exceed > 5%.
[b]Education levels are categorised according to International Standard Classification of Education guidelines: Low: no education, pre-primary, primary, lower secondary education, compulsory education, initial vocational education. Medium: upper secondary general education, basic vocational education, secondary vocational education, post-secondary education. High: specialised vocational education, university/college education, (post)-doctorate, and equivalent degrees.

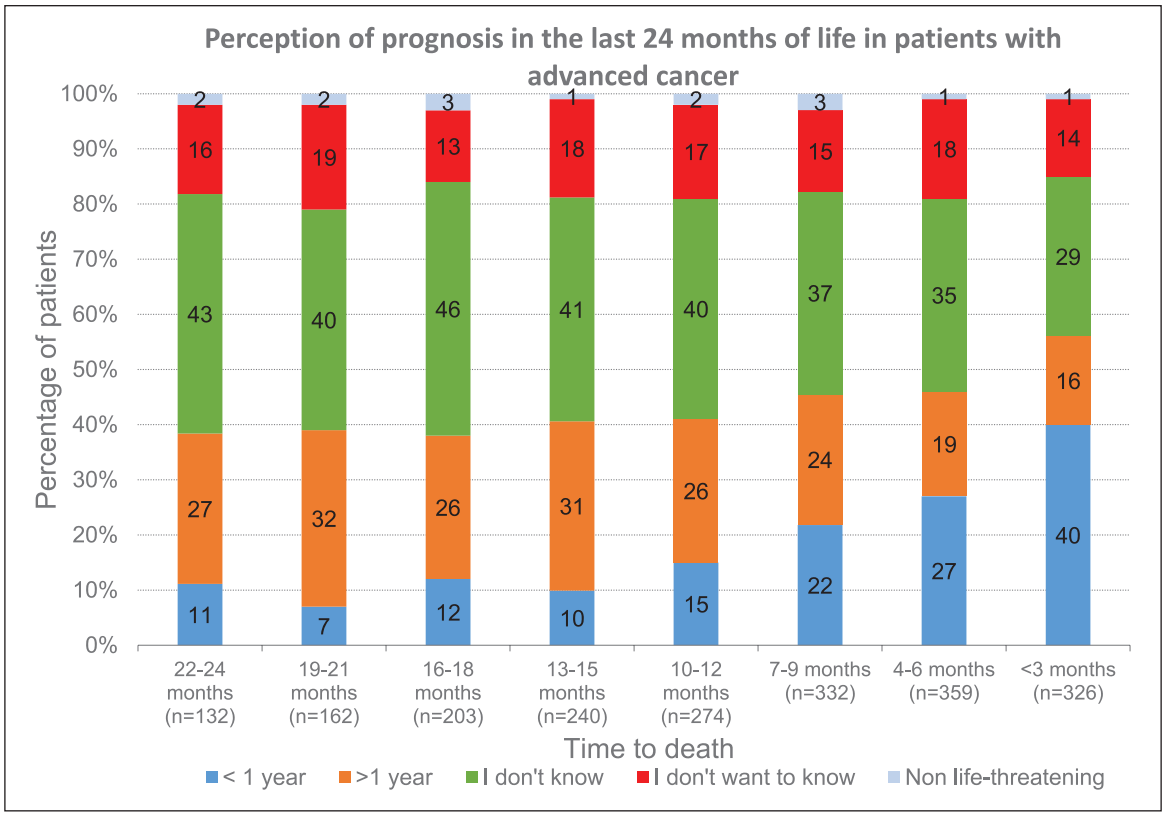

Figure 2. Proportions of perceived prognosis in the last year of life in patients with advanced cancer (*n* = 801).

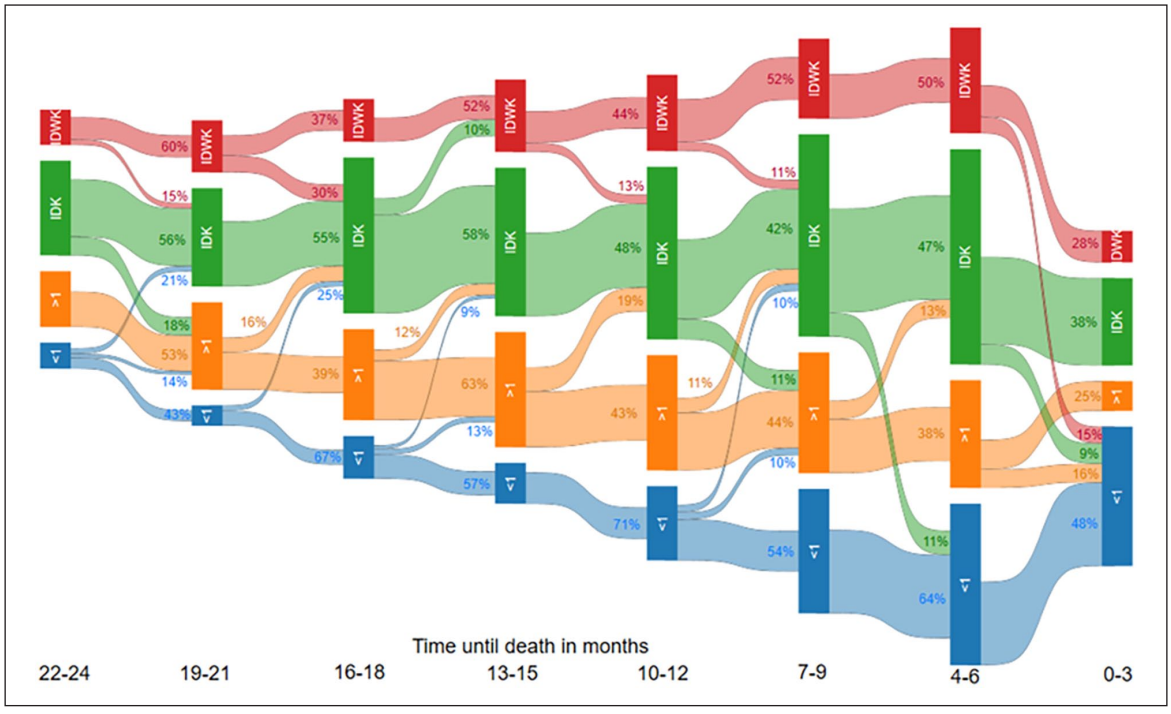

Figure 3. Direction of changes in perception of prognosis in the last 24 months of life of patients with advanced cancer (*n* = 726).
Perception of prognosis defined as: < 1: Less than 1 year, >1: More than 1 year, IDK: I don't know, IDWK: I don't want to know. Percentages illustrate the proportion of patients changing their perception of prognosis from one time category to another. Percentages do not add up to 100 due to the variation in available datapoints between patients

Table 2. Mixed effect logistic regression analysis to explore the association between having a specific perception of prognosis and time to death (*n* = 2550 observations).

	Less than 1 year Yes (*n* = 458) versus No (*n* = 2092)		More than 1 year Yes (*n* = 668) versus No (*n* = 1882)		I don't know Yes (*n* = 985) versus No (*n* = 1565)		I don't want to know Yes (*n* = 384) versus No (*n* = 2166)	
Factors	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Time to death								
>12 months	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*
10–12 months	***2.31***	**1.19–4.46***	**0.57**	**0.35–0.93***	1.07	0.69–1.65	0.98	0.50–1.92
7–9 months	**4.23**	**2.26–7.90***	**0.51**	**0.31–0.82***	0.93	0.60–1.43	0.82	0.42–1.59
4–6 months	**11.35**	**6.10–21.10***	**0.24**	**0.14–0.41***	**0.64**	**0.41–0.98***	1.56	0.83–2.92
0–3 months	**24.76**	**12.18–50.34***	**0.18**	**0.10–0.34***	**0.45**	**0.27–0.76***	0.91	0.42–1.96
Age at death	1.00	0.96–1.03	0.97	0.95–1.00	1.03	1.00–1.05	0.97	0.94–1.01
Gender								
Male	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*
Female	0.58	0.29–1.16	0.67	0.38–1.18	1.51	0.90–2.55	1.60	0.74–3.48
Religious								
No	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*
Yes	**0.49**	**0.24–1.00***	0.75	0.42–1.36	**2.21**	**1.27–3.83***	0.78	0.35–1.78
Partnered								
No	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*
Yes	0.56	0.23–1.36	1.79	0.84–3.80	1.22	0.63–2.37	0.69	0.26–1.83
Children								
No	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*
Yes	0.92	0.37–2.28	0.92	0.81–3.10	0.99	0.49–1.97	1.02	0.36–2.86
Education								
Low	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*	*Ref*
Medium	**3.48**	**1.46–8.31***	1.58	0.81–3.10	0.66	0.37–1.21	**0.36**	**0.15–0.86***
High	**20.28**	**7.71–53.36***	**6.16**	**2.88–13.17***	**0.14**	**0.07–0.45***	**0.11**	**0.04–0.33***
Quality of life	**0.95**	**0.93–0.96***	**1.03**	**1.01–1.04***	1.01	1.00–1.02	1.00	0.98–1.01

*Significant p-value ($p < 0.05$).

their perception and 16% changed it towards one of less than 1 year.

Most patients who did not know their prognosis (38%-58%) or did not want to know their prognosis (28%-60%) remained relatively persistent in their perception throughout the last 24 months of life. In the last 6 months of life, 9% of patients who did not know their prognosis and 15% of patients who did not want to know their prognosis changed their perception of prognosis towards one of less than 1 year.

Associated factors with having a specific perception of prognosis

Time to death was associated with a higher likelihood of having a perception of prognosis of less than 1 year and a lower likelihood of having a perception of prognosis of more than one year or not knowing the prognosis (Table 2). No association was found between time to death and not wanting to know the prognosis.

Patients who reported to be religious had a lower likelihood of having a perception of prognosis of less than 1 year (OR 0.5, 95% CI 0.2–1.0) and a higher likelihood of not knowing their prognosis (OR 1.3, 95% CI 1.3–3.8) compared to patients who were not religious. Higher educated patients had a higher likelihood of knowing their prognosis (more (OR 6.2, 95% CI 2.9–13.2) or less than 1 year (OR 20.3, 95% CI 7.7–53.4)) and a lower likelihood of not knowing (OR 0.1, 95% CI 0.1–0.5) or not wanting to know their prognosis (OR 0.1, 95% CI 0.0–0.3) compared to lower educated patients. Higher quality of life was associated with a lower likelihood of having a perception of prognosis of less than 1 year (OR 1.0, 95% CI 0.9–1.0) and a higher likelihood of having a perception of prognosis of more than 1 year (OR 1.0, 95% CI 1.0–1.0).

Discussion

Main findings

In this large longitudinal study of patients with advanced cancer, we found that the patients' perception of prognosis changes in the last year of life. Especially in the last 6 months of life, when most changes are towards a more

realistic perception of prognosis (less than 1 year). Time to death was associated with an increased likelihood of having a perception of prognosis of less than 1 year. In addition, time to death was also associated with a decreased likelihood of having a perception of prognosis of more than 1 year and a decreased likelihood of not knowing the prognosis. However, patients who did not want to know their prognosis remained relatively persistent in the last year of life and was not associated with time to death.

What this study adds? In this study, the proportion of patients with advanced cancer who were aware that their prognosis was less than 1 year increased from 15% to 40% in the last year of life. Especially in the last 6 months of life, most changes in perception of prognosis were towards a more realistic prognosis (less than 1 year). A change in the perception of prognosis in the last few months of life may be related to a natural deterioration as the patient approaches death. This could also be seen in the association between lower quality of life and an increased likelihood of having a realistic perception of prognosis. This deterioration may force patients to face their poor prognosis. A more realistic perception of prognosis has also previously been shown to be associated with higher levels of anxiety, depression, and a lower quality of life,[27,28] which may also be part of the natural process of dying and letting go of life.[29]

In the last 3 months of life, 40% of the patients perceived their life expectancy to be less than 1 year, so most patients either did not know their prognosis or had an optimistic perception of their prognosis. The low percentage of patients aware of their prognosis is consistent with previously published results ranging from 16% to 53%.[5–13] While most patients are unaware of their limited prognosis, previous studies have also shown that the majority of patients would like to receive information about their prognosis. A Brazilian cross-sectional study in 90 outpatients with advanced cancer showed that 88% preferred to receive prognostic information from their oncologist,[30] and an Australian study of nurses found that $>$ 75% of their patients requested prognostic information.[31] Known reasons for physicians' reluctance to provide prognostic information include fear of discussing a poor prognosis, fear of taking away hope, fear of damaging the relationship with the patient, uncertainty about the patient's prognostic preferences, sensitivity to cultural and family issues, and inability to provide an accurate estimate of the patient's life-expectancy.[31,32] These findings highlight the need for oncologists to regularly explore patients' prognostic preferences and provide them with accurate information when requested, even when patients may be reluctant to do so.

There is also a group of patients who explicitly do not want to know their prognosis, who remain relatively persistent in not wanting to know in their last year of life. Most of the studies published to date have focussed on knowing or not knowing the prognosis, and little is known about patients who do not want to know their prognosis. The few studies that have looked at this specific patient group found that patients who are unable to understand (medical) information and patients who experience death anxiety are less likely to want to know their prognosis.[33,34] In addition, patients who do not want to know their prognosis are often more optimistic and have a stronger fighting spirit than patients who do want to know their prognosis.[34] Nevertheless, according to a recent Dutch online survey study (n = 74), patients with advanced cancer who do not want to know their prognosis do still want to discuss their wishes and preferences regarding their prognostic disclosure and end-of-life care goals.[35]

Patients who are aware of their limited prognosis are more likely to actively engage in advance care planning, which is associated with an increased likelihood of dying at home, increased use of hospice care, a decreased chance of hospitalisation in the last 30 days of life, and a decreased likelihood of initiating or continuing low-effectiveness and/or life-prolonging treatments.[2–4,7,8,13] Patients may change their perception of prognosis in the last year of life and adjust their wishes and preferences regarding end-of-life care accordingly. Physicians should continuously explore the wishes and preferences of their patients and be aware that their perception of prognosis, and thus end-of-life care preferences, may change. Furthermore, physicians should also be aware that some patients may not want to know their prognosis but may still want to discuss their end-of-life goals.

Strengths and limitations

The prospective longitudinal multicentre eQuiPe study allowed us to assess changes in the perception of prognosis in the last year of life in patients with advanced cancer. The study had a high response rate (65%) and almost half of all deceased patients completed a questionnaire in the last 3 months of life (43%). However, there are some limitations. First, the eQuiPe study was mainly designed to assess the quality of life and quality of care of patients with advanced cancer and their relatives. The data collection was prospective in nature, still some prognostic factors related to prognostic awareness were missing, which led to unaccounted confounding in the analysis. Second, the generalisability of our results may be limited due to selection bias. It is well known that patients with a better overall health status are more likely to be invited by their physician and to participate in research. This is reflective in our study population as it is slightly higher educated and younger compared to the general population of patients who died of cancer in 2018. Third, the study period ran from November 2017 to March 2020, which means that the follow-up data was partially collected during the COVID pandemic. However, previous studies have

shown that the pandemic did not affect the care of patients with advanced cancer in the Netherlands.[36,37] Furthermore, our population consisted mainly of Catholics (61%) or non-religious patients (32%). Further research should be conducted to explore the possible influence of other religions on the perception of prognosis. In addition, this study population included too few patients with changing perceptions of prognosis to run a regression model specific to each direction of change. Further research is needed to investigate which factors, if any, are associated with a specific change in the perception of prognosis. Finally, the questionnaire used to measure the perceived perception of prognosis was self-developed and needs to be validated. An end-of-life discussion with the physician or palliative care team may influence the perception of prognosis. Unfortunately, no data were available on the frequency and content of these discussions. The effect of end-of-life discussions on perceptions of prognosis should be further investigated.

Conclusion

Perception of prognosis in patients with advanced cancer changes in the last year of life. In the last 6 months of life, most changes are towards a more realistic perception of prognosis. Becoming aware of how much time is left may influence wishes and preferences of the individual for end-of-life care. It is therefore important for physicians to realise that patients' perception of prognosis may change as the disease progresses and to invite patients to discuss their needs and wishes on a regular basis. It is worth noting that patients who explicitly do not want to know their prognosis tend to maintain a consistent preference for not knowing. In such cases, it is still important to explore their end-of-life wishes and preferences, but without revealing prognostic information.

Acknowledgements

The authors thank the registration team of the Netherlands Comprehensive Cancer Organisation (IKNL) for the collection of data for the Netherlands Cancer Registry.

Author contributions

All authors contributed to the concept and design of this study. Material preparation and the formal analysis were performed by M.A.J. Versluis and supervised by N.H.J. Raijmakers, L.V. van de Poll-Franse and Y.M. van der Linden. The first draft of the manuscript was written by M.A.J. Versluis and all authors commented on previous versions of the manuscript. Permission to publish the final manuscript was given by all authors.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The eQuiPe study was financially supported by the Roparun Foundation.

Ethics approval

The eQuiPe study was performed according to the principles of the Declaration of Helsinki and reviewed by the Medical Research Ethics Committee of the Antoni van Leeuwenhoek hospital in Amsterdam, The Netherlands (METC17.1491).

Consent to participate

All patients gave written informed consent to participate in the eQuiPe study.

ORCID iDs

M.A.J. Versluis https://orcid.org/0000-0001-7908-294X

H.W.M. van Laarhoven https://orcid.org/0000-0003-3546-9709

N.H.J. Raijmakers https://orcid.org/0000-0002-3000-2520

References

1. Ferlay J, Ervik M, Lam F, et al. Global Cancer Observatory: Cancer today. Lyon, France. International Agency for Research on Cancer. https://gco.iarc.who.int/today (2024, accessed September 2024).
2. Ray A, Block SD, Friedlander RJ, et al. Peaceful awareness in patients with advanced cancer. *J Palliat Med* 2006; 9(6): 1359–1368.
3. Enzinger AC, Zhang B, Schrag D, et al. Outcomes of Prognostic disclosure: associations with prognostic understanding, distress, and relationship with physician among patients with advanced cancer. *J Clin Oncol* 2015; 33(32): 3809–3816.
4. Hasegawa T, Okuyama T, Uemura T, et al. Prognostic awareness and discussions of incurability in patients with pre-treated non-small cell lung cancer and caregivers: a prospective cohort study. *Oncologist* 2022; 27(11): 982–990.
5. Fried TR, Bradley EH and O'Leary J. Changes in prognostic awareness among seriously ill older persons and their caregivers. *J Palliat Med* 2006; 9(1): 61–69.
6. Loučka M, Vlčková K, Tučková A, et al. Prognostic awareness in advanced cancer patients and their caregivers: a longitudinal cohort study. *Psychooncology* 2021; 30(9): 1449–1456.
7. Agarwal R, Shin P, Knezevic A, et al. Accuracy of curability expectations in patients with gastrointestinal cancers. *Cancer Med* 2023; 12(1): 20–29.
8. Gray TF, Plotke R, Heuer L, et al. Perceptions of prognosis and end-of-life care outcomes in patients with advanced lung and gastrointestinal cancer. *Palliat Med* 2023; 37(5): 740–748.
9. McLouth LE, Gabbard J, Levine BJ, et al. Prognostic awareness, palliative care use, and barriers to palliative

care in patients undergoing immunotherapy or chemo-immunotherapy for metastatic lung cancer. *J Palliat Med* 2023; 26(6): 831–836.
10. Satija A, Bhatnagar S, Ozdemir S, et al. Patients' awareness of advanced disease status, psychological distress and quality of life among patients with advanced cancer: results from the APPROACH study India. *Am J Hosp Palliat Care* 2022; 39(7): 772–778.
11. Hiratsuka Y, Oishi T, Miyashita M, et al. Prognostic awareness in Japanese patients with advanced cancer: a follow-up cohort study. *Jpn Clin Oncol* 2023; 53(5): 410–418.
12. Ng S and Ozdemir S. The associations between prognostic awareness and health-related quality of life among patients with advanced cancer: A systematic review. *Palliat Med* 2023; 37(6): 808–823.
13. Carmona-Bayonas A, Rodriguez-Gonzalez A, García-García T, et al. Can oncologists prompt patient prognostic awareness to enhance decision-making? dData from the NEOetic study. *Oncologist* 2023; 28(11): 986–995.
14. Ozdemir S, Ng S, Wong WHM, et al. Advanced cancer patients' prognostic awareness and its association with anxiety, depression and spiritual well-being: a multi-country study in Asia. *Clin Oncol* 2022; 34(6): 368–375.
15. Nipp RD, Greer JA, El-Jawahri A, et al. Coping and prognostic awareness in patients with advanced cancer. *J Clin Oncol* 2017; 35(22): 2551–2557.
16. van der Velden NCA, Han PKJ, van Laarhoven HWM, et al. Prevalence and predictors of physician-patient discordance in prognostic perceptions in advanced cancer. *Oncologist* 2023; 28(8): e653–e668.
17. Arai D, Sato T, Nakachi I, et al. Longitudinal assessment of prognostic understanding in patients with advanced lung cancer and its association with their psychological distress. *Oncologist* 2021; 26(12): e2265–e2273.
18. Verkissen MN, Hjermstad MJ, Van Belle S, et al. Quality of life and symptom intensity over time in people with cancer receiving palliative care: results from the international European Palliative Care Cancer Symptom study. *PLoS One* 2019; 14(10): e0222988.
19. Giesinger JM, Wintner LM, Oberguggenberger AS, et al. Quality of life trajectory in patients with advanced cancer during the last year of life. *J Palliat Med* 2011; 14(8): 904–912.
20. Hwang SS, Chang VT, Fairclough DL, et al. Longitudinal quality of life in advanced cancer patients: pilot study results from a VA medical cancer center. *J Pain Symptom Manag* 2003; 25(3): 225–235.
21. van Roij J, Zijlstra M, Ham L, et al.; eQuiPe study group. Prospective cohort study of patients with advanced cancer and their relatives on the experienced quality of care and life (eQuiPe study): a study protocol. *BMC Palliat Care* 2020; 19(1): 139.
22. van de Poll-Franse LV, Horevoorts N, van Eenbergen M, et al.; Profiles Registry Group. The patient reported outcomes following initial treatment and long term evaluation of survivorship registry: scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. *Eur J Cancer* 2011; 47(14): 2188–2194.
23. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993; 85(5): 365e76–376.
24. Kaasa S, Bjordal K, Aaronson N, et al. The EORTC core quality of life questionnaire (QLQ-C30): validity and reliability when analysed with patients treated with palliative radiotherapy. *Eur J Cancer* 1995; 31A(13-14): 2260–2263.
25. Giesinger JM, Kieffer JM, Fayers PM, et al.; EORTC Quality of Life Group. Replication and validation of higher order models demonstrated that a summary score for the EORTC QLQ-C30 is robust. *J Clin Epidemiol* 2016; 69: 79–88.
26. Sangha O, Stucki G, Liang MH, et al. The self-administered comorbidity questionnaire: a new method to assess comorbidity for clinical and health services research. *Arthritis Rheum* 2003; 49(2): 156–163.
27. Chen CH, Wen FH, Chang WC, et al. Associations of prognostic-awareness-transition patterns with emotional distress and quality of life during terminally ill cancer patients' last 6 months of life. *Psychooncology* 2023; 32(5): 741–750.
28. Chan WCH. Being aware of the prognosis: how does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context? *J Palliat Med* 2011; 14(9): 997–1003.
29. Cassel E (ed.). *The nature of suffering and the goals of medicine*. 2nd ed. Oxford University Press, Oxford, United Kingdom, 2004.
30. Paiva CE, Teixeira AC, Minto Lourenço B, et al. Anticancer treatment goals and prognostic misperceptions among advanced cancer outpatients. *Int J Environ Res Public Health* 2022; 19(10): 6272.
31. Bryant J, Hobden B, Waller A, et al. Oncology nurse perceptions about life expectancy discussions: a cross-sectional study exploring what patients want to know, and why doctors don't disclose. *Contemp Nurse* 2022; 58(5-6): 424–434.
32. Hagerty RG, Butow PN, Ellis PM, et al. Communicating prognosis in cancer care: a systematic review of the literature. *Ann Oncol* 2005; 16(7): 1005–1053.
33. Kaplowitz SA, Campo S and Chiu WT. Cancer patients' desires for communication of prognosis information. *Health Commun* 2002; 14(2): 221–241.
34. van der Velden NCA, van Laarhoven HWM, Burgers SA, et al. Characteristics of patients with advanced cancer preferring not to know prognosis: a multicenter survey study. *BMC Cancer* 2022; 22(1): 941.
35. Westendorp J, Evers AW, Stouthard JM, et al. Mind your words: oncologists' communication that potentially harms patients with advanced cancer: A survey on patient perspectives. *Cancer* 2021; 128(5): 1133–1140.
36. van de Poll-Franse LV, de Rooij BH, Horevoorts NJE, et al. Perceived care and well-being of patients with cancer and matched norm participants in the COVID-19 crisis: results of a survey of participants in the Dutch PROFILES registry. *JAMA Oncol* 2021; 7(2): 279–284.
37. Slotman E, Weijzen F, Fransen HP, et al.; On-behalf-of-the-COVID-and-Cancer-NL Consortium. Continuity of care for patients with de novo metastatic cancer during the COVID-19 pandemic: A population-based observational study. *Int J Cancer* 2024; 154(10): 1786–1793.