Characteristics of patients with advanced cancer preferring not to know prognosis: A multicenter survey study

Naomi van der Velden, Hanneke van Laarhoven, Sjaak Burgers, ... Ellen Smets and Inge Henselmans

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Een op de drie mensen met uitgezaaid kanker wil prognose niet weten.

Eerste resultaten @kwf.nl PROSPECT studie: Een op de drie mensen met uitgezaaid kanker wil prognose niet weten. Dit zijn o.a. vaker mensen die zich nog goed voelen en een sterke vechtlust hebben. Dokters vaak niet op de hoogte van wens om niet te weten.

https://linkd.in/dcuqfiv

#cancerresearch Vertaling weergeven

Characteristics of patients with advanced cancer preferring not to know their prognosis

For some patients with advanced cancer not knowing prognosis I...
Prognostic information

• Communicating prognosis is important for decision-making in palliative cancer care
• Not all patients want prognostic information (about 20%)
  • Hope
  • May evoke negative emotions
  • Too uncertain or useless
• Characteristics of patients not wanting to know their prognosis

What do you think? (give 1 or 2 characteristics in the chat)
Goals present paper

**Investigating:**

1. the proportion of patients with advanced cancer preferring not to know prognosis;
2. reasons underlying patients’ prognostic information preference;
3. characteristics associated with patients’ prognostic information preference;
4. concordance between physicians and patients’ actual prognostic information preference
Sample and procedure

• Cross-sectional survey study (seven hospitals)
• Patients with advanced cancer
  • Incurable metastatic/inoperable tumor
  • Estimated median overall survival of $\leq 12$ months
• Physicians
  • Medical oncologists and oncologists in training
• Power analysis: 331 patients
Measures

• Patients’ prognostic information preferences (aim 1)
  • Life expectancy estimate (yes/no)
  • 5/2/1-year mortality risk (yes/no)

“Are you a person who wants to know the likelihood of dying from your cancer within one year from now?”

Yes               No
Measures

• Patients’ underlying reasons (aim 2)
  • 26-item Considerations Concerning Cancer Information Questionnaire (CCCI)
    • Reasons for wanting limited information (staying optimistic, unable to comprehend, not wanting to be a burden, avoidance of frightful information)
    • Reasons for wanting complete information (expectations of others, reducing anxiety, gaining autonomy, sense of control)

“I don’t need to know everything because it may frighten me”

| Never | 1 | 2 | 3 | 4 | Always | 5 |
|-------|---|---|---|---|--------|---|
Measuring characteristics (aim 3)  

- **Background characteristics**
  - Age, gender, education, nationality, religion, presence of children, health literacy, subjective numeracy

- **Clinical characteristics**
  - Tumor type, line of systemic treatment, time since diagnosis, quality of life
  - Patients’ perceived likelihood of dying within one year
Measuring characteristics (aim 3)

- **Personal characteristics**
  - Fighting spirit (i.e., viewing cancer as a challenge)
    - “I am determined to beat this disease” (1–4, “does not apply at all to me” to “totally applies to me”)
  - Trait optimism
    - “I feel nervous and restless” (1–4, “not at all” to “very much so”)
  - Trait anxiety (State and Trait Anxiety Inventory)
  - Uncertainty intolerance (i.e., perceiving ambiguous situations as desirable)
    - “If I am uncertain about the responsibilities involved in a particular task, I get very anxious” (1–6, “strongly agree” to “strongly disagree”)
  - Patients’ trust in the physician (Trust in Oncologist Scale)
Measures

• Physicians’ perceptions of patients’ prognostic information preference (aim 4)
  • “Is this patient a person who wants to know the likelihood of him/her dying within one year from now?”

  1  2
  Yes, I think so  No, I don’t think so
Sample characteristics

- Table 2, p.5 (too big for this slide, haha)
- Patients (n=524)
  - About half was male; mean age was 64 years
- Physicians (n=54)
Patients’ prognostic information preferences (aim 1)

![Prognostic information preference](image)

**Fig. 1** Patients’ preferences for information about a life expectancy estimate and the 5/2/1-year mortality risk.\(^a\) \(n = 522/524\) patients reported their preference to know a general life expectancy estimate (2 missing) and \(n = 523/524\) patients reported their preference to know the 2-year mortality risk (1 missing). Abbreviations: \(n\): sample size
Patients’ underlying reasons (aim 2)

| Reasons                                      | Cronbach's alpha | Patients preferring not to know 1-year mortality risk | Patients preferring to know 1-year mortality risk |
|----------------------------------------------|------------------|-------------------------------------------------------|--------------------------------------------------|
|                                              |                  | $n = 161/524$ mean ± SD                               | $n = 363/524$ mean ± SD                           |
| Reasons for wanting limited information      |                  |                                                       |                                                  |
| Staying optimistic (CCCI, 1–5) $^c$          | .87              | 3.4 ± 1.1***                                          | 2.3 ± 1.1                                         |
| Avoiding frightful information (CCCI, 1–5) $^c$ | .89              | 2.5 ± 1.1***                                          | 1.8 ± 0.9                                         |
| Feeling unable to comprehend information (CCCI, 1–5) $^d$ | .85              | 1.9 ± 0.9*                                           | 1.7 ± 0.9                                         |
| Not wanting to be a burden to the physician (CCCI, 1–5) $^c$ | .89              | 1.6 ± 0.8                                            | 1.6 ± 0.9                                         |
| Reasons for wanting complete information     |                  |                                                       |                                                  |
| Gaining a sense of control (CCCI, 1–5) $^e$ | .86              | 3.4 ± 1.1                                             | 4.2 ± 0.9***                                      |
| Meeting expectations of others (CCCI, 1–5) $^f$ | .79              | 2.1 ± 1.1                                             | 2.4 ± 1.3**                                       |
| Reducing anxiety (CCCI, 1–5) $^e$             | .85              | 2.5 ± 1.1                                             | 2.9 ± 1.3***                                      |
| Gaining autonomy (CCCI, 1–5) $^f$             | .71              | 2.6 ± 1.0                                             | 3.1 ± 1.1***                                      |
Characteristics of prognostic preference (aim 3)

Patients preferring not to know the 1-year mortality risk

• **Background characteristics**
  - Age, gender (female), education (low), nationality, religion, presence of children, health literacy, subjective numeracy (low)

• **Clinical characteristics**
  - Tumor type, line of systemic treatment (second/third), time since diagnosis, quality of life (better)
  - Patients’ perceived likelihood of dying within one year (perceiving the likelihood of dying as extremely unlikely)
Characteristics of prognostic preference (aim 3)

Patients preferring not to know the 1-year mortality risk

- Personal characteristics
  - Fighting spirit (stronger)
    - “I am determined to beat this disease” (1–4, “does not apply at all to me” to “totally applies to me”)
  - Trait optimism
    - “I feel nervous and restless” (1–4, “not at all” to “very much so”)
  - Trait anxiety (less)
  - Uncertainty intolerance (i.e., perceiving ambiguous situations as desirable)
    - “If I am uncertain about the responsibilities involved in a particular task, I get very anxious” (1–6, “strongly agree” to “strongly disagree”)
  - Patients’ trust in the physician (Trust in Oncologist Scale)
Concordance between physicians and patients’ actual prognostic preference (aim 4)

Table 5  Concordance between physicians’ perceived and patients’ actual preference to know prognosis

| Physicians’ perceived information preference | Patients preferring not to know 1-year mortality risk % (n) | Patients preferring to know 1-year mortality risk % (n) | Total |
|---------------------------------------------|----------------------------------------------------------|---------------------------------------------------------|-------|
| Patient prefers not to know                 | 50.3 (81) \(^b\)                                         | 42.9 (153) \(^c\)                                       | 234   |
| Patient prefers to know                     | 49.7 (80) \(^c\)                                         | 57.1 (204) \(^b\)                                       | 284   |
| Total                                       | 100 (161)                                                | 100 (357)                                               | 518   |

\(^a\) n = 518/524 (6 missing)

\(^b\) Concordance between physicians’ perceived and patients’ actual preference for information about the 1-year mortality risk

\(^c\) Discordance between physicians’ perceived and patients’ actual preference for information about the 1-year mortality risk

\(n\) Sample size
About one-third of Dutch patients with advanced cancer don’t want information about their prognosis. As physicians often are unaware of patients’ wish (not) to know prognosis, we encourage physicians to explicitly explore patients’ prognostic information preferences and the underlying reasons.

These are the first results of the PROSPECT study, which I conducted for my PhD. Read the full article in BMC Cancer:

https://lnkd.in/dcUqfiv

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Vertaling weergeven

Characteristics of patients with advanced cancer preferring n...
Let’s talk about…

• Framing
  • “Are you a person who wants to know the likelihood of dying from/surviving your cancer within one year from now?”