Using three scenarios to explain life expectancy in advanced cancer: attitudes of patients, family members, and other healthcare professionals

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Abstract

Aim To evaluate a web-based tool for estimating and explaining three scenarios for expected survival time to people with advanced cancer (patients), their family members (FMs), and other healthcare professionals (HCPs).

Methods Thirty-three oncologists estimated the “median survival of a group of similar patients” for patients seeking quantitative prognostic information. The web-based tool generated worst-case, most likely, and best-case scenarios for survival based on the oncologist’s estimate. Oncologists presented the scenarios to each patient and provided a printed summary to patients, FMs, and HCPs. Attitudes to the information were assessed by questionnaires. Observed survival for each patient was compared with the oncologist’s estimated survival time and the three scenarios.

Results Prognosis was discussed with 222 patients: median age 67 years; 61% male; most common primary sites pancreas 15%, non-small-cell lung 15%, and colorectal 12%. The median (range) for observed survival times was 9 months (0.5–43) and for oncologist’s estimated survival times was 12 months (2–96). Ninety-one percent of patients, 91% of FMs, and 84% of HCPs agreed that it was helpful having life expectancy explained as three scenarios. The majority (77%) of patients judged the information presented about their life expectancy to be the same or better than they had expected before the consultation. The survival estimates met a priori criteria for calibration, precision, and accuracy.

Conclusions Patients, FMs, and HCPs found it helpful to receive personalized prognostic information formatted as three scenarios for survival. It was feasible, acceptable, and safe to use a web-based resource to do this.

Keywords Prognosis · Prognostic discussions · Life expectancy · Doctor-patient communication · Scenarios for survival · Advanced cancer

Introduction

Conversations about prognosis are important for people affected by incurable cancer and help patients and their families make decisions about treatment, plans for the future, and choices about end-of-life care. Patients who have a good understanding of their life expectancy are less likely to choose futile treatments and aggressive medical interventions toward the end of life; are more likely to accept palliative care services earlier; have better quality of life at the end of life; and have surviving carers with better quality of life during the bereavement period [1–3].

Despite this, many oncologists provide patients with minimal information about life expectancy or avoid such discussions altogether [4–6]. Reported reasons for this include fear of upsetting patients, fear of providing inaccurate information, and insufficient training in
prognostication [7, 8]. As a consequence, many patients
do not fully understand their situation and goals of treat-
ment. Conversations about prognosis are often deferred
until the last months of life, robbing patients and families
the opportunity to plan and discuss their wishes while they
are well. When conversations about prognosis do occur,
they are rarely documented in the patient’s medical record
or letters to other healthcare professionals [9, 10]. This
makes it difficult for all healthcare professionals involved
in the patient’s care to know what has been discussed and
may result in patients receiving inconsistent information.

Most patients want some information about their
expected survival time, and many want information about
specific scenarios, for example, the longest survival with
treatment, average survival, and shortest survival with-
out treatment [11–13]. We previously surveyed 505 peo-
ple with a cancer experience about their preferred format
for presenting information on expected survival time to a
hypothetical patient with advanced cancer and found that
88% preferred three scenarios for survival (worst-case,
most likely, and best-case), and only 5% preferred a single
estimate of the median survival time [14].

In previous work, we showed that certain percentiles
of an overall survival (OS) curve provide a useful basis for esti-
mat ing three scenarios for survival [15]. For example, the
90th percentile, the time when 90% of people are still alive
and 10% have died, can approximate the worst-case scenario
(shortest 10% of survival times) and the 10th percentile,
the time when 10% of people are still alive and 90% have
died, can approximate the best-case scenario (longest 10% of
survival times). We have also shown that simple multiples
(0.25, 0.5, 2, and 3) of an OS curve’s median can be used
to estimate its percentiles [15–23]. To illustrate, the 90th
percentile (representing the upper bound of the worst-case
scenario) is approximately one-quarter of the median OS; the
75th percentile (lower bound of the most likely scenario) is
approximately half the median OS; the 25th percentile (upper
bound of the most likely scenario) is approximately double
the median OS; and the 10 percentile (lower bound of the
best-case scenario) is approximately three times the median
OS. For example, if the median OS is 12 months then the
worst-case scenario is less than 3 months (0.25 x 12), the
most likely scenario is 6 to 24 months (0.5 to 2 x 12), and the
best-case scenario is 36 months or longer (3 x 12).

Using these simple rules of thumb, we developed a web-
based tool (iTool) to help oncologists estimate and explain
individualized scenarios for survival to patients with incurable
cancer seeking quantitative information about their prognosis.
With consumer input, we developed a one-page summary to
help explain this information to patients, family members or
carers (FMs), and other healthcare professionals (HCPs).

The aim of this study was to evaluate the iTool for esti-
mating and explaining personalized information about life
expectancy in people with advanced cancer, their medical
oncologists, FMs, and other HCPs.

Patients and methods

We conducted a multi-site, single-arm, phase 2 trial. The target
population was adults with incurable cancer attending the clinic
of a participating medical oncologist and indicating that they
wanted quantitative information about their prognosis (either
spontaneously or when their oncologist offered to discuss prog-
nosis). FMs were eligible if present during the consultation
when life expectation was discussed. HCPs involved in a partici-
pating patient’s care and receiving letters from the oncologist
as standard of care (e.g., general practitioner, referring surgeon,
radiation oncologist) were also invited to participate.

Participating oncologists were provided with access
to the iTool for the duration of the study (available at
https://ctc.usyd.edu.au/3scenarios/). When a patient
wanted information on their expected survival time, we asked the oncologist to estimate the patient’s life
expectancy defined as “the median survival of a group
of similar patients” based on studies of patients in the
same situation, prognostic tools, or their personal clinical
experience. The iTool calculated ranges for the three sce-
narios using simple multiples of the oncologist’s estimate
based on our previous work [16]. This information was
printed for the patient and FMs to take home (Supple-
mentary Text 1), and copies were placed in the patient’s
medical record and sent to HCPs with the oncologist’s
standard letter.

Following the consultation, the oncologist entered the
patient demographics and cancer details and completed a
questionnaire about the perceived usefulness of the iTool
for that patient, including if it was helpful, easy to use,
stressful, or lengthened the consultation (Supplementary
Text 2). After providing written, informed consent, patients
completed a questionnaire about the prognostic informa-
tion they received (Supplementary Text 3). FMs and HCPs
completed similar questionnaires regarding the information
they received (Supplementary Text 4 and 5). The study was
approved by the health research ethics committee at all par-
ticipating sites.

The primary measure of effect was the proportion of
patients who agreed or strongly agreed that “having my life
expectancy explained this way was helpful.” Other measures
of effect included the proportions of patients who agreed or
strongly agreed that “Having my life expectancy explained
this way”: made sense, gave hope, or made them feel worried
or anxious. Patients were asked if the information about their
life expectancy was better, worse, or about the same as they
had thought before the consultation. Patients were also asked
if they agreed it was helpful to be told each of the scenarios (best-case, worst-case, and most likely).

Patients also completed three other questionnaires:

1. The Short State Trait Anxiety Inventory (STAI), a six-item short form of the state scale of the Spielberger STAI [24]
2. The Herth Hope Index, a 12-item adapted version of the Herth Hope Scale with three subscales measuring temporality and future, positive readiness and expectancy, and interconnectedness [25]
3. The Life Orientation Test Revised (LOTR), a 10-item scale measuring levels of optimism [26]

A higher score indicated greater levels of either anxiety, hope, or optimism with each scale, respectively.

At the end of the study, participating oncologists completed a second questionnaire to determine their attitudes to using the iTool when discussing prognosis with their patients (Supplementary Text 6). Oncologists were sent emails asking them to update the survival status of each patient at time points corresponding to simple multiples of their estimated median survival time: 0.25, 0.5, 1.0, 2.0, 3.3, and 5.

For comparability with previous studies, we defined a point estimate of life expectancy (estimated median survival time of a group of similar patients) as precise if it was within 0.67 to 1.33 times the observed survival time [15] and hypothesized that approximately 20% to 30% of estimates would meet this definition. For each patient, we calculated the ratio of the observed survival time (OST) to their oncologist’s estimated survival time (EST) and used the Kaplan–Meier distribution of the ratio (OST/EST) to account for censored observations (patients still alive at their last follow-up). We expected oncologists’ EST to be well-calibrated (i.e., approximately equal proportions (50%) being longer than the observed survival time (OST/EST < 1) and shorter than the observed survival time (OST/EST > 1)).

Based on the broad concept of accuracy used in our previous work, we also hypothesized that approximately:

- Five to ten percent of patients would die within one-quarter of their oncologists’ estimate (OST/EST ≤ 0.25).
- Fifty percent of patients would have a survival time within half to double their oncologists’ estimate (0.5 ≤ OST/EST ≤ 2).
- Ten percent of patients would live beyond three times their oncologist’s estimate (OST/EST ≥ 3) [20].

A sample of size of at least 70 patients was calculated to provide > 95% power to distinguish the observed proportion of patients finding the iTool helpful from hypothetical true proportions of 80% or more versus 60% or less with an allowance of 20% for incomplete data. Associations between baseline characteristics and responses to questions about the prognostic information were assessed with logistic regression. Statistical analyses were done using R version 4.0.4.

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**Fig. 1** Consort diagram
Results

Between August 2012 and May 2016, 33 oncologists used the iTool to explain life expectancy to 222 patients (Fig. 1), of whom 201 consented to participate in the evaluation part of the study and 146 returned completed questionnaires (response rate 73%). Completed questionnaires were returned by 102 FMs and 140 HCPs. All 33 participating oncologists completed a questionnaire following each patient consultation (oncologist questionnaire 1), and 21 of the 33 oncologists completed a questionnaire at the end of the study (oncologist questionnaire 2).

The baseline characteristics of participating patients are summarized in Table 1. The median age was 67 years, and the majority (61%) were male. For most patients, the iTool was used more than 8 weeks after their diagnosis of incurable cancer, and at a third or subsequent consultation. The median estimated survival time was 12 months (range 2 to 96 months).

The vast majority (91%) of patients agreed or strongly agreed that the survival information presented by the iTool was helpful (Table 2). More patients preferred to hear each of the three scenarios (worst-case 81%, most likely 86%, and best-case 92%) than to be told the estimated median survival (78%). Seventy-seven percent of patients responded that the information about their prognosis explained as three scenarios for survival was about the same as, or better than, they expected before discussing it with their oncologist.

The attitudes of oncologists, HCPs, and FMs to having the information estimated and explained this way are summarized in Table 3. The median number of times each oncologist used the iTool was four (range 1 to 50). In 96% of consultations, oncologists agreed or strongly agreed that explaining life expectancy as three scenarios was helpful. There were very few consultations where oncologists agreed or strongly agreed that using the iTool significantly lengthened the consultation (9%). The majority of HCPs agreed or strongly agreed that having the information presented this way would be helpful for themselves (84%) and their patients (73%) and was more informative than the prognostic information they usually received (88%).

Associations between patients’ baseline characteristics and agreeing or strongly agreeing that presenting the life expectancy information as three scenarios was helpful are summarized in Table 4. Higher scores for hope were associated with a higher likelihood of agreeing that the information was helpful (OR 5.7, 95% CI 1.2 to 27, p = 0.03).

The median observed survival time was 9 months (range 0.5 to 43). Oncologists’ estimates were well-calibrated, with 54% (95% CI 46 to 61) of patients living longer than their EST and 46% (95% CI 39 to 54) living shorter than their EST. As hypothesized, 27% (95% CI 20 to 34) of oncologists’ point estimates of life expectancy met our arbitrary criterion for precision (within 0.67–1.33 times the OST). The proportions of patients with OSTs falling within prespecified ranges for the three scenarios corresponded closely with our a priori hypotheses: 7% (95% CI 3 to 10) of patients died within their estimated worst-case scenario; 51% (95% CI 43 to 59) lived within their estimated most likely scenario; and 13% (95% CI 8 to 23) lived within their estimated best-case scenario. Figure 2 shows the distribution of the OST/EST ratio for each patient.

At the end of the study, 81% (17/21) of responding oncologists agreed or strongly agreed that the iTool made discussing prognosis easier; 52% (11/21) agreed or strongly agreed that it made them more prepared to discuss prognosis; and

Table 1  Patient baseline characteristics (N=222)

| Characteristic                                      | N (%)a               |
|----------------------------------------------------|----------------------|
| Median age, years (range)                          | 67 (27–90)           |
| Sex, male                                          | 137 (61)             |
| Education (available for 146 patients who completed the patient questionnaire) |                     |
| Year 10 or less                                    |                      |
| High school/post high school qualification         | 58 (40)              |
| Unknown                                            | 81 (55)              |
| Spoken English level                               |                      |
| Fluent/Native                                      | 211 (95)             |
| Adequate                                           | 7 (3)                |
| Poor                                               | 4 (2)                |
| ECOG performance status                            |                      |
| 0                                                  | 46 (21)              |
| 1                                                  | 130 (59)             |
| 2                                                  | 43 (19)              |
| 3                                                  | 3 (1)                |
| Cancer type                                        |                      |
| Pancreatic                                         | 34 (15)              |
| Non-small cell lung cancer                         | 34 (15)              |
| Colorectal                                         | 26 (12)              |
| Prostate                                           | 25 (11)              |
| Breast                                             | 19 (9)               |
| Kidney                                             | 17 (8)               |
| Other                                              | 67 (30)              |
| Time from diagnosis of incurable cancer            |                      |
| ≤ 8 weeks                                          | 99 (45)              |
| > 8 weeks                                          | 123 (55)             |
| Consultation number                                |                      |
| Initial                                            | 65 (29)              |
| Second                                             | 26 (12)              |
| Third or subsequent                                | 131 (59)             |
| Estimated survival time                            |                      |
| <3 months                                          | 3 (1)                |
| 3–<9 months                                        | 81 (36)              |
| 9–15 months                                        | 72 (32)              |
| >15 months                                         | 66 (30)              |

*a Unless otherwise specified
86% (18/21) agreed or strongly agreed that they would like to continue using the iTool beyond the study.

Discussion

The majority of responding patients, FMs, and HCPs found it helpful to receive personalized scenarios for survival generated by the iTool. While 40% of patients found the life expectancy information upsetting, the majority of patients and FMs still found it helpful to be told each of the three scenarios, including the worst-case scenario. Most responding patients (77%) reported that the life expectancy information they received was the same or better than they had expected before the consultation. A higher score for hope was associated with higher likelihood of responding that the survival information was helpful. As hypothesized, oncologists’ point estimates of life expectancy for individual patients were well-calibrated but imprecise. However, scenarios for survival time calculated by the iTool using simple multiples of the oncologists’ estimates corresponded closely with our a priori estimates: approximately 10% of patients died within one quarter of their EST, approximately 50% lived within half to double their EST, and approximately 10% lived longer than three times their EST [16].

These favorable attitudes to using the iTool were consistent with our previous findings that people with cancer prefer to receive prognostic information formatted as three scenarios (worst-case, most-likely, best-case) rather than a point estimate of the median survival time [14]. Our previous work involved a hypothetical patient so it was reassuring to find similar results when real patients were presented with a personalized estimate of their own prognosis in this format. Participating oncologists reported that the iTool was easy to use and made them better prepared to discuss prognosis.

Our data indicate that the iTool could help overcome commonly cited barriers to discussions about prognosis including: lack of tools, lack of time, not knowing what to say, and fear of upsetting patients and family members [8, Table 2]

| Table 2 | Attitudes of patients to receiving personalized scenarios for survival using the web-based tool (N=146) |
|---|---|---|
| Proportion who agree with each statement | N (%) | 95% CI |

- **Having my life expectancy explained this way:**
  - Is helpful: 126/138 (91) 85–95
  - Makes sense: 136/142 (96) 91–98
  - Helps them make plans: 126/144 (88) 81–92
  - Gives them hope: 78/140 (56) 47–64
  - Reassures them: 89/139 (64) 56–72
  - Improves their understanding: 122/138 (88) 82–93
  - Makes them feel worried or anxious: 41/138 (30) 23–38
  - Upsets them: 58/140 (41) 34–50
  - Would be useful for their family members: 107/142 (75) 68–82
  - Would be useful for their family doctor: 127/141 (90) 84–94

- **Being told the following scenario was helpful:**
  - Best-case: 131/142 (92) 87–96
  - Most likely: 122/142 (86) 79–91
  - Worst-case: 115/142 (81) 74–87
  - Being told the time half a group of people would live longer or shorter than was helpful: 110/141 (78) 70–84

- **Preference for scenario to be told about first:**
  - Best-case: 28/143 (20) 14–27
  - Most likely: 49/143 (34) 27–43
  - Worst-case: 14/143 (10) 6–16
  - Order is not important to me: 52/143 (36) 29–45

- **How life expectancy information compared to expectations:**
  - Better than expected: 44/142 (31) 24–39
  - About the same as expected: 66/142 (46) 38–55
  - Worse than expected: 32/142 (23) 16–30

- **It was helpful for me to receive a printed summary of this information: 127/140 (91) 85–94

*aIncludes agree and strongly agree responses
Oncologists reported that using the iTool prolonged less than 10% of consultations, an important finding given fear of prolonging consultations is a reported barrier to discussing prognosis [8, 27]. Most patients found it helpful to receive a printed summary of information about their prognosis. Similarly, more than 70% of HCPs agreed that the printed three scenarios for survival information they received was more informative than the prognostic information they usually receive from oncologists, and that this information would help them make management and treatment decisions with their patients. We previously reported that quantitative information about prognosis was rarely included in letters from medical oncologists to HCPs [9]. Providing the one-page printed summary to HCPs could help ensure members of the multidisciplinary care team are aware of the estimated prognosis, and of what the patient has been told. This should improve the consistency of information and perhaps even improve patient care.

Fear of upsetting the patient is a commonly reported barrier to discussing prognosis [8].

### Table 3 Attitudes of family members and carers, healthcare professionals, and oncologists to the information provided by the web-based tool

| Attitudes of family members and carers (N = 102) | N (%) | 95% CI |
|-------------------------------------------------|-------|-------|
| Proportion who agree\(^a\) that the survival information presented by the iTool is helpful | 214/222 (96) | 91–99 |
| Proportion who agree\(^a\) that the survival information presented by the iTool is reassuring | 151/182 (83) | 74–90 |
| Proportion of consultations where the oncologist agreed\(^a\) that explaining life expectancy as 3 scenarios is helpful | 92/101 (91) | 84–95 |
| Proportion of consultations where the oncologist agreed\(^a\) that having life expectancy explained this way for the patient is helpful | 196/222 (88) | 83–92 |

\(^a\)Includes agree and strongly agree responses

\(^b\)Number of consultations, 33 oncologists completed a questionnaire after each patient consultation

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Fear of upsetting the patient is a commonly reported barrier to discussing prognosis [8]. Interestingly, oncologists
in this study agreed that patients would find the prognostic information upsetting in only 16% of consultations. This may be because they perceived the format of presenting three scenarios was less upsetting or perhaps that the patients they selected for the study were those less likely to be upset by the information. We found 40% of patients agreed that the prognostic information they received was upsetting, yet despite this, over 90% agreed that the information was helpful. We previously reported that providing patients with ranges for three scenarios was judged to offer more hope than providing a single point estimate of survival [14]. It is possible that providing ranges for three scenarios helps patients understand the uncertainty of survival estimates and allows them to hope for a realistic best-case scenario. Most patients found that the information presented about their life expectancy was either about the same as, or better than, they expected, even when given their worst-case scenario. Previous studies reporting that patients with advanced cancer are more likely to over-estimate their survival compared to their oncologists have generally compared a point estimate made by the patient with a point estimate made by the oncologist [2, 21, 28]. Another possible explanation is that the majority of patients in our study (59%) received their survival time scenarios at a third or subsequent consultation, and there may have been other, earlier discussions about prognosis.

This study and approach to discussing prognosis has several key strengths. We developed an easily accessible, web-based tool designed to help oncologists explain “worst-case, most likely, and best-case scenarios for survival time” to people affected by cancer. We studied the attitudes of patients receiving personalized information about their own

| Variables                                      | Agree or strongly agree | Disagree, strongly disagree, or unsure | Odds ratio (95% CI) | P value |
|------------------------------------------------|-------------------------|----------------------------------------|---------------------|---------|
| Age, years                                     |                         |                                        |                     |         |
| < 50                                           | 14/16 (88)              | 2/16 (13)                              | ref                 | 0.60    |
| 50–70                                          | 63/70 (90)              | 7/70 (10)                              | 1.3 (0.24–6.9)      |         |
| > 70                                           | 49/52 (94)              | 3/52 (6)                               | 2.3 (0.35–15)       |         |
| Sex                                            |                         |                                        |                     |         |
| Female                                         | 44/46 (96)              | 2/46 (4)                               | ref                 | 0.22    |
| Male                                           | 82/92 (89)              | 10/92 (11)                             | 0.37 (0.08–1.8)     |         |
| Cancer type                                    |                         |                                        |                     |         |
| Prostate                                       | 18/19 (95)              | 1/19 (5)                               | 2.3 (0.23–22)       | 0.78    |
| Kidney                                         | 12/13 (92)              | 1/13 (8)                               | 1.5 (0.15–15)       |         |
| Non-small cell lung cancer                     | 19/21 (91)              | 2/21 (10)                              | 1.2 (0.20–7.1)      |         |
| Pancreatic                                     | 16/18 (89)              | 2/18 (11)                              | 1.0 (0.17–6.1)      |         |
| Colorectal                                     | 16/18 (89)              | 2/18 (11)                              | 1.0 (0.17–6.1)      |         |
| Breast                                         | 13/13 (100)             | 0/13 (0)                               | NA                  |         |
| Other                                          | 32/36 (89)              | 4/36 (11)                              | ref                 |         |
| Education level                                |                         |                                        |                     |         |
| Year 10 or less                                | 49/55 (89)              | 6/55 (11)                              | ref                 | 0.38    |
| High school or above                           | 71/76 (93)              | 5/76 (7)                               | 1.7 (0.50–6.0)      |         |
| Short State Trait Anxiety Inventorya           |                         |                                        |                     |         |
| Below median (13)                              | 60/65 (92)              | 5/65 (8)                               | ref                 |         |
| Above median                                   | 64/70 (91)              | 6/70 (9)                               | 0.89 (0.25–3.1)     | 0.85    |
| Herth Hope Indexa                              |                         |                                        |                     |         |
| Below median (38)                              | 58/68 (85)              | 10/68 (15)                             | ref                 | 0.03    |
| Above median                                   | 66/68 (97)              | 2/68 (3)                               | 5.7 (1.2–27)        |         |
| Life Orientation Test Reviseda                 |                         |                                        |                     |         |
| Below median (16)                              | 46/51 (90)              | 5/51 (10)                              | ref                 | 0.77    |
| Above median                                   | 77/84 (91)              | 7/84 (8)                               | 1.2 (0.36–4.0)      |         |
| Estimated median survival                      |                         |                                        |                     |         |
| < 9 months                                     | 44/48 (92)              | 4/48 (8)                               | ref                 | 0.64    |
| 9–15 months                                    | 37/42 (88)              | 5/42 (12)                              | 0.67 (0.17–2.7)     |         |
| > 15 months                                    | 45/48 (94)              | 3/48 (6)                               | 1.4 (0.29–6.5)      |         |
| Time since diagnosis of incurable cancer       |                         |                                        |                     |         |
| ≤ 8 weeks                                      | 47/50 (94)              | 3/50 (6)                               | ref                 | 0.40    |
| > 8 weeks                                      | 79/88 (90)              | 9/88 (10)                              | 0.56 (0.14–2.2)     |         |

*aHigher score indicated greater levels of either anxiety, hope or optimism
life expectancy and also the attitudes of oncologists, FMs, and HCPs. We included patients with a wide range of ages, cancer types, and estimated life expectancies. This supports the applicability of the iTool in people with advanced cancer seeking quantitative information about their prognosis from receptive oncologists. Our data support the accuracy of scenarios for survival time based on simple multiples of their oncologist’s estimate of life expectancy.

The main limitations of this study are the biases inherent to a single-arm design. Participating oncologists may have had greater interest and expertise in discussing prognosis and may have selected patients they judged likely to welcome information presented this way. Our response rate for patient questionnaires was 73%; the 55 consenting patients who did not return a questionnaire may have had less favorable views. We did not assess patients’ understanding of the information presented about their prognosis. Our study involved only 33 oncologists. The generalizability of these findings requires further study, especially in the current era of increasing use of immunotherapy.

**Future directions**

Changing the behavior and practice of doctors is difficult. Australia has mandatory workshops on communicating prognosis for advanced trainees in medical oncology. Incorporating the iTool into this training offers an opportunity to increase its use. The [www.cancersurvivalrates.com](http://www.cancersurvivalrates.com) website is another useful resource for oncologists and people affected by cancer who seek quantitative information about prognosis. This website provides information based on recent data collected by the US SEER program and now provides information presented as three scenarios when the estimated median survival time is less than 3 years. These resources can help start and facilitate conversations about prognosis between patients and their doctors. Further research is needed to evaluate patients’ understanding of presented information about prognosis.

**Conclusion**

We have provided strong evidence supporting the recommendation that oncologists use three scenarios for survival time when thinking and talking about prognosis in advanced cancer. It was feasible, acceptable, helpful, and safe to use a web-based resource to do this.

*Our web-based tool can be accessed via the link [https://etc.usyd.edu.au/3scenarios/](https://etc.usyd.edu.au/3scenarios/)*

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**Data availability** The authors have full control of all primary data and agree to allow the journal to review their data if requested.

**Code availability** Not applicable.

**Declarations**

**Ethics approval** This study was performed in line with the principles of the Declaration of Helsinki and approved by the health research ethics committee at all participating sites.

**Consent to participate** Informed consent was obtained from all individual participants included in the study.

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**References**

1. Eidinger RN, Schapira DV (1984) Cancer patients’ insight into their treatment, prognosis, and unconventional therapies. Cancer 53(12):2736–2740
2. Weeks JC, Cook EF, O’Day SJ et al (1998) Relationship between cancer patients’ predictions of prognosis and their treatment preferences. JAMA 279(21):1709–1714. https://doi.org/10.1001/jama.279.21.1709
3. Wright AA, Zhang B, Ray A et al (2008) Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA 300(14):1665–1673. https://doi.org/10.1001/jama.300.14.1665
4. Gordon EJ, Daugherty CK (2003) ‘Hitting you over the head’: oncologists’ disclosure of prognosis to advanced cancer patients. Bioethics 17(2):142–168
5. Helft PR (2005) Necessary collusion: prognostic communication with advanced cancer patients. J Clin Oncol 23(13):3146–3150. https://doi.org/10.1200/JCO.2005.07.003
6. Baile WF, Lenzi R, Parker PA, Buckman R, Cohen L (2002) Oncologists’ attitudes toward and practices in giving bad news: an exploratory study. J Clin Oncol 20(8):2189–2196. https://doi.org/10.1200/JCO.2002.08.004
7. Hancock K, Clayton JM, Parker SM et al (2007) Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. Palliat Med 21(6):507–517. https://doi.org/10.1177/0269216307080823
8. Vasista A, Stockler MR, Martin A, Lawrence NJ, Kiely BE (2020) Communicating prognostic information: what do oncologists think patients with incurable cancer should be told? Intern Med J 50(12):1492–1499. https://doi.org/10.1111/imj.14739
9. McConnell D, Butow PN, Tattersall MH (1999) Improving the letters we write: an exploration of doctor-doctor communication in cancer care. Br J Cancer 80(3–4):427–437. https://doi.org/10.1038/sj.bjc.6603774
10. Moth EB, Parry J, Stockler MR et al (2015) Doctor-to-doctor communication of prognosis in metastatic cancer: a review of letters from medical oncologists to referring doctors. Intern Med J 45(9):909–915. https://doi.org/10.1111/imj.12776
11. Kaplowitz SA, Campo S, Chiu WT (2002) Cancer patients’ desires for communication of prognosis information. Health Commun 14(2):221–241. https://doi.org/10.1207/S15327072HC1402_4
12. Hagerty RG, Butow PN, Ellis PA et al (2004) Cancer patient preferences for communication of prognosis in the metastatic setting. J Clin Oncol 22(9):1721–1730. https://doi.org/10.1200/JCO.2004.04.095
13. Greisinger AJ, Lorimore RJ, Aday LA, Winn RJ, Baile WF (1997) Terminally ill cancer patients. Their most important concerns. Cancer Pract 5(3):147–154
14. Kiely BE, McCaughan G, Christodoulou S et al (2013) Using scenarios to explain life expectancy in advanced cancer: attitudes of people with a cancer experience. Support Care Cancer 21(2):369–376. https://doi.org/10.1007/s00520-012-1526-4
15. Stockler MR, Tattersall MH, Boyer MJ, Clarke SJ, Beale PJ, Simes RJ (2006) Disarming the guarded prognosis: predicting survival in newly referred patients with incurable cancer. Br J Cancer 94(2):208–212. https://doi.org/10.1038/sj.bjc.6602908
16. Kiely BE, Soon YY, Tattersall MH, Stockler MR (2011) How long have I got? Estimating typical, best-case, and worst-case scenarios to explain life expectancy in advanced cancer. BMJ 342(d):d3244. https://doi.org/10.1136/bmj.d3244
17. Kiely BE, Martin AJ, Tattersall MH et al (2013) The median informs the message: accuracy of individualized scenarios for survival time based on oncologists’ estimates. J Clin Oncol 21(2):369–376. https://doi.org/10.1200/JCO.2012.44.7821
18. Weeks TA, Kiely BE, Stockler MR (2014) Estimating scenarios for survival time in men starting systemic therapies for castration-resistant prostate cancer: a systematic review of randomised trials. Eur J Cancer 50(11):1916–1924. https://doi.org/10.1016/j.ejca.2014.04.004
19. Vasista A, Stockler M, Martin A et al (2019) Accuracy and prognostic significance of oncologists’ estimates and scenarios for survival time in advanced gastric cancer. Oncologist 24(11):e1102–e1107. https://doi.org/10.1634/theoncologist.2018-0613
20. Smith-Uffen MES, Johnson SB, Martin AJ et al (2020) Estimating survival in advanced cancer: a comparison of estimates made by oncologists and patients. Support Care Cancer 28(7):3399–3407. https://doi.org/10.1007/s00520-019-05158-5

21. Kiely BE, Alam M, Blinman P, Tattersall MH, Stockler MR (2012) Estimating typical, best-case and worst-case life expectancy scenarios for patients starting chemotherapy for advanced non-small-cell lung cancer: a systematic review of contemporary randomized trials. Lung Cancer 77(3):537–544. https://doi.org/10.1016/j.lungcan.2012.04.017

22. Vasista A, Stockler MR, West T, Wilcken N, Kiely BE (2017) More than just the median: Calculating survival times for patients with HER2 positive, metastatic breast cancer using data from recent randomised trials. Breast 31:99–104. https://doi.org/10.1016/j.breast.2016.10.007

23. Moth EB, Blinman P, Stefanic N et al (2020) Estimating survival time in older adults receiving chemotherapy for advanced cancer. J Geriatr Oncol 11:617–625

24. Marteau TM, Bekker H (1992) The development of a six-item short-form of the state scale of the Spielberger State-Trait Anxiety Inventory (STAI). Br J Clin Psychol 31(3):301–306. https://doi.org/10.1111/j.2044-8260.1992.tb00997.x

25. Herth K (1992) Abbreviated instrument to measure hope: development and psychometric evaluation. J Adv Nurs 17(10):1251–1259. https://doi.org/10.1111/j.1365-2648.1992.tb01843.x

26. Scheier MF, Carver CS, Bridges MW (1994) Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a reevaluation of the Life Orientation Test. J Pers Soc Psychol 67(6):1063–1078. https://doi.org/10.1037//0022-3514.67.6.1063

27. Granek L, Krzyzanowska MK, Tozer R, Mazzotta P (2013) Oncologists’ strategies and barriers to effective communication about the end of life. J Oncol Pract 9(4):e129–e135. https://doi.org/10.1200/JOP.2012.000800

28. Fenton JJ, Duberstein PR, Kravitz RL et al (2018) Impact of prognostic discussions on the patient-physician relationship: prospective cohort study. J Clin Oncol 36(3):225–230. https://doi.org/10.1200/JCO.2017.75.6288

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