

“The median isn’t the message”: How to communicate the uncertainties of survival prognoses to cancer patients in a realistic and hopeful way

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Abstract

This study investigated how doctors communicate the uncertainties of survival prognoses to patients recently diagnosed with life-threatening cancer, and suggests ways to improve this communication. Two hundred thirty-eight Norwegian oncologists and general practitioners (GPs) participated in Study 1. The study included both a scenario and a survey. The scenario asked participants to respond to a hypothetical patient who wanted to know how long (s)he could be expected to live. There were marked differences in responses within both groups, but few differences between the GPs and oncologists. There was a strong reluctance among doctors to provide patients with a prognosis. Even when they were presented with a statistically well-founded right-skewed survival curve, only a small minority provided hope by communicating the variation in survival time. In Study 2, 177 healthy students rated their preferences for different ways of receiving information regarding the uncertainty of a survival prognosis. Participants who received an explicitly described right-skewed survival curve believed that they would feel more hopeful. These participants also obtained a more realistic understanding of the variation in survival than those who did not receive this information. Based on the findings of the two studies and on extant psychological research, the author suggests much-needed guidelines for communicating survival prognoses in a realistic and optimistic way to patients recently diagnosed with life-threatening cancer. In particular, the guidelines emphasise that the doctor explains the often strongly right-skewed variation in survival time, and thereby providing the patient with realistic hope.

KEYWORDS

cancer care, decision psychology, hope, prognostic uncertainty, psycho-oncology, risk communication

1 | INTRODUCTION

A few years ago, I received an incurable cancer diagnosis. In my first meeting with my oncologist, I informed him, “My strategy is to hope for the best. What is the best I can hope for?” My doctor clearly did

not want to give me false hope. He told me that my condition was serious and that survival time was difficult to predict in a specific case. I searched the Internet for medical literature and found a review study indicating that the median survival time was 10 months from diagnosis. A difficult message. Was there any hope?

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1.1 | The median is not the message

Soon after, I came across and found hope in the famous evolutionary biologist Steven Jay Gould's (2004/1985) essay "The median isn't the message." Gould had experienced a similar situation 30 years earlier. He had received an incurable cancer diagnosis, but his doctor was unwilling to provide specific information about his survival. Gould (2004/1985, p. 140) searched the medical literature and discovered that the median survival time was 8 months. He reasoned, "The distribution of variation had to be right-skewed ... the upper (or right) half can extend out for years and years ... my favorable profile made me a good candidate for that part of the curve." Gould died 20 years later of another cause.

In the research literature on diagnosis-specific survival times, the median is the most common measure of central tendency, partly because the median is not influenced by extreme outliers. Accordingly, patients searching the Web for their prognosis are likely to find median survival times when they search for answers to the question "How long can I expect to live with my condition?"

According to Gould, the main reason that the median should not be the (only) message given to patients is precisely because it does *not* reflect information about outliers. Median survival time represents the middle value in a distribution, but it obscures the hopefulness inherent in the situation, namely the possibility of being one of the long-term survivors or "lucky outliers." The hope lies in the uncertainty, that is in the variation in survival times of individuals with the diagnosis.

1.2 | Communication of uncertainty

My own experience indicates that clinical practice has changed little since Gould received his diagnosis. When I asked my oncologist about my prognosis, I was given roughly the same vague answer as Gould was: "It varies, and it is hard to say in a specific case." Our doctors conveyed neither the full extent of the variation in survival time nor the right-skewed shape of the distribution. They did not provide all the facts, nor did they encourage us to have hope.

The quality of medical practice is closely related to how uncertainty within the field is addressed (Eddy, 1984; Han, Klein, & Arora, 2011; Katz, 1984; Seely, 2013). Uncertainty characterises all aspects of medical practice. Few aspects are more uncertain than prognoses, and communicating a prognosis typically involves communicating uncertainty.

1.3 | Questions

Every day, many people worldwide experience what Gould and I did, namely surprise at receiving a life-threatening cancer diagnosis. Most of them want to know their prognosis and particularly their expected survival time (Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005). Because of informed consent, most Western doctors are legally obliged to communicate survival prognoses and their uncertainty to patients (e.g. Gordon & Daugherty, 2003).

However, evidence-based guidelines for communicating this information do not exist. According to the neurologists Holloway, Gramling, and Kelly (2013), "The new science of prognostication—the estimating and communication [of] 'what to expect'—is in its infancy and the evidence base to support 'best practices' is lacking" (p. 764). The situation is similar in the case of cancer: "Prognosis is an issue that most doctors and patients describe as difficult to discuss and the best way of presenting prognostic information to optimise patient understanding, psychological adjustment and decision-making is uncertain" (Hagerty et al., 2005, p. 1005).

There is some literature that suggests guidelines for communicating prognoses to patients with *advanced* (metastatic) cancer (Back et al., 2008; Clayton et al., 2007; Kiely et al., 2013). However, this study is limited to the communication of a survival prognosis to patients *recently* diagnosed with life-threatening cancer, that is to patients who have not yet lived with cancer. Unfortunately, established evidence-based "best practice" guidelines for how to communicate this information have not been established. This study represents an initial attempt to address this gap.

Specifically, I began the study by asking the following two questions: "How do today's doctors communicate the uncertainties of survival prognoses to patients *recently* diagnosed with a life-threatening cancer diagnosis?"; and "Do oncologists and general practitioners (GPs) communicate this information differently?" These two descriptive issues were explored in Study 1 with oncologists and GPs. In Study 2, the prescriptive question "How should information be communicated?" was investigated with (healthy) university students.

2 | STUDY 1: HOW DO DOCTORS COMMUNICATE THE UNCERTAINTIES OF SURVIVAL PROGNoses TO PATIENTS RECENTLY DIAGNOSED WITH LIFE-THREATENING CANCER?

2.1 | Method

The participants comprised 118 Norwegian oncologists (age: *mean* = 41, *SD* = 11; years of experience: *mean* = 12, *SD* = 10) and 120 Norwegian GPs (age: *mean* = 49, *SD* = 11; years of experience: *mean* = 20, *SD* = 12). Women comprised 64% of oncologists and 42% of GPs. All participants were recruited via email. In the email, an oncologist (known to most of the oncologists and some of the GPs) encouraged the doctors to participate in the study. In the same email, the prospective participants were informed that the topic of the study was the communication of expected survival time to recently diagnosed cancer patients and the effects of different approaches to this communication. They were also told that approximately 20 min would be required to answer the survey. The doctors were not incentivised to participate in the study.

The GPs asked to participate were the approximately 200 GPs in the Oslo area on the email list they regularly use. The approximately 150 oncologists asked to participate were stationed throughout

Norway. They received the request through local email lists used by oncologists in the area. So, approximately 60% of the GPs (120 of 200) and 80% of the oncologists (118 of 150) who were asked (by email) to participate in the study did so. Because I have no information about the GPs (80 of 200) and the oncologists (32 of 150) who did not participate, I do not know how representative the sample is. The total 238 participants were randomly assigned, in equal numbers, to three conditions (C1–C3), as explained below.

2.1.1 | Vignette-based method

The doctors in all three conditions were first given the following instruction:

Imagine that you have a patient recently diagnosed with life-threatening cancer, and that you and your colleagues are quite certain that the diagnosis is correct. Imagine that your patient wants to know what the diagnosis entails, in particular, imagine that (s)he wants your honest answer on how long (s)he can be expected to live with this disease.

Imagine further that your basis for answering the patient is a recent comprehensive study on how long patients with the same diagnosis lived. These patients were of the same kind (age-group, sex etc.) as your patient, and the treatment they received was similar to the treatment you can offer your patients today. The study was recently published in a leading medical journal. In short, you have good reason to believe that how long the patients in this study lived after they got the diagnosis, gives a very good indication on how long a patient who get the same diagnosis today can be expected to live.

In the conditions C1 and C2, the doctors were then shown a markedly right-skewed survival curve from the above-mentioned study (Figure 1), accompanied by the following description:

The curve shows that half of the patients who received the diagnosis were alive 3 years later, that is, the median survival time was 3 years. Further, the extensive study showed (as depicted by the curve) that 75% of the patients were alive after two years, 20% after 5 years and, at the end of the 20-year study, 3% were still alive.

The participants in C1 were thereafter asked, based on the findings in the above study, to provide an *open-ended answer* to the patient's question on how long (s)he can be expected to live. In C2, on the other hand, the participants should answer the patient by choosing between two alternative answers, respectively a "Median" (M) and a "Right-Skewed" (RS) alternative.

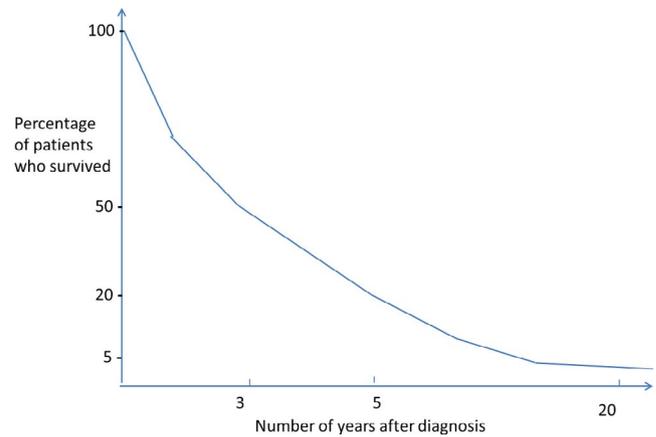


FIGURE 1 The survival curve provided to participants in C1 and C2

The M-alternative was:

Since it varies how long patients who get this diagnosis live, it is difficult for me to say how long you, as an individual, will live. Research has shown that three years after they get the diagnosis you have now received, half of the patients are dead and half of them are still alive. For example, in a recent study where they followed 100 patients who had received this diagnosis, they found that half of the patients, that is 50, were still alive 3 years later. But again, it is not possible for me to say with certainty how long you, in particular, will live.

The RS-alternative was:

Since it varies how long patients who get this diagnosis live, it is difficult for me to say how long you, as an individual, will live. Research has shown that three years after they get the diagnosis you have now received, half of the patients are dead and half of them are still alive.

However, some live much longer than three years. For example, in a recent study where they followed 100 patients who had received this diagnosis over a period of 20 years, they found that half of the patients, that is 50, were alive three years later, 20 were alive after 5 years and three of the 100 were still alive after 20 years. So, a few can live very, very long with the diagnosis you have now received. But again, it is not possible for me to say with certainty how long you, in particular, will live.

In short, the M-answer informed the patient of the median survival time, that survival time varies and that the survival time for an individual patient is difficult to predict. The RS-answer

TABLE 1 Questions in the questionnaire used in Study 1

1. Imagine that you have a good estimate (prognosis) of how long a recently diagnosed cancer patient can expect to live. When the patient insists on knowing their survival prognosis, will you then (typically) give the patient the prognosis, not give the patient the prognosis, give a more optimistic estimate (a longer survival time than predicted), or a more pessimistic estimate (a briefer survival time than predicted)?

2. When recently diagnosed cancer patients ask you how long they can expect to live, in what way(s) do you communicate the uncertainties of such prognoses?

By using (tick one or more of the options below):

Median/percentiles ("Half will be alive after 4 years") ---

Probabilities ("80% chance") ---

Relative frequencies ("8 out of 10") ---

"Lucky outliers" ("Some may survive for very long") ---

Survival curves (Visualisation using survival curves) ---

Verbal expressions (e.g. "Good chance," "Very uncertain") ---

3. Do you have a fixed (standardised) way of conveying prognostic uncertainty, or do you adapt your communication approach to the individual patient's ability to understand terms such as "median," "probability," and "percent"?

4. In general, how problematic do you find responding to recently diagnosed cancer patients' requests for information about how long they can expect to live? (1: completely unproblematic-7: very problematic)

5. When communicating a survival prognosis, to what extent do you find the following aspects problematic (1: completely unproblematic-7: very problematic):

a. The (often) high degree of uncertainty in providing a survival prognosis for an individual patient?

b. The communication of this uncertainty in an accurate and understandable way?

c. The conflict between communicating a realistic prognosis and taking care of the patient's needs (e.g. their need for hope)?

d. The risk that, in retrospect, you may be blamed by patients and their relatives for giving an incorrect prognosis?

e. The discomfort of communicating a (frequently) sad message?

f. The risk of being criticised by your colleagues?

6. When you have a good estimate (at the group level) of a cancer patient's expected survival time, how certain will this survival prognosis (typically) be? Estimate the percentage:

additionally provided an explicit description of the survival curve's right skewedness and emphasised the *small* possibility of being a lucky outlier.

In C3, the participants got only the following information about the findings in the above study: "The study found that half of those who got the diagnosis were still alive after three years, that is, the median survival time was 3 years. The study also found that the patients' survival time varied as it usually does in the case of severe cancer diagnoses, that is, the survival curve had a form that survival curves for patients recently diagnosed with life-threatening cancer typically have."

The participants in C3 were thereafter asked, based on the information they got about the study, to provide an *open-ended answer* to the patient's question on how long (s)he can be expected to live.

In addition, the doctors, in all three conditions, were asked what they would say to another hypothetical patient who had received the same diagnosis 3 years ago, who remains symptom free and who wants an honest prognosis.

2.1.2 | Survey

Subsequently, the doctors received a questionnaire consisting of six sets of questions (listed in Table 1) about how they generally communicate the uncertainty associated with survival prognoses.

2.2 | Results and discussion

If they did not answer a question, the participants were informed that they would not be asked more questions. Of the 238 doctors who participated in the study, only 146 (61%) answered all the questions related to the vignette and completed the questionnaire. The other 39% of participants answered only some of the questions, so the numbers of respondents per question vary.

No significant difference in the participants' replies with respect to sex, age and years of experience was found. The results reported below are therefore not segmented according to these demographic characteristics.

2.2.1 | Reluctance to provide a prognosis

Seventy-four of the 92 participants (80%) who failed to complete the study declined and withdrew from the study when asked to provide a survival prognosis to the hypothetical patient based on statistical information from the study described in the scenario. In C1, 32 of the 79 participants (41%) declined; in C2, only 12 of the 79 participants (15%) declined; and in C3, 30 of the 80 participants (38%) declined. In C2, the condition in which the doctors chose between two alternatives, 67 of the 79 participants (85%) remained in the study after this question, indicating that the doctors found it considerably easier to provide a prognosis when they were not asked for an open-ended answer.

Among the remaining 97 doctors in C1 (47) and C3 (50) who had to provide an open-ended answer, 53 (55% overall; 60% of oncologists; 48% of GPs) emphasised that it was "impossible" or "difficult" to give a prognosis to an individual patient.

Even when the doctors were asked to consider a more general situation in which they had a decent estimate for how long a patient could expect to live, and the patient insisted on being informed (see question 1, Table 1), 51 of the (remaining) 164 doctors who answered the question (31% overall; 35% of oncologists; 27% of GPs) would refuse to provide a specific prognosis.

Together, the high dropout rate that was observed when doctors were asked to give a prognosis based on highly relevant statistical information and the remaining doctors' answers to the other

TABLE 2 Mean ratings of how problematic the doctors considered different aspects related to the communication of survival prognosis (1: not problematic at all–7: highly problematic)

Aspect of the communication	All	Oncologists	GPs
	M (SD)	M (SD)	M (SD)
Problematic, overall	4.46 (1.61)	4.05 (1.46)	4.86 (1.67)
The uncertainty	5.22 (1.54)	4.85 (1.46)	5.60 (1.54)
Communication of the uncertainty	4.08 (1.46)	4.00 (1.50)	4.15 (1.42)
Conflict (realism vs. hope)	4.42 (1.40)	4.45 (1.48)	4.40 (1.33)
Blamed (by the relatives)	3.36 (1.55)	3.32 (1.63)	3.39 (1.47)
Discomfort (communicating sad message)	3.57 (1.43)	3.43 (1.33)	3.71 (1.53)
Criticism (from colleagues)	2.47 (1.34)	2.45 (1.38)	2.49 (1.31)

questions above indicate a strong reluctance among doctors to provide patients with a prognosis even when the patient strongly desires it, and they could provide the prognosis on well-founded, relevant statistical information.

2.2.2 | Lack of communication about the variation in survival time

Of the 50 remaining doctors in C3 who were informed of the median survival time, only 10 (20% overall; 35% of oncologists; 0% of GPs) informed the patient that some individuals may live much longer than the median. Only two of the remaining 29 oncologists and none of the remaining 21 GPs in C3 informed the patient that the variation in survival time is typically right-skewed for patients with recently diagnosed incurable cancer (Stockler et al., 2006).

Even in C1, only eight of the remaining 47 doctors (17%; 17% of oncologists; 17% of GPs) mentioned the existence of lucky outliers, despite having received both a graphical and a verbal description of the strongly right-skewed survival curve as well as being explicitly informed (in the study described earlier) that 3% of patients with the diagnosis were still alive after 20 years.

By contrast, in C2, the condition in which the participants were first given the same information as in C1 and were subsequently asked if they would give the patient the M-answer or RS-answer, a large majority, that is 49 of the remaining 67 doctors (73%; 72% of oncologists; 74% of GPs), chose the RS-answer.

Therefore, when the doctors (in C2) were explicitly reminded of an alternative way to communicate survival times, that is by communicating that the variation in survival time is strongly right-skewed, three out of every four doctors chose this alternative. When this answer was not provided as an explicit alternative (in C1), only one of every five doctors (who had received the same information as in C2) communicated this information.

The second hypothetical patient, who had already lived with the diagnosis up to the median survival time, had a considerably increased probability of being a long-term survivor. This fact was only incorporated into the answers of a minority of the doctors (48 of 164, 29% overall; 32% of oncologists; 27% of GPs). In both C1 and C2, the conditions in which the doctors received a detailed description and visualisation of the survival curve, only two of the (remaining) 56 GPs and none of the (remaining) 58 oncologists communicated to the patient the fact that the probability of being a lucky outlier had doubled since the time of diagnosis.

2.2.3 | Aspects that the doctors found problematic

The doctors rated the inherent uncertainty in drawing an inference about an individual patient from probabilistic knowledge as the most problematic aspect of conveying survival prognoses (question 5a, Table 1). They found this uncertainty ($M = 5.22$, $SD = 1.54$) significantly more problematic than they did find all the other potentially problematic aspects that they were asked about (Table 2). For example, a paired-samples t test showed that this uncertainty caused the doctors greater discomfort than did delivering a sad message ($M = 3.57$, $SD = 1.43$; $t = 10.500$, $p < 0.001$, 2-tailed).

They also judged the *communication* of uncertainty to patients (i.e. lay audiences), which is known to be highly problematic (e.g. Hoffrage, Lindsey, Hertwig, & Gigerenzer, 1999; Spiegelhalter, Pearson, & Short, 2011), as considerably less problematic ($M = 4.08$, $SD = 1.46$) than the inherent uncertainty in drawing an inference about an individual patient from probabilistic knowledge ($M = 5.22$, $SD = 1.54$; $t = 8.449$, $p < 0.001$; paired-samples t test, 2-tailed). However, instead of explaining the uncertainty, many doctors provided answers such as they “cannot say anything concrete” and “cannot give a number.” Excerpts of the doctors’ responses to the vignette exemplify how the doctors typically explained to the patient why they would not share the uncertain prognosis (Table 3).

According to Campbell et al. (2010, p. 463), “Doctors report fear that patients and their colleagues would judge them poorly for prognostic errors.” However, our Norwegian doctors rated “the risk of being criticized by your colleagues” as the least problematic aspect of communicating a survival prognosis ($M = 2.47$; $SD = 1.34$).

2.2.4 | Doctors expect to express the prognosis as a point estimate

Most doctors answered the hypothetical patient in a way that indicated that they thought a survival prognosis must be expressed as a specific number of years. This belief was demonstrated by, for example, the lack of a large difference between the percentage of doctors who expressed that it was difficult/impossible to give a prognosis in C1 (55%), the condition in which the doctors received an explicitly described right-skewed survival curve, and in C3 (54%), the condition in which they received information on the median survival time only.

TABLE 3 Excerpts of doctors' typical responses to the hypothetical patient in the vignette

"All the survival data that we have are averages for large groups of patients, and they have no relevance to individual patients."

"These are statistical calculations, and it is important to remember that one particular patient could have results that are outside what the statistics show."

"This question is difficult, and it is not possible to give a concrete answer in a single case (like yours)."

"In general, I can say that I never talk about expected survival times or statistics to individuals because knowledge at the group level (statistics) can never be used at the individual level. That makes no sense."

"The most important point to understand is that an individual is not a statistic and that we have to feel [sic] the correct information to provide to the particular patient. We can never give a definite prognosis for a particular patient, and therefore, it is always wrong to quantify the prognosis."

In the survey, the doctors estimated (question 6, Table 1) that when they possess good statistical knowledge (at the group level), the certainty of the survival prognosis for a particular patient is approximately 50% (overall mean = 49%, $SD = 20\%$; oncologists: $M = 48\%$, $SD = 20\%$; GPs: $M = 49\%$, $SD = 20\%$). This estimate is high, given the apparently widespread opinion among the doctors that survival prognoses are expected to be given as point estimates.

2.2.5 | Different ways in which the doctors communicate uncertainty

In the vignette-based part of the study, 45 of the (remaining) 97 doctors (46%; 39% of oncologists; 57% of GPs) in the conditions that required open-ended answers (C1 and C3) informed the patient of the median survival time. Additionally, in the survey (question 2, Table 1), approximately the same percentage of doctors (43%) reported that they might communicate the median survival time (Table 4).

Of the doctors who conveyed the median survival time to the hypothetical patient, 69% did so in a positive way; that is, they used the median to convey hope, for example "half of the patients live longer than 3 years." However, a substantial proportion of the doctors (e.g. five of 20 oncologists) incorrectly communicated the median survival time as the mean survival time. Other statistics were rarely used. For example, only 10 of the remaining 47 doctors in C1 (21%; 13% of oncologists; 30% of GPs) informed the patient of the 5-year survival rate even though this standard survival percentage was made explicitly available to the doctors.

In the survey, half of the doctors (50%) reported that they might inform their patients that some individuals may live for a long time with the diagnosis (Table 4). However, few doctors mentioned this fact in their open-ended answers (in C1 and C3), even among the doctors (in C1) who had been provided with the right-skewed distribution in Figure 1.

The percentage of doctors who reported in the survey that they might illustrate the uncertainty using graphical illustrations of

TABLE 4 Different ways in which the doctors reported that they communicate the uncertainties of survival prognoses

Variable	Percentage		
	All	Oncologists	GPs
Median/percentiles ("Half will still be alive after 4 years")	43.0	42.7	43.8
Probabilities ("80% chance")	14.8	14.6	15.0
Relative frequencies ("8 of 10")	14.8	9.3	20.5
Lucky outliers ("Some may in fact survive for very long")	49.6	52.0	49.3
Survival curves (Visualisation with survival curves)	11.4	8.2	15.0
Verbal expressions (e.g. "Good chance," "Very uncertain")	67.1	79.4	57.5

survival curves (11%) is consistent with the minority of doctors in C1 who communicated the entire variation in survival time (4 of 47, 9% overall; 4% of oncologists; 13% of GPs).

Overall, as indicated above, there were some discrepancies between how doctors informed patients about median survival times and right skewedness in the clinical scenario and the actual self-reported performance when the issues were generally addressed.

2.2.6 | Oncologists vs. GPs

All the oncologists had experience communicating expectations of survival time to recently diagnosed cancer patients. Most of the GPs (73%) also reported having such experience.

Overall, GPs considered providing survival prognoses to be more problematic ($M = 4.86$, $SD = 1.67$) than did the oncologists ($M = 4.05$, $SD = 1.46$, $t = -3.119$, $p = 0.002$; independent-samples t test, 2-tailed). Specifically, the GPs considered the uncertainty related to drawing an inference about an individual patient from probabilistic knowledge as more problematic ($M = 5.60$, $SD = 1.54$) than did the oncologists ($M = 4.85$, $SD = 1.46$, $t = -2.991$; $p = 0.003$, independent-samples t test, 2-tailed). The between-group differences with respect to the other problematic aspects of providing survival prognoses were not significant (Table 2).

In the survey, a much larger percentage of GPs (21%) compared to oncologists (9%) reported that they might use relative frequencies for communicating uncertainties (Table 4). Another apparent difference is that (for question 1, Table 1) many more GPs (15%) than oncologists (5%) reported that they typically provide patients with more optimistic estimates. However, neither these differences nor the between-group differences in the vignette-based part of Study 1 were significant.

Overall, even though the oncologists had considerably more experience communicating uncertain survival prognoses to patients than did the GPs, no significant difference was found between how the two groups communicate prognostic uncertainty.

The findings of Study 1 are consistent with those of many other studies. For example, Christakis and Iwashyna (1998, p. 2389)

TABLE 5 Questionnaire used in Study 2

1. Hope: "After receiving this answer from your doctor, how hopeful do you imagine you will be with respect to how much time you have left to live?" (1: not hopeful at all–7: very hopeful)
2. Realism: "Based on the information I received from the doctor, it is realistic to expect that I have FROM (minimum) ___ years TO (maximum) ___ years left to live."
3. Accuracy: "To what extent do you believe that your relatives would judge themselves accurately/inaccurately informed, if you died after (a) 1 year; (b) 8 years; (c) 20 years." (1: completely inaccurately informed–7: completely accurately informed)

surveyed 697 internists and found that "the physicians disdain prognostication: 60% find it "stressful" to make predictions; 59% find it "difficult"; (...) 80% believe patients expect too much certainty."

2.2.7 | Lack of standard communication approach

Although no major between-group difference was found, the responses to most questions within each group were wide-ranging. Therefore, there is clearly no consensus among Norwegian doctors concerning how survival prognoses should be communicated. The obvious reason for this lack of consensus is the absence, as mentioned earlier, of established national or international evidence-based best practice guidelines for communicating survival prognoses to patients who have recently been diagnosed with life-threatening cancer. Kiely, Tattersall, and Stockler (2010, p. 2802) emphasise, in particular: "Although patients, caregivers, and health care professionals have identified hope as an integral part of prognostic discussions, the key practical questions of how to define, quantify, and convey realistic hope remain unanswered." This observation motivated Study 2.

3 | STUDY 2: HOW SHOULD PROGNOSTIC UNCERTAINTY BE COMMUNICATED TO PATIENTS RECENTLY DIAGNOSED WITH LIFE-THREATENING CANCER?

3.1 | Why doctors should explain uncertainty

The findings of Study 1 indicate that doctors are reluctant to convey survival prognoses to their patients. However, several studies show that most patients want to know their realistic prognosis (Hagerty et al., 2005). Consequently, if doctors refuse to give their patients survival prognoses, many patients (or their relatives) will search for the prognoses themselves. They will then often find median survival times because the survival data in pertinent clinical trials are typically summarised as a median. Most patients, however, are unfamiliar with the concept of "median" and understand it to mean "average" (Davey, Butow, & Armstrong, 2003). More importantly, the median "does not account for the fundamental statistical principle of range, an essential part of understanding survival curves" (Levin, 2015, p. 142).

In addition to providing the median survival time, which patients can often easily find by themselves on the Internet, a doctor could make the statistics more meaningful by explaining the *variation* in survival time, thereby providing realistic hope, which often improves patients' quality of life and survival times (e.g. Barefoot et al., 2011; Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000).

Another reason why doctors, when requested, should provide patients with survival prognoses is that knowledge about the probability of the possible treatment outcomes is a precondition for shared decision-making and informed consent, both of which are central tenets of modern patient-centred medicine (e.g. Parascandola, Hawkins, & Danis, 2002; Reyna, Nelson, Han, & Pignone, 2015). Finally, detailed explanations of prognoses can improve relationships between patients and doctors, build trust and make patients more optimistic (Campbell et al., 2010; Gordon, Joos, & Byrne, 2000; Hagerty et al., 2005; Katz, 1984; Mack et al., 2007; Parascandola et al., 2002).

Accordingly, these considerations raise the question of *how* to communicate a survival prognosis and its uncertainty realistically and in the most hopeful way to patients recently diagnosed with life-threatening cancer.

How survival prognoses should be communicated is an empirical question. Kiely et al. (2013) is one of the few studies that have systematically compared the effects of different ways of communicating the uncertainty of survival prognoses to patients. However, unlike the current study, in which doctors are asked how they would communicate a survival prognosis to *recently* diagnosed patients, Kiely et al. (2013) studied how to communicate such a prognosis to patients with advanced metastatic cancer.

3.2 | Hypothesis

Based on analyses of the survival times of patients after diagnoses of incurable cancer, one study determined that if the estimated median survival time of an individual patient was M , approximately 50% patients will live from $\frac{1}{2}M$ to $2M$, 10% will live less than $\frac{1}{6}M$, and approximately 10% will live at least $3-4M$ (Stockler et al., 2006). Kiely et al. (2010, p. 2803) argue that the best way to communicate both hope and realism to patients with (advanced) metastatic cancer is to communicate all three possibilities, that is to "estimate and explain the typical, best-case and worst-case scenarios."

Although I generally agree with this position and believe this approach also is sensible when patients have recently been diagnosed but have not yet lived with cancer, I would like to propose three modifications. First, Kiely et al. (2010, p. 2803) argue, "Quantifying and explaining the best-case scenario representing the best 10% of patients is preferable to describing an individual long-term survivor, and is more realistic." I disagree. Good reasons for *also* communicating information about specific long-term survivors exist. One reason is that studies show that most patients want, as I did, to know the best case they can hope for. For example, one study found: "The majority of [cancer patients] wanted to know longest survival time with treatment (85%)" Hagerty et al., (2004, p. 1721).

The oncologists Kiely et al. (2010, p. 2802) ask themselves, “But how do oncologists find hope?,” to which they respond: “A potential source of hope stems from our experiences with patients who manage to defy the odds and become long-term survivors. Such experiences can help us envision, and therefore convey, hope.” So, why not also give patients hope by informing them of such “lucky outliers”?

Moreover, in the case of lucky outliers or other emotionally charged events, people are more attentive to the possibilities than to the actual (small) probabilities involved, as highlighted by research on so-called *probability neglect* (Rottenstreich & Hsee, 2001; Sunstein, 2002).

Second, Kiely et al. (2010) suggest using percentages to communicate the proportions of patients who are likely to end up in the best, worst and typical categories. However, it is well known from decision psychology that “statistics expressed as natural frequencies improve the statistical thinking of experts and nonexperts alike” (Hoffrage et al., 1999, p. 2261). Gigerenzer and Galesic (2012) explain why frequencies are superior to single-event probabilities for communicating risk. It is also well documented that if the probability of being a lucky outlier is provided as a relative frequency, for example “2 of the 100 individuals who receive this diagnosis will live for longer than 20 years,” people will experience stronger positive emotions than if they are told, “2% of those who receive this diagnosis will live for longer than 20 years” (Gigerenzer, 2002; Slovic, Monahan, & MacGregor, 2000).

Third, research on decision psychology indicates that laypeople, who often have low numeracy skills, will better understand explanations of uncertainty in visual form (e.g. Politi, Han, & Col, 2007; Spiegelhalter et al., 2011). The uncertainty, that is the variation in survival time, can thus be better understood when also visualised as a right-skewed survival curve rather than only being presented as proportions of patients in each survival time category.

In summary, I hypothesise that the best way to communicate the uncertainties of survival prognoses is to explicitly visualise a strongly right-skewed survival curve and to describe it using relative frequencies. In addition, the doctor should emphasise (when true) that some patients who receive a particular diagnosis may survive for much longer than the median survival time. Study 2 was designed to test this hypothesis.

3.3 | Method

The participants of Study 2, which was a pen-and-paper study conducted in a classroom, were psychology and computer science students at the University of Oslo, Norway ($N = 177$). They were asked to imagine that they had recently received a serious cancer diagnosis, might not have long to live and had asked their doctor how long they could expect to live.

The study comprised two conditions in which a hypothetical doctor gave either a “T-answer” or an “H-answer,” corresponding to, respectively, the typical (and traditional) answer given by the doctors in Study 1 and the hypothetical approach. The T-answer conveyed the median survival time along with a statement indicating that survival time varies and is difficult to predict for a particular patient. The H-answer additionally provided information about the survival curve’s right skewedness. This answer was identical to the RS-alternative in C2 in Study 1. That is, the participants were informed of the median survival time, that survival time varies and that the survival time is difficult to predict for an individual patient, and, in addition, they were given an explicit description of the survival curve’s right skewedness, and the *small* possibility of being a lucky outlier was emphasised.

The dependent variables were judgements of the degrees of hope, realism and accuracy, which were rated using the participants’ responses to the questions shown in Table 5.

3.4 | Results and discussion

Participants who received the H-answer believed they would feel more hopeful than did those who received the T-answer. The H-answer also gave participants greater hope in that they judged living longer to be more realistic than did those who received the T-answer (for all the results, Table 6).

More surprisingly, those who received the H-answer also considered the realistic minimum survival time to be longer than did those who received the T-answer. Overall, the H-answer gave participants a more realistic understanding of the distribution in survival time around the median than did the T-answer, that is an understanding of the variation in survival time that greatly conformed to the typical spread found in the case of patients diagnosed with incurable cancer (Stockler et al., 2006).

Variable	H-answer	T-answer	t-value	p-value
	M (SD)	M (SD)		
Hope	3.86 (1.08)	3.55 (1.08)	-2.492	0.014
Realism (maximum)	11.40 (7.67)	6.49 (2.16)	-5.752	<0.001
Realism (minimum)	2.76 (1.53)	2.05 (1.07)	-3.555	<0.001
Accuracy—1 year	3.77 (1.83)	3.91 (1.96)	-0.497	0.620
Accuracy—8 years	5.28 (1.32)	4.37 (1.87)	-3.748	<0.001
Accuracy—20 years	4.60 (2.01)	2.60 (1.68)	-7.177	<0.001

TABLE 6 Effect of the T-answer compared to the H-answer in Study 2

Note. Between-subjects comparisons = *t* tests (two-tailed) for independent samples

Finally, the participants judged that their relatives would be more accurately informed if they lived 8 or 20 years and if the doctor gave the H-answer rather than the T-answer. No significant difference between the two conditions was found if the patient lived only 1 year (Table 6).

Accordingly, it can be concluded that the participants believed that the H-answer (which was devised in accordance with my hypothesis that a beneficial communication approach should involve describing the right-skewed distribution of survival time), compared with the T-answer (which was similar to the typical answer that patients received from doctors in Study 1), would significantly raise their hopes. The H-answer also offered participants a more realistic understanding of the expected survival time, and the participants judged their relatives to be more accurately informed if they had been given the H-answer rather than the T-answer.

4 | GENERAL DISCUSSION

4.1 | Scepticism about the relevance of probabilistic knowledge

According to the oncologists Kiely et al. (2010, p. 2803), "One of the reasons we struggle to communicate information on life expectancy is a lack of obvious data on which to base our estimates." However, the results of Study 1 indicate that a substantial proportion of doctors would not inform a hypothetical patient about the uncertainty of the survival prognosis, even when they could base their explanation on a relevant, well-founded survival curve.

This finding concurs with previous findings that in general, clinicians rarely communicate degrees of uncertainty to patients (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999; Politi et al., 2007). For example, an extensive analysis of more than a thousand discussions with patients by primary care doctors and surgeons found that only 16%–18% of discussions satisfied the minimum criteria necessary for patients to make an informed decision. Discussions of uncertainty about the risks and benefits of treatment occurred only 1%, 6% and 16.6% of the time for basic decisions, intermediate decisions and complex decisions respectively (Braddock et al., 1999).

Scepticism about the relevance of probabilistic knowledge has a long tradition within medicine (Berwick, Fineberg, & Weinstein, 1981; Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz, & Woloshin, 2008; Katz, 1984), as illustrated by a statement by the famous physiologist Claude Bernard in 1865: "Statistics that the mortality law for this operation is two out of five ... means literally nothing scientifically and gives us no certainty in performing the next operation; for we do not know whether the next case will be among the recoveries or the deaths" (Bernard, quoted in Gigerenzer et al., 2008, p. 76).

Excerpts from the doctors' typical answers to the hypothetical patient in Study 1 (Table 3) indicate that this sceptical attitude towards probabilistic knowledge is very much alive in the medical field today. For example, in Study 1, a female oncologist, age 55, with 16 years' experience, replied: "All the survival data that we have are

averages for large groups of patients, and they have no relevance to individual patients."

Overall, the findings of Study 1 support Katz's, (1984, p. 35) old claim: "Medical knowledge is engulfed and infiltrated by uncertainty (...) Yet the reality is generally brushed aside as doctors move from its theoretical contemplation to its clinical application in therapy and, even more so, in talking with their patients."

4.2 | The problem is not prognostic uncertainty, but how it is communicated

The findings of Study 1 indicate a widespread opinion among doctors that not only they but also their patients feel that the uncertainty of survival prognoses is problematic. However, research shows that patients and their relatives understand and accept that a prognosis (often) is and must be uncertain (Evans et al., 2007; Parascandola et al., 2002).

The doctors who participated in Study 1 reported that they considered the inherent uncertainty of a prognosis to be significantly more problematic than the communication of this uncertainty to patients. For patients, the reverse might be true. Several studies have shown that the way in which uncertainty is communicated is more decisive for patient satisfaction than is the existence of the uncertainty (Han et al., 2009; Johnson, Levenkron, Suchman, & Manchester, 1988; Ogden et al., 2002; Politi, Clark, Ombao, & Legare, 2011). In brief, a patient's response to the physician's uncertainty has been found to be highly dependent on the technique employed by the physician to express uncertainty (e.g. Ogden et al., 2002).

The fact that many of the participants in Study 1 declined and dropped out at the point of decision-making can be attributed to some extent to the doctors' inability to comprehend the curves. This finding is consistent with that of many other studies, indicating that training workshops on frequencies, curves and, more generally, how to present statistical information to laypeople might be required for doctors. For example, Christakis and Iwashyna (1998) found that most of the 697 internists (57%) in their study reported inadequate training in prognostication. Kiely et al. (2010, p. 2803) also highlight the necessity of training: "Current literature and communication courses provide excellent guidance on how to broach discussions about prognosis, but little guidance on how to estimate and explain the likely survival time."

4.3 | Communication guidelines

4.3.1 | The necessity of guidelines

In Study 1, only four of the 164 doctors reported that they communicated survival prognoses to recently diagnosed cancer patients in a standardised way (question 3, Table 1). To ensure that patients who request information about their expected survival time receive this information in a satisfactory manner, the communication approach must be standardised to some extent. Without such standards, patients will receive answers that vary considerably depending on the

doctor they ask. Clear communication guidelines could eliminate or at least reduce this variation. Moreover, the findings of Study 1 show that many more of the doctors communicated both realism and hope to the patient if they were explicitly reminded how to do so. Therefore, guidelines are clearly required, but what should they look like?

4.3.2 | Communicate the full variation in survival time

Gould (2004/1985, p. 140) claimed: "Variation itself is nature's only irreducible essence. Variation is the hard reality." In stark contrast to Gould's understanding, many doctors in Study 1 expressed, explicitly and implicitly, that there is no alternative to providing a survival prognosis as a point estimate. They did not seem to realise that an alternative approach would be to describe "the hard reality," that is the variation in survival times among those who receive the diagnosis, and to do so in a way that provides hope to the patient.

Kiely et al. (2010) suggest that when communicating prognoses to patients with (advanced) cancer, the full variation should be communicated as the probability of ending up in the best, worst and typical survival time categories. None of the doctors who participated in Study 1 came close to communicating the prognosis in this way.

Earlier, I proposed that Kiely et al.'s (2010) suggestion could be improved by using relative frequencies instead of probabilities and by visualising the often right-skewed variation in survival times for the patient with a survival curve. However, research shows that the downward curve of survival graphs is sometimes interpreted as highly negative by patients (Davey et al., 2003). This negative interpretation highlights why it is particularly important that the doctor spends time explaining the survival curve to the patient.

4.3.3 | Emphasise the possibility of becoming a long-term survivor

The hypothesis investigated in this study also differs from Kiely et al.'s (2010) suggestion in that the current study considered the phenomenon of probability neglect. Analogously to how casinos exploit this phenomenon, one can use it in a positive way when communicating survival times to patients recently diagnosed with life-threatening cancer. When communicating a survival prognosis, one can highlight (when true) that some patients can survive for a long time with the diagnosis. The patient will then imagine the possibility of a very positive outcome and unconsciously downplay the fact that the probability of the outcome is very small (Rottenstreich & Hsee, 2001). If the doctor can provide concrete examples of such long-term survivors from their own practice or a nearby practice, research indicates that the patient's feelings of hope will further increase (Slovic et al., 2000).

Even if there is a need to promote hope, promoting unrealistic hope may have a cost, particularly for patients with advanced cancer. Encouraging such patients to imagine possibilities of low-probability events may generate unrealistic expectations and prompt poor

decision-making (e.g. requesting active treatment when there is a slim chance of benefit and a high chance of considerable morbidity). However, for patients who suddenly and unexpectedly receive a life-threatening cancer diagnosis, it is difficult to conceive that informing them that they have a small possibility of being a lucky outlier may have similar costs.

4.3.4 | Summary: How to communicate survival prognoses in a realistic and optimistic way

When recently diagnosed cancer patients request information concerning their expected survival time, they want both realism and hope. The doctor must first explain that what (s)he can do is to provide statistical information for a group of patients rather than an individual patient. Thereafter, the doctor (if (s)he possesses the relevant information) should communicate the uncertain prognosis by first communicating the median survival time M in a positive, hopeful manner (e.g. "Half of the patients will live longer than M "). Subsequently, (s)he should describe, using relative frequencies, and visualise, using a survival curve, the often strongly right-skewed variation in survival time. The doctor should finish by emphasising (when true) that some patients who receive the diagnosis may in fact survive for considerably longer than the median survival time, and, if possible, give concrete examples of such long-term survivors.

If these guidelines are followed, the patient will receive realistic, accurate information in a way that psychological research and the findings of Study 2 indicate is likely to provide the patient with a hopeful yet realistic understanding of the prognosis.

4.4 | Limitations and the need for more empirical research

In Study 1, it was impractical to study actual doctor-patient interactions. I therefore used vignettes. In clinical practice, when a doctor is faced with a scared, anxious and stressed patient, the doctor's response could be very different. In Study 1, the doctors had the option to withdraw from answering, but when faced with a patient in real life, the situation is different. Conducting the same study by exploring actual doctor-patient interactions could have produced very different results. So, ideally, such studies should also be performed.

A clear weakness with Study 1 is the high dropout rate. However, I know which question prompted 80% of the doctors to drop out, and in the discussion, I rationalised why they may have declined when confronted with this question. The high dropout rate following this question is consistent with the findings of many other studies. Overall, the findings of Study 1 accord well with previous research.

A limitation of Study 2 is that only the effect of a single hypothesis about how to communicate uncertainties in survival prognoses was compared with the effect of doctors' typical communication approach (as elucidated in Study 1). Many other possible communication approaches exist that were not tested.

Another limitation of Study 2 is that it was restricted to the communication of hypothetical survival prognoses to *healthy* participants. It is well known that persons who have or have had cancer tend to reply differently to doctors and the general public when asked questions such as how they consider the value of intensive chemotherapy for a very small probability of benefit (e.g. Slevin et al., 1990). The same holds true for physicians. For example, doctors who have themselves been diagnosed with chronic diseases are more open to discussing prognoses and related concerns with their patients (Klitzman & Connelly, 2008).

However, since Study 2 was restricted to *recently* diagnosed patients who had suddenly received a cancer diagnosis but had not lived with cancer when they asked for the prognosis, I consider it relevant and justifiable to use non-patients as participants. Moreover, the answers I received from the healthy students in Study 2 also accorded well with the reactions of two persons who unexpectedly received a life-threatening cancer diagnosis, Gould (2004/1985) and the present author.

Nonetheless, a related limitation of Study 2 is the fact that the participants, psychology and computer science students, are not representative of the general population with respect to their numeracy skills and ability to comprehend statistical information. They are mathematically savvy, which means that they are more likely to understand a right-skewed survival curve than is the general population. Although decision psychology studies show that laypeople understand uncertainties better in the form of visuals, this finding does not necessarily apply to graphs that require some mathematical interpretation such as the curves used in this study (Davey et al., 2003). According to Spiegelhalter et al. (2011, p. 1393), "there is limited experimental evidence on how different types of visualizations are processed and understood, although the effectiveness of some graphics clearly depends on the relative numeracy of an audience." Future studies with the general population are required to assess whether and to what extent laypeople understand right-skewed survival curves.

Patients clearly differ in ways beyond numeracy. They differ in terms of other cognitive differences and personality, and the way they process information depends on their personality. For example, Sorrentino, Bobocel, Gitta, Olson, and Hewitt (1988, p. 369) distinguish between uncertainty-oriented individuals, "predisposed to resolve uncertainty and to attain clarity about themselves and their environment," and certainty-oriented individuals, "who may in fact be representative of the majority of people outside of academia [who] may look for external guidance and rely on judgmental heuristics more as the importance of the decision increases." Ideally, different types of patients should receive survival prognoses in different ways. Many empirical studies must be performed to achieve this goal.

Hence, for several reasons, Study 2 constitutes only a small first step towards establishing a set of evidence-based best practice guidelines for communicating uncertainties in survival prognoses to patients recently diagnosed with life-threatening cancer. Additional empirical studies are clearly required.

4.5 | An addendum

In my second meeting with my doctor, I again searched for hope and asked: "If I am still around 10 years from now, would you then have a finding to write a case study about?" He answered, "Oh no, 10 years is far from enough." The findings of Study 2 suggest that he should have told me so in our first meeting.

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