Most oncologists agree that thinking and talking about life expectancy is an important part of caring for people with incurable cancer. Thinking about life expectancy helps oncologists make important decisions, including (1) when to discuss starting or stopping anticancer therapy; (2) who to enroll in a clinical trial where life expectancy is an eligibility criterion; (3) timing of referral to palliative care and hospice; and (4) timing of discussions on end-of-life care and advanced directives.

Most patients want information on life expectancy and many want specific estimates of best case, worst case, and typical scenarios for survival. Such information helps patients make treatment decisions, set appropriate goals, plan for the future, and prepare for death. Not all patients want prognostic information, and not all who want it will request it. Each patient encounter should be considered separately because information needs differ between patients and within the same patient at different times. Physicians should repeatedly check if patients want information about life expectancy, and if so, what type of information they want.

Discussing life expectancy is difficult and many physicians will avoid such conversations, communicate euphemistically, be overly optimistic, or delay discussions until patients are close to death. In a study of initial consultations between oncologists and incurable cancer patients, most patients (75%) were informed that their disease was incurable; however, only 58% were told about life expectancy, 35% received a quantitative estimate, and fewer than 10% were given a time frame of life expectancy. In another study physicians reported they would provide a frank estimate of life expectancy only 37% of the time and would usually (63%) provide no estimate, a conscious overestimate, or a conscious underestimate. The reasons for this reluctance to discuss life expectancy include insufficient training, fear of upsetting the patient, fear of providing inaccurate information, and lack of time.

Cancer patients’ understanding of life expectancy is frequently imperfect, with many overestimating the probability of long-term survival and likely benefits of therapy. The benefits of improved understanding were demonstrated in two studies which found that patients who were aware of their life expectancy were less likely to seek aggressive medical interventions with little or no survival benefit, less likely to receive inappropriate intensive care at the end of life, and more likely to enroll in hospice programs earlier. There is little evidence that information on life expectancy causes patients harm, especially if the information is tailored to their stated information preferences. Increased prognostic information has not been
associated with increased anxiety and there is a suggestion that a lack of information may heighten anxiety.\textsuperscript{7,14} Similarly, awareness of life expectancy in itself has not been associated with increased depression.\textsuperscript{14,15}

**IMPROVING HOW WE THINK AND TALK ABOUT LIFE EXPECTANCY**

**Estimating Life Expectancy During Palliative Chemotherapy**

Discussions about starting chemotherapy for incurable cancer are likely to provoke thoughts and questions about life expectancy, even if not always explicit. There is a paucity of information to guide physicians on the specifics of how to estimate survival and how to explain it in a way that conveys meaning without destroying hope. This is especially a problem for those who are probably many months away from dying, and a probable contributor to oncologists’ reservations about discussing life expectancy. Data are required for estimating survival. Survival data from groups of patients in routine practice with similar characteristics (demographics, disease, and treatment) would be ideal but are rare. In the absence of such ideal data, clinical trials can provide detailed survival information that is readily available and easily accessible.

We previously proposed that the percentiles of an overall survival (OS) curve can approximate the worst case, most likely, and best case survival scenarios.\textsuperscript{16} The 90th percentile (survival time for the 10% doing worst) can represent the worst case scenario. The interquartile range (survival times for the middle 50% of patients, from the 75th to the 25th percentiles) represents the most likely scenario. The 10th percentile (survival of the 10% of patients doing best) can represent the best case scenario. We have also reported that the survival curve in heterogeneous advanced cancers is approximately exponential, allowing its percentiles to be estimated by simple multiples of its median\textsuperscript{16} (Figure 1). We tested this method in contemporary trials of first-line chemotherapy for advanced breast cancer and lung cancer. We found that for most OS curves, about one quarter of the median was accurate for estimating the worst case scenario (90th percentile). About half to double the median was accurate for the most likely scenario (75th to 25th percentiles), and about three times the median was accurate for the best case scenario.\textsuperscript{17,18} Although these multiples need to be tested in other advanced cancers, they provide simple rules of thumb for physicians to estimate and explain life expectancy. Physicians could use the median OS from a pertinent clinical trial as a starting point, and then adjust that median according to the characteristics of the individual patient at hand. For example, the median could be adjusted down for patients with poorer performance status than those in the trial. This adjusted median can then be multiplied by 0.25, 0.5, 2, and 3 to make estimates of the worst case, lower and upper ends of the most likely range, and best case scenarios, respectively.

**Estimating Life Expectancy After Progression on First-Line Chemotherapy**

Progression on chemotherapy is another event likely to provoke thoughts and questions about life expectancy. In this situation, the time to progression may provide information that helps predict survival time after progression. For example, patients with rapid progression on first-line therapy would be expected to survive a shorter time than anyone experiencing a sustained response or prolonged stable disease before progression.
We explored the relationship between OS and time to progression in first-line chemotherapy trials for advanced breast cancer. We found that for each trial, the median OS was typically about three times the median progression-free survival (mean, 3.0; interquartile range, 2.4 to 3.5). Hence, survival time after progression was about double the time to progression. If this ratio, or another, holds true for individuals, then it would help inform estimates of their survival after progression on first-line chemotherapy. For example, if someone progressed on first-line chemotherapy at 6 months, then the expected survival time following progression would be about double this or 12 months. More meaning could be conveyed by again thinking and talking about best case, worst case, and most likely scenarios for survival following progression.

**Using Clinical Trial Data for Routine Practice**

The main limitation of using data from clinical trials to help estimate life expectancy is that patients in clinical trials tend to do better and live longer than those treated similarly in routine clinical practice. Unfortunately, there are few data available on the survival of those treated outside of clinical trials. It is important to collect this information because such patients make up most of our day-to-day oncology practices. In the meantime, we should learn how to modify and apply trial data to people treated outside of trials. These modifications are likely to be small for the majority of patients in routine practice who would meet all or most eligibility criteria for clinical trials. Others, including those with a poor performance status or major comorbidities, are commonly excluded from clinical trials and would require larger modifications or different sources of survival data on which to base survival estimates. People with rare tumors are likely to have even less reliable survival data and other sources of information, like survival registries, are required.

An alternative source of information for estimating survival could come from comprehensive databases of patients treated outside of trials. Such databases could include details of patients’ demographics, tumors, treatments, and the dates of important time-points like diagnosis, start of chemotherapy, progression on first-line chemotherapy, and death. If recorded accurately, this information could help physicians estimate survival times in routine practice. Comparing such information with that from clinical trials could help determine how trial data should be modified for patients outside of trials.

**Explaining Life Expectancy to Patients**

We believe that estimating scenarios for survival is a useful method for thinking about life expectancy, but we have yet to determine the best way to explain this information to patients to ensure that it is understood, they feel supported, and the appropriate balance of realism and hope is conveyed. This requires careful consideration because certain words and phrases can have a large impact on how the information is interpreted. Most patients prefer positively framed information, the percentage surviving, rather than negatively framed information, the percentage dying. The best order for presenting the three scenarios also needs consideration. Feedback from patients and consumers is needed to perfect the words and phrases, and adjustments may be required to suit individual patients.

**Implications of the Best Case Scenario**

A sense of hope is important for patients with incurable cancer, and should not be limited to the unrealistic hope of cure. Physicians must learn to convey hope in discussions about life expectancy. Describing a best case scenario (eg, survival time for the 10% of patients doing best) when discussing life expectancy helps physicians to envisage and convey hope. However, estimating the best case scenario is difficult because many clinical trials are published before the longest survival times are reached so long-term survival data are limited. Publication of survival outcomes after longer follow-up is required to address this problem. In the absence of more data, estimating the best case scenario as about three times the median survival of a group of similar patients seems reasonable. It is important to keep the best case scenario open-ended (ie, “3 years or more” rather than precisely “3 years”) because this more accurately reflects the data, the uncertainty of the estimate, and because it too conveys realistic hope.

Most oncologists have patients who have beaten the odds and lived longer than expected. Some of them will have outlived the best case scenario that was (or would have been) estimated for them at diagnosis. After surviving longer than expected, these patients may ask for information about their future life expectancy. We are not aware of specific data that helps answer such questions, but an OS curve used to estimate initial prognosis also can be used to estimate subsequent prognosis. If a survival curve is approximately exponential, then an individual from that population who is still alive (at any point along the curve), can still be expected to have (1) a worst case for subsequent survival of about one quarter of the curve’s median, (2) a most likely scenario of living about another half to double the median survival, and (3) a best case of living about another three times the median survival. For example, someone alive and well 7 years after first-line chemotherapy for castration-resistant prostate cancer may ask about their likely future survival. If we assume that the survival curve for men starting such chemotherapy is exponential with a median of 2 years, then the median survival of individuals...
Implications of the Worst Case Scenario

The worst case scenario (e.g., survival time for the 10% doing worst) can be estimated as about a quarter of the median survival of similar patients. While the worst case scenario is unlikely and will only eventuate for 10% of similar patients, it is a possibility that all patients should consider. Explaining the possibility of the worst case scenario may help the physician open discussions about stopping chemotherapy, advanced directives, preferences for end-of-life care, and involvement of palliative care. As patients get closer to death their need for prognostic information may increase. Conversations will change from being about something abstract to consider in the medium term, to being something concrete to prepare for in the short term.

Patients may not require a precise understanding of their prognosis to alter their treatment preferences and plans. For example, patients who believed that they would survive for at least 6 months favored life-extending therapy over comfort care at more than double the rate of those who simply understood that there was at least a 10% probability that they might not survive 6 months. Explaining the worst case scenario, as something that is unlikely (will only apply to 10% of similar patients), but still a possibility that should be prepared for, may have a similar effect. Simultaneously presenting the best case scenario as equally likely, allows patients to realistically hope for the best.

Adequate warning of death gives patients time to resolve unfinished business, remember personal accomplishments, and say goodbye to important people. Confronting the possible worst case scenario may force patients to think about their lives and goals. Some may wish to stop work, to spend their remaining time with family, friends, or traveling. Patients also may consider making or revising a will, arranging their finances, and appointing a power of attorney. Other considerations include whether to arrange for superannuation to be paid out in advance, and whether to claim against life insurance policies before death. Patients with dependent children have additional responsibilities and concerns. Information about life expectancy is essential to help parents arrange care for their children and to decide when to talk about dying with their children.

Considerations for Older Patients

Oncologists are managing increasing numbers of older patients with incurable cancer. Survival data are required to enable appropriate treatment recommendations and to provide accurate prognostic information for this growing subgroup. Older patients with incurable cancer are at risk of being over- or under-treated, and a poor understanding of life expectancy, by both physicians and patients, may contribute. Clinical trials frequently exclude or under-represent older patients and other sources of data are required. It is possible that older patients will want different information about life expectancy than younger patients, but physicians should not make assumptions about preferences for prognostic information based on age. In a study of older patients with metastatic colon cancer, only 44% of physicians correctly perceived their patient’s preferences for prognostic information. Co-morbidities, polypharmacy, and functional status also must be considered when estimating life expectancy in older patients. Two questions to address in older cancer patients are: Is the patient going to die of cancer, or with it? Is the patient going to live long enough to suffer from his/her cancer? Consideration of a patient’s life expectancy without cancer also may be helpful. For example, the life expectancy of an 85-year-old Australian is 6 or 7 years. Explaining life expectancy without cancer may help older patients both gain perspective about the impact of their cancer, and make appropriate treatment decisions and plans.

Considerations for Adolescents

Adolescents with incurable cancer are another group who may have special requirements for prognostic information. Adolescents often have physicians and parents trying to protect them from the truth and physicians may minimize, distort, or delay information about life expectancy. This is likely to increase anxiety and fear, like in adults, and prevent adolescents from taking part in treatment decisions. Physicians can find an adolescent with incurable cancer confronting and emotionally difficult and avoid the topic of life expectancy. Many feel the need to rescue the patient and feel failure and frustration when they cannot. Specific training about estimating and communicating life expectancy is required for physicians caring for adolescents and their families.

Assessing the Accuracy of Estimates

Empirical data are needed to establish the accuracy of any method for estimating survival, for example, by comparing estimates of survival in real patients with
their actual survival times. Fears of inaccuracy may cause physicians to avoid providing survival estimates.9

Although accuracy is important and worthy of evaluation, it is unrealistic to provide a single estimate of life expectancy. Such single point estimates convey unwarranted precision and leave little room for hope. Rather than not providing estimates at all, physicians should learn to explain and emphasize the uncertainty of any predictions, first because this is realistic, and second, because it forms the basis for realistic hope. Providing estimates of the worst case, most likely, and best case scenarios can communicate the inherent uncertainty of survival estimates while conveying hope.

Developing a Tool and Training Physicians

A tool that helped estimate life expectancy and provided words and diagrams to convey the information would help physicians. Physicians could provide an estimate of survival for an individual, based on the median of a similar group of patients, and the tool could calculate estimates of the best case, worst case, and most likely scenarios for survival. A summary of the information could be printed for the patient to take home. Specific training on how to use such a tool to estimate and explain life expectancy could be incorporated into existing communication skills workshops on breaking bad news and discussing prognosis.

Improving Written Communication of Life Expectancy

Training physicians and providing them with a tool to help estimate and explain life expectancy also may improve documentation of life expectancy discussions in patients’ records and letters to referring doctors. Such information is considered important by the majority of doctors referring patients to oncologists. For example, one study found that 96% of general practitioners and 82% of referring surgeons would like information about prognosis, and what a patient has been told of their prognosis, included in the reply letter from the oncologist.24 Despite this, only 31% of such letters included such information.21 Improved written communication about prognostic estimates also might help insurance companies and lawyers when considering requests to pay out insurance policies.

SUMMARY

Thinking and talking about life expectancy can help people with incurable cancer and their physicians. Information tailored to the needs of each patient is required. Estimating and explaining best case, worst case, and typical scenarios for survival conveys more realism, meaning, and hope than providing a single estimate. Better numerical data on survival times in routine practice, and more specific training should improve physicians’ ability to estimate and explain life expectancy. Patients will ultimately benefit from improved understanding, decision-making, and planning.

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