Thinking and Talking About Life Expectancy in Incurable Cancer

Belinda E. Kiely,[a] Martin R. Stockler,[a,b,c] and Martin H.N. Tattersall[b,c]

Most patients with incurable cancer want information about the impact cancer will have on their future, and many want specific estimates of the most likely, best case, and worst case scenarios for survival. With improved understanding of life expectancy, patients are better equipped to make appropriate treatment decisions and plans for the future. Although physicians acknowledge that patients with incurable cancer want prognostic information and benefit from this, most struggle to provide it and experience difficulty in making reliable estimates, communicating them, and tailoring the information to the individual patient. In this review we address some of the implications that arise from thinking and talking about life expectancy with people who have incurable cancer, particularly those considering first- or second-line chemotherapy.
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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.[1,2] 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.[3] 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.[4-6] 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.[7] 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.[8] 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.[9,10]

Cancer patients' understanding of life expectancy is frequently imperfect, with many overestimating the probability of long-term survival and likely benefits of therapy.[11,12] 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.[11,13]

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

[a]NHMRC Clinical Trials Centre, University of Sydney, NSW, Australia.
[b]Department of Medical Oncology, Sydney Cancer Centre–Royal Prince Alfred and Concord Hospitals, Sydney, NSW, Australia.
[c]Sydney Medical School, University of Sydney, NSW, Australia.
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Address correspondence to Martin H.N. Tattersall, MD, MSc, FRACP, Sydney Medical School, D06-Blackburn Building, The University of Sydney, NSW 2006, Australia NSW, 1450, Australia. E-mail: martin.tattersall@sydney.edu.au
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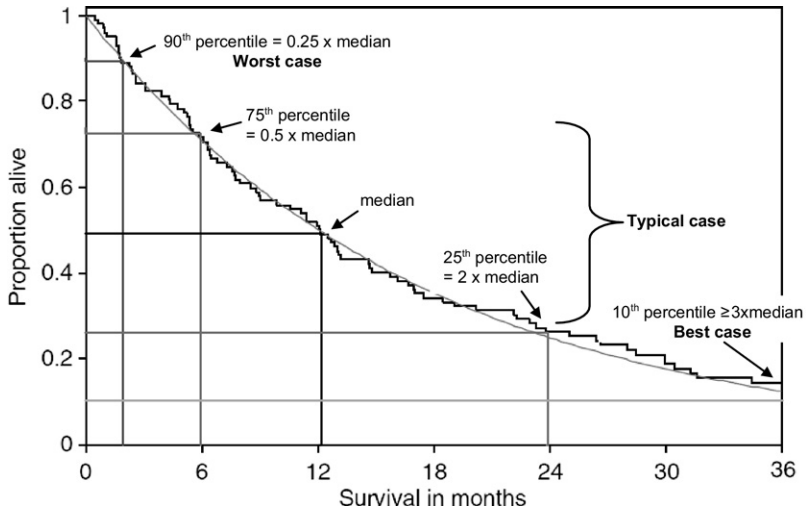

Figure 1. Overall survival curves (stepped curve) are approximately exponential (smooth curve). The percentiles of an OS curve can be used to estimate scenarios for survival.

associated with increased anxiety and there is a suggestion that a lack of information may heighten anxiety.[7,14] Similarly, awareness of life expectancy in itself has not been associated with increased depression.[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.[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[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.[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.