HOW LONG HAVE I GOT? ATTITUDES OF PATIENTS TO REceiving SURVIVAL INFORMATION FORMATTED AS THREE SCENARIOS

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Aim: We developed a web-based tool to help oncologists estimate and explain best-case, typical, and worst-case scenarios for survival to patients with advanced cancer. We report here on the attitudes of patients seeking prognostic information and being given it in this format.

Methods: Oncologists were encouraged to use the tool whenever a patient with advanced cancer requested quantitative prognostic information. For each patient, the oncologist estimated the ‘median survival of a group of similar patients’ and used the tool to calculate ranges for the 3 scenarios based on this estimate. Oncologists presented the information using standardized oral and printed formats. Patients completed a questionnaire about their attitudes to receiving this format of information.

Results: 47 patients of 6 oncologists have completed the questionnaire. Patients’ characteristics were: median age 68 years; male 72%; high school education 56%; ECOG PS 0-1 73%; >8 weeks since diagnosis of advanced cancer 66%; primary cancer of kidney 22%, prostate 20%, pancreas 18%, colon 11%, breast 9% and other 20%. The median estimated survival time was 9 months (range 3-48). Most patients agreed that ‘having my life expectancy presented this way’ was helpful (89%), made sense (96%), improved my understanding (81%), and will help me make plans (83%); about half agreed that it was reassuring (55%), gave hope (52%), made me feel worried or anxious (49%), and was upsetting (58%). Most agreed that being told each scenario was helpful: best-case (89%), typical (83%), worst-case (85%), and median (74%). Most agreed that receiving a printed summary was helpful (85%); and, that the information would be helpful for their family members (76%) and family doctor (85%). The prognosis was considered about the same as expected by 47%, worse than expected by 28%, and better than expected by 26%. Preferences for the scenario to be told first were typical 28%, best-case 17%, worst-case 11%, and not important 45%.

Conclusions: The vast majority of patients seeking information about their survival time found it helpful to receive such information as 3 scenarios, and agreed that it would be helpful for their family members and doctors to receive this information.

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