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Communication of Expected Survival Time to Cancer Patients: How It Is Done and How It Should Be Done

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Abstract : Most patients with serious diagnoses want to know their prognosis, in particular their expected survival time. As part of the informed consent process, physicians are legally obligated to communicate such information to patients. However, there is no established (evidence based) 'best practice' for how to do this. The two questions explored in this study are: How do physicians communicate expected survival time to patients, and how should it be done? We explored the first, descriptive question in a study with Norwegian oncologists as participants. The study had a scenario and a survey part. In the scenario part, the doctors should imagine that a patient, recently diagnosed with a serious cancer diagnosis, has asked them: 'How long can I expect to live with such a diagnosis? I want an honest answer from you!' The doctors should assume that the diagnosis is certain, and that from an extensive recent study they had optimal statistical knowledge, described in detail as a right-skewed survival curve, about how long such patients with this kind of diagnosis could be expected to live. The main finding was that very few of the oncologists would explain to the patient the variation in survival time as described by the survival curve. The majority would not give the patient an answer at all. Of those who gave an answer, the typical answer was that survival time varies a lot, that it is hard to say in a specific case, that we will come back to it later etc. The survey part of the study clearly indicates that the main reason why the oncologists would not deliver the mortality prognosis was discomfort with its uncertainty. The scenario part of the study confirmed this finding. The majority of the oncologists explicitly used the uncertainty, the variation in survival time, as a reason to not give the patient an answer. Many studies show that patients want realistic information about their mortality prognosis, and that they should be given hope. The question then is how to communicate the uncertainty of the prognosis in a realistic and optimistic – hopeful – way. Based on psychological research, our hypothesis is that the best way to do this is by explicitly describing the variation in survival time, the (usually) right skewed survival curve of the prognosis, and emphasize to the patient the (small) possibility of being a 'lucky outlier'. We tested this hypothesis in two scenario studies with lay people as participants. The data clearly show that people prefer to receive expected survival time as a median value together with explicit information about the survival curve's right skewedness (e.g., concrete examples of 'positive outliers'), and that communicating expected survival time this way not only provides people with hope, but also gives them a more realistic understanding compared with the typical way expected survival time is communicated. Our data indicate that it is not the existence of the uncertainty regarding the mortality prognosis that is the problem for patients, but how this uncertainty is, or is not, communicated and explained.

Keywords : cancer patients, decision psychology, doctor-patient communication, mortality prognosis
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