

Bridging the communication gap between oncologists and patients receiving palliative therapies

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Abstract: The discussion of prognosis is a regular component of oncology practice. When the prognosis is poor, the disclosure can be difficult for both patients and physicians alike. In a recent article by Chen *et al.*, stage IIIB and IV lung cancer patients were surveyed on their beliefs about radiotherapy they were receiving. A significant proportion of patients expressed the belief that radiotherapy, which they were receiving purely with palliative intent, was likely to cure their cancer. Misunderstanding the goals of treatment can have important consequences with respect to informed decision-making and end-of-life planning. There are likely many factors contributing to this misunderstanding, both from the perspective of the patient as well as the physician. Discussing incurable disease in a clear, honest manner without taking away hope can be very challenging for the physician. Even when done well, patients often do not hear or completely understand the message. Focusing on active treatment may in fact perpetuate the patient's belief that they can be cured. In this article, some of the factors contributing to inaccurate beliefs are discussed. Awareness of the issue, and approaching the patient in a somewhat different manner when disclosing prognosis, may help patients to develop more appropriate beliefs about their disease and treatment. Ultimately the goal is for patients to make decisions that align with their beliefs and values, which can only be done if they have clear understanding of prognosis.

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For patients with lung cancer, the goal of cure many not be possible due to a host of baseline patient, tumor, and treatment factors including the presence of widespread metastatic disease, very advanced locoregional disease, poor pulmonary reserve, and/or the presence of significant comorbidities. Over half of patients present with metastatic disease associated with a median survival of less than one-year (1). In these cases, the discussion of prognosis can be difficult and may revolve around maintaining quality of life, treatments for palliation of specific symptoms, and end-of-life planning.

Recent research presented at the American Society of Radiation Oncology (ASTRO) and published in the

Journal of Clinical Oncology by Chen *et al.* (2) explored the expectations of 384 patients receiving palliative radiotherapy for stage IIIB-IV lung cancer. They were asked to answer questions regarding their beliefs about the goals of radiation. Patients had to be receiving or already received radiation, and be 4 or more months from initial diagnosis. Those who were too ill to complete the survey could have a surrogate do it for them. Sixty-seven percent of respondents felt that RT was very or somewhat likely to help them with problems they were having because of their cancer, and 78% felt that RT was very or somewhat likely to help them live longer. A provocative finding from the survey was that 64% of patients felt there was some chance

of cure, and 43% felt that it was very or somewhat likely. Only 36% correctly understood that radiotherapy was not at all likely to cure their disease. On multivariate analysis, age over 55 and nonwhite race were associated with higher levels of inappropriate belief of cure, while requiring a surrogate to fill out the survey due to illness was associated with more accurate beliefs regarding the goals of palliative radiotherapy.

Presumably, most clinicians have experienced this phenomenon before. It is not uncommon for patients to hope they are the exception and it is not surprising that patients believe in a cure that does not exist. However, the proportion of patients with this misconception may be the true surprise. According to this data, nearly two-thirds of patients are agreeing to palliative radiotherapy with the misunderstanding that radiotherapy may cure their disease. This may be a reflection of the very select group of patients included in the study. Of the 832 patients with stage IV or wet IIIB disease who had received or were going to receive radiotherapy, only 384 were alive and answered the radiotherapy questions at the time of the survey. It is possible that patients with worse disease, who died sooner, would have been more accurate in their beliefs about radiation. This is supported by the observation that patients, who required a surrogate to complete the survey, as they were too ill themselves, had a more accurate understanding of the goals of radiation.

A fundamental question is whether it truly matters whether or not patients have inappropriate beliefs about treatment. We submit that it does matter for many important reasons. The ethical principle of autonomy is reflected in the practice of informed consent and shared decision-making. This requires an understanding of the purpose of treatment, risks and benefits, and alternative treatment options. Particularly in the palliative setting, it is important for patients to understand the goals (and limitations) of proposed care. When survival time is potentially limited, patients might decide against having treatment that involves multiple trips to the cancer centre, being far from home and family supports, and potential treatment related side effects that can reduce health-related quality-of-life. End-of-life planning and decision making should be addressed when a patient feels well and ideally as early as practically possible. A randomized controlled trial published in the *New England Journal of Medicine* (3), demonstrated that early referral to palliative care for patients with metastatic lung cancer led to a significant survival difference (11.6 vs. 8.9 months). Extrapolating from

these results, a scenario might exist where a patient with a poor understanding of their prognosis may not be referred for early palliative care and may paradoxically exhibit worse outcomes.

There are a variety of factors in lung cancer patients that may predispose them to misconceptions regarding cancer prognosis. Patients with incurable lung cancer have a poor prognosis compared to some other solid tumors, with a five-year survival rate on the order of 5-10%. Most people want to believe they are within that group. As well, a diagnosis of lung cancer can be associated with a societal stigma and emotional effects (e.g., guilt, shame, etc.) as 90% of cases are due to smoking exposure. In spite of these factors at play in a lung cancer diagnosis, the misconception of the goals of palliative treatment is by no means limited to palliative radiotherapy, or to lung cancer. A similar study from the same database investigated the expectations of lung and colorectal cancer patients receiving palliative chemotherapy for stage IV disease (4). The results are strikingly similar. When asked how likely palliative chemotherapy was to cure their disease, 69% of patients with lung cancer and 81% of patients with colorectal cancer felt there was at least some chance of a cure. We suspect that inaccurate expectations are likely prevalent in many cancer (and non-cancer) palliative situations.

How then does the true goal(s) of treatment get lost in translation between oncologist and patient? This is a complicated question with many potential answers. There are factors from both the physicians' and the patients' side of the medical interaction. As a general rule, physicians are disclosing to patients when disease is not curable (5,6). From a physicians' perspective, outcome can be difficult to accurately predict for an individual patient, and different physicians may give different estimates (7). As well, prognosis can be presented any number of ways, including overall survival, median survival, or measures of response that do not include estimates of cure. The same information presented in different ways can confuse the issue for lay patients without an understanding of statistical nomenclature. Take for instance the following statements, which are all factual and correct but can provide different degrees of information to the patient.

(I) Patients with stage IV lung cancer have incurable disease. (explicitly negative);

(II) Patients with stage IV lung cancer have a five-year survival of less than 10% (implied negative outcome);

(III) Patients with stage IV lung cancer have an average survival of about 10-12 months (hidden negative outcome)

as 50% of patients live longer than 10-12 months);

(IV) Patients with stage IV lung cancer have a range of survival characteristics and the prediction of survival is difficult for any one individual patient (no comment on survival characteristics or mortality at all).

A patient presented with accurate, truthful information clearly could have widely differing ideas of prognosis depending on how the physician chose to present the information. Not all physicians support frank disclosure of prognosis (8). Even in those who do, the message can be overly optimistic (9). Many physicians are concerned that discussing prognosis may take away hope or emotionally harm patients and may hurt the formation of a doctor-patient relationship at a critical juncture (10,11). However, by attempting to balance hope with honest prognostic information, clinicians may confuse patients with mixed or vague messages. A patient might interpret a "40% chance the cancer will respond" to treatment as a "40% chance of cure" (10).

Pressures outside the patient-doctor relationship could be affecting how prognosis is presented. An article by Lisa Rosenbaum in *The New Yorker* (www.newyorker.com) discussed a recent trend in the United States toward tying reimbursement, both of a hospital and of individual physicians, in part to patient satisfaction. However, a satisfied patient is not always a well-informed patient. Through multivariate analysis, Weeks *et al.* (12) demonstrated that the risk of inaccurate beliefs of the goals of palliative chemotherapy was higher in patients who rated their physician's communication most favorably. Those who reported lower scores on physician communication in fact had a more accurate understanding of the purpose of chemotherapy. In the realm of palliative oncology, where inaccurately optimistic messages may lead to happier patients, physicians and hospital systems may in fact be penalized for appropriately informing patients about prognosis and the limitations of care.

When prognostic information is clear, accurate and direct, there are complex reasons why the patient may not still fully comprehend the prognosis and goals of care. Even when oncologists rate their information giving as good, patients still fail to recall important details (13). Jacobsen *et al.* describe a differential diagnosis of misunderstood prognosis (7), many of which apply to this specific situation. Unexpected bad news can overwhelm a patient's ability to understand or recall further conversation. After the first consultation, patients may only recall approximately 25% of the discussion, and up to 40% of particularly salient

points (14). They may also choose not to acknowledge prognosis for any number of other reasons including: lack of rapport or trust with the physician, or protecting their family. They in fact might not actually understand what is being said: language barriers, lower educational attainment, or medical jargon can all lead to suboptimal understanding. Direct (or indirect) effects of the cancer, drugs, or other underlying diseases can have profound effects on patient cognition.

Decision aids have been studied as a means to overcome the communication challenges associated with discussing poor prognosis and making treatment decisions. Information is written in layman's terms, and presented in an unambiguous, accurate, and honest manner. Besides being written without medical jargon, and without conflicting ideas, decision aids may help patients who no longer hear the discussion once the bad prognosis has been presented. They would be able to review the information once they are emotionally ready to do so. This approach was assessed in a pilot study of a decision aid used for palliative chemotherapy in the setting of 20 patients with stage IV lung cancer (15). A 25-page booklet addressing treatment options, toxicity, and survival was designed, with material being presented in graphic, verbal and numeric format at a grade 7 level. The vast majority felt the decision aid was clear, useful, and balanced. Most said they would have used it in their own decision-making if they had the opportunity to do so. However, in spite of clear, explicit information that chemotherapy in stage IV lung cancer was not offered with curative intent, all of the patients felt that metastatic lung cancer was potentially curable after reading the decision aid.

If improved communication and presentation of information is not enough, perhaps the problem of discussing prognosis needs to be approached in a completely different manner. The concept of "adaptive leadership", developed by Heifetz in the context of organizational leadership, might be a useful way to reframe the approach (16). In its simplest form, adaptive leadership describes challenges as technical and adaptive. Technical challenges are those problems which can be addressed by physicians and allow the use of expertise and evidence. Examples include prescribing treatment for cancer or performing a surgical procedure. Adaptive challenges are much harder to address. In medicine, adaptive challenges occur when patients are required to do the "work" involved, which can involve learning, changing behaviours, and adopting new ideas and attitudes. There are losses and

trade-offs to be accepted in this approach. It requires the patient to make changes to their internal landscape, something that the physician cannot do for them. Obvious non-oncological examples in medicine include lifestyle modifications for obesity, hypertension, and other chronic issues. However, adjusting beliefs about a cancer diagnosis, treatment, and prognosis also require such a change in attitudes and behaviours. There is a gap between what the patient expects of their future, and what is reality (17), and it is in this gap that a patient needs to do their work. Behaviour might change when a patient believes their cancer cannot be cured, accepting or rejecting treatment or starting end-of-life planning (14). Hope for a cure might be traded for other hopes, such as maintaining a good quality of life. Successful use of this concept has been reported in the palliative setting in the ICU, helping families make the transition to withdrawal of care (18).

The challenge for the physician lies in allowing the patient to do the work needed to adapt. We may be doing a disservice to patients by trying to treat an adaptive problem (learning to accept a diagnosis of incurable cancer) with a technical solution (giving radiation or chemotherapy). The *et al.* (6) reported the role of “collusion” between patients and physicians as a means of sustaining inaccurate ideas of cure. In an observational study of 35 patients with small cell lung cancer, it was noted that while most patients were informed they had incurable cancer, further prognostic details were not given or were vague and ambiguous. The conversation would then rapidly shift from bad news to an offer of treatment. Discussions at subsequent visits focused almost completely on side effects, test results, and the treatment schedules. Both physician and patient would instigate and support the focus on therapy. However, patients and families later expressed regret, when they realized their “optimism was based on illusions”. The choices they made might have been different had they not been so focused on treatment only.

The adaptive problem of coping with a terminal diagnosis is in fact not our problem to solve, but the patients. However, that does not mean there is no role for the physician. Adaptive leadership includes “leadership” for good reason, as the role of the physician in this situation may be to guide patients toward understanding their prognosis. However, this is not a very tangible skill. How can we help patients to adapt? Keep the following in mind when discussing prognosis with patients:

- Expect that the patient will not fully comprehend or accept the message. Guide them through the goals of care

throughout their disease course to help them understand at their own pace. It is not a one-time conversation (19);

- Recognize the desire to turn to a technical treatment to solve both the patients and physicians discomfort with the bad news. Be aware that immediate discussion of treatment might give the illusion of curable disease and takes away from the patient learning to cope with their prognosis;

- Focus on the big picture before giving details. Jansen *et al.* demonstrated that recall of information was decreased when more detail was given (20). This was particularly evident in information given regarding prognosis. Recall was not affected by the quantity of information discussed about diagnosis or treatment;

- Balance honesty and hope by reframing hope toward more realistic and explicit goals of care (10);

- Check how much the patient understands during and after the discussion. Patients’ understanding is checked in as little as 10% of consultations (5). However, this is an effective feedback mechanism for the physician and can help guide further discussion and identify barriers to understanding.

Discussing prognosis is key part of patient care and requires a specific communication skill-set and individualization to each patient. This is increasingly recognized and clinical practice guidelines are being published that explicitly address this (21). Future efforts may involve development of educational tools to help physicians in clinical practice, in particular focusing on developing skills in assisting patients with adapting to their prognosis.

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