

Prognosis Disclosure in Oncological Medicine

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Background

“Faced with mortality, scientific knowledge can provide only an ounce of certainty: Yes, you will die. But one wants a full pound of certainty, and that is not on offer.” -Paul Kalanithi [1].

Cancer, to patients is more than just a diagnosis, and their lived experiences in the journey go far beyond the cleverly invented interventions, medications, and investigations. One would think that clinical outcome predictions, like weather forecast, should become more and more accurate as the event being predicted draws closer, but this is often not the case. A full pound of certainty, in Paul Kalanithi’s words, could guide patients in prioritising treatment options, putting affairs in order, going on a cruise this summer, or delaying it till next year [1]. It could guide patient relatives in deciding whether to go home tonight or remain by the bedside to see mum take her last breath. In this article, we discuss prognosis disclosure in general terms, its ethical aspects, challenges, and possible solutions.

Prognosis, in medicine, entails the likelihood of an individual developing a particular outcome (complications, disease progression or death) over a specific period, usually based on his or her clinical and non-clinical parameters [2]. Prognosis disclosure has been found to have myriads of benefits including, empowering patients to participate in treatment decision-making, reducing rates of inappropriate investigations, hospitalisation, and interventions [3]. Conversely, patients who are ignorant of their prognoses are more likely to hold unrealistic expectations and pursue futile treatments, which could be detrimental to their overall quality of life. Most cancer patients are open to having prognostic discussion with their physicians. A multi-centre longitudinal survey conducted in the United States (US), involving 590 patients with advanced cancer showed that majority of patients (71%) wanted to have discussions about life expectancy [4]. More so, over the last few decades, there has been a paradigm shift towards having more open discussions about cancer diagnosis and prognosis with patients, possibly due to improved shared decision-making, less paternalistic approach to medical care, rising rates of medicolegal actions and health care consumer rights activism, and increased public awareness of cancer [3].

Despite the clear benefits of prognosis disclosures and progress made so far, physicians are still more comfortable having discussions about available treatment options with patients than they often are about discussing cancer prognoses [3]. For instance, the US study showed that only about one-sixth (17.6%) of patients who were interested in knowing their prognoses reported ever having this conversation with their oncologists [4]. This hesitancy can be attributed to attributed to a myriad of factors, including the fact that physicians may not wish to dash hopes or cause grief or damage their relationships with patients and/or relatives, and the difficulty in establishing an equilibrium between honesty and empathy. Other factors include uncertainty as to the best way to share the information, determining what the patient wants or needs to know, and not coming across as being insensitive to sociocultural issues [4, 5].

Principlism and Prognosis Disclosure

Of all diseases, cancer diagnosis possibly causes the most psychological distress and anxiety [6]. Also, major treatment decisions around other non-oncological co-morbidities are often hinged on cancer prognosis. What physicians can often find challenging is not necessarily what to say, but what not to say. Whilst we do not intend to engender false hopes, we do not want to inadvertently douse any flame of hope. The four key ethical principles (beneficence, non-maleficence, autonomy, and justice) find relevance in prognostic disclosure [7]. Beneficence - the obligation to always act for patients’ benefit- requires that a physician provide relevant information that could guide patients in decision-making. Non-maleficence - an obligation not to harm or cause pain or suffering- requires that physicians do not withhold necessary information from patients (or relevant parties) or disclose prognosis in an insensitive and unempathetic manner. The principle of Autonomy obliges physicians to empower patients to exercise self-determination and respect their decision, regardless of how irrational it may seem. Justice, on the other hand, is a duty to exercise fairness and equity. This means that prognostic information should be tailored to patients’ levels of understanding, needs and peculiarity.

Whilst physicians strive to respect these four ethical principles, these ethical pillars almost irreconcilably conflict with one another. For instance, prognostic disclosure could potentially make a depressed

patient gloom-ridden (non-maleficence), at the same time, one feels obliged to have this discussion with them, if they genuinely want to know (Autonomy and beneficence). Patients of sound mind may neither be interested in having this conversation (autonomy) or even take it on board, whilst pursuing potentially futile interventions. In this context, not truthfully disclosing this to their surgeon, could make them go through an inappropriate major surgical procedure, in what could be his/her last 3 months of life (non-maleficence) and a waste of resources (justice). Therefore, physicians must carefully consider when, how, why, where and the appropriateness of information disclosure.

Challenges and Possible Solutions

Estimating cancer prognosis is challenging; equally, communicating this with patients and relevant parties comes with its own challenges. Firstly, the best approach to presenting prognostic information to cancer patients, to promote clear understanding and aid shared decision-making, remains uncertain. Secondly, the abundance of more effective therapeutic options and multiple lines of treatments has led to better outcomes in oncological medicine. The massive explosion of knowledge and research breakthroughs has transformed what seemed like a sleepy and depressing field of medicine for many years into, indisputably, one of the most dynamic and exciting specialities. Therefore, the ever-increasing range of possibilities implies that, prognoses of different cancers are now increasingly dynamic. We believe that these developments will make discussing cancer prognosis with patients even more challenging in the future.

In addition, remote consultations are now increasingly being adopted globally, particularly since the beginning of the COVID-19 pandemic. It is however important to consider the appropriateness of the setting and medium of conversation. Having prognostic disclosures over the telephone is often not ideal as it effaces the non-verbal domains of communication. It is difficult to read body languages and non-verbal cues. Therefore, disclosing this information to patients in a face-to-face setting may be more ideal. Furthermore, within cultures and religions, there are different expectations and views that need to be respected.⁵ To add another layer of complexity to this, patients' desires for information may evolve over time in their journeys through treatments and investigations. Hence, it is important to bear in mind that one discussion at one time point may not be sufficient for some and that one size does not fit all.

From experience, patients often have different preferences on how they would like prognostic disclosures to be made. For instance, some patients are keen to have information in months and years, while some are satisfied with "your chances are good". For some, numbers and figures mean a lot to them. This, they quite often find useful in conceptualizing risks and benefits of treatments. For instance, some patients find it more useful if they are told, treatment A could offer an additional survival benefit of 3 months while treatment B could offer 6 months overall survival benefit. Similarly, some are more likely to appreciate benefits by telling them in percentages (for instance 5-year survival rate of 30%). Hence, the content of prognostic information should be tailored to individuals' needs and preferences.

Physicians often base their estimation of prognosis on figures and Kaplan-Meier estimates available from Randomised Controlled Clinical Trial data. For instance, patients with metastatic pancreatic cancer who had FOLFIRINOX (Folinic acid, 5-fluorouracil, irinotecan, and oxaliplatin) chemotherapy regimen in the French study had a median overall survival of 11.1 months.⁸ Hence, it is not incorrect to give this group of patients an average life expectancy

of 11 months when consenting them for this treatment. However, a major challenge with this approach is that clinical trials often recruit a carefully selected group of patients, who are usually not entirely representative of those seen in routine clinical practice. For instance, this study excluded patients older than 75 years, which makes it even more difficult to apply the data to a relatively fit 76-year-old retired athlete in a real-world clinical setting. Furthermore, the 11.1 month is an average figure, which is by no means specific to individual patients.

Estimation of life expectancy with limited familiarity with a patient or with little experience in that disease subtype can be challenging. This could translate into overoptimistic or over-pessimistic estimates, with detrimental consequences. A prospective study carried out in Chicago sought to assess doctors' prognostic accuracy in patients with advanced diseases. The study recruited 343 doctors who were saddled with the task of providing surviving estimates of 468 patients selected across 5 hospice programmes.⁹ The results showed that only 20% of predictions were accurate, with a higher tendency towards overestimation of life expectancy (63%). Interestingly, the study also showed that the more experienced doctors were more likely to be accurate. Our feeling is therefore, that physicians' experiences in different cancer subtypes, may be more reliable than raw trial data. This is however instinctive, subjective, and difficult to teach or reproduce. Improvements in various life-prolonging interventions for both oncological and non-oncological conditions mean that cancer patients are increasingly more complex with other co-morbidities. Therefore, where possible, a multi-disciplinary approach to prognostic estimation (for example, a neurologist when dealing with a cancer patient with Parkinson's disease) should be considered when formulating life expectancy, as these may be more accurate than individual predictions hinged solely on oncological diagnoses. Moreover, as a rule thumb, it is advisable not to give exact numbers; some level of vagueness is allowed.

Although myriads of prognostic tools and algorithms are available, these should, at best, be used as an aid, and not a substitute for clinical judgment. Also, apart from use of prognostic tools, we believe that, periodically auditing one's predictive accuracy, getting communication feedbacks, and reflecting on the lessons from different cases would be useful in improving one's skill in this area. Finally, of recent, we have witnessed increased adoption of Artificial Intelligence (AI) in different aspects of clinical medicine and oncological care. We anticipate that, in the future, there may be even more roles for AI in improving prognostic accuracy in both early and advanced cancers, thus aiding shared decision-making.

Conclusion

Prognostic disclosure is a key aspect of cancer management today. The usefulness of prognosis for the oncology teams, patients, families, and other parties implies that measures to improve accuracy and effectively communicating it in a sensitive manner cannot be underestimated. Where possible, barriers to having this important conversation with patients and their relatives, in an honest and open manner, should be removed and the disclosed information should be tailored to the needs and peculiarities of patients.

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