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Truth disclosure on prognosis: is it ethical not to communicate personalized risk of death?

Summary

Predicting risk of death based on personalised and objective clinical indicators is an improvement over intuition and clinical judgment. Risk assessment can benefit clinicians by improving prognostic certainty, and truth disclosure helps patients and families by preventing futile management. Some argue that consent should be obtained before a patient is given an estimate of their prognosis as disclosure of bad news can overburden patients. In this article we argue that it is unethical not to use existing person-specific information to guide diagnosis and shared decision-making on management in partnership with well-informed patients. Disclosure of a poor prognosis should be normalized in personalized medicine, performed incrementally and with sensitivity so that it is acceptable to patients, and only occur if patients want to know it. However, a requirement of consent for truth disclosure should not be mandatory. Despite some level of imprecision, personalized risk estimations can be used to tailor management to the patient's informed wishes, and ensure that healthcare providers and families are acting ethically in the patient's best interest.

Keywords: risk assessment, prognosis, truth disclosure, clinical ethics, personalized medicine

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3 Prognostication is a challenging art, and science. Through advanced age, increasing frailty
4 and chronic illness, treatment becomes increasing complex and the clinician's ability to
5 prognosticate is tested further. Prognosis does not solely rely on the natural history of a major
6 disease but on the interaction with other comorbidities, the choice of treatment and response
7 to it, and other patient-specific socio-demographic influences, all of which may impact on the
8 accuracy of the prediction. Yet prognostication has become a lost skill: at the end of the
9 nineteenth century *prognostication* took up about ten percent of medical textbooks, but by
10 1970 it was hardly addressed.¹ As a result, although modern physicians commonly
11 encounter situations that require prognostication, they feel "poorly trained to do it, and find
12 the whole process difficult and stressful" and, therefore, may favor partial or non-disclosure
13 altogether.²

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22 Personalized medicine has been broadly defined as "*the tailoring of medical treatment to the*
23 *individual characteristics, needs and preferences of a patient during all stages of care,*
24 *including prevention, diagnosis, treatment and follow-up*".³ Data to assist personalized
25 decisions tailored to individuals, thus departing from the "one size fits all" paradigm⁴ is
26 valuable as disease trajectories vary, and individuals respond differently to treatment options
27 and value different states of health. The development of prediction tools for all ages, and in
28 particular the very old,⁵ provides information on likely outcomes, including death, and is but
29 one essential component of truthful communication.

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37 Delivering a prognosis, especially a bad one, is complex, takes time, and requires sensitive
38 communication filled with good judgment, skill, empathy and compassion. Some patients
39 may hold beliefs that can distort their understanding or expectations of cure; others may
40 choose to know less as disease progresses or ask more about the risk of treatments; and
41 families may want to know more about what to expect of the course of illness and the time to
42 death. So proficiency in tactful disclosure becomes necessary when dealing with older
43 patients suffering complex co-morbidities.⁶ However, many patients and families may find
44 confronting such an explicit prognosis challenging. This is largely because popular culture
45 continues to promote the myth that there is an effective treatment for every illness and that
46 medical technology, no matter how painful or expensive, should be used at all costs. All
47 deaths are, therefore perceived as "failures" of medicine.⁷ Even today, some medical and
48 nursing schools' curricula do not emphasise sensitive communication training; and some
49 health systems are yet to abandon paternalistic attitudes and therefore are still not

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3 systematically encouraging patient autonomy, either through voluntary or mandatory
4 approaches. The solution is not to avoid the difficult discussion using unpredictability of
5 disease progression as an excuse and thus deny the patient their right to know, but to improve
6 expertise in providing a personalized prognosis in order to empower patients to take control
7 of their immediate or future care.
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12 Although giving information on the progression and recurrence of illness, along with advice
13 and shared decision-making, is now a routine- and accepted- part of cancer care, there is
14 concern that unwanted information may overburden patients and families and take away
15 hope, so that in geriatric and critical care populations providing a prognosis is sometimes
16 viewed as overriding patient autonomy and potentially causing harm.⁸ It has therefore been
17 suggested by others that consent for disclosure should be obtained before a patient is told
18 their risk of death. Yet, in routine practice with non-terminal patients anyone who consults a
19 physician implies consent to being given a professional opinion on their probable diagnosis,
20 prognosis and treatment. While some prognostically important tests require explicit informed
21 consent, as for HIV testing, neither evidence nor law provide clear guidance on the need for
22 or benefit of detailed, written consent for discussions about other diagnoses. At present, the
23 judgment about whether or not to disclose prognosis is often left up to the physician. The
24 appropriateness of disclosing prognosis to elderly patients who have their lost decision-
25 making capacity and do not have a surrogate decision-maker is particularly concerning,
26 because such patients would not be able to make subsequent decision. It is said that “*consent*
27 *was developed for research ethics, not for clinical care.*”⁹ While consent to perform invasive
28 procedures is the norm and a service requirement, we believe consent to communicate
29 prognosis is both a moral obligation and an ethical requirement that fosters patient autonomy.
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43 Although it is important to respect the right of patients not to know their prognosis, telling a
44 patient their risk of death can help them wisely direct their subsequent treatment. There are
45 many benefits provided by an accurate estimation of a patient’s time to death and their
46 clinical course prior to death: for patients and their relatives being clearer that cure is unlikely
47 and burdensome interventions can be harmful, provides opportunities to discuss preferences,
48 consider comfort and palliative care if indicated, and coordinate services accordingly.¹⁰ In
49 fact, increased certainty regarding disease trajectory can be liberating for some, as it puts a
50 timeframe to the end of suffering, assists in the planning of their final days with good quality,
51 and helps them to embrace the inevitable: death from old age, frailty, chronic illness, and
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3 multi-organ failure,¹¹ concepts that modern society often attempts to deny. For clinicians, an
4 accurate prognosis can help avoid futile and potentially harmful therapies, assist end-of-life
5 care that best responds to patient and family values and preferences, and ensure better
6 stewardship of scarce health system resources.¹² But delivery of patient-centred care would
7 of course include adherence to the patient's disclosure preferences.
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12 One of the pillars of personalized medicine is the sharing of prognostic data between patient
13 and clinician so that patients engage in a proactive and dynamic decision-making
14 partnership.¹³ Not only is outcome estimation a necessary step in routine practice, many
15 clinicians find it a rewarding experience, as patients often welcome their guidance at a
16 seminal time in their lives. Factors such as education, age, disease type, availability of social
17 or medical support, religion or cultural background, family dynamics and the way in which
18 prognosis is delivered impact on people's openness to the news of an impending death.
19 Certainly, no one wants to receive or digest bad news, and there will always be those who
20 prefer little or no disclosure of poor prognosis in terminal illness; this is their right.
21 Nevertheless, we believe it is unethical and unjust not to formulate an explicit person-specific
22 prognosis when the information and technology that can do so are available. Withholding that
23 information undermines justice and autonomy, except if the concept of autonomy extends to
24 the right to not know.¹⁴ The estimated risk of death and the benefits of less aggressive
25 interventions should be disclosed to all patients, unless they choose otherwise, and it is not in
26 the patient's best interest to withhold information or give false hope with overoptimistic
27 outcome predictions, as this may lead to loss of patient trust. In the case of chronic or
28 progressive disease, ideally, patients and healthcare professionals will have the opportunity to
29 revisit disclosure preferences, as with other goals of care, over time, as these may change.
30 The timing of re-discussion will need to be individualised to the patient.
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45 A more accurate, personalized prognosis also allows patients to more confidently formulate
46 advanced care directives, reflecting their values and goals. The absence of health care
47 directives, based on accurately estimated likely outcomes, hampers wise decision-making and
48 often leads to regret when clinicians or families have to make decisions on behalf of patient
49 without knowing their wishes. Without them clinicians can also experience job dissatisfaction
50 and moral distress if they feel urged to comply with family requests to administer futile
51 treatment. While patients may change their mind in either direction about treatment
52 preferences as their age increases, their disease progresses and their ability to partake in
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3 decision-making varies , accurate prediction of their individual risks may make this change
4 of mind less likely. An individualised prognosis that is based on the unique health
5 determinants of an individual's profile will improve patient's understanding of their own
6 disease, and clarify their own goals of care. Since all involved in delivering care will have a
7 realistic perception of the patient's life expectancy, prevention of unnecessary, potentially
8 harmful treatments would be prevented, distributive justice ¹⁵ may be achieved, and the
9 family's anticipatory grief may also be reduced.
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16 In summary, despite the ever-present uncertainty in healthcare, personalised risk prediction
17 near the end of life is possible, and a professional responsibility. Prognostic disclosure should
18 be normalised and offered regulatory support without the barriers of formal consent
19 procedures. Timely communication of a poor prognosis and risk of death needs a sensitive,
20 incremental approach and should be in a format that patients and families find acceptable and
21 can understand. Precise predictions of the future are never possible, but well validated
22 actuarial science and recent advances in information technology, genetics and other areas of
23 medical biology now make it possible to formulate much improved estimates of the likely
24 outcomes for individual patients. Even if some level of imprecision remains, personalized
25 risk estimations should inform care pathways, as they make it possible to tailor management
26 to the patient's informed wishes, and ensure that physicians, family and other healthcare
27 providers are acting in the patient's best interest.
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