

Prognosis: Important Information when obtaining Informed Consent

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Abstract

Informed consent must be obtained in advance of all personal care, investigations, and treatments. For informed consent to be complete and valid, the person giving consent must be capable of making decisions, act voluntarily, and be provided with all necessary information to arrive at a decision that will be in the best interests of the patient. Information sharing has generally focused on available options, risks and benefits of a given intervention, and implications of foregoing the intervention. However, it is difficult to interpret such information without a discussion about the clinical context, natural history of disease, and its associated prognosis. Prognostication, consisting of both the computation (formulation) and disclosure of prognosis, is a key facilitator and enabler for the delivery of truly patient-centered care. Studies have demonstrated that despite patients desiring prognostic information, significant gaps in communication occur between physicians and patients. In a majority of cases of patients with advanced illness there is evidence that disclosure of prognosis has not occurred, thus raising the question as to whether the “informed consent” in this setting is ethically and legally valid.

Keywords: Prognosis; Prognostication; Informed consent; Palliative care; Advanced illness; Terminal illness; Advance directives; End-of-life care

Abbreviations: AAMM: Active and Aggressive Medical Management; CPM: Conservative Palliative Management; CES: Clinical Estimates of Survival; PEG: Percutaneous Endoscopic Gastrostomy; PCC: Patient-Centered Care; POA: Power of Attorney; SDM: Substitute Decision Maker

Introduction

Informed consent is a legal requirement for decision-making that is founded upon the ethical principal of autonomy [1]. The process of obtaining informed consent endeavours to respect patients' rights to make personal decisions and protect patients from healthcare professionals carrying out interventions (personal care, diagnostic or therapeutic) in an autocratic or paternalistic fashion [1,2]. Obtaining informed consent is fundamental to the delivery of patient-centred care [3] as it is the method by which patients, or their Substitute Decision Makers (SDMs), arrive at decisions about treatment that respects and is responsive to the individual's wishes, values, beliefs, and preferences, and that are in their “best interests” [1,2]. The process of obtaining informed consent from patients or their SDMs requires healthcare professionals to disclose the benefits, risks, and alternatives to the proposed intervention or non-intervention within a given clinical context [1,2]. Providing accurate and comprehensive information is essential in the process of informed decision-making and as such should include information about prognosis, namely, information about a patient's future prospects.

Historically, formulating a prognosis was prestigiously regarded as a core clinical skill and competency of physicians. The Latin terms *quoad vitam* and *quoad sanationem* refer to the traditional main elements of prognosis, namely, mortality prediction and morbidity (functional status) prediction [4]. In contemporary times, prognostication became marginalized, owing to quantum advances in diagnostics and therapeutics, and is predominantly equated with mortality or survival prediction [5]. It is recognized that prognostication, which is the process of predicting a patient's future, combines both a science and an art [6]. The science of prognostication relates to the computation (formulation) of survival predictions, while the art of prognostication is

the ability of physicians to professionally and sensitively communicate information to the patient and their families [6,7].

Prognostication, especially the scientific dimension, is experiencing a renaissance within healthcare. There is an evolving literature on prognostic factors, tools, instruments, and models applicable in a variety of the clinical settings that are making the domain of prognostication increasingly “evidence-based”. For example, in newly-diagnosed cancer cases there are actuarial data, outlined in Surveillance, Epidemiology, and End-Results program of the National Cancer Institute (SEER) [8] that are predictive of long-term survival. In advanced cancer, Karnofsky Performance Status Score (KPS) [8], (Palliative Performance Scale (PPS) [8], Palliative Prognostic Index (PPI) [8], and Palliative Prognostic Score (PaP) [8] are predictive of short-term survival. In advanced non-cancer illness, PPS and PaP are useful in predicting survival of less than six months [8,23]. For patients admitted to Intensive Care Units (ICU), the Acute Physiology and Chronic Health Evaluation Score (APACHE) [9] and Simplified Acute Physiology Score (SAPS) [10] are widely available and validated. Moreover, recent research is also demonstrating the potential of novel prognostic factors such as certain biochemical and hematologic parameters, and the presence or absence of wounds to further sharpen prognostic accuracy [11]. However, despite the existence of data on such factors, instruments, and models, physician utilization remains low, with a tendency to offer “Clinical Estimates of Survival” (CES). Studies have demonstrated that physicians using CES's tend to overestimate survival by a factor of 5.3 [12].

In the landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) study in 1995

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identified major problems with end-of-life decision making [13]. The shortfalls identified in SUPPORT led Steinhauser in 2000 to report on the factors that are considered most important by patients and their families at end-of-life: pain and symptom management, good physician-patient communication, being prepared for what to expect, achieving a sense of completion in life, clear decision making, and being treated as a “whole person” [14]. The consequences of inadequate attention to prognostication are considerable for the patient, family, and society. In addition, in many countries, the failure to disclose prognoses to terminally ill patients is becoming a medical-legal issue [15]. In a number of cases where prognostic information was not disclosed, the rulings were in favour of the plaintiff [16]. In the United States of America, the states of California and New York have “Palliative Care Information Acts” that mandate the disclosure of prognostic information by healthcare professionals in the setting of terminal illness [17]. Moreover, failure to prognosticate is associated with numerous significant concerns that apply to the complete spectrum of bioethics [6].

Several studies have demonstrated that most patients with advanced illness desire disclosure of prognostic information [18-20]. Unfortunately, healthcare professionals demonstrate resistance to disclosing prognostic information [12,21]. A systematic review involving 46 studies related to truth-telling in discussing prognosis with patients with terminal illness showed the majority of health care professionals failed to convey prognostic information to patients and family members [22]. In a recent Canadian study involving 569 patients with advanced illness, only 18% of patients and 30.1% of their family members recalled any discussion with physicians regarding prognosis [23]. Even simply stating that an advanced illness is incurable or terminal represents a cursory prognostic estimate. Given the inherent uncertainty and probabilistic nature, prognostic quotations should never be stated in exact terms, but rather as ranges (days to weeks, weeks to months, months to years), or as median survival [6,8]. Physicians have an obligation to provide information about prognosis in order that patients make informed decisions. However, patients also have the right to refuse to be informed of information about prognosis. In the latter scenario, the patient may direct the substitute decision maker to be the recipient of information pertaining to prognosis [24].

Case presentation

Illustrative Case: An 88 year-old woman with advanced dementia was transferred from her nursing home to the local ER with “failure to thrive”. Over the past year, she became incontinent and unable to walk and over the past 3 months has been mostly bed-bound. She had three prior admissions to hospital with pneumonia, febrile episodes, and “eating problems”. Each time, she displayed progressive dysphagia, was given IV fluids and antibiotics and discharged back to the nursing home. Clinically, she displayed flexion contractures in her lower limbs, complex pressure ulcers involving her sacrum and both heels, and a Palliative Performance Scale score (PPSv2) of 30%. An assessment by a speech & language pathologist reveals complete dysphagia. The patient was transferred to the ER with an advanced directive that reflected that all active and aggressive interventions, including cardiopulmonary resuscitation and mechanical ventilation, of a potentially life-prolonging nature, should be carried out. Neither the emergency room physician nor the admitting internist perused it. Irrespective of this omission, the advanced directive was signed five years earlier at a time when the patient had a PPSv2 of 70%. Without discussing the context, natural history, or prognosis of advanced dementia, the admitting internist asked her daughter: “Do you want your mother fed?” Her daughter answered “of course” and subsequently promptly agreed/consented

to a Percutaneous Endoscopic Gastrostomy tube (PEG) insertion. Unfortunately, one day after PEG insertion the patient developed aspiration pneumonia, suffered a cardiac arrest and was pronounced dead after an unsuccessful resuscitative attempt. Her daughter was very upset and could not understand why her mother deteriorated and died so suddenly. Her daughter filed a formal complaint with the hospital ombudsman in advance of pursuing legal action on the grounds that the informed consent process was incomplete. Her daughter subsequently stated that if her mother’s case had been discussed as a chronic progressive illness that was incurable, thus terminal, she would have likely foregone the insertion of the PEG and elected for a “comfort care only” approach.

Illustrative case discussion: This case exemplifies an incomplete informed consent process. The negative outcome was fuelled by the lack of inquiry about the status of advance directives by the two hospital based physicians. The nursing home was also negligent in not promoting the updating of advanced directives as the patient’s global condition deteriorated expectedly, as per the natural history of her disease. While complete active and aggressive medical management was in the patient’s best interest while her PPSv2 was 70%, it becomes increasingly ineffective, burdensome, and potentially deleterious at a PPSv2 of 30%. The physician biased the decision to insert a PEG tube by not discussing the context, natural history of disease, or prognosis. In addition, there was no exploration of the patient’s goals/objectives, values, wishes, or preferences in keeping with the principals of patient-centered care. Moreover, the risks of inserting a PEG tube and the post-insertion risk of aspiration were not discussed. The daughter faced an “impossible question”, about whether she wanted her mother “treated” or “fed” and when presented in this fashion, there is only one answer, “yes”. Such questions are highly emotionally charged and, when posed without a context, tend to promote acceptance and adoption of the particular intervention. The physician did not seize an important opportunity to complete the process of informed decision-making by acknowledging and discussing the terminal nature of advanced dementia [25]. Recent studies show that patients with advanced dementia have up to 50% six month mortality after their first episode of pneumonia, febrile episode, or “eating problem” [25], and the presence of pressure ulcers additionally impart a hazard ratio for death of almost 2.5 [26]. Moreover, there is no evidence that feeding tubes neither improve survival nor quality of life in this clinical context [27,28]. Thus, had the daughter been given the prognostic information pertaining to her mother’s scenario coupled with knowledge of the patient’s preferences, values and wishes, not only would have been able to make a better decision for her mother, but likely would have been better prepared for a negative outcome.

Ten Reasons why information about prognosis is not provided:

- 1 Physicians are not formally trained in the science and art of prognostication as evidenced by its virtual absence within medical curricula and competency frameworks such as CanMEDS [6,29]. Physicians have poor knowledge regarding the parameters of informed consent [29].
- 2 Physicians are socialized to avoid prognostication [6] and may equate prognostic discussions with nihilism.
- 3 The quantum growth of diagnostic and therapeutic modalities has rendered physicians to become death-denying [6].
- 4 Physicians feel uncomfortable in the delivery of “bad news”. It is easier and less stressful to perpetuate a “conspiracy of silence”.
- 5 Physicians may fail to acknowledge the terminal nature of chronic progressive diseases such as dementia.

- 6 Physicians may avoid discussions around natural history of disease and prognosis as they associate death with professional failure [6].
- 7 Vested financial interests may promote continued active and aggressive intervention despite their futility [31].
- 8 Physicians believe that prognostic data will make patients lose hope as they regard it akin to delivering a “death sentence” [6].
- 9 Physicians may justify their avoidance in adopting prognostication through their belief of “self-fulfilling prophecy”- the thought that negative news causes unfavourable outcomes, while positive news generates favourable outcomes. At present, there is no scientific evidence for this supposition [6].
- 10 A physician’s personal religious or spiritual beliefs may influence, bias, or inhibit/prohibit the discussion of prognosis [32].

Ten Benefits of providing information about prognosis:

1. Provision of prognostic data allows patients and their SDMs to be informed and make informed decisions. That is, patients can make decisions in alignment with their wishes, values, beliefs, and preferences.
2. May be helpful in the creation of advance directives [6].
3. Facilitates the development of time-sensitive goals and objectives [13,33]. For example, if an advanced cancer patient is informed that their median life expectancy is three months, they may elect for a final vacation rather than accepting recruitment into a chemotherapeutic clinical trial.
4. Promotion of autonomous decision-making [6].
5. May facilitate timely transition to a completely palliative philosophy that may enhance the probability of achieving higher levels of comfort, dignity, and quality of life [13].
6. May promote earlier planning of future care needs such as home-based palliative care that may reduce the probability of an undesired institutional death [13].
7. This also facilitates patients to “get their affairs in order” and put proper closure on relationships, business dealings, etc [13].
8. Reduced levels of late-stage “futile” intervention [16] associated with significant reductions in health care expenditures.
9. When family members are counselled about the natural history of disease and prognosis they are less likely to harbour “false hope” and this may reduce their probability of developing complicated bereavement [19].
10. Prognostication may help minimize potential “harm” to patients that may result from the adoption of aggressive, unproven, or futile treatments [1].

Conclusion

There are implications when physicians and other health care professionals do not utilize prognostic data and/or neglect to provide this information to patients and their family members. Information on prognosis can promote informed decision-making that results in meeting our ethical obligations to be patient-centered. Moreover, information on prognosis allow patients to plan their remaining life and healthcare, create advance directives, and avoid potentially burdensome interventions that may not be aligned with their wishes, values, beliefs, and preferences. And finally, it allows healthcare

professionals to meet legal obligations to obtain informed consent. Discussion of clinical context and natural history of disease may serve as a natural segue into a more formal discussion about prognosis. Significant gaps exist within the training and certification of physicians as it relates to prognostication. Therefore, it is recommended that prognostication becomes a core tenet within medical curricula and within medical specialty certification competency frameworks such as CanMEDS [29]. Informed consent that was secured with the disclosure of prognostic information will allow patients to “live their lives the way they want to” [7].

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