



‘I Don't Have a Crystal Ball’ – Why Do Doctors Tend to Avoid Prognostication?

«Ich habe keine Kristallkugel» – Warum vermeiden Ärztinnen und Ärzte Prognosen?

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Abstract: Uncertainty, fear to harm the patient, discomfort handling the discussion and lack of time are the most cited barriers to prognostic disclosure. Physicians can be reassured that patients desire the truth about prognosis and can manage the discussion without harm, including the uncertainty of the information, if approached in a sensitive manner. Conversational guides could provide support in preparing such difficult conversations. Communicating ‘with realism and hope’ is possible, and anxiety is normal for both patients and clinicians during prognostic disclosure. As a clinician pointed out: ‘I had asked a mentor once if it ever got easier. – No. But you get better at it.’

Keywords: Prognosis, uncertainty, communication, doctor-patient relationship

Zusammenfassung: Unsicherheit, Angst, der Patientin/dem Patienten zu schaden, Unbehagen im Umgang mit dem Gespräch und Zeitmangel sind die am häufigsten genannten Hindernisse für die Offenlegung der Prognose. Ärztinnen und Ärzte können sich darauf verlassen, dass die Betroffenen die Wahrheit über die Prognose wissen möchten und dass sie deshalb das Gespräch über die Prognose ohne möglichen Schaden führen können, auch wenn die Informationen unsicher sind, wenn diese Themen einfühlsam angesprochen werden: Gesprächsleitfäden könnten bei der Vorbereitung solcher schwierigen Gespräche helfen. Es ist möglich, «mit Realismus und Hoffnung» zu kommunizieren, und eine gewisse Angst und Unbehagen sind bei der Offenlegung der Prognose sowohl für Patientinnen und Patienten als auch für Klinikern und Kliniker normal. Wie ein Kliniker bemerkte: «Ich fragte einmal einen Mentor, ob es jemals einfacher wird. – Nein. Aber man wird besser darin.»

Schlüsselwörter: Prognose, Unsicherheit, Kommunikation, Arzt-Patienten-Beziehung

Résumé: L'incertitude, la peur de nuire au patient, l'inconfort durant la discussion et le manque de temps sont les obstacles les plus cités à la communication du pronostic. Les médecins peuvent être rassurés sur le fait que les patients désirent la vérité sur leur pronostic et qu'ils peuvent affronter la discussion, y compris l'incertitude de l'information, sans dommages, si celle-ci est abordée de façon sensible. Des guides de communication existent et pourraient aider à préparer ces difficiles conversations. Communiquer «avec réalisme et espoir» est possible; un sentiment d'anxiété associé à la communication du pronostic est normal, tant pour le patient que pour le médecin. Comme souligné par un clinicien: «J'avais demandé un jour à mon mentor si cela devenait plus facile. – Non. Mais on s'améliore.»

Mots-clés: Pronostic, incertitude, communication, relation médecin-patient

Background

Prognosis, together with diagnosis and treatment, is one of the fundamental aspects of medicine. The prognostic process implies complexity, expectations and emotions, both from patients' and doctors' side, and has important consequences on the planning of care [1, 2]. Data shows that patients suffering of advanced illness, oncologic and not, want to discuss about [3] but are often unaware of their

prognosis, or they dramatically overestimate it [2, 4, 5, 6]. This phenomenon has remained unchanged over the last decades of research [7, 8, 9, 10, 11, 12].

The prognostic (un)awareness has complex origins. Personal characteristics such as ethnicity, religiousness, performance status play a role in the understanding of the prognosis [13, 14, 15, 16]; another important contributing factor is the attitude of the physician toward the prognostic discussion [17, 18, 19, 20, 21].

Methodology

This article is based on a literature research that does not correspond to a formal systematic review of all available studies on the topic [101]. PubMed, GoogleScholar and Scopus were used as main search engines. In a first phase, different research terms were used in various combinations (MeSH Terms: prognosis, attitude of health personnel, attitude to death, doctor-patient relation, physician ethics, physician standards, life expectancy, practice patterns). The bibliography of pertinent articles was also manually screened. Christakis' book 'Death Foretold: Prophecy and Prognosis in Medical Care' [102] was consulted as a source of contents and literature. The findings were then synthesized in a textual format.

Results

The availability of scientific literature on this topic has varied during the last decades. In the 1990s, prognosis was regarded as the 'orphan child' of medical literature, which focussed mainly on treatment [22]. The sinking mortality rates after the introduction of revolutionary cancer therapies such as chemotherapeutical agents in the 1950s [23] were generating an optimism in which the prognostic reflexion seemed not to have a place. In the beginning of the 2000s, the doctor-patient communication gained attention; the medical literature on the topic targeted mostly the breaking of bad news [24], with only few studies or guidelines focussing specifically on prognostic communication [25]. In the last decade, however, the scientific interest on prognosis has been rising. Croft et al. [26] even propose a new model of clinical practice centred on prognosis more than diagnosis. The number of articles on PubMed including in their titles the terms 'prognosis' or 'prognostic information', for instance, tripled between 2010 and 2020 (1844-5870 articles) [27]. The growth of palliative care, the increase in chronic disease and the avoidance of futile treatments are cited factors contributing to this regained interest [21, 28]. Using this new body of evidence, the aim of this work is to analyse the factors contributing to the physicians' avoidance of prognosis and whether their concerns are funded.

Patients and their families desire prognostic information

The evidence confirming that patients and their relatives desire prognostic information is now overwhelming: nearly all patients with advanced disease state want specific, realistic and individualized information about prognosis [2, 3, 5, 25, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38]. Preparation for death (for practical, psychological, and spiritual reasons) and therapy choices are among the most mentioned

motivations [29]. Although this reasonably reflects the clinical practice, it should be kept in mind that a selection bias might be an issue interpreting the scientific evidence on this topic: patients participating in the surveys might feel more comfortable addressing prognostic issues than those refusing to participate.

What do patients exactly want?

The specific content of the desired prognostic information is more uncertain. Nearly all patients with advanced illness want some general indication of prognosis, such as curability and a general estimate of life expectancy [32-34]. More variable across the clinical studies is the proportion of people desiring specific time estimates [31, 33, 35, 39, 40, 41, 42]. Description of the best-, average- and worst-case scenarios are among the patients' most preferred way to receive time estimate communication [31, 43, 44, 45, 46]. Words and numbers are preferred over visual presentations [31, 47]. Simply asking patients 'how much information' they want is not enough, and more in-depth questioning is necessary to understand their perspectives, fears and needs [48].

When should the discussion take place?

In a survey with patients with metastatic cancer, more than 2 out of 3 patients wanted a prognostic discussion when first diagnosed with metastasis, the other (mostly younger patients) preferred to negotiate the timing of the discussion [31]. In general, patients tend to prefer discussing late in illness trajectory: when the disease is getting worse, at the end of the therapy or when losing self-sufficiency [49]. This may seem contradictory to the high interest found in nearly all patients in discussing end-of-life issues in general. It might be related to the human ambivalence toward the truth, more difficult to capture in clinical studies. In a qualitative study with in-depth interviews with patients, Deschepper et al. underlined the simultaneous desire to hear more about prognosis and to avoid facing death [50].

In general, patients prefer to discuss prognostic information over several consultations: both prognosis and preferences change over time [17, 31, 51, 52], and the emotional distress can affect cognition and understanding of a first prognostic disclosure [53].

From whom should the information come?

The understanding of prognosis is not limited to the information provided by the physician, as patients often seek information from other sources, such as family, friends or informative material [54]. However, strong evidence shows that patients identify their doctors as an important source of information and expect them to address the topic [30, 31].

What about those not wanting to know?

The most common reason reported by patients declaring not wanting to know their prognosis is that the inaccuracy of the estimate renders the information useless [31]. The characteristics of those patients are variable across studies. Patients with a shorter expected survival, those with higher anxiety scores [31], and with lower education level [55]

were found to be less likely to want prognostic information. Contradictory information is found about association with gender [39, 56, 57] and education level [55, 57]. In general, if patients understand that the medical information can be tailored to their preferences, they are more likely to desire it [18]. Attention must be brought to the fact that, as mentioned before, patients' desire for information fluctuates over time and evolves with the illness progression.

Prognosis is too little discussed

What do patient say?

Patients with a life-threatening illness are often unaware of their prognosis. In a survey including patients with advanced colorectal cancer under palliative chemotherapy, 80 % of them believed the treatment to be curative [58]. In another study analysing the prognostic awareness among patients with advanced cancer, only 5 % of participants demonstrated accurate illness understanding, defined as awareness of incurability and accurate estimate of life expectancy [59]. A variety of other studies showed similar results [60, 61, 62, 63, 64].

However, the origins of prognostic awareness are complex, with psychological issues such as denial and overwhelming playing a role in understanding and recalling the information [65].

Patients are not only unaware but report very low rates of prognostic discussions. 60–90 % of patients with advanced COPD, renal failure necessitating dialysis or metastatic cancer report never having discussed prognosis with their doctors [5, 12, 66, 67]. In a vast cohort study among patients with advanced cancer, only 18 % of patients wanting to be informed on life expectancy recalled a prognostic disclosure [2].

The recall bias is a known significant issue in self-reported questionnaires or interviews [68]. Moreover, it has been estimated that the majority of medical information provided by healthcare practitioners is forgotten immediately or incorrectly remembered [69]. Thus, the question that cannot be answered with patient-reported information is: is the prognostic information given in an inefficient way or not given at all?

What do doctors say?

In surveys, physicians report to always discuss the curability or incurability of diseases; when it comes to prognostic estimates, things become more variable [70–72]. Only between 1/3 and 1/2 of doctors of various specialties report systematically discussing life expectancy in incurable diseases, and this number increases only to up to 2/3 in situations in which the patient has less than six months to live [70, 73, 74]. In a study with in-depth interviews with Swedish physicians from various specialties, one third of them used to withhold important information during clinical encounters in order to maintain a positive attitude and preserve hope [75]. Physicians referring patients to an outpatient hospice program stated that even if patients with

cancer requested survival estimates, they would provide a frank estimate only 1/3 of the times, and either no estimate, a conscious overestimate or underestimate the rest of the times [76]. Hemato-oncologists reported discussing prognosis at diagnosis, mostly in general terms of chances of cure; one in five respondent reported either never revisiting it or doing so only at imminent death [77].

The prognostic discussions are poorly documented in medical records [78] and in doctor-to-doctor communication [79]; when documented, they seem to take place very late in the illness trajectory (in a median of 1–3 months before death) [80, 81].

Palliative care specialists assess prognosis and understanding of it more frequently than oncologists [82]. No association between doctor gender and self-reported tendency to discuss prognosis was found in one meta-analysis [83].

Who should initiate the discussion?

Since the prognostic process is emotionally charged and confronts both patients and doctors with their own mortality [29], initiating the discussion is undoubtedly difficult. Patients and relatives often wait for the conversation to be started by their clinician [30, 55, 84], while clinicians rely on patients to raise the topic [19–21, 70, 85, 86]. Patients tend to display an interest in receiving a prognostic estimate rather than formally requesting one, or they ask for it only when the clinician provides an opportunity to do that [87]. Physicians underestimate patients' needs for information and overestimate their understanding; they furthermore incorrectly interpret patients not asking as not wanting to know [88]. Consequently, this can result in a perpetual cycle of non-discussion, as brightly highlighted in a paper titled 'After you' [89]. Interestingly, this situation of collusion has been described by one oncologist as 'necessary' and 'serving the vital function of preserving hope' [90].

What is the reality?

Even if physicians admit not systematically discussing prognosis, there is a large gap between doctor- and patient-reported prognostic discussions. Many hypotheses about the cause of this gap have been formulated. Physicians may inflate their own plans to discuss prognosis in hypothetical situations [40, 88]; they may believe they gave an information they did not provide [91]; the prognosis may be approached in vague terms and thus misinterpreted by patients [15, 88, 92].

A few studies have investigated what happens during the real-life clinical encounters. Henselman and colleagues [85] recorded consultations between oncologists and patients with short life expectancy (less than one year): the life expectancy was discussed in less than one third of conversations about palliative chemotherapy and the topic was always addressed by the patient. Singh [93] taped conversations about CT-scan results with patients affected by incurable cancer, with one third of the scans showing a progression of the disease: only 4 out of 128 visits contained frank prognostic discussions, 3 of them initiated by the pa-

tient. Numerous implicit prognostic clues were given (e.g. ‘the tumor is growing’) but not further developed. Audrey [92] recorded discussions on palliative chemotherapy during oncology consultations: the survival benefit of the therapy was addressed in vague terms (‘buy you some time’) or not discussed at all in 75% of the cases. The same seems to apply to non-oncologic situations. Ahluwalia [94] analysed audio-recorded visits between internists or cardiologists and elderly patients with heart failure: most patients’ concerns about the future (ranging from expression of fear of dying to explicit requests of prognostic estimates) were not addressed by physicians, who avoided the discussion by hedging or changing the subject.

The poor communication on the subject is confirmed by studies examining the concordance between patients’ and doctors’ estimates of prognosis [95, 96]: in the majority of the cases, agreement is low, patients tend to be more optimistic and to ignore that their perception differs from the medical one [64, 91].

Prognosis is important for an appropriate care planning

Positive consequences of a good prognostic discussion/awareness

There is solid evidence showing that a realistic sense for prognosis is related to a better concordance between patients’ and medical goals; to a preference for comfort care over more aggressive treatment; to a higher rate of advanced care planning, reduced hospital admission rates and early hospice referral; and to an improved quality of life [2, 8, 15, 67, 80, 84, 97, 98]. Furthermore, in some countries prognostic estimates are essential to gain access to palliative programs or financial support [99].

Patients’ self-estimated prognosis is not enough

Data show that self-estimated prognosis of patients with advanced disease is substantially more optimistic than real-life expectancy [11, 64, 95, 96]. Smith-Uffen [6] observed that when patients with advanced cancer were asked to provide a worst-case scenario, nearly half of the estimates were longer than the real observed survival.

Prognostic discussions work

Does the prognostic information given by the clinicians substantially influence the prognostic awareness of the patients? Or is prognostic awareness a more existential issue, only superficially scratched by the health professionals?

Research shows that doctors have a room for action. Vlkova [16], in a recent systematic review on factors influencing prognostic awareness, identified doctor-patient dialogues as positively associated with prognostic awareness. It can be argued that the association between prognostic awareness and doctor-patient discussion can be bidirectional (i.e. patients with a spontaneous good awareness could have started the conversation with their doctors more often). However, the review included studies

assessing the causality effect of those discussions, for example with patient interviews taking place before and after the prognostic disclosure [100].

Barriers and challenges in tackling discussions on prognosis in clinical practice

1. Uncertainty

Doctors’ concerns

Medicine is a science of uncertainty and an art of probability.

Sir W. Osler

The prognosis has an intrinsic uncertainty. Physicians’ estimates are known to be optimistic (although not as optimistic as patients’, see above) and not very accurate [103, 104]. The other healthcare professionals are inaccurate as well, with nurses providing a better estimate by imminent death [105] and with a slightly better result in multidisciplinary discussions [11]. The survival time for an individual person cannot be extrapolated from the statistical survival time in clinical studies [106], as brilliantly illustrated in Stephen Jay Gould’s essay ‘The median isn’t the message’ [107]. Moreover, survival rates in trials differ from real-life ones [108]; and new therapies and exceptional responders (outliers) expand the range of possible survival [109, 110]. For non-oncologic life-threatening illnesses, disease trajectory is even more difficult to foresee [4, 20]. Prognostic tools are valuable complements, but cannot replace physician estimations [111, 112]. So, this is a real issue: prognosis is uncertain. How do doctors deal with this?

Uncertainty can cause greater discomfort than delivering the bad news itself [113]. Doctors identify uncertainty as one of the bigger barriers to discuss life expectancy and seem to react to this discomfort by avoiding end-of-life care discussions [18–20, 80, 85, 114, 115, 116]. In surveys, statements like ‘cannot say anything concrete’, ‘cannot give a number’ as way of dealing with uncertainty are recurrent [113, 117]. In a vignette case study with general practitioners, the willingness to discuss prognosis was augmented by available prognostic information (compared to if the physician had to estimate it himself) [118]. Less experienced physicians reported higher stress from clinical uncertainty [119]. In addition, doctors fear being poorly judged by patients or colleagues for inaccurate prognostic estimates [21, 113, 120].

Patients’ perspective

‘That’s my point,’ the oncologist presses. ‘When the data are poor, how can your oncologist truthfully tell what is best?’ ‘I understand that you can’t make up an answer where there is

none,' the patient responds, 'but it's the way you say it that counts. I think you'd find that a lot of patients can deal with uncertainty, provided it's explained properly.' 'But I can't give you reassurance if I'm not reassured myself!' protests the oncologist. 'If PubMed can't inform me, how can I educate you?' The oncologist is becoming irate at the patient's inability to understand his simple logic. The patient shakes his head at the obtuse doctor.

*Hope is based on knowledge, not ignorance.
What remains unspoken is unspeakable.*

Michael A. Simpson

This conversation described by Srivastava [121] goes straight to the point. By avoiding the topic, doctors probably tend to believe that patients cannot understand or deal with uncertainty. However, evidence suggest that this is not the case if the discussion is conducted in a sensitive manner [122–124]. Conversation guidelines to help physicians dealing with the unavoidable element of uncertainty are increasingly published [18, 45]. As an example, 'best-case/worst-case' scenarios are described as a way doctors can integrate uncertainty without avoiding to give a survival estimate [43, 125]. This method of communication has been judged as helpful by oncologic patients [44, 46]. A qualitative study analysing conversation between palliative care doctors and family members [126] shows beautiful examples on how a collaborative management of uncertainty is possible.

2. Fear to harm the well-being of patients, destroy hope and worsen the doctor-patient relationship

Doctors' concerns

Providing hope is a clinical imperative for oncologists [19, 90, 127]. Balancing honesty with hope in situations in which the prognosis is grim is a real challenge. Communicating a prognostic estimate, physicians fear to destroy patients' hope and causing anxiety or depression [18, 19, 84, 89, 128, 129]. As mentioned before, one oncologist goes so far as to describe the exclusion of the prognostic discussion from the clinical encounters as 'necessary' to preserve hope [90]. In a qualitative study, prognostic disclosure was described by many oncologists as a violent act ('hit someone in the face with this', 'hammer them', 'pound prognosis in') [19]. In the same survey and in other scientific works [52, 130] physicians often indicated that they consciously avoided prognostic disclosure in order to protect not only the patient but also the doctor-patient relationship [20, 131]; and most of them said they tried to actively increase patients' hopes by being positive about therapies and by relativizing the statistic data ('I've always had patients who've outlived all the numbers').

Patients' perspective

Data show that patients can face the prognostic disclosures without detrimental consequences to their emotional well-being [2]. Among patients with end-stage renal disease, most reported being comfortable talking about end-of-life care issues, and those who reported being uncomfortable still felt the discussion was necessary [132]. Two different issues must be differentiated: the immediate emotional and psychological reaction to the prognostic disclosure [53, 133] and the long-term psychological outcomes. Literature on this topic is of varying quality, but most findings suggest that prognosis disclosure does not increase patient anxiety, depression or hopelessness across all age groups, from adolescents to elderly people [80, 131, 134, 135, 136, 137, 138, 139, 140, 141]. Even among patients reporting the prognostic discussion to be upsetting, only very few of them regret it [142]. On the contrary, realistic prognostic disclosure instead of an avoiding approach, is regarded by patients as a way of fostering hope [25, 140].

One study from Korea [143] found that patients with higher prognostic awareness had lesser emotional functioning and existential well-being. This finding raises the question that goes beyond the scope of this work of cultural differences in the approach to prognosis [144, 145].

Regarding doctor-patient relationship, data show that prognostic communication has either no impact or a positive one on the therapeutic alliance [2, 135, 139, 146, 147].

3. Discomfort, inability or unpreparedness to handle the conversation

*Handle them carefully, for words have
more power than atom bombs.*

Pearl Strachan Hurd

Doctors' concerns

The discomfort to handle a difficult conversation is often cited as a reason for the physicians' avoidance of prognostic disclosure. Baile et al. [129] examined the reaction of oncologists from different countries in having difficult conversations: the majority reported that it was stressful to deal with families' and patients' emotions and to handle their own negative feelings during prognostic discussions. In a survey, Ptacek [148] asked physicians what makes delivering bad news (not specifically prognosis) so difficult. Among others, doctors listed the following factors: when you know the patient well *and* when you don't know the patient enough; when your involvement has been active *and* when it has been reactive; when you have been caring for the patient for a long time *and* for a short time. Another study [149] reported that the stress level was similar in doctors' following recommendations about communication strategies and in those who did not; and was unrelated to the years in practice or the frequency of giving such news.

Possible reactions

Research indicates that practice alone does not necessarily improve communication [150]. Communication is a skill that can be learned with various methods [151, 152], although Bernard [153] suggests that skill training may be more useful to people already predisposed to a good communication. Formal communication training of clinicians is now beginning to be part of the university curriculum [154, 155], but in a very recent past the majority of physicians were not receiving communication training, or rated their training as inadequate [21, 95, 148, 150, 156]. Training may make doctors more confident [157] and more effective [158, 159]. It is more uncertain if training actually reduces the stress of delivering bad news. In summary, as Arnold and Koczwara [160] underline, 'dealing with human tragedy is never easy, irrespective of how skilled one may be. The natural response to human tragedy is sadness and compassion. (...) Perhaps, breaking bad news can never be easy – perhaps it shouldn't be easy'.

4. Lack of time

Doctors' concerns

It is not enough to be busy.

The question is: what are we busy about?

Henry David Thoreau

Lack of time, feeling rushed or fatigued are also cited factors contributing to the reluctance of approaching prognosis during clinical encounters [148, 150, 161, 162]. In one study, this was identified as the most frequent important barrier about end-of-life communication [132]. However, it is remarkable that patients with a long illness trajectory and allegedly more opportunities to discuss prognosis do not seem to be better informed [5, 163].

Possible reactions

Time and resources are institutional factors that are known to be problematic [164]. Time spent with the patient for in-hospital clinicians has been decreasing in the last decades [165], contributing to the dissatisfaction of doctors and to the risk of burnout [166]. Suggestions to tackle this problem are beyond the purpose of this work.

5. Other potential barriers to address prognosis and prognostic information

Sense of failure

Technology and therapy advances in medicine can create an erroneous perception of infallibility of the medical professions leading to unrealistic expectations ('I want my miracle', writes an oncologist when his favorite patient relapses [167]) [160, 168]. The sense of failure and guilt facing therapy inefficiency or the impending death of the pa-

tient is a widely recognized experience among oncologists [169, 170], although literature on this topic is scarce and this feeling has been examined mostly in relationship to burnout risk [171]. This sense of failure can have a deleterious influence on patient care, leading for instance to aggressive attempts of salvage therapy instead of a palliative approach including prognostic evaluation and end-of-life care [167].

Self-fulfilling prophecy

The phenomenon of the self-fulfilling prophecy implies that the description of a future event does influence the probability of the event itself. Christakis [172], as one of the biggest theoreticians of self-fulfilling prophecies in medical care and in prognostication, describes this report from a general internist:

I often had the distinct impression when I talked to patients that I was changing the future (...). If I told the patient that I thought he would die, I felt strangely responsible, not just for what I said, but for what would happen.

The most frequent hypothesis that has been formulated is that predictions may foster changes in patients' and doctors' attitudes (e.g. compliance with therapy, withdrawing of life-sustaining measures). A mysterious, more transcendent element is also present in physicians' narratives. This belief or 'magical thinking' can be present by patients and families as well [49]. The scientific interest in this phenomenon has been waning.

Personal fear of death and illness

The confrontation with one's own mortality is a challenge for every human being [173] and the discomfort when talking about death is widespread among doctors [20]. The degree and consequences of death anxiety among physicians is poorly investigated [174]. In clinical practice, indirect signs of this fear can be seen in the hesitance about using the word 'die' or 'death' and using euphemisms instead, metaphors or implicit language [19, 175, 176].

Request of family members

In contrast to the past, it is now an unacceptable practice to withdraw prognostic information to patients following the family's request. The respect of autonomy, including the end-of-life phase, is one of the ethical pillars of medical practice in our culture [177]. The practice in non-Western countries may still differ [129, 145].

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Conflict of Interest

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