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Discussing Prognosis with Empathy to Cancer Patients

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Abstract

Purpose of Review Our goal was to provide healthcare professionals (HCPs) with evidence-based data about what can be done to handle prognostic discussions with empathy.

Recent Findings First, disclosing prognosis involves a good reason to do so and making sure that the patient will be able to process the discussion. Second, communication tips are given for the three dimensions of empathy: "establishing rapport with the patient," which should not be overlooked; the emotional dimension, which involves an accurate understanding of the patient and communication skills; and the "active/positive" dimension which is about giving hope, explaining things clearly and helping patients take control with shared decision-making and a planned future.

Summary Although communication tips are helpful, empathy training should be based more on the development of HCPs' emotional skills, in order to help them regulate their emotions and thus be more comfortable with those of patients and families. Furthermore, research into empathy toward minorities and relatives is needed.

Keywords Prognosis · Empathy · Communication · Emotional skills · Cancer care · Bad news

Introduction

The question of prognosis is a central topic in cancer care, and most patients and their relatives are confronted with it at least once in their disease trajectory [1, 2]. Their awareness of prognostic information such as the curability of their cancer, treatment goals, and life expectancy is related to positive patient outcomes that are discussed below. However, it remains difficult and stressful for physicians to disclose dismal prognostic [3, 4]. To alleviate their own distress, some physicians tend to avoid these conversations [5, 6] or focus primarily on treatments [7, 8], which they feel more comfortable about. In fact, prognostic disclosure requires high empathic skills that should meet patients' needs and psychological resources while handling the distress generated by the information, in both patients and physicians. Consequently, it is not surprising

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to observe inaccuracy in many patients regarding their prognosis [9], with most patients underestimating the severity of their cancer [10–12]. In order to help health care professionals (HCPs) with this sensitive issue, the goal of this treatise is to provide them with evidence-based information and experience-related reflection as to how to deliver prognostic information with empathy while protecting oneself as an HCP. To this end, we first review important data on prognostic disclosure to understand what is at stake. Drawing on empathy research, we then give information about what can be helpful for patients and HCPs.

Finding Motivation for Prognostic Disclosure

HCPs may have a negative attitude toward prognostic disclosure. They may perceive it as harmful to patients and their relatives without providing them with any real benefit, while making themselves feel very uncomfortable in such moments. However, although it is difficult to deal with and accept, prognostic awareness is also critical and beneficial for patients and relatives. It gives patient certainty [13], allows them to plan their life accordingly [2, 13–15] and their relatives to prepare for the death of their loved one [16, 17], while promoting resilience [17]. It facilitates the implementation of early palliative care, which improves patients' quality of life [18, 19]

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and survival [20], promotes hospice enrollment [21, 22], and supports patients' informed choices about treatment options [2, 23, 24] and advanced care planning [25].

Another barrier to prognosis communication is the physician's fear that such discussions may undermine the patients' trust in the physician and the doctor-patient relationship [26]. However, previous findings have shown otherwise. Highquality prognostic communication with the physician—i.e., the physician takes time to provide understandable information in a sensitive manner—increases patients' feeling of being listened to and understood [27] and improves the doctorpatient relationship [28] as patients trust their physician and even feel hope [1, 2, 29]. We return later to this a priori counterintuitive result regarding increased hope in a context of bleak perspectives.

In view of these data, it appears that prognostic disclosure, when timely due and delivered in a sensitive manner, is in the interest of both patients and HCP themselves. Not telling the truth puts the nursing staff in a delicate and annoying situation [30]. HCPs should keep in mind the benefits of prognostic discussions to avoid feeling the distress of believing that they are doing something harmful for no other reason than the patients' right to know. As we show below, this distress is undoubtedly an obstacle to empathy. The reasons why prognosis discussions are worthwhile should also be explained to family caregivers, who generally fear that it will cause stress and a loss of hope in their loved ones [15, 31] and thus avoid disclosure and withhold related information from them. In spite of their worries, family caregivers can be of helpful advice to HCPs about the communication approach to adopt with their relatives [32...].

Given the potential advantages of talking clearly about prognosis, HCPs should feel confident that they are doing the right thing when broaching the topic with patients and thus feel more comfortable about it. It should lower the stress felt in such consultations. By being relaxed themselves, HCPs meet the patients' need for a calm presence when hearing bad news [33••] and convey a feeling of hope to them [34]. However, caution is always required, as the damage could outweigh the benefits of such discussions in a minority of patients, leading to anxiety [13, 35], as feared by HCPs [36]. Therefore, providing prognostic information with empathy starts with the skill of being able to identify with which patients the topic should be carefully broached, as acknowledged by HCPs themselves [32••].

Distressed Patients

Poor prognosis always remains a terrible shock for patients and their relatives [33••]. It requires certain psychological resources to accept and process the information that one's life may come to an end within a limited and unexpected time, under circumstances involving both physical and possible mental limitations. This is why patients with task-oriented coping, i.e., patients who face problems and see what they can do to improve these situations, are more willing to receive explicit prognostic information whereas patients with avoidant coping, i.e., patients who do not face problems and instead try distractions to avoid thinking of them, prefer nondisclosure [37]. Awareness of prognosis in palliative care is higher in patients at peace with life [38], and it reduces psychological symptoms and improves quality of life only when coupled with a high acceptance of prognosis [39], which corroborates the need for psychological resources to face awareness of near death. In the same vein, distressed cancer patients prefer not to discuss prognosis [40] and the issue of forgoing intensive and burdensome treatment [41]. They thus protect themselves from bad news they would be unable to deal with emotionally, even with the most empathetic physician. Indeed, after bad-news consultations during which the failure of treatment is revealed, patients with low emotional resources maintain a poor emotional quality of life, regardless of physician empathy. In contrast, those with moderate or high emotional resources are sensitive to physician empathy: the more the physician is perceived as empathic, the better their emotional quality of life [42]. HCPs should bear this in mind. They alone cannot alleviate the distress of patients with low emotional resources, so they should not feel guilty about the negative reactions that patients may sometimes have.

Therefore, detecting distress is of utmost importance. Its prevalence is particularly high in metastatic cancer patients [43] and detection should not be considered as an easy task for which clinical acumen suffices. Patients' distress is highly underdetected [44], and screening for it properly requires the use of validated tools, such as the distress thermometer, along with clinical exploration by physicians, psychologists, and the HCPs involved with the patients.

This exploration must be explicit, through conversations and direct questions, as perspective-taking only (i.e. adopting another's perspective by putting oneself in the other's shoes) is not enough to get a clear picture of others' emotions [45]. Sometimes, HCPs do not dare ask questions to patients about their emotional state or concerns, as they fear a defensive reaction, which sometimes does happen. For example, to the simple question "How are you feeling?" some patients snap: "Bad, what do you think?" In that case, we simply recommend calmly replying that we fully understand the reaction, as the question can seem weird or even inappropriate, but that, given the wide variety of reactions we may get, it is crucial to ask questions in order to avoid missing important emotions or concerns and help the patient accordingly.

When distress is detected, it is better to postpone the prognosis discussion as it may be harmful to the patient, but also because this distress biases the processing of the information delivered [46], leading to inaccurate awareness of prognosis. Consequently, all the benefits mentioned above would be lost. Therefore, these patients must be addressed to psychosocial care first and alongside be provided with a progressive process of prognosis disclosure. Extensive evidence has shown the efficiency of psychosocial [47] and psychological [48] care in reducing cancer patients' emotional distress, especially in those who are single or living alone [47].

As regards the question of when discussing prognosis, inconsistent results have been found according to various patients' preferences [49]. In a large sample of people aged 65 or more presented with a hypothetical patient with limited life expectancy, only 44% wished to discuss life expectancy at an estimated 2 years from death, 62% at 1 year, and 74% at 6 months [14]. The closer they are to death, the more necessary it seems to talk about it.

After addressing the rationale for prognosis discussion and the necessary empathic skills to detect patients to whom supportive care should be proposed, empathy in the prognosis conversation itself is discussed.

Empathy: What Are We Referring to Exactly?

As 43 definitions of empathy are currently available [50], it is critical to define what the term refers to in order to inform medical practice concretely. Drawing on the seminal definition of Mercer and Reynolds [51] and the theoretical framework of Lown [52], medical empathy is the affective motivation and concern (i.e., empathic concern) for patients that makes it possible to (1) accurately detect (i.e. empathic accuracy) and understand (i.e. openness and acceptance) the patient's situation, perspective, and feelings; (2) sensitively communicate that understanding and check its accuracy (i.e. communication skills); and (3) act on that understanding with the patient in a helpful way (i.e., helpful behavior). The best way to achieve empathic accuracy is to probe for information, which involves getting patients to feel comfortable, carefully listening to what they have to say and asking for more detail. It also involves a so-called "other-oriented perspective-taking," i.e., taking patients' perspective by imagining how they feel and think, and not how one would feel and think in their place. The latter process, called "self-oriented perspective-taking," involves the risk of personal distress [52] that hampers empathy and is interpreted by patients as a sign of hopelessness for their future [33••].

Empirical analyses of physician empathy in cancer settings revealed three correlated dimensions [53], including two that overlap those of the definition: an "emotional" dimension bearing upon accuracy, understanding, and communication skills; an "active/positive"¹ dimension which is about giving hope while being honest, explaining things clearly, helping patients take control and plan the future with shared decision-making; and an "establishing rapport with the patient" dimension, i.e., making the patient comfortable by being warm and friendly, listening carefully to them.

We review what can be done concretely with patients for each dimension of empathy.

Establishing Rapport with the Patient

First, building rapport includes basic politeness (introducing oneself, treating patients with respect, friendliness), a warm attitude especially in voice tone and careful listening [54••] without looking at one's notes or computer. It is of utmost importance in medical settings, although it is not at the core of empathy from a social sciences point of view. In many studies, patients emphasized acts of kindness from HCPs as particularly valuable rather than an accurate understanding of their experience, concerns, and perspectives [55, 56]. Interestingly, empathy is sometimes considered not as important as medical expertise, honesty, and respect [57].

Communication skills training for HCPs may seem overly complex and long to them, considering the expectations of patients, their own motivation, and their baseline communication skills. Establishing a good rapport without necessarily having an accurate understanding of patients could efficiently inform HCP-patient relationship training, which could thus appear less off-putting for the most reluctant HCPs. It should be noted that rapport cannot be established in 5 min, especially in a prognosis discussion. Consequently, in spite of the compartmentalization of cancer care, it is advisable for HPCs to avoid engaging in such discussions with a patient they do not know at all.

The Emotional Dimension of Empathy

The emotional dimension of empathy involves being accurate in understanding patients' concerns, needs, and emotions *and* communicating appropriately with them. Some patients even expect HCPs to be able to "read" them and guess exactly how much and what type of information they want to know [33••]. Such care is possible, but it means patients have to share certain information with their HCPs. Patients' disclosure is all the more important given that investigating patients to understand their perspective is a time-consuming and demanding task, considering the large caseload and cognitive load HCPs are already confronted with. Therefore, inviting patients to express their needs and concerns is an empathic component, although patients should also be aware that they should play an active role in the process. Empathy is not the result of the actions of HCPs only. Patient-coaching enhances doctor-

¹ This dimension is coined "cognitive" in the publication [53] but I prefer the term "active/positive."

patient communication [58] and communication training should thus address the role of all parties involved: HCPs, patients, and relatives. There is little research about HCPs' empathy toward the latter [59] compared with research about patients. This is regrettable since the influence of caregivers' coping in patients' quality of life has often been demonstrated (e.g. [60]). The needs of relatives should therefore also be considered carefully in empathy research.

Accuracy alone is not enough: it needs to be coupled with communication and action. Indeed, a study on emotion recognition in medical students showed that patients could perceive empathy only in extravert ones [61]. Interestingly, there was no effect of emotion recognition or extraversion alone. The authors concluded that the perception of empathy depends both on accuracy and an appropriate bedside manner and that paying patients lip service does not make HCPs empathic to patients. The bedside manner of an HCP needs to be tailored to his/her patient's needs and preferences. Fortunately, it seems that accuracy goes together with further actions. For example, medical students with a high level of accuracy behave in a more committed way toward patients than their counterparts with a low level of accuracy [62].

Emotional empathy also involves providing an answer to patients' emotions. This is difficult for HCPs [63] and can even discourage some oncologists from initiating palliative care discussions [64]. In fact, approximately 10 to 30% of "empathic opportunities" also called "empathic windows" (i.e., patients' verbal or non-verbal hints that suggest an underlying emotion or concern that needs to be addressed) are missed by HCPs (e.g. [65]). This is all the more relevant as patients' requests for estimates about their life expectancy are often not formulated directly. They usually come in the form of empathic opportunities such as "I'm just a bit concerned about the way it's going downhill" [66, 67]. Such empathic opportunities arise more often when the communication is centered on the patient [66, 68]. Practical tips can be found in the literature to respond to patients' most common emotions [69••]: sadness, anxiety, anger, and numbness or shock. For example, the widely spread acronym NURSE stands for the following: name the emotions "It seems you are worried," show understanding "I can only imagine how difficult this if for you," respect "I'm impressed with how well you...," support "My entire staff and myself are here for you and we will be with you all the way," and explore the emotion further "We've just discussed a lot, tell me more about what you are feeling right now." In fact, data suggest that in bad news contexts, the name and respect dimensions are not expected by patients, whereas support statements are the most expected, followed by understanding and exploration [54...]. Yet, in prognostic consultations with advanced breast cancer patients, the dimensions that were less communicated by oncologists were support and exploration [65].

Although these communication tips can be very helpful. there is more to being empathic. It involves being fully present, being at ease with the emotions and suffering of the patient, without developing personal distress. It means being able to regulate one's emotions quickly in order to be available to support the patient. All these skills together correspond to the definition of what is referred to as "emotional skills" (ES) [70]: identification of emotions (those of patients, i.e., empathic opportunities but also one's own emotions in such situations), understanding of emotions (those of patients but also one's own emotions as the messenger of bad news and the witness of upsetting emotions), regulation of emotions and facilitation of patients' expression of emotions with exploration. This explains the association between ES and empathy [71] and also that between ES and fewer burnouts [72]. A belief shared by some clinicians is that empathy leads to burnout, but this is true only in HCPs with low ES [73, 74] and in those who experience strong feelings of grief about past losses in the ward and a sense of failure [75]. ES have a protective effect that is necessary to counteract the negative emotional load of cancer wards. Indeed, HCPs' secondary traumatic stress (i.e., exposure to extremely stressful events such as traumatized and suffering patients) [76] and death anxiety [77] are associated with avoidant communication about the end of life. In short, it seems difficult to manage other people's emotions if one's own emotions are not acknowledged, understood, and regulated. Fortunately, interventions aimed at increasing ES in residents have shown promising results [78, 79] although they are still rare.

The "Active/Positive" Dimension of Empathy

The active/positive dimension of empathy is related to clear explanations, action planning, and helping the patient take control with shared decision-making. In the first study exploring the link between patient-perceived physician empathy and patient survival in lung and pleural mesothelioma cancers, physician empathy assessed in bad news consultations (i.e., change of treatment because of treatment failure) was unexpectedly related to an *increased* risk of death [80]. However, and importantly, this striking result was found only for the emotional dimension of empathy and not for the "active/positive" one [80]. A very high level of emotional empathy may convey the message that the situation is really bad and may worry patients [81, 82]. Therefore, the "active/positive" dimension of empathy, which is easier for most physicians as it is not oriented toward emotions, may be particularly relevant in prognosis, especially with patients who are not sensitive to emotions.

Even if physicians generally feel more comfortable explaining things (e.g. disease, treatments) [7, 8] than responding to emotions, they sometimes underestimate their patients' need for information about their situation (disease progression, test results, etc...) and their wish to participate in their treatment plan [83], be it active or palliative. Information provides empowerment, as it helps patients get a feeling of control in a situation where they are losing control over their life. This is probably why in a study comparing patients' preferences for sentences conveying prognostic information, the preferred option was the one containing the most information, including reasons for hope [37]: median (e.g., 2 years on average), range (e.g., but it may vary from 1 to 4 years), acknowledgment of uncertainty (e.g., but it does not tell us what will happen to you), hope (e.g., we will do our best to make sure that you will have a better-than-average outcome) and prepare statement (e.g., on the other hand, if you do progress faster than average. I think it is a good idea to prepare yourself for the unexpected). For patients to regain a feeling of control, they need to be given a plan that includes the next steps of care. Providing information regarding the next steps of care is deemed among the most empathic actions [54••], even if the envisaged care is palliative. Furthermore, even when patients declare that they prefer their oncologist to decide for them, they are *less* satisfied with decisions than when they receive empathic communication that leads to decision-making [84]. Although that study examined localized cancer patients and not advanced ones, it is clear that patients need to experience autonomy, even when they themselves are not aware of this basic psychological need [85].

In the active/positive dimension, hope is also critical. At first sight, it can appear weird or impossible to give hope while discussing a dismal prognosis, as thought by some HCPs who thus avoid discussions [32..]. Yet, conveying hope has to be tried since patients need it [33, 86], including children [87]. Fortunately, physicians can be helpful in this regard [34]. In fact, hope is not only about the hope of living in spite of cancer. It is also about short and intermediate goals, the belief that each day has potential, the feeling that life has value and worth and feeling connected with others, as confirmed by cancer patients [88]. Patients' need for hope is met by the reassurance given by HCPs that, whatever happens, the best care will be given to them and that the entire staff will be with them. This can translate into the proposition of supportive care and pain control, for example. Oncologists underestimate the patients' need to do something themselves to get well [89], yet the proposition of participating in support groups is highly endorsed as empathetic by patients [54...]. It allows them to hope for a good quality of life that enables them to maintain goals and a life that is worth living. Reassuring patients of one's presence and telling them that they will not be given up on is especially important in isolated patients [33..]. In a study on healthy women randomly assigned to watching two versions (supportive vs. standard) of scripted video-vignettes of a bad news consultation, those who watched the supportive video demonstrated a lower level of arousal in heart rate variability measures [90]. The supportive video differed from the standard one only by four additional sentences reassuring the patients that the best care would be provided, that the staff would always be present and promising that shared decisions would be made.

Even in its temporal dimension, hope can be maintained. Hope for a miracle is widespread with 78% of an American sample of cancer patients showing at least some level of belief in miracles and almost half endorsing the strongest possible belief [91]. Perplexingly, among patients with moderate to strong beliefs in miracles, news of cancer progression did not change their understanding of prognosis as compared with before disclosure, whereas those who were less sensitive to miracles understood the news [91]. The hope for survival is then possible even after discomforting news. However, in my experience, many patients actually know the truth deep down inside, even those who seem to be the most in denial. This is why, as long as this misunderstanding does not lead to problematic behaviors such as wanting to adopt a child whereas the aware spouse disagrees or problematic treatment choices (e.g., a hard willing to undergo aggressive treatments), I do not see the point in disconfirming these protective beliefs. If the patient has somehow prepared his/her death, for example by talking about financial resources to his/her family and by telling them things they do not usually talk about (e.g., about love, disclosure of secrets or affirmation of values) as a way to say good-bye, there is no point in breaking hope. The key message is that, before diminishing hope, HCPs need a good reason to do so, other than their "duty" as HCPs. Most importantly, eliciting patients' and relatives' wishes about the quantity and nature of information they desire about prognosis will help in the ethical dilemma of hope as opposed to knowing and autonomy [92].

Conclusion

There are some helpful guidelines (e.g., AEGIS [93•] for a good synthesis) to help HCPs with the issue of prognosis and empathy. However, they cannot alone rehumanize HCP-patient relationships, which are the core of empathy. They may actually be counterproductive [94] as they may convey the idea that it suffices to follow a procedure to be empathic, when it is exactly the opposite. Empathy is about openness, genuine interest, and attunement to patients' and their relatives' needs. Furthermore, evidence suggests that such guidelines may not fully meet patients' needs [95] nor those of clinicians, who depart from such protocols in difficult conversations with patients because of clinical complexity [96]. They may even feel guilty and unskilled as they do not follow the guidelines.

Empathy training should therefore be reconsidered with a shift from "what to do" toward "how to reduce distress and

feel better, as HCPs, in order to be more available for patients and their relatives." This kind of support could consist of both a practical reflection on working conditions and processes to gain time and energy, as well as the development of emotional skills. Importantly, such interventions should be completely tailored to a specific environment, e.g. "such a type of HCP in such a department in such a hospital." They may otherwise even be harmful, as when a successful wellness program for emergency nurses was delivered to emergency medicine residents: for 72% of the latter, the program worsened their burnout [97]. Feedback by attendees pointed to the instructors' poor understanding of residents' stressors and work, resulting in a lack of relevance. The other advantage of more targeted coaching is that it would be more attractive for HCPs who are not interested in communication and empathy training, yet who are sometimes those who would actually need it most. Such coaching should primarily target young HCPs, for whom prognosis discussions are particularly difficult [5] resulting in lower awareness of prognosis in their patients [11]. Some patients are particularly at risk of non-awareness of prognosis-non-white, male, and older patients and patients with lower income and education [98•]-and should thus be the primary targets of reflections about empathy. In fact, physicians underestimate the information needs of Black and Hispanic parents of children with cancer [99] and offer fewer optimistic cues to Black and Latino patients than to other patients [100]. Therefore, when there is a discrepancy between patients and HCPs in terms of age, education, culture, ethnicity, etc., the latter should be invited to intensify their empathic and communicational efforts.

Finally, although prognosis discussions are often the responsibility of one physician in the field, many HCPs, including general practitioners, nurses, psychologists (and even physiotherapists or others), should be involved, at least by not avoiding the topic of prognosis when it is raised by patients. Patients will seek information from these HCPs anyway [32, 101]. The interdisciplinary communication is undoubtedly helpful both for HCPs, who will feel supported and not isolated in their work, and patients, who have a whole team ready to respond to their needs. For example, the presence of an oncologist during discussion about the results of a scan is associated with a higher likelihood of the patient acknowledging being at a late stage of the disease [102]; palliative care physicians discuss broader topics with patients than other physicians [103]; nurses often know patients quite well and are sometimes already involved in prognosis disclosure [104], but this practice needs to be expanded.

In conclusion, although progress has been made in how to communicate prognostic information with empathy, there is still room for improvement. Further research into empathy toward minorities and relatives is particularly needed. Empathic practices should also be revised and become more based on the emotional skills of HCPs, in order to regulate their own emotions and thus be more comfortable with the emotions of patients and families. Emotional skills will also help them find their own style of empathy and develop confidence in their ability to build rapport with patients, which should help them to take patients' perspective and help them accordingly. Finally, the way interventions are designed to improve empathy should also be reconsidered and become more based on the specific settings and constraints of each department and profession, rather than on a priori guidelines that are not always relevant to HCPs' motivation and goals or to patients' expectations.

Declarations

Conflict of Interest The author does not have any potential conflicts of interest to disclose.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by the author.

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