

Providing Hope in Terminal Cancer: When is it Appropriate and When is it Not?

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Abstract

Hope is essential in the face of terminal cancer. Generally in Western societies, patients and their families prefer their doctor to engage them in transparent, realistic, authoritative, empathic and open communication about the diagnosis and prognosis of cancer but this topic is not well studied in the Asian context. With the exponential increase in information about cancer and the many permutations in cancer treatment, rational and otherwise, the doctor-patient relationship is even more critical in planning the best treatment strategy and also in rendering both particular and general hope in the patient's war against cancer. Overall, the majority of drugs tested against cancer have failed to reach the market, and those that have, only provide modest benefits, several major therapeutic breakthroughs notwithstanding. Commoditised medicalisation of the dying process ingrained into the contemporary consciousness can potentially create unrealistic or false hope, therapeutic nihilism and a drain on the resources of both the patient and society. These factors can also detract from the dignity of dying as an acceptable natural process. Hope cannot be confined only to focusing merely on the existential dimension of improving survival through technological intervention. Psychosocial and, where appropriate, spiritual interventions and support also play major roles in relieving suffering and providing hope to the patient. Hope cannot be a victim of misinformation from self-interested external parties, nor be an obsession with just buying promises of extending survival time without sufficient regard for quality of life and achieving a good death.

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Introduction

“Hope is the elevating feeling we experience when we see — in the mind's eye — a path to a better future.”

Jerome Groopman, MD

Professor of Medicine

Harvard Medical School, United States

From *The Anatomy of Hope*

Hope is a universally valued, central and enduring primal human emotion that has sustained and uplifted humankind from the dawn of time. Professor Jerome Groopman proceeds to emphasised in his bestselling book that “true hope has no room for delusion”.¹

Hope, in the fight against cancer, is oxygen to live on meaningfully. Oncologists must respect and actively engage in the patients' desire for hope in the face of a disease that evokes great helplessness, and patients are commonly gripped more by a fear of dying than the fear of death itself.

Undoubtedly, the last several decades have seen

exponential progress in cancer advancement that has significantly impacted on the lives of cancer patients. A once-fatal disease, childhood leukaemia is now curable in over 80% of stricken children. The introduction of platinum chemotherapy has improved cure rates for even advanced testicular cancer and the revolution in molecular targeting therapy has ushered in novel drugs like imatinib (Gleevec) that has induced meaningful remissions in chronic myeloid leukaemia and an uncommon cancer, gastrointestinal stromal tumour (GIST). In spite of the real advances made in cancer biology, diagnosis and treatment, the latter which can cost up to one billion United States (US) dollars to bring a single drug to the market,² many cancer drugs only provide modest incremental benefits for cancer patients³ and many more cancer drugs fail to give any real improvements.

Cancer treatment expenditure has escalated dramatically. In 2005, the total cost of cancer care in the US was \$209.9 billion² and health insurance family coverage premiums increased by 73% between 2000 and 2005.⁴ Medical bills account for over half of bankruptcy filings in the US. Cost-sensitive and cost-benefit decision-making in cancer

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management is becoming unavoidable.

The Media and Medicine

The Information Age communicates unparalleled knowledge and empowers patients for making more informed decisions related to their disease. This can enable them to arrive at a more realistic sense of hope. Conversely, the Information Age can also disseminate hype and false hope. Famously, the 3rd May 1998 issue of *The New York Times* ran a front page story of a mouse study led by the now late Professor Judah Folkman.⁵ Folkman identified proteins that blocked blood vessels feeding cancers and showed dramatic tumour shrinkage in the tumour-bearing mice that received the said drugs. In this article by journalist Gina Kolata, Nobel Prize winner James Watson was quoted as saying that “Judah is going to cure cancer in two years.”⁵ Both drugs failed spectacularly in early phase human clinical trials. By the year 2000, cancer had not been cured. Here was an example of the power of media spreading unmet hope.

In 1971, then US President Richard Nixon declared “War on Cancer” in his State of the Union address, vowing that cancer would be eradicated in the foreseeable future. In this new millennium, after 200 billion dollars of public and private funding support for cancer research, and over 1.5 million scientific papers later, those bold promises of defeating cancer now seem far too optimistic. In a wired flat world, it can be confounding for the lay person to distinguish accurate medical facts from medical fiction.

Oncologists and Hope

Cancer specialists who possess irreplaceable training and experience in cancer management must engender realistic hope by harnessing the most optimal strategy for their cancer patients. They must stay up-to-date of current knowledge, objectify the healing process and yet be empathetic patient advocates. Hagerty et al⁶ studied cancer patients in their advanced stages who were asked for the qualities of their caregivers that best provided hope. Ninety-eight percent of these patients wanted their doctors to be realistic and still individualise their management, being expert yet collaborative in discussing their care plan. Ninety percent of patients felt that if doctors were up-to-date in their knowledge of treatment, it created much hope. Eighty-seven percent gained hope if their doctor knew their cancer very well, and this assured them their pain would be well controlled. Eighty percent of patients felt hopeful if their doctor had a sense of humour. The study summarises 6 styles of conveying hope.

1. Realism
2. Emotional support, being open and responsive

3. Facilitating coping with the dying
4. Information provision
5. Discussing therapeutic options including second opinion
6. Sharing personal information

Breaking Bad News

The Hagerty study covered a largely Western population (Australian) characterised by a safety net healthcare, but overall, the above conclusions would have universality to cancer patients worldwide. Clearly, self-determinism and patient autonomy, then medical paternalism, take on a broader mantle in the doctor-patient relationship in the modern time. A 1961 study by Oken demonstrated that 90% of 219 doctors studied did not tell their patients about a diagnosis of cancer.⁷ The study was repeated in 1979, where 97% of physicians surveyed indicated a preference for communicating a diagnosis of cancer to their patients.⁸ In Singapore, the families of elderly cancer patients with incurable cancer commonly appeal that the patient not be told of his or her diagnosis and/or prognosis. The most often cited reason is that it would destroy the patient’s feeling of hope. Paradoxically, studies have shown that communicating poor prognosis and outcome in the face of terminal cancer do not extinguish a sense of hope in the patient and may even enhance it.⁹ I believe that as much as possible, a diagnosis of cancer must be conveyed to the stricken individual, regardless of age, social, ethnic or religious backgrounds. The physician need not portray a stark, existential picture but instead positively frame the situation in more indirect and subtle expressions that would still preserve hope for the patient and their family.¹⁰ Still, many oncologists tend to defer discussions of end-of-life management and hospice decisions until late in the patient’s cancer journey.

In a landmark legal case of *Arato versus Avedon*,¹¹ Miklos Arato was diagnosed with pancreatic cancer which was surgically resected, then followed by chemotherapy delivered by the oncologist, Dr Avedon. Mr Arato was cancer-free at that point. Documented evidence showed that a general discussion of prognosis did ensue between doctors and Mr Arato. His cancer recurred, and Arato died within a year. His family sued the surgeon and oncologists for not conveying their definition of accurate prognostic information, specifically that 95% of patients with pancreatic cancer die within 5 years. The oncologist stated in trial that the high mortality rate might “deprive the patient of any hope of a cure”, and that Mr Arato never asked about his life expectancy nor directly ask for prognostic information. The surgeon stated that Mr Arato had displayed great anxiety about his cancer, and hence disclosure of prognosis was “medically inappropriate”. In the first instance, a jury

verdict and the Supreme Court judge ruled in favour of the defendants — that physicians had no obligations under informed consent to disclose statistical life expectancy. The Court of Appeals overruled this decision, in favour of the plaintiffs, only for the ruling to be reversed once again by the Supreme Court of California. The Supreme Court ruling stated that:

“The contexts and clinical settings in which physicians and patient interact and exchange information material to therapeutic decisions are so multifarious, the informational needs and degree of dependency of individual patients so various, and the professional relationship itself such an intimate and irreducibly judgment-laden one, that we believe it is unwise to require as a matter of law that a particular species of information be disclosed.”

The Supreme Court alluded to the importance of sustaining hope for cancer patients in explaining its judgement.

A Case of Advanced Pancreatic Cancer

Mr T is a 62-year-old Chinese male presented with epigastric pain, backache and weight loss. A computed tomography (CT) scan revealed a head of pancreas mass with surrounding enlarged lymph nodes and an endoscopic ultrasound with biopsy of the pancreatic mass confirming an adenocarcinoma. The surgeon planned towards a Whipple’s procedure, but discovered during surgery that the tumour mass was locally invasive with infiltration of the surrounding structures, rendering definitive surgery not possible. The surgeon conveyed this to Mr T in the postoperative period. The medical oncologist then explained that his cancer was potentially not curable, and recommended chemotherapy with either gemcitabine¹² alone or gemcitabine with oral capecitabine.¹³ The patient enquired about the combination of gemcitabine and erlotinib,¹⁴ which had also shown survival benefits in patients with advanced pancreas cancer. The medical oncologist expressed that the median survival improvement of less than 2 extra weeks with the addition of erlotinib was not very meaningful and the additional cost was high, adding several thousand dollars more per month to his chemotherapy.¹⁵ The patient then asked if the chemotherapy would shrink the cancer sufficiently for a complete surgical removal of cancer. The surgeon and medical oncologist explained that while this was possible, the opportunity was slim. He responded to a 6-month course of chemotherapy with reduction of pain, weight gain and some tumour shrinkage, but not enough for complete surgical removal. Eventually, his cancer progressed to his liver and lungs. At this point, second line treatment options offered to him included 5-fluorouracil and oxaliplatin, docetaxel or a clinical trial using erlotinib only. He also enquired about a cancer vaccine called Rixin-G with promising early

phase clinical trial efficacy¹⁶ offered overseas. The medical oncologist emphasised to the patient that none of these therapies would be curative, and none proven to prolong life. The medical oncologist offered that his average lifespan was likely only a few months, although a small number of patients could live till one year and beyond. The patient was determined to see the birth of his first grandchild in 8 months’ time.

Advanced pancreatic cancer is one of the most aggressive solid tumours with a median survival of about 3 to 6 months. The majority of drugs tested against pancreatic cancers, including most chemotherapy drugs and also the newer biological agents, have not significantly extended survival in this disease. The first-line therapeutic decision of either gemcitabine alone¹² or gemcitabine with oral capecitabine contributes to not just a modestly better survival but also improves response rates and clinical benefit by alleviating symptoms.¹³ The oncologist must be able to effectively communicate the benefits of treatment in lay language to provide the most accurate information of side effects, cost, benefit and overall outcome. For example, gemcitabine provides an extra median survival benefit (still significant) of about 1 month over the previous standard drug therapy 5-fluorouracil.¹² If survival data is discussed in this manner, it seems unimpressive. Using a different, yet equally factual perspective, the oncologist could also explain that stage IV pancreatic cancer patients treated with gemcitabine, (overall well tolerated) provided a survival rate of 18% at 1 year whereas those treated with 5-fluorouracil had a 1-year survival rate of only 2%.¹² This equally accurate statistical statement presents a more hopeful perspective for a patient and the family. Almost all drug combinations with gemcitabine have failed to improve on these odds, except for the addition of oral capecitabine, where in a subset of patients, added survival benefit is achievable,¹³ and with oral erlotinib, where an addition of almost 2 weeks is added to median survival.¹⁴ Oxaliplatin, 5-fluorouracil and irinotecan based combination chemotherapy may be an alternative first-line treatment instead of gemcitabine. In communicating the benefits of treatments to patients, it is essential to explain terms like ‘progression-free survival’, ‘overall survival’ and ‘clinical benefit response’. Ultimately, ‘overall survival’ represents the most important endpoint of benefit for cancer drug efficacy, with real gains in lifespan. ‘Progression-free survival’ is the time that cancer growth remains under control as a result of treatment, and this may or may not translate into real survival time gains (overall survival).³ In the classical study of gemcitabine (versus 5-fluorouracil) in pancreas cancer, clinical benefit response (measure of improvement in pain, performance status and weight) in the gemcitabine arm was seen in 23.8% and in 4.8% in the 5-fluorouracil arm.¹² This quality-of-life

endpoint was a major factor when the Food and Drug Agency (FDA) approved this drug. A single point median survival may not be an ideal way of expressing real outcome as it does not necessarily represent the patient's own outcome. The late Harvard evolutionary biologist, Professor Steven Jay Gould, who died of cancer remarked that a median survival of 8 months for his advanced cancer did not mean he would be dead in 8 months.¹⁷ It meant that half of such similar patients would still be alive after 8 months. This epiphany gave him renewed hope, and indeed he survived well after the median of 8 months. Painting a best case scenario for the patient based on real outcomes analysis is an important exercise in giving realistic hope.

In Singapore, a discussion with cancer patients and their families about hospice care may still be a taboo topic, signalling the end of therapeutically-driven hope. In many societies, the hospice carries a stigma of an institution that would accelerate the dying process, the end of hope. Atul Gawande in his article *Letting Go*, recounted a 34-year-old non-smoking new mother with advanced lung cancer who struggled with the dilemma of hospice care when her conventional treatment options had been exhausted. The patient was persuaded to the goal of hospice as aiming to achieve a good death including freedom from pain, anxiety and fear, and learning to reconcile the dying process. Gawande quoted a study of 4493 Medicare patients with either terminal cancer or congestive heart failure showed no difference in survival time between the hospice and non-hospice patients with breast, prostate and colon cancer, and pancreatic and lung cancer patients who stayed in the hospice.¹⁸ The will to live on may be related to specific reasons — to see a young baby grow every day, to await the birth of a grandchild, or to attend the graduation of a loved one.

To construct hope in a statistics-and-data-driven health information culture, the physician has to harness the art of medicine, to process and transmit complex information to the patient in a clear, coherent, humanistic and positive way and initiate sensitive, honest disclosure. At different milestones of the patient's cancer journey, the definitions of hope will change, from one where the target is to shrink the cancer to potentially extend life, to one which is more holistic and transformational, including freedom from pain, the contemplation of one's legacy and possibly seeking spiritual answers. The oncologist must encourage and help the patient explore and refocus upon these broader scopes of hope. Healthcare professionals and loved ones form an integral psychosocial pillar to alleviate the "suffering of the mind" that confronts most cancer patients, which may also include advance care planning, encouraging integration into support groups and managing financial concerns.

In these times of soaring health expenditure, cost-benefit

analyses must weigh on decisions to recommend treatments. By adding erlotinib to gemcitabine, the incremental cost-effectiveness ratio is US\$410,000 per year of life saved or US\$7885 per week of life saved. Erlotinib can result in more diarrhoea for the patient, and when adjusted for the quality-of-life impact of diarrhoea, the incremental cost-effectiveness ratio increases to US\$430,000 (low impact of diarrhoea) and to US\$510,000 (high impact of diarrhoea) per quality-adjusted life year (QALY).¹⁵ These numbers far exceed the acceptable benchmark of cost-effectiveness of US\$50,000 to US\$100,000 per QALY, questioning the significant value of erlotinib added to gemcitabine for making a difference in advanced pancreas cancer. Cost has become a critical issue related to hope in cancer treatment. Countries and individuals who are economically challenged do limit their access to best care practices in cancer management. Health authorities in countries for which social safety nets exist already consider the cost-benefit of new cancer drug impact at a larger societal and population "greater good" level. In such health systems, drugs with the highest benefit do generally receive strong reimbursements and subsidies. In countries like the US where third party private insurance captures a big market in healthcare coverage, overconsumption of healthcare can occur as a result of moral hazard.² Individualising cancer care and communication with the patient and family must include financial counselling.

Direct revenue gained through prescribing and procedures, especially on the background of information asymmetry, can lead to excessive treatments with possibly marginal or no gains in clinical outcomes. In this context, the vulnerable cancer patient may fall prey to therapeutic nihilism, where the provision of (unrealistic/false) hope is linked to profit for one party over another. When a patient with advanced pancreatic cancer has progressed following first and second lines of conventional chemotherapies, subsequent lines of treatments render very small real gains for the patient except for a very small group. In this regard, experimental options outside the limits of evidence-based medicine (since there may be none at this point) may appear as the only hope. The oncologist must offer wise counsel on such alternative options, not deliver false hope which may incur further financial, physical and emotional burden. The Hippocratic Oath reminds us to, "first do no harm". In a free market healthcare system, it is critical that the trust between doctor and patient is preserved and not be eroded, a fundamental compact for building real hope.

In the context of clinical trials, full disclosure of all potential risks involved and potential benefits must be communicated to the patient, dissociated from investigator or institutional self interest. The patient may see such offerings as "providing hope" where hope would otherwise

be extinguished. Personalised medicine by identifying the right drug target to the right patient phenotype or genotype is an example of how scientific trial design can potentially render higher rates of benefit to cancer patients and make clinical trials more attractive to patients, than mainly to wish to support a study in hope of making a contribution to the fight against cancer and to bring hope to someone else.¹⁹

Conclusion

Hope over disease and death cannot be synonymous solely with cancer control and gain in physical survival time.²⁰ Providing psychosocial,²¹ lifestyle,²² as well as spiritual²³ interventions have proven to improve survival in cancer patients.

The burden of communication and care of cancer patients assumes a new dimension with the now multiple channels of access via telephone, emails, short text messaging and social networking sites like Facebook.²⁴ In the face of patients going through the emotional cycle of shock, anger, denial, and loss, the physician has to be careful that the distinct demarcation of the doctor-patient relationship does not get blurred, nor the relationship become casually over-familiar, over-demanding on the time and energy of the doctor. Professional burnout is a real concern and psychiatric morbidity and emotional exhaustion are especially frequent amongst oncologists.²⁵ Still, the physician must professionally be available to the patient and their families and be arbiters of both particular hope (systematised project to achieve tangible gains in hope) and general hope (absolute trust in the future with no predetermined goals).²⁶ Ivan Illich criticises the medicalisation of the dying process, in that it devalues and dehumanises suffering and dying which should ideally be accepted as meaningful processes of life. The concept of “a good death” may be marred by potentially futile treatments that represent an unnecessarily aggressive war against the inevitable, which should instead be edified in its natural dignity.²⁷ The late Dame Cecily Saunders introduced the concept of ‘total pain’ to describe the complex combination of physical, emotional and spiritual pain in patients with terminal illness.²⁸ Multidisciplinary palliative care aiming at achieving a good death must strive towards a pain-free and symptom-free journey, confronting and reconciling the dying process, addressing emotional and spiritual distress, attaining closure and closeness with loved ones, and settling unresolved matters, thus providing hope where a technology-centric battle against physical life-limiting disease offers little further mileage.

“Hope is definitely not the same thing as optimism. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out.”

Vaclav Havel

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Providing Hope in Terminal Cancer: When is it Appropriate and When is it Not? Article. Jan 2011. Ann acad med singap. Han Chong Toh. Hope is essential in the face of terminal cancer. Generally in Western societies, patients and their families prefer their doctor to engage them in transparent, realistic, authoritative, empathic and open communication about the diagnosis and prognosis of cancer but this topic is not well studied in the Asian context. Advance planning on the part of the patient in terms of making their wishes known and education of the health care professionals is essential in promoting effective communication, thereby avoiding conflict in these difficult end-of-life decisions. View. Show abstract.