Alberta Doctors' Digest

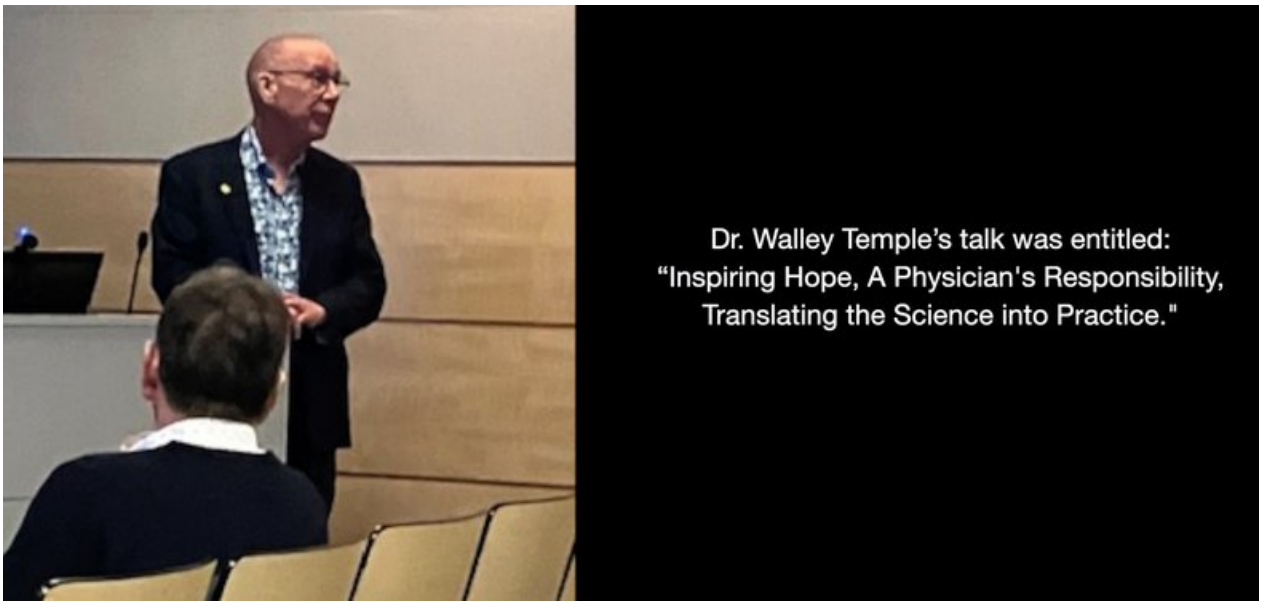
Inspiring hope: A physician's responsibility

Much of human activity is driven by hope. But hope on planet Earth has been in short supply these last few years. It’s taken a beating with wars, pestilence, deliberate division and polarization, and a dreadful sense that things could get out of hand and war could engulf the world at the twitch of a power-hungry, reckless, autocratic finger pressing a button.

In the 1980s work on the interaction of cancer and hope was done by Ronna Jevne and her group at the Cross Cancer Institute and University of Alberta. I recall her saying: “Hope lets you live with uncertainty.”

On March 20 of this year, I attended noon rounds at Calgary’s Tom Baker Cancer Centre. Dr. Walley Temple was presenting – part of the Alberta Cancer Foundation’s Spring Hope Campaign. It’s unusual for a retired surgeon to be giving rounds. They were on an unusual but important subject – a fundamental topic patchily taught in medical schools – and one that is actually difficult to teach well because it’s not a formulaic skill but one that has to be modified on each occasion of giving bad news where two human beings are interacting with perhaps an additional person in the room.

And what is that? It’s the necessity, when discussing difficult or bad news with patients, to give the news honestly in a comprehensible way but with as much hope as is reasonably possible. Dr. Temple’s talk was entitled: “Inspiring Hope, A Physician's Responsibility, Translating the Science into Practice.”



Dr. Walley Temple

I first met Walley Temple when I worked in Edmonton at the Cross Cancer Institute. We discussed the results of an historic clinical trial (NSABP trial B-05) in which we had both participated, assessing breast-conserving surgery alone or with radiotherapy versus the standard approach (at the time) of modified radical mastectomy. The B-05 results showed that patient survival after breast-conserving surgery plus radiotherapy was similar to the more radical surgery. Dr. Temple had no problem accepting these results since he knew the clinical trial was well performed and statistically valid, and we discussed new approaches to managing the disease using systemic therapy approaches.

Many surgeons then had a hard time accepting that the previous era was over. That was 100 years of the Halstead operation and of understanding breast cancer progression as a mechanistic infiltration through lymphatics with results depending on the surgical skill of nodal and lymphatic dissection. We had entered a new biological-approach era, where the malignancy's innate biology was the major survival determinant.

The following is a summary of the March 20 lecture and the 2017 paper interspersed with some personal comments, asides and memories of this topic. Walley's article was published in the Journal of Surgical Oncology. He told me he worked on it for over a year!

Dr. Temple introduced his talk with quotations from historical figures:

"Everything that is done in this world is done by hope." Martin Luther

And in Greek mythology, Pandora, the first mortal woman, received from Zeus a box which she was forbidden to open. The box contained all human blessings and curses. But Pandora opened it. All the curses were released and all the blessings were lost – except one: hope. Zeus knew that without hope mortals could not endure.

On the other hand, not everyone has agreed that hope is always helpful: "Hope in reality is the worst of all evils because it prolongs the torments of man," wrote the gloomy Friedrich Nietzsche.

Also, in the *Timaeus*, Plato adopts a negative attitude towards hope calling it "gullible hope."

Defining hope and its measurement

Hope is a wish – usually counter to prevailing circumstances – for an outcome more favourable than is likely or possible. More simply, hope is a human desire that despite a gloomy outlook, a positive outcome is possible. However, hope is actually multi-dimensional with several spheres or realms.

There are other, more nuanced definitions of hope. Some definitions include associated feelings of freedom, resiliency and energy. Dr. Kaye Herth, a prominent nursing researcher at Minnesota State University, identified three realms:

1. The first is a "cognitive-temporal realm," for example, the hope for a cure or remission.

2. The second realm might be termed an “expectancy realm,” with hope/expectation for pain and symptom control.
3. The third might be called a “relationship realm,” with the hope that one will continue to be valued by friends and relatives even while realizing that a cure or remission is not occurring.

Earlier in the 1980s, Dufault and Martocchio, two nursing researchers, divided hope into two components:

1. Goal orientated, occurring over time.
2. A more generalized, goal-independent inner experience transcending time.

The first realm in medicine (and specifically oncology) can also be counter-productive if driven by an unrealistic search for a cure, which can bring the patient into the eternally thriving field of quackery with its false hope, snake oil and quick profits. A few patients may undertake this futile exercise. Pointing out the lack of acceptable evidence for the latest “cure” can help, but a patient will often decide, despite counselling, to take on this kind of search.

So how do you measure such a vague, variable concept as hope? Most people think they understand what hope means, but its implications vary widely with each medical practitioner’s personality. Its measurement has been attempted by Herth using the Herth Hope Index (HHI). The index uses a dozen items correlated with good health. It is widely used internationally, and its reliability has been assessed in many countries and languages. It has been deemed “acceptable” according to groups attempting to test its construct validity and reliability. But most conclude that “more research is needed.” However, Herth’s research provides support for the physician’s duty to support patients’ hopes as far as truth can.

The changing face of hope

Our hopes differ greatly at life’s different stages: the child’s hopes of Christmas or birthday gifts, the young adult’s hopes of a good job or fruitful relationship, the middle-aged adult’s hopes for financial security and the elderly person’s hopes for a satisfying completion to a fulfilling life.

Likewise, hopes can change through the course of an illness. The patient with a localized cancer hopes for a cure; the patient with a recurrence hopes for a long remission while still hoping for a cure; the patient with metastatic disease may hope for palliation of symptoms and long-term control of the disease while patients with more advanced cancer receiving palliative care may hope for a dignified, pain-free death.

Research does indeed show that hope extends into the thinking of patients with advanced disease, but not necessarily in the sense of a “miraculous cure.” Herth’s three broad categories of hope can be at play here. While hope for a remission or cure may continue in this setting (cognitive temporal), other areas of hope can come into play: the hope for pain and symptom control with the hope for a peaceful death (expectancy realm) and the continuing hope to be valued and respected (relationship realm.)

Critically, patients also describe hope being damaged by negative experiences or feelings of isolation and in some instances of abandonment (“there’s not much I can do to help here…”), uncontrollable pain and devalued personhood.

Discussing bad news with patients

As a medical student in Edinburgh Medical School, I vividly recall a ward round with one of the consultant surgeons at the Edinburgh Royal Infirmary. This would have been in the late 1960s. Mr. Farquarson was an amiable person (in the barber-surgeon tradition, UK surgeons still hold to the title of “Mister.”) He believed that informing patients that they had cancer was unkind and intrusive.

On the ward round, I remember him talking to a middle-aged man lying in bed and saying that what he had was “an inflammation of the bowel which we have removed.” Mr. F. not only believed in keeping the patient in the dark but also that often it was even unfair to tell the family their relative had “cancer.” Those days are well and truly over, but it’s possible that the reason for acting that way was the lack of any organized palliative care.

You can teach some moves on how to give bad news, but it is such an individual-dependent skill. However, there are some agreed approaches. The first is to determine what level of understanding the patient and family has of the disease. In the case of a malignancy, it may be necessary to go over their understanding of a particular malignancy, its staging, the concept of spread, distant metastasis and some basic pathology. It’s important to adopt a compassionate, unhurried tone of voice and pace of speech. You should go over the clinical status and the therapeutic choices with a realistic assessment of benefits and toxicities. You must emphasize the uncertainty of prognosis. If survival issues come up, it’s best to avoid “median survivals”. It’s more helpful to talk in ranges and broad survival-time likelihoods. Some physicians use touch in appropriate circumstances (e.g. with another person in the room).

Dr. Temple believes that too often patients receive bad news as a routine telling of “the facts.” Hope research provides good evidence for much benefit in breaking bad news in a compassionate way.

Most doctors know intuitively that offering hope as a component of breaking bad news is helpful. Here we don’t mean a fatuous, unrealistic “cure hope” for quackery with no supporting evidence, but hope based on the inevitable clinical uncertainty surrounding any patient with complex disease. Breaking bad news can be stressful to the giver of the news due to minimal training, inaccurate prognostication, emotional stress, differing perceptions, and opinions among the family of what a patient should hear, and fear of conveying a hopeless clinical picture. These days most patients in Canada and most other countries want as full a disclosure as possible. The main clinical issue now is *how* to disclose it.

Controlled studies are supportive of this notion. As Dr. Temple puts it, being aware “that hope is multi-dimensional, and discovering or seeking to understand how hope operates in the individual patient will enable and enhance a sensitive, kindly and open disclosure of bad news. Although disclosure of bad news severely challenges the time-related dimension of hope, the other dimensions, especially the relationship dimension, stay intact. With time, even the challenged temporal dimension can recover as patients align their aims to more of a present focus.”

In breaking bad news to a patient, we must acknowledge uncertainty with respect to timing – after all, median or average survivals are just that, and there is a wide range of survival time above and below the median.

Walley Temple, as a surgeon, may not have been able in some cases to do anything physically helpful, but it was always evident to a patient that he was going to do the best he could possibly do.

References available upon request

Banner image credit: Gerd Altmann, pixabay.com