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### 'The Death of Cancer' The Patient Perspective

Summary: Cancer affects everybody's life at some point. 'The Death of Cancer,' written by one of oncology's leading figures, Dr Vincent T. DeVita, documents his own journey for the cure. Dr Peter Kapitein gives his personal review on the book.

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n 2005 I was diagnosed with lymph gland cancer and became interested in the medical industrial complex: everything that has to do with healthcare and especially the care of cancer. As a patient advocate, I am empowered through Inspire2Live to improve the quality of life of cancer patients by working on the best treatments for patients and by making these treatments even better. We connect patients, doctors and scientists and initiate projects.

Recently I read the book 'The death of cancer' by Vince DeVita (DeVita and DeVita-Raeburn 2015). Although it was written in 2015, I became aware of its existence recently. Vince DeVita is a pioneer and someone who thinks and always investigates with the patient in mind. He starts with the patient in front of him and, by taking the story of this patient as the starting point, he takes the steps needed to treat them. Science should start with the patient: what does it need for them to survive and what do we need to study for that best outcome? Science should serve our needs and be there for the patient and not the other way around.

Each page resonates the conversations I have had with Dr Bob Pinedo and still have. DeVita: 'You did not give up and you never let go just because a patient has a fatal illness' (DeVita and DeVita-Raeburn 2015). Pinedo resembles DeVita: 'You do not

give up on a patient, the patient can stop by themself, but a doctor never does' (Pinedo 2017). That qualifies a good doctor and DeVita argues more and more against the 'Dr No's.' Doctors who stop treatment because they, themselves, do not know or refuse to consult a colleague for advice or to take over the patient, or because standard practise fails in this patient. Protocols have brought us a long way, but not every patient fits into the protocol. What then fits is 'evidencebased medicine,' as David Sacket intended: 'Evidence-based medicine includes the integration of clinical expertise with the best available external evidence in addition to the patient's preference' (Sackett et al. 2000).

What is described beautifully and impressively is the pioneering work with the first chemotherapy for blood cancers. While reading, I realise that I am still alive because people like Vince DeVita have done their job and they did not always do that with a helpful and encouraging tailwind. The opposition was heavy. Cancer was treated with surgery and radiation and it was not considered ethical to treat patients with chemotherapy and make them suffer. These are arguments that you still hear now, but from people that do not speak out anymore. Chemotherapy has been proven to contribute to its treatment for cancer patients. DeVita shows beautifully how we get cancer under control,

through the three paradigm shifts that have taken place: the recognition that combination chemotherapy can cure cancer, that targeted therapy is successful and that immunotherapy works in most patients.

What DeVita explains is why it is so difficult to cure cancer. Many treatments focus on one particular hallmark of cancer: then it does not work or only for a short while, then the disease returns and the patient dies. DeVita shows this on the basis of a simple explanation of the famous article in Cell 'Hallmarks of cancer: the next generation' by Douglas Hanahan and Robert Weinberg (2011). Initially there were six hallmarks: in an amended version it has been brought to eight. Treatment must focus on all of these eight hallmarks. For the time being, this is impossible (according to DeVita) under the current regulation. If you want to treat according to these hallmarks, you will have to use all information available during the trial or initial treatment in order to be able to use all the information that is currently available and to help the patient. 'Combination antihallmark therapy? Forget it' (DeVita and DeVita-Raeburn 2015). This is of course extremely frustrating for patients and certainly for patients with 'unmet medical need.' They benefit from personalised medicine and if the regulation is a barrier, they die, while there is a well-defined strategy and opportunity based on the results of the research of top scientists such as Hanahan and Weinberg.

While reading, you increasingly have to think about the 'War on cancer' and that is for good reason. In a beautiful chapter DeVita describes his role and especially his collaboration with Mary Lasker. This widow of the rich philanthropist Albert Lasker, who died of cancer, had a mission and that was to get cancer under control. She was not only rich, but also had an influence at the highest level and arranged the 'War on cancer' under Nixon. The NCI came out of the NIH and got its own budget. DeVita became the director. What unfortunately did not work, was to free the

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FDA from the NIH and transfer it to the NCI. If you read this and the other chapters, you will feel uncomfortable. DeVita had a powerful position, a lot of money to spend on research and the people to change the working method. And yet many did not succeed or did. but slowly. We can clearly see this at a time when we know of better treatments and we know there is a better approach. Painful is the description of Bernie Fischer who shows that with a limited operation of breast cancer patients, followed by adjuvant chemotherapy, the survival is equal to that of a total mastectomy, where women are seriously mutilated. Even DeVita only managed to change this after six years, while Fischer's work was scientifically regarded as solid, but it jeopardised the income of the surgeons and radiotherapists. 'Most surgeons and radiotherapists would never admit that they opposed Fisher's findings because they threatened the doctor's income: instead, they questioned his integrity' (DeVita and DeVita-Raeburn 2015). If I see, for example, the resistance nowadays that exists to have intervention radiology replace certain surgical procedures and for which there is also proof that this is better for the patient, you would not be happy. When I see how much effort we have to make in order to change the way we work for cancers with unmet medical need, such as pancreatic cancer and brain tumours 'People are not dying because drugs do not exist but because they cannot access them' (DeVita and DeVita-Raeburn 2015), you would not be happy.

So has nothing changed or improved? It appears not, but the good news is that DeVita comes to the conclusion that 'The death of cancer' will be realised by personalised medicine. We will treat patients on all eight (and perhaps Hanahan and Weinberg will discover one or two more) hallmarks and adjust the method in the trials and treatments. Phase three studies are no longer necessary. It simply does not relate to the definition(s) of personalised medicine that have in common that we have to give an individual patient with her specific form of cancer, presently a unique treatment. This is an uphill battle, but I know that this is going to happen.

The 'war on cancer' was a success, although many trivialised it. It was a success because survival made a huge leap. And let's not pretend that the money was wasted. DeVita shows in a beautiful way that cancer research has always cost little when compared with other things: per inhabitant the United States spent \$125 in 1969 on the war in Vietnam. For cancer research only \$0.89. Let's turn this around and spend more money for saving lives than for destroving them.

#### Verdict

Vince DaVita is a hero and never left a patient alone. An example for Dr. No. A must-read for the students who are still unspoiled and not biased and for whom this applies: 'Nothing is impossible' (DeVita and DeVita-Raeburn 2015). ■

#### **KEY POINTS**



- Cancer will affect us all directly or indirectly
- A good doctor will not give up on a patient. A bad one will also avoid admitting the treatment isn't working
- The verdict of what is a fatal illness is subjective on both the patient and the physician side
- Cancer is difficult to cure because most therapy focuses on one type of treatment.
- 'The death of cancer' will be effective with the use of personalised medicine
- Inspire2Live encourages patients, clinicians and researchers to work together to get cancer under control by 2021



DeVita V, DeVita-Raeburn E (2015) The Death of Cancer. Sarah Crichton

De ontdekkingsreis van Bob Pinedo (2017) René Steenhorst. Prometheus

Hannahan D, Weinberg R (2011) Hallmarks of cancer: the next generation Cell 144(5) 646-674

Sackett DL et al. (2000) Evidence-based medicine: how to practice and teach EBM, 2nd ed. Edinburgh & New York: Churchill Livingstone.