

Discouraging Research: a Potential Unintended Major Consequence of Nationalized Healthcare

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Abstract

Healthcare costs are increasing and the price of healthcare is causing an ever more serious problem (for people who do not have insurance to access basic healthcare and companies providing a health benefit to their employees) making healthcare systems that offer “free care” seem attractive. Let us not forget that this problem exists in part because of research to date that has yielded choices. The article below examines a real example of how nationalized healthcare can keep new/future treatment options from patients and discourage research. In light of the potential influence of the British National Health care approach, we need to reconsider our new U.S. Healthcare Bill and work expeditiously but carefully to reduce healthcare costs and find alternative ways to provide the benefits of modern medicines/technology without discouraging research for future breakthroughs.

Article

I was diagnosed with Stage 4 Kidney Cancer at age 32, about 3 months after my daughter was born. At the time of my diagnosis, median survival was about 11 months. For over 17 years, I have witnessed the unrelenting turnover of patients in the waiting room...my friends who ultimately lost their lives after valiant and relentless searches for a cure. As one of the very few (<<1%) long term surviving patients of metastatic kidney cancer, an uncured disease, who is sitting on death row waiting for a technology breakthrough, I feel it necessary to share my experience and research on healthcare...especially in light of the potential influence of the British National Health care approach on our own new United States Healthcare Bill.

I heard Dr. Peter Clark speak in Oct 2010 at the 9th International Kidney Cancer Symposium, an annual forum which brings together key people from leading laboratories and centers working with kidney cancer, for the exchange of ideas/information to continue to frame directions for future research and treatment. Dr. Clark is the Chair of the National Institute for Health and Clinical Excellence (NICE) Appraisal Committee in the UK. From Dr. Clark, I learned that NICE is the organization in Britain responsible for providing national guidance on promoting good health and preventing/treating ill health. NICE provides standardization on what drugs, devices, surgeries, and treatment practices are approved for the National Health Service (NHS) for the general UK population.

In the UK, healthcare is free at the delivery point. However, like all publically funded healthcare systems, the NHS cannot afford intervention for every single patient and pay for every new medical treatment which becomes available. The NHS is funded by taxes and has a budget set by the government. NICE looks at how well treatments work, and also how well they work in relation to how much they cost the NHS. In the evaluation of whether to add a new technology/option to “NICE guidance”, NICE considers clinical effectiveness combined with cost and quality/quantity of life considerations via a health measure called the “quality-adjusted life year”, QALY. Each drug is considered on a case-by-case basis. Generally, however, if a treatment costs more than £20,000-30,000 per QALY, it would not be considered cost effective and it would not be included in “NICE guidance”. (Note: £ is the British currency...current exchange rate is ~1.6 U.S. Dollars (\$) per one per British pound (£). For more info, search on “quality-adjusted life year” or paste in <http://www.nice.org.uk/newsroom/features/measuringeffectivenessandcosteffectivenessstheqaly.jsp>). The reader may be able to identify/have experience with the challenge of how to manage potential break-ins on a set budget. NICE tries to apply special considerations to therapies that can extend life however, Dr. Clark acknowledges that UK healthcare is subject to much political intervention/interference. When new healthcare technologies/options become available – if it is to be added to “NICE guidance”, something may have to be displaced...or there may have to be alignment on a NHS budget increase.

In 2012, the only available kidney cancer therapies in the UK are Pazopanib (2011), Sutent as a 1st line therapy (2009, 3 yrs after FDA approval) and interferon. Therapies that my longer term kidney cancer

survivor friends and I have had access to in America between 1992 and 2012 (interleukin-2, sorafenib, temsirolimus and everolimus) are still not available in the UK. In 2009 and again in 2012, NICE considered and declined to include in “NICE guidance” the therapies sorafenib, temsirolimus and Bevacizumab as a 1st line treatment and sorafenib and sunitinib as a 2nd line treatment (<http://guidance.nice.org.uk/TA178>). NICE concluded in 2010 that everolimus did not provide enough benefits to patients to justify its high cost, even when special considerations were applied (<http://guidance.nice.org.uk/TA219>).

Therapy	FDA approval in Kidney Cancer	NICE recommends	Review Decision	Reference #	
Proleukin®	interleukin-2	1992	NO		
Nexavar®	sorafenib	Dec-05	NO	Aug-09, May-12	TA178
Sutent®	sunitinib	Jan-06	YES 1st line / NO 2nd line	Mar-09 / Aug-09, May-12	TA169 / TA178
Torisel®	temsirolimus	May-07	NO	Aug-09, May-12	TA178
Afinitor®	everolimus	Mar-09	NO	Ju-10, Apr-11	TA219
Avastin®	Bevacizumab	Aug-09	NO	Aug-09, May-12	TA178
Votrient®	pazopanib	Apr-12	YES	Feb-11	TA215
Inlyta®	axitinib	Jan-12		In progress	

Reality is that if my longer term kidney cancer survivor friends and I were British citizens, we would not be alive. This example illustrates how there can be a 3rd party in the room during a clinical consult with your oncologist...the therapy is out there but effectively, the government says no. People “shut down” at the mention of “Death Panels” however from my vantage point, that is what NICE is. I encourage you to take your own look at NICE. Check out all of the available documentation ...especially any summary on the stakeholders. It is very clear how a therapy available in 2005 or 2007 is still not available in the UK in 2012. What company is going to continue to invest in new treatment development when the government can block its availability still, 5 - 7 years after spending 500\$M (maybe even 750\$M now with inflation) across a 10 year gauntlet to get FDA approval? The UK NICE debates and declines to include new treatments in “NICE guidance” while thousands of doctors across America are learning how to treat their patients with the new therapies and trying to figure out how to combine them synergistically to find the next break through that may lead to the cure.

This example applies to other diseases besides cancer. Please don't make me, my kidney cancer survivor friends, your family and loved ones, and the millions of other Americans like us, victims of nationalized healthcare. Don't kill the Golden Goose...when what we need is more golden eggs (for many diseases). People waiting for cures need new treatment development to be profitable in order that more talented physicians and scientists can continue to contribute to the cause. Most new discoveries are developed by private industry, not by the National Cancer Institute (NCI) or other government agency. One of the things that makes this nation great is that through American ingenuity and entrepreneurship, there is an essential part of our healthcare system that employs Americans to find new drugs, devices, surgeries, and treatment practices that ultimately have a positive influence on/benefit the world. Healthcare systems in other countries are sometimes free. It does not necessarily follow that the free healthcare includes the advances in modern medicine from the last decade or two...unfortunately in some cancers and other diseases that can be terminal, delays in access to the latest treatments can mean loss of life. Free healthcare does not eliminate the problem of “spending down”, the activity of converting all of your worldly assets to cash to pay for potentially lifesaving medical care and using that cash until it's gone.

Healthcare costs are increasing and the price of healthcare is causing an ever more serious problem. Let us not forget that this problem exists in part because of research to date that has yielded choices. We need to reconsider our new U.S. Healthcare Bill and work expeditiously but carefully to reduce healthcare costs and find alternative ways to provide the benefits of modern medicines/technology without discouraging research for future breakthroughs. How to reduce costs is a topic for a future paper.

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 Blessed to be 50

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