Comparative twin study: Access to healthcare services in the NHS and the American private insurance system

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What the NHS will ultimately look like under Conservative party leadership has yet to be determined. But the potential impact of American private healthcare interests remains part of the discussion. There continues to be ongoing conversation around the strong interest the American health industry has in the UK market. [1] During his visit earlier in the year, US President Donald Trump again raised the issue of opening the National Health Service (NHS) to the American private health insurance market. [2] This revives ongoing debates about the benefits of universal health coverage systems like the NHS compared to the benefits of America's largely private, insurance-driven model.

This is of particular concern because while Americans are assured that they receive the world's best healthcare, review of health outcomes show Americans' health often fares comparatively poorly to other high-income countries, despite the US spending significantly more. [3,4] Furthermore, there is mounting evidence that the US healthcare system can bankrupt even well insured individuals. [5]

However, there is little in the literature to reflect comparative experiences *of those using* the two systems. That's where we come in. Our experiences are highly idiosyncratic, of course—but we are identical twins, both having been treated for breast cancer within the past five years. Nora, a London-based university professor, received her care through the NHS; Nancy, a US government employee (with what is considered in the US an excellent employer insurance plan), was treated in the US. We both received treatment at well-regarded university teaching hospitals. Here's our experience:

Medical history

Moving to the UK from the US in 2008 aged 55, Nora enrolled in the NHS, with the understanding that if needed, for-profit, private healthcare was available. This was not necessary. Assigned to a local GP, in an initial check-up, Nora reported a medical history that included a strong family history of breast cancer. This initiated a referral to a genetic counsellor and the local hospital's breast clinic, where she received annual mammograms starting in 2009. In 2012, a routine mammography identified a lump and she was called back for a needle biopsy. Identification of cancer led to two lumpectomies (two days in hospital per lumpectomy) however there was difficulty in identifying margins of the lesion and after consultations with her surgeon and surgical team, Nora elected to have a double mastectomy. This was undertaken in 2014, during a six day hospital stay. Nora took six weeks off work, (and had the option to stay out longer), her time off covered by her employer. She continues to have routine follow-up including anti-cancer medication, annual check-ups, and bi-annual bone density screenings. Current status: In remission.

US based Nancy works in Washington, DC, but retains an apartment in her hometown of New York City. In part, this is because prior to the 2010 Affordable Care Act, (widely known as Obamacare) a previous bout of breast cancer in her early 40s meant she had a "pre-existing condition." [6] She was therefore ineligible

for healthcare coverage in many American states. Since New York was one of the states that did not exclude Nancy from coverage, she retained it as her primary residence despite working hundreds of miles away. In other words, access to health insurance has been a factor in determining her job/career options since 1994.

Joining the Federal Government in 2007, Nancy enrolled in one of several pre-selected private health insurance plans where the employer pays 60% of the premium and employees are responsible for the 40% "matching payment." Employee payments are automatically deducted from bi-weekly paychecks. Plans vary, but most also include an "out-of-pocket deductible" of several hundred to several thousand dollars per year—costs that must be paid by the employee before insurance "kicks in." Nancy's plan permitted her to retain her New York-based healthcare providers, including her long-time oncologist.

In late 2015, after 20 years in remission, Nancy's annual mammography detected a lesion in one breast. Over a four month period, Nancy underwent several MRIs, two biopsies, and an outpatient lumpectomy, followed by a month-long course of radiation. To minimize time off work, with the permission of her New York based oncologist, she moved her post surgical radiation care to a Washington, DC hospital near her office. This necessitated her personally identifying and establishing relationships with a second medical team, coordinating a transfer of her medical records, and familiarizing herself with a new medical facility. In the end, Nancy took only two weeks off, in part by scheduling "crack-of-dawn" radiation appointments so she could still report for a full day of work. She continues to have regular check-ups. Current status: In remission.

Accessing the systems

General taxation and mandatory salary deductions pay for the NHS, which supports not only healthcare, but also some dental care, some social services, and public health initiatives. All treatment is free at point of delivery. For Nora this ranged from her initial genetic counselling to her most recent annual check-up. No bills were sent or presented to her at any point. Because Nora was over age 60, all medications also were, and continue to be, free. (Under age 60, England's NHS now charges £9.00—US $ 11.75—for any medical prescription).

In the US, although Nancy was "fully covered" by her employer's insurance plan, she was still responsible for 40% of the annual insurance company's enrolment premium—$3,500 per year. Other expenses were covered on a complicated, opaque formula arrived at through negotiations between her healthcare providers and insurance company. Significantly different from the NHS plan, under the US private healthcare system, Nancy is largely responsible for sorting out all payments at point of delivery. Some procedures and physician visits were fully covered; others were covered at varying percentages of the total cost; and occasionally, were disallowed. In theory, the highest amount Nancy was responsible for should have totalled no more than $5,000 "annual out-of-pocket maximum deducible." Since her diagnosis and treatment extended over two calendar years (December-March), she should have paid no more than $10,000 towards uncovered charges. In the end, however, she paid more than $14,000 over and above the substantial amount already paid by her insurance company and her annual $3500 premium.

Nancy, a single woman with no partner to assist her, found that in addition to facing a life-threatening disease, the financial hardships she encountered, even as a fully covered patient, and the stress created by the ongoing need to manage, negotiate, and often correct bills from doctors, hospitals, lab visits and insurance company was incredibly taxing.

Some providers refused to deal with insurance companies, only accepting direct payments: i.e. they insisted that she pay them "up front" and then submit their bill to her insurance company for reimbursement. For example, her surgeon, to whom she was referred by her oncologist, refused to deal with insurance companies. His office quoted her a price of "between $7,000 to $10,000" for a lumpectomy, although when she expressed concern about affording this, the office secretary assured her that his final bill "would probably be less." After numerous phone calls—and obtaining the mandatory "pre-approval" from her insurance company, Nancy had the operation as an outpatient. This was apparently done to keep costs down for her insurance company—no explanation was offered as to why this was an outpatient rather than inpatient procedure. Following the operation, the surgeon's office "worked with her on billing" and ultimately, only charged $6,900. Her insurance company sent her $3,900 with which to pay the surgeon, leaving her to pay the $3,000 balance. (For mysterious reasons, the insurance company also decided that only $1,302 of her $3,000 payment qualified towards fulfilling her annual $5,000 "out-of-pocket maximum.") Fortunately, she had enough personal savings to pay this bill without obtaining a loan.

Billing and payment issues continued throughout treatment. Would the insurance company cover the $4,600 oncologist-ordered Oncotype test to determine if chemotherapy was needed? Maybe, maybe not. While she waited several weeks for their ruling, she was required to submit an application to the California-based lab for "patient assistance" that included an intrusive questionnaire examining her private finances to see if she was eligible for their subsidized rate. (She was finally approved for the subsidy and her insurance company did cover the test.)

Many bills were only partially covered, leaving her responsible for tracking what had been paid by insurance, what she was responsible for, and how much of her payment the insurance company would apply to its enigmatic "out-of-pocket annual maximum." For some procedures, 100% of her payment was applied towards the maximum, but for others, the applied amount was 80% or less. She had no idea why. Sometimes, she was able to "get a deal" from the hospitals' billing departments by calling and paying her portion of an outstanding bill in full with her credit card. However, this only worked if she called and personally negotiated with diverse billing departments (blood lab, surgical, radiology, etc.).

Having surgery at one hospital and radiation at another meant dealing with billing departments at both. It also increased the number of mistakes. For example, halfway through radiation, she received a bill for nearly $40,000 from the second hospital because their billing department had erred in submitting her insurance information and unilaterally decided she was uninsured. This, too, was ultimately resolved in Nancy's favour, but caused her weeks of worry waiting for the billing department to correct its error.

Nancy's previous experience with cancer treatment in the 1990s made her aware of the need to keep meticulous records on payments to health providers and insurance companies. She initially hoped that technological improvements over the past two decades would improve her experience. It did incrementally: this time it only took six months of focused attention after the end of treatment to sort out

her finances rather than the two years needed to resolve bills from her previous bout with cancer. However, she continued to receive new, unanticipated bills for months: for example, an unexpected bill from her December 2015 surgery only arrived in May 2016.

Discussion

Obviously, this is an idiosyncratic comparison, but on behalf of both of us, we can say the following: cancer is always a daunting medical diagnosis. To the list of life and death questions that any cancer patient reflects on, there are other issues—family, work, future—that all who face cancer must consider.

Nora was able to confront many of these issues without worrying about a mounting pile of bills and ongoing monetary negotiations with her healthcare providers. Nancy's primary attention was focused on managing the complex financial issues surrounding her illness.

While many US insurance companies and politicians loudly proclaim that national insurance systems such as the NHS "do not work," in our experience, this is far from true. There are undoubtedly many problems with the NHS and the system itself is currently under severe strain. [7] But in the UK, access to healthcare is considered a right—not a privilege—and 64.6 million UK residents receive healthcare free at the point of delivery every year. [8]

There are other issues involved in a universal healthcare system that receive less attention. For example, in the UK, people, young and old, change jobs without fear of losing healthcare for themselves or their families. But for millions of Americans, health insurance is provided by their employer. Should they, their partner or children need care—cancer, diabetes, a diagnosis of autism—the condition may be covered only so long as they stay in their current job. Prior to the Affordable Care Act, such people were often locked in a job for years—even decades—because they could not afford to lose their current insurance and a new employer's insurance would not cover their pre-existing conditions. Obamacare allows millions with pre-existing conditions coverage for the first time, but not all those with pre-existing conditions enrol and coverage differs by state. Furthermore the Trump administration has clearly stated they seek to end the entire programme.

Another concern in the US is that, even for those with excellent insurance, most practices accept only some but rarely all, insurance plans. Patients must "shop around" and often travel far distances, to find a healthcare provider that will accept their specific insurance plan. This barrier to healthcare will likely increase if Obamacare is taken out of the picture.

In the US, even those with excellent insurance plans, like Nancy, still struggle under a system that needs serious review; and those who cannot afford health insurance (or enough health insurance), go without or delay seeking care, sometimes with life-threatening consequences. Health insurance companies can decide what they choose to cover, and as in Nancy's case, negotiate with doctors and hospitals to establish what percentage of medical costs they will cover and what will be covered by patients—even fully insured patients.

Ultimately, the issue is not just about healthcare or about money. At its heart, we argue, this is a human rights issue and a social justice concern. It is a question of what type of society we want to be. In the UK, a national system of healthcare, paid for by all citizens through taxes, provides a universal safety net. The US has settled for a complicated mix of private insurance and government subsidized programmes, often managed by private companies. The result is not just whether one has or does not have insurance. In the US, even for those with excellent insurance like Nancy, the issue also is the amount of time, energy and frustration a person or a family faces in navigating a labyrinthine and often unforgiving for-profit system.

One more reflection

Nancy incurred an additional set of health expenses following surgery, during the months she spent negotiating her health care bills. Her previously unremarkable blood pressure skyrocketed. An additional round of doctors' appointments, medicines, and bills (with inevitable co-payments) were needed to keep her blood pressure in check.

Nora had no blood pressure problems, but then, she did not face piles of bills and was not involved in dozens of phone calls arguing with insurance companies and hospital billing offices. Her only additional expense was that, because food in her hospital was adequate but not outstanding, her husband paid £6.95 for a ready meal from Marks & Spencer's the night before discharge. Her taxi ride home was covered by the NHS.

- **See also**: The US healthcare system can be a callous and financially menacing force

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ePatient_Dave • 5 days ago

> There continues to be ongoing conversation around the strong interest
> the American health industry has in the UK market.

Good Lord no!!

I'm a US kidney cancer survivor and member of the BMJ patient advisory panel, a businessman who has become a speaker and advocate for the patient's perspective in the future of care. After attending hundreds of events in dozens of countries I blogged American healthcare is a malignant tumor that can't stop killing its host. Please read it to understand - the system is profoundly effective (honestly) at pursuing its unintended design goals - the optimisation and protection of *the investors' concerns*. Look at the data I linked to there.

If you get into the "malignant tumor" metaphor you can see how

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