Twins Nora Ellen Groce and Nancy Groce compare the NHS with the US private insurance system

What the NHS will ultimately look like under the Conservative party has yet to be determined, but the potential impact of American private healthcare interests remains part of the discussion.[1] During his visit last year, US president Donald Trump again raised the matter of opening the NHS up to the American private health insurance market,[2] reviving debate around the benefits of universal health coverage systems like the NHS compared with the largely private, insurance driven US model.

While Americans are assured that they get the world's best healthcare, evidence shows they often fare poorly compared with other high income countries, despite the US spending significantly more.[3][4] There is mounting evidence, furthermore, that the US system can bankrupt even well insured people.[5]

There is little in the literature, however, 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 who have both 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 to be an excellent employer insurance plan, was treated there. We both had 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 registered with the NHS with the understanding that, if needed, for-profit, private healthcare was available. This was not necessary. Nora reported a strong family history of breast cancer to her local GP at her initial check-up. 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, and she spent two days in hospital per lumpectomy. There was, however, difficulty in identifying the 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 take longer. Her time off was covered by her employer. She continues to have routine follow-up, including anticancer drugs, annual check-ups, and biannual bone density screenings. She is currently in remission.

Nancy works in Washington, DC, but retains an apartment in her hometown of New York City. This is partly because, before the 2010 Affordable Care Act, (widely known as Obamacare), a previous bout of breast cancer 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 her from coverage, she kept it as her primary residence despite working hundreds of miles away. Access to health insurance, therefore, has been a factor determining her career options since 1994.

Joining the US federal government in 2007, Nancy enrolled in one of several pre-selected private health insurance plans. Under this plan the employer pays 60% of the premium and employees are responsible for the 40% “matching payment.” Employee payments are automatically deducted from their pay. Plans vary, but most also include an “out-of-pocket deductible” of between several hundred and 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 oncologist.

In late 2015, after 20 years in remission, Nancy’s annual mammography detected a lesion in one breast. Over a four month period she underwent several magnetic resonance imaging scans, two biopsies, and an outpatient lumpectomy, followed by a month long course of radiation. To minimise time off work, with the permission of her New York oncologist, she moved her postsurgical radiation care to a hospital near her office. This meant establishing relationships with a second medical team, coordinating the transfer of her medical records, and familiarising herself with a new medical facility. In the end, Nancy took only two weeks off work, in part by scheduling appointments at the “crack of dawn” so she could still report for a full day of work. She continues to have regular check-ups. She is currently in remission.

Accessing the systems

General taxation and mandatory salary deductions pay for the NHS, which supports 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 presented to her at any point. Because Nora was over 60 years old, all drugs were, and continue to be, free. (For those under 60, NHS England now charges £9 (€10.53; $11.59) for any 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—$3500 a year. Other expenses were covered according to a complicated, opaque formula arrived at through negotiations between her healthcare providers and insurance company. Under the US 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, some were disallowed. In theory, the most Nancy was

responsible for should have totalled no more than the $5000 “annual out-of-pocket maximum deducible.” Since her diagnosis and treatment extended over two calendar years (December to 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 as well as 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, laboratory visits, and the insurance company, was incredibly taxing.

Some providers insisted that she pay them up front and then submit their bill to her insurance company for reimbursement. Her surgeon, to whom she was referred by her oncologist, refused to deal with insurance companies. His office quoted her a price of “between $7000 and $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 with no other explanation offered. Following the operation, the surgeon’s office “worked with her on billing” and ultimately only charged $6900. Her insurance company sent her $3900 with which to pay the surgeon, leaving her to pay the $3000 balance. (The insurance company also decided that only $1302 of her $3000 payment qualified towards fulfilling her annual $5000 “out-of-pocket maximum.”) Fortunately, she had enough savings to pay this bill without a loan.

Billing and payment problems continued throughout treatment. While she waited several weeks to see if the insurance company would cover the $4600 Oncotype test the oncologist ordered to determine if chemotherapy was needed, she was required to submit an application to the California based laboratory for “patient assistance” that included a questionnaire examining her private finances to see if she was eligible for their subsidised 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 with her credit card. This only worked, however, if she called and personally negotiated with diverse billing departments.

Having surgery at one hospital and radiation therapy at another meant dealing with billing departments at both. It also increased the number of mistakes. Halfway through radiation therapy, for example, 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 resolved in Nancy's favour, but caused her weeks of worry.

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 advances 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. She continued to get new, unanticipated bills for months: an unexpected bill from her December 2015 surgery arrived in May 2016, for example.

Discussion

Obviously, this is an idiosyncratic comparison, but we know the following to be true: cancer is always a daunting diagnosis. To the list of life and death questions that any cancer patient reflects on, there are other matters—family, work, future—that must be considered.

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

While many US insurance companies and politicians loudly proclaim that national insurance systems such as the NHS "do not work," this is far from true. There are undoubtedly 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 its 64.6 million residents all receive healthcare free at the point of delivery.[8]

There are other aspects of universal healthcare systems that get less attention. For example, people in the UK change jobs without fear of losing healthcare 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 if they stay in their current job. Before the Affordable Care Act, such people could be locked into a job for years—even decades—because they couldn't afford to lose their current insurance and a new employer's insurance wouldn't cover their pre-existing condition. Obamacare allowed millions with pre-existing conditions to have coverage for the first time, but not all of those who are eligible enrol and coverage differs by state. Furthermore, the Trump administration has said that they will seek to end the programme.

Another concern in the US is that, even for those with excellent insurance, most practices accept only some insurance plans. Patients must shop around and often travel great distances to find a healthcare provider that will accept their plan. This barrier to healthcare will likely increase if Obamacare is ended.

In the US, even those with excellent plans, like Nancy, still struggle under a system that needs serious review. Those who cannot afford health insurance (or enough health insurance) go without or delay seeking care, sometimes with life threatening consequences. 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, this is not just about healthcare or money. This is a human rights matter and a social justice concern. It is a question of what type of society we want. 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 subsidised programmes, often managed by private companies. The result is not just whether one has or does not have insurance. Even for those with excellent insurance, the problem is also 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 healthcare bills. Her previously unremarkable blood pressure skyrocketed. An additional round of doctors' appointments, drugs, and bills (with inevitable co-payments) were needed to keep her blood pressure in check.

Nora had no blood pressure problems, but then, she didn't face mountains of bills or have to spend time 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 M&S the night before discharge. Her taxi ride home was covered by the NHS.

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Footnotes

- Nora Ellen Groce is a professor in the department of epidemiology and healthcare at University College London. She holds a doctorate in anthropology and works on matters related to global health and international development, with particular expertise in global disability research.
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References

1. ↲

   Opinion: The Observer view on the risk the Tory party poses to the NHS. 3 November 2019. www.theguardian.com/commentisfree/2019/nov/03/the-observer-view-on-the-risk-the-tory-party-poses-to-the-nhs.

   Google Scholar

2. ↲

   Meyer D. There's one subject in the UK that's as toxic as Brexit: Trump just waded into it. 4 June 2019. https://fortune.com/2019/06/04/trump-brexit-nhs.

   Google Scholar

3. ↲

   Sawyer B, McDermott D. Petersen-Kaiser health system tracker. 2019. www.healthsystemtracker.org/chart-collection/quality-u-s-healthcare-system-compare-countries/#item-start.

   Google Scholar

4. ↲

   1. Papanicolas I,
   2. Woskie LR,
   3. Jha AK

   . *Health care spending in the United States and other high income countries. JAMA2018;319:1024-39. doi:10.1001/jama.2018.1150 pmid:29536101*

   CrossRefPubMedGoogle Scholar

5. ↲

   1. Dobkin C,
   2. Finkelstein A,
   3. Kluender R,
   4. Notowidigdo MJ

   . *Myth and measurement: the case of medical bankruptcies. N Engl J Med2018;378:1076-8. doi:10.1056/NEJMp1716604 pmid:29562153*

CrossRefPubMedGoogle Scholar

6. ↲

US Government. Patient Protection and Affordable Care Act. 2010. www.healthcare.gov.

Google Scholar

7. ↲

Doctors at breaking point in underfunded NHS. Guardian. 1 April 2019. www.theguardian.com/society/2019/apr/01/doctors-at-breaking-point-in-underfunded-nhs

Google Scholar

8. ↲

NHS. NHS England: about NHS England. www.england.nhs.uk/about.

Google Scholar