

Lao Tsu, in 700 BC, advised leaders (so they say), "Go to people, live with them, love them, learn from them. Start with what they know, build with what they have, and work with the best leaders, so when the work is done, people can say, 'We did this ourselves.'"

As for my optimism about the NHS—sorry, Richard, I simply can't help it. I do meet many leaders, in whom I have great faith, but I also meet many of the dedicated staff (some unhappy, some not) and patients (some displeased, some not) almost all of whom continue to be incredibly loyal to a pathfinding system of care that the United Kingdom started a half century ago. They are smart enough to know a good thing when they have it, even while they demand that it get better. I would trade the UK's NHS, warts and all, current leaders in the bargain, for my nation's healthcare chaos any day.

Competing interests: DMB is the president and CEO of the Institute for Healthcare Improvement, which has had several agreements and contracts with the NHS over the past several years to help progress the modernisation plan. CH is on secondment to the Department of Health and in his work at the University of Birmingham has been involved in leadership development programmes for clinicians and others. The full

Summary points

The NHS does not seem to have a single, identifiable leader, and perhaps it should in order to hasten the pace of improvement

The problem of the NHS is less with leadership at the top and more with leadership at a local level

But don't all major organisations have an identifiable leader?

Wanting a heroic leader is magical thinking

Leaders don't have to be visible to be effective

competing interests of RS can be accessed at http://bmj.bmjournals.com/aboutsite/comp_editorial.shtm

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The power of stories over statistics

Thomas B Newman

Neonatal jaundice and infant safety on aeroplanes provide two lessons on the power of narrative, rather than statistical evidence, in determining practice

University of California, San Francisco, UCSF Box 0560, San Francisco, CA 94143-0560, USA
Thomas B Newman
professor of epidemiology and biostatistics and paediatrics

newman@itsa.ucsf.edu

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I've always been more comfortable with numbers than with narrative, demanding data rather than accepting anecdotes. Recently, however, as a result of research in two unrelated areas—neonatal jaundice and infant safety on aeroplanes—I've been increasingly impressed with the power of stories over statistics. So I've decided to branch out from my usual publication format and tell a few stories of my own.

Treating jaundice in newborns

The jaundice story is one of me trying to treat jaundice in newborns according to the best evidence. Ironically, the more of an expert on the evidence I have become, the more difficulty I have practising according to that evidence. This is because becoming a "jaundice expert" means becoming familiar with rare but tragic stories of children with kernicterus. These stories are so powerful that it is hard to keep them from trumping other evidence in determining practice.

My neonatal jaundice story starts in the early 1980s, when I was a resident in paediatrics at the University of California, San Francisco. At that time, we treated babies with phototherapy when they had bilirubin concentrations above 14 mg/dl (239 μ mol/l), and did exchange transfusions for concentrations above 20 mg/dl (342 μ mol/l). Unfortunately, the early 1980s was not a good time to be transfusing blood in San Francisco. Although we did not know it then, the

blood supply was contaminated with HIV. We also did not know that most of these exchange transfusions were unnecessary.

In 1983, in an article entitled "Bilirubin 20mg/dL = vigintiphobia," Watchko and Oski questioned the "fear of twenty" that led to exchange transfusions for jaundice in healthy babies.¹ Subsequently my colleagues and I reviewed and re-analysed existing studies and came to the same conclusion: that jaundice in healthy newborns was being overtreated.^{2,3} We recom-



There's a story behind the "kinder, gentler" treatment thresholds for jaundice in newborns

JAMES STEVENSON/PL

mended a "kinder, gentler" approach,⁴ that was largely adopted for a 1994 practice guideline of the American Academy of Pediatrics (AAP).⁵ For newborns more than 3 days old, that guideline recommends intensive (inpatient) phototherapy for bilirubin concentrations ≥ 20 mg/dl, exchange transfusion for bilirubin concentrations above 25–30 mg/dl. Since then there has been a dramatic shift towards less treatment of neonatal jaundice.⁶ That's the good news.

The bad news is that, beginning in the mid-1990s, reports of kernicterus have increased.^{7–9} These cases of kernicterus have mostly been blamed on very early discharge of mothers and babies after delivery, with inadequate follow up—so called "drive-through deliveries." But some cases seem to have occurred because of lack of clinicians' attention to the dangers of neonatal jaundice. The problem is with babies not being followed and then presenting with very high bilirubin concentrations, rather than with the "kinder, gentler" treatment thresholds. Still, this is something for which I may have some responsibility, since my colleague Jeffrey Maisels and I have been among the main proponents of the view that the dangers of neonatal jaundice are almost certainly less than was previously thought.

Has kernicterus increased? What is its current incidence? We don't know, because there has been no uniform surveillance. In studies from the Northern California Kaiser Permanente Medical Care Program spanning several years, my colleagues and I have not identified any cases in about 239 000 births between 1991 and 1998.

Getting to know the stories

Meanwhile, in the 1990s, I began to get calls from lawyers who wanted me to serve as an expert witness in medical liability cases involving children with alleged kernicterus. In several of these cases I got to know the families involved—from reading their stories in depositions, seeing them on videotapes, or even meeting them personally. These stories are uniformly poignant and heartbreaking.

It was through her son Cal's medical malpractice case that I first met Sue Sheridan. She has become an extremely articulate and capable spokesperson for improvements in patient safety. After an article about Cal and her appeared in *USA Today*¹⁰ other parents of children with kernicterus contacted her, and together they formed Parents of Infants and Children with Kernicterus (PICK).

I have been amazed at how successful PICK has been at raising awareness of kernicterus, despite the small number of members.^{11 12} I felt the power of these mothers and their stories during deliberations of the AAP committee in charge of developing guidelines for managing jaundice in newborns, on which I serve. I have now met many of the women in PICK and know that they want the AAP to recommend that all newborns have bilirubin measured before they leave the hospital. I like and admire these women and want to be on their side, heroically fighting to prevent an awful disease. On the other hand, I am a proponent of evidence based medicine and am reluctant to endorse a new screening recommendation that is not based on good evidence. In this case, the "evidence" is primarily the poignant stories of the kernicterus cases.

An attack of vigintiphobia

I feel the power of the stories also in my own practice caring for newborns. I remember one evening when my wife and I were home watching a rented video. I got a call from a home health nurse about a baby with a bilirubin concentration of 20.5 mg/dl, whom we had started on home phototherapy the day before for a bilirubin of 19.5 mg/dl. The nurse reported that the breast milk had come in and the baby was nursing better and had gained weight, so she had elected to continue the phototherapy at home, rather than following the AAP guideline and admitting the baby to the hospital for intensive phototherapy.

Intellectually, I knew this plan was reasonable. But I was seized with an attack of vigintiphobia. I kept envisioning the child developing kernicterus. So I kept asking my wife to stop the film so I could fret about what to do. Ultimately, I did not call the home health nurse back to advise her to admit the baby to hospital, and of course the baby did just fine. But that evening the vigintiphobia was intrusive to the point that I remember thinking, "Who needs this? Next time I'll just follow the guidelines and admit such kids to the hospital, so I don't have to worry and can enjoy my movie."

Safety of infants on aeroplanes

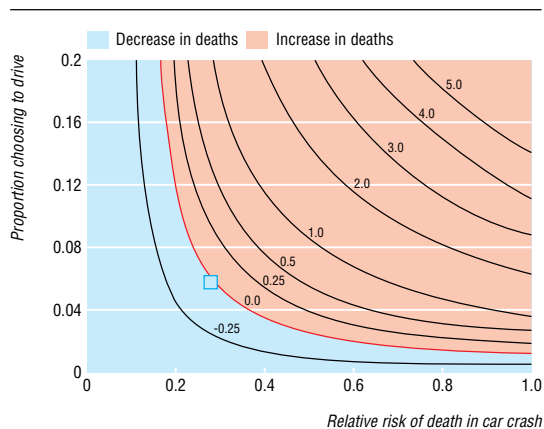
Unlike the situation with neonatal jaundice, infants' safety on aeroplanes is only a recent interest of mine. In fact, I had not given this issue much thought until late in 2001, when the AAP endorsed a proposed new requirement that children under 2 years of age ride in infant safety seats on aeroplanes, rather than being allowed to travel free on a parent's lap.¹³ This statement was a disappointment to me because I have been trying to get the AAP to make its position statements more evidence based and the statement included little evidence to support the proposed regulation.

The history of this issue dates back at least to 1989, when an unrestrained child died in the potentially survivable crash of United Airlines flight 232 outside of Sioux City, Iowa. The US National Transportation Safety Board then recommended a regulation requiring universal child restraint to the US Federal Aviation Administration (FAA). In 1994, another "lap child" died in a potentially survivable crash, and the board again asked the FAA to take action. This time the FAA agreed to study the issue, and in 1995 it presented a report to Congress.



The death of one of the "lap children" on United Airlines flight 232 in 1989 prompted calls for child safety seats

ED PORTER/AP



Estimated numbers of deaths per year in the United States that could be caused or prevented by a regulation requiring safety seats on commercial aeroplanes for children <2 years old, as a function of the proportion of families choosing to drive and their relative risk of death (per 100 million vehicle miles travelled) compared with the US national average. Square indicates the base case estimate, in which the relative risk is about 0.3; the policy will lead to a net increase in deaths if more than about 6% of families choose to drive

The FAA estimated that only about five aeroplane crash deaths could be prevented over 10 years by adopting universal child restraint on aeroplanes.¹⁴ On the other hand, because the additional cost of an aeroplane ticket for a child is likely to lead some families to drive rather than to fly, the FAA estimated the regulation would cause an increase of about 87 deaths over 10 years, due to road deaths resulting from diversion to travel by car.

The FAA analysis was not accepted by the safety board and received a hostile reception at a congressional hearing. A major point of dispute was the FAA's estimate that 20% of families with children under 2 years old would choose to drive rather than fly if they needed to buy a ticket for their young child.

Brian Johnston, David Grossman, and I decided to take our own look at the proposed regulation.¹⁵ To avoid the contentious estimate of the proportion of families that would switch to car travel, we left that variable as an unknown and simply estimated numbers of deaths that might be saved or caused as a function of this unknown proportion (figure). Even assuming 70% lower than average fatality rates per hundred million vehicle miles travelled, we found that if more than about 5-10% of families chose to drive rather than fly the policy would lead to a net increase in fatalities. Even ignoring these possible highway deaths, the estimated cost per death prevented was about \$6.4 million for each \$1 cost of the round trip aeroplane ticket for the child, or \$1.3 billion if the ticket cost \$200.

A powerful story

Unlike the case with neonatal jaundice and kernicterus, we have excellent data about the risks of plane crashes. However, as was the case with jaundice, the stories are more powerful than the statistics. In this case, Jan Brown Lohr, chief flight attendant on United flight 232, told a particularly compelling story in testimony before Congress:

It was a golden July day when disaster struck. The number two engine exploded, severing all hydraulic lines and leaving the pilots with only the number one and number

three wing engines to manoeuvre the airplane. I have never known such terror...

As we waited for the brace signal from the cockpit, I mentally reviewed if everything had been covered and remembered that we had several lap children. I picked up the microphone again and instructed those parents to place their children on the floor, which would give some advance time to brace themselves, as well as their children...

What followed has been viewed countless times—an unbelievable impact that mere words could never adequately describe—the plane breaking into three sections, being engulfed in a flash fire, and my section finally stopping upside down in a corn field.

I was finally forced to leave the wreckage due to prohibitive and deadly smoke. The first person I encountered was a mother of a 22 month old boy—the same mother I had comforted and reassured right after the engine exploded. She was trying to return to the burning wreckage to find him, and I blocked her path, telling her she could not return. And when she insisted, I told her that helpers would find him.

Sylvia Tsao then looked up at me and said, "You told me to put my baby on the floor, and I did, and he's gone."¹⁶

When I read this testimony on the internet I was close to tears. I began to wonder whether to continue writing my scientific paper on the costs and benefits of the proposed regulation. And I understood how rational people could favour the regulation—no flight attendant and no family should have to go through what was described in the testimony.

I did complete and submit the article about infant safety seats on aeroplanes,¹⁶ just as I had left the baby at home on phototherapy. But I was impressed enough with the power of stories in both of these areas that I decided to look into the area further.

The power of stories

What makes these stories so powerful? Firstly, the brains of human beings seem built to process stories better than other forms of input.¹⁷ Secondly, the storytellers themselves are important. It's not just that these awful things happened, it's that they happened to the person telling the story. This enables a connection with the listener or reader beyond what would be possible if the story were recounted by a dispassionate observer, and it infuses the storyteller with a passion to tell the story over and over again, thus multiplying its influence.

Thirdly, the powerful effect of these stories relates to the way people estimate probabilities. If we are trying to estimate the risk of kernicterus, one method we use is to base the estimate on how readily we can recall or imagine a case, and in what level of detail. This technique, called the availability heuristic, leads us to overestimate probabilities of events that we can easily and vividly imagine.¹⁸ It presents a challenge to subspecialists who, if they write guidelines, are likely to write them with a distorted sense of probabilities.¹⁹

Finally, these stories are compelling because they describe particularly tragic outcomes and because they seem to offer a solution—a way to extract some meaning and redemption from tragedy by preventing its reoccurrence. There may be 100 children with idiopathic cerebral palsy for each one with kernicterus, but because there isn't a clear way in which their disabilities could have been avoided, they do not make as compelling a story.

The trouble with stories

The trouble with these compelling stories, however, is that their apparent simplicity and focus can lead to the neglect of complicated considerations of what else we might do with our resources, and how we should make these decisions. A problem for those promoting evidence based policies is that we are at a disadvantage when we cannot identify the specific people who would benefit or be harmed. As David Bishai wrote in an editorial that accompanied our paper on child safety seats on aeroplanes, "The infants who die in these car crashes do not crash and die statistically. They really crash. They really die . . . [But] the name and photo of the dead infant in the car crash will not haunt anybody in the world of aviation safety."²⁰

Lacking specific stories, we are reduced to impersonal numbers and calculations that are often viewed with distrust. As Congressman Jim Lightfoot of Iowa, whose district includes the site of the flight 232 crash, said during the congressional hearing at which the FAA presented its report: "The question, I think, Mr Chairman, comes down to how many more children must die, how many more have to be hurt before we reach the threshold of FAA's ghoulis cost-benefit ratio?"

Harnessing the power of stories

What can be done about the power of stories over statistics, and how can it be more appropriately harnessed? First of all, we should be careful about having experts in particular diseases write guidelines for preventing those diseases. The number of interventions that might be recommended for disease prevention (in contrast to disease treatment) could be limitless, so a widened perspective that includes some awareness of other ways the resources could be spent is important.

Secondly, raise awareness of this problem—teach writers of treatment guidelines about problems like the availability heuristic and about the power of stories and storytellers. The first step to overcoming these biases is knowing how and why they occur.

Thirdly, those of us trying to maintain a broader public health perspective need to collect and tell our own stories. Although perhaps less dramatic, stories about suffering caused by misappropriation of resources are much more common, which means they can be told from personal experience by many more people. For example, I have begun to tell more stories from my own experience of children who have suffered from lack of access to basic health care because of its high cost and of families traumatised by excessive medical intervention.

Finally, we need to discuss how decisions should be made, separately from particular decisions. I tried this in an informal conversation with several of the PICK mothers. I explained that when I am caring for normal newborns just after delivery it's unusual for me not to feel at least a little rushed. I posed the question: how should I decide how many minutes to allocate to different prevention issues? How should I choose between the dangers of jaundice, and, for example, those of guns in the household, passive smoking, or prone sleeping position? My goal was to achieve some

Summary points

Ideally, public policies and choices of medical treatments should be based on the best available evidence

But these policies and choices are made by people, and people respond strongly to stories

acknowledgment that one part of the calculation must be an estimate of how common the problem was and how much difference talking about it might make. The answer I got from the mothers was perhaps not surprising. It went something like this: "That's your problem. Our problem is preventing kernicterus!"

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Competing interests: TBN has acted as a paid expert witness on cases relating to kernicterus, or allegations thereof.

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