

A PATIENT'S JOURNEY

Lessons from patients' journeys

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Previous articles in this series

- Psychotic depression (*BMJ* 2012;345:e6994)
- Klinefelter's syndrome—a diagnosis mislaid for 46 years (*BMJ* 2012;345:e6938)
- Kallmann syndrome (*BMJ* 2012;345:e6971)
- Non-coeliac gluten sensitivity (*BMJ* 2012;345:e7982)
- Restless legs syndrome (*BMJ* 2012;345:e7592)

Peter Lapsley, patient editor at the *BMJ*, reflects on the lessons that have emerged from the first 100 articles in the Patient's Journey series

Over the past seven or eight years, I have been helping patients to get their stories published, obtaining doctors' perspectives on them, and, with colleagues, developing the guidelines for drafting patients' journeys, hoping that these might increase the usefulness of such articles to doctors (box).

I describe here some of the wide range of lessons that have emerged from the patients' journeys that we have published.

Certainty and uncertainty

We have repeatedly learnt that although doctors are comfortable with uncertainty, patients are far less so. They want prompt and accurate diagnoses, taking the view that a condition cannot be treated effectively if the doctor doesn't know what it is. And they need a label to explain their conditions to family and friends. Of the numerous examples of this, one of the more recent was an account of trachea-oesophageal atresia.¹

Although medicine is a constantly evolving discipline, many patients fail to recognise that doctors don't have a solution for every problem. Patients also tend to regard their conditions as unique, as if their doctor doesn't see dozens of patients with similar problems each week. Doctors may easily dismiss apparently common conditions, and this is demoralising for patients and potentially dangerous—Dismissiveness can lead to misdiagnosis, or a missed diagnosis, of a serious condition.

Our guidance to authors of patients' journeys

To some extent, our published guidance to authors of patients' journeys dictates the sort of articles we get. The following list is not exhaustive, but our advice suggests that the articles should demonstrate one or more of the following lessons.

- Some doctors take too long to arrive at a correct diagnosis. By reading about patients' journeys, other doctors might diagnose the condition sooner, which would benefit their patients
- Some aspects of conditions and diseases are very important to patients but doctors may be unaware of these aspects
- Evidence based interventions may exist that could have profound effects on patients' lives and of which doctors should be more aware

We have seen these lessons repeated in so many patients' journeys.

We are always open to suggestions for improving our series

Time to diagnosis

Some patients may be as responsible as doctors for delayed diagnoses, often because the condition "creeps up on them," becoming gradually worse. By the time they seek medical advice the disease may be far advanced—and possibly terminal.

Quite often, too, patients are either embarrassed by their symptoms or reluctant to "waste the doctor's time." Doctors see embarrassing conditions all the time, but their patients do not, and doctors need to be sensitive to their feelings.² Similarly, it doesn't usually help patients to be told that their problems are trivial or routine: they will have consulted a doctor because they are concerned. They need their worries allayed, not dismissed.

Doctors too can be responsible for delays, taking too long to correctly diagnose a condition. Attachment to a "working diagnosis" long after the appearance of new signs and symptoms is a particular trap, as the general practitioner who was managing a case of ovarian cancer as irritable bowel syndrome admitted.³

One of the most important lessons from the series has been the importance of considering apparently unlikely diagnoses as well as the most obvious ones, a lesson eloquently expressed in "Sir Karl Popper, swans, and the general practitioner."⁴ Perhaps the least forgivable delay occurred in a case of Klinefelter's syndrome: the condition was correctly diagnosed when the patient was 14 years old but the diagnosis was then "lost" and he went untreated for 46 years until the condition was correctly diagnosed again.⁵

More worrying, though, are cases of rare conditions, where uncertainty should have led to early referral for a specialist opinion. That is one reason why rare conditions feature more often in the Patient's Journey series than in the rest of the Practice section of the *BMJ*: we hope that these articles may trigger recollection when, very occasionally, a patient presents with one. The case of xeroderma pigmentosum described in Alex Webb's account⁶ would have not have taken so long to diagnose if his doctors had taken the message of Karl Popper's swans to heart.

Social, physiological, and psychological consequences

Every patient's journey explains the consequences for the patient, their family and friends, and their relationships with their health professionals.

Unsurprisingly, several of them have been gruelling—to me as a layman, at least. The account of the mesothelioma from which the author was to die was particularly so,⁷ as was the account of obstetric fistula, which occurs mostly in developing countries and usually leads to women being disowned by their husbands and families and left to beg in the street.⁸

Almost as saddening have been the accounts of the burdens placed on carers by chronic, terminal conditions, vividly demonstrated in husbands' accounts of the deaths of their wives from motor neurone disease⁹ and dementia.¹⁰

Doctors mostly see patients for only a few minutes occasionally and focus during that time on the illness itself, so it's easy for them to forget about the effects that the illness is having on the patient's everyday life. Indeed, rarely does a doctor know what a patient does on leaving the surgery, the things that interest and preoccupy them, their needs and aspirations, and their capabilities and limitations. Key to the successful treatment of a condition—or of multiple conditions—is to “see the person in the patient.”¹¹

Another lesson to have emerged from the articles is how modest adjustments could vastly improve patients' experience of treatment. Irritating difficulties abound: with travel; long waits for appointments in both primary and secondary care; long waits between follow-up appointments. These last two, in particular, tie in with the observation that doctors know little about how patients behave when away from their surgeries. They also fuel the public perception that the health service is oblivious to the fact that patients have their own lives to lead.

New or underused interventions

This is one of the aspects that causes us a fair amount of soul searching. We don't see Patient's Journey articles as a means of providing opportunities for doctors to promote new treatments for which there is little or no evidence base for efficacy and safety. Some submissions have been attempts to “drum up business” for a new intervention. If a treatment is believed to work in a particular condition, the *BMJ* would need a proper study to provide robust evidence of that. A promising result in a single patient is scarcely admissible as evidence.

Some of the “underused” interventions are organisational, rather than clinical, an excellent example being seen in an account of a patient's two hip replacements at the same hospital,¹² 12 years apart, during which time postoperative treatment had been greatly improved by the development of a team based approach. Another underused intervention involves the benefits of continuity of care and the development of good working relationships between patients and health professionals, demonstrated clearly in the patient's journey about psoriasis.¹³

Underused interventions include such life enhancing resources as skin camouflage, shown vividly in the patient's journey about facial disfigurement.¹⁴ And the catalogue of aids to mobility and daily living given in one patient's account of his road to recovery from spinal cord injury¹⁵ should serve to remind doctors of resources they either knew nothing of or about which they may have forgotten.

And now for the good news

One lesson that shines through almost all the patients' journeys is the admiration and respect that patients have for clinicians. This is not because they know that their treating physicians will be invited to write about their cases; it is genuine and honest and reinforces the findings of surveys that have shown repeatedly that the great majority of patients who have used the NHS recently think it is excellent.

From a more personal point of view, as a non-doctor, I have been greatly surprised by the sheer number of medi-

cal conditions and interventions of which clinicians need to have at least some understanding. Even though we have published about 100 patients' journeys so far, we receive a constant stream of new offerings, usually instigated by doctors. Indeed, we currently have more than 10 articles accepted and awaiting publication and many more in the pipeline.

When the series began in 2006, the articles were written solely by patients and tended to be better suited to the colour supplements of Sunday papers than to the *BMJ*, the role of which is to help doctors make better decisions. Recognising this, we introduced the “doctors' perspectives” boxes, usually written by the patients' own treating physicians, giving a brief overview of the condition or intervention, saying what he or she learnt from this particular case and suggesting lessons the *BMJ*'s readers might take from it. That seems to have worked well. It should come as no surprise, though, that the best patients' journeys are those written by doctors who have themselves been patients. They know what they have and have not been taught and can see the lessons for doctors in the stories they have to tell; lay patients are rarely so well informed.

I have been impressed, too, by doctors' willingness to learn from patients' stories. Where things have gone wrong, doctors have almost always said so. Perhaps the most dramatic examples are a patient's account of ovarian cancer,³ which led to an in-practice review (in which she was included) and to a general practitioner's suggestion that she write the case up for the Patient's Journey series; and a woman's gruelling account of being conscious but paralysed through an emergency caesarean section¹⁶; she and her anaesthetist have since discussed in detail what happened and become friends.

In a few cases, the patients' doctors have sought to correct what they regard as inaccuracies in patients' stories, rather than exploring the misunderstandings. Far better to leave the inaccuracy in and say in the doctor's perspective box, “Is that what the patient thought I meant? I wonder why.”

Reassuringly few healthcare units have reacted badly to what's been written about them, instead trying to resolve the patient's concerns. It points up one of the biggest lessons of all: that doctors and patients can view aspects of the same “treatment” very differently. There is no privileged vantage point from which to decide who is right and who is wrong. This leads us to what may be the most significant lesson of all, the importance of good doctor-patient communication, which needs to be as jargon-free as possible, be empathetic, and bridge educational, social, and age related boundaries. It is good that British medical schools now place so much emphasis on this.

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A PATIENT'S JOURNEY

Fatigue in primary biliary cirrhosis

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

This patient developed severe fatigue as a result of primary biliary cirrhosis in her 40s. She describes her frustration with the reluctance of successive clinicians to recognise the severity of her fatigue and the damage it was doing

I was diagnosed with the liver disease primary biliary cirrhosis (PBC) in January 1986, at 42 years old. Unusually, my general practitioner recognised it and immediately referred me to the Freeman Hospital in Newcastle. Many people take years to get a diagnosis, as doctors often do not recognise the symptoms or attribute them to other illnesses such as

depression. At the hospital I was told that there was no treatment for my disease but that they would look after me. I was told that it affected about nine women for every one man, and there were more known cases in northeast England than anywhere else in the world. However, I knew no one else with this disease, I had never heard of it nor had any of my friends, and so it was a very lonely time.

By the time I was diagnosed, I knew I was different from my friends. I was always more tired than they were; less able to cope with a day out; ached all over, especially in my legs and arms; and could not lift heavy pans easily. I was used to being an active person: I played squash and badminton, did a lot of walking and gardening, did my own decorating, and had a good social life. As a single parent with two teenage children, this was a difficult time for me. I did not tell

THE CLINICIANS' PERSPECTIVE

Fatigue is a common and debilitating symptom in chronic inflammatory disease that can affect all age groups and can impact enormously on quality of life. One of the problems frequently faced by patients who experience fatigue is a sense of disbelief by friends, family, and even healthcare professionals as to the nature and origins of the symptom that affects them so dramatically. This sense of lack of belief in those around them can contribute to the social isolation exemplified by Tilly's description, and which patients are always prone to because of their lack of physical capability. In the UK, our group based in Newcastle has worked with the patient support group LIVERNorth for over a decade, and we have begun to change the perception of fatigue in one particular chronic disease, the autoimmune liver disease primary biliary cirrhosis (PBC). However, we continue to be surprised by the lack of appreciation of those both inside and outside our field as to the enormity of the implication that fatigue has for individuals who experience it.

PBC is a cholestatic autoimmune liver disease in which fatigue is experienced by at least half of patients. In about 25% of patients the fatigue is severe enough to have a serious impact on the life quality of patients through loss of capacity to work, to undertake hobbies, and to lead a normal social life. Critically, fatigue is not associated with severity of underlying liver disease, nor does it seem to respond to therapy with ursodeoxycholic acid, an agent that slows progression of the disease. The lack of association with disease severity can lead all too often to a scenario where the doctor perceives PBC to be well controlled because of improved liver biochemistry, whereas the patient finds this apparently well controlled disease is still giving them life altering fatigue.

Equally critically, in PBC there is no evidence to suggest that fatigue is a result of depression or associated comorbidity, neither of which are seen at increased frequency in the disease. Despite this, there is a tendency for clinicians to make assumptions about the presence of depression simply because a patient is fatigued. This

assumption can further challenge the patient-physician relationship and can lead to a pattern of clinical "buck passing" as the various clinicians involved in the management of these often complex cases argue that the fatigue is "not my problem" (although, of course, it always remains the patient's problem).

As our work on mechanisms of fatigue in PBC leads towards specific therapies (our group has shown cardiac, skeletal muscle, and a range of other biological associates of fatigue in PBC and is about to commence trials of therapy, delivered in an always supportive environment that seeks to help patients to understand their problem and to cope with its impacts) there is a new hope for fatigued PBC patients. The history of fatigue in PBC, the impact the symptom has on patients, and the approach taken by a frequently sceptical (but ultimately wrong) medical profession which in many cases increased rather than reduced that impact holds important lessons for other chronic inflammatory diseases where patients are still experiencing the issues outlined by Tilly.
Julia Newton, David Jones

my children about my illness and tried to hide it from them. I used to take them to school then go home and sleep for several hours each day, setting the alarm for 2 pm so that I could pull myself together, iron a shirt and blouse for the next day for their school uniforms, and think about what I could make for an evening meal (most days it was a take-away or something very simple).

As the years passed, I became more and more fatigued. I was always tired, but I could not sleep properly at night. My daughter went to university, and I am embarrassed to say it was a relief because I then only had my son at home for most of the year. Eventually, he also left home, and that made my life easier because they did not see how I was coping, and on my bad days (which by then outnumbered my good ones) I could stay in bed until lunchtime if necessary. Some days I managed to get up, shower, get dressed, and do something. Those were good days. Normal days were those when I got up eventually, had a shower by lunchtime, and then just sat and read or watched television for the rest of the day. On bad days I usually stayed in bed, although I would tend to get up around 4 pm and sit in my dressing gown until it was time to go back to bed. My social life deteriorated to the point where I rarely went out in the evenings, and during the day I did not like to plan ahead as I was never sure how much I would be able to manage. When friends visited I used to make a supreme effort to act normally and would put on a good show while they stayed with me, but when they left I would be so exhausted I would be tearful and I would take several days to recover.

"That can't be a problem: your blood tests are fine"

During this time I often mentioned the fatigue to the hospital doctors, who varied greatly in their attitude to it. Some were very sympathetic, although they couldn't really offer any treatment. Others obviously felt I should pull myself together. One suggested I try to take up squash again. Almost universally there was a sense that, as my liver function tests were quite good, this could not really be a problem related to my liver disease. Eventually, David Jones became my consultant. He always believed in the fatigue, and, although there was still no treatment, just knowing that he took on board what I was saying was a great help and made me feel better.

In 1994 a group of liver patients set up a support group, LIVERNORTH, based at the Freeman Hospital. I was a founder member and joined the committee as honorary secretary. This brought me into contact with many other people with PBC and helped me, as it meant I no longer felt alone. Talking to others, it was apparent that most of us had the same problem with fatigue, and we also realised that we had problems with memory. We compared notes on how we coped—in reality we did not cope very well—and on our shared experiences with doctors who just didn't understand or accept fatigue as a problem. I felt I had "dumbed down" and no longer expected so much of myself. There were times when I would be in the middle of some housework and would just have to walk away and take to my bed, abandoning the ironing, vacuuming, or whatever. The ironing board would stand unused for days, the vacuum cleaner would remain in the middle of the room, and I would walk round it but would not have the energy to put it away. Because my brain was still working reasonably well, I knew I was not coping. At meetings we talked about

USEFUL RESOURCES FOR PATIENTS AND HEALTH PROFESSIONALS

- LIVERNORTH (www.livernorth.org.uk/index.htm)
 - A support group for adult patients with liver disease based at the Freeman Hospital in Newcastle upon Tyne. Run entirely by volunteers, all its services are provided free to liver patients and their carers and families in northern England
- Although it is a regional charity, LIVERNORTH has members throughout the UK. It has also helped produce a DVD, *Patient's Guide to PBC (Primary Biliary Cirrhosis)*, which is available in both European and North American formats and has been sent to people throughout Europe and North America (<http://www.ennovations.co.uk/primary-biliary-cirrhosis-dvd>)
- PBCers Organisation (<http://pbcers.org/>)
 - A US based patient support group
- Canadian PBC Society (www.pbc-society.ca)
 - Can be contacted via info@pbc-society.ca

how we no longer achieved what we thought we should—we certainly could not keep up with our "normal" friends. I walked with a group but eventually stopped as I was told, very nicely, that I was slowing them down too much: to be honest, it was a relief to be able to stop as it had become a nightmare for me.

The problem with fatigue is that it is hidden. I don't look different from other people: when I say I am tired they tell me how tired they are, and if I try to explain the difference they do not understand what I am talking about. When I was first diagnosed my GP told me that I would never get any sympathy as I would always look reasonably well and my symptoms would have no impact on other people's understanding of my life. The fatigue that I and my fellow PBC patients contend with is mind numbing. You feel as if you are in a fog, you can hardly lift one foot in front of the other, everything is so difficult. You go shopping and then cannot unpack the groceries, so the frozen food defrosts and has to be thrown out. You plan a meal and forget to turn on the oven; if you do turn on the oven and cook the meat, you cannot manage to do the vegetables so it ends up being sandwiches.

In 1999 I had a liver transplant as my liver had deteriorated to such a point that I was not able to function, and a transplant was the only option. While I am better than before my operation, I continue to feel tired, although it is not the same as the previous fatigue. Recently, PBC patients were asked if we would be prepared to consider participating in a trial of a drug that might improve our fatigue, but which could have side effects. My answer was immediate: I would consider any treatment that might improve my fatigue. When I discussed it with other PBC patients, they all had the same attitude. Everyone said they would consider any treatment that might offer a way out of this existence. We feel we are in a no man's land—on the outside looking in, or sometimes locked inside and cannot get out. We do not feel part of the normal population, and this is very sad. We would love to be the lively, energetic people we once were, and if there is anything that can make us feel that way, we will take it like a shot.

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