

Our patients remain with us: that is what experience means

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Lancet 2006; 367: 1626–27

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“A bit crowded in here!” The registrar puts his head around the door of my weekly public hospital diabetes outpatient clinic room. Is it really so crowded when he pops in for a moment’s advice on insulin dosage? When I first started working here in his position more than a quarter of a century ago, we had three desks to a room. The exalted (elderly to me!) physician sat at the middle desk with a humble registrar to either side, each with a patient. The unfortunate patients of those days completely lacked privacy, so that a mumbled reply to: “How’s the morning erection then?” elicited a “Speak up, man!” from the great man’s desk in the middle of the room.

The registrar quickly surveys my room, which has not evolved much in the 25 years that I have served in the public health system, despite the new building and greater privacy. Two students still lounge against the wall, and the room is still decorated with an eye chart, a cheap travel poster, and a graphic health warning about diabetic complications. The basic furniture (chairs, a bed, a desk) is now augmented by a computer, although a pile of notes still spills over the desk, allowing the odd page to escape to be re-filed out of order. The registrar’s eyes barely skim the ordinary middle-aged woman waiting with downcast eyes for her physician (would he call me elderly?) to deal with the interruption.

Crowded? Maybe, but not in the way he sees it. After so many years in practice, my room is often crowded, but not with people that anyone else can see. They come and go, murmuring in my ears, telling their tales from the past. Sometimes they tug at my sleeve and other times they look over my shoulder, as I examine a patient. They may nudge me gently in the ribs, or grab my elbow to take me back to look again to remind me of something I have seen before and should have recognised. While I sit, apparently gazing unseeing into the distance, I am actually following a pageant of characters replaying real-life stories far more dramatic than any book or film script.

The downcast appearance of my female patient triggers such an appearance from one of my “ghosts”. My ghostly visitor rushes into the room and winks at me and I am suddenly lost in a story that reminds me of the depth of passion possible in the most ordinary person’s life. This particular ghost was once also a plain looking, hard-working woman with similarly poor glycaemic control. She admitted to drinking a little too much. My therapeutic plan for improving her diabetes control was to suggest that she tried harder to improve her diet and exercise and stop her drinking. She finally told me that this was difficult because her husband was a joyless man, a heavy drinker, and a miserable, jealous man who never let her go out, insisting she sit at home and drink with him.

A year later she suddenly turned up at the clinic with excellent glycaemic control: her husband had died and

she had time and opportunity to look after herself, and to go out and enjoy life again. While she was out, she had met a new man. And she had started a happy sex-life! I cannot say which factor improved her diabetes, but my therapeutic interventions had definitely not been responsible. She was radiant, although still the same small, plain looking woman you would not notice among others sitting at the clinic.

Another year passed and she had a new blow from fate: a nasty sacral cancer, which would necessitate removal of most of the sacrum. We were by now very close and discussed her fears, expecting only that she could get limited survival but not much quality of life. She was courageous and resigned.

The next clinic visit some time later was one of jubilation. She had done more than survive the surgery: she was well, and still experiencing a successful sex-life even without much sacrum. And she still had excellent glycaemic control! What a joy she continued to bring to her life, still with her ordinary outer appearance nothing like the femme fatale of a Hollywood movie. She helped to remind me that the external manifestations of beauty we prize so highly nowadays are not the essence or even an essential part of true *joie de vivre*. She went on enjoying herself and it was a pleasure to see her.

The cancer eventually returned. I do not remember how long it took, exactly, but eventually radiotherapy could not stop it. We met at a final clinic visit where we knew we were saying goodbye. We kissed each other’s cheeks with a tear and a hug, knowing we would never meet again in this world.

I turn back to my current patient. I was about to read her a litany of orders about less food, more exercise, and regular home blood testing to improve her glycaemic control. Instead, I decide to ask her a little more about her life and listen and as she confides, hesitatingly at first, the problems she faces in her home. I know we will be spending much longer talking about how she can make her sad life fit with my rigid demands for optimum glycaemic control. But I realise I will learn a lot more this way myself and we will get to a solution of sorts, eventually making another story and I will have added another companion to my own journey.

As the woman leaves, a heavy-set man replaces her, tough and strong and used to commanding people. He is in a hurry and not keen to waste his time with me, although I am eager to get him to use that time on himself and his health. Slipping down next to him is another big chap whom my current patient cannot see. Only I can see him, but I remember him well. This “ghost” was an ex-commando, tough as they come. His diabetes had suddenly gone out of control: not like him at all, a man so precise, so rigidly adherent to protocol.

“What is wrong with you?” I remember chiding this big fellow rather harshly, when he had turned up in my clinic. He had sat still at first. Then, his shoulders had heaved, and a tear had trickled down his face. Then, this big granite-faced man had sobbed inconsolably. “My dog...died!”

We both sat contemplating this awful loss. This was many years before an evidence base had developed about the beneficial effect of animals, and most particularly dogs, on the wellbeing of the sick, the elderly, and in particular those with diabetes.

I cannot recall the number of times since then I have found that (with some variations) “my dog died!” has been the root of a significant deterioration in people with diabetes. Although laboratory experiments (and I have tried to do such experiments myself) cannot ethically replicate mental stress of comparable degree in people, our patients’ daily lives illustrate the impact of the “slings and arrows” of real life on glycaemic control. How then to explain the happily married woman whose excellent glucose control continued without a ripple when her husband died, but deteriorated abruptly a year later when her cat passed on? Regardless, all my registrars are taught to ask about the dog’s health, not only because the dog forces the owner to walk and a fat family dog is a bad metabolic risk indicator. Beware the day the dog dies! My ghostly ex-commando reminds me that big, tough muscular men can have glycaemic deterioration because of emotional issues that a young registrar may regard as minor.

The clinic is still overcrowded with the living, and I turn from my ghost to the man in a hurry, knowing I must find a way to relax him and let me get through to

his guarded emotions. “Do you have any pets?” I ask. He relaxes, smiles, and replies in a warmer voice “Yes, I own the cutest dog in the world. Here is her photo.” He leans closer to me, to show the photo on his mobile phone. I suddenly feel certain he will eventually let me get close enough to help him start to take care of himself.

I push the ghosts away as I have lots more work to do before lunch and I know I will see them all soon enough. Our past patients will always remain with us: that is what experience is. Double-blind trials lead to fixed clinical endpoints (and so they should) as the basis for the evidence-based medicine we are so proud of practising these days. But experience (as the great Lord Tennyson said before I did) is an arch through which we continue to travel forever. Our past patients, unseen by others, travel with us. As their numbers increase, so should our wisdom. They teach us about medicine, improving our skills by reminding us about the things we have seen (or missed) before. As I age, I see that what we call experience often consists of our past patients (who are surprisingly forgiving on the whole) returning to remind us gently of our previous errors so we do not repeat them.

They crowd around us, whispering, nudging, poking us to try to help us remember something from this incredibly privileged journey we have made together. And some special patients teach us something about life itself, how best to live it, and how to leave it with dignity. I can only hope for the sake of my registrar and the many others to follow him that they gather many companionable ghosts around them, to teach them both about medicine but most importantly about life.