WHOLE PERSON CARE

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WHOLE PERSON CARE: WHERE CLINICAL EXCELLENCE AND PATIENT SERVICE MEET*

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As I pondered what to say at your final Orientation lecture this morning, I reflected on what I would like to have been told as a new intern; what is it that would not only get me through the stresses of internship, but actually sustain me in both my future professional and personal roles?

That was a lecture that I never heard as an intern; I learned the long and hard way.

So today, 37 years after my own internship (here at St. George Hospital), I would like to reflect on my own professional life, and to tease out for you some of the transcendent themes that will hopefully help you, not only to survive, but to thrive in your new career.

I first speak generally about the concepts of "excellence", and "service". To me, whether you survive, thrive or dive is all about how you resolve the ever-present tension between "clinical excellence", and "patient service".

^{*} An address delivered on 31st January, 2014 to new interns at the completion of their orientation program.

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The first priority of any healthcare system must be clinical excellence. By this I mean high quality training and supervision of staff, regular peer review, and an effective system of clinical audit. Clinical excellence is related to the concept of improvement in health outcomes (e.g. prevention, or cure) for patients and for communities. In this regard, our health service in New South Wales (NSW) scores well, aided by the establishment of the CEC (Clinical Excellence Commission) in NSW¹.

However, the pursuit of clinical excellence does not always correlate with the patient's perspectives of their health-related goals nor their satisfaction with the healthcare service. In spite of our "clinical excellence", organisational issues such as long waiting lists, lack of privacy, poor co-ordination of services, poor communication amongst healthcare professionals, and the depersonalisation of care can tarnish the high levels of clinical excellence which we achieve. A really first class healthcare system must combine professional excellence with superb personal service. However, because organisations are composed of "persons", I would like to speak about this nexus between clinical excellence and patient service from a very personal point of view.

In photographs taken of me as a final year medical student, and subsequently, as a high-powered medical registrar and a research scientist, you will note that I look very similar. And why do you think that is so?

Like most of you, I was trained as an applied scientist in a system which made a priority of teaching huge numbers of facts, a system which favoured expertise over professionalism, a system which told me that I was a scientist, and a system which taught me to use cold clinical judgement with the aim of "fixing" patients. There was no room for error and no room for "not-knowing". I was taught not to get too close to patients lest the interaction adversely affect my clinical judgement, or affect me personally. In short, like many of you today, I was trained as an applied scientist, albeit, in health (Fig. 1).

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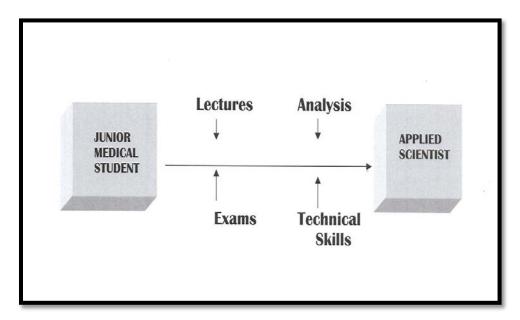


Fig. 1 A traditional journey through the medical curriculum

Over the past few years, a great deal of worthwhile literature has been written outlining the gruelling and depersonalising effects of traditional medical training on young graduates⁴.

I was trained to pursue clinical excellence. A very brief resume of my achievements in pursuing clinical excellence during my formative years indicates that I was Dux (1st Place) of my High school (1970), Dux of my medical year (1977) – I have a bronze medal to prove it --I gained my Royal Australasian College of Physicians (RACP) exam at 1st attempt (1979), then my Royal Australian & New Zealand College of Radiologists (RANZCR) exam with 1st prize (1984), then gained my PhD in Pathology (1991), with 9 publications. Passing exams had become an art-form. For a brief 12 month period, I even became an honorary doctor to a Buddhist-based hospice service. Having sufficient publications, I was appointed as an Associate Professor before I turned 40 years of age, then full Professor at 41 years of age.

Through the journey from junior medical student to the completion of my PhD degree, my physical appearance remained the same. There were no new haircuts, no change in style of dressing, no external innovations that might have reflected deeper, more profound inner changes to my personality and character that might have resulted from my medical education. I looked, felt and behaved the same as I always had.

I know all about the "pursuit of clinical excellence". I know how necessary it is, I know how essential it is, I know how seductive it can be.

To illustrate my pursuit of scientific enquiry, I recall as a medical registrar prowling the wards at Royal Prince Alfred Hospital late one night trying to arrange the removal of a terminally-ill patient's brain. I wanted to write him up as an interesting case of a para-neoplastic syndrome. He died that night - alone. I was delighted, the brain was removed at 2 am, and another paper was published⁵. There were many other examples where, in retrospect, I realise that I had regarded the world of clinical medicine as if it were a giant research laboratory in which I could pin to corkboard, and dissect, my many patients, like frogs in a physiology laboratory. Wasn't this just what our pioneers and heroes in Medicine over the past hundred years or so had done? Perhaps I thought I could walk in their footsteps and leave my own imprint on medical science. Perhaps this was how I thought I could give meaning to all those years of study.

There seems, I now realise, to be a thin line between altruistic clinical excellence and self-interest. The highly-competitive environment in which scientific accomplishments are recognized makes it easy to fall prey to self-interest in order to make your mark.

Even the word "care" was redefined in this environment. I truly believed that I was "caring" because I was ordering every test imaginable, or because I was working long hours, or because I had read journals extensively about this or that syndrome. I was convinced that my frantic days at work confirmed that I was a truly "caring" young doctor.

Increasingly, however, as I became a little more senior, the clinical excellence which I had pursued, and achieved, no longer seemed to either sustain nor satisfy me. Although I was recognized as an "expert", I was also feeling increasingly inadequate and uncomfortable, especially in those relatively common clinical situations for which there are no protocols, for which there were few clinical criteria to decide what to "do" next. I think of the tearful patient; the patient whose disease had stopped responding to treatment; the patient who had been cured but was still out of work and was finding it hard to fit back into society; the patient approaching the terminal phase of their illness.

I had been trained to "do something". Yet, on many occasions, my therapeutic toolkit was empty, and I felt dispirited, even wounded, in these encounters. I had been trained to believe I should have all the answers, and that I should feel unaffected by the plight of patients, all in the interests of scientific objectivity. Many a time when I would have preferred to run away from difficult clinical situations, I just had to sit and be quiet with patients; I often felt I had little to offer. Sometimes, I still feel quite inadequate in those same situations. But, I no longer feel defeated.

Probably my worst experience was visiting a female patient with terminal breast cancer. The patient was a local GP, and we had got to know each other well over a year or two. When I walked in to see her, she

had such severe shortness of breath from lymphangitis that she could only utter a word or two between gasps. And her family, six people in all, were standing at her bedside. I can still see them gazing intently at me. What was the Professor going to do? Surely, he would have the answers.

I had no answers. I wished at that moment that I had not come. I felt wounded, and quickly rushed out of the hospital, in search of a private space in which to recover. I now call this feeling "the fear of falling". No one likes the prospect of falling, but we all experience that fear of falling from our pedestals, and the higher the pedestal, the greater the potential fall. In learning to fall, sometimes we just need to learn 3 small, healing words - "I don't know".

Several weeks later, a patient and his family were leaving my office. They told me how much better they felt for having seen me, even though I had just sat there and listened, and (in my own judgement) had done nothing. I had to set aside my persona as a doctor; they realised that there was nothing I could do about the cancer. They understood that there was no quick fix. But, somehow, that was OK. They weren't looking for a miracle. I realised that what they most needed at that time was me. Just me. Someone who paid attention, someone who was fully present to listen, someone with whom to share the pain, even if that someone could not fully understand what they were going through.

Similar experiences followed. I trained myself to be quiet, and to focus more upon the *person* in front of me rather than their disease. In the midst of all my inadequacy, I was becoming strangely "adequate", not by what I knew, but by who I "was', by how I was prepared to make myself vulnerable. It seemed that my humanity was making me adequate in times when my technical skills were being exhausted.

We all want to make a difference. But, how do we do this? By ordering as many tests as we can think of, by working inhumane hours, by reading lots of journals? Yes, it is true that we need a spirit of enquiry. But, at other times, we need a spirit of contemplation and stillness. According to Balfour Mount, the Canadian physician who first used the term "palliative care" in the 1990's, "You make a difference", wrote Mount, "when you take the time to sit down and listen, when you stay there in the face of unanswerable questions".

These experiences surprised me and caused me to reflect on the nature of the relationship between a healthcare professional and a patient, and indeed, upon the whole purpose of Medicine.

You see, when a patient comes seeking help, we often fail to see the person (Fig. 2); as applied scientists, all we see is what we have been trained to see. We become blind to other options.

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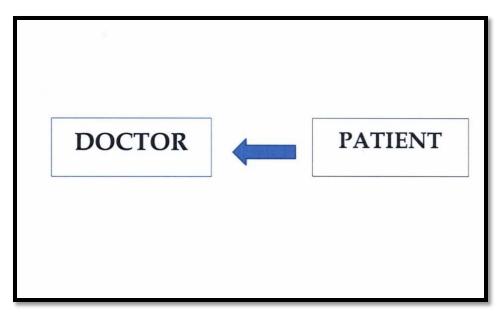


Fig. 2 The traditional dynamic of the doctor-patient relationship [adapted from Hutchinson and Brawer²: Wilson and Cunningham³]

The truth is that we have been trained to see patients as "patients", without always understanding the nature of the person of the patient (Fig. 3).

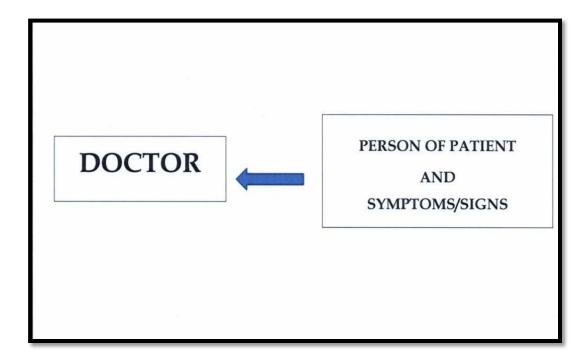


Fig. 3 The Patient is represented as a person who presents to a doctor with symptoms and/or physical abnormalities [adapted from Hutchinson and Brawer²: Wilson and Cunningham³]

We often do not understand nor take into account personhood – what it means to be not just any person – a body like any other – but what does it mean to be *this* person. The vast majority of our time is consumed by, and focussed on, investigating, diagnosing and treating disease – the person is irrelevant (Fig 4). And, generally, it must be said, that we do a good job in what we have been trained to do.

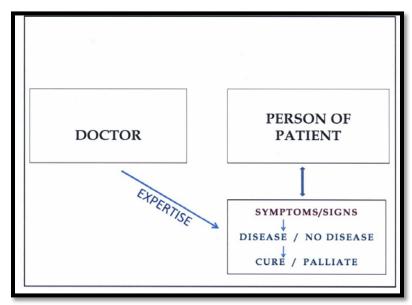


Fig. 4 Traditional medical education has encouraged doctors to flourish as experts by focussing on the biomedical aspects of the patient. The personhood of the Patient may go unrecognised [adapted from Hutchinson and Brawer²: Wilson and Cunningham³]

Many of my colleagues believe that a fundamental aim of healthcare, and of doctors, is to relieve suffering^{7,8}. But, how can we do this if we focus solely on physical disease in our patients? The answer is, "we can't". We might cure disease, we might relieve some troublesome symptoms, but we can never come close to healing the sick person. Unless we recognise suffering, and know what will reduce suffering (by using ourselves), we risk becoming reduced to the status of technicians, or "experts". Even those whom we may cure may not necessarily return to a wholesome life, nor enjoy a sense of well-being. Many "cured" persons can be deeply wounded by their experiences of having their disease eradicated. And, as Eric Cassell reminds us, suffering happens only to persons, not to isolated anatomical parts⁷. If we cannot see the person of the patient, if we do not see ourselves as persons, then it will be beyond our reach to relieve suffering (Fig. 5).

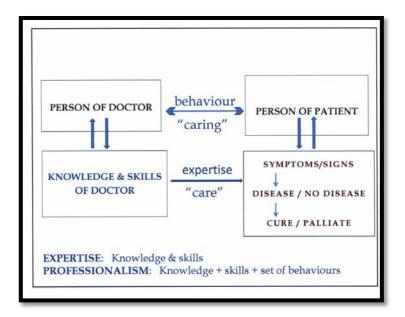


Fig. 5 When the doctor acknowledges his/her personhood as a dynamic relationship with that of the Patient, opportunities for healing become possible. A different skill set is required by the doctor to engender healing [adapted from Hutchinson and Brawer²: Wilson and Cunningham³]

It also became important for me to look critically at my sources of professional and personal satisfaction. I had seen too many senior colleagues become tarnished, cynical and burnt-out, and I could see myself in that position in 15-20 years. Are we destined, I wondered, to travel some inevitable and aimless journey of wandering alone in the desert to realise that we need to re-invent ourselves, or alternatively to retire from a life's work that has become a dry emotional wasteland? There is an abundance of helpful advice about how to look after ourselves out of work-time, such as getting enough sleep, being with close friends and family, getting exercise, reading books, remaining active and engaged in life. But, finding satisfaction in your work, on the ward, in the daily grind of our busy clinical lives, is just as important. What are some of the things that might sustain us as the terrain grows increasingly arid? What do you think are some of the answers? Although I had been earnest, sincere and well- meaning, I had lost sight of my own personhood; I had not understood that one of the secrets to being fulfilled was to become part of the therapeutic equation (Fig. 6).



Fig. 6 The possibility of interpersonal connection ("service") despite individual woundedness

Increasingly, what gave me satisfaction in my isolation as an expert was a fledgling openness and ability to connect with patients, learning to use my 'self' as a therapeutic instrument, particularly in those scenarios when there was no more treatment left to prescribe, where there were no protocols left to follow. Who I was often became more important than what I knew. Gently and sensitively, I found that I could now offer "caring" as well as "care".

I saw my work less as a job, but more of a calling, that same calling that I had first received at the age of 4 years; and I began to feel sustained as I drove home each evening. I began to reflect on those things during the busyness of my day that had surprised, inspired, or touched me. And yet, the events of my work day had not changed; a lot of it was still routine and mundane. But I learned to take the time, and to really pay attention to what I had simply gazed at, hurriedly, in the past.

Dr. Rachel Remen tells the story of Harry, an emergency physician⁹. Harry had delivered hundreds of babies in his time; indeed, his work had become monotonous, even, and routine. One morning, while attending at another "routine" delivery, the baby girl opened her eyes to the world for the very first time, and the first person she saw was Harry. In Remen's words, Harry "had never let himself experience the meaning of what he was doing". Harry had "been there as a physician, but not as a human being" (p. 159-160).

I had thought that being an applied scientist who practised to high standards of clinical excellence was the end of the story. There was more - there was a need to become a good doctor, a professional not just an expert, a need to uncover and put to good, ethical use personal abilities which had been bleached out of me during my training in medical school. I had been trained, not educated. I had remained the same as I had always been, rather than allowing myself to be transformed.

And so, while the pursuit of clinical excellence and its maintenance was, and still is, a high priority in clinical practice (I still love to kill cancer), I have also learned a second crucial skill set. The skill set involves being curious about persons; becoming vulnerable with patients and their families; listening empathically; learning the therapeutic value of touch; learning how to use silence, and to not be afraid of it; how to tolerate uncertainty (I still dislike uncertainty); how to develop mindful presence, realising that it is not my agenda that counts; seeing the patient as a person, and importantly, seeing the process of making a meaningful connection with our patients as an act of self-care. In clinical scenarios which we find difficult, connection becomes our protection. In caring for my patients regardless of whether I can cure them or not, I am simultaneously caring for myself. How counter-intuitive is that! But it is all about seeing my ordinary world with new eyes. There is a transcendent importance in the therapeutic relationship that is beneficial to the patient and the healthcare provider. In essence, I was learning the meaning of "service" and experiencing a paradigm shift in the way I related to others.

In the colloquial sense of the word, many of us equate "service" with the concept of "servitude", a sense of inferiority, a sense of needing to sweep up the crumbs from under the master's table. Not so, at least according to Remen⁹, who views "service" in clinical practice as something that counterbalances, and needs to be integrated into, the valuable "fixing" roles that we all have with our patients. According to Remen⁹, service is a way of being in relation to others, and it implies a sense of equality between persons, "a relationship between equals". "Service" implies a readiness to share our humanity. Remen recognises the sustaining nature of "service", and its transpersonal dimension: "our service strengthens us as well as strengthening others. Whereas fixing is draining, and over time we may burn out, service is sustaining. When we serve, our work itself will renew us. We serve with ourselves, and we draw from all of our experiences." In particular, Remen suggests that "our limitations serve us; our wounds serve; even

our darkness can serve. My pain is the source of my compassion; my woundedness is the key to my empathy. It is because I am aware of my wounds that I can enter into a healing relationship. I learnt that I can only serve those to whom I am profoundly connected¹⁰." Therefore, in all our woundedness, and lack of perfection, we can still bring something valuable, our humanity, to offer to others (Fig 7). In this sense, "service" may be akin to, though lacking the intensity of, the intimate experiences of spiritual "oneness", described by Buber as "I-Thou".¹¹

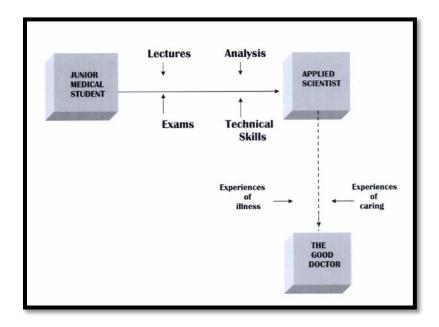


Fig. 7 The way in which personal experiences of illness and caring may promote the transformation from applied scientist to "good" doctor, or physician-healer

As a radiation oncologist, I still need to fix people, and I still need to pursue clinical excellence. But my clinical work in serving enriches and sustains me. Here am I today, feeling as enthusiastic as I was 37 years ago. Many "ordinary" experiences now become "extraordinary" as I participate in the stories that patients need to tell, and as I use who I am, as imperfect as I may be, as a therapeutic intervention. My toolkit is now rarely empty, for, I have now **become** the toolkit, and in Nouwen's words, "there is always more healing space to give" Rather than feeling defeated by his perceived inadequacies, the author of *Wal's story* comes away from a typically "ordinary" clinical encounter feeling "sustained, and whole, once again" 13.

In the final phase of his prostate cancer, Anatole Broyard, a writer for the New York Times, made this point: "Not every patient can be saved, but his illness may be eased by the way the doctor responds to him—and in responding to him, the doctor may save himself. But first, he must become a student again;

he has to dissect the cadaver of his professional persona; he must see that his silence and neutrality are unnatural. It may be necessary to give up some of his authority in exchange for his humanity, but as the old family doctors knew, this is not a bad bargain. In learning to talk to his patients, the doctor may talk himself back into loving his work. He has little to lose and everything to gain by letting the sick man into his heart. If he does, they can share, as few others can, the wonder, terror, and exaltation of being on the edge of being, between the natural and the supernatural "¹⁴.

To summarize, as you enter your careers, pursue excellence and knowledge. Develop the skills needed by a competent professional. We all need expertise. We all need to pursue clinical excellence.

Secondly, look after yourself, but also look out for each other. Enjoy those activities and relationships that you have outside of work. Inside of work, and I'm sorry to say this, you will often find yourself unsupported, frustrated, lonely and inadequate. It is therefore equally important to work on those activities which will sustain you at work. Continually maintain your new eyes and your sense of worth, meaning and purpose. Stay connected to what matters. No one else will do it for you. Self-care within the workplace is mandatory, not optional. Some of these activities might include:

- 1. Working on your communication skills so that you no longer want to run away from awkward clinical situations that we all have to face. Be aware that communication is not all about saying the "right" words; it is more about bringing your humanity to the situation, and allowing your humanity its soft, yet full, voice.
- Journaling and reflective writing; a simple exercise when you return home is to ask yourself 3 questions, and write down your answers---what surprised me today? What inspired me today? What touched me today? Your responses might be "nothing, nothing and nothing". That's OK keep doing it.
- 3. Mindfulness i.e. being fully present in each moment can be a powerful way to reduce stress, and to become more effective in your interactions, and
- 4. Small group reflection amongst your peers (e.g. a drink at the pub) can also be profoundly therapeutic. Cry with each other if you need to. Tell your trusted friends how you feel. If you consistently ignore your feelings your humanity it may become a way of life to suppress all that makes you most human. Ultimately you risk feeling nothing we call this burnout; some never recover.

Finally, don't be satisfied with being an expert. Pursue patient service as radically as you pursue clinical excellence. I find that the closer I draw to patients, the more I bring myself to the clinical encounter, the more effective I become, the more clear-headed I become in applying my clinical excellence, and the more I (re)discover myself – who I really am. I become more authentic. Through personal experiences of

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illness and caring with patients, the reality is that we are changed (Fig 7); as we make ourselves vulnerable to serve, a sense of worth, meaning and purpose will often mysteriously illuminate those grey and cloudy skies which had previously made us blind. My researchers and I have found this to be true when we examine the experiences of young medical students when they come to oncology and palliative care for the first time¹⁵. Preconceived negative thoughts that students have about oncology are often transformed by direct interactions with patients. Our patients are also changed, and many will become our greatest teachers. Students learn that patients will help us rediscover the skill-set and commitment to healing that we may have misplaced, or even suppressed, during our rigorous training.

Suddenly, it is as if we wake up to a new day with new eyes.

Today, we stand proud of you; your parents are proud of you as are your other relatives. Your friends are proud of you, your colleagues are proud of you and your teachers are proud of you. Why are we all so proud of you? Is it because you did so well in your final exams? Is it because you can now put in an IV line quickly, or a urinary catheter, or a chest tube? Or is it because you can suture so effortlessly? Or, are we proud of you because of what your future holds? The world is now at your feet.

Of course, we are proud of you for all these reasons. We are proud of you, not only because of what you know and what you have learned, but because of who you are. Proud that you will not only use your skills, your ability and your training, but proud in the anticipation that you will be open and ready to use yourself as therapeutic instruments in relieving suffering, and do your part to bring about healing – proud that you will both "cure disease, and heal the sick".

Thank you. ■

ACKNOWLEDGEMENTS

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