More than the sum of our parts

Humanity is needed for cancer treatment to be complete

Australian cancer care is among the best provided in the world. Yet, many cancer patients choose to either forgo aspects of conventional treatment or seek unproven complementary therapies.[1,2] My own recent cancer treatment prompted me to wonder whether these choices may, at least in part, be due to the failure of Western medicine to address the psychological and emotional needs of cancer patients. Cancer patients suffer from a greatly increased incidence of psychological disorders.[3-5] Does the emotional trauma inflicted by an insensitive health system contribute to this?

The purpose of this article is to describe what I experienced as deficiencies in these aspects of my care; specifically, a focus on pathology at the expense of the person, and a failure by staff to acknowledge the patient's emotional needs and the psychological implications of the treatments that are offered.

My story began — as do so many stories — with the unexpected finding of a lump in my breast. In what seemed like no time, I was boarding the "breast cancer train". On the day of my diagnostic ultrasound and biopsy, I went in an instant from being a healthy young mother to a cancer patient. From there, events followed swiftly — admission to hospital, surgery, chemotherapy and radiotherapy.

I received excellent medical care, which saved my life, and many of the clinicians who treated me were professional and empathic. Unfortunately, though, this was far from universal, and I was surprised and dismayed by the lack of basic humanity and courtesy from some of the health professionals I encountered. There often seemed to be a complete lack of a normal human response by staff to the difficulties I was facing. I remember that first, terrifying day of diagnosis, when I picked up my infant son in a stunned state to return home to a life which would never be the same. Not one of the medical imaging staff asked how I felt, or even made the comment that this must have been an awful experience for me — a simple empathic statement that would have made this ordeal just a little less painful.

Things did not improve. From the radiologist who did not take the trouble to introduce himself before taking the fateful biopsy, to the unidentified radiotherapy technicians, who drew on my naked torso with texta, nonchalantly and permanently marking me with tattoos with the understatement "you won't even be able to see them!", I had the feeling that I had ceased to be considered as a whole human being, but had become, instead, a collection of body parts.

While in hospital, the common hospital policy of placing patients in mixed-gender shared rooms caused further distress. It seems indicative of a system that values convenience over the feelings of patients. This practice made me feel uncomfortable, and I can only imagine how disturbing this is for an older generation, especially after undergoing more intimate operations such as mastectomies or prostatectomies.

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> "As the infusion commenced and I bid adieu to my ovarian function, a well meaning volunteer chattered away about her experiences as a wildlife carer"

During my hospitalisation, the attitude of the overworked and harried staff often seemed lacking in compassion. Arriving for admission after many sleepless nights, I was met with the news that my diagnosis was more serious than I had hoped, requiring a more complex operation and a postoperative stay in hospital. By the end of that day, when I finally arrived back on the ward after the surgery, I was exhausted and in a perilous emotional state. I felt so alone in my grief, trying to come to terms with so many losses and horrendous possibilities. Eventually, some comfort came — not from the staff, but from my fellow patients. It seemed to me as though the nurses did not consider that the provision of emotional support was an important part of their role. Maybe this was a by-product of the increased workloads and emphasis on the many medical tasks that nurses must now perform. Or perhaps the burden of caring for endless cancer patients had blunted their sensitivity?

Many of the things we do as health professionals that are mundane and thoroughly predictable to us can, to patients, be truly bewildering, if not frightening, even if the patient is a doctor who "should know" what is involved. I felt that during both chemotherapy and radiation therapy, the staff did not understand or acknowledge just how strange and confronting these processes are for those undergoing them.

Walking up to the chair in which I was to receive chemotherapy for the first time, I felt the sort of dreadful resignation that I imagine one would feel about an impending execution. As a young woman, worse than the thought of hair loss and nausea was the possibility that, by accepting the infusions that may save my life, I was surrendering my future fertility. The nurses, wrapped in protective gear, approached with the chemotherapy, "FEC", a fierce-sounding acronym for a bright red cocktail, which to my non-oncological eye was almost amusingly poisonous-looking. As the infusion commenced and I bid adieu to my ovarian function, a well meaning volunteer chattered away about her experiences as a wildlife carer and a tea lady offered a festive-looking treat. Facing a trauma that was left unnoticed, and unacknowledged by those treating and attending me, seemed particularly ghastly and surreal. Perhaps the physical barriers protecting the staff from accidentally being exposed to cytotoxic agents also served a symbolic purpose, insulating them from what could, understandably, become an

overwhelming exposure to each patient's pain and suffering.

Radiotherapy was even more disquieting. A conveyor belt-like procession of patients was shuttled from Waiting Room 1 to Waiting Room 2 via the change room, and then into the inner sanctum of Waiting Room 3. On the way in, I glimpsed the computed tomography pictures of my own skeleton, which were in clear view. This was a macabre sight, serving as a stark reminder that, underneath it all, I was composed of bone, and flesh, and that these components, which I had taken for granted, had failed me spectacularly.

The treatment room was situated beyond a labyrinth-like arrangement of thick concrete walls. The machine was large, imposing and otherworldly. Above it there was a black screen with stars printed on it, adding to the interplanetary mood of the whole venture. During this first treatment, the technicians had chosen a breathtakingly tactless soundtrack: "Another one bites the dust". The buzzing, aloneness and music combined to create an eerie, and quite sinister, atmosphere.

At my next treatment, I noticed the technician holding a thermometer up to the machine; by the next day, without explanation, a large fan appeared, freezing the unsuspecting patient beneath. When I asked about this, I was startled to hear that the machine was overheating. And it seemed such an unsophisticated solution that I half expected a hose or water cannon to be deployed next should the fan fail. I had superstitiously banished the microwave oven from my kitchen, yet here I was being irradiated by the mother of all microwaves, which could not even thermoregulate itself! Having only a rudimentary understanding of radiation oncology, this small and doubtless routine mishap was truly alarming to me.

While the medical complications of chemotherapy and radiotherapy had been thoroughly explained, there was no attempt made to prepare me psychologically for these treatments. I had many concerns about the Gawler program,[6] but I found some of the approaches they taught did go some way towards meeting this otherwise unmet need: meditation and imagery techniques enabled me to tolerate some of the most challenging moments of my treatment. Meditation, in particular, has been shown to improve patients' ability to cope with cancer and its treatments,[7] and could perhaps be offered more widely as a standard component of management.

While some specific interventions such as this may require the involvement of mental health experts, I am not suggesting that all cancer patients require treatment from specialist psychiatrists or psychologists as a matter of course. Ordinary human suffering need not be pathologised and delegated to these professions, whose expertise may be better reserved for those whose distress develops into an actual disorder. But I do not think it is too much to expect that all staff, to whom we entrust our lives, demonstrate their credentials as, first and foremost, decent human beings. Introduce yourself before you take a chunk out of somebody's chest. Ask them how they are feeling, even if you don't know what to do with the answer to your question. Remember that, even though this is the millionth time you have seen and done this, it is the patient's strange, unknown, and even frightening first time. And try, always, to look beyond the diseased part you are treating to the person underneath. Perhaps then the rhetoric of patient-centred care can begin to approach reality.

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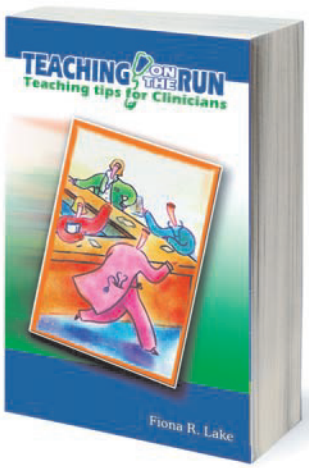

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