Patient designs

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In 2009, Don Berwick, former president of the US-based Institute for Healthcare Improvement, gave an impassioned speech at the International Forum on Quality and Safety in Healthcare about why he was afraid of becoming a patient (http://patientsassociation.ca/video/don-berwick-what-patient-centred-care-really-means). It wasn't, as one might expect from a prominent researcher of medical error, the danger of adverse events. When it came to safety, he said, he would have his caregivers well on side. What "chilled" Berwick was the expectation of indignity, and of the inability to exert influence over what would happen to him. He went on to make a plea for patient-centred care, the core of which, he said, is "that property of care that welcomes me to assert my humanity and my individuality and my uniqueness".

Patient-centred care is not a new idea, but it has proved elusive to define and even more difficult to consistently implement. An Australian psychiatrist's reflection on becoming a patient (*page 522*) confirms that Berwick's fears are well founded. When Hall boarded the "breast cancer train", she yearned to experience humanity somewhere in the course of her journey; but she found it in her fellow patients rather than in health care workers.

Ideally, patient-centred care should start well before the clinical encounter. In some spheres, patients are emerging as not only participants in their health care but also as collaborators, contributing to the design of both research and practice. At a recent meeting of minds described by Dear and colleagues (*page 507*), consumers — people affected by colorectal cancer — joined health professionals, researchers and others in prioritising the "gaps" to be filled in colorectal cancer clinical trials research in Australia. The study participants identified that a high proportion of current and recent trials concern drug management of advanced disease, and called for more focus on secondary prevention, individualised treatments and follow-up care. Consumer priorities also included research questions related to quality of life and palliative care, including the experience of dying at home compared with dying in a hospice, and the burden of home death on family members.

There is no more important time for patient-centred care than at the end of life — whether or not the death is cancer related. Sarode and colleagues (*page 524*) sought to fulfil the "clear and unambiguous" wish of a patient with end-stage progressive motor neurone disease to die in her own home. They describe the patient's transfer and planned withdrawal of supported ventilation once she had indicated her readiness to say goodbye to life. Their honest appraisal of the costs and benefits, including perspectives from family members, proves that even the published record can and should be patient centred.

Intuitively, treating patients in their own homes — "hospital in the home" (HITH) — should make patient-centred care more achievable. Caplan and colleagues (*page 512*) put patient and carer satisfaction, as well as the effect on other clinical outcomes, to the test in their meta-analysis of HITH studies, grappling with the diverse range of randomised controlled trials that have attempted to compare HITH with inhospital treatment. Of the more than 1500 trials identified, about 60 met their inclusion criteria. Overall, they found that HITH improved patient outcomes, including mortality and patient and carer satisfaction.

In a linked editorial, Montalto and Leff (*page 479*) highlight the difficulty of conducting such a meta-analysis when the term HITH has been used to describe so many things — from the provision of intensive care technology and expertise to post-discharge community care and outpatient treatment. They assert that an internationally agreed definition is needed to advance HITH research. Who knows, maybe the expert group that is set up to tackle this issue will boast a consumer or two in its ranks!

In the meantime, we hope that every episode of care, wherever it is delivered, can eventually be described using Berwick's proposed, expanded definition (http://content.healthaffairs.org/content/28/4/w555.full):

> The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care.

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Careers follows p 528

MJA Careers

Career overview — Medical oncology

Making a difference

Oncologists combine science with humanity

Where humanity meets science

Oncology has its fair share of sadness, but it is far from the depressing specialty that many believe it to be, according to this issue of *MJA Careers* (*page C1*), in which medical oncologists talk about the satisfaction of combining science with humanity to treat people with cancer. In Medical Mentor (*page C5*), we meet Professor Bogda Koczwara, president of the Clinical Oncological Society of Australia, who traces her career as a medical oncologist at Flinders Medical Centre and describes how her career has enriched her view of life. "One of the hidden gifts of oncology is that you learn about the fragility of life", Professor Koczwara says. In Road Less Travelled (*page C6*), Dr Ana-Louise Martin says acting skills can hone doctors' communication skills, while Money and Practice (*page C7*) sets out strategies for doctors who want to ease out of full-time work into semi-retirement.