Room for a view

On subjects, objects and patients

A few weeks ago we buried a close friend. He was a well recognized researcher; acknowledged by innumerable book authorships, awards and honorary doctorates.

He was a physician by commitment and a researcher out of passion. His clinical work and research was with children. His patients and their parents felt honoured to participate in his studies. As well, many healthy children volunteered to be part of his research. Even though he had many coworkers, some permanent and some transient, the children related to him as their physician and as the researcher with whom they worked. He knew the children by name and by fate. He spent time with his patients and their families and established relations with each.

His tumour was deemed inoperable from the outset. The prognosis was dire. A specialist sought out for a second opinion advised him to "go home and pray." He agreed to join a new, aggressive chemo-therapeutic protocol. After the initial eligibility work-up and wait for a judgment, he started with his weekly routine.

He knew the children by name and by fate.

He had tests on Tuesdays, infusions on Wednesdays, and diagnostic images were interpreted on Thursdays. He was seen by the research nurse weekly and by a series of study physicians once a month. His management met all the objective criteria of high quality care. Symptoms and adverse effects were promptly recorded and occasionally responded to — as long as they matched a protocol checkbox — and largely ignored otherwise. Doubts, fear and depression, however, were not outcome variables of interest.

Whether it was his constitution or life style, whether it was the effect of treatment or whether it was a fluke: he lasted much longer than predicted. His physicians labelled him their "star patient" since he outlived all other subjects in his cohort — as if there had been a competition. Quality of life was a different story.

One year after the onset of his disease he was informed by one of the study physicians that he had "reached the end point of the study." He ceased to be of research interest and dropped off the horizon.

He was left pretty much to his own devices until the family found access to community-based palliative care. Only then did quality of life re-emerge as an issue. During the final phase of his illness he and his family were supported by their primary care physician together with an attentive palliative care specialist and her dedicated colleagues from a broad spectrum of health professions. Continuity of care was maintained until his last breath and beyond. This stage was not part of a research protocol; it was just old-fashioned caring.

One might argue, appropriately, that this is a personal, anecdotal account that permits no generalization. But the literature suggests otherwise.[1-3] This experience seems to transcend cultures and health care systems.[4]

Nor has medical education been particularly successful in training young physicians to exhibit (and experience?) empathy in affectively charged clinical encounters. In fact, empathy with patients seems to decline during medical school.[5]

The root cause for the failure of physicians to collaborate more effectively with terminal patients may well be the subconscious attempt of professionals to shield themselves from the realization: "There, but for the grace of God, go I!"[6] Ironically, we have only one certainty in life: the knowledge that each one of us will die one day. Furthermore, about one-third of us will die of cancer.[7]

One is reminded of Somerset Maugham's *Death in Samarra*. Neither avoidance nor flight will protect us from our ultimate fate. Multi-million-dollar studies into stem cells and monoclonal antibodies will postpone death, but not prevent it in the end. It is research on ways to improve physician–patient communication, provide sustainable continuity of care and universal access to palliative care that will contribute to making the inevitable more dignified and less frightening.

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