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Medical paternalism: who knows best?

Since the death of Steve Jobs, writers and media outlets worldwide have enlightened us about his ways of working. Apple's illustrious leader relied not on customer-centric focus groups but on his intuition. When queried about how market research affected the iPod's design, Jobs responded with his now famous guiding principle: "it's not the customer's role to know what they want".¹ This proposition could have implications for physicians and patients.

On the day that Jobs died, I attended a prostate cancer workshop that used tablet computers to present a series of clinical dilemmas while offering opportunities for participants to complete multiple choice quizzes and pose questions. Throughout the programme, the number of therapeutic options available provided both a source of intellectual stimulation and frustration. External beam or isotopic irradiation? Hormonal therapy with antiandrogens plus or minus luteinising hormone-releasing hormone agonists? Surgery with or without robotic assistance? I wondered how, with this dizzying spectrum, even a highly intelligent patient could identify his or her best alternative.

A few hours after the workshop, I received a text message reporting that Jobs had lost his battle with pancreatic cancer. My thoughts might well have drifted to the iPad technology that had enabled the interactive session. Instead, however, it was Jobs' credo that inspired my questions: is it a patient's role to know what he or she wants? Is the patient even capable of accurately evaluating the options? And having been diagnosed with an illness, is a patient's emotional state conducive to clear decision making?

What about the physician's role? My institution is committed to simulator-based training modules that are designed for vivid experimentation in medical education. During simulations, I marvel at the learned

behaviours of young oncology fellows tasked with counselling actors who play the part of a patient with cancer. Typically, the young doctors succinctly summarise options A and B, and then condone almost any selection made by their mock patients.

Recently, I witnessed an actress portraying a 30-year-old woman with limited stage small-cell lung cancer. When the patient objected to temporarily losing her luxuriant hair, the doctor-in-training reassured her that it was fine to decline prophylactic cranial irradiation—a treatment that confers a survival advantage. Only devout Kantians, I think, preaching autonomy as their supreme core value, would not find such behaviour maddening. But could it be also immoral, or even cruel? This example might be extreme, but are we as clinicians certain that we do not replicate similar patterns frequently in our clinic? And are we senior physicians truly attending closely to what our patients and trainees are saying?

The word paternalism has come to represent a system under which an authority supplies needs or regulates conduct of individuals under its control. Clinicians are socialised to recoil at such possibilities. Psychiatrists justifiably engrafted paternalism into the medical discourse on the basis of concerns about coercive tactics pressuring mentally incompetent human beings.² I do not contend that people seek paternalism in its strict form, but I suggest that, nowadays, many patients might be signalling a yearning for paternalism of a kinder, gentler variant.

Jobs possessed innate instincts enabling him to understand end users. We can cultivate humanistic paternalism by developing insights about our own so-called consumers (admittedly a term that is distasteful to many of us).³ At a minimum, the effort would entail discovering what our patients need, determining how best to present options (sometimes including the option



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of no treatment), then offering our learned viewpoint. We might seek help from colleagues such as chaplains, from patient caregivers, or simply draw on our ability to understand others. Through skilled listening we can build trust and use our clinical judgment to make customised recommendations. Dare we call this approach “Medical Paternalism 2.0”?

Patients are not obliged to accept our opinions, of course, but when we are well prepared, rather than shirking responsibility for decision making, we can extend the clarity and guidance that patients should expect from their medical professionals.

Benjamin W Corn

Tel Aviv Medical Center, Institute of Radiotherapy, Tel Aviv, Israel
bencorn@tasmc.health.gov.il

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A tale of two tumours and a plea for progress



Dr P. Marazzi/Science Photo Library

Melanoma and acute myeloid leukaemia (AML) share important characteristics: both are non-epithelial malignancies and affect a substantial proportion of young people,¹ with roughly a third of patients diagnosed younger than 60 years. Notably, the incidence of primary melanoma is rising faster than that of any other common cancer and has quadrupled since the 1970s.¹ Although most people with primary melanoma are cured, the incidence of metastatic disease is roughly equal to that of acute myeloid leukaemia, with about 2000 new cases per year in the UK.¹

However, survival statistics indicate large differences between these cancers. For young people with AML, outcomes have improved steadily over the past 40 years, and roughly 40–50% of these patients are cured with cytotoxic chemotherapy.² As with other solid tumours, cures are rare for metastatic melanoma; median overall survival is 6–9 months³ and 20 years of life are lost with each death caused by the disease.¹ The differences between the disorders are a result of disparities in the availability of effective systemic treatments. Nevertheless, much progress has been made in the treatment of AML because of high rates of entry into clinical trials.

Unlike AML, melanoma is generally refractory to cytotoxic chemotherapy. However, few therapeutic developments have meant that the alkylating agent dacarbazine has been a standard treatment for advanced disease for several decades. This situation changed in 2010, when the first of two phase 3 trials^{4,5} showing an overall survival benefit of ipilimumab—a

monoclonal antibody targeting CTLA4—for patients with metastatic melanoma was published. Notably, disease control for several years has been reported with ipilimumab,⁶ and some patients might be cured, although the present data are insufficient to confidently address this possibility. However, long-term disease control is rare and seen in no more than 10–20% of patients.

By contrast, in 2011, the selective BRAF inhibitor vemurafenib was associated with a response rate of about 50% in BRAF-mutant metastatic melanoma and an improvement in overall and progression-free survival compared with dacarbazine.⁷ Although vemurafenib has been associated with substantial responses in patients, median progression-free survival is only 5–6 months (compared with 5–6 weeks with dacarbazine). Crucially, ipilimumab (US\$120 000 per year) and vemurafenib (\$112 000 per year) are costly. Therefore, a strong economic and societal argument exists for the identification of patients who would benefit from these treatments, an effort that would rely on participation in clinical trials with rigorously designed tissue collection protocols.⁸

The recent development of effective drug treatments for melanoma was based on an improved biological understanding of the disease. Although the development of vemurafenib and ipilimumab are landmarks in cancer therapeutics, both have substantial limitations in terms of how many patients benefit, the development of resistance, side-effects, and cost. Further improvements must be made and now is the