

Dying in the 21st Century Out of our control?

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Most of us with the good fortune to live in wealthy countries have grown used to the idea that we can make choices. Life is a supermarket, shelves filled with affordable and enticing goods, and we have both the means and the empowerment to make seemingly limitless choices. Some of our choices are “bad”, in the sense that they do not serve our best interests, but we have the freedom, within limits, to choose badly.

The backdrop to this sociological phenomenon, the consumer society, includes a particular notion of individual autonomy, usually (and probably incorrectly) attributed to the writings of J S Mill. The “negative freedom” – the right to be left alone – gave birth to the positive freedom to choose how to live our own lives.

In parallel with the rise of the consumer society, the same lucky citizens have also enjoyed a remarkable increase in life expectancy. As an example, over 90% of Australians now live to be old, with an expected age at death over 82 years. Lifespan has not changed significantly, however, so death rates in Australia and elsewhere are rising, and set to rise dramatically in the next 30 years.

Unfortunately the increased life experienced by our aging population is still marked by severe and worsening disability, and this trend, the widening disability gap, is also set to continue.

Dying in the 21st century in a wealthy country is now dominated by elderly people with significant disability, sometimes cognitively impaired, faced with making complex end of life care choices. Just as we have chosen throughout our lives what to eat, where to live and whom to marry, we now are obliged to decide how to die. Consumer surveys suggest that people generally want to die painlessly at home, in control and surrounded by friends, but this is rare in Australia, and highly variable in other countries such as the UK. It seems that our choices are no longer valued when we are dying.

In response to this new dilemma (noting that there were no choices to make 50 years ago), we are encouraged to take control in anticipation of our loss of capacity and decline toward death by writing an advance care directive. The idea, supported by US court decisions in the 1970's, is that our autonomy, in the crude sense outlined above, extends beyond our lack of capacity. So choices we made before becoming incapable remain binding on friends, family and future doctors. In this way we can control our future care beyond our loss of insight, control, capacity and even consciousness. Websites and government programs dedicated to helping us plan in this way have proliferated in the past decades. The intention, to preserve the sense of control over our increasingly unpredictable lives, is in line with the usual requirements of the consumer society in which we have grown old.

From the outset there was convincing evidence that this model was faulty. Negative trials, like the multi-million dollar SUPPORT trial in the US showed that there were confounding factors at work, which led to clearly stated and documented wishes not being followed. It became increasingly clear that the patient was not an atomized individual according to the accepted Western

model, but a social being, and that doctors were highly constrained and regulated in their behavior. In combination, these two factors meant that patients were usually treated according to standard protocols and in line with their family's wishes regardless of the preferences recorded in an advance care directive.

The solution chosen in the aftermath of the failed SUPPORT trial was to initiate more complex advance care planning strategies, generally promoting iterative conversations with trained facilitators that include the family, and, as far as possible, relevant doctors. Scientific reviews of the burgeoning literature suggest that these more complex and labor-intensive interventions have more success, but still fall short of expectations.

Despite the ongoing disappointments, the drive toward increased patient control is gathering pace with the advent of "shared decision making". Initially formulated by Cathy Charles from McMaster University in Canada, this recasts the doctor/patient relationship as one where preferences rather than information is exchanged, and puts the relationship between doctor and patient on a completely new footing. The underlying sentiment is that the doctor's professional knowledge and personal biases combine to produce a preference for a particular form of treatment. Set against this, the patient has personal insights about her values and goals of treatment that produce a complementary or conflicting set of preferences. The medical encounter is intended to establish common ground, by giving more information about the reasons for the doctor's preference (in part by using decision aids), and for the patient to integrate this into their own understanding of their illness and life goals. How this model will work in end of life situations and with diminishing capacity remains unclear. However it is said now to represent the "Pinnacle of Patient-Centered Care". Perhaps, but it is my belief that there are fundamental and largely unaddressed obstacles to providing real choice to patients at end of life.

One is the limited ideal of autonomy currently driving the debate. It is clear to anybody working in clinical medicine that notions of who we are and how we make decisions are irreducibly relational. It is rarely possible to separate the wishes and preferences from an elderly patient from those of her family, children and other loved ones. And most people wouldn't want us to. More recent accounts of "relational autonomy" better fit with the reality of end of life decisions in the real world, and would be unquestioned in much of the non-Western world. This raises immediate political difficulties, as relational autonomy is associated with liberal notions unpopular in conservative jurisdictions.

A second problem is the constraints placed on doctors. There is little wriggle room in modern medicine. It highly regulated, supposedly evidence based, professionalized and legally exposed. For shared decisions to thrive there has to be at least some degree of equipoise between the options offered as reasonable choices. This is rare in general, but exceedingly so at end of life.

A third is nothing less than the entire structure and funding model of Western medicine, which greatly favors tertiary and hospital care over that provided in the community. Any attempt to honor patients' wishes about preferred place of death would involve a considerable reallocation of resources to the community and away from hospitals.

Fourth, treatment with a palliative (comfort rather than cure) intent would have to become an integrated part of medical management of all seriously ill patients, and not a separate function delegated to a different specialty. The choice to be palliated should not be a choice to be referred elsewhere.

And finally, the medical system at all levels would need to become proactive in creating genuine opportunities for choices to be available. This means asking more, offering more education, taking choice seriously and pushing back against a legal system that has favored defensive medicine and overtreatment even in the same breath as pushing “patient autonomy”. In dying, as in life, we need to be granted the freedom to choose, and even to choose badly.