

Decision making at the end of life: shifting sands

Two decades ago, when patient groups expressed dissatisfaction with the endpoints of clinical trials in advanced disease, trialists began to supplement conventional indices such as survival time with measurements of 'quality of life'. Sometimes, however, they encountered the paradox that quality of life was unchanged or even improved despite manifestly worsening symptoms. The explanation lies in 'response shift'—the process whereby, in the face of severe disease or impending death, individuals abandon their usual roadmap of values and adopt new perspectives.¹ These response shifts have implications for how patients experience illness and how they make decisions about treatments. They may also influence how health professionals or health researchers understand their experience and, accordingly, how well we help people cope with decisions in serious illness.

Let us suppose that, as disease becomes rapidly worse, the patient is forced to stop work? If work is part of the scaffolding of life, this event itself may prompt basic existential questions such as who am I without my work? If I can no longer take care of this and that responsibility, how do I function as a parent or provide care to my own parent or spouse? What is my role in the community now that I can no longer do what I did (so well) for so long? This fundamental reconsideration may cause the individual to recognize what is truly important or essential to his or her being and legacy—an insight that transcends the 'temporary' roles that occupy much of our energy when we are healthy.

To the clinical researcher, response shifts might at first seem unlikely to influence the tide of scientific quests. We are coming to see, however, that these 'private perturbations' are deeply relevant not only to the way we measure the effects of treatments and psychosocial interventions but also to perceptions of health as they change with the passage of time.² In the research context, take a Swiss trial reported by Bernhard and colleagues.³ These workers looked at patients randomized to three postoperative strategies after resection of colon cancers—observation, 5-fluorouracil/levamisole, 5-fluorouracil. In all three groups, quality-of-life measures pointed to reframing of perceptions, and the degree to which this happened was related to measured

effects on appetite, functional performance and nausea/vomiting. In several trials the quality-of-life indices have run counter to conventional endpoints.⁴⁻⁶ A meta-analysis indicates that response shifts are particularly notable in relation to fatigue and global quality of life, with effect sizes of an order that most trialists would deem clinically important.⁷

For those patients who return to normal health, any process of reframing (re-evaluation, reappraisal) is likely to be truncated by resumption of workaday life, where there is little time or room for such reflection. For patients whose disease trajectory worsens, however, the 'shifting sands' take them progressively further from former reference points and may assume great relevance when palliative care or life-sustaining treatment come into discussion. A patient who experiences the reality of some unpleasant late effect of disease may decide, despite earlier opposition, to request life-sustaining treatment.⁸ Palliative care clinicians are particularly well aware of this phenomenon—hence their somewhat negative attitude to recording patients' wishes and to long-term planning of specific care.⁹⁻¹¹

So, where does this leave us with advance planning? We know that, in certain patients, the application of life-sustaining treatment at the end of life does little but sustain suffering.¹² The challenge is to devise 'advance directives' (living wills) that allow for the possibility of response shifts. One way, of course, is to revisit the document again and again with the patient, as health worsens.¹³ But how often? What event or indicator should catalyse a return to this discussion? How do patients feel about repeated discussion of these difficult topics? These questions are worthy of qualitative and quantitative research. Another approach relies on a distinction promoted by Fins¹⁴—namely, 'contract' versus 'covenant'. Fins notes that, in the process of advance care planning, some individuals expect their wishes to be acted upon strictly as specified by them (i.e. 'contract'); others to have their *core* values understood and acted upon whether or not the action runs counter to a specific statement or preference expressed in their living will (i.e. covenant). Clearly, we need to discover the usefulness of these constructs in practical terms. For planning purposes one would wish to discover, well in advance, the preferences of patient and proxies for contract or covenant, and whether they agree. Further, it would be helpful to know whether, in general, the expressed preference for contract or covenant bears on the likelihood that a patient will change his or her mind about life-sustaining treatment having discovered that advanced

disease is more bearable than expected?¹⁵ A deep exploration in these terms might help us to narrow the difference between patients' wishes and what actually happens at the end of their lives.

Carolyn Schwartz

DeltaQuest Foundation Inc, 31 Mitchell Road, Concord, MA 01742; and Division of Palliative Medicine, Department of Medicine, University of Massachusetts Medical School, Worcester, MA, USA

Correspondence to: Carolyn Schwartz ScD, DeltaQuest Foundation, 31 Mitchell Road, Concord, MA 01742, USA

E-mail: carolyn.schwartz@deltaquest.org

REFERENCES

- 1 Schwartz CE, Sprangers MAG. *Adaptation To Changing Health: Response Shift In Quality-Of-Life Research*. Washington, DC: American Psychological Association, 2000
- 2 Schwartz CE, Repucci N, Becker J, Sprangers MAG, Fayers PM. The clinical significance of adaptation to changing health: a systematic review of response shift. (Unpublished)
- 3 Bernhard J, Hurny C, Maibach R, Herrmann R, Laffer U. Quality of life as subjective experience: reframing of perception in patients with colon cancer undergoing radical resection with or without adjuvant chemotherapy. Swiss group for clinical cancer research (sakk). *Ann Oncol* 1999;**10**:775–82
- 4 Schwartz CE. Teaching coping skills enhances quality of life more than peer support: results of a randomized trial with multiple sclerosis patients. *Health Psychol* 1999;**18**:211–20
- 5 Schwartz CE, Sprangers MAG, Carey A, Reed G. Exploring response shift in longitudinal data. *Psychol Health* 2004;**19**:51–69

- 6 Schwartz CE, Feinberg RG, Jilinskaia E, Applegate JC. An evaluation of a psychosocial intervention for survivors of childhood cancer: paradoxical effects of response shift over time. *Psychooncology* 1999;**8**:344–54
- 7 Norman GR, Sloan JA, Wyrwich KW. Interpretation of changes in health-related quality of life: the remarkable universality of half a standard deviation. *Med Care* 2003;**41**:582–92
- 8 Schwartz CE, Merriman M, Reed G, Hammes B. Measuring patient treatment preferences in end-of-life care research: applications for advance care planning interventions and response shift research. *J Pall Med* 2004;**7**:233–45
- 9 Teno JM. Advance directives: time to move on. *Ann Intern Med* 2004;**141**:159–60
- 10 Teno J, Lynn J, Connors A Jr, et al. The illusion of end-of-life resource savings with advance directives. Support investigators. *J Am Geriatr Soc* 1997;**45**:513–18
- 11 Teno J, Licks S, Lynn J, et al. Do advance directives provide instructions that direct care? Support investigators. *J Am Geriatr Soc* 1997;**45**:519–20
- 12 The Support Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA* 1995;**274**:1591–8
- 13 Das AK, Mulley GP. The value of an ethics history. *J R Soc Med* 2005;**98**:262–6
- 14 Fins JJ, Maltby BS, Friedmann E, et al. Contracts, covenants and advance care planning: an empirical study of the moral obligations of patient and proxy. *J Pain Symptom Manag* 2005;**29**:55–68
- 15 Schwartz CE, Wheeler HB, Hammes B, et al. Early intervention in planning end-of-life care with ambulatory geriatric patients: results of a pilot trial. *Arch Intern Med* 2002;**162**:1611–18