

Treatment goals: health care improvement through setting and measuring patient-centred outcomes

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Health care costs are rising in a manner that is not sustainable, much health care spending is wasted, and quality of care is variable. Despite widespread and long-standing acknowledgement of these issues, there is uncertainty whether existing strategies will lead to substantial health care improvement.

Clinical decision making — the choice of diagnostic tests and treatments provided to patients — is a major determinant of variation in practice^{1,2} and is responsible for more than 80% of all health care expenditure.³ As such, it is the most important driver of health care cost and quality. Improving clinical decision making may have the capacity to improve health outcomes and reduce waste.

How a patient feels, functions and survives after an episode of health care are the direct patient-centred measures of what that episode of care has achieved. However, the existing systems for health care delivery are neither systematic nor comprehensive with respect to the evaluation of the actual achievement of patient-centred outcomes.

Our aim in this article is to introduce the concept of treatment goals as a process that provides a formal framework within which patients and clinicians would set measurable and achievable patient-centred outcome goals at the outset of an episode of care. The setting of goals is already an integral component of clinical decision making, but the concept of treatment goals proposes to extend this by making the setting of goals explicit, systematic and comprehensive, then measuring their achievement. This may facilitate high-quality care by creating a direct link between clinical decision making and patient outcomes.

Drivers of costs and quality in health care

The purpose of health care systems is to optimise the health of the people they serve. However, there is extensive evidence that sometimes health care systems fail to improve or optimise health despite substantial and rising expenditure.^{2,4-6} The proportion of gross domestic product (GDP) used in health care services is 8.7% in Australia, 10.3% in New Zealand, and 17.4% in the United States.⁷ The cost of health care is rising, and rising at a rate that is substantially higher than the rate of growth in GDP.^{8,9} Based on current projections, expenditure on health care in the US will equal GDP in 2082.¹⁰ By definition, this is not sustainable.

Although the effect of population ageing on rising costs is well documented, the major driver of increasing costs is clinical decision making, particularly regarding the use of new diagnostic and therapeutic technologies.¹¹ In the US it is estimated that 21%–47% of all health care spending is wasted.¹² This corresponds to between US\$558 billion and US\$1.2 trillion per year. The major contributors to waste are failures of care delivery, failures of care coordination, unnecessary treatment, administrative complexity, pricing failures and fraud.¹²

It is our observation that health care systems are predominantly treatment-oriented and that this is “the tail wagging the dog”. Process is only important to the extent that it generates outcomes. A system focusing on defining desired outcomes (ie, goals of treatment in terms of a patient’s health goals), working out what treatment options to use to try and achieve those goals, and then measuring the success in achieving those goals would focus on achieving health, rather than the means by which it is delivered. The animated cartoon *Orthopedia vs anaesthesia* represents the extreme and absurd manifestation of a treatment-oriented approach to health care.¹³

Meaning of patient-centred outcomes

The concept of patient-centred outcomes has long been familiar to clinical trial researchers as a direct measure of how a patient feels, functions or survives.¹⁴ In general, Phase III randomised controlled trials (RCTs) have a patient-centred outcome as their primary end point. Any end point that is not a direct measure of how a patient feels, functions or survives is a surrogate. The importance, and primacy, of patient-centred outcomes as end points for clinical trials is emphasised by the observation that there are innumerable examples of divergence between the effect of a candidate intervention on surrogate outcomes compared with patient-centred outcomes.¹⁵ Thus we can be confident that patient-centred outcomes are both important and valid.

More recently, the concept of patient-centred care has been proposed as a major goal of health care reform in the US.^{3,16-19} Patient-centred care is defined as care that is “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions”.¹⁹

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While few would argue that the delivery of health care should be patient-centred, the extent to which this is currently achieved as part of routine care is unknown, at least in part, because there is no comprehensive measurement of patient-centred outcomes after the delivery of health care. On the contrary, many existing metrics used to evaluate the health care system may have serious limitations because they are not patient-centred.

Health care improvement must employ patient-centred measures

The managers of health care systems undertake many measurements of process and outcome to evaluate and improve the system's performance. Some of these measurements have become the subject of targets designed to influence clinical decision making, including surrogate outcomes such as waiting times, infection rates and compliance with guidelines.²⁰

The economist Charles Goodhart has formulated an eponymous rule that can be paraphrased as "if a surrogate target is used for policy purposes it immediately loses the information content that previously qualified it as a valid target". This occurs because the implementation of a target that is a surrogate measure can be "gamed" or lead to distraction, so that true (patient-centred) outcomes can be worse, even when targets have improved.^{21,22}

While measuring surrogate outcomes is often easier, the use of patient-centred outcomes in clinical trials is proof that it is possible and feasible to measure patient-centred outcomes. A proposal that aims to integrate patient-centred care with patient-centred outcomes is treatment goals, using the achievement of patient-centred outcomes as the prime metric for evaluation of performance.

Treatment goals: a possible framework for health care improvement

Treatment goals would be applied to individual patients for each episode of care. The components of such a system would be as follows.

- Clinicians would determine, in discussion with their patients, the agreed goals of an episode of care, with a requirement that these goals would be specified as patient-centred outcomes.
- The goals would specify the targeted:
 - minimum duration of survival
 - minimum level of function
 - minimum level of symptoms.
- The goals could include contingent or trade-off arrangements that rank potentially competing goals.

- The treating clinician would endorse the goals as being realistically achievable in his or her professional opinion.
- The agreed treatment goals would be stated explicitly, written in the medical record, communicated to all clinical staff involved in patient care and acknowledged within the record, and comprise an integral component of formal consent.
- If the original goals were to become unachievable, within or between episodes of care, they would be revised so only achievable goals, including palliative goals, were specified.
- Clinicians would decide on diagnostic tests and treatments that, in their opinion, would be most likely to achieve the goals.
- After an appropriate period of follow up, the goals would be formally evaluated as achieved or not achieved. This would be the major method by which quality of care is evaluated.
- Goals and their achievement would be audited and feedback given to treating clinicians.

Clinical decision making that involves a focus on setting and measuring the achievement of patient-centred treatment goals offers several possible advantages. First, in order to set goals, clinicians must understand the priorities of their patients, so that patient preferences and values are incorporated into clinical decision making. There is substantial evidence that clinicians sometimes make invalid assumptions about patient preferences and values.² Second, a focus on patient-centred goals requires clinicians to consider what is actually achievable and ensures that patients and families understand what is achievable. If a treatment option that might have been applicable in a different clinical context is not being recommended, it would be explained that this is because it cannot achieve the patient-centred goals.

Third, this focus allows quality and business improvement activities to be aimed at achieving the patient-centred goal that the patient has specified and the clinician believes is achievable. This would facilitate the removal of a multitude of surrogate end points of uncertain value, to focus only on patient-centred outcomes. Why target a proxy, when it is feasible to target and audit the real thing? The achievement of the goals of treatment has the potential to be a universal metric of performance which, at its simplest, is a binary outcome measure determined by whether the goals were achieved. This simplifies evaluation of outcome and aligns patient's interests with the metrics used to evaluate outcome.

Fourth, patient-centred goals provide incentives for clinicians to coordinate their care because, in patients who have multiple coexisting illnesses, it is the combined and balanced impact of all treatments for all illnesses that determines

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patient-centred outcomes. Fifth, a treatment goals approach aligns incentives for clinicians to avoid treatments of low value, either because of a low likelihood of effectiveness or because of the risk of complications that would impact on patient-centred outcomes. It undermines the fallacy that if some medical treatment is good, more must be better.²³

There is no substantive empirical evidence to evaluate the hypothesis that goal-oriented care would result in better outcomes and reduce costs. However, it may be relevant that patients with recently diagnosed advanced non-small cell carcinoma of the lung randomised to receive early palliative care integrated with standard oncological management (possibly goal oriented) compared with standard oncological management (possibly treatment oriented) had not just better quality of life, less depression and less aggressive end-of-life care, but also a longer median survival.²⁴

The request to “do everything” is treatment oriented, but to do everything that can achieve patient-centred outcomes is goal oriented. It shifts the focus of patient care from providing treatments (health care) to providing outcomes (health), allowing clinicians to focus on delivering what is actually important to patients.

Limitations

There are substantial limitations and potentially insurmountable barriers to our proposal for a treatment goals approach. First, this framework may not be suitable for emergency care, where treatments must be initiated urgently. Nevertheless, emergency care still has patient-centred goals, and such goals could be discussed and determined after clinical stabilisation. Furthermore, emergency care often occurs in the context of pre-existing health issues. A systematic approach to setting treatment goals would incorporate contingencies for future deteriorations before they occur.

Second, some highly effective interventions only achieve patient-centred goals over years or decades, so the time interval for appropriate evaluation may be impractical in some situations. Third, there may be a risk of gaming, in which clinicians aim only for easily achievable goals. In a treatment goals approach, the extent of the goals as well as their achievement would be subject to review, and the involvement of the patient and their family is likely to lead to understandable resistance to the setting of goals that have insufficient ambition. It is more likely that the opposite may be a problem, that patients and families are reluctant to accept limited goals when palliation is the only achievable goal. Perhaps a system in which patients can easily obtain additional independent clinical opinions of the achievable patient-centred goals may be useful.

Finally, how patients would feel and respond to being asked to set patient-centred goals is unknown. Patients may

find this approach too confronting, particularly if only palliative goals are achievable. It can be argued that patients should always be accurately informed of their prognosis and that neither patients nor clinicians benefit when expectations are unrealistic. There is also evidence that a substantial proportion of patients who have a progressive fatal disease are not aware of their prognosis. Among patients receiving chemotherapy for metastatic lung or colorectal cancer, 69% and 81%, respectively, believed that the chemotherapy was potentially curative.²⁵ It may be that it is more commonly clinicians who are uncomfortable with these discussions rather than patients and their families.

Relevance to intensive care medicine

An intensive care unit may be a suitable location to pilot and evaluate our proposal, due to the combination of the high cost, the wide range of potentially achievable patient-centred outcomes, and the fact that patient outcomes are generally known within a few months. ICUs provide treatments that include advanced life support for patients with failure of one or more organ systems, as well as monitoring and early intervention for patients undergoing high-risk elective surgery. The benefits of treatment in an ICU can be enormous—many young, fit patients survive critical illnesses such as trauma and infection solely because of the availability of the ICU.²⁶ However, for some patients, treatment in an ICU is of low or no marginal value in achieving patient-centred outcomes. Admission to ICU close to the end of a patient’s life has been recognised as a major contributor to waste in the US health care system, in which one in four deaths among the elderly occur during a hospital admission that includes admission to an ICU.²⁷

Conclusion

In the early days of coal mining, a canary would be carried into the mine as an early indicator of rising levels of toxic gases, which would cause the bird to sway on its perch before collapsing, prompting the miners to evacuate and search for the gas leak. The ICU is very much a canary in the health care mine; an important early indicator and magnifier of systemic problems. Just as in the coalmine, however, resuscitating the canary without fixing the problem is a wasteful distraction and ultimately counterproductive for the health care system.

We describe a model for clinical decision making in which a patient–clinician interaction leads to the specification of treatment goals that the clinician believes are achievable. We believe this formalises what happens already, particularly in intensive care medicine, as well as other specialties

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such as palliative care, rehabilitation medicine and geriatrics. What is novel is that such an approach would be universally adopted, would be explicit and audited, and would serve as a key performance indicator. Our proposal represents a shift from decision making based on treatment choices to decision making based on the setting and achievement of goals. In this model, goals are rightly the province of patients, but decision making about how the goals should be achieved and what is achievable lies with clinicians. Each component of the patient–doctor relationship plays to its strength. We agree that “clinicians are experts on the medical options and implications, whereas patients and families are experts on the patient’s values and preferences”.¹⁸

Our objective is to evaluate this concept within a program of research that is initially designed to determine if patients and clinicians can set agreed goals, if such goals can be exclusively patient-centred and if they are measurable. If this is achievable, further work would be conducted to determine if treatment goals can be implemented and to evaluate the impact on health care improvement.

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Competing interests

None declared.

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