

Shared goals of care – the case for change

Introduction

In 2016, a five-year programme was funded by the Health Quality & Safety Commission (the Commission) to help New Zealand hospitals implement three workstreams to improve the care of adult patients (excluding obstetrics) who acutely deteriorate while in hospital. The workstreams are:

- a recognition and response system (including a standardised national vital signs chart and early warning score, and a localised clinical escalation and response system)
- a patient, family and whānau escalation process
- approaches for determining, communicating and documenting shared goals for patient care.

This document provides information about the third workstream. More information about the programme is available on the Commission's website www.hqsc.govt.nz and will be added to as work gets underway.

The problem

Unwanted or unwarranted treatments at the end of life can contribute to suffering for patients, families and whānau, moral distress for clinicians, and unnecessary expenditure for the health system.¹⁻⁸ Taking action to plan and provide end-of-life care is a challenge for acute care clinicians.⁹⁻¹¹ The challenge has been characterised variously as ethical,¹² emotional,¹³ prognostic,¹⁴ associated with inadequacies in educational preparation of clinicians and resourcing of acute care services,¹⁵ and arising from a death-denying culture focused on the provision of acute life-sustaining treatments in the hospital environment.¹⁶ Complex factors contribute to failures to adequately plan and manage end-of-life decision making and care in acute hospitals, which is why multifactorial approaches to improvement are needed.



Decision making

Despite the complexity, it is generally agreed that enabling patients and their families and whānau to be involved in decision making is central to improving end-of-life care.¹⁷⁻¹⁹ In the context of serious illness, it is vital that clinicians understand a patient's wishes. They can then use this information to establish shared goals of care and put in place patient centred and clinically appropriate care plans. Documented goals of care should represent the outcome of a shared decision making process between the patient and the clinical team. At a minimum, goals of care should identify the overall direction for an episode of care (eg, curative, restorative, palliative or terminal²⁰), and any agreed limitations on medical treatment.

The default response to acutely deteriorating patients is to provide every feasible treatment unless otherwise stated. Any system intended to detect acutely deteriorating patients will inevitably identify those who are actually dying.¹¹⁻²¹ At the point of critical deterioration, dying patients are unlikely to be able to participate in an informed discussion of their preferences for further care and treatment. Unless a patient has been involved in an earlier discussion of their values and preferences, and these have been clearly communicated and documented, responding clinicians will inevitably encounter situations where invasive investigations or therapies may be inappropriate or even counter to the wishes of the patient.

Communication and participation

Effective communication is necessary to elicit patients' values and preferences for care and allow informed choices to be made about complex medical treatment options. Ideally such conversations occur prior to episodes of acute deterioration so patients, families, whānau and clinicians are able to participate fully in developing shared goals of care without the pressures of an evolving and emergent clinical crisis.²² When shared goals provide the basis for clinical treatment plans, the risk of a patient receiving unwanted or unwarranted treatments at the end of life is reduced.²³⁻²⁴

Treatment options

Treatment options for critically unwell patients have become far more complex than the binary 'do' or 'do not' resuscitate decisions needed many years ago. The myriad of available treatment options often requires patients and clinicians to make decisions about possibilities such as non-invasive ventilation, inotropes, third- or fourth-line chemotherapy, dialysis, or even the appropriateness of hospital admission or treatment with antibiotics. Many clinicians are unfamiliar with the risks and benefits of such interventions – particularly when a patient is frail or has multiple medical problems – and may struggle to determine appropriateness of use in the context of an individual patient's clinical presentation. This problem is further complicated by the inherent lack of continuity as a result of on-call cover when critical deterioration occurs after hours. In these circumstances, responders who are unfamiliar with the patient's medical history frequently encounter minimal or absent documentation concerning the patient's wishes for their own care, and the rationale or goals for the current treatment plan. Poor communication between community- and hospital-based services, and inconsistent or inadequate documentation of agreed treatment limitations add to the difficulties of providing care for acutely deteriorating patients near the end of life that is appropriate and aligned with their wishes.²⁵⁻²⁶

Proposed approach

The purpose of the shared goals of care workstream is to:

- support consumer and clinician co-design processes to develop tool(s) to guide discussion and agreement of shared goals of care in acute hospital settings
- support consumer and clinician co-design processes to develop consistent ways of communicating and documenting discussions about shared goals of care across different services
- provide guidance about identifying hospitalised patients who would most benefit from goals of care conversations (ie, those at high risk of deterioration or death during an admission)
- support the inclusion of required knowledge and skills in clinical training and educational curricula
- provide expert guidance about how to use shared goals of care to inform end-of-life decision making in the event of acute deterioration
- link shared goals of care for hospitalised patients to the national advance care planning programme
- provide links to resources supporting the delivery of best practice end-of-life care in hospital.



Local-level collaboration

The Commission intends to work in collaboration with district health boards and consumers to develop a national approach to the process of determining, communicating and documenting shared goals of care (within the context and capacity of local information technology systems). Local approaches to the timing and conduct of shared goals of care conversations will probably be needed, but a nationally consistent framework will be developed to guide and document these discussions, so the content can be communicated effectively across different services. A co-design process is proposed, working together with clinicians and consumers to make tools, resources and other materials fit for purpose.

Link with advance care planning

Our work will link to the work of the national advance care planning programme to maximise opportunities for building on existing resources and capabilities, minimise duplication of effort and help shared goals of care conversations be seen as part of the continuum of end-of-life planning. Advance care plans are likely to inform shared goals of care in situations where a patient no longer has capacity to speak for themselves. Figure 1 illustrates the different target populations and settings for advance care planning, and shared goals of care activities.



Figure 1: Target populations and settings for advance care planning and shared goals of care activities

Current status

New Zealand status quo



Most New Zealand hospitals currently use 'do not resuscitate' orders, which represent the end of a spectrum of treatment options. To date, a small number have adopted treatment escalation plans, which have more graded options for limiting medical treatment (for example, 'not for ventilation'). In many centres there appears to be growing interest in developing a goals of care approach; where this is the case, the focus has tended to be on the development of new documentation approaches.

International approaches



Internationally a number of approaches to improving hospitalised patient involvement in end-of-life care decisions have been described, with varied levels of evidence to support their effectiveness. Approaches include treatment escalation plans, goals of care documentation, training resources, quality standards and care bundles.²⁰⁻²⁷ More information about many of these approaches is in the evidence summary developed as part of scoping the patient deterioration programme: www.hqsc.govt.nz/assets/Deteriorating-Patient/PR/Evidence-summary-FINAL-Jun-2016.pdf

End-of-life care decision aids

Decision aids are tools to support clinicians and patients to work through the options, risks and outcomes for a particular intervention, treatment or other health care choice. A number of existing decision aids focus on issues such as cardiopulmonary resuscitation, stopping dialysis or other treatments, or making decisions about artificial hydration and nutrition. Guidance for the development of decision aids is available from: <https://decisionaid.ohri.ca/methods.html>

Links to example decision aids focusing on end-of-life issues are listed below.

<https://vimeo.com/48147363>

<http://thecarenet.ca/docs/CPR%20Decision%20Aid%20revised%20to%20PDF%20brochure%20Nov%203%202009.pdf>

https://decisionaid.ohri.ca/docs/das/Critically_Ill_Decision_Support.pdf

<https://www.healthwise.net/cochranedecisionaid/Content/StdDocument.aspx?DOCHWID=tu2951>

<https://www.healthwise.net/cochranedecisionaid/Content/StdDocument.aspx?DOCHWID=tu1430>

<https://www.healthwise.net/cochranedecisionaid/Content/StdDocument.aspx?DOCHWID=tu6095>

Next steps

The Commission is releasing this case for change document to key stakeholders for discussion.

The initial focus for the work will involve us:

- engaging with clinical and professional groups and health services to identify relevant existing work
- identifying opportunities to lead and coordinate work at a national level
- building capability for co-design in health services
- liaising with the national advance care planning programme to maintain strong linkages as this work develops.

There will be opportunities for interested people to participate by sharing their expertise, experiences and information about current and developing practice.

Feedback on the programme and on the content of this document is welcome.

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