

Consumer report and reflections from the 2018 Patient deterioration New Zealand conference

Sheila Beckers

Thank you to the Health Quality & Safety Commission for offering me the opportunity to attend this conference, and funding my travel, accommodation and conference costs. I attended as a consumer representative from the Capital & Coast district health board's kōrero mai project team and am also reporting back to the Whanganui DHB consumer advisory group (Te Pukaea).

Why do patients deteriorate?

Patients deteriorate for many reasons. Some of these reasons are preventable. Research shows that failure to recognise, escalate and respond to a patient who is getting worse in a timely way, with the appropriate clinical skills, can cause harm. The Commission has developed a five-year national patient deterioration programme which aims to improve outcomes and reduce harm for adult patients who deteriorate in New Zealand hospitals.

The Commission is working with DHBs to implement three key phases of the patient deterioration programme:

- establish efficient recognition and response systems
- create patient and whānau escalation processes (kōrero mai project)
- develop shared goals of care plans for palliative patients.

About the conference

- A joint Health Quality & Safety Commission and Australia New Zealand Intensive Care Society initiative.
- This is the first time there has been a national conference in New Zealand focused on patient deterioration.
- Participants included medical and nursing staff and educators, people with health leadership and quality responsibilities, and a sprinkling of consumers.
- Over 30 people presented from New Zealand and Australia.
- Co-design principles underpin the national patient deterioration programme.

Co-design

Co-design is an approach to the planning and implementation of new processes, policy, strategy, services and initiatives which attempts to actively involve all stakeholders in that design, to help ensure the result is usable, and meets the needs of those it is designed for. In a health context, co-design is a framework within which health providers and consumers work together to design future health services that put patients and their family/whānau at the centre of any care being delivered and received.

Kōrero mai

Kōrero mai is a Commission initiative which supports DHBs to design a patient and family/whānau escalation process if a patient deteriorates. Patients and their family/whānau often know if the patient is getting worse, even when vital signs remain normal. Kōrero mai project teams use co-design to create a clear pathway for patients and their family/whānau to seek help if they are

worried about deterioration in the patient's condition, and they feel that they have not been listened to by staff. Kōrero mai projects have been underway in DHBs since July 2017.

Day one (29 November 2018)

The current state of recognition and response systems within NZ and Australia; future steps for the patient deterioration programme in coming years.

- To remind everyone in the room of the importance of the patient and whānau voice in all care efforts, the conference started with Matt's story. Matt was 15 when he died after what should have been a standard appendectomy. But staff missed signs that he was deteriorating. Matt shouldn't have died.
- We also learned about 'Patient A' who died in Wellington Regional Hospital after staff failed to notice his deterioration. Patient A shouldn't have died. The kōrero mai initiative was created as a result of the Health and Disability Commissioner's report into gaps in Patient A's care.
- Recognition and response systems in NZ hospitals include:
 - the implementation of a standardised vital signs chart with early warning score (EWS) from July 2017. The score is calculated from routine adult patient vital sign measurements and increases as vital signs become increasingly abnormal. The EWS should trigger an escalating clinical response from staff with the right skills to intervene and manage the patient's deterioration
 - a dedicated Patient at Risk (PAR) service – a specialist, nurse-led team who support ward staff in looking after acutely unwell adult patients in various ward settings
 - a medical emergency team (MET) or rapid response team (RRT) available to respond to medical emergencies in a timely manner, and not just in the event of a cardiac arrest.
- Presenters from five DHBs shared snapshots of their process in establishing and implementing improvements to their recognition and response systems for patient deterioration.
- We heard about some of the first cohort of kōrero mai projects. Some great tools were created to support patients and their family/whānau to speak up when they are worried. Data shows that implementing these patient, family and whānau escalation processes work.
- A communication workshop showed us the importance of care and empathy when having tough conversations. Not all patient deterioration is reversible or unexpected, and it can be hard to say so. Patients and whānau experience both emotional and cognitive responses when difficult conversations are had. A role-play example, which involved an extremely authentic actor playing someone with a deteriorating genetic condition, was very powerful. But it caused much distress to some workshop attendees. This was a poignant reminder to everyone present that a patient's culture, beliefs, and values must be respected and understood, for communication to be truly patient-centred, effective and meaningful.

During the morning tea break there was a short consumer meeting. This was initiated by Laura Ellis from the Commission and was an excellent idea. It was nice to be able to identify fellow consumers amidst the 200+ conference attendees. Thank you, Laura!

Day two (30 November 2019)

We learned about the success of rapid response systems in Australian hospitals. Inequity was an important discussion topic.

- A presentation about the Māori perspective of patient deterioration from Bay of Plenty DHB staff brought us out of the research and statistical fog and put humanity back in the centre of the room. Their stories of inequity, failings by clinical staff to provide appropriate or timely care, and the danger of judgement and assumptions, reminded us of the importance of the patient and whānau voice. Each speaker told us what matters for Māori whānau, and the importance of staff respecting tikanga Māori – the Māori world-view.
- Heather Gunter shared further life-threatening health crises she and her family have endured since Matt died. She told us how hard it is to trust in our health care system, and those working in it, when all trust has been lost. She had us all in tears. Sometimes life really is cruel.
- A presentation about deteriorating elderly patients prompted questions for me:
 - How can the care of deteriorating elderly patients be improved, so that patients and their families are heard, the care plan is appropriate, and is agreed upon by all parties involved?
 - Who decides when a patient is too elderly, or too sick, to have life-saving or life-enhancing treatment eg, at what age is someone too old for a hip replacement? Or for bypass surgery?
 - How are the care options prioritised, and when are the difficult conversations had?
 - What are the patient and their loved ones' rights if staff decide that palliative/end-of-life care options are the only way forward?
 - How do clinicians balance their moral want to keep elderly patients alive, when the treatments may do more harm than good?
- Five doctors shared their research papers which addressed topics including the use of a medical emergency team in specific units, and balancing perceptions within palliative care calls; EWS modifications for patients who do not want to be resuscitated; and decisions and conversations around resuscitation and end-of-life care.
- The last presentations discussed deteriorating patients who are dying: using data to identify patients who are dying, the harm done by failure to recognise and respond to sepsis infections in patients and missed opportunities in palliative care and treatment.

Barriers to preventing harm when patients deteriorate

- Staff can normalise the abnormal: reassuring patients when they have concerns rather than listening and applying critical thinking skills.
- Communication failures and barriers: all patients have the risk of deteriorating. Taking the time to talk and listen is important for all patients and their family/whānau.
- Multiple shifts of staff every 24 hours, and poor communication at handovers, reduces continuity of care and the baseline of a patient's wellbeing gets lost. But patients and whānau know that baseline through being present over time, and notice signs that staff miss.
- Knowing the difference between people who have an irreversible condition and are dying, and sick people who have a reversible condition that can be aggressively treated.
- Silo-style, solar-powered care: surgeon vs duty doctor vs nursing staff vs allied health staff. All experts in their own field but not across all the patient's needs or problems. For example, surgeons consult with patients about their surgery, but may not be observant of co-morbidities

like COPD (chronic obstructive pulmonary disease). Then as the sun sets, staffing is reduced, but there's the same number of patients. One presenter spoke of there being 27 doctors in general medicine in his hospital during the day, but only 7 on weekends. Yet Saturday is the busiest day!

- Both the mums who shared their stories of massive failures in the care of their sons, are nurses. They knew their own hospital systems, facilities and processes. Yet they were ignored. They couldn't get the hospital staff to listen, or to act on their concerns. If health staff are unable to be heard, how do the rest of us believe we have the right and knowledge to question staff?
- Nurses also feel that they aren't being heard by doctors. A nurse asked a presenter how staff can get through to clinicians who won't listen to their concerns. I quietly praised Whanganui DHB for their local initiative 'Speaking up for safety'. All Whanganui Hospital staff attend a workshop which teaches them the escalation pathway that has been established for them to speak up if they are worried that a patient is getting worse. The patient safety team at Whanganui Hospital has data to show that staff are now doing this and, as a result, some patient harm has been prevented or reduced.

More about inequity in New Zealand health services

- Outcomes for patients from rural settings who deteriorate, even after transfer to a bigger hospital, are worse than for those who start off in city hospitals.
- Assumptions are made by staff about disabled patients eg, assuming someone in a wheelchair is deaf! Or assuming a disabled patient does not have enough quality of life to be allowed access to life-saving or life-enhancing treatment.
- Are clinical staff willing to have the difficult conversations? Do not attempt CPR (DNACPR) conversations can happen too late, or not at all. Advance care plans, resuscitation/end-of-life care plans, and shared goals of care should be done *before* a crisis touch point.
- Visibility of care goals and treatment plans important, so loved ones understand what has been agreed upon by palliative/elderly patients and their care providers.
- How do staff discuss with elderly and palliative patients and their whānau, the reality that interventions may make the outcome worse for the patient?

More about the Māori perspective

Research shows Māori deteriorate more quickly in hospitals than European New Zealanders. Interactions that involve judgements and assumptions diminish the mana and wairua of the patient and their whānau, and also reduce confidence or trust in the health system and its people.

Yet what works for Māori patients and their whānau would be good practice for all:

- whānau inclusion
- taking time to build relationships – consultants are full of knowledge but too sharp, too quick
- communicating in a language that patients understand – as simple as 'ring the bell'
- respecting mana tangata (human rights, the value of each person)
- understanding the Māori world view: wellness (hauora) is a combination of physical, emotional, spiritual, and whānau (te whare tapa whā)
- see the experience through the eyes of the patient and whanau.

Personal reflections

Wow. A big conference with many highly-skilled and experienced health care professionals in the room. As a consumer from outside the health community I was initially way out of my comfort zone.

There were graphs galore, data, research findings, and loads of acronyms. Thank you to those sitting around me who translated acronyms and explained clinical information I didn't understand!

The key message in all presentations was that deteriorating patients and their loved ones matter, and that the Commission has used robust research and planning to implement their programme to reduce harm, and improve outcomes, for deteriorating patients in NZ hospitals.

A presenter commented that 'patients rarely deteriorate suddenly, but clinicians often suddenly notice deterioration'.

In other words, there is usually a period of deterioration – often noticed by patients themselves or their loved ones. But clinicians or other staff often only notice when a crisis occurs eg, cardiac arrest. Noticing when a patient is getting worse, and responding quickly with the appropriate skills, can reduce harm, reduce the demand for intensive care services, and save lives.

Matt's story and the experience of Marama Tauranga, whose teenage son suffered peritonitis due to assumptions and fob-offs from clinicians, should be told in every medical/nursing training program, and in all DHB professional development workshops throughout New Zealand.

Research shows there's been progress. The clinical recognition of, and response to, deteriorating patients in New Zealand hospitals is improving. Using resources and initiatives such as the New Zealand EWS chart and PAR teams nearer the 'top of the cliff' means less harm to patients.

The kōrero mai project will give patients and their whānau throughout the country a clear pathway to escalate their concerns, and bypass immediate staff, to seek the help they need. Some DHBs have already gone live and their teams shared some great ideas:

- 'if you have something to tell, ring the bell!'
- a traffic light system (green, orange, red) on posters to guide patients and their loved ones
- 'kōrero mai – talk to me' posters, stickers, badges, and business cards
- at Canterbury DHB a patient/family concern prompt has been added to the NZEWS chart
- the Bay of Plenty DHB modified the kōrero mai questions to ensure they reflected Māori needs and enabled answers to be truly honest for Māori. Tauranga Hospital has a kaupapa Māori ward.

Communication is key. Listening as well as talking. It is important for staff to allow time for the concerns and questions from patients and their loved ones to be expressed and answered in a way they understand. Some deteriorating patients are dying – tough decisions may need to be made. Communicating compassionately and being respectful of patient and whānau values and preferences can help ease the trauma for those who are at their most vulnerable.

Finally, I now understand the need for the Commission's national, formalised programme to improve the way hospitals recognise and respond to deteriorating patients throughout New Zealand. And I see the bigger patient safety picture within which the kōrero mai project is embedded. Though a national and formalised process takes much longer to complete than local initiatives, each DHB can modify the framework, in consultation with local consumers, to best meet their own community needs and values. But ultimately the patient deterioration project ensures all DHBs are accountable to the same nation-wide standards for improving safety, reducing harm, and improving outcomes, when adult patients in their hospitals, get worse.