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Clinical Communiqué

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Editorial

Associate Professor Nicola Cunningham

Welcome to the September edition of the Clinical Communiqué for 2023. Each year, on the 17th of September, the world recognises and celebrates the importance of patient safety. This crucial juncture came about at the 72nd World Health Assembly in May 2019, where all 194 member states of the World Health Organisation (WHO), adopted the World Patient Safety Day Resolution (Resolution WHA 72.6), and endorsed the establishment of an annual World Patient Safety Day in recognition of the importance of patient safety as a global health priority.

The objectives of World Patient Safety Day are to increase public awareness and engagement, enhance global understanding, and spur global solidarity and action to prevent avoidable harm in health care and promote patient safety. In September 2020, the WHO urged the world to, “speak up for health worker safety!” In September 2021, the focus was on “the need to prioritise and address safety in maternal and newborn care”, while 2022 saw the theme of “medication safety” highlighted. This year, the theme for World Patient Safety Day is “Engaging patients for patient safety”, with the call to “Elevate the voice of patients!”.

In my experience of more than two decades of reading and reviewing coronial findings, the disconnect between the concerns of families, carers, friends, and patients themselves, and a health care system’s response, is all too painfully common. A breakdown in communication, an unheard voice, a silenced question, is a familiar thread that runs through almost every story. Those moments may not have always been found by the coroner to be the main cause of preventable harm, but they were almost certainly a contributing factor, and undeniably, a source of long-term suffering for those whose concerns went unanswered.

The two cases in this edition were from different decades but sadly told the same story. Families who felt they were not listened to by the nurses and doctors caring for their loved ones. A perceived lack of engagement and a failure of escalation that led to the patients’ deaths. In many respects, it is incomprehensible that it has taken this long, where yet another decade has passed, for the world to formally recognise, on a global scale, the importance of engaging patients for patient safety.

What is heartening to see is some of the incredible work that individuals and organisations are putting into humanising health care – that is, strengthening the patient voice by placing them in their rightful place at the centre of the health care system. Such a fundamental and obvious notion, yet such a complex paradigm to achieve. It requires culture change, and co-designing policies and procedures with patients (consumers), at all levels of the health care system and by national and international regulatory bodies. Without a consumer focus on all that we strive to achieve in health care, there will always be missed opportunities for improvement.

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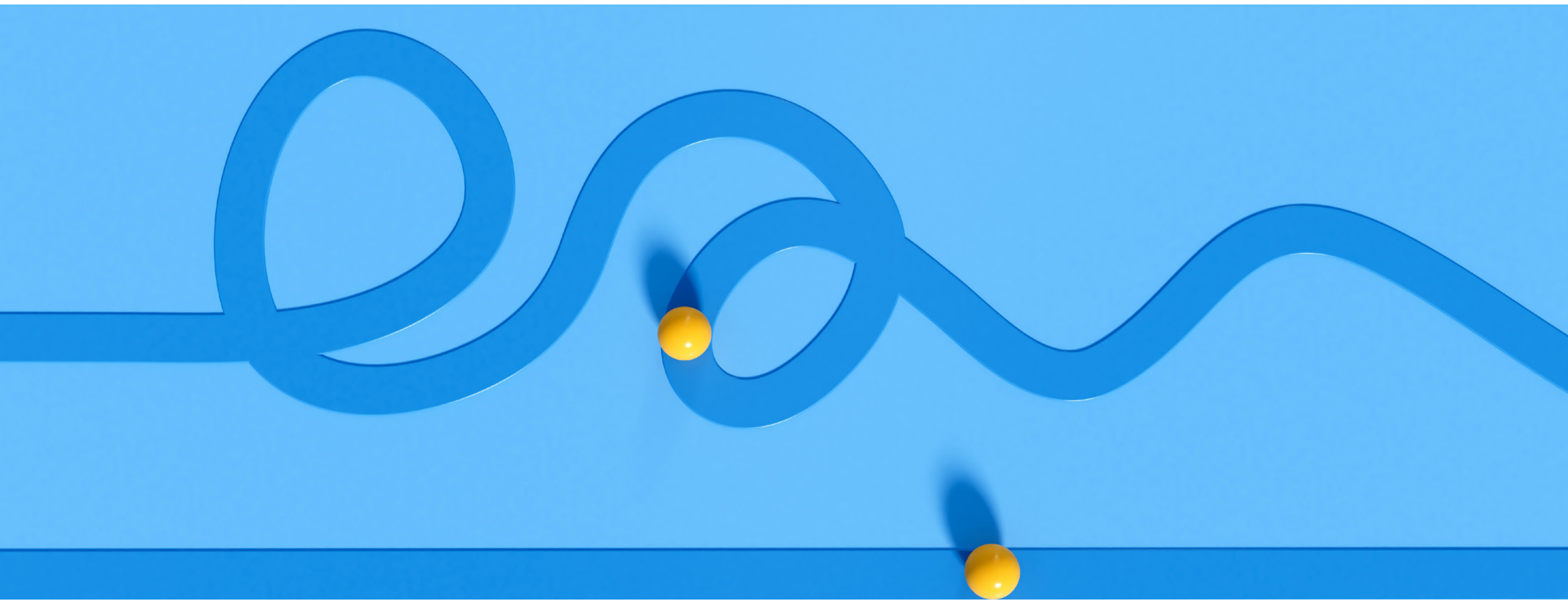
FEEDBACK

The editorial team is keen to receive feedback about this communication especially in relation to changes in practice. Please contact us at: cc@thecommuniques.com

Editorial (continued)

The two expert commentaries in this edition were written by two incredible women who have dedicated their careers to advocating for consumer-centred health care. Elizabeth Deveny is the Chief Executive Officer of Consumers Health Forum of Australia (CHF), the national peak body representing the interests of Australian healthcare consumers. Belinda MacLeod-Smith is a health consumer leader who amongst her many areas of expertise, is involved in partnering and co-design in health care with Safer Care Victoria. It is an immense privilege to read how their personal experiences have shaped their work, and it is their courage in sharing their own stories that speak to their dedication in achieving equitable and safe health care for all.

As I put this edition together, I was struck by a singular recurring thought. I am a clinician… but I am also a user of the health care system. As a daughter, a mother, a partner, a friend, I have had my own good and bad experiences of the health care system, and I know that there will be many more moments to come where I exist as the health care user accessing services and not the clinician providing care. That is the universal, inescapable, actuality for all clinicians. So why then, do we still have so much to learn about consumer-centred health care? How did such a chasm develop between the outlook of clinicians versus the experiences of consumers that we needed the emergence of consumer advocates to open our eyes to the failings in the system? I look to the consumer advocates that I have come to know as good friends and wise colleagues in my various work roles, and I thank them. For their insights, and for their persistence in holding a mirror up to us all. For continuously reminding us that we can do better – for their loved ones, and for our own. Thank you for elevating the voice of patients.



Case #1 Missing the moments

Case Number 2014/35 Qld

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i. Clinical Summary

Mr A, an 87 year old man, presented to a private hospital (the Hospital) with a history of decreased oral intake, lethargy, and vomiting for about two days. His general health included hypertension, diabetes and hypercholesterolaemia. He was taking oral medications for these conditions.

Dr B (an emergency physician) found that Mr A was somewhat confused, dehydrated, with a low-grade fever and a mild increase in white cells on testing. He conducted an abdominal examination and recorded that it was 'unremarkable'. His initial provisional diagnosis was a urinary tract infection. Mr A was admitted for intravenous fluids and antiemetic medication and his care was referred to Dr C, a general physician. Mr A was not reported to have been in pain at any time during his admission.

Dr C recommended continuing the intravenous fluids and to await the results of the urine test. However, Mr A was disorientated and incontinent of urine so a sample could not be collected. He had several more episodes of vomiting that were described as 'dark green', and a finding of 'abdominal distension' was recorded in the nursing notes by the evening and night staff. They made him 'nil by mouth' until he could be reviewed by a doctor.

Dr C saw Mr A the following morning. The nursing team leader who normally would have accompanied Dr C on his ward round became ill and was not replaced so Dr C conducted the ward round on his own. Dr C had not read the nursing notes and he did not examine Mr A's abdomen. He ordered a CT head and a physiotherapy review.

During the day, Mr A's daughter was concerned about her father's condition and expressed her concern to a nurse. She questioned the need for a CT head when his abdomen was distended.

The CT head was performed and did not reveal any acute changes.

In the evening of that same day, nurses noted Mr A to be vomiting still and that his abdomen was distended. He had not opened his bowels and had ongoing urinary incontinence. His vital signs were within normal limits.

At 0023 hours the following day, Mr A was found unresponsive and was unable to be resuscitated.

The initial cause of death for Mr A was stated to be 'aspiration pneumonia' on his death certificate and his death was not reported to the coroner. Notification to the coroner was made by the Hospital's Director of Medical Services (Dr D) however, after a review of the medical records revealed questions about the diagnosis of Mr A's condition, his clinical deterioration, and difficulties reported by the family in bringing their concerns to the treating team.

The Hospital conducted a Root Cause Analysis (RCA) Review into Mr A's death to address these questions. The coroner then received preliminary advice from the Clinical Forensic Medical Unit (CFMU) that raised the possibility of a missed diagnosis of bowel obstruction and the need for further information.

ii. Pathology

A partial autopsy was performed which showed obstruction of the small bowel due to adhesions. The loops of bowel trapped by the adhesions were strangulated. Death was found to be due to dehydration, electrolyte imbalance, sepsis, and toxins from the necrotic bowel.

iii. Investigation

In view of the concerns raised by the Hospital and the CFMU, and the findings of the partial autopsy, the coroner held an inquest to determine the appropriateness of the health care provided to Mr A.

Statements were received from several witnesses including the nursing staff that were rostered on during the period of Mr A's admission, Dr B, Dr C, independent experts, Dr D and Mr A's daughter.

In general, it was agreed by the physician and the experts that the apparent absence of pain in Mr A's case in light of his diagnosis was unusual.

Dr C, the general physician, stated that the CT head was to investigate for a neurological condition that might explain Mr A's confusion and vomiting. He was not aware that a urine sample had not been collected. It was not his usual practice to read nursing progress entries and he would rely on verbal updates from the nursing team leader during his ward round, however since Mr A's death, he had changed his practice to include reviewing nursing notes.

Mr A's daughter described seeing her father look very weak, with a 'swollen stomach' and laboured breathing. She became increasingly distressed with the apparent lack of concern being shown by the Hospital staff, and felt she was not given an adequate explanation for why a CT head had been ordered for her father rather than investigating his 'stomach' to manage his apparent deterioration. She left the hospital as she did not want her father to know she was upset, and "regrets to this day that she had not stayed with him in what's turned out to be his final hours".

Evidence was given by one expert, a general practitioner with extensive experience in residential aged care, who was generally critical of Dr C's management.

Two other experts (a general physician and a general surgeon) were of the opinion that the management of Mr A was appropriate. They both stated that it was also not their routine practice to read nursing notes.

In general, it was agreed by the physician and the experts that the apparent absence of pain in Mr A's case in light of his diagnosis was unusual.

The coroner's investigation was assisted by the findings of the RCA Review conducted by the Hospital which identified lost opportunities and failures of systems in the care provided. The following factors were found to have contributed to Mr A's missed diagnosis:

- No agreed communication process to allow family/care concerns to be escalated.
- The failure to replace the nursing team leader who became unwell, which meant there was a missed opportunity for assessment and communication escalation.
- Inconsistency in communication between the medical practitioner, the team leader and the nurses caring for Mr A which impacted on the opportunities to recognise and manage the patient's changing condition.

At the time of Mr A's death there was no formal process for escalation of patient or family concerns where the patient was deteriorating. The coroner noted that as a result of their RCA Review, the Hospital had rolled out the Queensland Adult Deterioration Detection Scheme, an early warning tool that supports nursing staff to identify adult patient deterioration and report to medical staff. The Hospital also established a 'Team Leader Resource Guide' to enable a standardised approach for the team leader role including minimum rostering requirements and sick leave replacement. It further introduced the 'Let us know' tool which provides information to families on how to raise concerns directly with the team leader.

iv. Coroner's Findings

The coroner found that poor communication, poor documentation, and lack of safeguards contributed to missed opportunities in this case. He commented on the general risk of handovers and the fact that clinical communication problems are a major contributing factor in 70% of hospital sentinel events.

Specifically in Mr A's case, the coroner found that there were no issues or concerns with respect to his treatment in the emergency department. He found that even though Mr A did not complain of or demonstrate signs of pain which would have been expected in this case, his vomiting and abdominal distension should have been investigated.

There were several missed opportunities: 1) the team leader was unable to accompany Dr C on his ward round and was not replaced when she was sick; 2) the physician did not read the nursing notes. Had he done this, the fact of Mr A's abdominal distension would have been made known to him; 3) A further missed opportunity was when Mr A's daughter raised her concerns regarding her father's deterioration and abdominal distension with a nurse. Her concerns were not acted upon.

The coroner found that the likely outcome, even if Mr A's bowel obstruction had been identified, was that surgery would not have been contemplated and he would have been palliated. Had the diagnosis been made however, Mr A and his family could have spent his last hours together in comfort.

Given the improvements made by the hospital following the RCA Review, the coroner did not make further recommendations.

v. Author's Comments

The communication deficits that contributed to Mr A's missed diagnosis were identified by the Hospital and action taken to prevent a recurrence. The findings of the Hospital's RCA Review highlighted the need for all medical and nursing staff to act when a family member of a patient raises concerns. It also highlighted the need for verbal communication of critical information to supplement a written handover model.

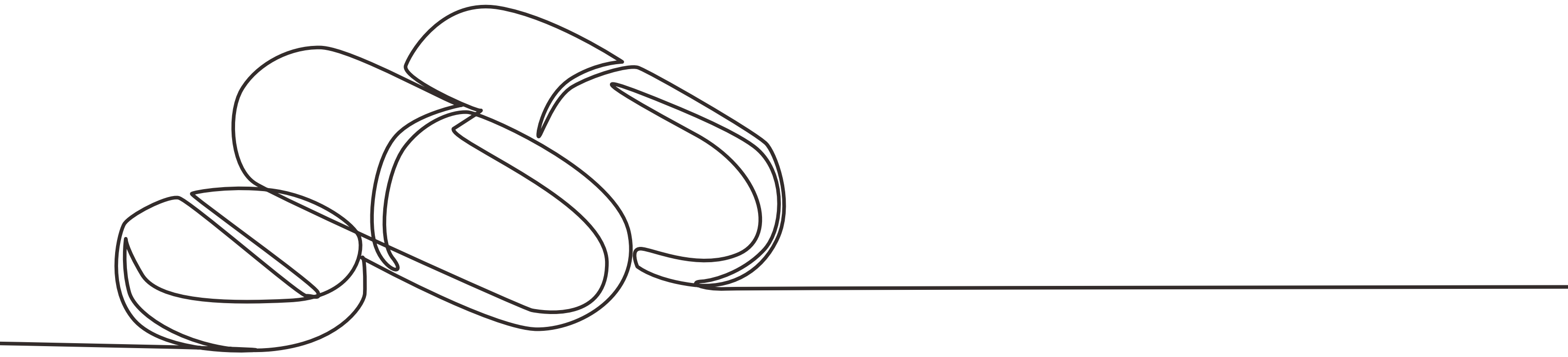
The missed opportunities in this case are potentially reproducible in many clinical settings. The adoption of guides and tools to mitigate the risk is a practical way to prevent communication breakdown and thereby ensure the best outcome for the patient.

vi. Resources

Dwyer T, Flenady T, Signal T, Browne M, Le Lagadec D, Kahl J, Murray Boyle C, Sobolewski A, Stitz L. Summary of findings: Validating the Queensland Adult Deterioration Detection System (Q-ADDS) 2019. Available at: http://staging.clinicalexcellence.qld.gov.au/sites/default/files/docs/resources/qadds-summary-of-findings.pdf.

vii. Keywords

Communication, family concerns, bowel obstruction, documentation, handover, RCA



Case #2 “I told them but no one came”

Case Number 5/07 Qld

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i. Clinical Summary

Mr JD presented to his general practitioner (GP), with an acute exacerbation of lower back pain. The pain radiated down his right thigh and was associated with altered sensation in that thigh and below his knee. Mr JD’s GP sent him for a CT scan of his lower back which showed fragments of disc in his right L3-4 vertebral region. His GP then referred him to the local district hospital for admission and wrote a referral letter that outlined the severe pain that Mr JD was experiencing, as well as his medical history of regular alcohol consumption (four glasses of wine each day), ex-smoker, and cardiomegaly. The GP described Mr JD as a large man of approximately 120kg.

The emergency department staff at the local district hospital consulted with the neurosurgical registrar at their nearest tertiary facility about Mr JD, and a plan was made for him to remain as an inpatient at the district hospital for pain management, with outpatient review at the neurosurgical clinic in four weeks’ time. Over the next two days, Mr JD was noted to be in severe pain at the morning ward rounds, and his pain medication was increased each time till he was taking oxycontin 30mg twice daily and amitriptyline, together with diazepam and ibuprofen. He was awake and cooperative and did not appear to have any neurological deficits.

On day 3 of his admission, a bed allocation decision was made by nursing staff to transfer Mr JD to an on-site palliative care cottage as the wards were full. He was transported to a larger regional hospital on Day 5 of his admission to undergo an MRI of his spine. The activity exacerbated his lower back pain, but he settled after being given his regular analgesia. At the ward round the following morning, it was once again noted that his pain was not improving, but he was mobilising with a walking stick. He was prescribed gabapentin and his diazepam was weaned. Dr B, the registrar in Mr JD’s treating team, contacted the neurosurgical registrar again for advice but was told that they had not received Mr

JD's MRI films. Mr JD complained that the pain in his right leg was constant and further attempts by his treating team to contact the neurosurgical team about his neuropathic-sounding pain were unsuccessful.

On day 9 of his admission, Mr JD's partner noticed he was turning blue and disinterested in his lunch. She approached the nurses' counter to report her concerns but was unable to find anyone to speak to.

Over the next couple of days, Mr JD reported severe pain, difficulty sleeping, pins and needles along his right leg, and that he was feeling dopey. His diazepam was reduced to 2.5mg twice a day, and his gabapentin was increased to 600mg twice daily. His severe pain continued but his observations were all within normal limits, and he did not have any signs of drowsiness. Of note, he was able to shower and toilet himself.

On day 9 of his admission, Mr JD's partner noticed he was turning blue and was disinterested in his lunch. She approached the nurses' counter to report her concerns but no one came. She contacted Dr B and insisted that Mr JD's pain medications be reduced. Dr B explained to her that there was a balance between managing pain and the side effects of medications but agreed to reduce the dosages of gabapentin and oxycontin and cease the diazepam. At their midday ward round, Dr B did not note any 'bluishness' to Mr JD but made the medication changes as requested. Dr B explained to Mr JD that the neurosurgical team had received and reviewed the MRI films and recommended a transfer to their hospital for surgery. Mr JD was pleased with the arrangements.

At 1pm, Mr JD conversed with the tea lady on her rounds. At 1:30pm, a nurse noted that Mr JD was snoring loudly when she entered his room to retrieve his chart. Shortly after 3pm, Mr JD was found deceased in his room.

ii. Pathology

An autopsy was performed, and the pathologist concluded that the cause of death was hypertensive heart disease, due to, or as a consequence of possible oxycodone and morphine toxicity and fatty liver. Blood samples were not taken immediately after Mr JD's death, and a delay of four days before the autopsy was able to be conducted, meant that the pathologist was unable to comment on the significance of the drug levels at the time of autopsy.

iii. Investigation

The coroner held an inquest into Mr JD's death to seek to explain how his death occurred and whether there were any changes to policies or practices that could reduce the likelihood of deaths occurring in similar circumstances in the future.

The coroner heard evidence from two experts – a forensic pharmacologist and a clinical pharmacologist, who both took the view that none of the medications, in the dosages that had been prescribed, would have caused serious toxicity and death. The clinical pharmacologist considered the cause of Mr JD's death to be a primary arrhythmia and opined that the outcome may not have changed if Mr JD had been transferred to the tertiary hospital.

Evidence was heard from the nursing and medical staff who provided care to Mr JD.

Their testimonies all described Mr JD as conversing appropriately, able to engage in daily activities, without signs of excessive sedation.

A Root Cause Analysis (RCA) Review was conducted by the hospital following Mr JD's death, and several changes were implemented as a result, including the re-formulation of the district hospital into primarily a geriatric unit with an emergency ward. This meant that patients with acute pain conditions would not be admitted in the future and were referred instead to the larger regional hospital. The review also noted that Mr JD had been moved to the palliative care cottage as an 'outlier', which might have restricted his access to nursing staff. The review team concluded however, that he was subject to as many observations and reviews as had been ordered by the medical team.

Mr JD's partner expressed her concerns about the lack of communication between the treating team and herself. When she left Mr JD on his last afternoon, she thought she would never see him alive again. She felt that he also believed he was dying. She told the coroner that if there had been a Nurse Advocate System in place, she might have been able to do more.

iv. Coroner's Findings

The coroner found that Mr JD died of hypertensive heart disease, while noting that none of the experts were able to rule out entirely the possibility of drug toxicity as a cause of death. The coroner accepted the recommendations made by the RCA review team, and added their own recommendations, including that:

- Queensland Health review its pain management and risk protocols generally but, in particular, the protocols applicable to primary care Level 1 hospitals.
- That Queensland Health investigates the introduction of Nurse Advocates into the hospital system to assist communication between a patient's family and medical staff.

v. Keywords

Back pain, medication, family concerns, sedation, communication, RCA

Stolen moments and lost lives: Is the Partnering with Consumers Standard alone enough to elevate patient voice in safety?

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As I sat next to my husband's bed in ICU, watching a horde of healthcare workers fight against the severe sepsis and total organ failure threatening to kill him, I wondered if it was my fault. I thought back to less than 72 hours earlier, when I'd watched a nurse tear off the tip of her glove so she could 'feel the vein better' as she inserted an IV cannula. I'd thought it a bit odd, to put on gloves only to remove the bit that prevented skin-to-skin contact. But when I hesitantly asked about it, I was told "don't be silly, nothing to worry about, I do it this way all the time."

This was in 2012, in the very early years of caring for my husband through his journey of congestive heart failure. That 2012 version of myself still had absolute, unquestioning faith and trust in all the medical professionals treating my husband. To hush me then was easy. To shut me up with a glib 'don't be silly, nothing to worry about' absolutely did the trick to shut me down.

But the guilt of not pushing harder, of not saying "stop, that's not aseptic technique!" That guilt and regret has lurked, driving me to be that 'difficult' spouse, propelling my relentless curiosity to understand the drivers of a system that so often demonstrates an inability or unwillingness to listen to patients and those who care for them.

In a case referred to in this edition of the *Clinical Communiqué*, one of the most powerful sentences for me is from the coroner's finding for Mr A, from his daughter who shared that **"She regrets to this day that she had not stayed with him in what turned out to be his final hours."** Irreplaceable moments and lifelong regret because of, in my opinion, inadequate listening and compassion.

For me, it's been over a decade since the "don't be silly" episode. In those ten years, I'm proud to say I've been a staunch advocate again and again for my husband, my children and many others – some of whom I'll never meet. I've done this at the bedside, the boardroom, behind podiums and on panels.

In recent years, I even had the opportunity to step into a health service leadership role responsible for the Australian Commission on Safety and Quality in Health Care (ACSQHC) Partnering with Consumers Standard. Being involved in accreditation preparation, and the survey process was an incredible privilege, and gave me useful insights into the 'reality' of accreditation.

The Partnering with Consumers Standard was enormously strengthened in the 2017 revision of the Standards. My favourite part of the revision is that every single one of the eight Standards was upgraded (in my opinion) to include at least three tangible actions related to partnering with consumers as a critical element.

Not only that, but the Partnering with Consumers Standard is on par with the Clinical Governance Standard as an **overarching system requirement** – *'The Clinical Governance Standard and the Partnering with Consumers Standard set the overarching system requirements for the effective implementation of the remaining six standards.'*[1]

Participating in a health service accreditation process helped me understand the mechanics of accreditation, and some of the excellent tools available to prepare for the process.

I still have a very dog-eared and highlighted Accreditation Workbook which I reckon is one of the best ways to get your head around Standards criteria, evaluation and measurement for all the Standards.

While the introduction identifies that it's been developed for quality managers or health managers responsible for supporting improvement activity, I genuinely commend it to clinicians and non-clinicians with a genuine interest in understanding which types of activities (evidence) support effective implementation of the Partnering with Consumers standard.[2]

The intention of the Partnering with Consumers Standard is to, "…create organisations where there are mutually valuable outcomes by having consumers as partners in planning, design, delivery and measurement and evaluation; and patients as partners in their own care to the extent that they choose."

As mentioned earlier, there are Partnering actions embedded across all eight Standards, and I flag one which I find specifically relevant to the cases in this edition of the *Clinical Communiqué:* Communicating for Clinical Safety. The Accreditation Workbook features excellent reflective questions for health services to consider. Two of my favourites from Action 6.10 in the Communicating for Clinical Safety standard are:

1. What processes are in place to support patients and carers to communicate critical information about their care to clinicians?
2. What feedback processes are in place to let patients and carers know that they have been heard and action has been taken, if necessary?

While both cases featured in this edition preceded the strengthening of the Partnering with Consumers Standard in 2017, it's the two questions above that came to mind as I read the coroner's recommendations. The sad reality is that these cases may still have happened even if processes were in place.

I mentioned insights into the reality of accreditation. My curiosity was sparked about broader system factors when it comes to 'the rules' versus 'the reality' of how safety happens in health services. For a non-clinician, policies and procedures about safety and quality seem to sit confusingly at odds with the actual harm experienced by patients and those who care for them.

Most of the time policies and procedures are there in black and white. What I hadn't factored in was the (new to me) concept of a safety culture ecosystem, and specifically patient safety culture.

Patient Safety Culture is defined by ACSQHC as being "…focused on the aspects of organisational culture that relate to patient safety. It is defined as a pattern of individual and organisational behaviour, based upon shared beliefs and values that continuously seeks to minimise patient harm, which may result from the process of care delivery."[3]

In reading more about patient safety culture, the human factor descriptions of four types of work helped me understand the seeming disconnect between rules and reality. Steven Shorrock, in his short piece 'The Varieties of Human Work', describes four types of work as:[4]

1. Work as prescribed - the formalisation of work as imagined (laws, regulations, rules, procedures)
2. Work as imagined - the work that we imagine we do currently or in the future
3. Work as done - actual activity that takes place in variable and unpredictable environments
4. Work as disclosed - what we say or write about work tailored to the purpose or objective of the message

Part of my husband's survival after sepsis involved being implanted with a left ventricular assist device as a bridge to transplant. As his carer, I was trained to do regular aseptic wound dressings for the driveline in his abdomen.

During my wound dressing lesson, the consequence of infection was heavily emphasised to me. I was fiercely protective about that driveline site, so you can imagine how I felt during a routine clinic check where I saw the clinician open the door, use a keyboard to check notes, then start to remove the dressing without washing/sanitising their hands.

At the time, I felt safe to say something – there was literally a poster on the wall that said, 'It's ok to ask if I've cleaned my hands.' So, I politely asked if they were going to clean their hands first.

I now know that back then, the poster was from the 'work as imagined' category. Turns out that it was not okay for me to ask about hand cleaning. The clinician became angry and defensive, and the whole appointment was awkward and uncomfortable.

Situations like that, when patients and carers question clinicians or raise concerns, make me wonder if there could be more cross-fertilisation in the current Standards with the excellent questions from ACSQHC's Australian Hospital Patient Experience Question Set (AHPEQS).

This set of 12 powerful questions is listed as a complementary measure for measuring patient safety culture. When I reflect on the first probing statement, 'My views and concerns were listened to', I'm curious about whether we'll ever see analysis and response to AHPEQS or similar listed as an example of evidence under the relevant Standards.[5]

The introduction to this commentary asks, 'is this Standard alone enough to elevate the patient voice in safety?' When I think about how the Partnering with Consumers Standard can be implemented, used, and measured, I have a single strident thought, "Not in isolation!"

The slogan for this year's World Patient Safety Day was "Elevate the voice of patients!" I encourage you to embrace systems thinking and consider the ecosystem of strategies you'll use to embed and give primacy to patients' views and concerns. Think about what your listening will look and feel like to patients, and the opportunities we have to work together to limit the number of stolen moments and lost lives.

RESOURCES

1. The Australian Commission on Safety and Quality in Health Care: Clinical Governance Standard. Available at: https://www.safetyandquality.gov.au/standards/nsqhs-standards/clinical-governance/clinical-governance-standard.
2. The NSQHS Standards Accreditation Workbook, p. 36 Available at: https://www.safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-accreditation-workbook.
3. The Australian Commission on Quality and Safety in Health Care: Patient Safety Culture. Available at: https://www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/patient-safety-culture/about-patient-safety-culture.
4. Shorrock, S. (2016, December 5). The varieties of human work. Humanistic Systems. https://humanisticsystems.com/2016/12/05/the-varieties-of-human-work/.
5. The Australian Commission on Quality and Safety in Health Care: Australian Hospital Patient Experience Question Set. Available at: https://www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/australian-hospital-patient-experience-question-set.

Engaging patients (and their families) to improve safety

Elizabeth Deveny
CEO, Consumers Health Forum of Australia

While coronial inquiries into health care failures often mark the point at which painstaking clinical and legal issues and language converge, at their heart are the cries of people in distress.

The case of Mr A in this edition of the *Clinical Communiqué* illustrates that simply and graphically, reporting that his daughter went home from the hospital as she did not want him to know she was upset about the care he was receiving and the lack of attention to her concerns. "She regrets to this day that she had not stayed with him in what turned out to be his final hours," the coroner reported, adding: "[Mr A] could have been made more comfortable and his family could have been with him. Instead, he died alone and in an undignified manner."

It's an important choice of words. We know that patients often use different indicators than health services do to assess quality and safety. For example, staff may focus on how well they worked together as a team to judge coordination of care, while patients and their loved ones measure the quality of care provided against the level of dignity and respect they received.[1]

As we mark World Patient Safety Day 2023, with its theme of 'Engaging patients for patient safety', we can take some comfort in growing efforts to enable patients and their families to escalate complaints. We need stronger voices in policy and practice, with organisations like Consumers Health Forum of Australia resourced to support this work.

We're told that, at the time of Mr A's death in 2013, there was no formal escalation process for patient or family concerns where the patient was deteriorating. However, after his death, "and very much because of it", the coroner noted, the private Hospital implemented the 'Let us know' process for escalation of family and patient concerns, similar to 'Ryan's Rule' as adopted in Queensland's public health system.

Like similar processes in other states and territories, Ryan's Rule is a three-step process to support patients of any age, their families and carers, to raise concerns if a patient's health condition is getting worse or not improving as well as expected.

Health Consumers Queensland was part of its development in response to the tragic death of two-year-old Ryan Saunders, who died in 2007 from an undiagnosed Streptococcal infection, which led to toxic shock syndrome. According to a recent media report, rising numbers of people in Queensland are activating Ryan's Rule: about 1,600 times in 2021, an average of 31 times a week — up 25 per cent on 2020 and 145 per cent on 2016.[2]

But how we interpret growth in complaints and safety/ care escalations is important.

Meanwhile, the latest figures from the Australian Health Practitioner Regulatory Agency (AHPRA) on general complaints about health care also show significant growth: in 2021-22, 18,710 complaints were made about 14,313 health practitioners (about 1.7 per cent of the entire registered workforce) — up 6.2 per cent on the previous year.[3] Patients and their families or other members of the public (61.7 per cent) were the major source, with the most common concerns being clinical care, communication and medicines.

But how we interpret growth in complaints and safety/care escalations is important.

Do they indicate rising health literacy and good health promotion and accountability within the system? Do they show a system under pressure and therefore eliciting more complaints and concern? Do they track and tell us what the system does in response — are they detecting patterns and cultures and responding with systemic change? Do they detect cultural safety issues for Aboriginal and Torres Strait Islander patients, families and communities?

Our view is that the health system is better than it used to be in regard to having patient and family complaint escalation processes in place. But how do we measure that? Where are the gaps and barriers? Do we need a national approach?

Data is key: we need to record, measure, analyse and harvest it, to understand what the key issues are, so we can train health professionals, services, and systems to avoid recurring issues.

A 2020 study in *BMJ Quality Safety* backs this up, saying that while complaints necessarily require case-by-case handling, what's needed is a distinct improvement pathway to address system-wide issues they may be revealing.[4]

There is also the question of health literacy. Yes, we now have, for example, posters and other alerts in health settings providing more information for patients and families to identify problems, what to do, what is not acceptable behaviour and how to escalate concerns.

But how many know to look for this advice and have the capacity to activate complaints, often at a time of crisis? Posters in a waiting room are no help when you are at home and distressed after a phone call with a loved one in hospital.

Australians need systems to join up. As the Australian Government's 'Healthdirect Australia' website shows, there is a smorgasbord of available pathways for making complaints.

Every state and territory has their own Health Ombudsman (sometimes more than one), with other options including AHPRA, the medical and health peak organisations and colleges, as well as the individual health service involved.

There are many places to complain, and they all receive and handle complaints differently. What burden or barrier does that place on patients and families? Do these organisations speak to each other? This complaints spaghetti means that the complaints process is opaque, and people often choose to not record poor experiences of care. Without the insights that complaints data analytics can provide, quality improvement priority-setting exercises are a stab in the dark.

The Communiqués, commendably, seeks to translate coronial lessons more widely.

Western Australia's Department of Health also produces an annual publication, From Death We Learn, that provides summaries of health-related coronial inquest findings, including key messages for a case or for a theme of cases and discussion points to encourage reflection, promote education and initiate quality improvement discussions.

However, just like the length of time it takes for research to be translated into clinical practice, we know it can take years for inquests to be completed, and even longer for their findings to trickle down. What would we learn from follow up with family members on the outcomes of a coronial inquest?

And finally, what if we still don't hear from the patient or family in those moments of fear, distress and indignity in a hospital room or ward when proper care is not being given? What if they don't feel safe to complain?

Unfortunately, I bring a personal insight to that.

My elderly mum had some poor care in hospital before she died a couple of years ago.

I won't go into the details but, being a long-term consumer health advocate, I was very mindful of her legislated right to good, safe care. Mum was scared to complain but I persuaded her that it was important for her continuing care.

It turned out she was right to be frightened. After we lodged the complaint, we both received what can only be described as appalling treatment from nurses on that ward. One hung up on me when I called to report concerns about Mum's health, and several spoke loudly and archly around us, making it clear that we were the enemy and they, the victims.

It was so distressing, and I suspect a key factor in the development of a period of delirium that Mum experienced. Mum called me terrified that the nursing staff were going to kill her. While I understand that Mum had risk factors for delirium, the fact that the experience centred on nurse aggression is not lost on me.

Of course, we know that on the whole nurses do a great job and many professionals can be challenged by feedback. But we also know that for every health consumer who has their complaint handled appropriately and sensitively, there is another consumer who does not.

We need to understand how and where that happens because, as with all issues in health care, this is not just about individual patients and health professionals, but culture, systems and structure.

RESOURCES

1. https://chf.org.au/sites/default/files/acsqhc_primary_care_standards_consultation_paper_response.pdf.
2. https://www.abc.net.au/news/2022-06-27/queensland-hospital-treatment-called-ryan-rule/101157236.
3. https://www.ahpra.gov.au/Publications/Annual-reports/Annual-Report-2022.aspx.
4. https://qualitysafety.bmj.com/content/29/8/684.

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