Improving systems of care: Facilitating family escalation of care in paediatric emergency care

Janet Anderson
Professor of Human Factors
Janet.Anderson@monash.edu

New Zealand Health Quality and Safety Commission Symposium
November, 2023

Detecting deterioration

- Need for patient/family involvement has been recognised for some time
  - WHO 2005, Council of Europe 2006, World Alliance for Patient Safety 2008
- Based on recognition that families and carers can detect subtle signs of deterioration that may not be obvious to someone who doesn't know the patient
- Patient/family involvement is designed to secure a step-up to urgent or emergency care and reduce the time taken to achieve this

Detecting deterioration

- Australian standards include family triggered escalation
  - Patients or family members should have the capacity to trigger escalations in care
  - Little guidance for implementation
- Barriers identified (Carter et al, 2017; Guinane et al 2017; Rainey et al, 2013; Mackintosh et al, 2020)
  - Patients unaware of who to contact and adopt a passive role
  - Patients lack of clinical knowledge and hospital processes especially if illness is complex
  - Communication difficulties and cultural differences
  - Staff concerns about partnering with patients
  - Staff and patient education needed, help patients to know what to look for

Australian experience (Gill, 2016)

- Australian standards include family triggered escalation
  - Patients or family members should have the capacity to trigger escalations in care
  - Little guidance for implementation
- Ryan's Rule 3 step process – speak to a doctor or nurse, if not satisfied speak to a senior clinician, if not satisfied call a number to request a review
  - 35% of calls resolved with communication, most valued the process and would use it again, 15% of patients transferred to higher care, clinicians interpret calls as complaints
- NSW REACH – receive, engage, act, call, help
- Evaluation focused on presence of a policy, number of calls, reason for calls
  - not on implementation, effectiveness in reducing delays, or effectiveness of response, potential for adverse effects such as increased anxiety

Victorian experience (White Paper SCV 2022)

- Variable processes for families to escalate care
- Adverse events in paediatric ED are increasing over time
- Children are spending longer in ED
- 21 sentinel events occurred (preventable incidents involving serious harm or death)
  - Sepsis occurred in over half of the SEs
  - 12 cases (52%) involved delayed recognition of deterioration and delayed response
  - In 7 cases caregiver concerns were not acted upon
  - Contributory factors – lack of knowledge, inexperienced staff, lack of supervision, failure to communicate changes in vital signs, tendency to normalise subtle signs of deterioration, stay fixed on a previous diagnosis despite changes, repeated abnormal results assumed inaccurate

Victorian experience (SCV White paper 2022)

- Recommendations of the White Paper -
- Share the responsibility to detect deterioration in paediatric patient between parents and clinicians.
- Parents should be provided with clear processes to escalate their concerns, and clinicians should respond with the same level of concern as clinician-initiated escalation
- Implement in all health services a process for parents to escalate issues where they feel they are not being heard.
- Clinicians should receive training in working with a differential diagnosis list, escalating concerns and proactively assessing parents' level of concern for their child as valid clinical knowledge/insight

Study hospital experience

- Series of high profile child deaths attracting adverse media attention
- Recurring theme in adverse events – parents say we knew something was wrong but nobody would listen
- If the carers were ever concerned their child was getting worse
  - 9 times more likely to go to ICU
  - 2.3 times more likely to be admitted
  - Stayed 1.7 days longer than average
- Decision making under extreme uncertainty, pressure, decreased resources and increased demand

Hospital improvement attempts

- Identified three avenues for improvement
  - Assess for concerns pro-actively
  - Ensure family/carer are empowered to express concerns and
  - Respond to concerns appropriately
- Education for staff
- Information for patients in waiting room
- Increasingly desperate search for solutions as adverse events continued
- Initial request was for a solution to be implemented in a month
- Have now engaged in long term organisation wide improvement program

Method

- Deep dive in 3 settings – **Paediatric ED**, Paediatric Inpatient Ward, Adult inpatient ward
- Observation of work as done by trained observers
- Semi structured interviews with staff to understand their views and experiences
- Semi structured interviews with consumers who have and have not escalated clinical concerns
- Organisational culture, teamwork and communication surveys

Themes in the Paediatric ED

- Proactive assessment of family concerns does not always happen
  - Most parents were not asked if they had concerns
  - Staff don’t know what to say
  - Staff forget to ask
  - Or are not aware of the need to ask
  - High staff turnover and new staff – loss of collective memory
  - Concerns not documented or included in huddle, handovers

Themes in the Paediatric ED

- Inconsistent provision of information to patients and families about how to escalate concerns
  - None had seen information
  - Triage nurse has no time to explain
  - Cultural and linguistic barriers
- Inconsistent staff responses when concerns are raised
  - Staff unaware of significance of parental concern
  - Response is reassurance not review
  - Seen as a nursing responsibility
  - No process for communicating concerns to different areas within ED
  - No follow up to ensure a response happens

Themes in the Paediatric ED

- The waiting room is a high risk area
  - No staffing ratios for WR nurses
  - No minimum skill level for WR nurses
  - No cover for breaks
  - WR nurse is first position to be lost when short staffed,
  - There can be a long wait for triage and no way to escalate before triage
  - If busy the space is very crowded with patients on the floor, hard to see deterioration or distressed patients
  - Patients don’t know who staff are and who to escalate to
  - Increasing numbers of inexperienced staff

Themes in the Paediatric ED

- When the department is busy, identification and response to family concerns does not always happen due to competing demands
  - Senior staff not always available, interrupted frequently, and can appear overwhelmed
  - Senior staff try to balance competing demands with few resources
  - Patients are reluctant to speak up when staff are so busy
  - Staff cannot provide the care they would like to at times of high demand
  - Mismatch in staff skills and time to respond – junior staff don't have the experience to respond

Organisational challenges

- Increasing demand and pressure on staff
- High staff turnover and burnout
- High numbers of inexperienced staff
- Lack of space when the ED is busy

Team challenges

- Inexperienced staff often don't have the necessary skills and knowledge to elicit and respond to concerns – need for training and orientation to emphasise this role.
- Senior staff are needed to respond to concerns but are a limited resource. How to distribute expertise and responsibility appropriately so that senior input can be provided?
- Senior staff do not have capacity for extra tasks – what can be removed to free up time?
- Processes for communicating, documenting, and following up concerns are highly variable – whole team should be aware and responsible for ensuring concerns are elicited and responded to

Technological challenges

- Not enough time to complete EMR documentation, so information is not up to date
- Patient/family concern field is not mandatory so can be skipped
- Patient/family concerns can be added in triage but field does not allow enough characters
- Visibility in the EMR –
  - need to scroll back to see history
  - nursing notes not visible to doctors

Cultural challenges

- How to move beyond asking a question or providing reassurance to partnering with patients and families?
- How to support families from different cultural backgrounds who may not be able to communicate or are reluctant to express concerns?
- How to raise awareness of the importance across the entire organisation?

Proposed solutions

- Better ways to raise patient awareness and encourage speaking up such as QR codes, updates on waiting room screens, translated material
- Partner with families by discussing differential diagnoses, need for tests, things to look out for, uncertainty and complexity
- Clear guidance from the organisation about how to manage times of high risk, and processes for raising staff awareness of high risk times
- Better structured teams with defined roles and responsibilities for eliciting and communicating concerns eg bright vest, student role definition, lines of communication
- Team processes for communicating and following up concerns in huddles, handovers, whiteboards
- EMR changes to ensure family concern is a vital sign and treated as such
- Support cultural change by monitoring and feeding back performance, success stories and positive patient experience stories

Proposed Evaluation

- Did we partner with consumers to recognise acute clinical deterioration? Experiences of patients and families -
  - Patients transferred to ICU from wards or ED
  - Patients transferred to resus from waiting room,
  - Serious Adverse Patient Safety Events involving patient death
- Are clinicians proactively assessing caregiver concerns?
  - EMR data on Family Worry field
- Do consumers know how to escalate if they are concerned?
  - Health Experience Surveys – did you know how to get help if child getting worse?
  - Question asked at routine Point of Care audits

A new approach to QI

- Based on Resilient Health Care and Safety II
  - A long list of work as imagined procedures will not be effective
  - More education will not be effective
  - Focuses on system design rather than trying to change behaviour
  - Builds a deep understanding of the work system – work as done in practice, not work as imagined in policy and procedures
- CARE-QI Handbook – available online
  - Provides guidance on how to use this approach for complex problems that are difficult to solve
  - Results in multifaceted interventions that target different aspects of the problem and the system

CARE-QI

- Understand the pressures and challenges of everyday work and how staff try to solve these problems
- Identify how system design can be improved to reduce the challenges and help staff to work more effectively
- A system should be able to
  - anticipate problems
  - respond appropriately
  - monitor progress
  - co-ordinate a team response and
  - learn how it is performing and how to improve

Benefits of CARe QI

- CARe QI is designed for
  - Continuous improvement,
  - Complex problems
  - A proactive approach
  - Complementing existing improvement methods
- Improves intervention design and sustainability based on a deep understanding of work as done
- More effective QI

Next steps

- Using the same approach examine different settings
  - Paediatric inpatient ward
  - Adult inpatient ward
- Implement interventions
- Evaluate effectiveness and iterate
- Produce an implementation road map for hospitals

MONASH University

Prof. Janet Anderson

Janet.anderson@monash.edu

Twitter: @ProfAndersonHF

Centre for Applied Resilience in Healthcare (CARe)

http://resiliencecentre.org.uk/