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Ambiguities, beliefs and behaviours: the challenge to transparency in healthcare error.

Exploring of the implementation of open disclosure of adverse events to patients in the UK.

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Background

- In 2009 the UK National Patient Safety Agency re-launched their Being Open (BO) framework.
- Between 2011 and 2013 we conducted a project looking at the implementation of the BO framework.
- This has been and remains challenging in practice BUT
- In the last 12 months transparency in healthcare has become a huge national and political focus.
- CQC are working on new guidance to support transparency in health and social care

Evidence

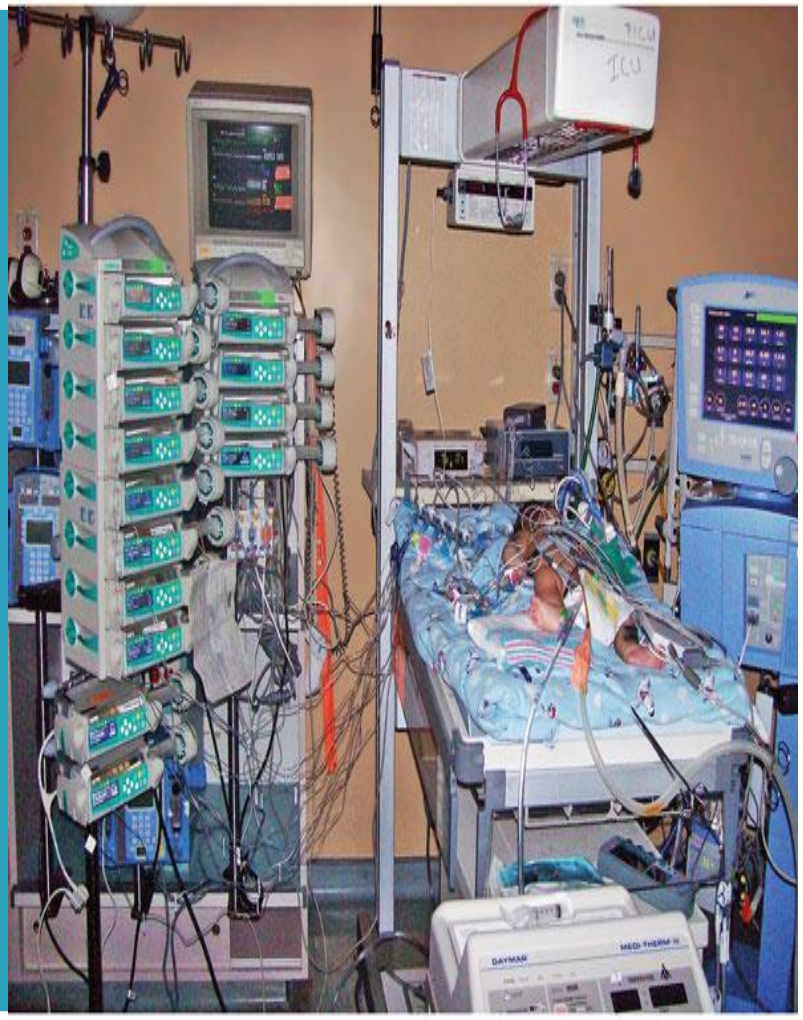
- We examined the evidence under the headings of the BO framework from 610 pieces of varied literature and over 80 interviews with stakeholders.
  - Acknowledgement
  - Truthfulness, timeliness and clarity of communication
  - Apology
  - Recognising patient and carer expectations
  - Professional support
  - Risk management and systems improvement
  - Multi-disciplinary responsibility
  - Clinical governance
  - Confidentiality
  - Continuity of care

Today….

- Challenging research
- Synthesis
- Rapidly changing context

Making sense of the complexity

- In a similar way to the more general literature of patient safety
- General sense that Interventions have improved outcomes for patients
- Not always based on evidence
- Work is needs to…
- describe the theory
- describe the practice in detail, detail the implementation process
- assess the outcomes including unintended effects



Theory development

- There are multiple value considerations at play here
- Considerations of context are both difficult and important for good judgement in and of practice.
- Conceptualisation of OD in both reviews and interviews highlighted the challenges in conceptualising acts of disclosure as processes
- These cannot be prescribed in any simple or linearly direct way from a broader principle of openness in healthcare or the moral concepts that lie behind this.

The act of disclosure v transparency in healthcare

The act of disclosure v broader concepts of transparency

- OD in relation to so called ‘never events’ presents a picture of greater agreement in that health services are morally obliged to communicate with patients and families in a way that is somehow ‘open’.
- However what exactly is required and why, still seems to be open to interpretation.
- The broader principle of transparency within healthcare has been highlighted
- The lack of distinction between moral constructs and behaviour may cause confusion for those attempting to implement the guidance
- A principle of candour

UK specific literature

- There was little literature from the UK which allowed us to determine understanding, views and interpretation of a policy of open disclosure of adverse events in UK.
- UK doctors are more likely to report that they would disclose errors to patient than a USA sample.
- So context is likely to be applicable in relation to attitudes and behaviour

Challenges in data collection

- Stakeholders were willing to articulate clear examples of situations where they had made or been involved in errors or disclosures.
- Those we approached were reluctant to engage in group discussions highlighting the considerable challenge of embedding discussion of real error and disclosure into quality and safety improvement efforts
- The persistent reluctance to engage in reflective and reflexive processes around particular errors hampers attempts to unpick ways in which this is embedded and linked to quality and safety reporting and management in practice.
- This reflects the continued lack of confidence of individuals employed in healthcare that professional and organisational systems will be supportive in managing the context in which a particular event has occurred.

The body of evidence

- 7 of the Being Open framework principles were well covered in the literature and / or in discussions
  - Acknowledgement
  - Truthfulness, timeliness and clarity of communication
  - Apology
  - Recognising patient and carer expectations
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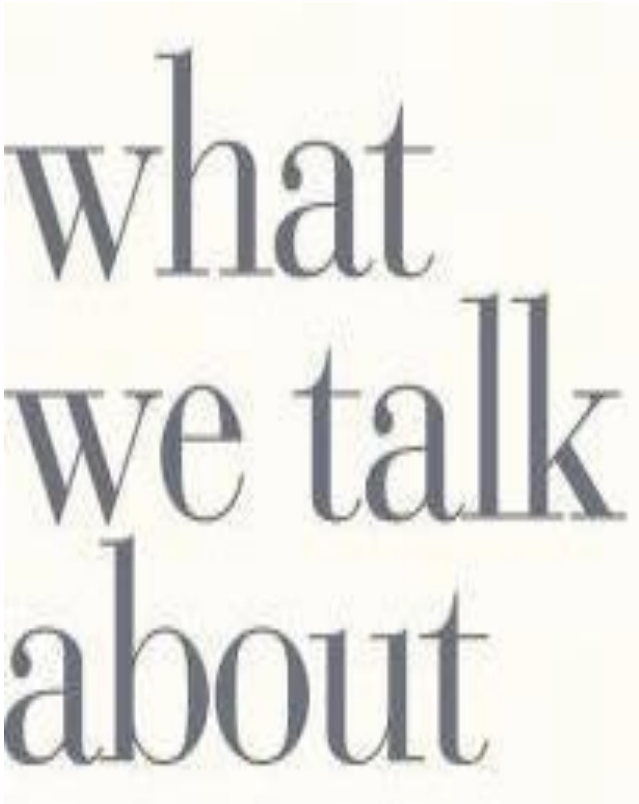
  - Continuity of care
  - Multi-disciplinary responsibility



A road less travelled

Effect of error and lack of disclosure

- Errors are emotive for everyone involved
- What is often underestimated is the impact that a lack of transparency in relation to error has.
- Non disclosure is often described as by patients as a bigger source of anger and frustration than error.
- ‘When they harm us, it is typically a passive event. When they consciously withhold information, cover up what happened, or seek to discredit us in courts of law to preserve their precious financial resources, they are actively harming us’

A National Institution?

Complex adaptive systems

The idea that health care systems are complex adaptive systems has been established for a number of years

Draws attention to basic tenets or principles

Recommendation of this approach is that policy should avoid elaborate checklists or specific instructions for change however health organisations rely heavily on such tools.

mainstream medical journals are emphasising the usefulness of the complex adaptive systems lens in understanding improvement and transformation.

Transformation in healthcare

"This really is an innovative approach, but I'm afraid we can't consider it. It's never been done before."

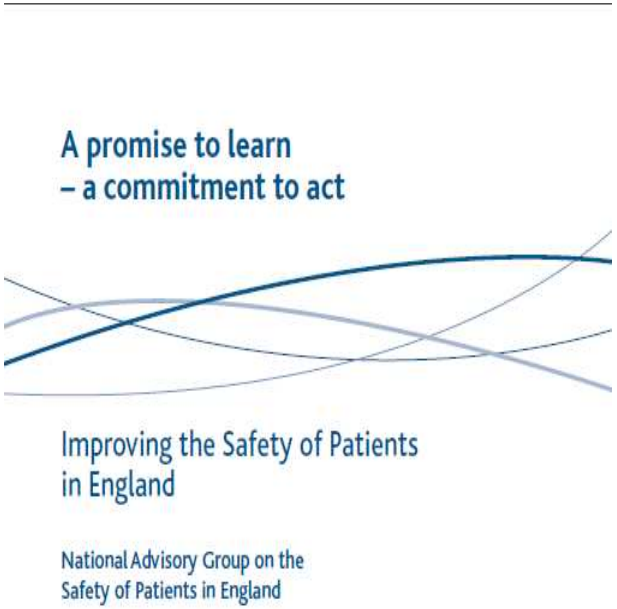
- The majority of literature describes small scale change
- Embedding a culture of openness in healthcare could be considered large scale transformation
- The recent Berwick report suggests a move away from top down efforts and a focus on the creativity of health professionals

LST

- Our review highlights examples where the principles of LST, which makes use of the engagement of individuals at all levels in leading change, have been applied.
- Common themes emerge
- Identified individuals leading on efforts to mobilise delivery of change in terms of disclosure.
- Usually accompanied by a stakeholder often from relatives who have been instrumental in helping to bring about change.
- Distributed leadership appears to focus on practice and relationships in leadership as well as developing leadership through mentoring.
- Pedagogical approaches which support and model good practice to promote leadership may be useful

LST lessons for just disclosure

- making it valuable and safe for staff and patients to engage in good disclosure practice is crucial to success
- promote the reflection of important values and principles in practice and provide cultural and interpretive support for those values
- important to focus on how this might be achieved



Clarification of concepts

- Pervasive problem around definitions of error and harm
- Defined solely by one side (the provider)
- Open to interpretation and would benefit examination and consistency
- Patients express frustration over inconsistencies
- Incentivising acting on patient feedback

Commitment to learning

- Open disclosure could connect to the valued commitment to learn from previous safety problems to prevent future errors and harms.
- Careful analysis of events will not predict how things might happen in the future but should be viewed as an opportunity for sensitive discussion and planning for how to avoid the situation, or more realistically, how to handle a situation if it happens again.
- The aspiration of the NHS to achieve zero harm (not zero error).

Engagement of professions

- Decisions about disclosure seem largely to fall in the domain of doctors.
- Transformative initiatives are often championed by nurses or non-clinical mangers (who have less power) involved in the system
- It was clear that professional regulatory guidance had most influence on the moral perspective articulated in practice.

- the duty of candour debate

Moving the Issues Forward

- Policy
- Further work could investigate conceptual variations between clinicians and patients to establish what is relevant to patients.
- Remaining need for standardisation of the process of disclosure unmet by current guidance to ensure quality and consistency
- Professional Organisations
- Clinicians need to be clear and confident about associations between apology and liability.
- Professional bodies could facilitate dissemination of any support for disclosure to optimise clinician engagement.

This cannot be stressed enough….

Over reliance on measurement and reporting of open disclosure could reduce the principle of openness to numbers of disclosures with a focus on documentation of disclosures which may lose information on aspects that represent a good quality disclosure.

Moving organisations forward

- Begin as soon as it becomes apparent that something has gone wrong
- Considered as a process; on-going from its inception to final closure and not regarded as a single entity
- Expert opinion stresses links between openness about adverse events and reduced organisational risk.
- Openness should have practical benefits, enabling learning from mistakes, improving systems and finding solutions however the mechanisms by which this may occur are under researched.
- There remains a lack of evidence to support what might be considered best practice with relation to individual v team disclosures and the role of risk management in the UK.

Individuals disclosing

- Patients express a desire to interact with staff involved in error and reports often describe staff who meet patients as courageous and authentic.
- Junior staff are often ‘protected’ from being involved in disclosures rather than using such opportunities for learning and modelling best practice.
- One approach is unlikely to meet the needs of all and practice needs to be flexible
- Consider language carefully
- Current consensus stresses the need to adopt an empathic and transparent process focused on the need of the patient or family rather than risk to the organisation.

Support and training

- The key to implementation is likely to be support and training
- For professionals and patients
- Support for practicing/coaching the conversations over time
- Exploring expectations
- Supporting honesty about events and uncertainty
- Supporting continuity of relationships
- Supporting learning from events
- Supporting just outcomes for professionals and patients.

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Thank You

"Ok, how about this motto: 'If you are unhappy for any reason, we will feel really bad'."