

COMMENTARY

## High reliability: the patient role and perspective. Using the patient experience as a catalyst for change

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### Abstract

Using personal and family experience of health care, issues that need to be addressed and the core values that need to be present when striving to achieve excellence in public service delivery are identified. Robust systems, adherence to guidance and protocols together with meaningful engagement with the end user are essential ingredients to deliver on the public's expectation that care be safe and quality assured. Organizational credibility is measured by the degree to which certain, non-negotiable attributes are demonstrated and clearly visible. These attributes include acceptance of organizational and individual responsibility and accountability. It is necessary that core values centre on the exercise of professionalism in a culture that facilitates transparency, open communication and demonstration of integrity, especially in the aftermath of adverse events. A style of leadership that engages with patients and insists that error is acknowledged in a way that facilitates learning and prevention of recurrence will not only advance healing for those involved but will also boost public confidence and enhance the reputation of individuals and the organization.

**Keywords:** Patient safety; patient experience

### Introduction

Personal and family experience of health care combined with the insights gained from interactions with numerous patients and health care professionals have allowed me to form some conclusions, albeit not evidence based in the formal sense. These conclusions derive from the patient experience of care and an understanding that when such experience is both valued and validated, it has the potential to drive improvement in all spheres of health care – policy making, standard setting, research, regulation, clinical practice, but most importantly in the area of education – providing the opportunity to bring about sustainable culture change in the company of the next generation of professionals.

All of that can only be effectively accommodated in a structure that ensures that we learn from the *raison d'être* of health care – the patient in the bed. Realizing that the patient is present throughout the full continuum of care,

is a repository of useful information and is undoubtedly the individual with the greatest vested interest in the outcome, is critical to arriving at an understanding of what constitutes truly patient-centred care.

### Patients and families, the untapped resource: World Alliance for Patient Safety

It was in that context that the World Health Organization (WHO) drew a line in the sand in 2004 when it designated the Patients for Patient Safety Programme (PFPS) as one of the original action areas of the newly-formed World Alliance for Patient Safety ([www.who.int/patientsafety/patients\\_for\\_patient/en/](http://www.who.int/patientsafety/patients_for_patient/en/)). Consequently, the perception of patients and families as an untapped resource and viewing the patient experience as a learning tool, was officially acknowledged by the global medical community.

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The Alliance programme accepted that taking account of the perspective of patients and their families in planning and delivering care

- is crucial to articulating the reality and identifying the gaps between the patient safety measures possible and the levels of safety being experienced by patients;
- is necessary to ensure services are driven by patient need and are authentically patient centred;
- is a useful validation tool in relation to the implementation of guidelines, processes and protocols;
- ensures that the patient's voice is heard in the global arena of health care

## Core values of PFPS

The core values of PFPS can be summarized as follows.

In that we operate as a collective with a common aim of health care improvement. Advocating for openness and honesty for all interactions between patients, health care systems and individuals, the goal is collaborative partnership resulting in meaningful engagement and empowerment with a deliverable of safer outcomes. PFPS views such a strategy as life enhancing for all – patient, family and clinician.

## PFPS Champion activities

PFPS has undoubtedly changed the lives of real people. At an individual level, the credibility of advocates has been strengthened in their own countries by being members of PFPS and associated with the WHO. Recognized as resource persons, they are invited to represent the patient perspective in a variety of fora:

- (1) Serving on patient safety commissions, task forces, committees addressing different aspects of patient safety, speaking at conferences, acting as advisers to patient safety projects, but, most importantly, engaging with the medical student body – the future of medicine.
- (2) Partnering with health care providers at all levels
- (3) Connecting with national offices of the WHO
- (4) Establishing patient safety organizations
- (5) Writing in local or national publications and journals on the topics of patient safety and PFPS

Starting with the story, we have developed and expanded into these other areas of endeavour, believing in and operating out of the maxim 'Nothing about us without us'.

## Who are PFPS Champions?

It is important to emphasize that we are not career advocates. We are volunteers who are committed to being collaborative partners and co-producers of safe care.

Circumstances have brought us to this work. We have not chosen this work ourselves, rather it is a responsibility that has been thrust upon us, one that we would gladly forfeit for the restoration of the lives and well-being of our loved ones who have been harmed by health care, albeit unintentionally.

We use these experiences as catalysts for change and to promote learning and health care improvement, e.g. through transparency and disclosure following adverse events.

## The effectiveness of the story

The most effective tool we patients have to bring about change is to relate our experiences – tell our stories – because our stories evoke feelings. In 1967, Vera Keane, wrote in the *Bulletin of Nurse Midwifery*: 'Facts do not change feelings and feelings are what influence behaviours. The accuracy, the clarity with which we absorb information has little effect on us; it is how we feel about the information that determines whether we will use it or not'.

For those of us who have had a negative experience of care (my own son died as a result of medical error), we accept that we cannot change the past but that the past can certainly inform the present, which we can then use to influence the future – and isn't it so much better if we do that together – in partnership?

That brand of partnership can be summarized as a process of empowerment of patients and families by enablers within the system.

Translating the aspiration to reality is often difficult to achieve. Jim Conway, Senior VP of IHI describes the push/pull dynamic of the partnership/engagement process as 'Making the status quo uncomfortable while making the future attractive'. You could liken advocates and PFPS champions as being somewhat similar to the piece of grit in the oyster causing sufficient irritation to bring about the pearl – in this case the pearl can be that of health care improvement. I think this is beautifully articulated in an

invitation received recently to join a high level committee which stated: ‘We want you to be a critical friend’.

The sincerity of the PFPS pledge of partnership goes unquestioned as articulated in the London Declaration, an output of the First Patients for Patient Safety Workshop ([www.who.int/patientsafety/patients\\_for\\_patient/London\\_Declaration\\_EN.pdf](http://www.who.int/patientsafety/patients_for_patient/London_Declaration_EN.pdf)):

We, Patients for Patient Safety, will be the voice for all people, but especially those who are now unheard . . .

And again:

. . . In honour of those who have died,  
those who have been left disabled, our loved ones today,  
we will strive for excellence,  
so that all people receiving healthcare  
are as safe as possible, as soon as possible.

This is our pledge of partnership – our patient pledge of partnership.

## Leadership and commitment

Health care professionals who are also driven by a passion for improvement operate out of a visionary style of leadership, which is key to the enabling framework and process. Was it not Helen Keller who said ‘there is one thing worse than being blind and that is having sight but no vision’.

The preferred leadership commitment says:

- (1) We will proactively engage patients in their own care.
- (2) We will capture in every way possible the lessons to be learned from the care experiences of our *raison d’être* (the patient).
- (3) Over and above that, we will embed patient and family into every aspect of our organization’s activities

Such a commitment can deliver a framework for safe care as that described in the report of the Irish Commission on Patient Safety and Quality Assurance: ‘Knowledgeable patients, receiving safe and effective care from skilled professionals in appropriate environments with assessed outcomes’. This is further reinforced in the report *Safety First 2006*, which states that: ‘Around the world, healthcare organisations that are most successful in improving patient safety are those that encourage close co-operation with patients and their families.’ While, in 2008, Lucian Leape said: ‘The time is now. If health and/or health care are at

the table, then the consumer – the public, patient, family member, must be at the table, every table, NOW!’

## Education and the future

Interaction with students in particular reinforces the conviction that as part of their education they must be exposed to, and develop for themselves, an appreciation of the value of the patient experience as they apply heart, intellect and skill to the benefit of patients and their own professional satisfaction. It is significant that the crest of the British Medical Association is surrounded by the words ‘With head, with heart, with hand’.

Formally embedding the patient perspective into health care education is key to patient safety, sustainable culture change and health care improvement. Research conducted at the University of British Columbia<sup>1</sup> highlights that: students remember what they learn from patients. The authentic and autonomous patient’s voice promotes the learning of patient-centred care.

When using the patient journey of my son as a learning tool through identifying some of the challenges in providing safe care together with offering some insight into what it is like for patient, family and clinician when things go wrong, I ask ‘can a tragic outcome be a catalyst for change in an improved service?’

For those who might doubt the value of the story, there is wisdom and relevance in the Indian saying

Tell me a fact and I’ll learn.

Tell me a truth and I’ll believe.

Tell me a story and it will live in my heart forever.

Patients and families have very powerful stories to tell, not alone because they illustrate that simple measures, timely interventions, can and do save lives but also because in the case of the acutely ill patient there is often quite a long antecedent period where successful intervention is possible. This precious time is lost when deterioration goes unrecognized and is not responded to promptly and effectively.

## Conclusions from the patient journey

On examining this particular patient journey/case history, identifying shortcomings and contributory factors to the tragic outcome is straightforward – deficits are not uncommon throughout 21st century health care.

**At primary care level**

- Inability to recognize the seriousness and progression of primary hyperparathyroidism
- Appropriate and timely interventions not taken (calcium levels initially 3.51 mmol rising 22 months later to 5.73 mmol and to 6.1 mmol at point of death)
- Selective and incomplete transmission of laboratory test results
- Non-receipt of vital information when communicating between professionals
- Absence of integrated pathways
- Link between uncharacteristic behaviour and test results not made – textbook presentations not recognized
- Absence of tracking of deteriorating test results, flagging them and triggering a referral
- Absence of direct communication with the patient

**Secondary Care**

- Senior team not advised/called over weekend
- Unsatisfactory team dynamic; no team member intervened/advocated for patient
- The impact of a weekend admission
- Expectation that the patient would survive until Monday. RIP Sunday
- Family expectations of a Tertiary Training Hospital not met

**The aftermath and response**

Albert Wu refers to the days immediately after an adverse event as ‘The Golden Moment’. This is the time that determines the course and direction of future health care and family interactions.

Despite initial honest and humane reactions from individuals for which families will always be grateful, in a short space of time that is often replaced by a process of corporate damage limitation, which polarizes families, individual clinicians and the organization.

For ordinary patients and families who find themselves forced into the litigation route, it can be a David and Goliath experience. Until the 11th hour every effort is made by the defendants to settle without admission of liability – a wearing-down strategy that lacks compassion and consideration for heart-broken people. Such cases need to be heard in a non-adversarial environment, where the focus

is not on blame but rather on honestly arriving at the truth, acknowledging what happened, and identifying ways to prevent a recurrence – in short learning from the tragedy.

**Open disclosure**

Open disclosure has to be part of the culture of each organization if learning and improvement are to be achieved. Disclosure is not about blame. It is not about accepting blame nor about apportioning blame. It is about integrity and being truly professional.

**Error and health care staff**

As patients we cannot give permission for error. However, we do understand that the practice of medicine is a complex and risk-laden endeavour.

Having witnessed how health care did not deal appropriately in providing growth, learning and support for the junior members of the care team as well as apparently abandoning more senior personnel, I am convinced that the current adversarial system does not serve anybody well. I am equally convinced that proper disclosure and dialogue with us as a family would have been far more beneficial to all parties and would have avoided almost 5 years of trauma and uncertainty brought about by the litigation process and the inappropriate responses that forced us down that route. All of which moves patients and families to construct a wish list to fit their circumstances and experience.

**Wish list for individual practitioners**

- Observe existing guidelines, best practice and standard operating procedures. Be prepared to challenge each other in that regard.
- Listen to and respect patients and families.
- Know your personal limitations; refer patients when necessary and without undue delay.
- Keep impeccable records, refer constantly to those records and initiate action based on them.
- Communicate effectively and completely within the medical community and with patients.

**Wish list for the system and individuals**

- Following adverse outcomes undertake root cause analysis, system failure analysis, critical incident investigation and include patients and families in that process.
- Replicate what is good and be constantly vigilant for opportunities to improve.

- Learn and disseminate learning by putting in place a fully compliant and just reporting and learning system.
- Practice dialogue and collaboration and meaningful engagement with patients and families.
- Create a coalition of health care professionals and patients, a grouping to mirror the PFPS model.
- When things go wrong, be honest and open and seize the opportunity to give some meaning to tragedy.
- Acknowledge error and allow learning to occur.
- Above all, do not allow yourself to be seduced by the notion that such things could not possibly happen in your organization; anything can happen to anyone, anywhere and at any time. Sir Liam Donaldson describes the five most dangerous words as: ‘it could not happen here’.

There are wonderful examples not alone of partnership but also of clinician disclosure. A US doctor, Rick Van Pelt, was advised to not make contact, apologise or disclose following the adverse event. The difficult meeting between the doctor and the patient whom he almost killed did take place because he saw it as the right thing to do. The sky did not fall. He says with great relief that on that day ‘a 800 lb gorilla got off my back’. He now jointly presents with the patient at conferences and together they founded the organization Medically Induced Trauma Support Services ([www.mitss.org/](http://www.mitss.org/)), an organization that supports patient, family and clinician when things go wrong.

## Systems and culture

System failure and culture are often proposed as the culprits in relation to health care difficulties. A combination of factors is more likely. However, if we accept that systems are designed by people, are maintained by people and can certainly be changed by people, then the future will be bright if we grasp that nettle. And if we acknowledge that people are the culture, then we can address that too.

Health care professionals deserve to be able to enjoy satisfying professional careers and patients deserve to be on the receiving end of safe and compassionate care. An effective safety culture and system is one in which organizations and individual practitioners can take pride. It also carries with it a responsibility to

- demonstrate individual and corporate adherence to procedures, protocols, best practice

- demonstrate individual and corporate commitment to the Hippocratic oath and to the ethical guides of each profession
- practice inclusively as reflected in the level of engagement and partnership with patients and carers
- be transparent and open when managing adverse events and critical incidents, supporting patient, family and staff by a combination of acknowledging error, achieving learning, preventing recurrence, allowing staff to recover and be more effective in the future and facilitating healing for patient and family.

## Partnership and collaboration

What is critical is that we preserve the very precious relationship of trust between doctor and patient. The results of a survey conducted by the Irish Medical Council revealed that 88% of respondents trust their doctor to tell the truth. While there is no acceptable level of error, error will occur and at that time we are challenged to behave with integrity and seize the opportunity to give some meaning to tragedy.<sup>2</sup>

The onus is now on each one of us to see that translated into (a) safer care for the *raison d’être* of health care (the man in the bed) and (b) ensuring a real sense of satisfaction for those working in health care who have been gifted with the opportunity to serve humankind on a daily basis.

## Reflection, guidance and individual wisdom

Translating aspiration into reality is a challenge. Erik Hollnagel’s reflection on patient safety is particularly apt in these times where there is enormous emphasis on evidence-based medicine and measurement. He says that ‘Safety is a core value, not a commodity that can be counted. Safety shows itself only by the events that do not happen.’

Informal guidance can also greatly add to regulation and professional codes of conduct, e.g. Atul Gawande suggests that ‘more than anything, what distinguishes the great from the mediocre, is not that they fail less, it is that they rescue more.’ Maybe that’s the piece that needs to change – that we concentrate more on rescue and being rescuers.

In relation to the occurrence and management of adverse events, Sir Liam Donaldson, Chair World Alliance for Patient Safety, both soothes and challenges when he says

‘To err is human. To cover up is unforgiveable but to refuse to learn is inexcusable.’

Yes we will live by our pledge and strive for excellence so that all people receiving health care are as safe as possible as soon as possible (PFPS London Declaration 2004).

### Conflict of interest

No conflict of interest has been declared.

### References

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