2015

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Recommended Citation

Available at: https://pxjournal.org/journal/vol2/iss1/3

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Reframing the work on patient experience improvement
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Abstract
In reframing the work on patient experience improvement Dr. Jocelynn Cornwell, chief executive of The Point of Care Foundation, challenges us to broaden our view on what is necessary to impact patient experience efforts. From a defined need to reduce avoidable suffering associated with health care delivery dysfunction, she suggests we extend the discussion in two ways: First, to include a concern for staff engagement, experience and well-being, and second, to position patient experience improvement as one type of quality improvement (QI) in healthcare, and urge practitioners to pay more attention to the lessons from QI in other domains. High quality, reliable patient experience is a primary goal in healthcare alongside others; too often it is treated as separate from other quality goals, deprived of the resources those goals command and taken less seriously. By broadening our view on patient experience improvement, Dr. Cornwell offers we will find not only greater engagement from all participants in healthcare, but also positive and sustained outcomes.

Keywords
Patient experience, staff engagement, employee engagement, quality improvement, NHS, quadruple aim

The Point of Care Foundation is an independent London-based charity, that works with the UK National Health Service (NHS) to increase the engagement, experience and well-being of healthcare staff and improve the experience of patients and families. We believe that improving patient experience is partly about reducing the avoidable suffering associated with health care delivery dysfunction, and partly about equipping staff to work with patients as partners, supporting them to retain their autonomy and manage their conditions as far as they wish to do so and are able. Examples of the avoidable suffering caused by health care delivery dysfunction include unnecessary waits and unnecessary pain; anxiety resulting from lack of coordination; lack of teamwork; lack of respect shown to patients and loss of trust in caregivers.

We agree with Press’ assessment of the ‘keys’ to improving patient experience, but would extend the discussion in two ways. First, to include a concern for staff engagement, experience and well-being as part of the “true culture of concern of care for the patient’s experience”. And second, to position patient experience improvement as one type of quality improvement (QI) in healthcare, and urge practitioners to pay more attention to the lessons from QI in other domains. High quality, reliable patient experience is a primary goal in healthcare alongside others; too often it is treated as separate from other quality goals, deprived of the resources those goals command and taken less seriously. Some challenges in improving patient experience are specific and need specific strategies to overcome them, but the majority are the same as the challenges in relation to reducing harm, reducing costs or improving clinical effectiveness.

Staff engagement, experience and well-being
In the last decade, research has shown that the experience of healthcare staff determines the experience of their patients. The NHS in England carries out annual national surveys of hospital staff and patients. From the results of the hospital surveys it is clear the two are related: hospitals that do well on the staff survey also do well on patient feedback, whilst hospitals that do badly on one, also do badly on the other. Other studies have shown that staff experience is the antecedent, it shapes patient experience, for good or bad, not the other way round. Staff well-being is linked to seven variables (‘well-being bundles’): local work group climate; co-worker support; job satisfaction; organisational climate; perceived organisational support; low emotional exhaustion and supervisor support. Organisations with high levels of staff engagement and well-being have lower mortality and patients are more satisfied with their care.

In the UK, as in the US, levels of health care workers’ engagement, experience and well-being are a cause for concern. Health care is significantly associated with higher levels of risk to the physical, emotional and mental health of workers. Stress and burnout occur more frequently in the healthcare sector than other industries, especially amongst doctors and nurses. In the 2014 NHS national staff survey, 39 percent of staff reported feeling unwell due to work–related stress in the previous 12 months.
Fourteen percent of staff reported physical violence and intimidation from patients and members of the public in the previous year; 28 percent reported bullying, harassment and verbal abuse from patients and the public, 24 percent reported the same experiences at the hands of their colleagues. Thirty seven percent of staff felt communication with their manager was effective, whilst only a fraction more, 41 percent, felt valued by their employers.

The data on staff engagement and well-being suggests there are limits to what health care organisations can achieve in relation to patient experience without strategies for improving the working lives of employees. The Triple Aim (enhancing patient experience, improving population health, and reducing costs) should be expanded to a Quadruple Aim, with the added goal of improving the work life of all healthcare providers. Organisations that have high levels of staff engagement and morale know the value of real team-work and nurture it. Their senior leaders are known to front line caregivers, and engaged with them. They have well-structured systems for appraisal and performance review; offer support for personal and career development; train their line managers in people management; provide time and space for staff to reflect together on the challenges of their work; and senior managers use hard and soft intelligence to target areas where there are problems, and provide additional support and remedial attention where and when it is needed.

Lessons for patient experience from the wider QI movement

One important insight from research in QI is that the ‘blunt end’ of health systems and healthcare organisations is in a dynamic enabling/disabling relationship to organisational culture, and influences the behaviour of managers and staff. The ‘blunt end’ is where the decisions, policies, rules, professional and regulatory frameworks, resources and incentives are generated that affect the ‘sharp end’, the front line where staff interact with patients. Decisions at the blunt end have a profound impact on the priorities and actions of managers at all levels of the organisation. For example, they determine staffing levels; how resources are allocated and whether clinical teams can access support for QI from clinical audit and data handlers and analysts. They shape the attitudes and behaviours of front line managers: how they spend their time (in the office or with patients out on the floor?), what takes their interest, what they avoid, what they reward and what they overlook.

Research in the care of frail older people in acute hospitals in England and Wales, illustrates the point. In the course of observing care on acute wards, researchers saw nurses rejecting older patients’ pleas for help to reach the toilet. Instead of helping the patients walk to the toilet, nurses urged the patients to remain by their beds and wait for a commode to be brought to them. For some patients, the result was traumatic: when they could not hold on long enough for the commode to arrive, and were forced to relieve themselves in the bed or on the chair, they felt ashamed and humiliated. The nurses did not deliberately set out to be cruel or uncaring, they were doing what they thought the system wanted them to do. For well-intended reasons of patient safety, the hospital boards - the blunt end – had decided to monitor patient falls in order to target action to reduce them. Result? Without opportunities to discuss competing priorities in their teams and with their managers (risk reduction v. preservation of the patient’s autonomy and dignity), the nurses and care assistants acted in line with what they believed to be the board’s orders, and took action to reduce the risk of patients falling on the way to the toilet.

Research in QI shows that real, personal commitment and time from senior leaders is essential for success. Boards, executives and senior clinicians have to generate and communicate a clear vision and explicit goals for quality of care, and have to translate them into measurable and meaningful objectives for people at the front line. Their input is essential to resolve problems in the wider system that if left untended will frustrate and demoralise front line staff who are trying to make improvements. In organisations where QI efforts achieve results, senior leaders commit real personal time to understanding the barriers to change and working with front line staff to tackle them. They consult front line teams before they start a new initiative; they commit personal time to working with the teams; provide encouragement and support; recognise success; and stick with them long enough to gain traction.

Evidence from a range of QI programmes shows that achieving and sustaining significant improvements in quality takes time. Internationally, the best healthcare organisations have been working to achieve results high over many years. In our experience, most organisations underestimate the time required to deliver real change. For example, it takes a minimum of six months and often longer to prepare for a new initiative: to make sure that the personnel who will be involved are not already committed to other projects; to free team leaders up to devote time to the work; to ensure the support functions (facilitators; analysts; project managers) will available to the team doing the work; to reserve training slots and communicate with all the relevant parties.

Improving the quality of care is rarely a linear process: there are false starts and setbacks; a crucial member of staff leaves and is not replaced; or spikes in activity delay projects and delay progress for weeks or months at a time. It is important for senior leaders and the teams doing the work to anticipate such events and be realistic about the
pace at which it is possible to make progress. In many cases, it can take at least eighteen months to two years to achieve measurable results.

Change is one thing, a change that results in improvement is another. Measuring change is critically important: it is the only way to tell the difference between the two. Health care organisations are data-rich environments, but data is mostly collected for performance and accountability purposes, not for improvement. Very often front line staff have surprisingly little exposure to performance information in general and in relation to their own service. Most front line staff need training in how to collect, analyse and interpret ‘hard’ and ‘soft’ data. In the UK, the lack of basic skills in measurement and improvement is a national challenge and there is now general recognition that achieving the Triple (and Quadruple) Aims means building capacity and capability in improvement knowledge, including skills in measurement.

**Factors specific to patient experience improvement**

Whilst quality in healthcare between and within organisations is variable, QI – as a body of knowledge, and a set of disciplines and practices – is still relatively underdeveloped. It is a mistake to imagine that front line staff are familiar with or trained to apply the evidence on QI or used to dealing with data. In the UK there are recent examples of health professionals challenging mortality data where it has reflected poorly on their service/ organisation. Little wonder perhaps that data on patient experience are frequently ignored and their validity challenged, but in relation to patient experience the problem runs deeper. Here, too often, the challenge is not to the data, it is to the goal. It is not unusual to hear health professionals protest for example: “A good experience for the patient is nice to have, but it’s not a must have.” “We can’t afford it.” “This is about being nice to patients. We’re already nice to our patients.” “Other people are employed to think about patient experience. It’s not my job.” “Our patients are satisfied with our service so why should we change it?”

It’s difficult to imagine the same kinds of remarks being made as forcefully or with as much sense of entitlement in relation to patient safety or clinical quality goals. What is it about patient experience that makes it different from the other quality goals? Is it because feedback from patients about their experiences draws attention to the attitudes and behaviours of front line caregivers? Even if most health care professionals want to deliver great care, the thought of engaging with patients about their experience of care often causes anxiety. Clinical and non-clinical staff alike are anxious about what patients will say about them. If they have not previously had experience of working with patients as partners in change projects, health professionals invariably expect them to be demanding and critical and believe they will have unrealistic demands that will be impossible to meet.

It is possible to overcome these anxieties, but it takes time, training and courage on the part of the staff and the patients. It is a mistake to bounce front line staff and the patients into engaging with each other without adequate preparation. They need time to think and reflect, and the first meetings between the two groups need careful planning, and skilled facilitation. Good training in effective improvement methods such as experience based co-design8 and patient and family centred care,9 help to build confidence in the undertaking.

The attitude of doctors towards QI initiatives in general is always important: where they get behind improvement activities and show leadership, projects can exceed expectations; where they are neutral and stand back, the work will happen more slowly, and may falter; where they are actively dismissive or hostile, the work will be blighted from the outset and have only limited impact. But in contrast with patient safety and clinical quality – where improvement activities are often led by doctors - doctors generally have not stepped forward to lead patient experience improvement. Why not? Is it because, in contrast with patient safety and clinical effectiveness, the origins of the movement for patient-centred care lie outside the medical establishment? In the UK, for example, it has been led by a variety of other groups including patients with HIV and AIDS; parents of sick children and babies in hospital; pregnant women; academic researchers and charities. Or, is it because the sources of the evidence for patient experience and improvement - patient surveys; complaints data; qualitative research with patients and their families - are not generally accepted within the paradigm of evidence-based medicine?

One of the difficulties we encounter is that that doctors often believe they know what their service is like for their patients, when in fact they do not. When they or their relatives are ill, the scales metaphorically fall from their eyes, and they see for themselves the avoidable suffering, the routine inconveniences and ‘low grade insults’10 patients experience. But without direct personal experience of that kind, doctors tend to judge the quality of their service by the quality of their own interactions with patients, without having an awareness that there is a ‘before’ and an ‘after’ that matters to patients or insight into the full range of factors that determines patients’ experiences (see for example a surgeon voicing amazement about how little he had known of his mother’s experience in his own hospital).11

Whatever the reasons for the historical absence of medical leadership for patient experience improvement, it is important to develop strategies that will overcome the problem. It is always good to start with the evidence. The
evidence that patient experience is positively related to patient safety and clinical outcomes has only become available relatively recently and it is (not) widely known. It is important for front line staff to be aware of the evidence and it helps if they are sufficiently familiar with it to be able to defend it to colleagues. It is useful to remind ourselves that it takes time for new insights and evidence to be accepted in complex systems and even more time for it to be adopted.

Other strategies we find helpful are to include doctors on the faculty that provides the training in patient experience improvement methods; actively helping doctors understand they have much more influence over their colleagues than they know; and encouraging them to spend even short periods of time using effective techniques, such as structured observations of care and shadowing their own patients, that immediately give them insights into aspects of their patients’ experience that they were previously unable to see. Most clinicians care about their own patients and take pride in the quality of their own service. Once they have evidence of patients experiencing avoidable suffering they are invariably willing to put their considerable energy and talents into finding solutions and making the experience better.

References