Should patient safety be more patient centred?

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Abstract

In a patient-centred health system the views, experiences and rights of the patient drive the way that care is delivered. There is now an increasing emphasis on patient-centredness as an essential characteristic of safe and high quality care, but to date the involvement of patients in patient safety activities has been limited. The views and priorities of patients are not always valued in safety and quality work, and their perspectives are rarely included in activities such as incident investigation. We propose six areas of action to make patient safety more patient centred and hypothesise that the replacement of industrial safety models with a patient-centred model of safety culture will improve clinicians’ ability to engage with safety initiatives.

What is known about the topic?

Recognition of the importance of patient-centred care has increased, however this perspective has not traditionally been incorporated into patient safety work.

What does this paper add?

This paper discusses the lack of patient-centredness in the current patient safety paradigm. Six areas for action are proposed to bring together the two philosophies of patient-centredness and patient safety and achieve better outcomes for patients and staff.

What are the implications for practitioners?

Health care clinicians understand their work as being about the individual patient. Improvement needs to be rooted in this understanding as safety models are incomplete if they do not address the way in which patients exist in the health system.

OVER THE PAST DECADE the demand for more patient-centred care has grown in unison with, and as a response to, demands for safer care.* Major patient safety inquiries have repeatedly shown the link between the marginalisation of patients, their families and carers and poorer quality care.1 The importance of involving

*While accepting the arguments for the use of “consumer” or “person” in preference to patient, the term “patient centred” is generally used in this article.
cal questions remain. Patient safety as a field of research and practice has drawn strongly and appropriately from the study of high risk industries. Studies of risk and safety in these industries focus largely on two dimensions: the human factors associated with operators and the processes themselves. In most of these industries, the pivotal relationships are between colleagues (or contractors) and machines. The pivotal role and relationship upon which health care is premised simply does not exist. Even in aviation and rail, where large numbers of clients are directly and adversely affected by errors, the clients themselves are completely removed from the process (unless, on rare occasions, it is clients who raise the alarm).

A focus on the mechanics and human factors affecting safety is imperative. This focus however, has resulted in a safety system where not one of the main measures of patient safety — incident reporting, chart review and the use of indicators derived from administrative data (coded from medical records) — incorporates the patient perspective. Solutions to patient safety problems similarly overlook patient experience or patient priorities. In this paper, the problem of the lack of patient-centredness in the current patient safety paradigm is discussed and some solutions offered.

**Patient-centredness**

Social changes in relationships between professionals and the public and in access to and use of information, along with increased public awareness of medical errors, raised by several high profile media cases, have led to more sceptical, empowered and questioning patients. Patients expect to be given information about their condition and treatment options, and to be involved in decision making about their care. Patients are most concerned about health professionals’ respect for their values, preferences and expressed needs; coordination and integration of their care; provision of information and education; assistance in their physical comfort (including pain management); provision of emotional support, and alleviation of their fears and anxieties; involvement of their families and friends; facilitation of the continuity and transition of their care; and assurance of their access to care when they need it.6

Definitions of patient-centredness vary. It is frequently “… understood for what it is not — technology centred, doctor centred, hospital centred, disease centred”,7 as much as for what it actively involves. If a broader social perspective is taken, the notion of patient-centredness includes: “… the rise of consumerism, with associated discourse of choice, responsibility and autonomy … [It] can also be viewed as a cause and consequence of litigation culture, with the foregrounding of consumer charters, informed consent and confidentiality”.8 (p. 13)

The concept initially focused on the clinician–patient relationship, and introduced a new view of the patient as an experiencing individual rather than as a disease entity.9 This view led to an awareness of the need to share information, power10 and decision making. There is now considerable evidence that interventions designed to inform, educate and involve patients in their health care are effective, improving experiences, clinical outcomes and resource utilisation.2 Yet, although patient-centred communication has been shown to be positively associated with patient satisfaction, adherence to agreed care plans and better health outcomes,7 currently only two-thirds of Australian adults report engagement in health care decision making.11

**Patient safety: what about the patient?**

A focus on the patient as the centre of patient safety is a relatively recent and still underdeveloped area of research. In the paper “Patient safety: what about the patient?”, Vincent and Coulter argued that “Patients who know what to expect in relation to quality standards can check on appropriate performance of clinical tasks”.12 (p. 77) Step one in patient-centred care, that is, informing patients about safety, is a sensitive issue — vigilance and interest are desirable, but risks
include patients developing fear of care or avoiding care altogether. It has been suggested that the assumption of technical competence at organisational and professional levels (that is system safety) is the norm for patients. However, of Australians surveyed by the Commonwealth Fund, 34% were very confident that they would receive high quality safe care, 46% were somewhat confident and 20% were not very/not at all confident.

A second step, actively involving patients in their care, and more specifically in preventing medical errors, has resulted in a variety of responses depending on factors such as the seriousness of their condition, their current physical and mental state, their age, culture, as well as education, literacy and language issues. (For an alternative but congruent taxonomy on patient involvement in patient safety see Davis and colleagues.) Lyons writes from a safety engineering view about patients' role in patient safety, and moves rapidly from role to responsibility. She argues that responsibility is unfair and that the patient represents an unreliable safety barrier, and attempts to encourage patients to form such a barrier are not cost-effective. Such a view gives no value to the worth and importance of patient empowerment.

There is as yet minimal evidence about the efficacy of patient involvement to improve their personal safety. One primary care study found that patients were effective ameliorators of error; their “attentiveness, vigilance and perseverance” arrested the error cascade in many instances. Education about patient safety may increase the likelihood of patients taking preventative action, for example, making sure that all treating doctors know about every prescription medication taken and any allergies, or making a choice to be treated by a more experienced surgeon, but patients remain less likely to question professionals. UK surgical patients were not willing to ask challenging safety questions — “Have you washed your hands?” There is as yet no research comparing patient self-reported willingness to ask safety-related questions with the actual relevant safety behaviours of patients.

Patient safety research and quality improvement

Patient safety research has only recently included the patient, and then to a limited extent. A recent series of articles on the epistemology of patient safety research lists the evidence that can generate recognition of the need for an intervention to improve patient safety: epidemiological data; internal or external performance management/audit data; error-reporting data; medical literature; and “the experiences of clinical and non-clinical staff”. The experiences of patients are not included. Patient outcomes are described as being either “… clinical (eg, morbidity or mortality) or patient derived (eg, quality of life or patient satisfaction)”. The concentration on physical harms is “not because they are more important, but because they seem to fit more closely into a safety rubric”. No explanation is given for this “fit”.

Where patients’ active role in patient safety has been examined, the results have reflected a privileging of the professionals’ knowledge. “In the specific case of AEs [adverse events] from medication, patients have been shown to identify these reliably. However, when asked more formally to identify patient safety incidents, they fail to distinguish between unpreventable adverse events and those relating to service quality”. An alternative interpretation is that the patients did not “fail” at anything — in one instance they did not apply the same analytic perspective or labeling used by clinicians to class some adverse events as unpreventable. Furthermore, stories told by Australian patients to the evaluators of the pilot of the National Open Disclosure Standard suggest that this kind of labeling — classing some events as unpreventable — was irrelevant to patients. They sought disclosure to understand what had happened to them, and for psychological as well as physical morbidity.

Incident reporting and analysis by frontline staff is encouraged because staff directly involved in patient care possess contextual information that is crucial for understanding error and determining possible system improvements. Patients, when given the opportunity, report quite different
Safety culture — a research measure that doesn’t include the patient

Organisational culture refers to the norms, values and beliefs within an organisation. Organisational climate refers to employees’ perceptions of the organisational culture. Industrial psychologists have been interested in the study of organisational culture in order to help develop workplaces where the staff are productive, satisfied and safe (workplace safety, especially in the building industry, has been a focus for considerable study). Many features of a “safety culture” have been derived from study of high reliability organisations. In these environments the safety that is of concern is the personal safety of the worker and their co-workers — there are no patients.

There is little evidence supporting links between organisational factors, medical errors and patient safety, yet a number of instruments to measure safety culture or climate in health care have been developed. A typical instrument is the Agency for Healthcare Research and Quality patient safety culture survey. It measures concepts including: communication openness; feedback and communication about error; frequency of events reported; handoffs and transitions; management support for patient safety; non-punitive response to error; organisational learning/continuous improvement; overall perceptions of patient safety; staffing; supervisor/manager expectation and actions promoting safety; teamwork across units and within units. None of the questions address the clinicians’ relationship to, and work with, patients.

Types of events compared with those reported by staff. Donaldson says, “Patients and their families often have a unique perspective on their experience of health care and can provide information and insights that healthcare workers may not otherwise have known”. Sometimes the most crucial bits of information will be held by the patient, yet, in Australia, reporting of incidents by patients is difficult, and in the usual Australian root cause analysis process, interview or participation of the patient in the investigation is not prioritised. Solutions therefore do not benefit from patient experience. In summary, the values revealed by current patient safety research and improvement activities demonstrate that the patient perspective is peripheral, if not invisible (see Box).

Making patient safety patient centred

Research has shown that a safe health care system needs to have patients at its centre, and be committed to safety as “the way we do business”. In order to achieve better outcomes for both patients and staff, these two philosophies, and their associated strategies, need to be brought into alignment. We propose six areas of action.

1. Prioritise use of patient-centred measures in health care

Measures determine staff and organisational priorities. There is considerable current interest in patient-reported outcome measures (these need to be used together with other outcome measures). Measures of patient satisfaction are known to be problematic and in some instances have been replaced by measures of patient experience. These measures focus on specific aspects of care (such as receipt of information about the side-effects of medications), and may be better at identifying the range of patient experiences and lead more directly to improvement. At the same time, only a few of these tools have been adequately tested, and as a result their findings are not always accepted and it can be easy to dismiss the feedback they provide. Another way of examining the experiences of patients is to use “patient stories” or narratives. Consideration of patient experiences from such narratives has been a factor that has driven much of the recent clinical redesign work in public hospitals in Australia and is essential to co-design of care. Until recently, most studies about involving patients in the planning and development of health care (87%) do not describe the effects of this involvement.

2. Develop shared expectations

In order to allow patients to form appropriate expectations, patients need to be informed about the currently acceptable standards within health care services, and their rights and responsibilities with regard to the quality of care. One way of facilitating this process is through the use of charters of health rights, which have been designed to help develop these expectations and
The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe.

The Charter recognises that people receiving care and people providing care all have important parts to play in achieving healthcare rights. The Charter allows patients, consumers, families, carers and services providing health care to share an understanding of the rights of people receiving health care. This helps everyone to work together towards a safe and high-quality health system. A genuine partnership between patients, consumers, and providers is important so that everyone achieves the best possible outcomes.

**Guiding Principles**

These three principles describe how this Charter applies in the Australian health system.

1. **Everyone has the right to be able to access health care and this right is essential for the Charter to be meaningful.**

2. **The Australian Government commits to international agreements about human rights which recognise everyone’s right to have the highest possible standard of physical and mental health.**

3. **Australia is a society made up of people with different cultures and ways of life, and the Charter acknowledges and respects these differences.**

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### What can I expect from the Australian health system?

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<tr>
<th><strong>MY RIGHTS</strong></th>
<th><strong>WHAT THIS MEANS</strong></th>
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<tr>
<td><strong>Access</strong></td>
<td>I have a right to health care. I can access services to address my healthcare needs.</td>
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<tr>
<td><strong>Safety</strong></td>
<td>I have a right to receive safe and high quality care. I receive safe and high quality health services, provided with professional care, skill and competence.</td>
</tr>
<tr>
<td><strong>Respect</strong></td>
<td>I have a right to be shown respect, dignity and consideration. The care provided shows respect to me and my culture, beliefs, values and personal characteristics.</td>
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<tr>
<td><strong>Communication</strong></td>
<td>I have a right to be informed about services, treatment, options and costs in a clear and open way. I receive open, timely and appropriate communication about my health care in a way I can understand.</td>
</tr>
<tr>
<td><strong>Participation</strong></td>
<td>I have a right to be included in decisions and choices about my care. I may join in making decisions and choices about my care and about health service planning.</td>
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<tr>
<td><strong>Privacy</strong></td>
<td>I have a right to privacy and confidentiality of my personal information. My personal privacy is maintained and proper handling of my personal health and other information is assured.</td>
</tr>
<tr>
<td><strong>Comment</strong></td>
<td>I have a right to comment on my care and to have my concerns addressed. I can comment on or complain about my care and have my concerns dealt with properly and promptly.</td>
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ensure that they are shared with staff. To support national agreement about the rights of patients the Australian Charter of Healthcare Rights was developed by the Australian Commission on Safety and Quality in Health Care (see page 394). The Charter provides information about the rights of patients and consumers to underpin the provision of safe and high quality care, and to support a shared understanding of the rights of people receiving care. The Charter was only released in July 2008, and it is not yet clear whether and how it will contribute to a more patient-centred health care system. This impact of the Charter needs examination, and, if necessary, other methods will need to be used to support shared health care expectations.

3. Encourage health literacy and patient empowerment

The promotion of strategies to inform, educate and involve patients in their care and safety will assist services in becoming more patient centred. Seeking to understand their health and health care and asking questions about it is the most powerful way that consumers can receive higher quality care, be more satisfied and reduce their likelihood of suffering a preventable adverse event. One resource that has been widely used in Australia to support involvement of patients in their health care is 10 Tips for safer care developed by the former Australian Council on Safety and Quality in Health Care. This small brochure provides advice to patients, their families and carers about actions they can take to improve the care they receive, including keeping a list of medications, discussing options for treatment and asking questions about ongoing health care plans.

Both the United Kingdom and the United States have committed to public health education programs that are designed to create demand from consumers for information. The US Agency for Healthcare Research and Quality has a website dedicated to talking to consumers about health care quality and the National Health Service in the UK has a “Centre for Involvement” for consumer engagement.

4. Provide public reporting on quality and safety that lets patients make choices

The role of the patient in improving safety can go beyond helping to ensure their own safety to include working with health care organisations to improve safety at the organisational and unit level (the UK National Patient Safety Agency involves patients in safety solution development and advocating as citizens for public reporting and accountability of hospitals and health system performance). Research in the US and UK indicates that consumers want more information about their hospitals’ performance. Telephone polling of more than 6000 US consumers indicated that hospital infection rates and environmental cleanliness would influence decision making for 94%. It has been claimed that much of the progress in patient safety over the past decade comes from involvement of patients and their proxies at policy level. In the US, advocacy from patient groups has resulted in legislation mandating the reporting of health care-associated infection. Patients can and do participate in co-producing care at multiple levels, from the individual encounter, at service and program level and finally at system level (including via their participation in electoral processes).

5. Pay attention to patient diversity

There is evidence that the involvement of patients and their families is particularly important when the culture of the patient is not the same as the system from which care is received. It has been claimed that “the failure to recognize the critical link between culture and language (of both the providers and recipients of health care) and patient safety stands as a ‘resident pathogen’ within the health care system that, if not addressed, unacceptably exposes patients from minority ethno-cultural and language backgrounds to preventable adverse events ...” Adverse event data show that US patients with limited English proficiency suffer a greater level of physical harm and more events due to communication error. An Australian study has confirmed findings that immigrant patients may not report serious problems with health care delivery, but
also suggested that the problems reported were largely preventable by language facilitation and patient and family involvement. Patient safety programs need to be informed by the perspectives of patients, consumers and their families and carers, including those from ethnically and culturally diverse backgrounds. In addition, the concept of “cultural safety” has been developed to help health professionals better understand the experience of Indigenous recipients of care and how to empower these patients in the health care situation.

6. Develop a patient-centred model for safety culture

Safety and quality in health care has not improved as rapidly as expected. One cause may be that the mental models pertaining to safety and quality held by health care staff may have little resemblance to the models used by safety experts. How relevant are safety surveys to health care workers’ views of their role and their understanding of the health care system? Doctors and nurses in a Swiss hospital were found to lack a systemic process-oriented vision; quality for these practitioners was seen as an essentially subjective measure and consisting of a combination of mastery of the technical and interpersonal aspects of care (safety was not mentioned). Australian and UK medical specialists have been found to hold similar views. Similarly, study of intensive care nurses from units that had participated in a successful safety project over several years to reduce central line-associated bloodstream infections found they had a narrow environmental characterisation of patient safety tasks, focusing on areas where they could carry out first-order problem solving (eg, the use of bed rails). The authors concluded that “nurses believe they can protect patients because of their commitment to their job and their personal abilities”. The current assumption is that the health care workers need education, so that they understand and then enact behaviours that are associated with the safety model. An alternate view is to seek to work more closely with current staff understanding and practice — staff do have a central preoccupation with the patient’s welfare. Therefore, education should include a focus on ensuring patient-centred care is provided, for this approach, of itself, improves safety. The National Patient Safety Education Framework (http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/C06811AD746228E9CA2571C600835DBB/$File/framework0705.pdf), developed by the former Australian Council on Safety and Quality in Health Care, is an education framework that describes all of the competencies required by health care workers to provide safe care. As well as having patient-centred care as one of its underlying principles throughout, the Framework also includes learning topics about issues such as involving patients and carers as partners in health care, communicating honestly, and being culturally respectful.

Conclusion

Health care clinicians understand their work as being about the individual patient. Improvement needs to be rooted in this understanding, as limits to the success and sustainability of safety and quality improvement activities may be linked to the importation of techniques from other industries where the client is peripheral to the safety of the process. Safety models are incomplete in the health sector when they do not address the way in which patients exist in the system. The methods used to measure patient safety have not been adequately cognisant of patient experience, values and preferences. The relationship between the culture of a health care organisation and the effects of this culture on patients will remain imprecise while neither the tools to measure safety and organisational culture nor the measures of the outcomes of clinical work are patient centred.

Competing interests

The authors declare that they have no competing interests.
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