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# **Patients' willingness and ability to participate actively in the reduction of clinical errors: A systematic literature review**

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## **Key words**

Patient participation, clinical error, safety, clinician-patient relationship, systematic review

## **Abstract**

This systematic review identifies the factors that both support and deter patients from being willing and able to participate actively in reducing clinical errors. Specifically, we add to our understanding of the safety culture in healthcare by engaging with the call for more focus on the relational and subjective factors which enable patients' participation (Iedema, Jorm & Lum, 2009; Ovretveit, 2009). A systematic search of six databases, ten journals and seven healthcare organisations' web sites resulted in the identification of 2714 studies of which 68 were included in the review. These studies investigated initiatives involving patients in safety or studies of patients' perspectives of being actively involved in the safety of their care. The factors explored varied considerably depending on the scope, setting and context of the study. Using thematic analysis we synthesized the data to build an explanation of why, when and

how patients are likely to engage actively in helping to reduce clinical errors. The findings show that the main factors for engaging patients in their own safety can be summarised in four categories: illness; individual cognitive characteristics; the clinician-patient relationship; and organisational factors. We conclude that illness and patients' perceptions of their role and status as subordinate to that of clinicians are the most important barriers to their involvement in error reduction. In sum, patients' fear of being labelled "difficult" and a consequent desire for clinicians' approbation may cause them to assume a passive role as a means of actively protecting their personal safety.

### **References:**

Iedema, R., Jorm C., & Lum, M. (2009) Affect is central to patient safety: The horror stories of young anaesthetists. *Social Science & Medicine*, 69(12),1750-1756.

Ovretveit, J. (2009) The contribution of new social science research to patient safety. *Social Science & Medicine*, 69(12),1780-1783.

### **Introduction**

This systematic review identifies the factors that both support and deter patients from being willing and able to participate actively in reducing the risk of clinical errors. There are important reasons for considering patients' active participation in reducing the risk of error. Firstly, the extent of harmful events occurring in healthcare organisations is of international concern. Secondly, patients' active participation is being encouraged as one way of reducing the problem. Thirdly, there is little evidence from patients themselves about their willingness or ability to be more involved. In this article we begin by providing the context for the policy recommendations. Then we describe our review methods. Following this, using thematic

analysis, we synthesise the data to explore why, when and how patients are likely to participate in helping to reduce the potential for errors.

As the focal point of healthcare delivery, it is thought that patients can provide a unique perspective on the system and in doing so help to identify risks and solutions for reducing harm caused by clinical errors (DH, 2006; WHO, 2005). To this end, patients' organisations have been promoting campaigns to encourage patients to: pay attention to the care they get; take nothing for granted; and not to be afraid to ask about safety or 'speak up' if they have questions or concerns about their care (JCAHO, 2011; WHO, 2004). Error victims have also been instrumental in campaigning for improvements in patient safety for example 'Consumers Advancing Patient Safety' in the USA and 'Cure the NHS' established by people who lost relatives or experienced poor care standards at the Mid-Staffordshire NHS Trust in England.

Peat et al. (2010) developed a framework describing three general courses of action by which patients can contribute to their safety. These include: 1) informing the management plan by sharing information with clinicians and asking questions about treatment decisions 2) monitoring and ensuring safe delivery of treatment for example by self-administration of medication (SAM) 3) informing systems improvement for example by providing feedback on care quality.

Alternatively, expecting patients to take more responsibility for their safety may increase their fear and anxiety by taking them beyond what they perceive as their responsibilities as patients (Koutanji et al., 2005). Healthcare settings provide complex stimuli for patients which may lead to uncertainty about how to act. Expert knowledge gives power within the

doctor-patient relationship to the doctor and the potential for patient exploitation and psychological dependency (Johnson, 1972). Patients' willingness and ability to act is likely to be influenced by what they perceive as clinicians' attitudes about what is acceptable and important in a patient's role or because they do not believe they have the expert knowledge to question clinicians' practice. The type of information available, the extent to which clinicians are prepared to provide information and doctors' use of medical jargon can give patients the impression of reluctance to share decisions with them making them passive rather than active participants in their healthcare (Coulter & Ellins, 2006). Consequently patients may conform to what they perceive as acceptable behaviour. Other barriers to participation include language and cultural differences, low health literacy and physical factors such as hearing, speech or visual impairment and illness severity (Coulter & Ellins, 2006; Khan et al., 2004).

Importantly, encouraging patients' involvement in error reduction may lower the wariness of staff (Lyons, 2007) and risk shifting responsibility to patients, deflecting attention away from healthcare systems and clinicians' communication skills (Watt et al., 2009), reinforcing a culture where patients are seen and see themselves as part of the problem which is counterproductive to improving safety (Esmail, 2006). This review seeks to address some of these complexities by synthesizing and analysing the literature in the context of patient safety in healthcare organisations.

## **Methods**

### Search strategy

Our search strategy was designed to find empirical data about actions that patients are willing and able to take to reduce the risk of medical error. We searched the literature according to methods outlined by Greenhalgh & Peacock (2005) for the synthesis of qualitative and quantitative data from numerous and dissimilar sources for the purpose of attending to broad policy questions. An initial set of articles (N= 19) thought by the researchers to be influential were obtained. We then hand searched the references of each article for titles and key words that included patient involvement in safety and citation tracked the titles, thereby identifying relevant journal articles that had subsequently cited those papers. Another key tool in the search process was the database search; we searched systematically for articles in MEDLINE, EMBASE, PsycINFO, ISI Web of Knowledge, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews and CINAHL. The search terms applied were: ‘patient\* safety’; ‘patient involvement \*safety’; ‘patients role \* safety’; ‘patient participation’; ‘error \* patient involvement’; ‘error \* patient participation’ and ‘error prevention \* patient’. In addition to the database searching, we hand searched 10 key healthcare, medical and nursing journals, over the same time period, including Social Science and Medicine, Quality and Safety in Health Care, BMJ, Health Expectations, International Journal of Nursing Studies, Journal of Advanced Nursing, Health Affairs, Archives of Internal Medicine, JAMA, and Health Psychology. We also included in our search organisation based websites related to patient safety including Agency for Healthcare Research and Quality, Joint Commission on Accreditation of Healthcare Organisations/ International Centre for Patient Safety, National Patient Safety Agency (UK), National Patients Safety Foundation (USA), Picker Institute Europe, The Health Foundation and the WHO.

The search period was limited to 1999 to 2011 with exceptions made for important articles that pre-date this period. This period corresponds with an increase in interest in patient safety following the seminal report 'To err is human' (Kohn et al., 1999). Studies were limited to those published in English and Spanish, as these languages were represented on the research team, with no restrictions on the basis of country of origin or the context in which studies were undertaken.

We excluded data on actions that clinicians can take directed toward patients to increase their safety such as education programmes to increase compliance with treatment regimens or to improve overall health (or reduce disease side effects with respect to long term conditions like diabetes mellitus). Similarly articles that explored interventions directed at patients, such as education, information and instructions related to their safety, requiring patients' passive involvement were also excluded. Articles about patients' involvement in decision-making generally, case reports and literature reviews were excluded. Finally, comment or opinion about patients' active participation in safety and studies involving the general population were excluded.

Firstly, we reviewed titles and key words and used these as our criteria for selecting abstracts. Then we reviewed the abstracts independently and then cross-referenced judgements on the papers. Duplicates were removed and complete articles obtained if the abstracts stated that the study was related to patient safety and that patients and/or carers were the primary research participants. Having agreed on the abstracts for inclusion, full papers were retrieved. Following this we read, reread, and discussed the papers again excluding those that did not meet our aims. We took a pragmatic approach in deciding not to exclude studies in terms of research quality. Only thirteen studies used a theoretical framework to support or explain the

empirical findings. These included the Theory of Planned Behaviour, the Health Belief Model, status characteristics theory, role theory, safety culture and the role of the bio-medical model in decision making. Many of the studies had problems of design and reporting such as inadequate details of sampling or data analysis. We have made inferences from studies not specifically designed to investigate patients' willingness and ability to participate actively in reducing the risk of clinical errors. Many of the studies relied on subjective measures of willingness to act. The methods used in the studies, as they relate to the themes which emerged from our synthesis are shown in Table 1.

**Insert Table 1 here**

Thematic analysis

Our interpretative approach to evidence synthesis involved reading and rereading the studies firstly to identify the methods employed to support patients' active participation. Next we hand searched each article for evidence of patients' willingness and ability to be actively involved. We then used thematic analysis and constant comparison to investigate similarities and differences across studies (Pope et al., 2007). Thematic analysis is an appropriate method of organising and summarising the findings from a diverse body of both qualitative and quantitative research (Dixon-Woods et al., 2005). Our emphasis was less on the quantitative analysis of data but aimed more on the searching out of any patterns in the data that might help build an explanation of why, when and how patients are likely to engage actively in helping to reduce errors. The process was iterative requiring rereading and discussion of the articles to further refine the categories and subcategories while seeking negative cases. The discussion and conclusion sections were the main sources used from the quantitative articles.



## **Results**

Overall, 139 abstracts of studies were identified (see Appendix A [INSERT LINK TO ONLINE FILES]). During screening 63 papers were excluded on the basis of the abstract because they did not fulfil the inclusion criteria or were duplications. A total of 95 articles were obtained for detailed review. An additional 27 articles were subsequently excluded; four were literature reviews, twelve reported on outcomes other than patients' willingness and ability to participate, three included educational interventions, one was a passive intervention, three were not empirical studies, two related to safety but not in the health context, one was the same study written for a different journal and another was a duplication. In total 68 papers were eligible for inclusion; these described the result of initiatives involving patients' in safety or studies of patients' perspectives of being actively involved in the safety of their care. Table 2 provides a quantitative summary of the main themes which emerged from our synthesis of the data. Studies contributed to more than one factor and more than once within factors for example, within socio-demographic factors one study finds younger age as a facilitator of willingness and poor literacy as a barrier to ability; Appendix B [INSERT LINK TO ONLINE FILES] provides further details of the articles reviewed.

**Insert Table 2 here**

### **Factors affecting patients' willingness and ability to participate**

#### Socio-demographic characteristics

Age was a common factor in a large number of studies. Older people were less likely to ask questions about hand washing or the purpose of their medication (Duncanson & Pearson 2005; Waterman et al., 2006), were less willing to engage with SAM, if they had not

experienced this before and preferred to assume a more passive role when invited to participate in the selection of performance indicators for a hospital in Italy (Deeks & Byatt, 2000; Gagliardi et al., 2008). However, Watt et al. (2009) found that older study participants refuted a suggestion by others that older people would find asking questions more difficult.

Younger patients and those with busy working lives appeared to be over-represented in studies of self-management of oral anticoagulant therapy (OAT) (Cromheecke et al., 2000; Fitzmaurice et al., 2005; Gadisseur et al., 2003; Murray, et al., 2004). Alternatively, Menéndez-Jándula et al. (2005) found that old age and low education did not appear to be major obstacles to this. Cromheecke et al. (2000) found no correlation between age, education and therapeutic control. Khan et al. (2004) included only people over 65 years in their study and found that while some older people had difficulty with the technique, they improved with practice. Furthermore, older people preferred to attend the clinic as it provided an opportunity for social interaction suggesting that age may be a confounding variable.

Women were found to be more willing to ask challenging questions of clinicians such as 'have you washed your hands' (Abbate et al., 2008; Davis et al., 2008). Conversely, men appeared more willing to self-manage OAT (Cromheecke et al., 2000; Fitzmaurice et al., 2005). Other studies found no association between gender and safety related attitudes (Burroughs et al., 2007; Deeks & Byatt, 2000; Hibbard et al., 2005; Schwappach, 2008).

Willingness to participate in error reduction strategies appeared to be associated with having higher education (Abbate et al., 2008; Davis et al., 2008; Dowell et al., 2005; Lozowski et al., 1993; Murray et al., 2004; Schwappach & Wernli 2010c). Other studies failed to confirm

education as a factor increasing willingness and ability (Chromheecke et al., 2000; Menéndez-Jándula et al., 2005; Schwappach, 2008; Watt et al., 2009).

Many of the studies excluded patients who were unable to speak the native language, indicating that language is seen as a considerable barrier to ability to participate in error reduction activities. Ethnic minority groups were reported to ask fewer questions perhaps due to lack of ethnic concordance with their physicians and not race per se (Stepanikova, 2006). Health literacy predicted better SAM in acute care among chronically ill Australian patients (Manias et al., 2004) and among ambulatory oncology patients in America (Weingart et al., 2009). Overall, despite a large number of studies investigating socio-demographic factors, the data in respect of age, gender and education were inconclusive to claim that socio-demographic characteristics were consistent factors predicting per se patients' willingness or ability to engage with safety matters.

Nine studies commented on the involvement of relatives, three of these involved parents of children receiving intensive care. Overall, relatives appeared to play an important role with: SAM in the patients' own home and in hospital (Manias, 2004; Phelan et al., 1996); self-management of OAT (Menéndez-Jándula, et al., 2005); and in the prevention of medication errors (Weingart et al., 2009). Relatives also had a role to play in 'speaking up' on behalf of family members (Dowell et al., 2005; Lozowski et al., 1993). Indeed speaking up for a relative or another patient may be easier than speaking up on behalf of oneself (Watt et al., 2009).

Illness related factors

Twenty-one studies reported various illness related factors such as confusion, general frailty, serious illness and depression that reduced patients' ability to participate actively in the reduction of error, often these factors resulted in people's exclusion from participation in the study. In studies of self-management of OAT the primary barriers to involvement were visual, hearing or motor impairment which restricted patients' ability to perform the required blood test competently (Cromheecke et al.,2000; Khan et al., 2004; Menéndez-Jándula et al., 2005). While confusion was an obstacle to SAM for elderly patients in a rehabilitation centre (Pereles et al., 1996). These findings suggest that one underlying cause of inability to be involved actively may be some age-related illnesses rather than age itself.

#### Cognitive factors

People who perceived a high risk of an error occurring were generally more willing to engage in protective behaviour such as: notifying staff of potential errors or asking them to comply with hand hygiene (Kovacs Burns, 2008; Schwappach & Wernli, 2010b); patients with MRSA were more likely to ask about hand washing than those without MRSA, patients without MRSA asked rarely or almost never (Luszczynska & Gunson, 2007); risk perceptions affected incident reporting among patients in psychiatric hospitals in London, where patients who perceived a threatening situation caused by other patients would often report it to staff (Quirk et al., 2005); patients with three or more drug allergies were more willing than patients without drug allergies to report preventable adverse events and near misses (Weingart et al., 2005); people who had personal experience of medication errors were likely to act to reduce the risk of similar errors (Nau & Erickson, 2005); and patients who kept their own records were often prompted to do so by the experience of a hospital losing a record of previous tests (Rassin et al., 2007). A common reason for unwillingness to

ask staff about hand washing was individuals' conviction that staff hand hygiene did not pose an infection risk for them (Abbate et al., 2008); supporting Tarini (2009) that patients or their relatives who feel vulnerable are likely to be vigilant.

Self-efficacy and positive attitudes towards preventability were also shown to increase willingness to act, for example by self-managing OAT (Hibbard et al., 2005; Schwappach & Wernli 2010c; Watt et al., 2009). Additionally, studies showed that the extent to which patients believed that their participation would prevent infections increased their intention to ask clinicians to wash their hands (Abbate et al., 2008; Longtin et al., 2009; Luszczynska & Gunson, 2007). Similarly, feeling more comfortable with error prevention increased willingness to act (Waterman et al., 2006). Extraversion was associated with patients' willingness to ask clinicians, including doctors, to wash their hands (Duncanson & Pearson, 2005; Longtin et al., 2009). Having a family member in hospital in the last year and having read about medical errors increased perceptions of efficacy in being able to prevent medical errors. This was then significantly linked with a greater reported likelihood of engaging in preventative action (Hibbard et al., 2005). Lack of self-confidence reduced patients' willingness and ability to self-manage OAT (Menéndez-Jándula et al., 2005) in part this was because learning a new task was more difficult for people when in a stressful situation (Hovey et al., 2010). Longer duration of care in a cancer clinic increased the likelihood of patients reporting concerns about safety (Agoritsas et al., 2005; Weingart et al., 2007). Watt et al. (2009) found that patients were able to detect dispensing and prescribing errors in primary care but less able to do so in hospital, in part due to unfamiliarity of packaging. Perhaps as patients become more familiar and comfortable with their surroundings they believe they have greater control of their situation which increases their willingness to take an active role (Entwistle et al., 2010).

In contrast, if patients' perceived their role to be that of passive recipient of medical expertise they were unwilling to engage actively with their safety for example by self-management of their condition or by challenge clinicians about their practice (Burnett et al., 2010; Entwistle, 2005; Forsyth, 2000; Hibbard, et al., 2005; Longtin et al., 2009; Manias et al., 2004; Schwappach & Wernli, 2010a). One study found that patients did not read medication instructions (Brown et al., 2006) and others found that patients were reluctant to mark their body to indicate the site of surgery (DiGiovanni et al., 2003; Waterman, 2006) suggesting a submissive attitude towards safety.

#### Clinician-patient relationships

An emergent theme was that a poor relationship with their clinicians made patients less willing and able to engage in error reduction (Kuzel, et al., 2004; Watt et al., 2009). Problems of miscommunication between the two parties both verbal (Britten et al. 2000; Brown et al., 2006) and non-verbal, such as no eye contact with nurses (Bolster & Manias, 2010) made patients reluctant to ask questions or challenge clinicians. Patients who were not asked about prior knowledge of medications were less willing to ask questions (Bolster & Manias, 2010). Parents of children being treated for cancer who were less satisfied with the emotional support they received from clinicians reported intervening more often to prevent or correct an error (Lozowski et al., 1993). Perceived lack of support may have reduced parents' trust in clinicians.

Access to information was positively associated with patients' ability and willingness to get involved with their own safety (Forsyth et al., 2010; Hurst, 2001; Unruh & Pratt, 2007). Information can increase self-efficacy and risk perceptions thereby increasing intention to act (Schwappach & Wernli 2010a), perhaps by giving patients an understanding of what they can

do (Smythe, 2010). Clinicians' ability to communicate with patients is important in this respect. Patients' ability to act is compromised by a poor understanding of drug dosages, clinicians' failure to assess patients' information needs and receiving conflicting or inadequate information about their treatment (Bolster & Manias, 2010; Britten et al., 2000; Entwistle et al., 2010; Hovey et al., 2010). Other obstacles of willingness to act were worrying about being labelled a "difficult" patient (Entwistle et al., 2005, 2010; Hurst, 2001; NPSA, 2004), fear of embarrassment and negative or judgemental reactions from clinicians (Ballinger & Payne, 2002; Brown et al., 2006; Burnett et al., 2010; Davis et al., 2008) including having their concerns dismissed, ignored, not believed or taken seriously and clinicians disagreeing with them without explaining why (Britten et al., 2000; Entwistle et al., 2010; Kovacs Burns, 2008; Ocloo 2010; Schwappach, 2008; Smythe, 2010).

Clinicians enabled patients' more active engagement by encouraging or instructing patients to ask questions or to participate in specific actions (Bernstein et al., 2004; Davis et al., 2008; Entwistle et al., 2010) and by demonstrating that they were willing to listen (Dowell et al., 2005). One study found that patients considered engaging with their own safety had the indirect benefit of strengthening their relationship with nurses (Schwappach & Wernli, 2010a). Simple visual reminders, encouraging patients to ask questions or tell clinicians to wash their hands such as leaflets, posters and 'it's okay to ask' stickers increased patients' willingness to do so (Duncan, 2007; Duncanson & Pearson, 2005; Lent et al., 2009; NPSA, 2004; Quinn, 2003).

The hierarchical, elitist and paternalistic culture of the medical profession was often a barrier to patients' willingness to engage with their safety (Davis et al., 2008; Ocloo, 2010; Weingart et al., 2009). It was seen as inappropriate to challenge clinicians (Ballinger & Payne, 2000);

some patients were fearful of questioning medical authority (Schwappach, 2008; Smythe, 2010) while others were afraid of being rude to or offending the doctor (Brown et al., 2006; Davis, et al., 2008; Randle et al., 2006; Schwappach & Wernli, 2010b; Waterman et al., 2006; Quinn, 2003). Other studies demonstrated patients' perceptions of doctors' as holding an elite position in the healthcare context for example patients were more willing to ask nurses than doctors to wash their hands (McGuckin et al., 1999, 2001; NPSA, 2004) and might ask challenging questions of the nurses while they left factual questions for the doctors (Davis et al., 2008). One study found that unwillingness to SAM by some patients was related to a concern that nurses would be blamed should patients make an error (Manias et al., 2004).

#### Organisational aspects

A common finding was that a busy setting was a strong barrier in preventing patients' active involvement in safety. When patients perceived that clinicians' time was constrained due to work pressure or staff shortages they were wary of engaging in error prevention behaviours (Bolster & Manias, 2010; Entwistle et al., 2010; Hurst, 2001; Schwappach & Wernli, 2010c). Other organisational constraints were lack of continuity of care and isolation in a side room for reasons of infection control (Hurst, 2001; Stelfox et al., 2003; Unruh & Pratt, 2007). Liberal visiting hours in a paediatric intensive care unit enabled parents to report more errors; although parents in this context could also cause errors such as disconnecting tubes inadvertently (Frey et al., 2009). The review found evidence that patients were generally willing and able to report formally incidents such as drug complications and medication errors as this did not require the overt questioning of clinicians (Jarernsiripornkul et al., 2002, 2003; van den Bemt et al., 1999; Waterman et al., 2006; Weingart et al., 2004). However, an important barrier is that generally patients were not made aware of the incident reporting system (Frey et al., 2009; Watt et al., 2009).



## **Discussion**

Overall, we found no compelling evidence that age, gender or education affect directly patients' willingness or ability to engage with their own safety. This contrasts with what is known about the prevalence of low health literacy and health inequalities among lower socioeconomic groups and older people (Coulter & Ellins, 2006). This contradiction should be a focus for further research. While the studies we reviewed found that older age was a barrier to safety related behaviour, our synthesis suggests that age is probably a confounding factor. Commonly people who were able were willing (Weingart et al., 2004). Important barriers affecting ability are illness, which is often aged related, and ability to communicate in the native language. Patients come to the clinical encounter carrying their own experiences, and they have a number of cognitive characteristics that affect their willingness to participate in their own safety. These include patients' beliefs about their self-efficacy in respect of the extent to which they can prevent and control errors and their attitude about the risk of an error occurring. As our synthesis demonstrates, the role of patients' attitudes and beliefs should not be underestimated as these perceptions create obstacles in the environment that patients themselves have to manage.

The review also shows that the relationship between patients and clinicians is particularly important in predicting patients' safety-related attitudes and behaviours. Studies demonstrate that patients' deferential attitudes towards clinicians are a barrier for patients' active engagement in helping to reduce clinical errors. The main issue identified was the power of the medical profession which has been often discussed in the literature (Vincent & Coulter, 2002). Many of the studies found that patients did not challenge clinicians because they felt that it was not their role to do so. Patients were also more likely to challenge nurses than

doctors, indicating that they are sensitive to the occupational hierarchy in healthcare organisations.

However, as our analysis indicates, at the interpersonal level clinicians have an important influence on patients' willingness and ability to participate in error reduction. Our review found that when clinicians encourage patients' involvement in safety then patients are generally willing to participate. This result supports the need for more effective patient clinician collaboration on safety issues (Entwistle et al., 2010). Other barriers to involvement include lack of clear written or verbal information explaining illness and treatment. Clinicians have an important role to play in addressing these communication barriers in the clinician-patient relationship.

Busy hospital settings discourage patients from engaging in error reduction behaviour. This is of concern because a busy ward is probably the time when patients are at greater risk. Indeed, the conditions that nurture the failures of foresight which eventually lead to error are rarely found at the individual level of analysis (Turner, 1976). To focus on the actions of individuals is to promote a culture of blame which is counterproductive to safety (Reason, 1998). The culture of safety within any organisation arises from the associated folkways, mores and codes of practice, namely the set of commonly accepted ways of doing things. It follows that it is readjustment of accepted cultural norms that will lead to reduction of errors (Turner, 1976). In the context of healthcare there is a gap between espoused theories (Agryris & Schon, 1996), what clinicians intend or believe they do (no harm) and their theory-in-use, or actual behaviour (to err is human). Policies encouraging patients' greater involvement are intended to bring these gaps to the attention of clinicians. Thus programmes designed to encourage patients to ask may fail when the espoused theory -'it's okay to ask'- meets

patients' theory-in-use - 'doctor knows best'. Certainly, the theories-in-use that underlie practice have developed in part to enable the normalisation of unsafe practices as a way for clinicians to cope with competing demands (Dixon-Woods et al., 2009), behaviour with which patients may collude.

Our analysis demonstrates that illness and patients' perceptions of their role and status as subordinate to that of clinicians were the most important barriers to their involvement in error reduction. Usually it is health, not healthcare, that is of value to patients. In itself, healthcare generally is negative and undesirable; people put themselves under the control of clinicians in anticipation of positive health outcomes because they have to. Implicit in this is patients' need to trust clinicians as they are in a situation of vulnerability, where there is task uncertainty and ambiguity in intended outcomes. These conditions create 'design blindness' (Friedman, 2001: 164) that is a dislocation between policy planning and implementation. In the context of patient safety the power and individualism of the medical profession has been cited as part of the problem (Collins et al., 2009), therefore deference to clinicians appears to be outmoded. Policy that tells patients 'don't be afraid to ask' while well intentioned, is blind to some of the possible underlying reasons why patients assume deferential behaviour in the clinical setting. Rather than perceiving active involvement in safety as protecting themselves from error, patients express concerns about being labelled "difficult" and clinicians responding negatively or defensively to being questioned; consequently patients may be actively protecting their personal safety by assuming a relatively passive role.

#### Policy and practice implications

In essence a policy of encouraging patients' to be more involved in reducing medical errors requires a 'demystification' of clinicians' claim to knowledge (Schon, 2007: 289) in the sense

that it is opened up to inquiry. Our analysis builds on Peat et al.'s (2010) approach for appraising interventions to support patients' involvement in safety and demonstrates that there are simple actions that clinicians can take in this respect. These include: actively listening to and taking seriously patients' concerns; providing a clear explanation when concerns or views differ from those of the patient; appearing to have the time to talk by making eye contact and other non-verbal behaviours such as sitting by the patient's bed; and, if acceptable to the patient, involving relatives in their care. Reassuring patients that it is okay to ask by using posters or information leaflets helps to reinforce this message. Forty-nine of the studies we reviewed involved hospital patients and those attending hospital out-patient departments; explanatory analysis of specific contexts would further assist policy makers to determine what works for whom and in what circumstances. Finally, by attending to the patients' perspective this article has demonstrated the importance of the clinician-patient relationship for patients to participate actively in reducing clinical errors. Further exploration of the clinicians' attitudes towards patients' engagement in safety would aid our understanding on how to effect more profound cultural change.

## **Appendices A & B**

Supplementary data associated with this article can be found, in the online version

## **References**

Abbate, R., Di Giuseppe, G., Marinelli, P., Angelillo, I.F., & the Collaborative Working Group (2008) Patients' knowledge, attitudes, and behavior toward hospital-associated infections in Italy. *American Journal of Infection Control*, 36, 39-47.

Agoritsas, T., Bovier, P.A., & Perneger T.V. (2005) Patient Reports of Undesirable Events During Hospitalization. *Journal of General Internal Medicine*, 20, 922–928.

Argyris, C., & Schon, D. A. (1996). *Organizational learning II: Theory, method, and practice*. Reading, MA: Addison Wesley

Ballinger, C., & Payne, S. (2000) Falling from grace or into expert hands? Alternative accounts about falling in older people. *British Journal of Occupational Therapy*, 63(12), 573–579.

Ballinger, C., & Payne, S. (2002) The construction of the risk of falling among and by older people. *Ageing and Society*, 22(3), 305-324.

Bernstein, M., Potvin, D., & Martin, D.K. (2004) A qualitative study of attitudes toward error in patients facing brain tumour surgery. *Canadian Journal of Neurological Sciences*, 31, 208-212.

Bolster, D., & Manias, E. (2010) Person-centred interactions between nurses and patients during medication activities in an acute hospital setting: Qualitative observation and interview study. *International Journal of Nursing Studies*, 47,154-165.

Britten, N., Stevenson, F.A., Barry, C.A., Barber, N., & Bradley C.P. (2000) Misunderstandings in prescribing decisions in general practice: qualitative study. *BMJ (Clinical Research Ed.)*, 320(7233), 484-488.

Brown, M., Frost, R., Ko, Y., & Woosley, R. (2006) Diagramming patients' views of root causes of adverse drug events in ambulatory care: an online tool for planning education and research. *Patient Education & Counseling*, 62(3), 302-315.

Burnett, E., Lee, K., Rushmer, R., Ellis, M., Noble, M., & Davey, P. (2010) Healthcare-associated infection and the patient experience: a qualitative study using patient interviews. *Journal of Hospital Infection*, 74, 42-47.

Burroughs, T.E., Waterman, A.D., Gallagher, T.H., Jeffe, D.B., Claiborne Dunagan, W., Garbutt, J., Cohen, M.M., Cira, J., & Fraser, V. (2007) Patients' Concerns about medical errors during hospitalization. *Journal on Quality and Patient Safety*, 33, 5-14.

Collins, M E., Block S. D., Arnold R. M., & Christakis, N. A. (2009) On the prospects for a blame-free medical culture. *Social Science & Medicine*, 69,1287–1290

Cromheecke, M.E., Levi, M., Colly, L.P., de Mol, B.J.M., Prins, M.H., Hutten, B.A., Mak, R., Keyzers, K.C.J., & Büller, HR. (2000) Oral anticoagulation self-management and management by a specialist anticoagulation clinic: a randomised cross-over comparison. *Lancet*, 356, 97–102.

Coulter, A., & Ellins, J. (2006) *Patient-focused interventions: A review of the evidence*. London: Picker Institute Europe.

Davis, R.E., Koutanji, M., & Vincent, C.A. (2008) How willing are patients to question healthcare staff on issues related to the quality and safety of their healthcare? An exploratory study. *Quality and Safety in Health Care*, 17, 90-96.

Deeks, P.A., & Byatt, K. (2000) Are patients who self-administer their medicines in hospital more satisfied with their care? *Journal of Advanced Nursing*, 31(2), 395-400.

Department of Health (2006) *Safety first: a report for patients, clinicians and healthcare managers*. HMSO: London.

DiGiovanni, C.W., Kang, L., & Manuel, J. (2003) Patient Compliance in Avoiding Wrong-Site Surgery. *The Journal of Bone and Joint Surgery*, 85, 815-819.

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B. & Sutton A. (2005) Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research and Policy*, 10, 45-53.

Dixon-Woods M., Suokas A., Pitchforth, E., & Tarrant C (2009) An ethnographic study of classifying and accounting for risk at the sharp end of medical wards. *Social Science & Medicine*, 69, 362–369

Dowell, D., Manwell, L.B., Maguire, A., An, P.G., Paluch, L., Felix, K., & Williams, E. (2005) Urban Outpatient Views on Quality and Safety in Primary Care. *Healthcare Quarterly*, 8(2), Suppl. 2-8

Duncan, C. (2007) An exploratory study of patient's feelings about asking healthcare professionals to wash their hands. *Journal of Renal Care*, 33(1), 30-34.

Duncanson, V., & Pearson, L.S. (2005) A study of the factors affecting the likelihood of patients participating in a campaign to improve staff hand hygiene. *British Journal of Infection Control*, 6(4), 26-30.

Entwistle, V.A., Mello, M.M., & Brennan, T.A. (2005) Advising patients about patient safety: current initiatives risk shifting responsibility. *Joint Commission Journal of Quality & Patient Safety*, 31, 483-494.

Entwistle, V.A., McCaughan, D., Watt, I.S., Birks, Y., Hall, J., Peat, M., Williams, B., & Wright, J. (2010) Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Quality and Safety in Health Care*, 19 (6), 1-7.

Esmail, A. (2006) Clinical perspectives on patient safety Chapter 1 in K Walshe & R Boaden (eds.) *Patient Safety: research into practice*. Open University Press.

Fitzmaurice, D.A., Murray, E.T., McCahon, D., Holder, R., Raftery, J.P., Hussain, S., Sandhar, H., & Hobbs, F.D.R. (2005) Self management of oral anticoagulation: randomised trial. *BMJ*, 331(7524), 1057.

Fitzmaurice, D.A., Murray, E.T., Gee, K.M., Allan, T.F., & Hobbs, F.D.R. (2002) A randomised controlled trial of patient self-management of oral anticoagulation treatment compared with primary care management. *Journal of Clinical Pathology*, 55, 845-849.



Forsyth, R., Maddock, C.A., Iedema, R.A., & Lessere, M. (2010) Patient perceptions of carrying their own health information: approaches towards responsibility and playing an active role in their own health – implications for a patient-held health file. *Health Expectations*, 13(4), 416-26.

Frey, B., Ersch, J., Bernet, V., Baenziger, O., Enderli, L., & Doell, C. (2009) Involvement of parents in critical incidents in a neonatal–paediatric intensive care unit. *Quality and Safety in Health Care*, 18, 446-449.

Friedman V.J. (2001) Designed Blindness: An Action Science Perspective on Program Theory Evaluation. *American Journal of Evaluation*, 22(2), 161–181

Gadisseur, A.P.A., Breukink-Engbers, W.G.M., van der Meer, F.J.M., van den Besselaar, Sturk, A.M.H., & Rosendaal, F.R. (2003) Comparison of the quality of oral anticoagulant therapy through patient self-management and management by specialized anticoagulation clinics in the Netherlands. *Archives of Internal Medicine*, 163, 2639-2646.

Gagliardi, A.R., Lemieux-Charles, L., Brown, A.D., Sullivan, T., & Goel, V. (2008) Barriers to patient involvement in health service planning and evaluation: an exploratory study. *Patient education and counselling*, 70(2), 234-241.

Greenhalgh, T., & Peacock, R. (2005) Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. *BMJ*, 331, 1064-1065.

Hibbard, J.H., Peters, E., Slovic, P., & Tusler, M. (2005) Can Patients Be Part of the Solution? Views on Their Role in Preventing Medical Errors. *Medical Care Research and Review*, 62, 601-616.

Hovey, R.B., Morch, A., Nettleton, S., Robin, E., Bullis, D., Findlay, A., & Massfeller, H. (2010) Partners in our care: patient safety from a patient perspective. *Quality and Safety in Health Care*, 19, 1-4.

Hurst, I. (2001) Vigilant Watching Over: Mothers' Actions to Safeguard Their Premature Babies in the Newborn Intensive Care Nursery. *Journal of Perinatal and Neonatal Nursing*, 15(3), 39-57.

Iedema, R., Jorm C., & Lum, M. (2009) Affect is central to patient safety: The horror stories of young anaesthetists. *Social Science & Medicine*, 69(12),1750-1756

Jarensiripornkul, N., Krska, J., Capps, P.A.G., Richards, R.M.E., & Lee, A. (2002) Patient reporting of potential adverse drug reactions: a methodological study. *British Journal of Clinical Pharmacology*, 53(3), 318-325.

Jarensiripornkul, N., Krska, J., Richards, R.M.E., & Capps, P.A.G. (2003) Patient reporting of adverse drug reactions: useful information for pain management? *European Journal of Pain*,7(3), 219-24.

JCAHO (2011) Speak Up Initiatives. The Joint Commission website.

<http://www.youtube.com/user/TheJointCommission>

Johnson T.J. (1972) *Professions and Power*. MacMillan Press: London.

Khan, T.I., Kamali, F., Kesteven, P., Avery, P., & Wynne, H. (2004) The value of education and self-monitoring in the management of warfarin therapy in older patients with unstable control of anticoagulation. *British Journal of Haematology*, 126, 557–564.

Kohn, L.T., Corrigan, J., & Donaldson, M.S. (1999) *To Err is Human: Building a Safer Health System*. Washington, DC: National Academies Press.

Kovacs Burns, K. (2008). Canadian patient safety champions: collaborating on improving patient safety. *Healthcare Quarterly*, 11, 95-100.

Koutanji, M., Davis, R., Vincent, C., & Coulter, A. (2005) The patients' role in patient safety: engaging patients, their representatives, and health professionals. *Clinical Risk*, 11(3), 99-104.

Kuzel, A.J, Woolf, S.H., Gilchrist, V.J., Engel, J.D., LaVeist, T.A. Vincent, C., & Frankel, R.M. (2004) Patient reports of preventable problems and harms in primary health care. *Annals of Family Medicine*, 2(4), 333-340.

Lent, V., Eckstein, E.C., Cameron, A.S., Budavich, R., Eckstein, B.C., & Donskey, C.J. (2009) Evaluation of patient participation in a patient empowerment initiative to improve hand hygiene practices in a Veterans Affairs medical center. *American Journal of Infection Control*, 37(2), 117-120.

Longtin, Y., Sax, H., Allegranzi, B., Hugonnet, S., & Pillet, D. (2009) Patients' Beliefs and Perceptions of Their Participation to Increase Healthcare Worker Compliance with Hand Hygiene. *Infection Control and Hospital Epidemiology*, 30, 830-839.

Lozowski, S., Chesler, M. A., & Chesney, B.K. (1993) Parental intervention in the medical care of children with cancer. *Journal of Psychosocial Oncology*, 11(3), 63-88.

Luszczynska, A., & Gunson, K.S.E. (2007) Predictors of asking medical personnel about handwashing: The moderating role of patients' age and MRSA infection status. *Patient Education and Counselling*, 68(1), 79-85.

Lyons, M. (2007) Should patients have a role in patient safety? A safety engineering view. *Quality & Safety in Health Care*, 16, 140-42.

Manias, E., Beanland, C., Riley, R., & Baker, L. (2004) Self-administration of medication in hospital: patients' perspectives. *Journal of Advanced Nursing*, 46(2), 194-203

McGuckin, M., Waterman, R., Porten, L., Bello, S., Caruso, M., Juzaitis, B., Krug, E., Mazer, S., & Ostrawski, S. (1999) Patient education model for increasing handwashing compliance. *American Journal of Infection Control*, 27(4), 309-314.

McGuckin, M., Waterman, R., Storr, J., Bowler, ICJW., Ashby, M., Topley, K., & Porten, L. (2001) Evaluation of a patient-empowering hand hygiene programme in the UK. *Journal of Hospital Infection*, 48, 222-227.

Menéndez-Jándula, B., Souto, J.C. Oliver, A., Montserrat, I., Quintana, M., Gich, I., Bonfill, X., & Fontcuberta, J. (2005) Comparing Self-Management of Oral Anticoagulant Therapy with Clinic Management. *Annals of Internal Medicine*, 142, 1-10.

Murray, E., Fitzmaurice, D., McCahon, D., Fuller, C., & Sandhur, H. (2004) Training for patients in a randomised controlled trial of self-management of warfarin treatment. *BMJ*, 328, 437–8.

National Patient Safety Agency (2004) Achieving our aims: Evaluating the results of the pilot Cleanyourhands campaign. [www.npsa.nhs.uk](http://www.npsa.nhs.uk).

Nau, D. P., & Erickson, S.R. (2005) Medication safety: patients' experiences, beliefs, and behaviors. *Journal of the American Pharmacists Association*, 45(4), 452-7.

Ocloo, J.E. (2010) Harmed patients gaining voice: challenging dominant perspectives in the construction of medical harm and patient safety reforms. *Social Science & Medicine*, 7(3), 510-516.

Ovretveit, J. (2009) The contribution of new social science research to patient safety. *Social Science & Medicine*, 69(12),1780-1783.

Peat M., Entwistle, V., Hall, J., Birks, Y., Golder, S., on behalf of the PIPS Group (2010) Scoping review and approach to appraisal of interventions intended to involve patients in patient safety. *Journal of Health Services Research and Policy*, 15(1),17-25.

Pereles, L., Romonko, L., Murzyn, T., Hogan, D., Silvius, J, Stokes, E., Lond, S., & Fung, T. (1996) Evaluation of a self-medication program. *Journal of the American Geriatrics Society*, 44(2), 161-165.

Phelan, G., Kramer, E.J., Grieco, A.J., & Glassman, K.S. (1996) Self-administration of medication by patients and family members during hospitalization. *Patient Education & Counseling*, 27(1), 103-112.

Pope, C., Mays, N., & Popay, J. (2007) *Synthesizing Qualitative and Quantitative Health Evidence*. Maidenhead: Open University/McGraw-Hill.

Quirk, A., Lelliott, P., & Seale S. (2005) Risk management by patients on psychiatric wards in London: An ethnographic study. *Health, Risk & Society*, 7(1), 85-91.

Quinn, C. (2003) Infusion devices: understanding the patient perspective to avoid errors. *Professional Nurse*, 19(2), 79-83.

Randle, J., Clarke, M., & Storr, J. (2006) Hand hygiene compliance in healthcare workers. *Journal of Hospital Infection*, 64, 205-209.

Rassin, M., Zilcha, L., Berger, M., & Silner, D. (2007) Personal medical documents management-How patients perceive, keep and manage their medical documents: A qualitative study. *International Journal of Nursing Studies*, 44(6), 862-868.

Reason, J. (1998) Achieving a safe culture: Theory and practice. *Work & Stress*, 12(3),293-306.

Schon D.A. (2007) *the Reflective Practitioner*. Ashgate Publishing Ltd.

Schwappach, D.L.B. (2008) "Against the silence": Development and first results of a patient survey to assess experiences of safety-related events in hospital. *BMC Health Services Research*, 8,59.

Schwappach, D.L.B., & Wernli, M. (2010a) Am I (un)safe here? Chemotherapy patients' perspectives towards engaging in their safety. *Quality and Safety in Health Care*, 19, 1-6.

Schwappach, D.L.B., & Wernli, M. (2010b) Chemotherapy Patients' Perceptions of Drug Administration Safety. *Journal of Clinical Oncology*, 28(17), 2896-2901.

Schwappach, D.L.B., & Wernli, M. (2010c) Barriers and facilitators to chemotherapy patients' engagement in medical error prevention. *Annals of Oncology*, 21(8), 424-30.

Smythe, E. (2010) Safety is an interpretive act: A hermeneutic analysis of care in childbirth. *International Journal of Nursing Studies*, 47(12), 1474-1482.

Stelfox, H.T., Bates, D.W., & Redelmeier, D.A. (2003) Safety of patients isolated for infection control. *JAMA*, 290, 1899-1905

Stepanikova, I. (2006) Patient–physician racial and ethnic concordance and perceived medical errors. *Social Science and Medicine*, 63(12), 3060-3066

Tarini, B.A., Lozano, P., & Christakis, D.A. (2009) Afraid in the hospital: Parental concern for errors during a child's hospitalization. *Journal of Hospital Medicine*, 4(9), 521-527

Turner B. A. (1976) The Organizational and Interorganizational Development of Disasters. *Administrative Science Quarterly*, 21, 378-397

Unruh, K.T., & Pratt, W. (2007) Patients as actors: The patient's role in detecting, preventing, and recovering from medical errors. *International Journal of Medical Informatics*, 76 S, S236–S244.

van den Bemt P.M.L.A., Egberst, A.C.G., Lenderink, A.W., Verzijl, J.M, Simons, K.A., van der Pol, W.S.C.J.M., & Leukfens, H.G.M (1999) Adverse drug events in hospitalized patients: a comparison of doctors, nurses and patients as a source of reports. *European Journal Clinical Pharmacology*, 55,155–8.

Vincent, C.A., & Coulter, A., (2002) Patient safety: what about the patient? *Quality and Safety in Health Care*, 11, 76-80.

Waterman, A.D., Gallagher, T.H., Garbutt, J., Waterman B.M., Fraser, V., & Burroughs, T.E. (2006) BRIEF REPORT: Hospitalized Patients' Attitudes About and Participation in Error Prevention. *Journal of General Internal Medicine*, 21, 367–370.

Watt. I. S, Birks, Y., Entwistle, V., Gilbody, S., Hall, J., Mansell, P., McCaughan, D., Peat, M., Sheldon, T., Williams, B., &Wright, J. (2009) A review of strategies to promote patient involvement, a study to explore patient's views and attitudes and a pilot study to evaluate the



acceptability of selected patient involvement strategies. Patient Safety Research Programme PS/034. University of York.

Weingart, S.N., Pagovich, O., Sands, D.Z., Li, J.M., Aronson, M.D., Davis, R.B., Bates, D.W., & Phillips, R.S. (2005) What Can Hospitalized Patients Tell Us About Adverse Events? Learning from Patient-Reported. Incidents Journal of General Internal Medicine, 20, 830–836.

Weingart, S.N., Toth, M., Eneman, J., Aronson, M.D., Sands, D.Z., Ship, A.N., Davis, R.B., & Phillips, R.S. (2004) Lessons from a patient partnership intervention to prevent adverse drug events. International Journal for Quality in Health Care, 16(6), 499–507.

Weingart, S. N., Price, J., Duncombe, D., Connor, M., Sommer, K., Conley, K., Bierer, B.E., & Ponte, P.R. (2007) Patient-reported safety and quality of care in outpatient oncology. Joint Commission Journal On Quality And Patient Safety, 33(2), 83-94.

Weingart, S.N., Simchowicz, B., Eng, T.K., Morway, L., Spencer, J., Zhu, J., Clearly, C., Korman-Parra, J., & Horvath, K. (2009) The You CAN Campaign: Teamwork Training for Patients and Families in Ambulatory Oncology. The Joint Commission Journal on Quality and Patient Safety, 35(2), 63-71.

WHO (2004) World Alliance for Patient Safety; Forward Programme 2004. Geneva: World Health Organization, 2004.

WHO (2005) World Alliance for Patient Safety; Forward Programme 2005. Geneva: World Health Organization, 2005.