Why professionals' response is pivotal when patients speak up about safety

The PIPS (Patient Involvement in Patient Safety) research team

Research has found that healthcare practitioners' behaviour is crucial in determining whether patients and carers can contribute to patient safety. The PIPS (Patient Involvement in Patient Safety) research team presents its findings[1].

Strategies to reduce adverse events in health care have mainly focused on systems of care and professional behaviour[2], but there is a growing interest in involving patients in safety initiatives[3]. We conducted a project[1] with the overall aim of investigating how patients and carers might appropriately be involved in effectively promoting their own safety. We found that healthcare professionals' attitudes and behaviour were vital in facilitating patient and carer involvement in safety.

The study

The study had three main phases, each of which built on previous work. The first phase comprised literature reviews[4,5], summarising current knowledge on patient roles, interventions and the potential for patients to contribute to reporting systems. The second phase involved primary research to generate new knowledge about patients' views on their experiences of, and contributions to, safety in healthcare settings. The third phase involved the development and piloting of a potential patient involvement strategy.

The literature review

From the literature we identified three broad routes by which patients' actions might contribute to their safety. Patients might help to make sure that:

- their treatment is appropriate for them (informing the management plan);
- treatment is given as planned and according to appropriate protocols (monitoring and ensuring safe delivery of treatment); and/or that
- problems and risks within healthcare systems are identified and reduced (informing systems and improvements).

A large volume of literature was identified which described a broad range of interventions. However, relatively few interventions to promote patient involvement had been tested and many of those that had, had not been rigorously evaluated. The only currently available high quality evidence of improved safety outcomes through patient involvement was with respect to self-management of anticoagulation therapy. We used insights from the broader review to develop an approach for appraising interventions intended to promote patient involvement in patient safety.

Primary research to investigate patients' views

The aims of the next phase of the research were to:

- determine patients' awareness of and concerns about health care safety;
- identify situations and ways in which patients or their representatives have acted (or considered acting) to help secure their own safety; and
- elicit patients' views about the various roles they might play to ensure their own safety, about interventions to encourage or support them in playing those roles, and about their potential contribution to safety reporting systems.

Qualitative research methods (in-depth individual interviews and focus groups) were used to describe, explore and explain patients' (and their representatives') views and experiences of safety in relation to using healthcare services.

Study participants (patients and their associated family members or representatives where appropriate) were strategically selected from six different groups with diverse clinical, demographic and social characteristics.

Within each clinical group, we included males and females across a range of ages and ethnic backgrounds. In addition, a second group of participants were recruited from national and local consumer or patient support groups, as it was anticipated that they might share collective views or experiences which might not be accessed via the accounts of individuals.

In total, 71 in-depth interviews were carried out, with patients and their representatives and/or carers, along with 12 focus group discussions (six "patient" and six "consumer") held with 68 participants.

Main results

Findings from the study revealed that patients were willing to engage with the topic of patient involvement in patient safety and that they had a broad understanding of the issues involved. Overall, study participants were largely unaware of national reporting systems, and they had limited knowledge of local systems.

Participants' reports suggested that they (or their family members) experienced a wide range of threats to their physical safety and psychological well-being when using healthcare services, and that they were prepared to act to protect themselves (or others) when certain circumstances prevailed.

Preliminary analysis was carried out on 35 individual interviews and 128 patient concerns were identified. The majority were said to have occurred during in-patient hospital stays. Concerns related to:

- errors in prescribing, dispensing and administration of medicines;
- missed diagnoses and delays in referral and treatment;

- poor communication;
- errors during screening and treatment procedures;
- potential threats to personal safety posed by other patients;
- deficiencies in inpatient nursing;
- inadequate hospital accommodation; and
- shortfalls in hygiene.

We found additional examples of these concerns in the remaining 36 interviews and in focus group discussions.

Acting to avoid error and avert harm

Participants recounted a variety of situations in which they had acted, or considered acting, to avoid error and avert harm, including situations in which they had spoken up or considered speaking up.

Detailed analysis of the specific situations described by individual participants revealed that decisions to act or not to act, and the type of action contemplated or taken, appeared to be associated with a number of factors, relating to:

- respondents as individuals (socio-demographic and biographical details, personal characteristics, point on the illness trajectory, feelings of physical or emotional vulnerability, whether alone or accompanied, whether acting for self or on behalf of someone else);
- the nature of the situation in which they found themselves (perceived immediacy and gravity of threat to safety, perceived "busyness" of the healthcare environment, the extent to which they were sure of grounds for action, fear of repercussions); and
- the anticipated or actual response from healthcare professionals (prior experiences, perception of nature of relationship with healthcare professionals, the perceived level of "challenge" associated with the proposed action).

A complex interplay between these factors seemed to be influential in respondents' decision making about whether or not to take action.

Examples of speaking up

Examples of situations in which participants had spoken up included where the patient perceived themselves (or another) to be in immediate danger of a serious error or harm. Speaking up on behalf of a family member (child, elderly parent or spouse) or a fellow patient, was more commonly reported than speaking up on behalf of oneself, and respondents appeared more ready to challenge or confront healthcare professionals in a direct manner when they were acting to protect another. In some situations, the initial act of speaking up was sufficient to prevent an error, avert harm or result in a problem being resolved. Where respondents felt that the response from the healthcare professionals had been unsatisfactory, the initial act of speaking up was often followed by a more confrontational interchange between patient and professional, or a verbal or written complaint.

Facing a delay in their own or a family member's treatment frequently led to participants speaking up. If the delay continued, and the person believed their own or their family member's condition was deteriorating, they were prepared to speak up more forcefully.

Patients were also prepared to speak up in situations where they felt "sure of their ground". Amongst the study participants, mothers of children with asthma were most likely to describe situations where they spoke up in a way which directly challenged the decisions of healthcare professionals, in order to enhance the safety of their children, based on their long-standing knowledge of the child's condition, and intimate knowledge of the child as an individual.

Positive responses versus the negative "cascade"

Where patients perceived that the relationship was positive, and that the healthcare professionals were open, communicative, empathetic and treated them with respect, they appeared more willing to take the risk of speaking up about their care, because they anticipated a positive responsive from the healthcare professional.

Where the patient's (or their representative's) speaking up met with an indifferent, defensive approach from the healthcare professional, an increasingly acrimonious chain or "cascade" of events might be triggered, culminating in one of two ways. Either the patient (or their representative) abandoned their attempt to obtain recognition of, or redress for, their concern; or they subsequently made a verbal or written complaint. This cascade usually followed the steps below:

- The patient perceives a threat to safety and/or a shortfall in care.
- The patient (or representative) "speaks up".
- Either the issue is resolved, or is not resolved.
- If it is not resolved, a more confrontational interchange with healthcare professional ensues (usually emotionally charged).
- The patient (or representative) pursues the matter.
- Finally, the patient or representative either "abandons" the attempt at resolution, or makes a verbal or written complaint.

Factors affecting involvement in safety

Study participants expressed a desire to be involved in promoting and enhancing their own safety, but differed widely in their views about which patient safety roles they considered appropriate for themselves or others to adopt, and the circumstances in which patients should act to promote their own safety.

People indicated that their willingness and ability to adopt patient safety roles would be affected by a range of factors which related to:

- themselves as individuals (including how ill or well they were feeling, and their emotional state);
- the nature of their relationship with healthcare professionals;
- the gravity of the situation in which they found themselves; and
- features of the wider health care system.

Study participants emphasised the importance of healthcare professionals' attitudes and behaviour in facilitating their involvement in safety roles. An enabling or facilitative environment was perceived as one in which staff:

- **Invited patients to ask questions** about their diagnosis, condition, investigations and treatment, took time to respond appropriately, and were prepared to provide information that was relevant to the individual patient at that particular time point.

> *"We cannot "legislate" patient involvement in healthcare safety, but if patients feel more comfortable in their dealings with professionals then it is more likely that patient roles in enhancing safety will occur as a matter of course."*

- **Gave patients permission to raise concerns**, and refrained from reacting in a dismissive, defensive or hostile manner, indicated to patients that their concerns would be listened to, acknowledged, and, if necessary, acted upon them, and ensured that patients did not suffer any form of recriminations because they brought their concerns to the attention of staff.
- **Responded to patients in a consistently positive manner.** Patients who met with a favourable response the first time they spoke up suggested they were more likely to do so on future occasions.

Consequently, patients' (and their representatives') perceptions about the nature of their relationship with healthcare professionals appeared to be crucial in their decision making about whether, how and to what extent, they might become involved in promoting their own safety.

Conclusions

It would appear that recommendations for consistent or blanket adoption of patient safety roles may not be appropriate, and that patients can not, and should not be expected to, routinely adopt safety roles as means of acting as a safety check in their own care. However, many would be willing and naturally inclined to play a role in their own safety if the context and the nature of the relationship with healthcare providers were appropriate.

The study findings appear to suggest that patient involvement in patient safety could be enhanced by a shift away from the current emphasis on the prescription of specific patient safety roles, towards a focus on the provision by healthcare professionals of a broadly supportive environment in which patients (and their representatives) are routinely given information and encouraged to be actively involved in their own safety and to raise concerns, if and when they feel able, without fear of recriminations.

In order to be able to offer patients the time and attention that might facilitate their involvement in patient safety activities, healthcare professionals need to be supported within the wider clinical environment.

Implications for practice

A central message from all three phases of the study is the importance of the healthcare professional and broader healthcare system in supporting patients to be involved in enhancing safety. Healthcare professionals need to be receptive and open to patient concerns and questions, and to facilitate patients' attempts to be involved in their care. Brusque, dismissive or disinterested attitudes in the professional can inhibit patients from carrying out many of the roles that have been proposed as means by which they might enhance their safety.

A positive patient-professional relationship seems to be crucial in enabling patients to contribute to improvements in healthcare safety. This makes a number of requirements of healthcare professionals, including appropriate attitudes and communication skills. It also places requirements on healthcare systems to make it easier for professionals to enable patient involvement in safety, for example, by ensuring that workload demands are reasonable.

Given this, we recommend that patient involvement in healthcare safety is better facilitated not by an emphasis on patient roles but by amending healthcare systems and supporting healthcare professionals to develop better relationships with patients. We cannot "legislate" patient involvement in healthcare safety, but if patients feel more comfortable in their dealings with professionals then it is more likely that patient roles in enhancing safety will occur as a matter of course, rather than as a response to an externally generated expectation.

Future research

Recommendations identified through this study include:

- an investigation of the desirability and feasibility of changing from recommendations that patients adopt particular roles or behaviours to promote their own safety towards efforts to facilitate more supportive professional behaviours and attitudes, and more supportive clinical environments;
- the development and evaluation of strategies to involve patients in the reporting of error and patient safety incidents; and
- a full scale evaluation of the use of patient narratives about their safety experiences to professional groups to promote greater awareness of safety issues.

Finally, there is a relative lack of data from primary care and future research could usefully investigate aspects of patient involvement in safety enhancement in this setting. HCRR

Acknowledgements

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