

THE UNIVERSITY *of York*

— DEPARTMENT OF —
HEALTH SCIENCES

Patient Involvement in Patient Safety

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On behalf of the PIPS Group



- 300,000 to 400,000 adverse events each year in the NHS

(Department of Health, 2000. *An Organisation with a Memory.*)

- Reduction strategies focused on systems and professionals
- Growing interest in involving patients in safety initiatives

PATIENT FACT SHEET

20 Tips To Help Prevent Medical Errors

Agency for Healthcare Research and Quality • 2101 East Jefferson Street • Rockville, MD 20852



AHRQ is the lead agency charged with supporting research designed to improve the quality of health care, reduce its cost, address patient safety and medical errors, and broaden access to essential services. AHRQ sponsors and conducts research that provides evidence-based information on health care outcomes; quality; and cost, use, and access. The information helps health care decisionmakers—patients and clinicians, health system leaders, and policymakers—make more informed decisions and improve the quality of health care services.



U.S. Department of Health and Human Services
Public Health Service

Medical errors are one of the Nation's leading causes of death and injury. A recent report by the Institute of Medicine estimates that as many as 44,000 to 98,000 people die in U.S. hospitals each year as the result of medical errors. This means that more people die from medical errors than from motor vehicle accidents, breast cancer, or AIDS.

Government agencies, purchasers of group health care, and health care providers are working together to make the U.S. health care system safer for patients and the public. This fact sheet tells what you can do.

What are Medical Errors?

Medical errors happen when something that was planned as a part of medical care doesn't work out, or when the wrong plan was used in the first place. Medical errors can occur anywhere in the health care system: in hospitals, clinics, outpatient surgery centers, doctors' offices, nursing homes, pharmacies, and patients' homes. Errors can involve medicines, surgery, diagnosis, equipment, or lab reports. They can happen during even the most routine tasks, such as when a hospital patient

on a salt-free diet is given a high-salt meal.

Most errors result from problems created by today's complex health care system. But errors also happen when doctors and their patients have problems communicating. For example, a recent study supported by the Agency for Healthcare Research and Quality found that doctors often do not do enough to help their patients make informed decisions. Uninvolved and uninformed patients are less likely to accept the doctor's choice of treatment and less likely to do what they need to do to make the treatment work.

What Can You Do? Be Involved in Your Health Care

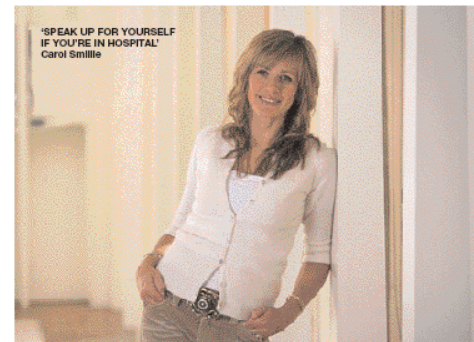
The single most important way you can help to prevent errors is to be an active member of your health care team. That means taking part in every decision about your health care. Research shows that patients who are more involved with their care tend to get better results.

Here are some specific tips, based on the latest scientific evidence about what works best:

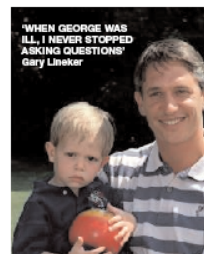
Please ask

TOP TEN TIPS FOR SAFER PATIENTS

- Find out all you can about your condition or treatment. Ask questions and look for other sources of information, such as on the internet or at the library.
- Ask the doctor or nurse to explain all the treatment options that are open to you, including any potential risks.
- If you're not quite sure what a doctor or nurse is saying, ask them to repeat it. Staff are always happy to explain medical terms in everyday language.
- If you're allergic to anything – or have reacted to a medicine or anaesthetic in the past – make sure your doctors, nurses and pharmacist know about it.



'SPEAK UP FOR YOURSELF IF YOU'RE IN HOSPITAL'
Carol Smille



'WHEN GEORGE WAS ILL, I NEVER STOPPED ASKING QUESTIONS'
Gary Lineker

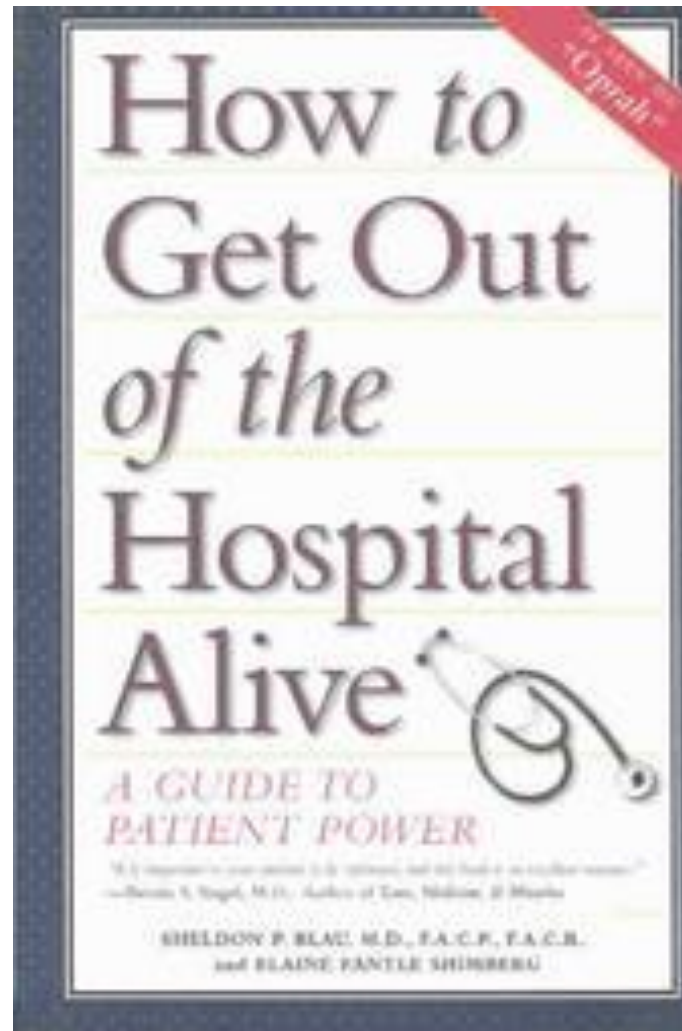
- Always read the instructions. Medication comes with a leaflet that explains how to take it and possible side-effects to watch out for. If it's not clear, ask your pharmacist, doctor or nurse.
- If you or your child are going to have an operation, check all the details on the consent form are correct before you sign it.
- When a family member or friend is in hospital and has trouble speaking for themselves you can ask questions for them.
- It's very important to make sure that the staff have the correct information about you. There could be other patients with similar names to yours, so you may be asked to confirm your name a number of times.
- If you're pregnant, or think you might be, make sure you tell the doctor or nurse before you have any treatment or X-rays.
- It's OK for you to ask doctors and nurses if they've cleaned their hands before they treat you.

▶ The National Patient Safety Agency (NPSA) helps the NHS learn from its mistakes so that it can improve patient safety. It does this by collecting reports on errors and other things that go wrong in health care so that it can recognise national trends and introduce practical ways of preventing problems. The NPSA doesn't investigate individual cases or complaints, but it does listen to public concerns and

use what you say to improve safety – so your story could help to prevent the same thing from happening to other people. Visit www.npsa.nhs.uk/pleaseask to find out how you can help the NPSA to make the NHS a safer place for patients. You can also find out about other organisations that can help if you want to make a complaint about your specific case.



National Patient Safety Agency



NHS
National Patient
Safety Agency

CLEAN HANDS? IT'S OK TO ASK

AS OUR PATIENT YOU SHOULD EXPECT TO SEE US CLEAN OUR HANDS BEFORE AND AFTER WE TOUCH YOU, BUT IF YOU THINK WE'VE FORGOTTEN, **IT'S OK TO ASK.**

cleanyourhands
campaign

onepartnership
National Patient Safety Agency

NHS
NHS Supply Chain

BIBALUN
Surgical Instruments

NICOLAS

gojo

To investigate how patients' (and their family members' and other representatives) might appropriately be involved in their health care to effectively promote their own safety

1. Focused set of literature reviews
2. Primary research to generate new knowledge about patients' views and experiences of their role in safety
3. Development and piloting of potential patient involvement strategy

Two Reviews

- a. Systematic review of the research evidence on the effectiveness of interventions used with the explicit intention of promoting patients' involvement in their care to enhance safety.

- b. Scoping review to identify the various roles/mechanisms by which patients might act to enhance their safety AND to examine the circumstances in which patients are able/willing to adopt these roles.

Systematic Review Findings:

- 14 studies, 1 review
- There is limited evidence for the effectiveness of interventions designed to promote patient involvement on patient safety incidents and in general is poor quality.
- Existing evidence is confined to the promotion of safe self-management of medication, most notably relating to the self-management of oral anticoagulants.
- Future research should focus on areas other than medication safety. In particular, interventions in most urgent need of evaluation are those that are currently widely used but unevaluated.

Scoping review of interventions intended to involve patients in patient safety

Scoping review findings:

- 745 reports of interventions, commentaries and explorations of patients' willingness and ability to adopt actions that might enhance their own or others' safety.
- Patients have largely not been involved in the development of interventions
- We know very little about patients willingness and ability to adopt recommended patient safety promoting behaviours
- Little exploration of negative effects of patient involvement

Scoping review of interventions intended to involve patients in patient safety

- Identified three broad routes by which patients' actions might contribute to their safety:

Patients might help to make sure that:

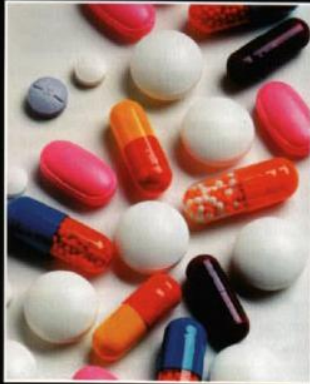
- their treatment is appropriate for them (informing the management plan)
- that treatment is given as planned and according to appropriate protocols (monitoring and ensuring safe delivery of treatment)
- that health systems are safe (making systems safer)

Appraisal tool for interventions

Using the organising framework to appraise interventions:

1. Identification of the route(s) by which intervention assumes patient behaviour might enhance safety
2. Identification of conditions that would need to be met for patient to adopt the behaviours
3. Examination of the support offered
4. Consideration of the potential negative effects

Your Role in Safe Medication Use



A Guide for Patients and Families

At the Clinic, Doctor's Office, and Pharmacy

- Learn as much as you can about the disease or condition for which the medication was prescribed. Are there alternatives to the recommended therapy? What are they?
- Find out everything you can about the medication. Listen to what your doctor or pharmacist says. Take notes. Ask as many questions as you think are necessary. If you don't understand the answer, ask again!
- Before you leave, ask the doctor, nurse or pharmacist if you can repeat the instructions that you've been given. This is a good way to clear up misunderstandings that might cause problems later.
- Make sure that each of your doctors is aware of medications that other physicians have prescribed for you. Tell them about any over-the-counter medications and homeopathic and herbal products you are taking. If you have any allergies, tell your doctor about them.
- Pharmacists are excellent sources of medication information. Try to take your new prescriptions and refill requests to the same pharmacy, so that you get to know your pharmacist, and he or she gets to know you.
- When you pick up a newly prescribed prescription, request to speak to a pharmacist and be sure to read all written handout materials thoroughly. If you are taking more than one prescription or, if you are obtaining medication at a site other than at the dispensing pharmacy, be sure to disclose this to the pharmacist. This is very important for the pharmacist to know.
- Make sure that the pharmacist knows about any allergies you have and any alternative/herbal therapies you may be taking.

- If you're greeted at the counter by a pharmacy technician or cashier, ask to see the pharmacist if you have questions. Some pharmacies have areas where you may speak privately with your pharmacist. If it's an especially busy time, you might want to call the pharmacist after you return home.
- Before you leave the pharmacy, open the bag and double-check the medication to make sure you've received the correct product.
- Remember that nurses can also share information about medications with you.

At Home

- Before taking the first dose:
 - Read the label. Make sure that the medication you have received is the one that your doctor ordered. If there is any difference in the appearance or shape of your medication between refills do not take it until you've discussed it with a pharmacist. Remember, many medications have names which sound or look alike.
 - Read the directions on the label and any written information you've been given. If any of it seems to contradict what you already know about the medication, call your doctor, nurse, or pharmacist.
- Recheck the label before each dose. Never take medications in the dark.
- If you develop itching or swelling or if you have trouble breathing after taking a new medication, get medical help immediately.
- Be alert for other side effects. If they become troublesome, call your pharmacist, nurse, or doctor.
- Take the medication exactly as prescribed. In some cases, you can stop taking a medica-

Intervention and 'route' by which might enhance safety

Share relevant information with prescribers to help ensure appropriate plans are formulated

Identification of conditions to be met

Patient capable of deciding what is relevant information

Patient will share this information with all prescribers

Health professionals will encourage (or not discourage)

Support offered

Is information about relevance provided?

Will health professional facilitate patient involvement by encouraging?

Potential negative effects

Patient may worry about what is relevant information

If patient not willing/able/well enough to perform

- One of the ways patients may contribute to improved safety is through participation in reporting systems.
- Many countries are committed to establishing a system for patients and the public to report, however, there is relatively little research to inform this development.
- This review looked at how various types of safety incident reporting systems have been developed and how they have solicited, received and used reports from patients and their representatives.
- To ascertain the extent to which patients have been involved in the systems' development and evaluation.

- A list of reporting systems which accept reports from patients and the public was developed from an extensive scoping review.
- A combination of a systematic search identifying: several overviews and reports of reporting systems; individual papers which describe or evaluate reporting systems; and internet searches for reporting systems.
- An identified contact was sent a copy of a short questionnaire.

- Eleven systems in a variety of countries were identified.
- The majority of reporting systems demonstrated little engagement/involvement with or by patients.
- However some exceptional systems were identified where patient reports had been successfully captured and used in reporting and learning.

Reporting: How, what and whom?

- The majority of systems only take reports related to pharmacovigilance
 - with the exceptions of the JCAHO in the USA and the National Reporting and Learning System in the UK who accept reports on more general harms and quality issues.
- Most reports are not anonymous although the National Reporting and Learning System (UK) and Med Watch (USA) do accept anonymous reports and some systems make personal details optional.
- Reports are a mixture of web-based forms, telephone reports and postal systems with dedicated cards which can be sent in by patients or healthcare professionals.

Reporting: How, what and whom?

- Most systems take reports from both patients and healthcare professionals.
- Institute for Safe Medication Practices (ISMP) and Joint Commission on Accreditation of Healthcare Organisations (USA), the Adverse Medicine Events Line (Australia) and Canada Vigilance Programme appear to be exclusive to patients and the public.
- Systems differ as to whether or not patients and the public are included in feedback as a result of their reports.
- The majority of systems appear to provide little in the way of feedback to reporters with Lareb (Netherlands) and KILEN (Sweden) seemingly the only ones to give detailed feedback to those who provide reports.

- All reports are fed into various regulatory bodies.
- Used to inform review bodies who examine adverse drug reactions, monitor and classify the seriousness of reactions or determine the safety of new products.
- The two Scandinavian systems explicitly mention feedback to the World Health Organisation (WHO) and the European Medicines Agency (EMA).
- The JCAHO in the USA (which is also responsible for accreditation of healthcare organisations) will conduct an unannounced, on-site evaluation of the organization they consider a report sufficiently serious. In other cases they may ask the health care organization to provide a written response to the report.

- For many of the systems we were unable to locate any data concerning the number of reports from the public.
- Much of the published literature we located will already be out of date and little information is available on numbers of patient reports generally.
- A combination of published literature and the questionnaires returned to us suggests that only small numbers of reports seem to come from patients.
- When reports are made ADRs are often different from those listed in product information. This finding was observed in the data from Australia, Netherlands and Sweden.
- The system with the most reports from the public seemed to be the Med Watch system in the USA with 30% of their reports coming from patients (publicity with each dispensed medication).

- Several sources have established that patient reporting of adverse drug effects can complement that of health professionals.
- Two of the reporting systems described have indicated that around a third of adverse effects of drugs reported by patients were new.
- There is evidence that patients are also able to identify and report other adverse events in healthcare but there is still relatively little experience of this.
- This review of current systems points to several ways in which they can be made accessible to patients in order to complement health professional reports.

- Systems into which patients are invited to report should be designed in consultation with patients.
- Many systems need to be better publicised.
- While the use of computers is increasing and, for many people, commonplace, over-reliance of systems on access to the internet may limit reports from some groups of patients.
- A system which provides anonymity for patients does not necessarily provide the feeling of security from reprisal which system providers possibly envisaged. What seems to be more important is that both patients (and professionals) feel that the evidence of safety events they provide is used appropriately for learning.
- The majority of reporting systems examined in this review demonstrate little evidence of real engagement with and/or uptake by patients.
- Where patient reports have been successfully captured and used in reporting and learning there seem to be concerted attempts to
 - publicize the system
 - make it highly visible to patients
 - provide clear information about how the information will be used.

Phase 2 aimed to:

- investigate patients' awareness of and concerns about health care safety
- identify situations and ways in which patients acted, or wanted to act
- explore patients' views about the various roles they might play to ensure their own safety

- Participants strategically selected from 6 different groups
 - patients with type 2 diabetes
 - women treated for breast cancer
 - parents of children hospitalised with asthma
 - people scheduled for joint replacement surgery
 - people who had raised a safety related issue with the Patient Advice and Liaison Service (PALs)
 - patients with severe and enduring mental health problems
- Additionally, a second group of participants were recruited from national and local ‘consumer’ or support groups

- Qualitative exploratory approach
 - Individual in-depth interviews (N=71)
 - Focus groups (N=12; 68 participants)
- Transcripts analysed using 'Framework'¹
- Team approach to analysis and interpretation
- Presented a summary of preliminary findings at a meeting for study participants
- 1. Ritchie, J. & Lewis, J. (2003) *Qualitative Research Practice*. London: Sage

THEMATIC FRAMEWORK USED IN ANALYSIS OF THE QUALITATIVE DATA

- **G ID**
- **E** Clinical Group
- **N** Age
- **E** Gender
- **R** Ethnicity
- **A** Occupation
- **L** Characterisation
- Roles
- **A** Barriers and Facilitators
- **W** Expectations/ reflections
- **A** General safety awareness
- **R** General attribution
- **E** Staff reaction
- **N** Reporting self
- **E** Reporting NHS
- **S** NHS Learning
- **S** Knowledge and Information

- S ID**
- P** Location
- E** What was undesirable?
- C** Why was it undesirable?
- I** What action?
- F** Alignment with/ against?
- I** Factors affecting action?
- C** Concern affirmation?
- E** Response to action?
- V** Response to response?
- E** Factors affecting response?
- N** Evaluation of?
- T** Ceased or continued?

- Patients were willing to engage with the topic and had a broad understanding of the issues involved.
- Study participants were largely unaware of national reporting systems and had limited knowledge of local systems.
- People reported experiencing a wide range of threats to their physical safety and psychological well-being.
- Respondents expressed a desire to be involved in promoting their own safety; however views concerning appropriateness of safety roles varied widely.

128 'index' concerns identified – situations or events mentioned at the start of problem narratives

- Deteriorations in condition that were missed or not taken seriously by HCPs
- Missed diagnosis and delays in referral and treatment
- Errors in prescribing, dispensing and administering medicines
- Errors in screening and treatment procedures
- Omissions or mistakes in communication
- Shortfalls in hospital accommodation and cleanliness
- Exposure to threats from other patients
- Deficiencies in in-patient nursing

Concerns about nursing care

Deficiencies in in-patient nursing were associated with:
preventable dehydration; lack of assistance with eating
and walking; monitoring of pain; emotional distress

'I was on a drip but for over 2 hours nobody noticed that the drip wasn't running right. I kept saying, I'm in a lot of pain...I was going mad with pain...eventually I got a nurse to, I said 'Will you get someone to check this for me? There's something wrong here.' My own anaesthetist, as soon as he had finished in theatre, he came down and put it right. And apparently it hadn't been dripping. Everything had been blocked up and nobody had noticed. He put me a fresh cannula in, started again. He was great...he just took over and said 'I am so sorry about this'.

(Woman in late 70s, after joint replacement surgery)

NPSA 'Top Ten Tips for Patients'

TOP TEN TIPS FOR SAFER PATIENTS

National Patient Safety Agency

- Find out all you can about your condition or treatment.
- Ask the doctor or nurse to explain all the treatment options that are open to you.
- If you're not quite sure what a doctor or nurse is saying, ask them to repeat it.
- If you're allergic to anything, make sure your doctors, nurses and pharmacist know about it.
- Always read the instructions. Medication comes with a leaflet that explains how to take it and possible side effects to watch out for. If it's not clear, ask.
- If you or your child are going to have an operation, check all the details on the consent form are correct before you sign it.
- When a family member or friend is in hospital and has trouble speaking for themselves, you can ask questions for them.
- It's very important to make sure that the staff have the correct information about you.
- If you're pregnant, or think you might be, make sure you tell the doctor or nurse before you have any treatment or X-rays.
- It's OK for you to ask the doctors and nurses if they've cleaned their hands before they treat you.

Patients' willingness/ability to adopt roles affected by range of factors relating to:

- ❑ themselves as individuals
- ❑ the nature of their relationship with healthcare professionals, and the anticipated or actual response from them
- ❑ the level of challenge associated with the role
- ❑ the context, including features of the wider health care system

‘Ask a family member or friend to accompany you when you go to the doctor or hospital’

P1: *‘I didn’t want my mum and daughter in floods of tears....I wanted to manage it myself....it was mine, my illness, my way of dealing with it, this is my way of coping...maybe some family members thought I was being a bit selfish...’*

P2: *‘I must be dead selfish then....I just thought everybody’d come. Anybody, the whole family....I’ll let them deal with their own emotions!’*

P1: *‘What it boils down to, it’s a very personal thing’*

(Extract from Focus Group 2, women treated for breast cancer)

SpeakUP™

**To prevent
health care
errors,
patients are
urged to...**

Everyone has a role in making health care safe. That includes doctors, health care executives, nurses and many health care technicians. Health care organizations all across the country are working to make health care safe. As a patient, you can make your care safer by being an active, involved and informed member of your health care team.

An Institute of Medicine report says that medical mistakes are a serious problem in the health care system. The IOM says that public awareness of the problem is an important step in making things better.

The "Speak Up™" program is sponsored by The Joint Commission. They agree that patients should be involved in their own health care. These efforts to increase patient awareness and involvement are also supported by the Centers for Medicare & Medicaid Services.

This program gives simple advice on how you can help make health care a good experience. Research shows that patients who take part in decisions about their own health care are more likely to get better faster. To help prevent health care mistakes, patients are urged to "Speak Up."

**Help Prevent
Errors in
Your Care**

SpeakUP™

The Joint Commission is the largest health care accrediting body in the United States that promotes quality and safety.

Helping health care organizations help patients

Factors which influenced speaking up

- Judgements about whether and to what extent situations are problematic
- Judgements about personal ability to assess problems
- Judgements about roles and responsibilities
- Judgements about the likely consequences of speaking up

'On your bike!'

'at one point somebody came to give me an insulin injection, which was a complete mistaken identify. And had I been feeble or semi-conscious, I don't know what would have happened. So I was compos mentis to say, 'On your bike! You're not going to give me an insulin injection!' I don't know whether it was a doctor or a nurse and he said, 'Oh, I've come to give you an insulin injection' and I said, 'No, I don't think you have'.

And so he just went and a nurse later on apologised and said she'd got mixed up and there was another [person with the same name] in one of the other wards' [patient bays]

(Patient undergoing joint surgery)

‘I made such a hash of it’

Participant (202) was a qualified health care professional in midlife, who had had surgery for breast cancer. Her *‘greatest worry’* about being hospitalised was the risk of infection. (202) said she was *‘not a complainer’*, and that she did not like to *‘speak up’* about things as she didn’t like to make a fuss. She described how she attempted to ask a nurse to use alcohol rub, as urged to in the posters on display on the ward.

‘I tried to [challenge the HCP] when somebody didn’t use the hand gel when they came to change my drip, but I made such a hash of trying to say ‘It says on that notice that I can challenge you’, and he misunderstood and brought me some hand gel, still went ahead and did me, and I thought I’m not going to ask again. I tried and got it all wrong...I obviously didn’t express it in a way he understood... ‘No, I’m telling you, you should be using it’, and saying what it says on the poster, it’s OK to challenge if you think they haven’t used it. I could see he hadn’t used any...he was rushing here, there and everywhere...but I blurted it out in a way he didn’t understand, and I felt too embarrassed to say, ‘No, that’s not what I meant.’

(Individual interview, woman who had received treatment for breast cancer)

‘the look I got from her’

‘I said, ‘That cream you are going to put on, she reacts to.’ And she [health care professional] said to me, ‘How do you know?’ [Daughter] couldn’t breathe, she was laid on the bed not able to breathe, she had oxygen on, and this young girl said to me ‘How do you know?’ I said to her. ‘She’s been coming here for 6 years and the cream irritates her and she’s also allergic to plasters.’

But she was going to put a plaster on, and the look I got from her...I didn’t say anything because [daughter] was really ill, so I didn’t say anything but you want to scream at some of them and say, ‘Why can’t you understand what I am telling you?’

If I did speak up sometimes I’d probably get thrown out...but then you’ve got to speak up because if they’ve made a mistake and you can prevent it, you know...’

(Individual interview, parent of child hospitalised with asthma)

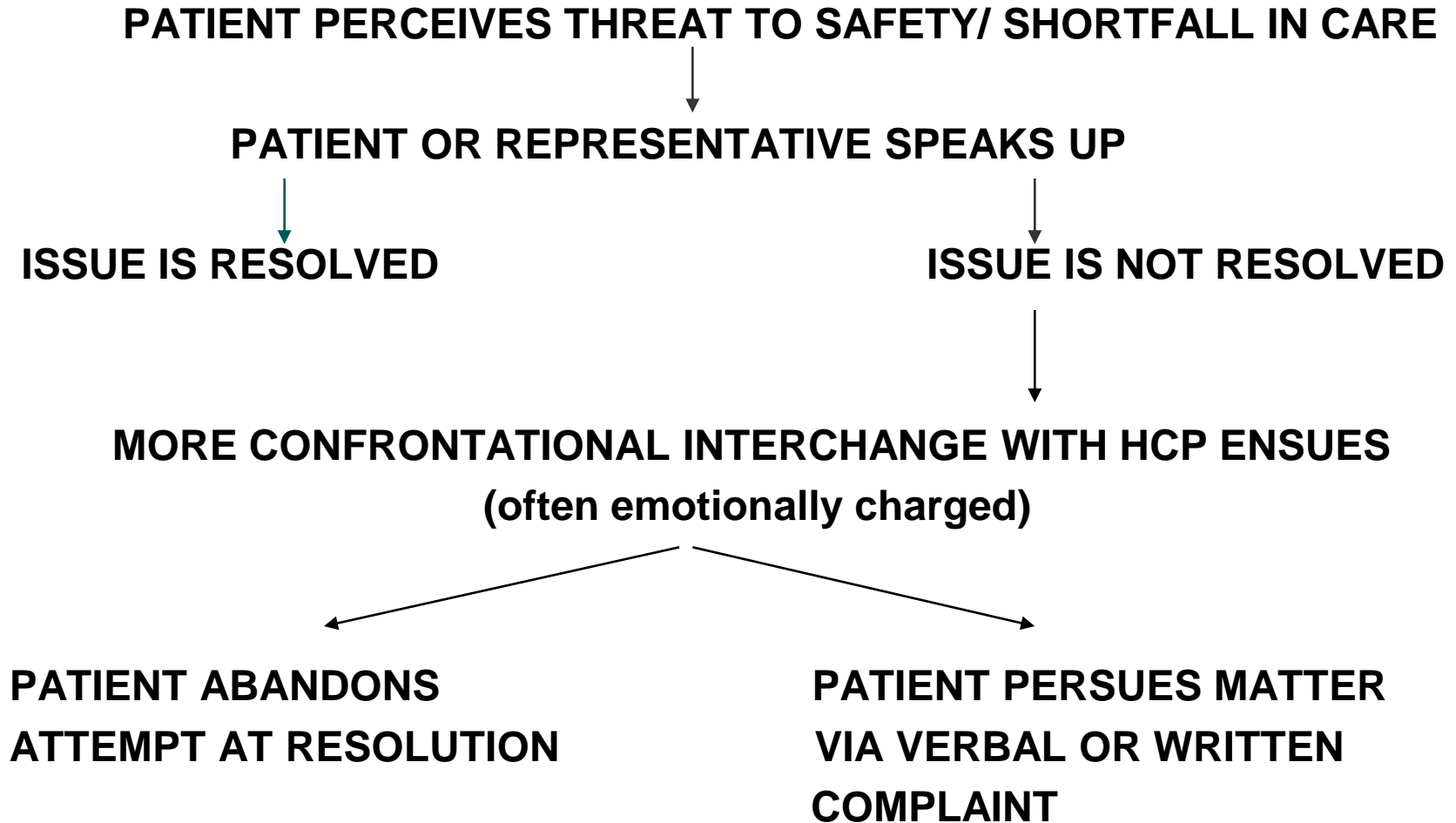
'it was a nuisance to them'

'If you asked for something they [nursing staff] would just ignore you...they wouldn't sort anything out for you, they made you feel so unimportant, and as if you were an absolute pain. It was partly the system's fault, in that they did have so much paperwork...My psychiatrist said I had particularly to have some medication at 8am, but it was given at 10am, because the take over [handover] was between 8am and 9am...so I knocked on the door...they told me to go away, and I was really quite distraught...I was very upset and afterwards they were a bit grumpy...'

And the next day, as soon as I knocked, it was different staff, obviously, I could hear them saying something about me. And they went and got the medication, but it was a nuisance to them. So eventually I did make a complaint to the psychiatrist because I was so angry. And she did take it very seriously and this particular nurse was reprimanded...when I came in [to the ward] in the future she would sort of blank me and I sort of felt alienated by the others...so you feel awkward, so you think, 'I am just going to stick to the 10 o'clock because they can't be bothered and I can't take the rejection.' So I just left it. I didn't bother any more, despite what the psychiatrist said...'

(Individual interview, woman with severe and enduring mental health problems)

Model of 'cascade' of events



Factors considered facilitative of speaking up

- Health care professionals' attitudes and behaviour were perceived as crucial in facilitating patient involvement
- In a facilitative environment, staff were said to:
 - adopt an approachable manner
 - invite patients to ask questions
 - give patients 'permission' to raise concerns
 - respond to patients in a consistently positive manner

Examples of positive responses from HCPs

‘I mean we have quite a good relationship [mother speaking about her relationship with staff on a paediatric ward]...so I feel comfortable to say something if something is wrong, I would say it, and they know I would, because they always say to me, especially the doctors... ‘Do you feel this?’ or ‘Do you want to say anything?’, and they know I would feel comfortable speaking to them...’

(Individual interview, parent of a child with asthma)

‘I found here that [speaking up] actually is quite easy because the staff were so approachable and positive and it wasn’t a question of complaining – more a question of bringing things to their attention that I thought they should know. But again, where we lived before I couldn’t have done it because attitudes were so different’

(Focus group participant, people with severe and enduring mental health problems)

- Participants identified various safety threats.
- Speaking up was generally considered difficult and met with diverse responses.
- Speaking up was influenced by the particular health care environment and experiences of patient-professionals relationships.
- A positive patient-professional relationship appeared crucial in enabling patients to contribute to improvements in safety.
- This requires appropriate attitudes and communication skills on the part of HCPs.
- In turn, HCPs need to be supported by health care systems that enable them to develop positive relationships with patients (eg reasonable workloads).
- If patients feel more comfortable in their dealings with professionals, it is more likely that patient roles in enhancing safety will occur as a matter of course.

- Ethnographic studies focussing on patient-HCP behaviour and contextual factors
- Views of health care professionals about patient involvement in patient safety
- Further research about how patients might be involved in safety initiatives in general practice

Phase 3: Using patient stories to enhance safety

BACKGROUND

- Health care professional response and attitude to patient involvement
- Personal experience is recognised as a powerful educational tool
- Few studies of patient involvement in health professional learning
- Students displayed an improved ability to communicate and empathise with patients (Klein 1999, Wood 1999)

OBJECTIVE

To assess the feasibility, acceptability and perceived usefulness of an educational intervention to involve patients in their own safety promotion by feeding back, to a staff group, their own safety experiences.

DESIGN

Exploratory study.

INTERVENTION

- Face-to-face feedback
- DVD
- Combination of face-to-face and DVD

SETTING

- Primary and secondary care, 3 participating centres

PARTICIPANTS

- Patients – purposively selected from phase 2 and were willing to be involved.
- Staff – primarily members of relevant clinical governance groups (CGG).

Story themes

3 patients and 2 patient representatives fed back their stories, 4 face-to-face and 1 DVD

- Healthcare staff response after things go wrong
- How healthcare staff send mixed messages to patients through their words and behaviour
- How failure of staff on an acute mental health ward to take seriously a patient led to loss of trust and violence
- The experience of a poorly executed discharge for the daughter of a sometimes muddled elderly patient
- The importance of planning for healthcare interventions for patients with challenging behaviour

Phase 3: Pilot study Findings

- The experience was, for the majority, a positive one.
- Failure of staff to engage often appeared to be related to other work pressures
- Most themes familiar to staff
- Stories stimulated discussion and reflection for both staff and patients.
- Provided neutral forum for open discussion (as opposed to complaints procedure).

However,

- Resource intensive and time consuming.
- Difficulty in finding appropriate staff group in primary care.
- Worthy of future research and formal evaluation.

Patient Involvement in Patient Safety

Overall Conclusions

- Patient involvement in safety is potentially acceptable and beneficial.
- The potential is likely to be mediated by a number of factors including patient, health professional, and system characteristics
- In most circumstances however, it is unlikely that patient involvement should be relied upon as a strategy for safety improvement.

Acknowledgements

- PIPS Group members:

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- This research was funded by the Department of Health, Patient Safety Research Programme, UK. The views and opinions expressed in this work do not necessarily reflect those of the funding body.
- Study participants - patients (and their representatives) and members of support and 'consumer' groups
- Clinical and other collaborators
- Ms Sandi Newby for project support

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