Why engaging with patients and families is important
The claim of modern health care is that it is patient centred. Yet, the reality for many patients and consumers is that they have had a long-standing battle to overturn entrenched views about the level of involvement patients should have in their own care. The tide is turning and in many nations around the world the consumer’s voice in health care is not only being heard but is being recognized by government, the professions and health-care providers.

Any health-care intervention has an element of uncertainty as to whether it will improve the health of the patient. Every consumer has the right to know what it means being a patient, and to receive helpful information about the quality of the care they will receive especially if they are to have any type of medical or surgical intervention. Informed consent allows them, in collaboration with health-care professionals, to make decisions about having the intervention and the recognized risks associated with that intervention. Such interventions may include, for example, a course of medication or an invasive procedure.

While most health-care interventions have good results or at least do no harm, poor outcomes do happen that can include errors, both random and systemic. The quality of a health-care system can be judged by the way it handles those errors. When health-care organizations fail to integrate consumer involvement in managing systemic risk, they lose access to important knowledge that cannot be gained from any other source.

The inclusion of open disclosure processes in many hospitals today reflects the increasing importance of professionalism and honesty with patients and their carers. This in turn is increasing opportunities for partnerships with patients.

Many consumer organizations are now turning their attention to organizational activities. The WHO initiative Patients for patient safety [1] is for consumers and focuses on education about patient safety and the system of health care as a contributing factor to adverse events.

Many patients having medical treatments, particularly when hospitalized, are in a vulnerable psychological state even when treatment goes according to plan. Symptoms akin to post-traumatic stress disorder can occur even following procedures that strike providers as routine. When a patient experiences a preventable adverse event, may be that the for emotional trauma is particularly severe.

This topic will provide an overview of consumer engagement activities that naturally divides into two dimensions: (i) learning and healing opportunities after an adverse event has occurred; and (ii) engagement of patients in preventing harm.

Keywords
Adverse event, advisory council, apology, communication, complaints, cultural norms, disclosure, education, error, fear, informed decisions, liability, mediation, patient and family, patient-centred, patient empowerment, patient engagement, patient rights, partnership, partnership councils, proactive, rapid response team, reporting, questions, Speak up campaign, stories, victims.

Learning objective:
The objective of this topic is to understand the ways in which patients and carers can be involved as partners in health care, both in preventing harm and learning and healing from an adverse event.
Learning outcome: knowledge and performance

What students need to know (knowledge requirements)

Students need to know:
- basic communication techniques;
- informed consent procedures;
- the basics of open disclosure.

What students need to do (performance requirements)

Students need to:
- actively encourage patients and carers to share information;
- show empathy, honesty and respect for patients and carers;
- communicate effectively;
- obtain informed consent;
- show respect for each patient’s differences, religious and cultural beliefs, and individual needs;
- describe and understand the basic steps in an open disclosure process;
- apply patient engagement thinking in all clinical activities;
- demonstrate ability to recognize the place of patient and carer engagement in good clinical management.

WHAT STUDENTS NEED TO KNOW (KNOWLEDGE REQUIREMENTS)

Basic communication techniques

Reviewing good communication

Before getting into the detail of open disclosure, it is useful to quickly review the principles of good communication and obtaining informed consent if these have not already been covered in the course.

Gaining informed consent

The consent process is a good barometer to judge how involved and engaged a patient is with their treatment. Some students think that consent requirements are fulfilled when the patient signs a consent form, but consent is much more than a signature on a form. The consent process enables the patient (or their carer) to consider all the options they have in relation to their treatment. Because this is such an important process, guidelines have been developed to assist health care professionals competently complete this task. Unfortunately time pressures and sometimes attitudes to patients shorten this process. The consent process has been developed over time paying attention to the statutory laws and statute laws in a particular country. Essentially consent has two main phases [2]:

1. The elements which inform the patient:
   - disclosure of information by the health-care practitioner;
   - an understanding or comprehension of the information by the patient.
2. Elements that enable the patient to make a decision:
   - a free and voluntary choice by the patient;
   - competence.

Medical students will usually observe the consent process when they are assigned to hospitals or clinics. Some will observe excellent examples of doctors and patients discussing treatments and the patients consenting or declining the treatment, but many will see patients giving consent with minimal information about their treatments.

Many students might be concerned about how much and what type of information should be disclosed and how well it must be understood before it can be said that the patient has been appropriately informed. How can the practitioner know that a patient’s decision is intellectually
unimpaired and voluntary? Is it free of intrinsic (stress, grief) and extrinsic (money, threat) pressures?

What a patient should know
Doctors are widely encouraged to use evidence-based medicine. For many treatments, there is a body of evidence on the likelihood of success and the likelihood of harm. It is important that such information is communicated to patients in a way that they can understand. Where there are printed resources to aid decision-making these should be used. Before a patient can decide whether to have the treatment or not they need to have information about the following issues.

The diagnosis
This includes test results and procedures. Without a diagnosis it is difficult for a patient to come to a decision about whether the treatment will be beneficial. If a treatment is exploratory, then this should be disclosed.

The degree of uncertainty in the diagnosis
Medicine is an error ridden profession; as more symptoms appear, the diagnosis can either be confirmed or changed. Disclosing uncertainty is essential.

Risks involved in the treatment
To enable patients to make a decision that suits them, they need to know:
• any side-effects;
• complications associated with the treatment or procedure;
• any outcome that may affect the patient’s physical/mental well-being;
• nature of risks;
• consequences of not having the treatment.

One way to communicate the risks and benefits to patients is to move from the general information about the treatment or procedure to specific information about the known risks and benefits (and uncertainties) associated with the specific treatment or procedure to the particular concerns and information needs of the patient or caregiver.

Patients need to know the range of options, not just the one favoured by the practitioner. In particular, they need to know:
• the proposed treatment;
• expected benefits;
• when treatment would start;
• length of treatment;
• costs involved.

The benefits of the treatment and the risks of not having the treatment
Some treatments, notwithstanding the risks, are better than no treatment because of the very poor prognosis.

Information on recovery time
The type of treatment or the decision to go ahead with a treatment or procedure may be influenced by other factors in the patient’s life: employment, family responsibilities, money, location of the treatment.

Name, position, qualifications and experience of health workers who are providing the care and treatment
Patients are entitled to know the level of training and experience of health-care professionals. If a practitioner is inexperienced, then supervision becomes more important and information about supervision may become part of the information exchanged.

Availability and costs of any service required after the transfer of care (discharge) from hospital
Patients may require the services of the community nurse or the general practitioner.
Aiding good communication
There are several tools to enhance good communication, e.g. the SEGUE framework developed by Northwestern University in the United States [3]:
- Set the stage
- Elicit information
- Give information
- Understand the patient perspective
- End the encounter.

Cultural competence
According to APSEF (Australian Patient Safety Education Framework), cultural competence is a term used to describe the knowledge, skills and attitudes that a health-care worker needs in order to provide adequate and appropriate health-care services to all people in a way that respects and honours their particular culturally based understandings and approaches to health and illness [4].
Cultural competence [5] in providing health services requires medical students to:
- be aware and accept cultural differences;
- be aware of one’s own cultural values;
- recognize that people from different cultural backgrounds have different ways of communicating, behaving, interpreting and problem-solving;
- recognize that cultural beliefs impact on how patients perceive their health, how they seek help, how they interact with health practitioners and how they adhere to the treatments prescribed;
- have an ability and willingness to change the way one works to fit in with the patient’s cultural or ethnic background so that they can be provided with optimal care.

Culture is a broad term that includes more than language and custom but also values, beliefs, behaviours, practices, institutions and the way people communicate. Students will observe that among their classmates there are different approaches to dress and food habits that may be related to culture or religion. Less obvious to them will be the underlying belief systems that their classmates adhere to.

It needs to be recognized that in many countries around the world, doctors and patients are only just beginning to think about patient safety and patient engagement. There are many debates to be had about how this transformation will affect the health-care service in those countries. While doctors should be culturally competent, it should also be recognized that for many countries around the world the patient safety movement is about a cultural change in the health-care system.

Benefits of patient and carer engagement
Compared with the medical profession and other health-care providers, health-care consumers have been the least represented stakeholder perspective in health-care safety and quality improvement efforts.

Because patients and their families are not as organized as other stakeholder groups, their interests and needs have not been well captured or well integrated into research activities, policy development, patient safety educational curricula, patient education or error/near miss reporting systems. Recently, patient safety leaders have observed that lack of progress may be due, at least in part, to our failure to effectively engage consumers of care as partners in ensuring the safety of care.

Is there evidence that patient engagement is effective?
While there are many ethical statements about the importance of partnerships with patients, there is little research about the extent to which partnerships with patients reduces medical error. A study by Gallagher, Waterman et al. [6]
indicated a strong willingness by hospitalized patients (91%) to be involved in error prevention activities. Their comfort level differed for different tasks. Patients were comfortable (85%) asking about a medication’s purpose, though nearly half (46%) were very uncomfortable about asking healthcare workers whether they had washed their hands.

In a 2005 article by Gallagher and Lucas [7] about disclosing medical errors to patients, the authors noted that seven studies had assessed patients’ attitudes to disclosure. These studies reported a gap between patients preferences and the fear by clinicians that sharing information with patients will expose them to medico-legal actions. Fortunately there has been a lot of effort put into developing Open Disclosure policies and since 2005 many hospitals have instituted an open disclosure policy without any obvious negative effects. A literature review on open disclosure is available on the web and can be found at http://www.health.gov.au/internet/safety/publishing.nsf/Content/703C98BF37524DFDCA25729600128BD2/$File/Open%20Disclosure%20literature%20review.pdf (accessed May 2008).

Patients’ experiences can teach us

We have not traditionally viewed the patient experience as particularly helpful in teaching, yet we are learning that patient stories and experiences of their illnesses can teach medical students and others a lot including: (i) the key role they can play in helping with the diagnosis; (ii) in deciding about appropriate treatments; (iii) in choosing an experienced and safe provider; (iv) in ensuring that treatments are appropriately administered; and (v) as identifying adverse events and letting people know about it as soon as possible [8].

Currently, the health-care system under-utilizes the expertise patients can bring to the health-care partnership. In addition to knowledge about their symptoms, preferences and attitudes to risk, they are a second pair of eyes if something unexpected happens [9].

What is disclosure? What must be disclosed?

Open disclosure refers generally to informing patients and their families of bad outcomes of medical treatment, as distinguished from bad outcomes that are expected from the disease or injury being treated. A number of definitions exist reflecting the uptake on open disclosure guidelines being developed and implemented in many countries. In Australia, open disclosure [10] is defined as:

the process of providing an open, consistent approach to communicating with the patient and their support person following a patient-related incident. This includes expressing regret for what has happened, keeping the patient informed and providing feedback on investigations, including the steps taken to prevent a similar incident occurring in the future. It is also about providing any information arising from the incident or its investigation relevant to changing systems of care in order to improve patient safety.
Open disclosure is the honest communications with patients and/or their families after an adverse event. The requirement to be honest is an ethical obligation and is documented in most medical ethical codes of practice. Basic questions would include: “What is the right thing to do in this situation?”, “What would I want in a similar situation?”, “What would I want if my loved one suffered an adverse event?” Many countries are yet to develop open disclosure guidelines for health-care professionals.

Do patients want disclosure of adverse events or errors that produce near misses?

A landmark study by Charles Vincent et al. [10] which examined the impact of medical injury on patients and their relatives and the reasons for taking legal action after such incidents gave impetus to consideration of the role and experience of patients. They interviewed 227 (out of a sample population of 466 or 48.7%) patients and relatives who were taking legal action in 1992 through five firms of plaintiff medical negligence solicitors. They found that over 70% of respondents were seriously affected by incidents that caused them to sue with long term effects on work, social life, and family relationships. The survey results showed:

- intense emotions were aroused and continued for a long time;
- decision to take legal action was determined by original injury and by insensitive handling poor communication after the original event;
- where explanations were given less than 15% were considered satisfactory.

Four main themes emerged from the analysis of reasons for litigation [11]:

- concern with standards of care—both patients and relatives wanted to prevent similar incidents in the future;
- they needed an explanation—to know how the injury happened and why;
- compensation—for actual losses, pain and suffering or to provide care in the future for an injured person;
- accountability—a belief that the staff or organization should have to account for their actions; patients wanted greater honesty an appreciation of the severity of the trauma they had suffered and assurances that lessons had been learnt from their experiences.

After an adverse event, patients want disclosure of an event that including:

- an explanation of what happened;
- an admission of responsibility;
- an apology;
- the assurance of prevention of similar events to others in the future;
- in some cases, punishment and compensation.

Common barriers to honesty with patients after an adverse event

Doctors and nurses may want to provide accurate and timely information to patients about an adverse event, yet fear that such communications may result in legal action or, at a minimum, confronting an angry patient or family member. Targeted education about the disclosure process may better prepare doctors for such an event. Doctors may also fear causing more distress to patients, loss of reputation, job, insurance cover or shame.

Open disclosure principles

There are now many guidelines available to assist clinicians through the open disclosure process:

- crafting an effective apology (Joint Commission Resources);
- open disclosure (Australian Commission for Safety and Quality);
- open disclosure guidelines (New South Wales, Health Australia);
- disclosure of adverse event (Department of Veteran Affairs);
When things go wrong: responding to adverse events (consensus statement of the Harvard hospitals).


**Key principles of open disclosure [12]** (New South Wales, Australia)
- openness and timeliness of communication;
- acknowledgement of the incident;
- expression of regret/apology;
- recognition of the reasonable expectations of the patient and their support person;
- support for staff;
- confidentiality.

The open disclosure process has many steps that should be taken. Senior clinicians are responsible for this process and medical students should never be left with responsibility for telling patients and families about an adverse event. They should try to observe and sit in on the interviews with patients so they can learn about the process and the value to patients and their families. Slide 13 is a flowchart of the open disclosure process used in New South Wales, Australia, that commenced in 2007.

The 2006 consensus statement of the Harvard hospitals *When things go wrong [13]: responding to adverse events*, places a much stronger emphasis on the need for emotional trauma support for both patient/family and health-care professionals involved. The importance of documentation to facilitate transparent communication with the patient and family and safety improvement initiatives that follow an event is emphasized in the Harvard framework for disclosing adverse events to patients and families.

The Harvard framework for disclosure [13]:

1. **preparing:**
   - review the facts;
   - identify and involve the appropriate participants;
   - use an appropriate setting.

2. **initiating conversation:**
   - determine patient and family readiness to participate;
   - assess the patient and family’s medical literacy and ability to understand;
   - determine the patient and family’s level of medical understanding in general.

3. **presenting the facts:**
   - simple description of what happened:
     - no medical jargon;
     - speak slowly;
     - be aware of body language;
   - do not overwhelm with information or oversimplify;
   - explain what is known of the outcome at that point;
   - describe the next steps;
   - sincerely acknowledge the patient’s and family’s suffering.

4. **actively listening:**
   - allow ample time for questions;
   - do not monopolize the conversation;

5. **acknowledging what you have heard.**

6. **responding to any questions.**

7. **concluding the conversation:**
   - summarize;
   - repeat key questions raised;
   - establish the follow-up.

8. **documentation:**
   - describe the event;
   - describe the discussion.
Advanced communications techniques and open disclosure

It is important to note that there is a strong emotional context to adverse events. Patients may be frightened, feeling vulnerable, angry or frustrated. Students will need to build on their basic communication skills to be confident in dealing with emotionally charged situations. There are many tools to assist communicating with patients and carers. Typical examples asking patients to describe their feelings might include:

- I imagine this is difficult news.
- You appear to be angry. Can you tell me what you are feeling?
- Does this news frighten you?
- Tell me more about what you are feeling about what I have just said.
- I’ll try and help you.
- Is there anyone you would like me to call?

Many medical schools have implemented communications training for students in recognition that good communication is a skill and requires teaching. Communication teaching sessions usually include teaching students how to ask the right questions, how to avoid being seen as “too defensive”, and how to show the patient that their concerns have been listened to and understood.

WHAT STUDENTS NEED TO DO (PERFORMANCE REQUIREMENTS):

- actively encourage patients and carers to share information;
- show empathy, honesty and respect for patients and carers;
- communicate effectively;
- obtain informed consent in an appropriate manner;
- show respect for each patient’s differences, religious and cultural beliefs and individual needs;
- describe and understands the basic steps in an open disclosure process;
- apply patient engagement thinking in all clinical activities;
- demonstrate ability to recognize the place of patient and carer engagement in good clinical management.

The communication tool SPIKES [14] is used to assist health professionals to communicate bad news in “end-of-life” situations. SPIKES can be used more generally to assist communicating with patients and their caregivers in a wide range of situations—managing conflict, the elderly patient, difficult patients or those from different sociocultural backgrounds. Medical students can start practising some or all of the attributes listed below.

Examples of clinical situations where this structure could be useful include:

Practising SPIKES

Step 1: setting (S)

Privacy

Students will observe in hospitals and clinics that sometimes privacy aspects of a patient’s care and treatment is not optimal. The setting is important if sensitive material will be discussed. The patient must be able to listen and ask questions with
minimal disruptions. It is very important that the health professional and the patient are fully engaged with each other. For example, if a television is on, politely ask the patient to turn it off—this helps focus the patient on what you are going to be discussing.

**Involve significant others**
Patients should always be asked if they want to have a family member present to support them and help with information. Some patients, particularly the frail and vulnerable may need a person to help them make sense of the information. It is particularly important to let patients know that they can have someone with them if they wish.

**Sit down**
Medical students are often alert to the problems caused by doctors standing over a patient and will often comment on it in their early student years. However, with time they come to accept that this is normal and how things are done. Students should practise asking the patient’s permission to sit down before doing so. Patients appreciate a doctor sitting down because it allows for direct communication and conveys to the patient that the doctor is not going to rush off.

It is important to always appear calm and maintain eye contact if this is culturally appropriate. Sometimes if a patient is crying it is best to look away and allow the patient some privacy and time to compose themself.

**Listening mode**
An important role of a doctor is listening to the patient and not interrupting them when they are talking. Maintaining good eye contact and remaining quiet is a good way to show the patient your concern and interest.

**Step 2: perception (P)**
A good technique to understanding a patient is to first ask the patient what they think is going on. Then after they have talked it may be appropriate to obtain the relevant clinical information. This will enable the clinician and you the student to understand where the patient is in relation to their understanding of their situation.

**Step 3: invitation (I)**
Many students worry about how much information they should disclose to the patient. Different countries will have different rules for this process. A general rule that probably applies to most countries and cultures is to focus on each individual patient’s informational needs. Patients are as varied as humanity and will differ in how much information they want or can cope with. Students should be guided by their supervisors in this area. Different clinicians will provide more or less; it is a good opportunity for the student to observe what works for the patient, and what works for different sorts of patients.

The informational needs of patients differ. If a patient has a family history of heart failure, the doctor may spend more time talking about the risks and paying attention to any anxieties the patient may have.

A simple rule to remember about risks is that all patients should be given information about treatments when there is potential for significant harm even if the risk is tiny and when side-effects, although minor, occur frequently. The application of this rule will help most clinicians to match patient informational needs. This approach enhances communication between the patient and the health provider by encouraging discussion.

Students will also observe that too much information at once can confuse patients.
Information overload can be avoided by asking some simple questions at the beginning of the consultation, for example:

*How much information would you like me to give you about your diagnosis and treatment?*

Medical students will quickly learn that patients will not retain important information given at a time of high anxiety, particularly if a difficult (for the patient) diagnosis is made. Some patients may not want a lot of information or make the decision about their treatment. However, discussion, explanations and answering questions are still necessary to maintain respect for autonomy.

**Step 4: knowledge (K)**

Effective communicators will always foreshadow to the patient that they will be covering some disturbing information. This gives the patient time to prepare, even if it is only a few minutes, for example: *Mr. Smith unfortunately I have some bad news for you…*

**Step 5: empathy (E)**

The following three steps will help students pay attention to the emotional needs of their patient:

- listen for and identify the emotion(s) and ask questions such as “How does that make you feel?” if you are unsure of the emotions being expressed or experienced;
- identify the source of the emotion;
- show the patient that you have identified their emotion and the origins of it.

It is inevitable that there will be some patients who are more difficult to treat than others. This could be because they have had previous bad health experiences and are angry, they could be frustrated because they have had to wait for treatment, they may be affected by drugs and alcohol, or have a mental illness. When a student comes across such a patient they should try to remember the dangers of stereotyping. It is not uncommon for specific groups to be discriminated against in a busy hospital. When a patient or patient group (for example, injecting drug users) is stereotyped by the health-care team it is crucial that students are aware of how their own prejudices or preferences may interfere with their objectivity and decision-making. Indeed more care is required in these cases, not least because personal opinions and attitudes may cloud objective clinical judgement which may result in the wrong treatment or misdiagnosis.

**Step 6: strategy and summary (S)**

Summarizing the information at the end of the consultation is always a good idea. Patients may ask more questions or remember something important. If new issues come up at this last minute, make a time for another meeting.

Students should be encouraged to practise these activities as soon as they enter hospitals and clinics and are seeing patients. Taking a history from a patient is a prime opportunity to actively engage with a patient by listening, asking closed and open-ended questions and asking the patient if they understand their condition. Encouraging them to ask questions is a first step.

**Promoting patients’ involvement in their own care**

It is known that patients who play active roles in the management of chronic health conditions seem to enjoy better outcomes over patients who play a more passive role in care [15-17].

Patients and their families can be made aware of opportunities to engage in adverse event prevention by:

- awareness raising/education about the risks of preventable harm;
- encouragement to speak up to providers about safety concerns.
HOW TO TEACH THIS TOPIC

Teaching strategies/formats
This topic can be broken up into sections to be included in existing curricula or can be taught as a stand alone learning activity. If the topic is being taught as a stand alone session, it can be delivered in a number of ways as listed below.

An interactive/didactic lecture
Use the accompanying slides as a guide covering the whole topic. The slides can be PowerPoint or converted to overhead slides for a projector. Start the session with the case study and get the students to identify some of the issues presented in the story.

A small group discussion session
One or more students could be presented with the topic and asked to lead a discussion about the areas covered in the topic. The students could follow the headings as outlined above and present the material. The tutor facilitating this session should also be familiar with the content so information can be added about the local health system and clinical environment.

Simulation exercises
Different scenarios could be developed about adverse events and the need to report and analyse errors. Role plays involving discussions between patients and medical student in different situations could include:
- where there is a conflict in information;
- where the student does not know the information the patient wants;
- when a patient is complaining about a student;
- debriefing a student who has received a complaint.

Teaching activities
There are a number of different methods for generating discussion about the areas in this topic.

Law and ethics associated with disclosure following adverse events
The examples in this Curriculum Guide largely stem from Australia, the United Kingdom and the United States.
- Have a look at the ethics statements of your peak national medical association. What does it say about disclosure? Compare this with the position of your professional colleges.
- Find out about consumer representation bodies in your country.
- Have a look at your local media for stories of patients championing their rights.
- Invite a member of a doctor’s insurance agency to talk about common errors and advice to reduce them.

Patient complaints procedures
Invite a senior respected clinician to talk about how complaints are handled in their clinical practice.
- In relation to either of the case studies in this module or to real cases that have happened in your area, get the students to write a letter of apology using, for example, the Harvard tools.
- Have a look at one of the case histories. Work out what might be the costs that one of the patients subjected to error would need to recover from an insurer or be placed upon family. For example, loss of a job and ongoing treatments or even death
- Informally ask doctors what they think about patients being helped to make complaints. Rehearse the arguments with a fellow student as to why listening to the consumer voice can be a good thing.
Communication and disclosure
• Either in pairs or small groups get one student to take the part of one of the patients in the cases where a serious error has happened. Let the other student take the part of the doctor communicating the error. Debrief the students to see how they felt and what they learnt.
• Ask the students for examples of patient and carer engagement that they have lived through or their family have lived through.

Patient empowerment
• Ask students in pairs or small groups to gather information from patients about what makes them feel safe and conversely what things make them feel unsafe about their care.
• In pairs, get the students to talk to patients about ways they feel they could contribute to their own safety, e.g. checking medication. Let the students come back as a group and present their findings.

Cultural competence
• In small groups ask the students to consider the case study about cultural differences and get them to reflect on any differences in how doctors should communicate with patients from different cultural groups.
• Take an example where a patient has a life-threatening illness, e.g. cancer. Discuss with students any differences there might be between cultures as to what the patient should be told.
• Repeat the exercise where a patient has had an adverse event. Discuss with the students whether there are cultural differences in the way patients might react.

Activities for students in their clinical placements
• Follow a patient on their journey through the health-care service.
• Follow the doctor who is consenting patients for a surgical list and reflect on that practice in relation to the framework for informed consent.
• Ask students to spend a day with another health professional (nurse, physiotherapist, social worker, pharmacist, dietitian, interpreter) and explore some of the ways those particular professions engage with patients and carers.
• Ask students when they have patient encounters routinely seek to information about the illness or condition from the patient’s perspective.
• Ask students to make inquiries of their hospital or health service about whether there are processes or teams to investigate and report on adverse events. Where possible, ask the students to seek permission from the relevant supervisor for them to observe or take part.
• Ask students to find out if the hospital conducts mortality and morbidity meetings or other peer review forums where adverse events are reviewed.
• Require the students to talk among themselves about errors they have observed in the hospital using a no-blame approach.
• Ask the students to select a ward or clinic where they are placed and inquire about a main protocol used by the staff. Get the students to ask how the guideline was written and how staff know about it and how to use it and when to deviate from it.

CASE STUDIES

Acknowledgment of medical error
Frank is a resident of an aged care facility. One night, a nurse mistakenly gave Frank insulin, even though he does not have diabetes. The nurse immediately recognised his error and brought it
the attention of the other staff, who in turn informed Frank and his family. The facility took immediate action to help Frank and arranged his transfer to a hospital where he was admitted and observed before being returned to the aged care facility. The nurse was commended for fully and immediately disclosing the incorrect administration of the insulin. Following this incident, the nurse undertook further training in medications to minimise the possibility of a similar error occurring.

Reference

The importance of listening to a mother
This case illustrates the importance of examining each patient as individual and not blindly following rules.

Rachael, a single mother, gave birth to her first child. He was a healthy newborn of 37 weeks gestation, weighing 2700 grams. The birth was normal and mother and baby were stable one hour after delivery. She was informed by the nurse that everything was OK with both of them.

Breastfeeding started six hours after delivery. The nurse verbally told the doctor about some difficulties with the mother’s breast and that the baby looked too sleepy. The hospital rules stated that that mothers were to be discharged 36 hours after birth, so the mother was prepared for early discharge.

Rachael was told by doctor A that everything was OK, that the baby has mild jaundice but that it will disappear in a couple of days because there was no incompatibility between the baby and mothers blood group, and breastfeeding should improve the next few days in this “healthy baby”.

Another doctor (B) told her to return in a week to the hospital. While staying at home breastfeeding difficulties continued and the baby's jaundice increased. Rachael was afraid, and took the baby to the emergency room when he was 72 hours old. The doctor did not check the baby’s weight but requested a bilirubin test. The result was 13.5 mg; he said that it was a low level for a 3-day-old baby and that everything was OK, so she should not have to come to the hospital when the baby was a week old. He advised Rachael to return in a week from that day and said, laughing, “Your baby is OK, do not be fearful. I know what I’m saying, I’m the doctor”.

Over the next few days the baby required breastfeeding every hour and a half, and Rachael’s breasts looked empty. She remembered having been told by the nurse while she was at the hospital not to take any supplements in order to stimulate milk production. Rachael's friends do not have children, so they said, “I do not know, but if the doctor said everything is OK, do not be paranoid, everything is OK”.

Rachael took the baby to the hospital according to doctor B’s advice, the baby was 10 days old, his weight had decreased 20% and his bilirubin test was 35 mg; during clinical examination the baby presented clear signs of bilirubin encephalopathy.

The hospital Advisory Board tried to understand why a healthy baby born from a healthy mother with a normal delivery developed this terrible and preventable situation.

Case from the WHO Patient Safety Curriculum Guide for Medical Schools working group. Supplied by Jorge Martinez, Universidad Del Salvador, Buenos Aires, Argentina.
Unpicking the concerns of patients / carers even when not fully expressed verbally is a key skill that needs to be mastered.

- We should never not take the mother’s concerns into consideration, and should always take them seriously.
- We should never make them feel that they are having inappropriate concerns.

A letter from a patient
This letter presents a patient’s perspective of her experience with her hospital.

I’m Alice, 25 years old. I had abdominal pain for six days and I was really frightened because my sister started a year ago with similar symptoms and now has intestinal cancer and is under a very aggressive treatment.

I decided to go alone to the hospital in order not to scare the whole family. I arrived at the hospital early in the morning. I didn’t know exactly what to do or who to see; it was my first time at the hospital. Everybody looked in a hurry and they did not look very friendly. Some of them looked as frightened as I was.

I took a deep breath and asked a young lady who looked at me and smiled as if she knew where the gastrointestinal department was located. She laughed a little and said, “I’m a medical student and I’m lost too. Let’s try together to find it, I have to go to the same place too”. She said, “Why don’t we go to the information office?” I thought it was a good idea, and all of sudden I started to feel in some way protected. A person I considered to be a health-care professional was with me.

We arrived at the information office to find it was crowded with a lot of people shouting, some of them angry. There was only one person providing information. Lucy, the medical student said, “I do not think we will get anywhere if we try to get information here”. I thought we could follow the signals I had seen at the main entrance. I said, “Let’s go”.

After walking through the crowd, we arrived at the main entrance. We finally arrived at the gastrointestinal department. Lucy said, “Oh, yes, this is the place, ask the nurse over there; I should go to take my class, good luck”.

The nurse told me that I shouldn’t come directly to the gastrointestinal department, that I should go to the emergency department and they would decide about my condition. So, I had to return to the emergency room. When I arrived, plenty of people were waiting; they told me I would have to wait. “You should have come earlier”, the nurse said (I arrived early!!).

A general practitioner eventually saw me and ordered X-rays and lab examinations. Nobody said anything and no explanations were provided to me. At that moment I was more scared than when I woke up with the pain.

I was at the hospital all day going from one place to another. At the end of the day, a doctor came and told me in few words you are OK, there is nothing to worry about, and I started “breathing” again.
I would like to say to the hospital authorities that they should realize that every person coming to the hospital, even if they do not have any important disease, is feeling stressed and often unwell. We need friendly people taking care of us, ones who try to understand our story and why we feel so bad. We need clear communication between health-care workers and patients. We need clear information on how we should use the hospital facilities in order to make best use of them. I understand that you cannot cure everybody—unfortunately you are not Gods—but I am sure that you could be friendlier to patients. Doctors and nurses have the incredible power that only with his/her words, gestures and comprehension of the patient situation, they can make a patient feel secure and relieved.

Please do not forget this power so incredibly useful for those human beings who enter your hospital.

With all my respect,

Alice

Case from the WHO Patient Safety Curriculum Guide for Medical Schools working group. Supplied by Jorge Martinez, Universidad Del Salvador, Buenos Aires, Argentina.

TOOL AND RESOURCES

WWW Key textbooks and references


Medical errors: Talking about Harmful Medical Errors with Patients. Seattle, University of Washington School of Medicine (http://www.ihi.org/IHI/Topics/PatientCenteredCare/PatientCenteredCareGeneral/Tools/TalkingaboutHarmfulMedicalErrorswithPatients.htm).


HOW TO ASSESS THIS TOPIC

Details of patient safety assessment are given in the Teacher’s Guide (Part A). However, a range of assessment methods are suitable for this topic including essay, MCQ, SBA, case-based discussion and self-assessment. Students can be encouraged to develop a portfolio approach to patient safety learning. The benefit of a portfolio approach is that at the end of the students’ medical training they will have a collection of all their patient safety activities. Students will be able to use this to assist job applications and their future careers.

The assessment of knowledge about patient engagement and open disclosure can include:
- portfolio;
- case-based discussion;
- OSCE station;
- written observations about the health system (in general) and the potential for error;
- reflective statements (in particular) about the
  - role patients play in hospitals or clinics;
  - consequences of paternalism;
  - role of senior clinicians in open disclosure process;
  - role of patients as teachers.

The assessment can be either formative or summative; rankings can range from unsatisfactory to giving a mark. See the forms in Appendix 2.

HOW TO EVALUATE THIS TOPIC

Evaluation is important in reviewing how a teaching session went and how improvements can be made. See the Teacher’s Guide (Part A) for a summary of important evaluation principles.

References

SLIDES FOR TOPIC 8: ENGAGING WITH PATIENTS AND CARERS

Didactic lectures are not usually the best way to teach students about patient safety. If a lecture is being considered, it is a good idea to plan for student interaction and discussion during the lecture. Using a case study is one way to generate group discussion. Another way is to ask the students questions about different aspects of health care that will bring out the issues contained in this topic such as the blame culture, nature of error and how errors are managed in other industries.

The slides for topic 8 are designed to assist the teacher deliver the content of this topic. The slides can be changed to fit the local environment and culture. Teachers do not have to use all of the slides and it is best to tailor the slides to the areas being covered in the teaching session.