



## **Course: To Err is Human**

### **Topic: Engaging with patients and carers**

#### **Summary**

**Modern health care claims to be patient-centred, but the reality for many patients is very different. The low level of involvement patients have in their own care is a major obstacle. However, things are changing and, in many countries, the patient's voice in health care is being heard and recognized by governments and health-care providers. When health-care organizations fail to integrate patient involvement in managing risk, they lose access to important patient knowledge.**

#### **Patient engagement**

Compared with the health-care professions, patients are the least represented stakeholders in health-care safety and quality improvement efforts. Because patients and their families are not as organized as other stakeholder groups, their interest and needs have not been captured or integrated into research activities, policy development, patient safety educational curricula, or reporting systems. Patient safety leaders have highlighted that lack of progress in this area may be partly due to a failure to engage patients as partners.

#### **Why engaging with patients and their families is important**

- Every patient has the right to receive information about the care they are receiving.
- Informed consent allows patients, in collaboration with health-care providers, to make decisions about interventions and potential risks.
- Many patient and consumer organizations around the world are turning their attention to activities that promote safe patient care.
- The WHO initiative '**Patients for Patient Safety**' focuses on patient safety advocacy and awareness-raising by patient 'champions'.
- Patient engagement activities divide into: learning and healing after an adverse event; and engagement of patients in preventing harm.

#### **Communication between providers and patients**

##### **1. Informed consent**

Respect for patients' autonomy refers to their right to make choices according to their own values. It is unethical for a health-care professional to interfere with the choices patients make, unless the person is unconscious or in a life-threatening situation.

- The consent process enables patients to consider options in relation to their care and treatment, including alternatives to the course of treatment proposed.
- Consent guidelines have been developed for health-care professionals.
- Time pressures and attitudes towards patients shorten this process.
- The consent process has two main phases: elements that inform the patient and elements that enable the patient's decision-making process.
- It is not uncommon for patients to discuss consent with pharmacists, nurses and other health professionals before or after they have spoken with their doctor.
- Financial considerations are extremely important for patients who may not have health insurance or other financial resources for a particular treatment being proposed.

## 2. What patients should know

Health-care providers are encouraged to use evidence-based health care. For many treatments, there is a body of evidence on the likelihood of success or harm. It is important that such information is communicated to patients in a way that they can understand. When there are printed resources to aid decision-making, these should be used. Before individual patients can decide whether or not to accept a treatment, they need to have information on:

- **The diagnosis or the main problem** including test results and procedures. Without a diagnosis or assessment of what the problem is, it is difficult for a patient to decide about treatment. If a treatment is exploratory, this should be disclosed.
- **The degree of uncertainty in the diagnosis or problem** as health-care is inherently error-prone. As more symptoms appear and more information is provided, a diagnosis may be confirmed or changed. Disclosing uncertainty is essential.
- **Risks involved in the treatment or solution** for patients to make decisions that suit them. They need to know about side-effects, potential complications of the treatment and any outcome that may affect their physical/mental well-being, as well as the consequences of not having the treatment.
- **Patients need to know the range of options**, not just the one favoured by the practitioner. They need to know:
  - the proposed treatment and expected benefits;
  - when treatment would start and its length;
  - the cost involved;
  - whether there is an alternative treatment that they might consider;
  - the benefits of the treatment; and the risks of not having the treatment.

Some treatments, notwithstanding certain risks, are better than no treatment at all.

- **Information on expected 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, such as employment, family responsibilities, financial concerns and the location of the treatment.
- **Name, position, qualifications and experience of the health-care workers** who are providing the care and treatment. If a practitioner is inexperienced, then supervision becomes important and information about supervision may become part of the information exchanged.
- **Availability and cost of any service or medication required.**

## 3. Tools for good communication

Tools have been developed to enhance good communication. One of these is the SEGUE framework developed by Northwestern University (Chicago, USA)

Set the stage; Elicit information; Give information; Understand patient's perspective; End the encounter

### Cultural competence

Culture is a broad term that includes language and customs, as well as values, beliefs, behaviours, practices, institutions and the ways in which people communicate. Cultural competence in providing health services requires health-care workers to:

- be aware of and accept cultural differences;
- be aware of own cultural values;
- recognize that people from different cultural backgrounds have different ways of communicating, behaving, interpreting information and solving problems;
- recognize that cultural beliefs affect how patients perceive their health, how they seek help, interact with health providers, and how they adhere to the treatments or care plans;
- be aware of the patient's (health) literacy;
- be able and willing to change the way they work to fit in with the patient's cultural or ethnic background, in order to provide the patient with optimal care;

- be aware that cultural competence includes people from low socio-economic backgrounds—marginalized citizens tend to be more passive and reluctant to voice their opinions or judgement.

**Cultural competence:** knowledge, skills and attitudes that a health-care professional 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.

### Patient engagement

- While there are ethical reasons about the importance of partnerships with patients, there is little research about the extent to which such partnerships reduce error.
- Some studies indicate a strong willingness by hospitalized patients (91%) to be involved in error-prevention activities.
- Patients were comfortable (85%) asking about a medication's purpose, but nearly half (46%) were very uncomfortable asking health-care workers whether they had washed their hands.

### Continuity of care

- Patients move through many health-care environments- from clinics, to hospitals, to outpatient clinics, to doctor's offices.
- Poor communication and teamwork can impact on continuity of care for patients. Inaccurate or incomplete information can lead to errors or patients being incorrectly treated.
- Patients are the only fixed points in the transitions of care. Including the patient in the information exchange would help the accuracy of these communications.

### Patients' experiences can teach us

The patient's experience is not traditionally viewed as a source of learning. But there is increasing evidence that patients' stories and experiences of their illnesses/conditions can teach health-care providers and students a lot, including the key roles patients play: (i) 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) in identifying adverse events and letting people know about them as soon as possible.

### What is open disclosure and what must be disclosed?

**Open disclosure** is a term used to describe honest communication with patients after they have suffered harm. The use of open-disclosure in many health-care facilities reflects the importance of professionalism and honesty in communicating with patients. Patients and their carers are more likely to be understanding about the underlying causes.

**Open disclosure** is a term used to describe the process of informing patients and their families of bad outcomes of treatment, as distinguished from bad outcomes expected from the disease being treated.

A study (Vincent, 2002) showed that decisions by patients or their families to take legal action were based on the injury inflicted and were influenced by insensitive handling and poor communication after the event. When explanations were given, less than 15% were considered satisfactory. Four main themes emerged from the analysis of reasons for litigation:

- concern with standards of care—patients wanted to prevent similar incidents in the future;
- the need for an explanation—to know how the injury happened and why;
- compensation—for actual losses or to provide future care 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 learned from their experiences.

### **Key principles of open disclosure**

- openness and timeliness of communication;
- acknowledgement of the incident;
- expression of regret/apology;
- recognition of the reasonable expectations of the patient and his/her carer;
- support for staff;
- confidentiality.

The open disclosure process includes many steps. Countries and institutions have developed their own frameworks for open disclosure. Examples include: the New South Wales, Australia open-disclosure process ([www.health.nsw.gov.au/policies/gl/2007/pdf/GL2007\\_007.pdf](http://www.health.nsw.gov.au/policies/gl/2007/pdf/GL2007_007.pdf)) and the Harvard Framework for disclosure (Harvard Hospitals. When things go wrong., 2006).

### **Common barriers to honesty with patients after an adverse event**

Health-care providers may want to provide accurate and timely information to patients about an adverse event, yet fear that such communication may result in legal action or, at a minimum, confrontation with an angry patient or family member. Targeted education about the disclosure process may better prepare health-care professionals for such an event. Health-care providers may also be ashamed and/or fear causing more distress to patients, as well as the loss of reputation, job and/or insurance coverage. Disclosure is not about accepting or apportioning blame, it is about integrity and being truly professional.

### **Advanced communication techniques and open disclosure**

#### **1. Ways to engage patients**

Health-care providers should:

- 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;
- remember that information exchange is a process not an event—leave open the opportunity for patients to return with more questions;
- show respect for patient's religious and cultural beliefs and individual needs;
- apply patient engagement thinking in all clinical activities;
- recognize the place of patient and carer engagement in good clinical management.

#### **2. SPIKES: a communication tool**

The communication tool 'Setting, Perception, Information, Knowledge, Empathy, Strategy and Summary' (SPIKES) is used to assist health-care professionals to communicate bad news in situations where the patients are at the end of their life. But SPIKES can be used more generally to assist communication with patients in a wide range of difficult situations.

##### **Step 1: Setting (S)**

- **Privacy:** The setting is important if sensitive material is to be discussed. The patient must be able to listen and ask questions with minimal disruption.
- **Involve significant others:** Patients should always be asked if they want to have a family member present to support them and help with information.
- **Sit down:** Patients appreciate a health practitioner sitting down because it allows for direct communication and conveys to the patient that the person is not going to rush off.
- **Listening mode:** An important role of a health-care provider is listening to patients and not interrupting them when they are talking.

##### **Step 2: Perception (P)**

It is helpful to first ask the patient what he/she thinks is going on. This can help the care provider to understand where the patient is in relation to their understanding of their situation.

### Step 3: Information (I)

- Health-care providers worry about how much information should be disclosed to the patient. A general rule is to focus on each patient's informational needs. All patients should be given information about treatments, whenever there is risk and when side-effects occur frequently. The application of this rule will help to match the information provided with the patient's informational needs. This approach enhances communication between patient and provider by encouraging discussion. The delivery of information should be carefully paced and appropriate for the patient's situation. Information overload can be avoided by asking simple questions or making simple statements at the beginning of the consultation.
- Patients will not retain important information given at a time of high anxiety, particularly if a difficult diagnosis is made. Discussion, explanations and answering questions are still necessary to maintain respect for the patient's autonomy. If patients have a list of questions they wish to discuss, their health-care provider should go through each of the questions.

### Step 4: Knowledge (K)

Effective communicators will always indicate 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 moments.

### Step 5: Empathy (E)

The following four steps can help providers pay attention to the emotional needs of their patient.

- **Listen for and identify the patient's emotion(s).** If the provider is unsure of the emotions being expressed or experienced, ask questions such as: *How does that make you feel?*
- **Identify the source of the emotion.** *'This is difficult news. Do you want to talk about what you are feeling? If you like, I can come back later and we can talk again when you will have had a chance to take it all in. I will do my best to answer any questions you may have.'*
- **Show the patient that his/her emotion is recognized** and where it is coming from.
- **Be quiet**—sometimes just being there and letting the patient absorb the information and giving them a chance to formulate any questions is important.

### Step 6: Strategy and Summary (S)

It is always a good idea to summarize the information discussed at the end of a consultation. Patients may ask additional questions or remember something important.

### Promoting patients' involvement in their own care

Patients who play active roles in the management of chronic health conditions enjoy better outcomes than patients who play a more passive role in their care. Patients and their families can be made aware of opportunities to engage in the prevention of adverse events through awareness-raising activities and education about the risks of preventable harm. They should be encouraged to speak up to providers about safety concerns.

Successful involvement of patients in their own care requires:

- an understanding of the strong emotional context to adverse events
- honesty, empathy and respect for patients and carers
- knowledge on how to listen carefully and communicate effectively.