

Health Law and Ethics

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MHA 633

Truth telling & breaking bad news

Lecture 8



Chapter

5-6

In the previous Lecture : Patient Autonomy - Confidentiality

Patient Autonomy

Informed Consent

Components of IC

Modes of Consent

Capacity to consent and special consideration

Patient Rights, Privacy and confidentiality

Measures to protect Privacy

What is Confidential?

Conditions to breach confidentiality

In this Lecture: Truth telling & breaking bad news

- ❖ What do we mean by breaking bad news (BBN)?
- ❖ Which news is 'bad' in clinical practice?
- ❖ Why should we care about BBN?
- ❖ BBN as part of the Communication Cycle/Pathway
- ❖ Practical approaches to BBN: (SPIKES, ABCDE, BREAKS, & Calgary-Cambridge framework for breaking bad news)



Chapter

Truth telling & breaking bad news



Share your experience

Have you ever been asked to tell someone the 'bad news'?

What were the news?

How did you do it?

How did the receiver of the news respond?

Breaking
bad news



What constitutes bad news?

- **Ideas?**
- “...pertaining to situation where there is a feeling of no hope,
- a threat to a person’s mental or physical well-being,
- a risk of upsetting an established lifestyle or
- where a given message conveys to an individual fewer choices in his or her life” (*Ptacek & Eberhardt TL, 1996*)
- “any news that drastically and negatively alters the patient’s view of her or his future” is bad news. (*Buckman, 1984*)

What constitutes bad news?

- Unfavourable diagnosis
- Irreversible, un-treatable, or non-stoppable diseases (or side effects, or complications)
- Disease recurrence
- Spread of disease
- Revealing positive results of genetic tests
- Stigmatization
- Late (to treat) stage diseases
- End of life decisions (DNR, resuscitation)
- Death

Why should we tell our patients the truth about their conditions?

Ethical

autonomy

Beneficence

Non-maleficence

Professional

Communicator

Advocate

Duty to care

Human rights

Right to know

Right to decide

Legal

Negligence

EOL decisions

Advance directives

Why do we need truth-telling?

- **Ethically:**

1. **Autonomy:** disclosure indicates information sharing; core components of informed consent: disclosure of information; comprehension; voluntariness; competency; and an agreement with the proposed procedure or intervention
2. **Beneficence:** without the 'truth', such informed decisions on what the benefit of the intervention is can never be reached. This means that the state of being 'uninformed' (or mal-informed) might lead people to miss a true benefit, or have illusions about a false one.
3. **Non-maleficence:** who determines harm(ful) aspects?
4. **Trust:** feeling of deception or being misled may erode trust in the system

On the other side

- ❗ patients ought not to be needlessly upset with worrisome news about their medical condition.
- ❗ Thomas Percival stressed in his influential book *Medical Ethics* (1803) suggested that truth-telling yields to the important obligation to shield information that could be harmful to patients.



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Why don't clinicians tell?

1. Uncertainty about many aspects of the conditions, especially those related to terminal illnesses
2. Knowledge brings forth the responsibility to act upon it
3. Not all truths are created equal (information is irrelevant to the care and general welfare)
4. Lack of proper communication skills
5. Fear (worry) about the patient's reaction to the information disclosed
6. A belief that it is 'in the patient's best interest' (who decides?)
7. Lack of adequate time to explain to the patient adequately
8. Language barrier
9. Justifiable (soft) paternalism

What is 'adequate disclosure'?

- **Professional standard:** Would a typical physician act differently from Dr. A?
- ' the **'reasonable person' standard:** "Would a hypothetical reasonable person want this information revealed to her at this, time?" and
- **the 'subjective' standard:** some individuals would simply want to know this genetic information. No explanation or justification or interpretation is required. They would just want to know at this time. It obligates Dr. A only if he has knowledge about a unique belief; in the absence of such knowledge the physician has no obligation to inform his patient

Grades of truth?

 How much info?
Whole truth

 Modified version of truth
Partial truth

 Until when?
Hiding

 Same as hiding?
Deception

Where to draw the line between:
lying, misinformation, disinformation, withholding
info, etc.?

If you hide truth or withhold
information to avoid
discomfort to the patient

**Lying to
the patient**

Obstructing autonomy

Ethical & legal obligation on the physician to
provide patients with as much information
about their illness as they desire

However, if truth is disclosed without
concern for patient's sensitivity



Patient Discomfort



Truth may be disclosed
without concern for
patient's sensitivity

Avoid discomfort of the
patient and withhold
information



Discomfort

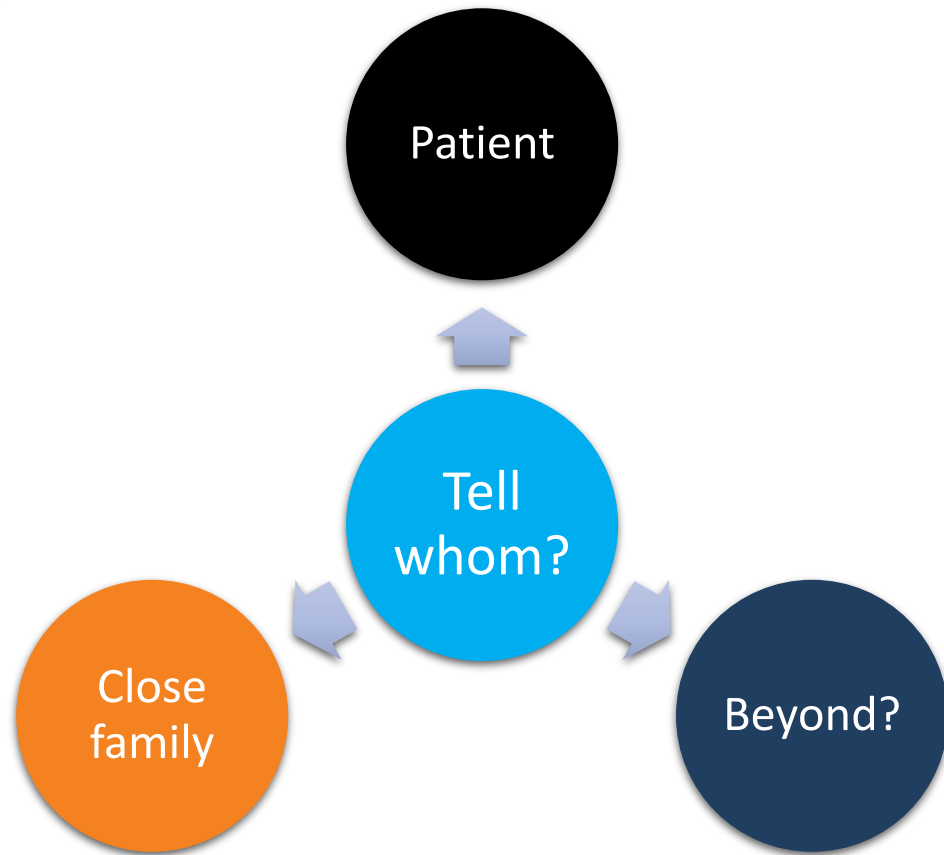


Lie

In defense of lying to our patients?

- Nyberg in his book, *The Varnished Truth*, challenges the truth telling "orthodoxy". Truth-telling is insufficiently nuanced and fail to take into account the circumstances that seem to warrant deception in everyday life.
Truth telling is "morally overrated."
- Deception is part of the civility (the "good manners") of society and may be as meaningful and important as disclosure. Truth may be "unsuitable" in some circumstances: friends, for example, do not always want the truth but rather, "I rely upon you to look after me."
- A friend tells you the truth "when it is in your interest to hear it" and will tell it compassionately. The atmosphere of trust rests in Nyberg's eyes on a "delicately balanced mixture of truth telling and deceiving."
- Other virtues, such as preventing pain, can be more important than honesty. We trust that our friends will know us well enough to know when they should best be silent.

Extent of the 'duty to tell'?



- **Consider these conditions:**
- X- recessive diseases
- STIs (spouse?)
- Occupational hazard (epileptic school-bus driver)

What does the law says?

• **Article 18**

- A healthcare professional shall, after explaining the treatment or surgery involved and outcome thereof, alert the patient or his family to the necessity of following the instructions provided and warn them of the consequences of failing to follow said instructions.
- A physician may, in cases of incurable or life-threatening diseases, decide, at his own discretion, whether it is appropriate to inform the patient or his family of the nature of his disease, unless prohibited to do so by the patient or if the patient designates a persons to be exclusively informed.

Legally

نظام مزاولة المهن الصحية

(المادة الثامنة عشرة)

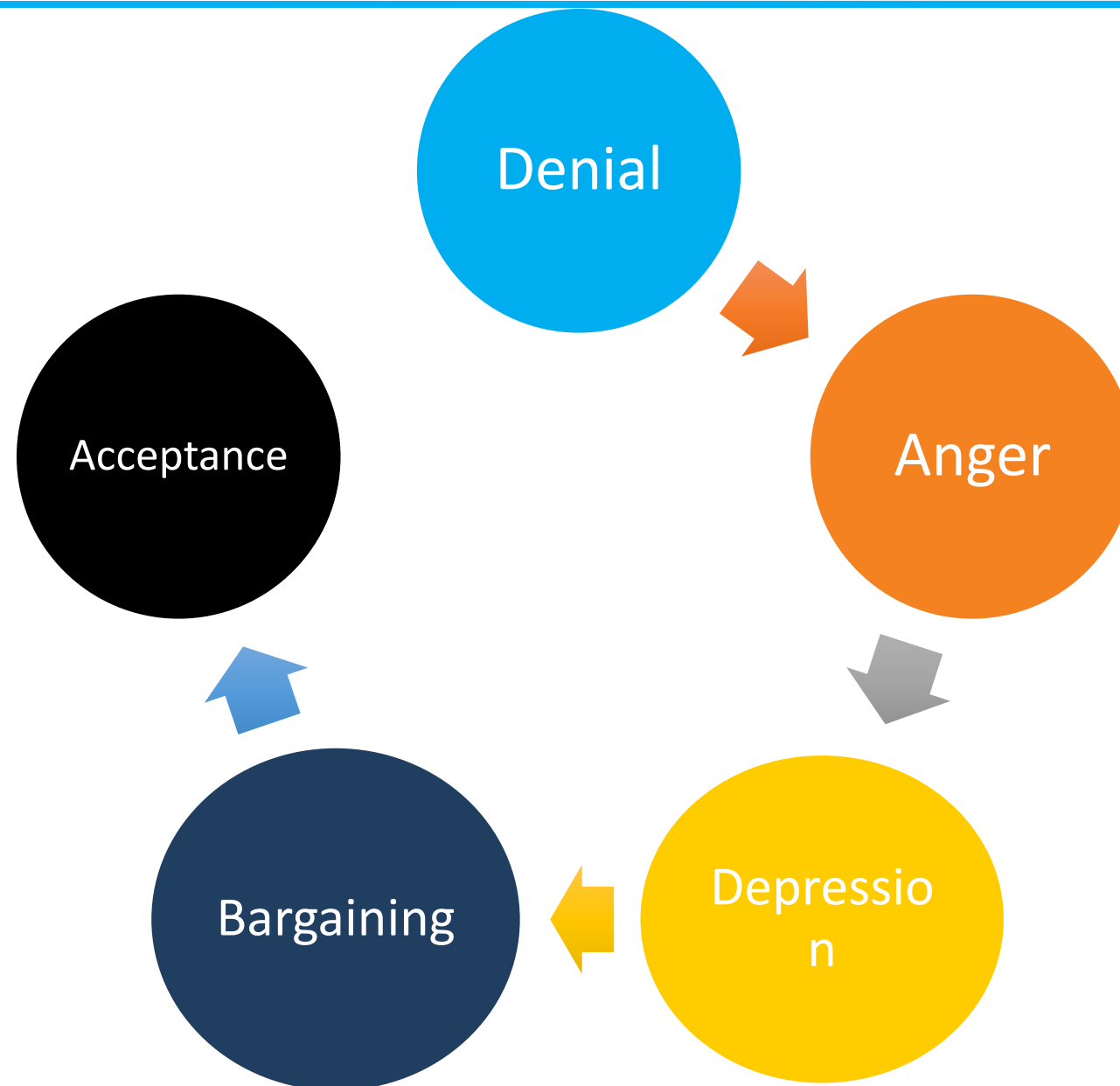
... وللطبيب في حالة الأمراض المستعصية أو التي تهدد حياة المريض بالخطر- أن يقدر وفقاً لما يمليه عليه ضميره مدى ملاءمة إبلاغ المريض أو ذويه بحقيقة المرض وذلك ما لم يكن المريض قد حذر عليه ذلك، أو عين شخصاً أو أشخاصاً يقتصر الإبلاغ عليهم.

Article 18: The doctor can assess, in untreatable diseases or those that endanger the live of the patient, following his conscious, whether it is in the patient's best interests to tell the patient or his/her family members with the nature of the condition, except if the patient asked the doctor not to; or if the patient has named specific person(s) to be told

How do/can people react to bad news?

BREAKING BAD NEWS USING THE SPIKES PROTOCOL





5 Stages of Grief and Loss –Kubler Ross Model

DENIAL	Person denies the facts when he receives bad news
ANGER	Becomes angry, irritated, jealous and resentful
DEPRESSION	Feelings of helplessness develop May take refuge in drugs
BARGAINING	Tries to get away from the truth in different ways
ACCEPTANCE	Accepts the fact that there is no more hope

Five stages of grief & loss model

- **Stage 1: Denial (الانكار)**

Initially, people are shocked when they receive bad news as general defence mechanism.

At the end of this stage, the person will start searching for facts, the truth of for someone to blame.

- **Stage 2: Anger (الغضب او رد فعل عاطفي آخر) or other emotional reaction)**

When someone can no longer deny what is happening, feelings of anger, irritation, jealousy and resentment arise (Sometimes directed at the bearer of the bad news.)

Five stages of grief & loss model

- **Stage 3: Depression (الإحباط - الاكتئاب)**

During this stage, the person involved feels helpless and misunderstood. There is a chance that they could take refuge in alcohol and drugs.

- **Stage 4: Bargaining (المساومة – البحث عن مخرج)**

At this stage, people are trying to get away from the dreadful truth in many different ways. This stage involves bargaining.

- **Stage 5: Acceptance (القبول والاستمرار في الحياة)**

When the person involved becomes aware of the fact that there is no more hope, they can accept the bad news and accept their grief. they will feel like taking up activities again and they will start making plans again.

How to break bad news?

SPIKES

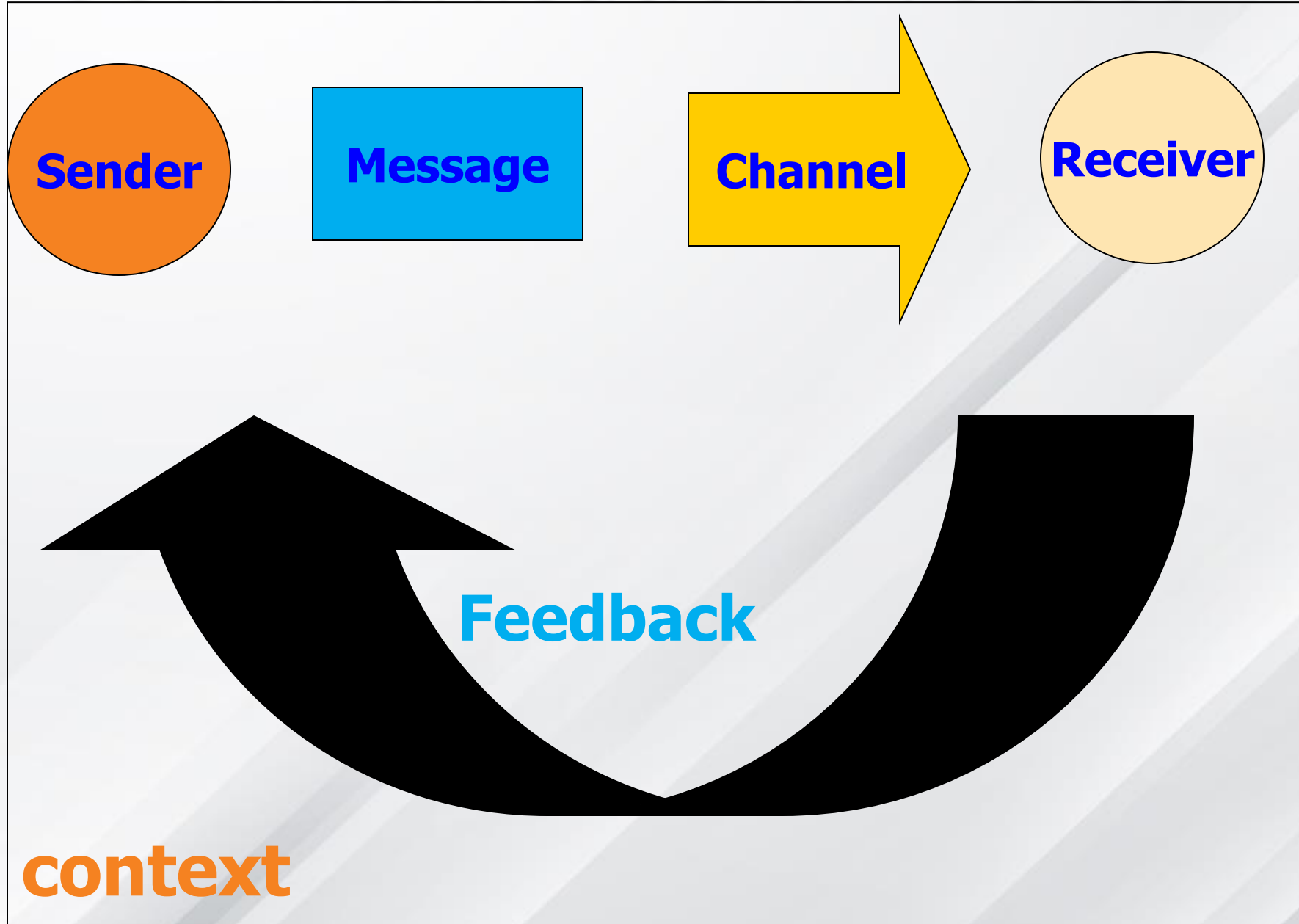
ABCDE

BREAKS

Calgary-Cambridge Framework



Communication Process



Practical approaches to BBN

SPIKES	ABCDE	BREAKS
Setting and Listening Skills Patient Perception Invitation to Give Information Knowledge Explore Emotions & Empathize Strategy and Summarize	A- Advance Preparation B- Build environment/ relationship C- Communicate well D- Deal with reactions E- Encourage & validate emotions	B – Background R – Rapport E – Explore A – Announce K – Kindling S – Summarize

SPIKES Approach (1)

- Setting and Listening Skills

- Physical space
- Body language and eye contact
- Positioning friends and relatives
- Open questions
- Facilitating: pausing, silence, nodding
- Clarifying
- Handling time (إدارة الوقت)

- Patient Perception

- Ask patient what they know, feel, fear, etc.

- Invitation to Give Information

- How does the patient want to be involved in decision-making

SPIKES Approach (2)

- Knowledge

- Give information in small chunks (قطع صغيرة)
- Check the reception
- Respond to emotions as they occur

- Explore Emotions and Empathize (تعاطف)

- Identify the emotion
- Identify the cause or source of the emotion
- Respond to show you have made the connection

- Strategy and Summarize

- Propose a strategy
- Assess response
- Agree to a plan
- Give a summary
- Make contract for next visit

BREAKS approach

- **B –Background:** in-depth knowledge of the patient's problem, “googling”, Cultural and ethnic background
- **R- Rapport:** establish a good rapport with the patient (علاقة)
 - Unconditional (غير مشروطة) positive regard,
 - Avoid patronizing تحقير attitude
 - Avoid hostile عدواني attitude and hurried manner.
 - Provide ample space for the windows of self-disclosure to open up.
 - Comfortable position.
 - Physical set up is very important (e.g. physical barriers must be removed to maintain eye contact, switch mobile off, pagers)
- **E – Explore:**
 - Start from what the patient knows about his/her illness → confirming bad news rather than breaking it.
 - Avoid premature reassurance تطمين سابق لأوانه,
 - Avoid absolute certainties about longevity العمر المتبقي
 - Discuss the prognosis in detail

BREAKS approach (2)

- **A –Announce:**

- A warning shot **طلقة تحذيرية** is desirable
- Avoid lengthy monolog, elaborate explanations, and stories of patients who had similar dilemma **معضلة**.
- Information should be given in short, easily comprehensible **مفهومة** sentences.
- Do not give more than three pieces of information at a time

- **K- Kindling:**

- People listen to their diagnosis differently (anger, denial, tears, silence, humor?). Be ready.
- Ask the patient to recount what s/he has understood.
- Do not to utter any unrealistic treatment options
- Beware of the “differential listening,” **سماع انتقائي** (patient will listen to only those information he/she wants to hear.)

- **S –Summarize:**

- Summarize the session and the concerns expressed by the patient
- Treatment/care plans for the future has to be put in nutshell.
- Offering availability anytime and encouraging the patient to call
- The review date also has to be fixed before concluding the session.
- Secure the patient’s safety (e.g. driving back home all alone → suicide?!

Back to the Communication Cycle

Sender	Message	Context
• Prepare yourself	• “shot across the bow” طلقة تحذيرية	• Don't stand
• Know about the condition	• Avoid jargon (ascites, metastasis, etc.)	• Not in the corridor!
• Know about the pt.	• Give in 'chunks' (pause, look, ask)	• No phone, no pager
• Alert to feedback (nonverbal)	• Not the whole truth at once	• Privacy
• Passionate	• Facts (less opinions)	• Comfortable seating
• Give time (Qs & emotions)	• End with a plan	• Emergency

What makes BBN difficult?

• Ideas?

- Uncertainty about the patient's condition & expectations
- Fear of destroying the patient's hope
- Fear of patients' inadequacy in the face of uncontrollable disease.
- Fear of patients' anticipated emotional reactions.
- Embarrassment at having previously painted too optimistic a picture for the patient
- Lack of self-confidence in conveying such news

Do Not's in the BBN

- *Do not* avoid seeing the patient or leave them anxiously waiting for news.
- *Do not* start giving information until it is required
- *Do not* hit and run
- *Do not* be non-judgemental (e.g. alcoholic cirrhosis or lung cancer due to smoking)
- *Do not* leave the hard job for someone else (your patient, your responsibility), unless necessary (examples?)

Do Not's in the BBN

- *Do not* share information (e.g. to relatives), unless appropriate and after consent
- *Do not* assume (mis)understanding
- *Do not* lie (really? ;)
- *Do not* give false hopes (science cannot always do miracles)
- *Do not* use terms such as “there is nothing more we can do for you”. be optimistic but do not promise success or anything else that may not be delivered
- *Do not* abandon patients after the BBN session لا تتخلى عن مرضاك

Useful resources

- **Breaking Bad News ...Regional Guidelines**, Developed from Partnerships in Caring (2000) DHSSPS (February 2003), http://www.dhsspsni.gov.uk/breaking_bad_news.pdf
- **'BREAKS' Protocol for Breaking Bad News**, Vijayakumar Narayanan, Bibek Bista, and Cheriyan Koshy (<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3144432/#CIT4>)
- **How to Break Bad News**, Edited by Horses4Ever, KnowItSome, Flickety, Dave Crosby and others (<http://www.wikihow.com/Break-Bad-News>)
- Silverman J., Kurtz S.M., Draper J. (1998) **Skills for Communicating with Patients**. Radcliffe Medical Press Oxford
- Buckman R. (1994) **How to break bad news: a guide for health care professionals**. Papermac, London
- Cushing A.M., Jones A. (1995) **Evaluation of a breaking bad news course for medical students**. Medical Education. 29: 430-35
- Maguire P., Faulkner A. (1988) **Improve the counselling skills of doctors and nurses in cancer care** BMJ 297, 847-849
- Sanson Fisher (1992) **How to break bad news to cancer patients. An interactional skills manual for interns**. The Professional Education and Training Committee of the New South Wales Cancer Council and the Postgraduate Medical Council of NSW Australia, Kings Cross, NSW Australia
- <http://www.alukah.net/culture/0/48344/#ixzz4RqU4EKeX>

Conclusion....Key messages

- ❖ **Prepare the patient**
- ❖ **Deliver information clearly and concisely**
- ❖ **Acknowledge emotions**
- ❖ **Maintain a calm and professional demeanor**
- ❖ **Check for understanding**
- ❖ **Offer support and resources**
- ❖ **Be honest and truthful**
- ❖ **Use the "SPIKES" protocol (or a similar framework)**
- ❖ **Consider the patient's perspective**

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Thank You