Principles of good HCP–patient communication

Professor Dame Lesley Fallowfield

SHORE-C

Brighton and Sussex Medical School, UK

Disclosures

- **Honoraria**: AstraZeneca, BeiGene, Eisai, Medscape, Pfizer, Veracyte, Exact Sciences, Novartis
- **Consultancy / advisory role**: AstraZeneca, Eli Lilly, Roche
- **Research**: AstraZeneca, Eli Lilly

Complexity of cancer

Better understanding of the genetics underlying molecular biology has facilitated many therapeutic advances in the past decade.

Better diagnostics and more targeted systemic therapies mean that more patients can survive well for longer.

But this is no longer simple to explain.

Patients experiencing emotional turmoil enter a strange new world with esoteric language and concepts.

Slide courtesy of Lesley Fallowfield.

This talk

General concepts about communication

Handling risk and uncertainty

Decision-making

Talking about trials

Psycho-social implications for communication with patients who have indolent cancers

Need for better educational programs for HCPs

Top tips and summary on communication about risk and uncertainty in hematological cancers

Slide courtesy of Lesley Fallowfield.

General concepts about communication

Benefits of good communication

Improves accuracy of data collection

Helps to draw out patients' problems

Affects adherence

Influences emotional and physical well-being

Improves the overall experience of care

Reduces risk of litigation and medical complaints

Reduces risk of burnout in HCPs

HCP, healthcare professional.
Slide courtesy of Lesley Fallowfield.

Many sad, bad, and complex areas

- Giving the diagnosis and prognosis
- Describing complex tests and treatments
- Talking about clinical trials and randomization
- Handling distressed patients and relatives
- Misinformation from the media or internet
- Transitions from radical to palliative care
- Dealing with unrealistic expectations
- Wanting unavailable novel drugs/treatments

Slide courtesy of Lesley Fallowfield.

Common communication deficiencies

Use of jargon

Talking at, rather than listening to; poor tolerance of silence

Incongruent non-verbal behavior

Failure to invite questions or check understanding

No summarizing of next steps

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Examples of unhelpful communication strategies

Patient – "Doctor, I'm so worried about my blood cancer getting worse without treatment now."

Subconscious or unrecognized communication behaviors include:

Avoidance

"When did you last have your bloods checked?"

Premature reassurance

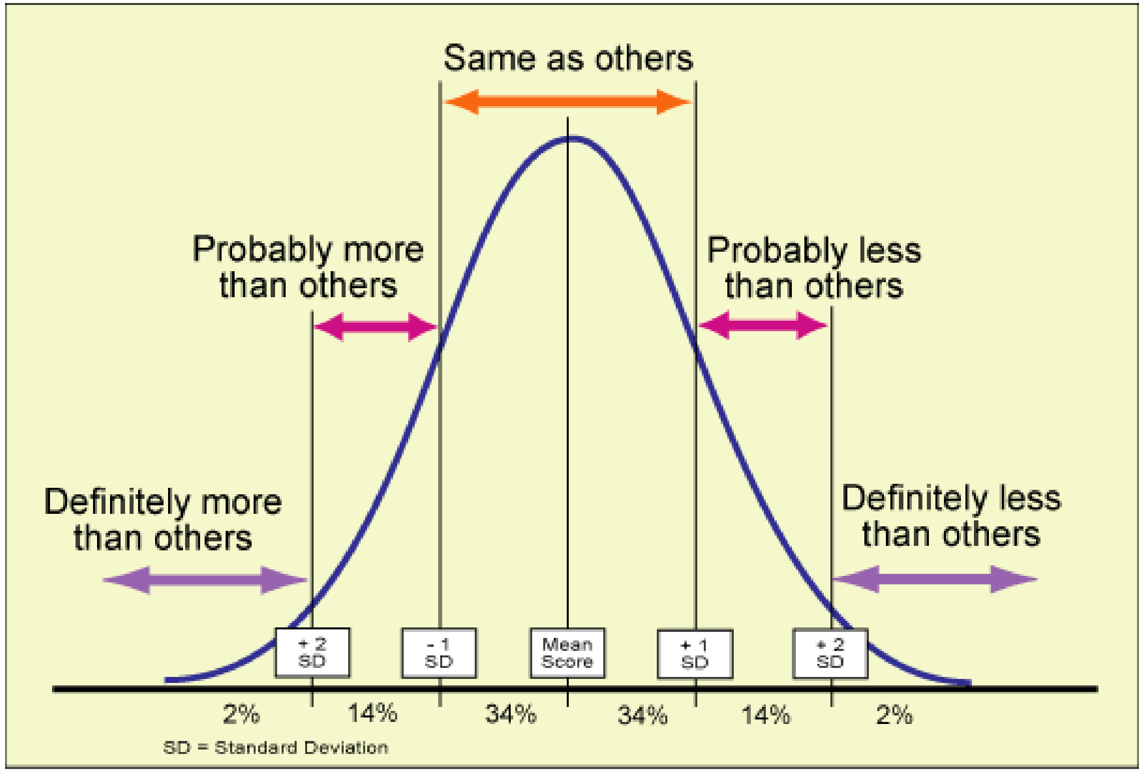
"I'm sure that won't happen any time soon, so don't worry."

Cold, professional detachment

"Well, it might, unfortunately; I don't have a crystal ball."

Slide courtesy of Lesley Fallowfield.

Predicting outcomes



- Prognostication is generally poor (arguably harder in hematology than in most other oncology areas)
  - HCPs often claim this is due to the unpredictability of cancer
  - If true, then a Gaussian curve would be expected, but error (90%) is in the optimistic direction
  - Better doctor knows patient in length and intensity of contact; more likely to overestimate survival[1] or be honest about prognosis[2]
  - ‘Doing something’ behaviors result, instead of the honest but painful conversations needed[3]

HCP, healthcare professional.
1. Christakis NA *et al. BMJ* 2000; 320 (7233): 469–472. 2. Fallowfield L *et al. Lancet Oncol* 2014; 15 (13): 1423–1424. 3. Fallowfield LJ *et al. Support Care Cancer* 2017; 25 (1): 237–244.
Slide courtesy of Lesley Fallowfield.

Handling risk and uncertainty

Discussing risk and uncertainty

Risk is a feature of everything we do in life and medicine

We hate uncertainty, but medicine is an uncertain science

Most facts are merely probabilities defined or refined by repeated hypothesis testing

Huge confusion exists about numbers, and health literacy and numeracy are poor

Much communication takes place against a background of fear and anxiety

Slide courtesy of Lesley Fallowfield.

Handling uncertainty

Uncertainty is a psycho-noxious experience for anyone

Even more difficult in the context of life-threatening disease to help patients feel reassured

Made worse when doctors' uncertainty extends to a choice of multiple treatments

Greater alarm if uncertainty involves watchful waiting or surveillance (perceived as no treatment)

Slide courtesy of Lesley Fallowfield.

Tolerance of uncertainty

Most patients would prefer that the benefits and harms of treatment options were definitive

Anxious patients have a low tolerance for ambiguity and uncertainty, which provokes fear, perceived vulnerability, and avoidance of decision-making

How tolerant both HCPs and patients are to uncertainty affects information exchange and decision-making

Less tolerant HCPs may order more tests or treatments[1]

Lower tolerance is associated with less likelihood of disclosing ambiguous results, extent of communicating uncertainty, and confidence with which it is discussed[2]

HCP, healthcare professional.

1. Luther VP *et al. Acad Med* 2011; 86 (7): 799–800. 2. Fallowfield L *et al*. *Breast Cancer Res Treat* 2019; 177 (3): 641–649.

Slide courtesy of Lesley Fallowfield.

Messaging format

Messaging formats affect **patients’ understanding** of harms, benefits, and risk perceptions, which influences behavioral intentions

People tend to **overestimate** harms presented in non-numeric formats and **underestimate** those in numeric formats

Personal experiences and an ability to **visualize** outcomes can be very influential

Slide courtesy of Lesley Fallowfield.

Need for good numeracy skills

Many scientific presentations/publications provide sub-optimal information about absolute risks and benefits

HCPs themselves have many misconceptions about AR and RR[1]

Doctors are more likely to recommend chemotherapy if data show RR, not AR or NNT[2]

Patients cannot make informed decisions if they have poor understanding about the AR with cancer treatments and the absolute harms of management described

AR, absolute risk; HCP, healthcare professional; NNT, number needed to treat; RR, relative risk.

1. Gigerenzer G *et al. BMJ* 2003; 327 (7417): 741–744; 2. Chao C *et al. J Clin Oncol* 2003; 21 (23): 4299–4305.

Slide courtesy of Lesley Fallowfield.

How good are you at interpreting numbers?

Imagine an RCT of novel drug vs. standard (N=2000)

Cancer deaths after 3 years: 40 in experimental arm and 60 in standard arm

Which of following statements are true?

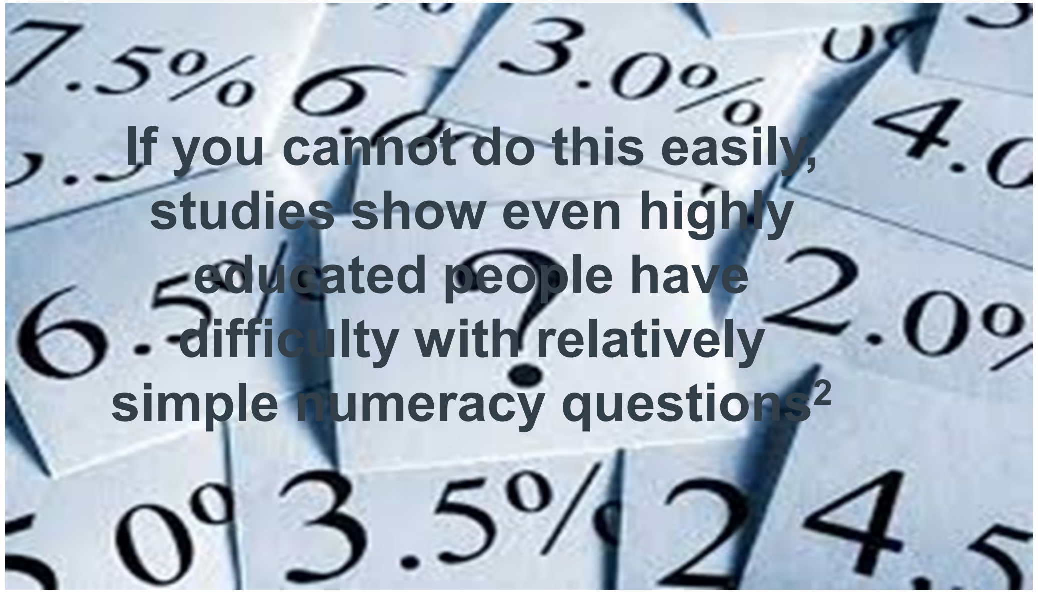
a) Deaths from cancer fell from 6% to 4%
b) Death rate fell by 2%
c) New drug can prevent 1/3 cancer deaths
d) Fifty patients need to take drug to save one life
e) These benefits may not be sustained with longer follow-up

RCT, randomized control trial.
Slide courtesy of Lesley Fallowfield.

Four-item numeracy (based on Schwartz *et al.*[1])

Basic probability:

- Converting % to a proportion
- Converting proportion to a %



If you cannot do this easily, studies show even highly educated people have difficulty with relatively simple numeracy questions[2]

A person taking Drug A has a **1%** chance of an allergic reaction. If **1,000** people take the drug, how many will have a reaction?

A person taking Drug B has a **1 in a 1,000** chance of an allergic reaction. What **%** of people taking the drug will have a reaction?

The chance of getting a serious viral infection is **0.0005**. How many of **10,000** exposed people might get the infection?

Imagine I flip a fair coin **1,000 times**. How many times will the coin land heads up?

1. Schwartz LM *et al. Ann Intern Med* 1997; 127 (11): 966–972. 2. Lipkus IM *et al. Med Decis Making* 2001; 21: 37–44.

Results from recent workshops for HCPs held in UK

Item (answer)	Oncologists (174)	Nurses (191)	Surgeons (167)
A person taking Drug A has a **1%** chance of an allergic reaction. If **1,000** people take the drug, how many will have a reaction? **(10)**	94%	76%	96%
A person taking Drug B has a **1 in a 1,000** chance of an allergic reaction. What **%** of people taking drug will have a reaction? **(0.1)**	82%	42%	74%
The **chance of** getting a serious viral infection is **0.0005**. How many of **10,000** exposed people might get the infection? **(5)**	68%	42%	66%
Imagine I flip a fair coin **1,000 times**. How many times will the coin land heads up? **(500)**	89%	76%	87%

HCP, healthcare professional.
Slide courtesy of Lesley Fallowfield.

Impact of numeracy on decision-making

Collective statistical illiteracy exists among society, patients, journalists, politicians, HCPs[1]

Risk usually presented as %. Study showed:[2,a]

- 20% didn't know which of 1%, 5%, or 10% was higher risk
- 30% unsure if 1 in 10, 1 in 100, or 1 in 1,000 were biggest risk

Written information – complexity of text and numerical formats often confusing

Icon arrays are easier to comprehend and more impactful than abstract numbers

Sometimes risk only discussed in terms of probability of occurrence, but need to focus more on probability and consequences

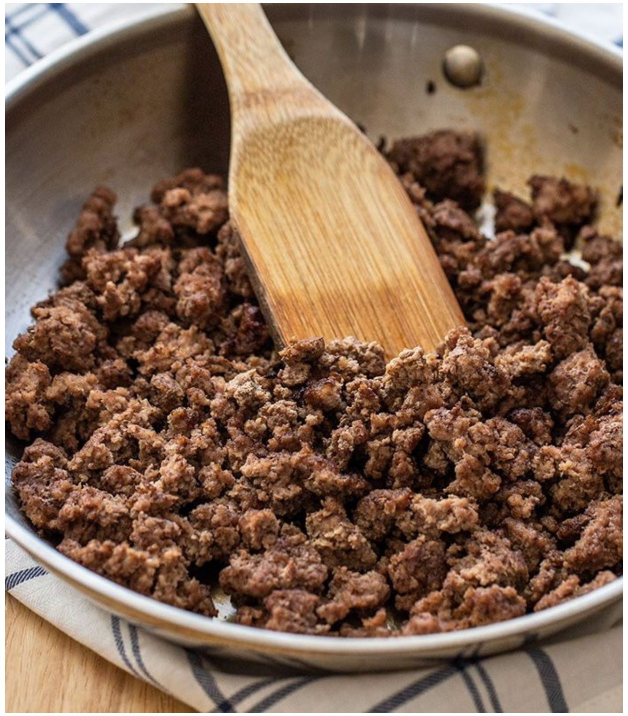
Low-numeracy individuals very susceptible to **framing effects**

[a] Representative national samples from Germany (n=1,001) and the USA (n=1,009). HCP, healthcare professional.

1. Gigerenzer G. *Arch Intern Med* 2010; 170 (5): 468. 2. Galesic M and Garcia-Retamero R. *Arch Intern Med* 2010; 170 (5): 462–468.

Slide courtesy of Lesley Fallowfield.

Framing effects



Framing influences opinion and choices

- Two groups had minced beef meal described as 75% lean or 25% fat
- The 75% lean group perceived meal as **less** greasy and **better** tasting than the 25% fat group
- Less-numerate individuals show stronger framing effects than high-numeracy individuals

Levin IP and Gaeth GJ. *J Consum Res* 1988; 15 (3): 374–378.

Ask the audience

Describing frequencies

You have received a prescription for a new drug to help with indigestion and learn that the side effects include:

Headaches

Constipation

Itchy rashes

Increased heart rate

These worry you, but your doctor explains that:

- Headaches are “fairly common”
- Constipation occurs “often”
- Itchy rashes are “unlikely”
- Increased heart rate is “very rare”

How many people out of 100 do you think get:

- Headaches …………
- Constipation …………
- Itchy rashes …………
- Increased heart rate …………

Slide courtesy of Lesley Fallowfield.

Expressing numbers

Verbal descriptors

‘Common’ or ‘rare’ are ‘elastic’ concepts that produce wildly differing estimates; overall risk grossly overestimated

Percentages confuse many

Especially if <1%

Natural frequencies work better

E.g. ‘affects fewer than 1 in 100 patients’

Combining a descriptor with a frequency is probably best

This is very rare;
it happens to fewer than
1 in every 100 patients

Helping patients to identify risks with other things they do or know about is also useful

Slide courtesy of Lesley Fallowfield.

How best to discuss numbers with patients

% (40) **Fraction (2/5)** **Frequency (4 in 10)**

Frequencies usually easier,
but remember denominator neglect; try to keep same one

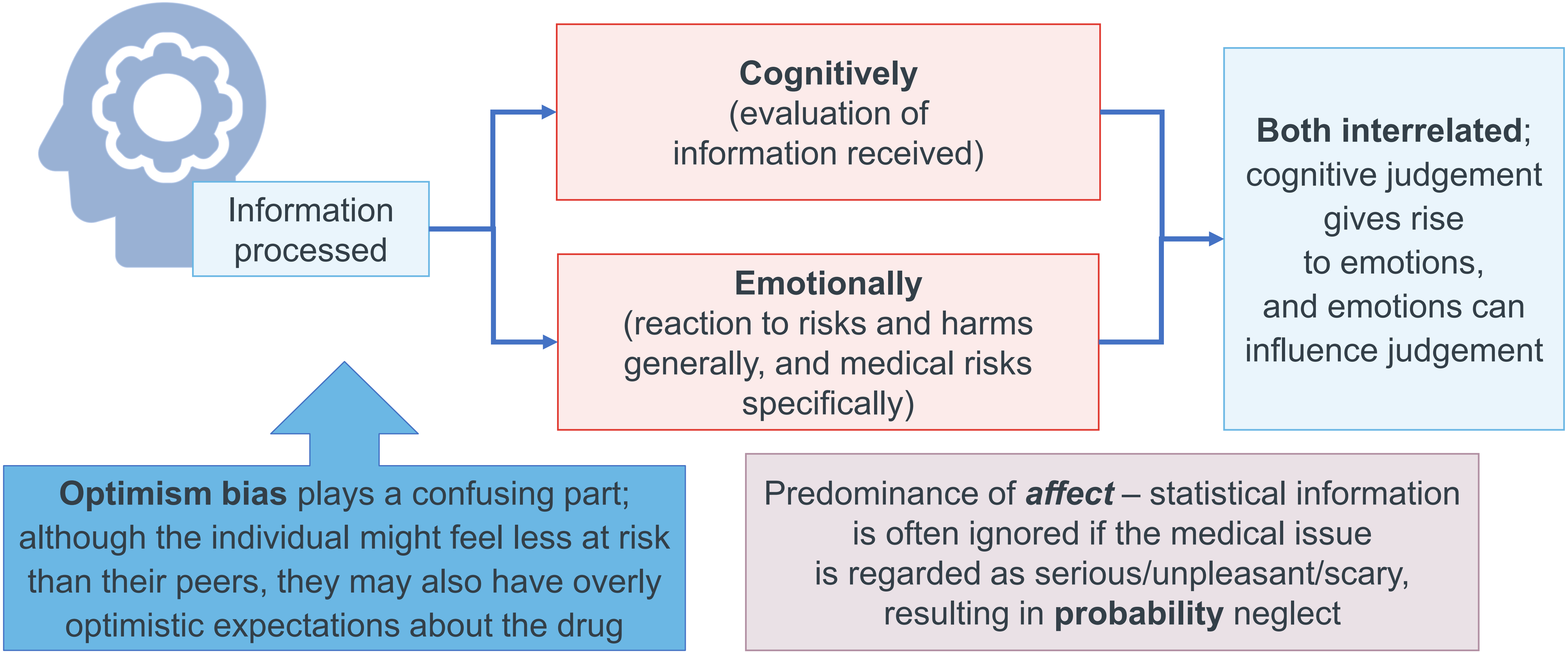
Instead of: *“with Drug A, around 5 in every 200 people get diarrhea, whereas with Drug B, 5 in 40 do”*

Compare Drug A (5 in 200) with Drug B (25 in 200)

Slide courtesy of Lesley Fallowfield.

Decision-making

Decision-making is rarely rational



Information processed

Cognitively
(evaluation of information received)

Emotionally
(reaction to risks and harms generally, and medical risks specifically)

Both interrelated; cognitive judgement gives rise to emotions, and emotions can influence judgement

Optimism bias plays a confusing part; although the individual might feel less at risk than their peers, they may also have overly optimistic expectations about the drug

Predominance of ***affect*** – statistical information is often ignored if the medical issue is regarded as serious/unpleasant/scary, resulting in **probability** neglect

Slide courtesy of Lesley Fallowfield.

Decision-making preferences

Passive	Doctor makes decision for me
Shared or collaborative	Doctor recommends treatment, taking account of my views
Active	Doctor offers information, but I make the final decision

Slide courtesy of Lesley Fallowfield.

What is ‘best’

Assumption that a shared approach is ‘best’ (value-laden assumption in itself)

Relationship is not usually symmetrical

Difficult for sick, anxious patients to convey values, lifestyle, and preferences unless there is active probing, so some decisions may seem irrational

Doctor has considerable power through knowledge and does not have to experience the consequences of treatment

Not easy to ‘share’ decisions if one has a clear view of what might be in a patient’s best interests

Slide courtesy of Lesley Fallowfield.

Patient expectations about decision-making

Ethical, legal, and social imperatives for autonomous, more collaborative decision-making, and shift toward more patient-centered care

Patients generally want more information and more overtly collaborative participation

Many putative benefits of improved information provision:

- Reduced fear and anxiety
- Less decisional regret
- Enhanced ability to employ coping strategies
- Better adherence to advice/management plans
- Improved overall quality of life

Slide courtesy of Lesley Fallowfield.

Giving complex information and dealing with information overload

The amount of information required for **educated, informed consent** is a problem:

Patient Information Leaflets and Informed Consent Forms (PILs and ICFs) may help, but research shows that few read them

Usefulness correlates with health literacy and numeracy, which are very low worldwide

A study of 154 PILs/ICFs showed that most were far too complex, with only 7.1% evaluated as ‘Plain English’[1]

Few complied with best practice literacy guidelines

Other research shows that the top reason for trial entry is ‘trust in the doctor’[2]

Implies that verbal communication has greater influence on patients’ decisions than written word

1. O’Sullivan L *et al*. *BMJ Open* 2020; 10 (9): e037994. 2. Jenkins V and Fallowfield L. *Br J Cancer* 2000; 82 (11): 1783–1788.
Slide courtesy of Lesley Fallowfield.

Health literacy and numeracy are low

Most health information leaflets are too complex for 43% of UK adults (61% if numeracy as well as literary skills required)[1]

One in five adults feels anxious when given numerical information[2]

Often, **irrelevant information** has more influence on those who are less numerate or who may make decisions based on less complete, poorly understood information

Only 49% have the expected level of numeracy of a primary school child[3]

Only 22% of working-age adults are functionally numerate[3]

HCPs must be able to convert numbers into concepts interpretable for individuals making personal risk judgements

HCP, healthcare professional.

1. Rowlands G *et al. Br J Gen Pract* 2015; 65 (635): e379–e386. 2. The Maths Anxiety Trust. Available at: https://mathsanxietytrust.com/index.html. Accessed December 2023. 3. National Numeracy. 2019 Autumn Report. Available at: https://www.nationalnumeracy.org.uk/sites/default/files/documents/Building_a_numerate_nation/building_a_numerate_nation_report.pdf. Accessed December 2023.

Slide courtesy of Lesley Fallowfield.

Enhancing decision-making

It is important that information is delivered to the patient in a kindly, well-paced, non-patronising manner that is appropriate for the individual. The patient will need information about:

- All options
- Therapeutic intent (cure, palliation, cancer control)
- What is involved: treatment regimens, visits required, length of treatment, associated risks, harms, putative benefits

Various studies in oncology over the past 20 years show a mismatch between patients' information/decision-making preferences and what actually occurs[1]

If information is insufficient, patients are easy prey for charlatans on Dr Google; some information is helpful or benign, whereas other information is dangerous or wrong

In general, social media can raise the treatment expectations of patients and relatives

[1] Tariman JD *et al*. *Ann Oncol* 2010; 21 (6): 1145–1151.
Slide courtesy of Lesley Fallowfield.

(Mis)information from the media/internet

Patients may access information from a variety of sources that may undermine that given by health carers

Some sites often make treatments seem fairly straightforward

Newspaper articles and the media describe the latest ‘wonder’ drugs, which might have only just finished Phase I/II trials

Typing *“which is the best treatment for CLL”* into Google in Nov 2023 produced >9 million hits. The first one was a center offering ‘cures’ without chemotherapies

CLL, chronic lymphocytic leukemia.
Slide courtesy of Lesley Fallowfield.

How to help

Get a motivated person in your team to look up treatment on the internet

Recommend certain ‘approved’ sites, but check them – they do not always have the same information that you have given out!

Read the newspaper articles and consider responses as a team if patients query treatment

Make sure that even peripheral MDT members are aware of the principles of the trial

MDT, multidisciplinary team.
Slide courtesy of Lesley Fallowfield.

Talking about trials

Randomization issues

Patients are rarely familiar with scientific methodology

Some may be quite suspicious about reasons for a no-treatment arm

Others may have clear preferences for an arm, which might not be available outside the trial setting

Slide courtesy of Lesley Fallowfield.

Difficult communication areas

Handling the uncertainty and anxiety about ‘best’ treatment

Giving complex information and dealing with information overload

Dealing with (mis)information, from social media and well-meaning friends

Explaining randomization

Slide courtesy of Lesley Fallowfield.

How to describe randomization

Paucity of research on the ‘best’ way to describe randomization

We surveyed 200 patients’ and 341 lay people’s preferences, then compared these with the preferred practice of 200 clinicians[1]

Patients and lay people most disliked the analogy ‘tossing a coin’, although this was most used by 26% of oncologists

The preferences of 600 heterogeneous patients using actual descriptions of randomization from an ongoing trial informed consent form showed:[2]

- Most disliked was technical, complex language from an NCI website (too complex)
- Most preferred description was from a cancer charity (giving reason for randomizing)

NCI, National Cancer Institute.

1. Jenkins V *et al*. *Br J Cancer* 2002; 87 (8): 854–858. 2. Jenkins V *et al*. *Br J Cancer* 2005; 92 (5): 807–810.

Slide courtesy of Lesley Fallowfield.

Cancer charity description

"Once you have agreed to enter the trial, you will be randomized to a course of treatment. This means that a computer will randomly allocate patients to treatment groups in the trial. This is done so that each group has a similar mix of patients of different ages, sex and state of health"

Jenkins V *et al. Br J Cancer* 2005; 92 (5): 807–810.

How to help minimize the anxiety

1) Start with issues that are clear and permit a **‘platform of certainty’**

“Having looked at all your test results and examined you, we know from all the research done that the best way to deal with this type of cancer is [standard therapy] *and so that is what we can offer you today.”*

2) Then move on to describe the trial

“We are always trying to find ways to improve how we treat this disease, so some of the best experts have designed a research study / clinical trial to do this. Would you like to learn more about the research?”

Slide courtesy of Lesley Fallowfield.

Psycho-social implications for communication with patients who have indolent cancers

What patients think about ‘watch and wait’ management

HCPs understand the logic for ‘watch and wait’ (W&W)/ active monitoring (AM) policies in chronic hematological cancers with their relapsing and remitting pathway

In the context of life-threatening disease, it is difficult for patients to be told that their cancer is incurable but treatable, and that they will only be given treatment at signs of progression to produce remission or improve quality of life

It is important to help patients understand potential iatrogenic harms associated with active treatment

HCP, healthcare professional.
Slide courtesy of Lesley Fallowfield.

Reactions and expectations of patients after diagnosis

Fear

Surprise at life-threatening diagnosis (especially if asymptomatic)

Incredulity of leukemia diagnosis but not being given treatment

Suspicions at no treatment being given – is this due to financial constraints?

Difficulty explaining no treatment to others

“Am I ill or not?”

Slide courtesy of Lesley Fallowfield.

During active monitoring

Patients report anxiety and some confusion as to what to look for

Studies show some experience a sense of abandonment,[1] feel ‘cast adrift’ and dislike apparent casualness, cursory lack of concern when seen – *“I am more than just a blood test”*

Difficult for friends and family to understand *“you don’t look like you have cancer”* so peer group support important

Misunderstanding of others that symptoms can affect their role and responsibilities even though no treatment, so important to give information to family

Patients describe **liminality:**[2] the transition between wellness and illness that limits their adaptation

1. Russell K. Exploring the Psychosocial Needs of Adults with Haematological Cancer Under Watch-and-Wait. Doctoral thesis. Available at: https://eprints.nottingham.ac.uk/73966/1/BRP%202223%2020315322%2019777779%20Final%20Thesis.pdf. Accessed: February 2025. 2. Stenner P *et al. Int J Environ Res Public Health* 2023; 20 (11): 5982.
Slide courtesy of Lesley Fallowfield.

Anxiety and depression in patients undergoing treatment or W&W management

A systematic review involved 18 studies measuring psychological morbidity in 2,720 patients undergoing treatment or W&W.[1]

	W&W	Treatment	*P* value
Anxiety (n=2,520)	24.5%	34%	0.195
Depression (n=2,720)	16.1%	31.3%	<0.05

- No significant difference in prevalence of anxiety between W&W and treatment[1]
  - Anxiety prevalence was higher in both groups than in a previous report for the general population (7%)[2]

- Depression prevalence was significantly higher with treatment than with W&W[1]
  - Depression prevalence was again higher in both groups than in the general population (5%)[2]

W&W, watch and wait.

1. Russell K *et al. Eur J Cancer Care (Engl)* 2022; 31 (6): e13678. 2. Steel Z *et al. Int J Epidemiol* 2014; 43 (2): 476–493.

Slide courtesy of Lesley Fallowfield.

Summary of psychological morbidity and implications for communication and support

Living with a chronic hematological malignancy has a negative impact on quality of life for patients undergoing W&W management or active treatment[1]

The apparent equal levels of anxiety irrespective of management policy is likely due to the threatening and uncertain nature of a cancer diagnosis for both groups

Higher depression in treatment groups than in W&W groups is possibly due to the perception that illness is now more severe

W&W is in contradiction to early intervention cancer policies for many countries and challenges lay expectations

Less frequent contact may exacerbate patients' feelings of vulnerability

Undoubtedly, more research is needed on interventions, maybe peer group support to help patients

W&W, watch and wait.

[1] Youron P *et al*. *Eur J Haematol* 2020; 105 (6): 755–762.

Slide courtesy of Lesley Fallowfield.

Need for better educational programs for HCPs

HCP, healthcare professional.

Training programs

There are plenty of communication skills programs, but evidence for transfer of skills to the clinic is lacking for many

More work is needed to ensure that conversations about serious illness are done well and occur earlier

They must include patient-centered domains

And take some account of the emotional toll on professional caregivers

Slide courtesy of Lesley Fallowfield.

Personal and professional boundaries

Effective communication is a core clinical skill with beneficial impact on HCP–patient relationships

Training should help doctors to communicate in a clear, honest, and empathic manner

Training must include something on navigating boundaries between personal and professional involvement

Encouraging doctors to get closer to the emotional needs of patients and carers puts doctors at psychological risk

HCP, healthcare professional.
Slide courtesy of Lesley Fallowfield.

Displaying empathy

Empathy and emotion are different

Empathy requires understanding of **a patient's** emotions or state of mind

Emotions are focused entirely on **one's own feelings**

Consequently, it is possible to:

- Be empathic without showing emotion
- Show emotion but not be empathic

Slide courtesy of Lesley Fallowfield.

Top tips and summary on communication about risk and uncertainty in hematological cancers

How to help

- Ethical requirement that information is standardized, but individuals’ needs differ depending on literacy / personality type, etc.
- Remember to signpost, group facts, check understanding, and summarize
- Acknowledge both patient anxiety and the volume of information; encourage patients to ask questions
- Ensure that all members of the MDT are on message

MDT, multidisciplinary team.
Slide courtesy of Lesley Fallowfield.

Rehearse difficult conversations

I wish you could just tell me what is best to do?

"I'm sure this is difficult, but if we knew exactly what might be best, we wouldn't hesitate to tell you. This is why we'd like you to consider entering the … trial, so that we'll be better able to advise patients in the future. Tell me what concerns you most and we'll try to help you make a decision that feels right for you."

I just don't like the idea of 'doing nothing'…

"Rest assured we'll not be 'doing nothing'. Active monitoring means careful assessment at each appointment and if it becomes clear that further treatment is needed, we will offer you that."

What if I don't do anything now and the cancer progresses?

"This is understandable, but if there are any signs of progression that would be helped by treatment, then the active monitoring will pick it up. Furthermore, if there is no progression, then you will have been spared unnecessary treatment."

Slide courtesy of Lesley Fallowfield.

Optimal communication

- Starts with a platform of certainty about the issues that are clear before moving on to uncertainty
- Grounded, credible, reality-based possibilities of likely outcomes with different treatment(s) should be offered; discuss the risks, not just the benefits
- HCPs must know the data and question their own motives for any recommendations
- Remember the poor health literacy and numeracy skills of most patients
- How familiar you become with medical concepts and terminology which are uninterpretable by patients

HCP, healthcare professional.
Slide courtesy of Lesley Fallowfield.

Communication considerations with patients

Many words and phrases are meaningless, counterintuitive, or ambiguous; numeracy and literacy levels are low

Health literacy affects retention of results and capacity for processing, understanding, and decision-making

Lay populations, especially if anxious with low tolerance for ambiguity, believe, in the context of life-threatening disease, that more treatment is better than less

HCPs' own communication about risk, harms, and benefits is subject to unconscious biases and misunderstandings

Need improved strategies when explaining things (otherwise, patients are probably not making informed choices about options)

HCP, healthcare professional.
Slide courtesy of Lesley Fallowfield.

Rob Buckman (1992)

"Almost invariably, the act of communication is an important part of the therapy: ***occasionally it is the only constituent****.*

"It usually requires greater thought and planning than a drug prescription, and unfortunately it is commonly administered in subtherapeutic doses."

Buckman R. Communication in palliative care: A practical guide. In: Oxford Textbook of Palliative Medicine. 2nd ed. Oxford University Press; Oxford, UK, 1998.

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SHORE-C

Sussex Health Outcomes Research & Education in Cancer

Slide courtesy of Lesley Fallowfield.