

Bridging the communications gap

How to build a dialogue with shocked, scared and sad patients

→ Anna Wagstaff

To give top-quality care an oncologist must understand the slightest changes in tumour characteristics. But when it comes to understanding human reactions and emotions, some scarcely know where to start. Doctors who want to explain treatment options or break bad news must first learn to make human contact with the patient.

What do you do if you are trying to explain the details of a cancer diagnosis and the pros and cons of treatment options, and you notice that your patient is fighting back her tears, clearly unable to focus on a word you are saying? You are running late and have several patients waiting. Do you:

- plough on regardless, and resign yourself to the fact that only a small proportion of what you are saying will be heard, understood and retained?
- adopt a positive, upbeat tone, even if that gives a more optimistic gloss than you feel is warranted?
- tell your patient it is normal to feel emotional in these situations, pause to give her time to collect herself, and then carry on where you left off?
- take time out to focus on your patient's feelings, invite her to talk about what lies behind them, try to

clear up any confusion and misperceptions, and show that you have understood her fears and concerns? This is not the sort of multiple-choice question you are likely to encounter in a medical oncology exam. Yet the dilemma is one that all medical oncologists are guaranteed to meet time and again, and a growing body of evidence suggests that finding effective ways to handle such encounters is very important for doctor and patient alike.

Over the course of their professional career, a medical oncologist will conduct on average around 100,000 patient consultations. It is estimated that 20% of these will involve difficult communications, where the doctor has to impart often complex information that is upsetting to their patient, and must find ways to engage them (to the extent that their patient wishes to be involved) in discussing options, and deciding on how to proceed.

Telling a patient he or she has cancer is only one of a succession of stressful en-

counters. Doctors may have to tell their patient that they need further diagnostic tests, that their cancer has recurred, that the treatment has failed to produce the intended result, or that no further options exist for curative treatment.

Even where the news is not so bad, matching medical and technical information about the disease and treatment options with the patient's personal preferences and priorities takes great skill. A frenetic working environment and the personal stress on doctors themselves can combine to make this task even harder.

BARRIERS TO COMMUNICATION

Time, or lack of it, is one problem. There is good evidence to show that communicating well takes very little extra time in a single consultation, but often saves a lot of time in the longer run. Nonetheless, it may not feel that way to a doctor who is under pressure. A related problem is the high efficiency and strict routine that hospital life requires from doctors.



LWA-SHARIE KENNEDY/CORBIS

“Protective families often pressurise doctors to lie to the patient about their diagnosis and prognosis”

Oncologists who are unable to slow down and focus their mind entirely on the patient in front of them tend to lecture and lack the listening skills to tailor their language, the type of information they give and the way that they give it.

Life experience is another factor. Oncologists' first experiences of such consultations comes when they are relatively young, and unlikely to have much experience of traumatic events within their own lives. Feelings of guilt or inadequacy that they have somehow let down a patient, or frustration that they could not deliver in the face of unrealistic expectations, can also complicate communications.

As medical practice has shifted from 'doctor-knows-best' towards a partnership between doctor and patient, this process of communication has come under increasing scrutiny. The rapidly developing discipline of psycho-oncology has amassed a substantial body of evidence that reveals three key points.

- The ability to communicate well with patients is a major source of job satisfaction to doctors, and protects them from stress, a low sense of personal accomplishment and burnout.
- Cancer patients place a very high value on their doctor's ability to communicate on the medical/technical and personal level; good communication helps them grasp complex information, which promotes a sense of control, makes them more likely to adhere to treatment advice, and helps them adjust psychologically to having cancer.
- Good communication can be learned, to the benefit of doctors and patients alike.

SWAYED BY THE FAMILY

Europe has been divided in its practice in communicating with cancer patients. Medical culture in northern Europe places a strong emphasis on truth telling and the patient's right to know. In southern Europe, 'paternalistic benevolence' remains strong, allowing doctors to decide what their patient should or should not be told.

Though the medical culture in southern countries has been changing in favour of greater honesty, protective families often exert pressure on doctors to lie, or at least obfuscate, when telling a patient about their diagnosis and prognosis. A recent survey conducted by the European Society for Medical Oncology (ESMO) revealed that many doctors, particularly in southern and eastern Europe, accede, at least in part, to the family's wishes rather than giving their patient an opportunity to decide what level of information they want.

Even among doctors with a strong commitment to telling the truth, many find this stressful and difficult. A survey conducted at an ASCO meeting revealed that more than two-thirds of the oncologists felt uncomfortable dealing with the emotional response of their patients. This discomfort tends to increase the longer the doctor has known the patient; studies have shown doctors are less honest with patients they know well.

An association has also been found between how difficult doctors find it to tell someone that they have run out of curative options, and a tendency to prescribe third- and fourth-line treatments where there is no evidence that this will be of benefit.

In the opposite corner are the doctors who cope with the emotional challenge by telling the truth in a very 'clinical' fashion, and insulating themselves from their patients' feelings by effectively ignoring them.

Both strategies are flawed. Patients nearing the end of their lives have choices to make about how to spend the time that is left to them. Is their priority pain control, strengthening relations with loved ones, avoiding inappropriately prolonged treatment, or something else? Giving unrealistic prognoses or offering useless treatments 'to keep hope alive' could rob them of the chance to make those choices, while subjecting them to ineffective therapies that decrease the quality of their final weeks or months.

If you refuse to respond to a patient's grief, fear or shock, it makes it hard to discuss the best treatment option.

If, on the other hand, you can show your patient that you care about their fears and concerns, and will address them as best you can, your consultation will benefit in two ways. First, it will reconnect you with a patient who would otherwise be sitting in isolated misery fighting back tears – it would remove a block to communication. Second, when you then go back to explaining about 3-cm, ER+ tumours spread to two lymph nodes, your patient will be more likely to perceive the medical talk as of direct relevance to her, and make an effort to listen and understand. She has seen you are relating to her as a patient, not just a diagnosis.

There is evidence that patients pick up quickly when their doctor wants to avoid displays of emotion, and

they respond by clamming up. They feel less free to ask questions or say if there is something they don't understand, making any true doctor–patient partnership unviable.

BRIDGING THE GAP

Nathan Cherny, Director of the Cancer Pain and Palliative Medicine Service, Shaare Zedek Medical Center in Israel, says that countless patient surveys, including those from southern Europe, show that the vast majority of patients want to be told the truth, but they want information delivered with sensitivity and care.

“Universally, patients want empathic and sensitive physicians but they don't want physicians who lie to them. If truth is delivered with empathy and sensitivity, with a message that no matter how difficult the situation, we are here to help you, the patient comes away empowered by greater knowledge and secure that they have a safety net of committed physicians that care about their well being – that's a very powerful tool to deal with difficult situations.”

As chair of ESMO's Palliative Care working group, Cherny is currently spearheading attempts to bring communication skills to the top of the mainstream agenda. The recent ESMO survey on communication with patients showed some positive results.

“Overwhelmingly oncologists see they have a role beyond just giving chemotherapy, and this includes looking after quality of life of patients with advanced and incurable illnesses. But the survey also revealed that there is a gulf between what they believe and what they actually do, and ESMO is involved in trying to bridge that gulf.”

The ESMO working group meets in Lugano in June 2007 to draw up recommendations. Cherny says that formulating a universal strategy will be a challenge, given differences in resource

levels and cultures between countries and even between institutions and hospital departments.

He anticipates that the strategy will endorse a model of skills training developed by psycho-oncologists over recent years, which focuses on learning an empathic response to patient emotions, through practice in simulated scenarios (see *Tricks of the Trade*, pp 18-19).

A good example of this kind of approach is the online course on Communication and Interpersonal Skills developed by the International Psycho-oncology Society (IPOS) in collaboration with the European School of Oncology (ESO), which can be accessed in English, French, German, Hungarian, Italian and Spanish (with Portuguese and Japanese versions coming online

soon), via their websites, or directly at <http://tinyurl.com/2lx6t2>.

Similar approaches are described in the SPIKES protocol for breaking bad news, outlined in *The Oncologist* (Baile, Buckman and Lenzi, 2000), and the OncoTalk course modules developed with funding from the US National Cancer Institute (<http://www.oncotalk.info/>). These all stress that printed material and audiovisual courses can be a way in, but that learning the skills requires practice, preferably in simulated role-play with expert feedback.

The aim of these courses is not to co-opt doctors into fulfilling an emotional support role, but to equip them to communicate complex information and elicit patients' priorities and preferences in emotion-laden situations.

Training the doctor

When oncologist Lanie Francis felt she was losing focus on the caring aspect of her role, she opted for communications training...



“I have always seen effective communication as an integral part of doctoring, and one of the key reasons I chose the field of oncology, but I found myself overwhelmed by the technical demands of my fellowship. I increasingly understood how physicians learned to compartmentalise the job, and focus only on the treatment. Discussing the emotional aspects of disease and the possibility of death had become a disruption to my own delicate balance of time and emotional energy. I felt fortunate to be able to examine this uncomfortable shift in my frame of reference.

“I learned that what I always perceived as the emotionally draining aspects of oncology – getting close to patients to care and feel for them – were rewarding, renewing, ultimately energising.

“After completing the course, and practising my skills on real patients, it remains clear that these conversations are difficult to have... Still, I listen to myself speaking to patients and using the tools I learned. I feel less flustered and my words are less tangled. I can focus on the person across from me, and I find what they need from me in that moment – and that seems like progress.”

Précised from Lanie Francis, Learning to listen: a fellow's perspective, *Journal of Clinical Oncology*, 1 July 2006.

“Patients want empathic and sensitive physicians but they don’t want physicians who lie to them”

A CULTURE OF CARE

Communication skills can be acquired, but these techniques will only be effective if backed by a genuine commitment to building a partnership with the patient. Patients are quick to spot fakes and phonies.

Andrea Schumacher, clinical psycho-oncologist at the department of haematology and oncology, Münster University Hospital, in Germany, says good communication is largely a matter of good manners. “I think the routine of everyday work in the hospital means

[oncologists] have too many things to do, and therefore they lose touch. Many doctors tend to forget how to behave as normal human beings – they work very efficiently, but with the workload they have, many function almost as robots.

“A good step in the right direction is behaving in a culturally acceptable way. To have good manners. Before you enter a patient’s room, you knock, and then you say ‘Good morning’. And the first time you meet, you say your name and introduce yourself. So many medical people forget this. They don’t

intend to be nasty. But this of course is unacceptable to patients. It makes a patient into some sort of unvalued human being.”

Cherny, from ESMO’s Palliative Care working group, talks about the need to foster a strong culture of care in every facility. “In each department there is a culture of what is expected in terms of the way you communicate with people. This in itself is a very powerful influence on physician behaviour.”

While he strongly supports improving communications skills train-

TRICKS OF THE TRADE

The approach taken by the communication skills courses is to break down the process of patient consultations into a series of discrete steps, and to suggest techniques for accomplishing each one. One course uses the acronym CLASS: Context and connection, Listening skills, Addressing emotions, management Strategy and Summary.

Step one: concentrate on creating an initial rapport, leaving the brisk routine outside the consulting room, and show that, for whatever limited time you can spend with your patient, your focus is entirely on them. This includes providing a quiet and private setting, ensuring there will be no interruptions, giving your patient a warm greeting, sitting at their level, and plenty of eye contact.

Step two: Find out what concerns your patient most, and what they understand about their condition and expect from the next step in their care plan. This technique, known as “ask and tell”, is a good way to clear up misperceptions, adjust unrealistic expectations and get things straight before giving any additional information. Open questions are important here. Patients will be more likely to talk about their main concerns in response to the question: “Tell me how you are feeling today”, than, “Are you having any problems?” “What are you hoping for from this consultation?” will elicit more information than, “Do you understand why you have been referred to me?”

Step three: Respond to what the patient has to say. This can be one of the hardest parts to get right, because, whatever the situation, the doctor needs to find a way to be encouraging, hopeful and supportive, while also being honest. Empathy is the key here – the aim being to show patients you are in tune with the way they feel, without feeling obliged to make out that ‘it will all be alright’ or that somehow you can solve everything. Psycho-oncologists take this in stages. Start by identifying the emotion – is your patient sad, angry, shocked, relieved? Then try to figure out what lies behind the emotion, in case it is not obvious. It is worth asking the patient or hazarding an informed guess, e.g. “it looks like this came as a bit of a shock to you.” Finally, show the patient you have understood what they are feeling and why, and that you feel for them, e.g. “I know this isn’t what you wanted to hear. I wish the news were better.”

Step four: Jointly decide on a strategy. Explain the options open to the patient, recommend a course of action, and reach agreement. The key here is presenting information in a way that can be easily digested. Avoid medical terminology; talk in terms of the person not the disease; give information in small amounts, stopping frequently to ask what the patient has understood; avoid over-reliance on statistics; use graphics and patient-friendly tools see box, p 21.

ing in the core curriculum for doctors, he doesn't believe this alone will have the desired effect in the absence of a change of behaviour higher up the ranks. He stresses the need to train senior oncologists, who act as role models for the next generation and define the culture in their workplace.

"Where students see a disparity between what they are taught and what they see practised around them by people who are their role models, the implicit message is that what you are being taught is not important in real life. This is why the trickle-down approach is very important."

IPOS President Luigi Grassi, based at the University of Ferrara, Italy, endorses this approach. Together with Anna Constantini from the University La Sapienza in Rome and Walter Baile and Renato Lenzi from the MD Anderson Cancer Center in Texas, he has adapted the OncoTalk method of teaching developed

A step-by-step guide. This video shows a simulated scenario of breaking bad news to a prostate cancer patient using the SPIKES protocol. Viewers can hear an analysis of the interaction by playing the clip on the right. The image is taken from *A practical guide to communication skills in clinical practice* – a set of four CD-ROMs by R Buckman, W Baile, and B Korsch (Toronto: Medical Audio Visual Communications, 1998)

Step five: The consultation should end by ensuring the patient has understood what has been agreed, that they are clear about what will happen next, and that they (and their family) understand their role in terms of following the treatment plan, attending follow-ups, keeping an eye open for potentially serious symptoms and so on. They should also know how to get in touch with their medical team if they have any questions.

Breaking bad news

These protocols also address particular situations. The SPIKES protocol for breaking bad news is similar to CLASS and is increasingly used in the clinic. Here, S stands for setting up the interview, P stands for perception, I stands for obtaining the patient's invitation to give information, K stands for knowledge, E stands for emotions and the final S for strategy and summary.

Amongst refinements is the suggestion that the patient is encouraged to bring a close friend or family member. SPIKES acknowledges that different patients want different levels of information. Statistical information, for instance on average survival rates, is something many patients find undermining and unhelpful. However, many patients value, above all, a sense of being in control, and knowing all the details can help.

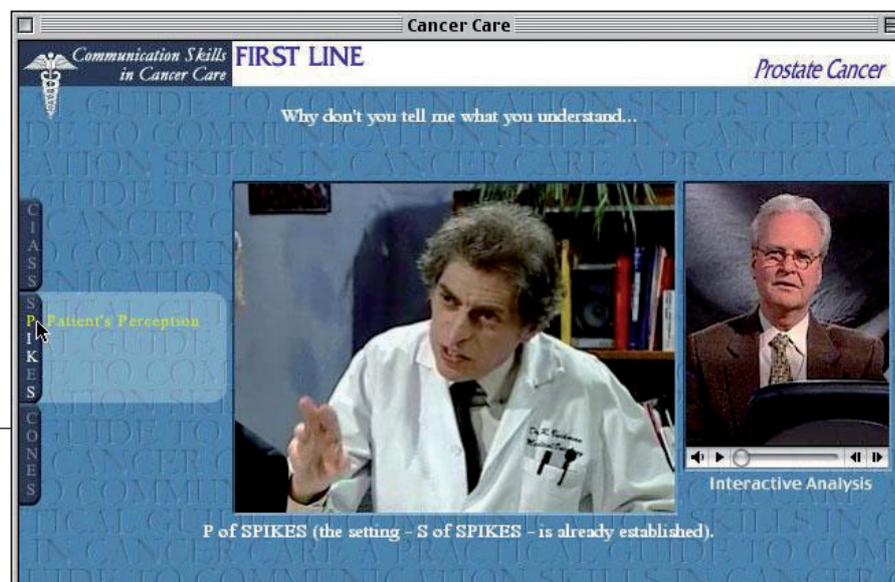
Warning patients that the news is not good – "I'm sorry to tell

you that..." – can help soften a blow. Doctors should avoid confusing bluntness for honesty. The focus should always be on what can be done to help the patient.

Telling a patient that strategies to control the cancer have failed is one of the hardest conversations a doctor can have. Patients want to believe there is some hope of a final reprieve, and doctors can find it hard to resist colluding by offering chemotherapy with no proven benefit, or playing up the prospects of a phase I or II trial.

Moving the discussion on to focusing on realistic options, and how to meet the patient's goals for his or her remaining life, whether surviving to see the birth of a grandson, preserving quality of life, or ensuring a dignified death, is a challenge.

The recommended techniques for doing this, and for talking about advanced care plans, hospice referral, do not resuscitate orders and other end-of-life issues, will be covered in a future issue of *CancerWorld*. A good introduction can be found in *Approaching Difficult Communication Tasks in Oncology* (Back, Arnold, Baile et al, *CA: A Cancer Journal for Clinicians* 2005) and in the relevant OncoTalk modules.



in the US for use in the Italian setting, and now teaches communication skills to oncologists from all over Italy. “We try to focus our attention on senior oncologists, in order to have a model for junior doctors. If senior oncologists do something that they value as improving their clinical practice, it is almost sure that young oncologists will learn the cultural atmosphere, and they will be motivated to attend workshops themselves.”

ENGAGING THE TOP BRASS

However, it can be hard to convince senior oncologists to attend a course to learn about something they have been doing all their professional lives.

Sylvie Dolbeault, head of the psycho-oncology team at the Institut Curie in Paris, has experienced the problem. Her team set up communications skills courses led by a specialist trainer with an actor playing the role of patient. The courses were designed around whichever scenarios the participants found hardest to handle, and they were a great success – for those who attended. “Our problem is that we did that for 18 doctors altogether, but we have 110 doctors here. We had to stop the programme because no doctors want to come.”

Dolbeault says that nurses show more interest in communication courses, but hospitals are often unwilling to give them the time or funding to attend.

Doris Schmitt, President of Germany’s largest breast cancer patient organisation, Mamazone, tells of a recent exchange about communication training with a senior doctor. “We don’t need it,” was the doctor’s opinion,

“because we are doctors.” Schmitt is a communications trainer by profession, and is herself a breast cancer patient. She became convinced that scared and shocked breast cancer patients have no chance of becoming real partners in care unless communication between doctor and patient is substantially improved.

“I first wanted to do seminars for doctors. But I realised that bad doctors would never come to my seminars. I realised that the better approach is to do seminars for patients because they are more interested and I can really assist them. And if they are stuck with a doctor who is very bad at communicating, they are trained, they will tell him, or they will leave him and see another doctor.”

Much to her surprise, she finds that doctors have been as enthusiastic about the results as the patients. “I feared they would all resist and say: ‘Here comes Jeanne D’Arc. She will whip our patients up into a fury.’ But they don’t. They say: ‘This is great, because we are very interested in informed consent, we are very interested in shared decision making, we are very interested in informed patients, because then we can talk together and decide, and compliance is better.’ Many doctors are saying ‘yes’ to these seminars.”

PATIENT PRESSURE

Patient pressure is making itself felt in other ways. Hospitals in France are paying increasing attention to evaluating patient satisfaction, with greater use of well-designed questionnaires, such as those developed for in-patients and out-patients by the European Organisation for Research and Treatment of Cancer

(EORTC). Dolbeault of the Institut Curie says that poor communication with patients and family consistently comes out as the main issue. “Before they were using very bad instruments that were not validated and which only said that satisfaction of patients was very good for everything in the hospital.”

Schumacher makes a similar point about Germany. “An increasing number of hospitals have started to use questionnaires that patients can fill out anonymously, so those hospitals get at least a rough idea about patient satisfaction. This is a good first step. Before, nobody noticed, nobody cared whether patients were satisfied or not.”

Patient pressure, notably arising from the patient parliament or états généraux in Paris in 1998, was a key factor behind the introduction of a ‘dispositif d’annonce’ – a blueprint for conveying information about a cancer diagnosis and treatment plan – which is codified in law as step 40 in the French cancer plan. The measure seeks to address many grievances expressed in patient testimonies. Patients had been informed of their diagnosis in a busy hospital corridor, by phone, or by a junior doctor who knew nothing of their case, and were left with no idea about what was going to happen to them, who would be responsible for their care, or what their outlook and options might be.

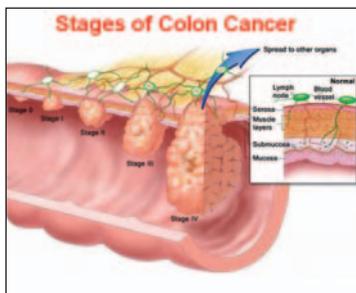
The dispositif d’annonce spells out the right of patients to be told about their diagnosis in a private setting, to be given adequate time to go through test results, and to see specified documentation regarding diagnostic tests and the recommended treatment plan.

“I realised bad doctors would never come to my seminars – the better approach is seminars for patients”

TALKING THE PATIENT'S LANGUAGE

Patients don't want to know about cancer. They want to know about *their* cancer, and what is the best management option for them. Good communicators tailor the information they have and the way they present it to the patient in front of them. The specific issue of communicating about risk and treatment options was also dealt with in a previous Grand Round (*CancerWorld* July–August 2006).

Statistics. Many patients find it easier to relate to concepts of 'low', 'medium' or 'high' risk than more precise numerical information. It's helpful to ask patients which they prefer.



This image, which shows different stages of colon cancer and is taken from www.adjuvantonline.com, is one of many online resources doctors can use to help explain to their patients the details of their diagnosis

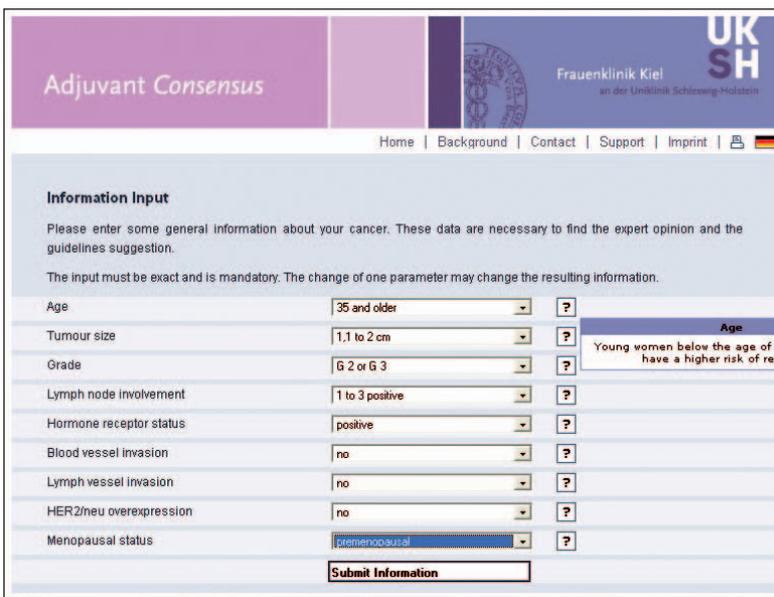
Language. If you are trying to give your patients the confidence to play an active role in their care, using medical terminology is counterproductive. Use 'spread', for instance, rather than 'metastasised', and watch out for phrases such as 'positive lymph nodes' – 'positive' equals 'good' in everyday parlance.

Graphics. Images are often more effective than words. Sketches can help show where and how invasive the cancer is, graphs can show how risk changes according to tumour characteristics and therapy, decision trees can help patients – and doctors – navigate through complex series of options

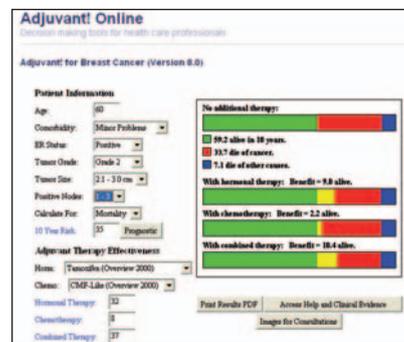
Interactive guidelines. In an effort to help his patients make informed decisions, Walter Jonat of the Kiel University

Hospital department of obstetrics and gynaecology has programmed in alternative decision-making algorithms, based on the latest St Gallen and the US NCCN [National Comprehensive Cancer Network] guidelines, respectively. Breast cancer patients can now visit www.adjuvantconsensus.com (the language adapts to the language of your browser), key in their tumour details, and find out for themselves exactly what the experts recommend. This simple tool, unveiled at the St Gallen conference in March, helps patients understand the basis on which treatment recommendations are made, and can provide a very effective starting point for discussing and deciding on management strategies. Jonat is keen to incorporate national and regional variants alongside the St Gallen and NCCN guidelines. It cannot be long before similar tools are constructed for other cancers.

Adjuvant consensus is not the first interactive tool for cancer patients. www.adjuvantonline.com pioneered this approach to enable doctors to show their patients a graphic representation of their risk of recurrence, based on individual prognostic factors, and the risk reduction that could be achieved by opting for various adjuvant therapies, or combinations thereof.



Interactive programmes, like www.adjuvantconsensus.com and www.adjuvantonline.com provide information on evidence-based treatment guidelines and evaluation of risk that is tailored to all the relevant prognostic factors of the individual patient's cancer



It also specifies that, immediately following this consultation, the patient should be seen by a nurse, who is responsible throughout the patient's time in treatment for assessing any needs for supportive care and making the appropriate referral. This includes psychological support as well as pain relief, nutritional advice, physical rehabilitation needs and even social and financial problems arising from their cancer diagnosis and treatment.

Dolbeault believes the *dispositif d'annonce* is a step forward, and has been accompanied by an increase in the number of psycho-oncology posts – around 180 new posts by 2006. But she worries that assigning a nurse to take care of psychosocial issues could let doctors who are poor communicators off the hook.

“Before, when there was no nurse, they were alone with the patients, so they knew that if they did not take care of psychological problems, nobody would. Now they know there will be another professional after them. So if they are not very willing or do not have time, or are under pressure for other reasons, they offload responsibility onto the nurse. And of course the patient will feel this very deeply.”

Grassi agrees that using legislation to force through change can be a mixed blessing and would like some leeway for physicians to exercise their own judgement.

“Sometimes patients show they don't want or are not able to bear the whole truth in the first interview, but they can be prepared gradually to have more information. So there can be laws saying what you should do, i.e. to inform

the patient, but finding the best way to inform the patient cannot be laid down in legislation; for this, specific courses in communication skills are needed.”

THE NEXT GENERATION

Grassi believes that the single measure that would most improve doctor–patient communication would be to include at least 50–100 hours of training by specialists in communication in the core curriculum in medical schools, and to consolidate this during residency programmes, with around 20–30 hours per year.

Very few countries currently provide this level of training. In the UK communication training has been taught as a compulsory and integral element of medical school for many years, using experience-based learning, role play and video. However, it is only very recently that a formal curriculum and evaluation method has been introduced into the medical oncology curriculum.

A similar level of provision exists in Switzerland, and Israel is rapidly moving in this direction. But most European countries have far fewer hours of the core curriculum devoted to communication skills, and what there is often relies heavily on lectures and theoretical work, which has been shown to be relatively ineffective. Many individual universities or cancer institutes have a strong tradition of teaching communication – such as Ferrara in Italy and the Institut Curie in France – but the majority of medical oncology students do not receive this training.

In France, second-year medical students get some teaching about ethics, but Dolbeault says this is almost

entirely theoretical and few doctors qualify with practical skills.

In Italy, most students do at least one course on clinical/medical psychology, psychosomatic medicine and psychiatry as part of the core curriculum, and Grassi believes this could provide an opening for introducing compulsory communications skills training.

In Germany communications skills training is not compulsory for medical students, and where it is taught, it is not evaluated as part of the student assessment.

AN INTEGRATED APPROACH

Cherny says the Memorial Sloan Kettering in New York is the only cancer centre, to his knowledge, to have instituted in-house training as an integral part of the whole facility; a core programme with a compulsory element for senior physicians, using simulated patients. “All senior consultants must go through the programme. For most trainees, it is currently an option.”

Some European centres seem slowly to be moving towards a general approach of integrating psycho-oncology and communication skills training into daily practice. The Institut Curie, for example, runs an internal communication skills programme, and employs an institutional psychologist, whose only responsibility is to help the medical staff, which includes individual supervision, group supervision, and teaching internees and students. She can also be called upon for immediate assistance in resolving specific communications problems.

Dan Stark, a medical oncologist who sits on the executive of the British Psychosocial Oncology Society, has

Local clinical psychiatrists provide drop-in, refresher and clinical problem-solving sessions

built a good relationship between his own department at St James' University hospital in Leeds and the local clinical psychology department. "Local clinical psychiatrists work with the oncology department in providing clinical services, they provide training to our trainees, and we have drop-in, refresher and clinical problem-solving sessions, which work very well."

At Schumacher's workplace, the Münster University Hospital in Germany, psycho-oncology is integrated into patient care by her presence at all multidisciplinary team meetings, although there is no communications skills training for trainees. "I go with the doctors on their rounds, and sometimes when we come out of a room I realise the communication was lacking. I can point this out to the doctor – and suggest ways they could have phrased it better. Usually doctors are very open about it, and are grateful that I point it out."

MOVING UP THE AGENDA

Grassi is confident that things are moving in the right direction. He believes the issue of how doctors talk to patients in the early, diagnostic, stage of cancer has moved up the agenda over the past 10 years, and he now wants to see similar attention being paid to the harder task of communicating with patients with more advanced disease.

The response to the IPOS online communication skills training course, so far tackled by 4,000 people, including medical students, oncology professionals, nurses and psychologists, indicates the level of interest. The problem is turning this interest into widespread attendance at competent skills training workshops.

Grassi's strategy is to foster strong networks linking psycho-oncology societies with medical oncology societies at a national level, "because medical oncologists are the people we want to reach." The locations of IPOS confer-

ences – Copenhagen 2004, Ferrara and Venice 2006, London 2007, Madrid 2008 and Vienna 2009 – were selected specifically to promote this sort of European networking.

Quite who will provide this training, and where, is another question. IPOS is thinking in terms of a travelling Psychosocial Oncology Academy that can link up with national oncology organisations.

Grassi stresses, however, that IPOS can only be a partner in this. "We have some skills that can be transferred to other people, but cancer care professionals, especially medical oncologists and palliative care specialists, are the

real protagonists, the ones working in the field. We can just help."

At a pan-European level, a good working relation with ESMO will be crucial. Grassi welcomes an invitation to do a joint symposium at ESMO's 2008 congress in Stockholm. Equally welcome is ESMO's commitment to move psycho-oncology and communication into the mainstream of oncology. It looks like the two societies may have plenty to communicate about, and Europe's patients may be able to look forward to moving several steps closer to their goal of becoming true partners in care.



Training the patient

Doris Schmitt is a breast cancer patient from Germany.

She started a communications skills course to help other patients play a greater role in deciding on their care

"Doctors and patients communicate on different levels. The doctor describes the therapy on a rational level, in his or her own language. On the other hand, the woman is captured in her feelings of fear and despair. Lack of knowledge about the disease often makes women speechless. I remember when I was diagnosed with breast cancer I thought, this is it, there goes my breast and maybe I am going to die. So I can really understand that it is very difficult to make a shared decision at that time.

"I realised that it is very important to receive risk-appropriate therapy, because there are different breast cancers. But I couldn't share a decision with my doctor because he couldn't tell me what I needed to know. It was from this experience that I decided to develop a communications course for patients.

"I start by asking: 'What is the name of your tumour?' Most patients hesitate and say, 'My doctor knows,' and I tell them, 'You have breast cancer, not your doctor. You should know.'

"I help them prepare for the doctors' consultation. 'Ask yourself: What would I like to ask my doctor? What do I want to achieve? What do I want from him? What will I do if he says no?' I tell them to make a list of subjects they want to talk about, and to have priorities, because doctors are always short of time.

"I tell them to feel self-confident. 'If you don't like the way your doctor is speaking to you, tell them. But there is a way to do it politely and not aggressively.'

"I want these women to learn they are clients, not victims, and if the doctor doesn't do a good job, they should change him."