

The news is bad... the message may be worse

→ Rhonda Siddall

Despite recognised regional differences in how doctors and patients deal with bad news, recent research shows every country has patients who seek information and others who avoid information, and doctors need training to cater for them all.

Telling a patient that cancer has spread is emotionally challenging. Torn between the desire to soften bad news and the duty to keep a patient informed, there is a risk of failing to communicate the gravity of the situation or alarming the patient to the point where it impacts on their care.

Too much information may bewilder and confuse; too little can leave the patient feeling lost and unsure. Too blunt a delivery seems cold and uncaring, while a gentler approach risks becoming patronising.

Patients differ in their attitudes to illness and their expectations of treatment.

However, Lesley Fallowfield, director of Cancer Research UK's psychosocial oncology group at the University of Sussex, UK, says there should be a presumption in favour of the truth. "Many doctors censor information on the basis of a misguided assumption that this is being kind."

Heide Preuss, aged 61, from Selm in Germany, was diagnosed with breast cancer in January 1995. She helped to set up the Mamazone group for women with breast cancer

who want to know as much as possible about their disease. Preuss said, "Doctors do not always understand the needs of their patients for information. Some doctors do not like their patients asking too many questions, so it is important that patients have other outlets for information."

However, Francesco de Lorenzo, president of the Associazione Italiana Malati di Cancro Parenti ed Amici (AIMaC), an Italian support group, says that patients vary in their need for information. "Some patients prefer to know everything, others would rather know nothing, and in between there are patients who want some information but only about certain aspects of their disease."

Given these scenarios, it is difficult for physicians to judge how much information is wanted.

While it has become accepted that most cancer patients want some influence over the management of their condition, patient surveys suggest that most prefer decision-making to be shared, with medical professionals making the final clinical decisions, after taking patient preferences into account.



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DOCTORS' PERCEPTIONS

Physicians are not always well equipped to determine exactly what their patients do want. Indeed, doctors' own attitudes often differ according to their training, cultural background, specialty and the stage and type of cancer they are treating.

This issue was highlighted earlier this year in a qualitative market research study on the management of bone metastases carried out for Novartis (*Zometa Insight Mining Research*. Synovate Healthcare, 2005). The study involved group discussions with oncologists, haematologists, gynaecologists and urologists from the UK, France, Germany, Italy and Spain, and one-to-one interviews with patients.

The discussions with doctors revealed wide regional variations in attitudes. Physicians in Spain were reluctant to use words such as 'cancer' or 'metastases'. One oncologist said:

"The word metastasis would scare them half to death even though most don't know what it is." In both Spain and Italy, physicians said they often give more information to the family than to the patient. Some doctors felt that the patient picked up messages from the doctor beyond the words being used. An Italian doctor said: "The patient will realise it is serious because my expression will change. I'll use a grave tone."

By contrast, doctors in the UK and Germany tended to focus on the facts. A UK oncologist said: "I'm a big believer in facts. You knock the patient down, then you build them up. You need to be honest." A German oncologist agreed. "It's important the patient understands exactly what is happening."

Antonella Surbone, who sits on the Educational and Ethics Committees of the American Society of Clinical Oncology

Some patients said people were less supportive once they heard the cancer had spread

(ASCO), believes that differences in the approaches taken by physicians reflect different cultural perspectives on the role of individuals and families.

“Truth telling to cancer patients is definitely related to cross-cultural differences. In countries such as the US, the UK and Germany, there is a strong emphasis on individual autonomy, which in the patient-doctor relationship is interpreted to mean patients expect to be fully informed and to be engaged with as equals. By contrast, in other cultures, more emphasis is placed on community and family values. Thus, in many countries, including Italy and Spain, doctors are expected to involve the family and to have a protective role towards their patients, especially when they are severely ill.”

BREAKING BAD NEWS

The Novartis study showed that information was usually provided ‘on demand’, and many physicians admitted to fudging or softening the truth to spare their patients’ feelings. The stronger the anticipated emotional reaction, the less the explanation.

Few physicians used any form of educational material. Many feared this would confuse or scare their patients and, instead, preferred tailored, personal explanations from healthcare staff. It was also felt that written materials would be only of benefit to younger and better-educated patients.

In the study a number of factors were shown to have influenced the way physicians broke bad news including:

- Age – younger patients tended to be better informed
- Gender – women tended to be better informed
- Socio-cultural level – higher-level groups tended to get more information
- Tumour type – information for breast and prostate cancer patients tended to be more upbeat, as it was felt these patients had better

prospects than those with multiple myeloma or lung cancer

- Cultural context – cancer becomes increasingly taboo towards southern Europe

Some physicians admitted that they found announcing the detection of bone metastases more difficult than delivering the original diagnosis of cancer, and expressed the desire for better psychological support for their patients.

Perhaps doctors could do with such support themselves. Most physicians admitted to ‘rationalised negativity’ in which initial feelings of disappointment, frustration and powerlessness quickly gave way to a determination to focus on positive aspects.

Oncologists appeared to be more willing than urologists to look on the bright side. The patient’s primary tumour type and the location and extent of the metastases also had a strong bearing on the doctors’ outlook. Physicians tended to be pessimistic about patients with lung cancer, while they felt there was still hope for women with breast cancer, even after metastasis. In the case of prostate cancer, many oncologists expressed frustration that they had seen these patients too late after the initial diagnosis.

PATIENT ATTITUDES

A parallel qualitative study of patient attitudes was carried out as part of the study. Thirty-seven breast, prostate, lung cancer and multiple myeloma patients with bone metastasis from the same five European countries were interviewed. Most understood that metastasis was an extension or spread of the original cancer, but their knowledge varied with their socio-economic level. The seriousness of metastasis was generally appreciated, though not always overtly acknowledged.

Italian and Spanish patients felt strongly supported and, to some extent, shielded by family, who often held more information than the

patient. German patients were most likely to have an idea of how long they could expect to live.

Patients found a diagnosis of metastases devastating once they understood its importance. Older patients were more likely to feel resigned, whereas younger patients expressed feelings of anger, resentment and a determination to fight the disease.

When the patients were asked about the impact that this form of advanced cancer made to their quality of life, most mentioned pain, fatigue and impaired mobility. There was a heightened fear of losing their independence. Patients felt that their condition would reduce their ability to participate in social activities and were acutely aware of the impact this might have on their partners and families.

The strong family support experienced by patients in southern Europe was felt to make living with advancing cancer easier. Patients in northern Europe often found that it put an unbearable strain on their family relationships.

Some patients described the news that the cancer had spread as like crossing an invisible line, after which support, even from other cancer patients, was likely to diminish. Many patients felt that advocacy/support groups were of little use, as they were mainly focused on 'survivors'.

AVOIDERS AND SEEKERS

Patients divided into two distinct groups: the avoiders and the seekers.

Most patients, especially those in Italy and Spain, were classified as 'avoiders'. These patients openly said that they did not want to know. "I can't cope," was one reaction. "It will just remind me of being ill. It will scare me. It will depress me." These patients tended to be older, relied on a relative to find out about their condition and were not interested in support groups.

The minority, who were described as 'seekers', tended to be younger and better educated

and often arrived at consultations bearing articles or lists of questions. These patients:

- Were keen on using the Internet and the media
- Read all the brochures
- Would seek out opinions from different doctors
- Were more likely to go to support groups (but only a minority found them useful)

Despite being well informed, these patients would usually defer to the doctor. However, the relationship between doctor and patient was not always easy.

Most patients use their doctor as their sole source of information, and indeed, the minority who used the Internet often found this information difficult to interpret.

Patients in the UK were more likely to use educational materials such as leaflets, booklets and videos. Cancer charities were also an information source for patients in the UK, Germany and Spain.

WHAT SEEKERS WANT TO KNOW

The questions asked by information seekers included:

- What are my chances?
- How long will I live?
- How much time do I have left?
- How bad can it get?
- Will I go downhill fast?
- What can be done to control it?
- What are the risks associated with this complication?
- Will I be able to continue my daily activities and hobbies?

They also expressed a need for simple language and visual support.

Most patients reported a generally good relationship with their physician, using terms such as 'complete trust', 'unconditional obedience', 'respect' and 'admiration'.

However, very few felt they had much influence over their treatment, either because

Patients divided into 'avoiders' and 'seekers'.

'Seekers' tended to be younger and more educated

they felt unable to make clinical judgments or because they were rarely presented with alternatives.

A QUESTION OF TRAINING

This patient survey suggests that physicians should improve their communication about metastatic disease to patients and families. Physicians should work with patients, family members and caregivers to determine the best methods of support, and tailor information to the individual patient. Patients want clear, understandable information about potential treatment options to improve mobility and independence.

The physician survey suggests that oncologists are generally correct in their assumption that most patients do not want to be involved in every single clinical decision. However, most patients want to retain independence and autonomy for as long as possible.

The survey also raised questions about the

actual words that doctors use. If patients do not know what metastasis is, should this word be used in doctor–patient discussions? Even if some patients do not want to be confronted with facts in too blunt a way, can it ever be justified to hide behind medical jargon? On the other hand, patients reported that the language used by their doctors was often very simple and ‘quite vague’.

Overall, the study confirms that many doctors make decisions on how much and how to tell patients based on their own temperament and professional experience, without a lot of external input. It concludes that a discussion of approaches and practice in breaking bad news should be a part of every doctor’s basic training, and their postgraduate education and continuing education. This could help ensure that while the level of information given varies according to the wishes of the patient, it won’t be dependent simply on the wishes of the doctor.

What we tell them

- I never ever say what the damage is to the patients, only to the family, aside... I’ve had too many reacting extremely badly before, so I shut up now – *Spain*
- In the USA people usually demand more info because they have to pay for their health care, so they want to know what they’ve got But not here! It is both because of cultural and economic factors – *Spain*
- It’s a bit like informed consent – you have a certain obligation to supply information – *Italy*
- The patients will realise it’s serious because my expression will change, I’ll use a grave tone – *Italy*
- We don’t want to put worrying ideas in their heads. It’s pointless to upset them like that – *France*
- Patients often don’t appreciate the significance of bone metastases, so you have to try to explain without frightening them – *UK*
- I’m a big believer in facts. You knock the patient down, then you build them up – *UK*
- I try to be upbeat, to say things in a non-dramatic way, how to confront issues and see what we can do – *UK*

What we want to know

- I only wanted to know where we would go from here, what would happen next – *Germany*
- The doctor consoled me and told me that she didn’t like to say it, but I prefer to know what I have – *Spain*
- I may not have been sufficiently clear in my questions, but the oncologist never responded clearly. He just said it was a consequence of my cancer, which I already knew – *France*
- I don’t want to know that much about my condition. It’s depressing and frightening. I want to forget cancer – *Italy*
- She was sweet, but she didn’t hide the severity of the condition. In any case, she reassured me that current treatments are very effective in combating this bone weakness and controlling pain – *Italy*
- I went crazy searching on the Internet and contrasting all the information – *Spain*
- I prefer not to know anything, my sister is more up on things – *Spain*