

# Lesley Fallowfield: getting the message across

→ Marc Beishon

It was while studying the benefits of offering patients a choice between radical and breast-conserving therapy that Lesley Fallowfield first demonstrated the importance of doctor-patient communication. Her findings haven't always been welcome, but cancer doctors who are now getting trained in talking to patients, and to each other, should know whom to thank.

Quality is a word that occurs regularly in discussions with Lesley Fallowfield, one of the pioneers of psycho-oncology, the branch of oncology concerned with behavioural, social and psychological aspects of cancer care and treatment.

Fallowfield, professor of psychosocial oncology at the new Brighton and Sussex medical school, in England, and director of Cancer Research UK's psycho-oncology group, has led passionate and forceful initiatives to establish quality-of-life measures as currency among the survival rate number crunchers. Further, she has made it her business to examine and expose one of the most sensitive areas of clinical work – the quality of doctor-patient communications in cancer consultations. And her work is now influencing the quality and success of almost all cancer areas, from phase I clinical trials to multidisciplinary teamworking to palliative care.

Today, no major cancer centre would dream of running without some of the supportive services that psycho-oncology has helped to develop

over the last 20 years or so. It is now a recognised cancer speciality, with international and national associations, and a rapidly expanding portfolio of research work.

But as Fallowfield comments, it was a struggle in the early years to get psycho-oncology on the agenda. "If you were really lucky you'd get a poster presentation on the last afternoon of a conference in the most obscure room, and manage to show it to half a dozen people," she says. "We are now giving keynotes at the plenary sessions of most major cancer conferences."

The entrenched attitudes of the medical profession to what can still be seen as 'soft' skills, and pigeon holing psycho-oncology into a purely supportive role for alleviating patient depression and anxiety, have been among the major barriers faced by Fallowfield. She recognises that doctors can be defensive and resistant to change with good reason. "It can mean them acknowledging that what they've been doing, or omitting to do, may have been damaging patients for years," she says.

When Fallowfield first started her psycho-



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**Team work.** Lesley Fallowfield with data-monitors Clare Coxon and Louise Parlour, who process hundreds of questionnaires from clinical trials each week

oncology career, early exchanges with the medical profession were often confrontational. “I started out predominantly as a patient advocate,” she says. “Now, the more time I’ve spent with healthcare professionals and watched and recorded them struggling in difficult clinical situations, the more I’ve realised that we just haven’t been giving them the support they need. You’ll never get doctors and nurses closer to the needs of patients and their families if no one cares about how they are coping with things.”

Nevertheless, a degree of friction was perhaps necessary for Fallowfield to make her mark. She recalls one talk to the UK’s Royal College of Physicians where she was berating doctors for concentrating on quantity rather than quality of life. “I was rather strident and attacking and was given a very rough ride,” she says. “Afterwards, Dame Cicely Saunders, founder of the world’s first modern hospice, and

an important person for me, came up and said, ‘Don’t give up – the only reason they are so angry is because basically you are right.’”

Trusting her instinct that she’s onto something when tempers rise has played its part in her research choices to date, but much networking among senior oncologists throughout the UK has resulted in considerable buy-in to Fallowfield’s ideas. Her team is now a partner in major national and international research initiatives, particularly quality-of-life measurement in clinical trials such as the UK’s huge ovarian cancer screening study, which is evaluating the psychosocial impact and acceptability of different screening methods in 187,000 women. Her team’s communication skills training for cancer teams, meanwhile, is being rolled out as part of England’s Cancer Plan.

Fallowfield says it has been the willingness, despite reservations, of senior oncologists to

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allow psycho-oncology research teams into their centres that has paved the way for such work, and she’s extremely grateful to them. Her own background in healthcare has also helped – as did the unstinting support and backing of an often controversial mentor, surgeon Michael Baum, who gave her the first break in the field.

“I started out as a nurse at Guy’s Hospital, London, after a traditional girl’s grammar school education that favoured the arts.” She feels that although medicine would have suited her well, “I’ve never regretted doing nursing – it’s given me a great insight into the research world I now inhabit.” While bringing up a young family, Fallowfield took several courses for fun at the UK’s Open University (where students work from home) “as I didn’t want my brain to seize up – and I discovered psychology”. She took a BSc in experimental psychology (“which we feel is the superior arm of psychology”) at the University of Sussex and progressed to a doctorate.

Things were going very well, with Fallowfield set for a successful career in psychophysics, until a best friend was diagnosed with acute myeloid leukaemia, and died. “She said I should do some research on why doctors don’t tell patients enough about their disease, and her death had a profound effect on me,” says Fallowfield, who was determined from then on to pursue a career in cancer. “I do think it can be dangerous to try and work through your own feelings by helping others, but it can give you a determination to change things and keeps you going through the tough times, and believe me it was very tough at the beginning in psycho-oncology.”

Fallowfield was fortunate to find several mentors who enabled her to switch her psychological expertise to oncology, none more helpful than breast cancer surgeon Michael Baum, then at King’s College Hospital in London, who gave her a first cancer job. She had been working on

ways of measuring perceptual problems and sensory losses reported by patients with optic nerve damage, which clinical tests at the time were unable to detect reliably, and put it to Baum that her skills lay in “measuring things people thought were immeasurable”.

Baum – himself interested in quality of life and an outspoken pioneer in patient communication about cancer – guided Fallowfield in her early work. She also benefited from working with Peter Selby and Robert Souhami, other top cancer physicians in the UK community who have both been clinical consultants to her psycho-oncology group and whom she describes as “inspirational individuals without whom I’d have never ever have achieved so much.”

It was with Baum that she carried out her first study – and stepped immediately into controversy. “We looked at a trial where women were randomised to have either a mastectomy or breast conservation. Before we started, it was assumed that all the psychological morbidity associated with breast cancer treatment was due to breast removal, so when trials around the world indicated success for conservation surgery in women with early-stage disease it was thought that we could save them from both mutilation and distress. But our study showed no difference between mastectomy and conservation for psychological morbidity and also sexual dysfunction.”

This finding came under fire, she recalls painfully, from many, including breast cancer support groups. “I’ll always remember being at a conference in the US when a vociferous member of a group called out, ‘Dr Fallowfield, I hope you’re proud of giving surgeons an excuse to hack off women’s breasts.’ It’s difficult to fly in the face of medical orthodoxy when there are such passionate feelings.” A constant theme since then has been to evaluate and follow-up research to ensure the quality of findings and



With children Jonathan, who is training to be a gastroenterologist, and Caroline, a paediatric nurse

make the most convincing case – which has often been an exhausting process.

Fallowfield's explanation for the counterintuitive results was that, while body image was important, it tended to assume significance only after women had coped with the immediate distress of having a potentially life-threatening disease. Further, in a study of women treated by surgeons who offered choice between different types of surgery or not, she found that those women offered a choice fared better psychologically – but it wasn't the treatment or the choice that made the difference, rather the communication from the doctor. "We found that the 'choice' surgeons offered so much more information about why they would recommend one treatment. We followed women in the study for three years and found that the first consultation was so vital in determining outcomes for adjustment, anxiety and depression – which led us to start looking at communication issues in more detail."

It was obvious, she adds, that the better

communicators had patients who were better adapted to their disease. However, too many doctors did not – and still don't – receive decent training in this area. Apart from being a great talker and listener herself, Fallowfield became so interested in communication skills that she went into training with a group called the US Task Force on the Medical Interview, which evolved into the American Academy on Physician and Patient, in 1993. "This was run by a truly great man, Professor Mack Lipkin [of New York University], who had developed a model of communication skills training for senior doctors. I trained for six years with him, going over to the States in my spare time."

Despite such initiatives, it is only relatively recently that medical schools and national bodies have realised that communications is a core competency for a doctor, and some have indeed started to implement more training in their curricula. But as Fallowfield points out, any change at junior level could take many years to be seen in widespread practice, which is why

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– impatient for action – she homed in on senior doctor training as making the fastest impact. In any case, junior doctors, she says, are more likely to be influenced by their senior role models. “We needed top-down as well as bottom-up training initiatives – and quickly.”

By this stage, Fallowfield had been working on quality-of-life assessment in clinical trials with centres around the UK, and was able to call in some favours from senior oncologists for her communications work. “Although people said I was mad to try this, some very high profile oncologists attended the initial courses and then became vociferous supporters, encouraging others to come along.” A communication skills training programme has now been developed over the past 15 years or so, a process that she says has been rather like developing a drug through the various phases: “Is it acceptable, what are the toxicities involved, how long should ‘treatment’ last, where should it be delivered and by whom?”

What Fallowfield and colleagues discovered was a dose–response relationship; namely, that only an intensive three-day residential programme can make a difference to long-term communication outcomes in the clinic. This has been established with a pretty large – and rare – randomised trial written up in the *Lancet* (2002,

359: 650-656), involving 34 cancer centres and 5,000 patients, with patient–doctor interviews followed up at three and 12 months. “No one had clearly demonstrated that you can transfer such skills to the clinic before,” she says, “and moreover that the effects were lasting.”

The communication model, which has since attracted international interest, uses actors to play roles, and equips doctors with a way to self-critique their own interviews. “It’s quite extraordinary how seldom people process what works and doesn’t work well for them,” says Fallowfield. Doctors are generally unaware, for example, of the way they ask questions. They often use closed, leading and multiple questions that elicit inaccurate data, and frequently they don’t respond empathetically – or completely bypass – patients’ more psychosocial concerns. Jargon and euphemisms are also rife. “Patients know you can’t fix everything and don’t expect it. But they’ll never forgive you for not acknowledging that they are having a tough time,” she says.

In case anyone is in any doubt about the role of communication, Fallowfield rattles off a list of benefits. They include having a more professionally and personally rewarding job, making better diagnoses and fewer errors, and managing symptoms better (both physical and mental). “Patients who understand the rationale for lifestyle changes are also more likely to carry out requests,” says Fallowfield. “Hospital stays and complications are lower as well. It’s not about being kind – it’s about being a better scientist.” And one for the bottom line – litigation costs could well be lower.

Perhaps the clincher is protecting against ‘burn-out’, which Fallowfield feels is far too high among oncologists. “Poor communications can contribute to burn-out, or vice versa – it works both ways – but when you look at what a typical hospital doctor does across a 40-year career you’ll find they conduct 150,000 to 200,000 interviews with patients and families – spending more time on this than drawing blood or wielding a scalpel. When you consider that in training doctors spend more time learning techniques they’ll barely ever use than on communication, you can see why we’ve got a problem, and why communication must be a core competency.”

## Few teams actually function as an integrated unit, and there can be alarming cracks in the façade

A spin-off from this work is communication within the much vaunted multidisciplinary cancer team. As Fallowfield and her researchers have discovered, because multidisciplinary working demands resources above those usually on offer, few teams actually function as an integrated unit and there can be alarming cracks in the façade. True to form, evidence has been gathered painstakingly by following patients as they see various team members and recording their impressions.

“We find out how the team members see each other and what they feel their roles are, and take them away and show them what happened in practice – for some it can be quite shocking.” A simple example is a colorectal team where a nurse specialist had missed a team meeting and talked to a patient about an impending colostomy – when a decision had been made to carry out a sphincter-saving operation. Sometimes raising the bar can be as simple as hiring a coordinator, or providing a room big enough for people to meet in, a car parking space, a crèche or a lunch, or start times that fit team members with young families.

But the issues involved in multidisciplinary working can go much deeper, ranging from the inhibiting impact of powerful egos among the senior doctors, to lack of awareness of team members’ information-giving roles. Fallowfield’s group have reported the unwillingness of anyone in the team to discuss with patients psychosocial issues such as sexual dysfunction, and frequently a lack of any discussion about family history. Doctors can wrongly assume someone else is covering these issues, or delegate the role to nurses who might not have taken part in the multidisciplinary discussions. Fallowfield adds that she’s finding now that many oncology staff are requesting specific training in communication with their colleagues, and some consider it more pressing than dealing with patients.

As an ex-nurse herself, she also makes the observation that, contrary to what is widely believed at least in Britain, “people [in clinical teams] respected each other a lot more in my day”, despite a more rigid hierarchy, especially between doctors and nurses, in those days. “As nurses have struggled to gain recognition as a more academic profession they have lost a lot of respect that people genuinely had for nurses with superlative practical skills. Today, many doctors don’t even know the names of the nurses on the wards, and nurses don’t seem to accompany doctors on ward rounds, so it’s little wonder that few know what has been said to a patient.”

After working her way up through the ranks as a psycho-oncology academic, Fallowfield became a professor at University College London in 1997, and in 2001 moved her group to the present location on the campus of the University of Sussex, joining the new medical school a little later. Her work has continued apace and cross-fertilised in various ways, for example in the clinical trials area, where communication, quality of life and new psychometric tests are all pertinent topics.

The communication aspect is critical when recruiting people to clinical trials, says Fallowfield. “Doctors often have idiosyncratic ways of discussing trials with patients; others think it will take too much time – a particular problem now that doctors have to meet targets for rapid throughput of patients. They also tend to approach only certain types of patients. We spent weeks filming doctors and research nurses talking about trials, and have produced educational materials that help them with time management, dealing with difficult personalities and how to explain concepts such as randomisation.”

Given the gross shortage of patients enrolled in trials, this is clearly important work. While recognising that some trials are genuinely pretty

hard to explain, Fallowfield says there are some key principles to learn, one of the most important being to establish a 'platform of certainty' and not say you are unsure how to proceed. "This means saying, for example, 'I know the best treatment is this and we'll offer it to you, but we're always interested in improving things and you may have heard about this...'. No one wants to hear that they've got cancer and their doctor doesn't know how to treat them."

She was surprised to find that there was hardly any material available to equip oncologists with an explanation of the core concept of randomisation. "We had to do some original work on this before developing the training materials," she says.

Measuring success of this training is hard, as there are many factors that can affect the uptake of trials, but her group is working with oncologists in Wales, a fairly self-contained and small country, randomising multidisciplinary teams to receive the training or not. "We think the key outcome is not how many patients go into trials, but how many eligible patients are at least offered them," she adds.

The importance of psycho-oncology also comes into its own when measuring the effects of clinical trials and everyday treatment. When Fallowfield first looked at quality-of-life measures, she found hopelessly outdated or inappropriate indicators used by clinicians. "They would measure things like whether someone went back to work or not," she says. She's since helped to develop and introduce new psychometric tools based on patient feedback, particularly for breast cancer, but she notes that new and updated methods will always be necessary because of rapidly changing treatment regimens.

Fallowfield has particular concerns about the later side effects of treatments, "It must be awful to successfully treat childhood cancer only to find that other cancers, cognitive impair-

ments and fertility problems develop later on." She adds: "A lot of adult treatment trials are closing earlier than originally designed, and we don't always have enough long-term follow-up data on side effects, which is worrying."

Fallowfield has continued to highlight other factors affecting quality of life, since that first breast mastectomy versus conservation study. She believes that while it is reasonable for oncologists to home in on potentially life-threatening side effects, such as endometrial cancers or cardiovascular problems, other non-life threatening ones may receive too little attention. One study that made the news recently showed that hot flushes associated with hormone treatment can deter women from continuing with the regimen. When asked why some doctors don't take hot flushes seriously enough and why insufficient effort went into relieving them, she was quoted by the BBC as saying: "No one ever died from one except from embarrassment. A Nobel prize should go to the person who stops women having hot flushes while undergoing such treatment. If quality of life was measured more often in clinics, not just clinical trials, then people would realise the extent of these non-life-threatening problems that patients suffer."

A study where quality-of-life measures were 'off the scale' (in a positive direction) was the UK ALMANAC trial of women having a sentinel node biopsy versus conventional axillary resection. Using a quality-of-life questionnaire, Fallowfield's team has shown that good arm movement, which is preserved using the sentinel node biopsy, is a highly valued outcome influencing overall quality of life.

The challenge now, she says, is to move quality-of-life measures into routine clinical assessments. "We have won the case for their use in clinical trials, but not in the clinic. Part of the answer lies in developing computerised tools that doctors can use quickly in the clinic. I

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suspect it would be a bold clinician who would change cancer management based on a patient's quality-of-life scores, yet the same doctor would have no problem changing tack if a tumour marker had gone off the scale. We hear so much about translational research – I wish people would show the same enthusiasm for translating some of our positive psychosocial research.”

Nevertheless, the achievements so far should not be underestimated, she says. “The drive to improve communication skills training since our incontrovertible demonstration of efficacy has really taken hold. The wide availability of patient referral and advocacy services in most countries, while they should never be an alternative to good patient–clinician communication, has also been a great advance. Specialist cancer nurses, especially in breast clinics, is another great plus, while the UK's hospice movement and research into end-of-life issues is a world leader.”

The immediate work programme for Fallowfield's unit also includes moving forward with the multidisciplinary teamworking research, and looking at underserved cancer patients such as those with brain, head and neck and prostate tumours. “We are also collaborating with cancer centres that talk to patients about participating in phase I trials as most of the work to date has focused on phase III work,” she says.

Properly testing complementary therapies is also on the agenda. “I'm wholeheartedly in favour of some of the therapies that assist patients in other ways, such as aromatherapy, but these must always be evaluated systematically. When people are diagnosed with cancer they can develop a kind of ‘skin hunger’ – often no one touches them anymore, apart from when carrying out clinical procedures. Relaxed people also don't feel as much pain.”

Personally, she would like a bit more relaxation, having worked flat out on her research for

some 22 years (including many international speaking and training engagements where she is in great demand). It would be remiss here not to mention her deputy (and golf partner) Valerie Jenkins, who co-ordinates and supervises much of the research of the 20 strong unit, where a psychology degree seems to be de rigueur for the research fellows. Jenkins, like Fallowfield, was originally a nurse before becoming a psychologist, so they share similar insights in the field of psycho-oncology.

Family life is very important to Fallowfield. She has two children, both in healthcare – a son training to be a gastroenterologist, and a daughter who is a paediatric nurse. She also has a ‘wonderful’ baby grandson.

“Life has been too chaotic over the past few years to enjoy fully my many interests. I adore music and have eclectic tastes – I'm as happy at a Rolling Stones concert as at the opera; I also read copious numbers of books, anything from biographies to Michael Crichton novels.

“I'm an enthusiastic but extraordinarily bad golfer, so I'd really like to get my handicap down this year. Developing a better golf swing is rather like becoming a better communicator – you have to stop doing something old if you want to do something new, and I've got into some very bad old habits.” Hopefully her recent knee surgery will permit her to do more walking on the Sussex Downs and along the seafront in her beloved Brighton.

“I think I'll see out my retirement here – if I'd ever been motivated by money I would have jumped ship a long time ago.”

There's an old joke that Fallowfield likes to tell about a drunk who's lost his keys. “Someone sees him looking under a street lamp – ‘Why are you looking there?’ they ask. ‘The light's better,’ he replies.” It's comforting to know there is someone exploring the darker areas of cancer – and producing quality evidence, of course.