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Giving bad news

Oncologists today need more help in dealing with stress, and could benefit from learning communication skills, according to a survey presented at the recent European Breast Cancer Conference (*Berlin, Germany, 15–19 April 2008*).

'In a clinical career spanning 40 years, the average hospital doctor will conduct 150,000 to 200,000 interviews with patients and their families,' said author Professor Lesley Fallowfield, from Cancer Research UK's Psychosocial Oncology Group (University of Sussex, UK). 'This represents more time than they spend feeling a pulse, wielding a scalpel or taking blood yet few have received any formal training in communication skills. And we wonder why we have a problem...'

The survey looked at doctor / patient interactions and emotional fallout among 462 physicians from the US and Europe. Almost half, 44%, found that telling a patient her breast cancer had recurred was one of the most stressful aspects of their job (*Current Medical Research and Opinion 2008;**24:**7*). 'Some doctors describe feelings of real fear of having the patient in the room because they just can't cope with giving the bad news of a recurrence,' says Dr. Mark Lansdown (Leeds General Infirmary, UK) who presented the study at the meeting. 'Addressing these issues is paramount; if clinicians are uncomfortable it is detrimental to the quality of the consultation.'

Dr. Andrew Wardley (Christie Hospital, Manchester, UK), said that discussing recurrence gives doctors a feeling of personal failure. 'Additionally, doctors are likely to have developed a closer relationship with the patient, and the disease is now incurable,' he said.

Recent studies show disturbing levels of stress and depression among oncologists. In 2005, a study assessing psychiatric morbidity in 1,794 hospital consultants, by Amanda Ramirez (Institute of Psychiatry, Kings College, London), showed that burnout was experienced by 41% of surgical oncologists, 52% of clinical oncologists, and 36% of radiologists (*Lancet 2005;**366**;742–44*). All these levels were up since an earlier study by the same group in 1994.

'COMMUNICATIONS IS AN EXPERIENTIAL SKILL; YOU DON'T MASTER HANG-GLIDING BY LISTENING TO A LECTURE'

Further, a 2007 study by Richard Burman (Christie Hospital, Manchester, UK) questioned 401 specialist registrars in palliative medicine and oncology and found that 26% experienced psychological distress and 15 had experienced suicidal thoughts (*Clin Med 2007;**7**:235–42*).

'There is a significant need to support physicians who regularly have to deliver bad, sad or difficult news about breast cancer recurrence,' said Fallowfield. 'While improved access to better treatments will reduce the frequency of negative conversations about recurrence, we also need to equip doctors with appropriate communication techniques to help minimise the burden on both patients and doctors.'

Professor Fallowfield and other oncologists are working with AstraZeneca to develop online training resources designed to help doctors have more effective conversations with patients. Fallowfield has also developed a 3-day course, launched in June, 2008, by the European Society of Medical Oncology (ESMO). The courses incorporate cognitive, experiential and behavioural components, and include role-playing consultations using actors.

'Communications is an experiential skill; you wouldn't expect someone to master hang-gliding or scuba diving merely by listening to a lecture. Yet funnily enough that's the way most medical people are taught communication,' said Fallowfield, who believes that doctors need to be taught how to be more efficient with the small amount of time they have in face to face consultations. 'They need to learn to sign-post where they are going, chunk things up under those headings and check back with the patient for understanding. The key is to provide patients with a road map of where they are going. It sounds really basic, but doctors don't know to do this unless they are taught.'

Janet Fricker

whose attendance at EBCC was supported by AstraZeneca UK Ltd

For further details of the residential course, see www.esmo.org. The breast cancer communication educational resources can be downloaded from www.breastcancersource.com

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EUROFILE

Progress in cancer screening?

In 2003, European governments made a commitment to introduce population-based screening for breast, cervical and colorectal cancer. Five years later, an evaluation prepared by the International Agency for Research on Cancer (IARC) showed that despite substantial progress, Europe is still a long way from reaching its goal.

Approximately 55 million examinations were performed on people attending screening programmes for breast, cervical or colorectal cancer in 26 EU states, in 2007. This is less than half the number expected if everyone in the EU target population was being seen. In addition, only 23 million of these examinations were provided by population-based screening programmes, pointing to a considerable level of 'inappropriate' screening.

There are significant differences between states. For breast cancer, one EU member state has no plans to introduce population-based screening, four have yet to begin and seven have yet to complete programme roll-out. In cervical cancer, two states have no plans, three are waiting to begin and three are implementing, while in colorectal cancer eight states have no policy, five are waiting to begin and five are implementing.

'Despite the substantial progress made so far, five years on we are only half way to implementing the common commitment to cancer screening,' said health commissioner Androulla Vassiliou, presenting the report to EU health ministers. 'I do not underestimate the difficulty of the work that remains.' She added that the Commission would consider updating the 2003 commitment in the light of the evidence in the report.

Lawrence von Karsa, head of the IARC's screening quality control group and the report's lead author, agrees that significant progress has been made. 'The report shows a very wide consensus on the need to implement population-based programmes,' he explained, 'but in terms of implementing the policy we have to understand that it takes a minimum of ten years to plan, pilot and roll out a programme. And if you try to do it quicker you are in danger of making mistakes.'

This does not mean that policy makers can sit back and wait for the work already underway to deliver results. 'Things are in motion and we cannot wait,' said von Karsa. 'We have to control the process. That's the message of the European guidelines [on cancer screening]. If you want good results, understand the process and manage the process.'

Two problems stand out in the evaluation report: funding and the expertise needed to implement population-based screening. In particular, the continuation of inappropriate screening is consuming resources that could help push forward population-based screening.

Funding is a matter for national governments, but the EU could help with expertise and advice. The report calls for a pan-European strategy to be established that would support EU states introducing population-based screening, both by providing expert advisors and sharing experience of those who have already completed the process.

'ACCREDITATION WOULD PROVIDE A STRONG MOTIVATION FOR SERVICE IMPROVEMENT'

According to von Karsa this should also include seed money for planning and management units, provided for a period consistent with the long-term nature of the process. 'I know of no funding programme in the EU which is appropriate to this long-term perspective,' he said.

One initiative now being planned is a pilot project for an EU-wide accreditation/certification scheme for breast cancer screening, diagnosis and management. Such a scheme would help show how widely breast cancer guidelines are being followed, empower the women using the service and provide a strong motivation for service improvement.

The pilot is being developed by von Karsa's group at IARC, in collaboration with the European Cooperation for Accreditation (EA), a group of government-mandated accreditation organisations across Europe. The idea is to combine the coordinated approach to accreditation, currently applied mainly in the commercial context, with the professional standards developed for cancer screening and diagnosis.

Von Karsa is keen that any scheme should help improve implementation of standards rather than simply pass judgement. 'Just having an accreditation/certification programme to see who is following the EU guidelines and who is not, that won't help,' he said. 'But if, by participating in this process, units learn how to become certifiable, and if that learning is documented and made widely available, this will lead to change and continuous quality improvement.'

Europa Donna, the European breast cancer coalition, supports an accreditation system to consolidate EU guidelines for breast cancer screening. 'There has to be a structure of people who are non-partisan and unbiased who then evaluate exactly what's been rolled out in each country,' said Susan Knox, executive director of the advocacy group. 'That needs to be moved on with some more urgency.'

However, not everyone thinks that greater public awareness about screening services will necessarily lead to more money becoming available, or persuade countries to stop non-population-based screening.

'The individual person is rarely concerned whether the test is population-based or opportunistic. This may be one of the reasons why it is difficult to have a forceful lobby for population-based screening and getting the necessary resources,' said Hildrun Sundseth, head of EU policy at the European Cancer Patient Coalition. 'Screening is mostly in the hand of experts who have vested interests and difficulty explaining what is at stake to the public.'

Ian Mundell
Brussels

See http://ec.europa.eu/health/ph_determinants/genetics/documents/cancer_screening.pdf

PODIUM

Cancer research in Europe: What next?

Professor Richard Sullivan (London School of Economics and Political Science, UK & Kings College Integrated Cancer Centre, London) is the former director of clinical programmes and centres at Cancer Research UK. He chairs the European Cancer Research Managers (ECRM) Foundation which aims to improve cancer research in Europe through better coordination and co-operation between EU Member States and candidate countries, and international research organisations.

Why are there so many European initiatives aiming to improve cooperation in cancer research?

It is a historically complex situation. Basically, there have been three eras of cancer research in Europe. The first was pre 2000–2001, an important junction, and not just in Europe. The EUROCARE survival statistics (comparing survival from various cancers in different European countries) had been published (Eurocare-1 in 1995; the larger Eurocare-2 in 1999) which caused a political storm in many countries, and which certainly lit the touch paper in the UK for all the changes which followed. The circumstances for dramatic change in the UK were all there: the two big charities merged (Cancer Research Campaign and Imperial Cancer Research Fund became Cancer Research UK), a fresh political party was looking for an early win and cancer research was well-ploughed, fertile but relatively dormant ground. The EUROCARE figures acted as the catalyst for change.

This was also era of the European Code Against Cancer. The importance of cancer as a major public health issue

(*Continued on pages 2090 and 2091*)

Disappointment over NICE's ruling on kidney drugs

Experts have greeted with dismay a preliminary decision by the UK's National Institute for Health and Clinical Excellence (NICE) on new agents for the treatment of renal cell carcinoma (RCC). NICE stated that: 'Bevacizumab, sorafenib, sunitinib and temsirolimus are not recommended as treatment options for advanced and/or metastatic RCC.'

People currently receiving the drugs should have the option to continue therapy until they and their clinicians consider it appropriate to stop, NICE said.

The recommendations were made in an appraisal consultation document and, at the time of writing, comments were still being received. NICE stated that the recommendations 'are preliminary and may change after consultation.'

In the meantime, 25 professors of cancer medicine complained about the decision in a letter to the national newspaper, the *Sunday Times*. 'We are dismayed at the decision by NICE on the rationing of drugs for patients with advanced kidney cancer,' they wrote.

'Once again, NICE has shown how poorly it assesses new cancer treatments. Its economic formulae are simply not suitable for addressing cost effectiveness in this area of medicine. Mean survivals obscure the fact the some patients will obtain prolonged benefit from these drugs. It is essential that NICE gets its sums right.'

Cancer Research UK also expressed concern, and called for a change in the way NICE reviews the value of drugs for rare diseases, where clinical benefit is proven but evidence is limited.

Professor Peter Johnson, the charity's chief clinician, said, 'We are disappointed at NICE's view that although these drugs are clinically effective, their high price means that they are not considered to be value for money for the National Health Service. These drugs have shown a small but definite improvement in an illness where there are few alternative treatments. If this decision stands it will be very frustrating for cancer patients and their clinicians.

'Although we understand that NICE often has to make difficult decisions, in this case there is a clear separation between what NICE finds to be valuable treatment, and clinical and patient opinion. Action is needed to bring these two positions closer together.'

Licence update for cetuximab

Merck KGaA has been given European approval for broader use of cetuximab (Erbitux) in metastatic colorectal cancer (mCRC). The drug is now licensed for the treatment of patients with epidermal growth factor receptor (EGFR)-expressing, KRAS wild-type mCRC in combination with chemotherapy, and as a single agent in patients who have failed oxaliplatin- and irinotecan-based therapy, and who are intolerant to irinotecan.

Professor Eric van Cutsem (University Hospital Gasthuisberg, Leuven Belgium) welcomed the approval 'as it provides us with another treatment option for our patients in the 1st-line setting'.

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Cancer research in Europe: (*continued*)

was starting to get into the European political psyche. The European Research Area was also a new idea, which underlined the need for hypothecated European funding for research and Commissioner Philippe Busquin wanted to move things forward. As a result, a big conference (*Towards Greater Coherence in Cancer Research, European Parliament, 19th Sept 2002*) brought together political support such as the Netherlands' MEP Wim van Velzen and cancer researchers who had worked at the European level for many decades.

For the first time, there was the prospect of real money and a lot of activities took place in parallel, through many influential people and institutions, particularly FECS, the Organisation of European Cancer Institutes (OECI), the EORTC, the European Institute of Oncology (EIO), the International Union Against Cancer (UICC) which was a much more Eurocentric organisation at this time. Individuals such as Prof Schroder were trying to create a European Cancer Research Initiative while the then Director of IARC Prof Paul Kleihues, attempted to set up a European Cancer Institute project along similar lines.

It's fair to say, however, that we failed to agree on a single vision. None of the activities really got anywhere, but they did have the effect of generating the required political focus across Europe and really put in place the needed cultural changes for the next steps. It was also at this time that the ECRM Forum (now the ECRM Foundation) began its activities as a policy research project funded by the European Commission.

What happened next?

In my view, the next era lasted from 2001 until 2005/6. At this stage, organisations were aligning and reorganising beyond traditional cancer research boundaries. ECL was attempting to define its role and establish where it could add value beyond tobacco control; also in the ensuing repositioning many organisations tripped up over each other and this inevitably led to some schisms opening up, for example between FECS and ESMO which resolved in time. The UICC was taken forward by Dr. John Seffrin from the American Cancer Society to become a global organisation with a different focus, emphasising tobacco control, and Prof Peter Boyle, with a much more progress vision took over at IARC, and set up Eurocan Plus, looking at the coordination of cancer research in Europe. A lot of work was carried out under Eurocan plus and as is the nature of these initiatives, its effect will take many years to roll out. However, it has already catalysed other organisations e.g. OECI to examine their own roles and the outcomes have been extremely beneficial for the research community. Certainly the new look ECCO is a breath of fresh air for Europe.

At the ECRM Forum, we thought this stage was going to be a little politically complex, so we focused on providing an evidence base for policy makers. The first ECRM report in March 2005 showed that the Commission was not adequately funding cancer research, nor for that matter were many Member States compared to the level of support enjoyed by the USA.

The report shocked people and generated anger, particularly towards the Commission. Furthermore, researchers in many Member States who weren't receiving adequate funding demanded to know why colleagues in Britain had money and they didn't.

What defines the 3rd era?

The third era started in 2005. What's happening is that the focus and authority for cancer research in Europe is shifting towards the big institutions and centres, not the funders, nor even governments, I would argue. I am absolutely convinced that this is the future, and it is a major opportunity. The ECRM is completing a substantial review of cancer centres in the USA and Europe and this is showing that European cancer centres, whatever their shape or form, are the dominant sociocultural focus for cancer research in Europe. Organisations such as OECI, ECCO and others are also going to have a really important role in shaping this collective future.

I applaud this shift. Human beings are tribal and hospitals and universities are good tribes to belong to. But we need to think about how we support national and international collaboration between such centres. Research is a sociable endeavour; human beings work with people they like, because they are friends and share interests. You can't force collaboration; that would be to fail to understand how it works. But few policy makers seem to understand this; supporting collaboration as a business approach is the wrong approach, in my view. We must find a way of supporting collaboration which recognises that cancer research is a creative process not a linear business model.

In the third era, some existing organisations such as IARC and EORTC will I am sure have to face additional issues about how they fit into this changing model. It remains to be seen how the future of National Cancer Control Programmes will work with the multiple parties involved – WHO Geneva, IARC, IAEA PACT programme, etc. It's essentially that research is recognised not as an add-on luxury but as a fundamental and integral part of any and all National Cancer Control Programmes. Certainly, the previous success of Europe against Cancer must be revived.

In Europe, fundamental biology and drug development are well-supported, and there is a reasonable argument that says that Europe is over-focussed in these areas and needs to look at the far wider church of cancer research – development of surgical technologies, primary prevention, etc. In themselves such a rebalancing of priorities across disciplines would pay dividends across the whole field of cancer research.

Won't smaller centres and countries lose out in this era?

There will always be inequality in funding. The UK, Germany, France, NL and Italy are spending more than other

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Cancer research in Europe: (*continued*)

Member States on cancer research, and therefore often take the best and brightest young people from them. The problem of supporting cancer research in new Member States is a real issue. These countries need to be active in cancer research, which may come down to a role for the Commission in providing funding for research infrastructure in new Member States. It will be a long road for many of these countries, but we know that service provision is better in countries which are research active and so it is important for them to develop national cancer research programmes.

Where has the move to institution-based power come from?

Over the last decade there has been a realisation that cancer centres provide the opportunity in Europe to link hospitals and universities together to bridge laboratory science with clinical research. Across Europe, centres have been growing in size and complexity (greater spread of research disciplines, more national and international collaborations) as well as developing their own fundraising capabilities. The rise and success of European cancer research institutions comes down to the intellectual calibre of the individuals going into research. You see centres built up from obscurity by a key individual, or collapsing when they lose their director. Good cancer centres provide the enriched environment from which to develop bright and motivated clinical and non-clinical cancer researchers. Furthermore they have the vision and understanding of what direction cancer research needs to take often absent from research funding organisations and governments.

You suggest that there are commonly accepted myths in cancer research?

One is fragmentation of the research effort; which implies that Europe was once in one piece. This is a complete myth. Europe has never been a whole and the chances of everybody ever sitting down and agreeing to do everything the same way are zero. In my view this doesn't matter a bit, indeed variety is a major source of creativity. Europe is by definition heterogeneous, and differences provide a creative force. The idea of major funders focusing on strategies that look for absolute cooperation, collaboration and a common direction is completely wrong. It usually means they want to dictate that direction. Cooperation and collaboration do not have a fixed shape, size, or direction in cancer research and the mechanisms need to be in place to allow and support this sort of heterogeneity.

Another myth is that of duplication of research effort. In science you need some duplication, but this myth is peddled again and again. There is absolutely no evidence to support the idea that Europe is really wasting resources. Indeed the data from the second ECRM report shows how much value for money Europe is getting from its cancer research spend.

Will there ever be a European Cancer Institute?

There will never be a cancer institute like the NCI in the USA; the time for something like that has long since past. Indeed such a monolithic approach would go against what makes European cancer research so good. At best, there should be a virtual institute, which brings major funders, and key opinion leaders round the table. It could be a discussion forum which keeps the spotlight on one of the biggest health issues for Europe over the next decades. It could embarrass member states into properly funding research themselves and using European funds as they are supposed to – as additional money. Too many member states abdicate their responsibility for funding cancer research. An ECI could continually keep the light shone on cancer research, improve the links between major centres and possibly provide collaborative framework funding, although I'm not convinced of the case for the latter function.

However, such an initiative needs to add real value. Too often such activities are in the stratosphere, too far away from cancer researchers to make a material difference to their day to day lives. What researchers need is a much more consistent flow of funding, and policies that support cancer research activity not drain time, effort and money away from them. So often now, the left hand gives and the right hand takes away (need I remind anyone of the effects of the Clinical Trials Directive?). Coordination of all European policies that affect cancer research would be a big help in driving innovation and this is something that needs to be addressed now, either through a European Cancer Forum or by the Commission.

Are we any closer to a common voice for cancer?

It would be nice occasionally, on the big issues, for us to agree and speak as one. We will never be totally aligned all of the time; that is the nature of science. But by and large, we agree on big issues like the Clinical Trials Directive. A single voice can too easily become dictatorial; we need a common voice that speaks softly and with weight. A 'common voice' that is used too often loses its power and impact. Diversity is a good thing, but politically at European level for big issues we need a cooperative voice. Ultimately the question we have to constantly ask ourselves is how all we are doing will improve outcomes for patients and their families. Regardless of the difficulties we should work on changes at the European level that will deliver real improvements in cancer control and cure.

Helen Saul