Sara Faithfull:

unleashing the potential of cancer nursing

Marc Beishon

Specialist cancer nurses have shown what a difference they can make in supporting patients – helping them manage symptoms and maintain an acceptable quality of life. Yet many cancer nurses are still undervalued and underused, with few opportunities for specialist training and little guidance on best practice. **Sara Faithfull**, cancer nurse, researcher, teacher and past-president of Europe's cancer nursing association, EONS, is working to change all that.

Last year, cancer nurse Sara Faithfull pulled off a major coup – she ran an entire clinical session at Prevent, a conference dedicated to the adverse effects of radiation, which was organised by ESTRO, the society for Europe's therapeutic radiologists and oncologists. "I brought in physiotherapists, nutritionists, dentists, nurse researchers and clinicians – it was a multidisciplinary conference stream and was very successful in terms of contacts afterwards – most times you never hear any more," she says.

It was significant, Faithfull adds, because not only was this the first time that ESTRO had had a nurse running such a programme, but also because the battle to get nursing and other allied health professionals established at such conferences and at this level is a long way from being won.

"Afterwards the chair said to me, 'There were a lot of nurses as speakers,' and I said, 'Yes, that's because I am a nurse.' I don't think he knew I was one. Unfortunately we have not been invited to the next Prevent conference, ostensibly because it's about 'bioscience.'"

A lot of medics around Europe simply do not see nurses as clinicians and researchers in their own right, says Faithfull, and she adds that, "from that Prevent session we have developed a package for nurses on managing side-effects and built a network for those working in radiotherapy. When we get these opportunities we can get things done."

Researching and implementing interventions, especially for the increasing numbers of people living with cancer and its after-effects, is a key goal for Faithfull, and one she believes cancer nurses are ideally placed for. As a professor of cancer nursing practice at the University of Surrey in England, and immediate past-president of the European Oncology Nursing Society (EONS), she has extensive experience not only of clinical work from her own previous and current posts, but also of critical training and workforce issues around the UK and Europe.

There are, she says, major obstacles in the way of developing the scale of research needed, and in rolling it out to a large and very diverse workforce around Europe. Not least is the lack of recognition of

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the role of oncology nurses, as typified by the ESTRO experience. "It goes much deeper though – a good example was the document on the future of cancer care, 'Responding to the challenge of cancer in Europe', which was presented at the 2008 EU cancer conference in Slovenia. It had chapters on presentation, screening, drugs, psychology and so on, and while recognising the importance of oncology nurses it did not have a chapter specifically on the provision of nursing or health services."

In part, Faithfull adds, this is because oncology nurses need to play their part to get their agenda heard. In the recent European Partnership for Action Against Cancer initiative, for example, the present EONS president, Sultan Kav, stressed the importance of nurses taking part "to demonstrate the critical importance of the role of the nursing workforce in delivering good cancer-related healthcare." It is reassuring, Faithfull adds, that in meetings so far EONS has been able to ensure supportive and palliative care are part of the Partnership discussions. "It is a good opportunity to knock heads together." She is also urging engagement with national nursing societies, patient groups and political bodies "to ensure the nurse's voice is heard during key debates".

With 22,000 nurse members through national societies, EONS participates as a founding member with other cancer societies at the key ECCO event, along with patient groups. But there is still a tendency for organisers to view their presence as representative and not as a primary contributor to cutting-edge issues in cancer treatment and care. "At ECCO we should be presenting our flagship nursing science and not just rounding up a geographical input from all the countries, as research simply is not very advanced in some places."

But while research findings about the role of nurses can be compelling, Faithfull acknowledges that much more needs to be done to raise the bar of nursing research to provide evidence to convince policy makers. "Take for example the delivery of chemotherapy. You want good symptom

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Back to better health. This high-performance testing facility in Surrey is where Faithfull and her team research how to improve rehabilitation and reduce late effects following treatment for prostate cancer, using individualised plans based on detailed cellular and cardiac function data gathered as the patients exercise in a controlled and quantifiable manner

management, provided by those trained to take care of people – nurses. Otherwise all that development effort on drugs can be wasted if patients can't continue with treatments because of lack of support. What is more, nurses trained in symptom management and drug interactions can take responsibility for prescribing and delivering care, instead of say waiting for a doctor to give drugs such as anti-emetics. And evidence shows that nurses make fewer errors with drugs as they are more likely to follow protocols."

Another major issue is the rapidly growing population of cancer survivors. "We now have in the UK 60% of people cured or in remission for common cancers; 13% of older people have had cancer during their lives; and many will also be having ongoing treatment such as hormone therapy. Even with metastatic disease people can live for many years."

There is a pressing need, she says, for more long-term involvement of community nurses who are equipped to work, for instance, with men suffering the after-effects of prostate cancer surgery, radiotherapy and hormone therapy, such as osteoporosis, metabolic symptoms, sexual dysfunction and incontinence.

It would also be helpful to have more posts like the one Faithfull now holds, with a remit to continue as a practising clinician alongside a teaching and research role. "As a nurse, once you move into education you tend to get separated from the clinical side, while in practice in hospitals or in the community it is very rare for nurses also to work as professional researchers. Contrast that with doctors, who are mostly able to pursue a clinical academic career."

Faithfull's route into nursing was a traditional one back in the 1980s – "I wasn't very academic then. But my mother was a nurse and I used to go to her hospital to help out during the school holidays and really enjoyed it. I thought then it was a real vocation that could give you mobility."

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"Specialist nurses increasingly manage therapies, which is necessary now we have a shortage of doctors"

She became a general nurse at a large hospital in London, and recognises the huge differences in nursing practice then when compared with today. "In the 1980s patients would stay in hospital for much longer and we only had 83% bed occupancy, and not much more than a drip to deal with. Today, we have the same patient–nurse ratios but now everyone is an acute case, the beds are full, and on an oncology ward many will be having highly complex treatments."

There have been accusations in the UK that, with increasing numbers of nurses becoming specialists and entering the profession with degrees, much of the old caring side of nursing has been lost. Faithfull agrees, but points out that pressure on most healthcare systems around the developed world has led to a more 'conveyor belt' approach, often with little continuity with the professionals that patients see through the course of treatment. "This doesn't mean that nurses don't care, but they have a wider range of responsibilities than in the past."

Nursing, she notes, has already become a two-tier – and in oncology, a multi-tier – profession, where many of the 'washing and caring' tasks are now carried out by auxiliary and foundation nurses, at least in the UK, while nurses at advanced levels increasingly manage therapies, "which is very necessary now that we have a shortage of doctors."

But if policy makers in healthcare systems just see nurses as 'part of the furniture', and do not value their caring skills, the quality of care nurses provide will often be poor, says Faithfull, adding, "It's also true though that nurses are good at sitting back and letting other people decide what's good for them." The answers, she believes, lie in more empowerment of, and better management skills for, senior nurses, and better multidisciplinary working. That needs to include practical matters such as improving the measurement of nursing outcomes, defining the support for patients, designing new types of follow up and improving communication, while everyday issues such as finding a parking space are often cited by patients as concerns, but are consistently overlooked.

Faithfull moved on from her general nursing position to work in neurology and a coma unit, helping people with strokes and those who had had accidents, before moving to the Royal Marsden in London, one of Europe's top cancer centres. "I joined to work in a brain tumour unit and went on to stay at the Marsden for 20 years. In oncology you see the best in people – they can be very brave in trying to overcome challenges, and you get to work with them much longer than you would with most acute care, so you have time to build relationships."

At the Marsden, Faithfull worked with Mike Brada – a former ESTRO president – on supportive care for brain tumour patients and their families. She took four months out to go to Papua New Guinea with Raleigh International – a UK charity that organises expeditions – before returning to the Marsden and deciding to do an undergraduate nursing degree at Surrey University.

"The growth in degree level and specialist nurses is of course one of the most important trends in recent years, plus the breaking down of professional boundaries between nursing and medicine. Some 13 countries in Europe now have specialist cancer nurses, and the UK NHS [National Health Service] has been a leader. But there's a big problem in the UK as our professional nursing body has not regulated it – there is no standard curriculum to study cancer nursing here."

This means that on oncology wards in the UK, and in some other countries, there can be a spectrum of specialist nurses with various titles, but no consistency on qualifications and experience, as without regulation a specialism is simply awarded on the job. "In fact across cancer nursing in the UK there are some 17 different specialist titles now in use – anyone can call themselves a specialist, but you could have two people with the same title working together but with vastly different experience."

At least in the UK there are colleges that offer courses for oncology nursing, such as Surrey. "But we have a shortage of training – there are few specialist breast, urology or haematology cancer courses, for

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example. Mostly, you have to learn special skill sets on the job. It's the same in some other countries such as France and Spain."

Other countries though have made greater progress with developing and promoting speciality cancer nurses. Faithfull cites the US and Ireland as two countries that have taken steps to regulate speciality nursing (in Ireland, a master's qualification is needed to be an advanced nurse practitioner and this is a regulated title).

But a country that stands out as lagging behind in developing nurses is Germany. "We have nurses from Germany and other countries come to the UK to do courses, but they can be frustrated by the lack of opportunity to put their skills into practice back home. We had a German student work on a European EONS project with us here and she was amazed – she didn't realise that nurses could work at higher levels and it was very inspiring for her."

Providing more skills and education is fundamental to valuing people and keeping them, says Faithfull, and this must include nurses working outside the main cancer centres, where the opportunities for on-the-job experience is limited. "We also have to realise that many of those who are teaching nurses are coming up for retirement, certainly in the UK."

Faithfull left the Marsden in 2002 to become a director of studies for the University of Surrey's advanced practice master's programme – the faculty of health and medical science has some 1500 pre-registration nurses on its undergraduate and diploma courses, plus 3000 others pursuing postgraduate and continuing professional qualifications. In recognition of her effectiveness in translating research into education, Faithfull was awarded her professorship in 2008, and she and a small group of colleagues now focus on modules in advanced practice in cancer care, such as pain and symptom management, cancer science, advanced assessment, advanced communications skills and palliative care interventions.

During her time as EONS president, and continuing now, Faithfull is helping to develop Europe-wide training and curriculum materials that can be applied at various levels by universities and professional bodies. "For example, we want to see an arrangement along the lines of the Erasmus student exchange programme for an advanced practice oncology qualification based on our materials. Most of the modules are already there and a lot of universities are using this curriculum for their courses, but we have not achieved standardisation yet. We also want to develop materials for those at foundation level, such as community nurses, and have it all online and translated into different languages. It's important that EONS can cover different levels so those starting out don't feel it is out of their reach."

Speciality EONS curricula include breast, elderly and lung cancer care, and a recent introduction is a pilot of an online radiotherapy training course. The training work is building on successful experience with other courses that are now staple parts of the education programme such as TITAN, which aims to improve nurses' skills and knowledge when working with patients with thrombocytopenia, anaemia and neutropenia. TITAN has been running since 2004, and has been translated into various languages with grants from EONS.

Translation is still important too at conferences, adds Faithfull, because unlike physicians, nurses around Europe do not routinely have good English – though English skills are improving with the rise of graduate-level nurses.

A general modernisation of the EONS presence

"Imagine not washing during a six-week treatment, but I helped to show this was a complete myth"

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With EONS board members pictured at their Spring Convention in the Hague last April. From the left (*back row*): Birgitte Grube (President elect, Denmark), Sultan Kav (President, Turkey), Kay Leonard (Ireland), Mary Wells (UK), Anita Margulies (Switzerland) (*front row*): Dimitrios Papageorgiou (Greece), Sara Faithfull (past-President, UK)

– a new journal, better website and office, technology for e-learning and so on – has also been part of Faithfull's contribution.

What triggered all this for Faithfull was acquiring 'a bug' for research that is now feeding the appetite for education. "After I worked on brain tumours I moved into the bigger field of urology, and again was fortunate to work with prostate experts such as David Dearnley and Alan Horwich at the Marsden, focusing on radiotherapy and side-effect management, which is what I did my PhD in. I got a scholarship from Cancer Research UK ."

The evidence base for nursing is still limited, she says. "It's partly because it's not funded and partly because people just assume it's there. For example, while there are now more than 35 experimental studies in managing skin care after radiotherapy, few are large-scale randomised trials. It's much more than when I started, but it's still not a lot when you consider this is a very common problem for cancer patients receiving radiotherapy." The problem, she adds, is that nurses are not good at articulating what a difference they can make – providing the best support, to which people, at what time, and how. "We need to do much more to measure and communicate the value of our therapeutic interventions."

A question she asks students on her advanced nursing course is: Give me the evidence that a specialist nurse will have more impact than a new scanner for detecting brain tumours. "It's relatively easy for doctors to measure their worth by the number of cancers detected and treated, but how do we measure quality of survival? It's not easy, but it is possible to describe and research therapeutic nursing and to be more definite about what we provide."

Faithfull's PhD work on radiotherapy and supportive care, she says, was ahead of its time and she initially had great trouble getting grants to follow up the work as she moved into her academic career. "We had so many rejections I was on the point of giving up, but patients said it was very important and the clinicians just didn't have the answers themselves."

There is a lack of knowledge about care during treatment as well as about long-term conditions. "For example, it used to be said that people couldn't wash when they were having radiotherapy as it could cause more skin toxicity. Imagine not washing during a six-week treatment course. I hope I helped to show this was a complete myth. But getting such evidence out into practice is really difficult, not only

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through education but in developing guidelines and influencing practice."

Following her PhD in radiotherapy and supportive care, Faithfull went on to publish a book with colleague Mary Wells on the topic, and the launch of the pilot e-learning course on side-effects by EONS is a logical move to increase awareness among nurses. As she points out, radiotherapy, despite being delivered to more than 50% of patients, is poorly understood by the public. "There is a relatively small number of people interested in researching the side-effects – there is a tiny number of papers about it compared with say the latest technologies such as IMRT [intensity modulated radiotherapy]. And with few people specialising in adverse-effects in most countries – we only have 20 radiotherapy nurses in the UK – many nurses don't understand the side-effects and so don't know how to assess them."

Long-term effects of all types of treatment have been of particular concern to Faithfull for some time now. "There is a lot more we should be doing on health promotion, after-care and follow-up, instead of just referring people back to cancer centres to check for recurrences. Again, though, we lack evidence, as most trials are only funded for short follow-ups. We have to rely a lot on sources such as the Department of Veterans Affairs in the US, where there is follow-up for insurance purposes, and we are doing work in the UK with the National Cancer Survivorship Group, where we are looking at existing datasets, such as the GP database and current clinical research on pelvic conditions and bowel cancer to gauge toxicity."

Key ideas, she says, are to help people 'self-manage' their conditions with Internet and smartphone applications, and telephone follow-up, and to provide local multidisciplinary teams that can ensure patients do not fall into gaps in care. "I've been working with men who have had prostate cancer, as they tend to get less care than women because they don't ask for it, and so have many unmet needs. They can have radiotherapy, for example, and not realise they should be getting more help with side-effects in the community. A nurse can marshal the right people to provide targeted advice, such as exactly how to exercise, what to eat, how to get hold of continence pads, sexual and erectile dysfunction services that are available and what raised blood pressure could mean if they are on hormone therapy and so on."

Faithfull has 'hands on' involvement with men with prostate cancer research as she is currently seconded one day a week to work with community teams on cancer survivorship, funded by Macmillan, the UK's cancer relief charity. She is involved with studies on urinary management, metabolic syndrome and bone health, which included looking at diet and exercise as a way of reversing musculoskeletal changes for men on hormone therapy. Bone health is a major issue for older men with prostate cancer who are on androgen deprivation therapy, and they are at high risk of fractures, she notes, adding that in future nurses could also integrate data from new biomarkers with health screening, which could flag up those most at risk.

Health promotion in general for all cancer types is neglected, Faithfull argues. "For example, a lot of nurses think that it's not worthwhile people giving up smoking, but it can have a big impact on side-effects such as skin problems and toxicity of drugs. Yet prescriptions of nicotine patches tend not to be part of cancer treatment. We need to focus more on getting people as healthy as possible during and after their treatment." She points to work by nurses at the Karolinska in Sweden on effective smoking cessation, and to research by nurses in the Netherlands on exercise and long-term symptom management.

She also points out that not all of this work need be put on the shoulders of hard-pressed healthcare services. "A lot of men are happy to pay for things like continence pads, if they know what best to buy and where, while we need to stop thinking of everything revolving around health facilities – with staff with the right skills, places like leisure centres could do a lot."

A key obstacle in the way of better nursing evidence, she adds, is nurses have not been part of a

research tradition, and where there are studies they tend to be isolated in certain hospitals or areas. "We have to move from individuals up to teams in much bigger groups that have the capacity for larger scale research." In some of her research work, Faithfull is working with a number of cancer centres in southern England to provide this scale.

Financing research is also of course a challenge, particularly as the funding often comes from very different sources to that of care. Charities fund 31% of specialist nurse posts in England, but charity funding for research tends to go towards biomedical studies rather than supportive care projects. And while research funds are available from sources such as the Department of Health and the Medical Research Council, this money is rarely ring-fenced for nursing alone, though nurses can apply. Developing bigger, multicentre studies can therefore be very difficult, although more supportive care research is funded now, with Faithfull herself a recipient in her survivorship work.

"Nurses also have good relationships with advocacy groups – we tend to be closer to them in any case – but they rarely fund supportive or psychological research, which is a shame. It is natural to look for cures though."

Lack of large pots of funding does curtail the kind of work Faithfull would like to see more of. "With small grants there is only so much you can do – mainly descriptive work about how people feel, much of which we have already done. What we really need is interventional research that tells us more about how we improve it. This would apply to issues such as fatigue, long-term urinary problems, sexual difficulties, skin management and dressings. A proper dressing study, for example, needs a lot of money for a multidisciplinary research on a decent scale."

And yet, where the evidence does exist to make improvements, adds Faithfull, it is often not practised consistently. "A good example is pain management – we have known for years what needs to be done for some symptoms, but still surveys such as EPIC [European Pain In Cancer] show there is a huge variation and we are still not getting it right."

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The question of how to ensure good practice is implemented is something EONS is now working on with the European Health Management Association. "There is other research involved here about how to make things work, such as relationships," she says. "Nurses also often have broader skill sets than doctors to make things work better, because we are trained in the social and psychological aspects of care."

One project where a deal of supportive care is in play is Faithfull's home, an old country cottage, and her garden, both of which are her main out of work pursuits. She is married to David, a computer analyst, and has a son interested in physics.

Professional aims for the next few years are clear. "I want to see more evidence-based health promotion and supportive care in widespread use, and care provided wherever it is needed, not just in acute settings. I want the UK to regulate specialist nursing and have a clear oncology nursing curriculum and I'd like to see the EONS curriculum become the standard benchmark for national use.

"Above all we will continue to fight for the voices of nurses to be heard."

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