Cancer nurses
partners in care

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Cancer nursing is changing across Europe. Nurses are studying to higher levels, taking greater responsibility and making more autonomous clinical decisions. One important result is that they are better able to help cancer patients make sense of what is happening and learn to become partners in their own care.

Cancer nursing developed as a specialty in the 1970s. At the Royal Marsden Hospital in London – one of three specialist cancer hospitals in the UK – Robert Tiffany encouraged other cancer nurses to study up to Masters level and extend their role in prevention, early detection, care, and even in an intensive care setting. He was inspirational in starting the International Society of Nurses in Cancer Care (ISNCC) and in 1984 was a founding member of the European Oncology Nurses Society (EONS).

The Royal Marsden is still a European leader in cancer nursing. In 2000, Shelley Dolan became nurse consultant in cancer critical care here, the first nurse in the UK to be made a consultant. Her consultancy involves her in work across the UK and internationally. Dolan chairs the Royal College of Nursing Cancer Care Forum, is on the board of the ISNCC and is an active member of EONS.

She says that almost all cancer patients want more control of their lives. "If you are to be master of your own destiny and you have a chronic illness, most people would like to be well informed and a partner in decision-making. To control pain and manage their condition at home, it is important that they understand what is going on."

Intensive care

The critical care unit at the Royal Marsden is an intensive care unit for cancer patients, who are likely to be on a ventilator and need cardiac monitoring or kidney support after complex major surgery. Patients are also admitted for treatment of a life-threatening renal failure, respiratory failure, cardiac arrest or major bleed, as a result of their cancer or treatment. The mean stay is three to four days, but 20% stay longer – up to 44 days.

Despite the relatively short length of stay, it is important, says Dolan, for nurses to get to know their patients. "This is an acute blip in a chronic illness and they could have many more blips, so it is really important that they have the best experience possible, or they are going to be scared if they have to face surgery again in three years' time. When I employ a critical care nurse,

Shelley Dolan, nurse consultant in critical care at London's Royal Marsden Hospital. She was the first nurse in the UK to be made a consultant

I am looking for technical expertise, knowledge and experience, but I am also looking for someone who can give a lot of love to the patients. They have a very hard diagnosis to deal with and the family has a very hard diagnosis to deal with. Suddenly you are in this environment where there are bells and buttons and machines all around you; it is very scary for you and your family. It is very important to me that we do everything you would expect a supportive care nurse to do. Even when the patient is sedated and on a breathing machine we talk to them as though they can hear every word that we are saying."

Contact continues after discharge, through a critical care 'cool off' service to help people with cancer cope with their psychological and emotional reaction. "As soon as they are discharged from the unit to the ward, one of my critical care outreach nurses makes sure that they are recovering and goes through any worries that they have.

"They come back to my clinic at three months, six months and a year. I do a physical examination but also let them tell their story of their critical illness, to make sense of what can be a very disorientating time, where night and day get confused. People may think they have been in a film. It can be very florid. They sometimes develop what we call 'critical care psychosis' where they think that everyone is trying to kill them and that the doctors are Russian spies. We help them to make sense of it, as though their brain needs a bit of help to put these images and flashbacks into the right place."

This story telling is now part of a research project at the Royal Marsden, and Dolan says that many patients express immense relief when they find they are not the only ones to have been deeply affected.

Cancer nurses administer chemotherapy, manage symptoms, and must understand the progression of the disease and possible side-effects of treatment. Dolan sees one of the key roles of her nurses as providing a point of reference and education for their colleagues. "Haematological conditions, such as leukaemia, lymphoma and myeloma, are quite complex diseases, and most intensive care nurses only see a

small number of those patients a year. These nurses will not necessarily understand about the complex chemotherapy, bone transplant and why patients are so sick."

The specialist knowledge of nurses is increasingly recognised across Europe as an important factor in patient outcomes. Experience has shown that knowledge and training of nursing staff is essential for optimal cancer care. The Wisecare+ project in a number of centres, including the Royal Marsden, showed the benefits of using new technology to help patients keep in touch with nursing expertise even after they leave hospital.

Pain reduction

One of the key roles of nurses is to minimise pain for patients. People with cancer often fear pain as much as any other aspect of the disease and in 90% of cases this can be effectively controlled.

At the Royal Marsden patients are asked before an operation where on a scale of 1–10 they would want their pain control following treatment. Dolan says that most cancer patients are stoical and realistic and, rather than asking for a 0, ask for pain to be kept to no more than a 3 or a 4.

"If you have had major surgery you will not do well afterwards unless you have good pain control. You have got to be able to breathe well so you can come off the ventilator, you have got to be able to cough and you have got to be able to walk, to avoid things like thrombosis. Patients in pain won't cough and won't do their physio properly and won't be able to walk about and will get all the complications that can arise. Pain is not just damage to a nerve. It is about sadness and anxiety. It is linked to our memory. If surgery was excruciating last time, that is what you think it will be again and it will be harder for us to achieve pain control."

Another important skill is to be able to understand patients' concerns and to explain clearly what is happening and about choice.

Dolan says that this means learning to listen, as people may express their real thoughts in casual throw-away remarks. "When people give us cues we need to hear them. When you are giving an injection if someone says 'I'm not sure if I am going to get through this' it is much easier to say: 'Of course you are. Don't worry' and rush off to do something else. But that would not be listening to the person; and would not meet the standards we want. It is much harder to expose yourself to their pain, their sadness and their fear."

Dolan rejects the idea that you have to choose between technical competence and a good bedside manner. "You do not want a science textbook on the ward who cannot relate to the humanity of the person who has cancer. On the other hand you do not want someone who is warm and fuzzy but does not understand the drugs and how they work. Healthcare is complex and you are delivering drugs that are very toxic. To expect nurses to look after people without a good education to the level of a degree is a big mistake. Some of the best bedside nurses are very highly qualified." And she points out: "All doctors have medical degrees, including the caring GPs and palliative care physicians who have a really good bedside manner.

"I hope we get to a stage where we all realise that total care of the patient is the aim and it is actually much more rewarding to work like that," says Dolan.

In the UK, nurses are able to prescribe if they have done an extended pharmacology course, but this has not yet arrived in the complex world of oncology. Dolan believes it will come sooner rather than later. "Our critical care outreach service is very much nurse led. Nurses carry out a physical examination of the patient, assess them and need to prescribe care. What

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Shelley Dolan with student nurse, Lai Man Chan. Dolan argues that nurses who care for patients with complex diseases like cancer, and are expected to deliver toxic drugs, need to be educated to degree level

they have to do at the moment is to run to find a junior doctor who will prescribe what they want. That is obviously not ideal. We want to bring fast appropriate access to care for patients."

Teamwork

In specialist centres like the Royal Marsden, the hierarchy between professions has largely disappeared. Dolan says: "We work as part of a multidisciplinary team, and surgeons, anaesthetists, intensivists and physicians hugely appreciate the work of the nurses and the nurses hugely appreciate them. They are all very keen that we work together to improve the system."

She feels nurses in general deserve greater appreciation and recognition. "I would want to see nurses across the world having access to study leave and study resource so that more nurses could undertake postgraduate degrees. I would like them to be rewarded financially and in career advancement. I want nurses to feel loved and supported in their work. It is a tough job and junior doctors and nurses do not go home and switch off. They go home and they worry. They need to know that they are appreciated. That hard-nosed culture – come in, get the work done and go home again – I don't believe that that applies in healthcare."

If the nurses have changed, so have the patients, 80% of whom are cared for at home. Dolan recalls: "When I first came into nursing many patients would just say 'that's fine' whatever you say. Until very recently cancer was not talked about to patients – so people had a 'lump' or a 'bump' or some 'abnormal tissue'. Now many patients come in having studied the Internet. They want to know about options and what is happening.

"If someone is going to have a disease for the rest of their life, they had better know about it, because they are going to have to manage their finances, their family and everything else and we are not going to be there. Health is not just about the medicines you take. It is about the food you eat. It is about whether you stop smoking and if you take exercise. The most fundamental area of healthcare is about getting people more healthy. It does have to be a partnership."