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The European Oncology Nursing Society (EONS) does not accept responsibility for the accuracy of any translated materials contained within this edition of the EONS Newsletter.

The aim of the EONS Newsletter is to provide a written resource for European nurses working in cancer settings. The content of the articles is intended to contribute to the growing body of knowledge concerning cancer care.

All correspondence should be addressed to the Editor-in-Chief at: eons.secretariat@cancernurse.eu
Welcome to the first edition of the new style EONS Newsletter, which aims to reach out to everyone involved in supporting and caring for cancer patients.

No professional group is better placed to do this than the cancer nurses of Europe, because, as our bannerline indicates, nursing really is at the heart of patient care. It is our role to understand the many different needs of each of our nurses on whom patients depend as they move through their cancer journey.

EONS helps to ensure that the patients’ needs – medical, emotional, spiritual, social and practical – are addressed, by developing resources with our partner professionals that educate, support and empower cancer nurses, enabling them to provide the best possible patient care.

The importance of the patient-centred, partnering role of cancer nurses in a modern health service is gaining increasing recognition. However, specialist training, professional responsibilities and team roles still vary widely across Europe.

While reaching out to our fellow professionals, the EONS Newsletter will therefore also continue to showcase the unique contribution we make to the health of European citizens, and provide a strong voice for all European cancer nurses on the issues that most closely affect them.

This edition of the Newsletter, which focuses on breast cancer care, is the first in a series of themed issues. Touching on subjects from symptom management to advanced disease, cancer biology, education and training, adherence and reaching marginalised groups of patients, it demonstrates just how many different aspects are involved in the role of the cancer nurse.

The issue was compiled by our guest editor, Debbie Fenlon, who has strong connections throughout the cancer nursing field through her long experience working as a specialist breast care nurse at the Royal Marsden Hospital in London and then as a researcher specialising in the problems that women face once they have been diagnosed with breast cancer.


I hope you enjoy our new style Newsletter and that you will also take time to explore the relaunched EONS website www.cancernurse.eu, which has been re-designed to better serve the needs of our members while also opening up to everyone involved in supporting and caring for cancer patients and their families.

With your help and feedback, we will continue to develop both the Newsletter and the website to ensure that they keep pace with your changing needs.

With broad experience of leadership and management in the healthcare field as well as 3.5 years experience as Executive Director of a European Medical NGO, Clair Watts joined EONS as the Executive Director in April 2009.
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The launch of EONS Breast Care Nursing Curriculum at this year’s ECCO–ESMO Congress in Berlin marks a milestone in the development of this specialty. For the first time, Europe has a single set of minimum training requirements that must be fulfilled in order to qualify as a breast care nurse. Though the requirements may be modest by the standards of some countries, they set a European benchmark that defines breast care nursing as a specialty that is patient-centred and carried out in partnership with the breast care team, the patient and their family.

The curriculum was drawn up by a panel of experienced breast care nurses from all over Europe. Some of them have contributed to this issue of the EONS Newsletter, which takes a broad look at the many aspects of this profession and the challenges and developments in the field.

Ilana Kadmon, who set up a breast care nursing service for the whole of Israel, discusses the need for agreed standards of education for the next generation. Yvonne Wengstrom, past president of EONS and Professor of Cancer Care and Eva Gustafsson from the Karolinska University Hospital in Sweden, share their thoughts on how to increase women’s adherence to endocrine treatment. Saskia Claassen, an advanced nurse practitioner in breast cancer working in the Catharina hospital in Eindhoven, the Netherlands, takes part in assessing breast clinics throughout Europe and makes sure that provision of breast care nursing is adequate. She gives us an insight into this work. Manuela Eicher, a research fellow at the University of Basel, Switzerland, describes how breast care nurses are well placed to respond to the changes in health care that are occurring throughout Europe.

Other contributions address the many varied aspects of the breast care nursing role. Mary Woods, consultant nurse in lymphoedema at the Royal Marsden Hospital in London and Surrey in the UK, gives us the latest on management of this condition. Kay Townsend, a lecturer at the University of Southampton, UK, gives an update on the complexities of breast cancer cell receptor sites and treatments. We have two contributions from the UK charity Breast Cancer Care. Emma Blows describes research about how to reach out to provide information and support to hard-to-reach groups in the UK, such as those from black and minority ethnic groups and older women with breast cancer. Liz Reed and Dora Wheeler have completed an important piece of work looking at the needs of women with secondary breast cancer.

This collection of articles shows that the needs of breast cancer patients go well beyond diagnosis and treatment – their needs are broad ranging and long lasting.

My hope is that our nurse training takes us beyond the medical model of acute care and treatment and that we focus on the experience of breast cancer through its diagnosis, treatment and on to long-term living. Practising as breast care nurses, we focus on the needs of the patient, whatever their needs and agendas are, irrespective of where they are on the disease trajectory or what treatment they are having. By doing this, we enable women with breast cancer to achieve the goals that they set despite the constraints set upon them by their breast cancer experience.

Debbie Fenlon spent 12 years at the Royal Marsden Hospital in London as a nurse specialist working with women with breast cancer. She is currently a Senior Research Fellow based at the Macmillan Research Unit at the University of Southampton, where she specialises in cancer survivorship.
EONS is on the move!

A message from the Board

Although summer is traditionally the time for slowing down the pace of work, there’s been no summer break for the EONS Board this year. Since spring, we have launched a new website, redesigned our newsletter and renovated the office. We give a very warm welcome to Clair Watts, who joined us in April as our new executive director, and threw all her energies behind carrying through these changes.

The new look website is now live at www.cancernurse.eu. Do please explore it if you have not already done so.

Both the look and content have been radically updated to ensure that you can access the very latest information with ease. We will continue to refine the website to ensure it serves the needs of members and other visitors. Please send any comments and suggestions to the EONS office (eons.secretariat@cancernurse.eu) so that we can continue this development process together.

With its project partners, the Board has continued updating EONS educational materials and developing new educational projects. The target programme, on the science behind targeted therapies, has been updated and relaunched as ‘target Update 2009’, with the highly successful first training course taking place in May in Dublin, Ireland (see opposite).

The curriculum of the BREATHE project (Breathing and Respiratory Education and Training for Health professionals with E technology) is now in the final stage of production, and will be launched on the EONS website in September.

The EONS Specialist Breast Care Nursing Post Basic Curriculum has now been finalised and will be officially launched at the ECCO15–ESMO34 congress in Berlin. You can find out more about EONS projects on the EONS website.

A lot of time has also been put into planning the programme for the Specialist Oncology Nursing track of the ECCO-ESMO congress in Berlin, as well as developing the EONS 7th Spring Congress programme.

The members of the Board look forward to meeting many of you in Berlin and hope that you will find the programme as stimulating and innovative as we do.

We also take this opportunity to thank everyone who submitted abstracts for presentation during the ECCO–ESMO congress, and we hope that those who are able to attend this congress will join us for a drink during the EONS General Meeting on Tuesday September 22nd at 6pm.

Your deadline for abstract and fellowship funding submissions for the EONS Spring congress (scheduled for April 15-16th 2010, in the Hague) has been set as December 17th 2009.

We look forward to receiving your submissions and your continuing support.

Ulrika Östlund,
EONS Board Secretary
Cancer and sexuality: patients’ questions answered in a Q&A booklet

Sexual dysfunction is a frequent long-term side-effect of cancer treatment. But patients report that they seldom remember discussing risks of sexual dysfunction before treatment or what can be done about the problem after treatment.

Although many oncology nurses are aware that patients and their partners can have sexual problems, most nurses do not provide information or support concerning sexual matters.

Furthermore, sexual difficulties are often not identified by the cancer care team, and most patients receive little or no assistance in dealing with the effects of cancer and its treatment on intimacy. Patients and their partners want information regarding the effects of illness, treatment and disability on sexuality.

In an effort to meet this need, a new information booklet has been compiled in the Netherlands: 80 questions and answers about cancer and sexuality.

The topics cover all cancer treatments that may affect sexuality and fertility, with the aim of making the information on sexuality accessible and understandable to patients with all types of cancer and their partners.

This information may help the patient to discuss expected sexual problems with their health care provider, if necessary. It should help patients to anticipate the expected sexual problems of their cancer or its treatment and to influence their quality of life in a favourable way.

Research has shown that different sexuality information is needed at different time periods: at the time of diagnosis and treatment, in the recovery period, and when the patient and their partner start rebuilding their sexual life. In the near future, hopefully, many of the sexual problems encountered may be prevented by providing adequate information and patient education at the right time.

In the first edition of the booklet, answers to the 80 questions were drafted based on the literature and multidisciplinary expert opinion given by 26 health care providers.

Though there is still a lack of consensus- or evidence-based information on sexuality after cancer, a start has been made in collecting structured feedback from patients/partners and colleagues in the field, which will be used to complete and rewrite the booklet.

Currently the booklet exists only in Dutch, but an English version is planned.

Corien Eeltink and Daniela Hahn
EPE award winners 2009
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Please register online at www.uicc-community.org.
Europa Donna welcomes move to define standards for breast care nursing

Europa Donna wants every woman with breast cancer to be treated by a team of specialists with a defined set of competencies. It welcomes EONS Breast Care Nursing Post Basic Curriculum as a step towards this end.

Ellen Verschuur

Europa Donna – The European Breast Cancer Coalition, is an independent non-profit organisation whose members are affiliated groups from countries throughout Europe. The coalition works to raise awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optimal treatment and increased funding for research. It does this through working at the level of local and national authorities as well as the institutions of the European Union.

Founded 15 years ago, Europa Donna has expanded from an initial three countries to its current 44.

THE EUROPEAN GUIDELINES

The coalition is committed to ensuring that all women in Europe have access to breast services in a specialist breast unit as defined by the EU Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis published in 2006.

A key component of this service is that care is provided by a multidisciplinary team and that women should receive advice, support, and counselling from a specialist breast care nurse, or a core team member with professional psychological training who is an integral part of this team.

The guidelines made a more general reference to this core team member precisely because there were no European standards or curriculum for this specialty that could be followed in all European countries. A workshop at the Parliament was held in October 2006 to discuss the variations in training and definition of this specialty across Europe with the aim that EU guidelines for this should be included in the next edition of the Guidelines.

Europa Donna therefore applauds EONS for responding to this need, carrying out this research and developing a curriculum defining the basic module that should be a minimum requirement for all breast care nurses practising across Europe.

Europa Donna believes this represents an important tool that can be used immediately, adapted as necessary, and that ultimately it will lead to developing and adopting EU guidelines for breast nursing that can be implemented in all European countries.

BREAST HEALTH DAY

Europa Donna launched on October 2008 Breast Health Day to disseminate the information found by recent studies from the International Agency for Research on Cancer (IARC) about the factors influencing the health of the breasts.

The coalition decided to embark on a major breast health campaign/public health education programme and launched breast health day on October 15th 2008, which included a public service announcement translated for all member countries.

A NETWORK OF SURVIVORS

Europa Donna is an European advocacy organisation with European strategy and goals. From the start, Europa Donna has developed a network of survivors working at the national level through the national fora. This gives the coalition a strong base from which it has been able to make a significant impact on European institutions and national health services in terms of optimising breast health services.

Further information can be found at:
www.europodonna.org
www.breasthealday.org
Over the past 20 years the role of breast care nurses has developed in different ways across Europe. The goal of defining a single European category of breast cancer nurse is now moving closer with a new set of training standards set by EUSOMA.

Saskia Claassen

The specialty of breast care nursing has developed over the last 20 years in the UK, Australia, US and Scandinavian and Benelux countries, to care for and support women and their families affected by breast cancer. Over time, breast care nurses have started to be employed in a wide range of roles relative to their education and experience. Role titles that have been used include Breast Care Nurse, Advanced Nurse Practitioner,1,2 Nurse Specialist, Specialist Breast Nurses3,4 and Breast Cancer Nurse5. These roles have developed in a variety of settings, often exclusive to a single area, including breast screening, diagnosis, surgery, radiotherapy, metastatic disease and follow up.

Evidence from randomised controlled trials suggests that there are psychological benefits from the intervention of the breast care nurse, including reduced distress,6 decreased anxiety and depression, and improved physical and social well-being.7-9 Studies have also shown significantly reduced levels of illness-related uncertainty up to six months after diagnosis,2 significantly lower levels of insomnia and dyspnoea, and alleviation of financial difficulties.10

Wherever they are integrated in multidisciplinary teams, breast care nurses seem to have a positive impact on the quality of breast centres. In a random sample of 72 breast cancer teams, in addition to reducing team workload, the proportion of breast care nurses correlated positively with overall clinical performance.7

Due to the wide variation of nursing practice and education across Europe, it cannot be assumed that nurses working in the field of breast cancer will have the education or opportunity to be able to work at a higher level of practice, yet they may wish to be better informed about the needs of women with breast cancer in order to provide optimal care.

INTERNATIONAL GUIDELINES

International guidelines on standards for the training of specialised health professionals dealing with cancer have been recently developed and published by EUSOMA (the European Society of Breast Cancer Specialists)5. They state, for example, that breast care nurses will need an understanding of issues relevant to their patients and need to be familiar with specific knowledge.

EUSOMA has also developed international guidelines for breast care units whereby breast care clinics throughout Europe can apply for accreditation. Once an application has been received, a group of specialists, including a surgeon, radiologist, pathologist and breast care nurse, will then visit the clinic to examine whether it meets the specified standards.

The role of the breast care nurse is seen as an important part of a breast care unit, and a clinic cannot
obtain accreditation if they have no breast care nurse. As an advanced nurse practitioner in breast cancer, working in the breast clinic of the Catharina hospital in Eindhoven in the Netherlands, I took part in such visits as a member of the EUSOMA team, during which I met with the breast care nurse(s) and the patient support staff. Our brief included scrutinising the provision of information, observing how care is organised and checking whether the clinic met the EUSOMA criteria. These include, for example, stipulations that there should be at least two breast care nurses, who must be available to counsel and offer practical advice and emotional support to newly diagnosed patients at the time the diagnosis is given and be able to further explain treatment plans. Breast care nurses should also be available on demand from patients in the primary breast cancer follow-up clinic and in the advanced breast cancer clinic.

The guidelines also require a breast care nurse to be present to support women receiving a diagnosis of advanced breast cancer.

During those visits it became apparent that there is indeed a wide variation of nursing practice and education across Europe, and not every country has formal education for breast care nursing. Some nurses have training in the hospital, but others gain their knowledge purely by experience.

Though all the visited hospitals had breast care nurses, to comply with the EUSOMA accreditation criteria, their educational level and role differed greatly. For example, many still work shifts, which has a major impact on their role – if breast care nurses are compelled to do a night shift, they will not be available to guide patients, have contact with the doctors or develop patient information.

One major step forward has been the decision by the European Parliamentary Group on Breast Cancer as well as EUSOMA to identify breast care nurses as crucial members of the multidisciplinary team. However, because of the wide variations in the level of education (if any), there is still a need for EU guidelines on breast care nursing and training.

The role of the breast care nurse is seen as an important part of a breast care unit, and a clinic cannot obtain accreditation without one.

**CURRICULUM FOR CANCER NURSING**

EONS has now developed a curriculum to train breast care nurses that can be used in all European countries, and is set to be launched at the ECCO–ESMO Congress on 20th September. The Breast Care Nursing Post Basic Curriculum was developed following the template provided by the broader EONS Post Basic Curriculum in Cancer Nursing 2005 (3rd edn). It remains, however, aimed at a basic level and is intended to be taken as a stand-alone module for working nurses who are studying part time.

The curriculum will be a very important step in enhancing the quality of cancer care in general and, in particular, the quality of care provided by breast care nurses in all European countries. It lays the basis for defining a single European category of breast care nurse, who would have the same role in every hospital, acting as a full member of the multidisciplinary team.

This development will contribute to help nursing care reach a high standard across the whole of Europe.

Details of the references cited in this article can be accessed at www.cancernurse.eu/communication/eons_newsletter.html
Five ways we can do better for patients with metastatic disease

Many patients diagnosed with metastatic cancer feel they are not given the level of care and information they received at the time of their primary diagnosis. A new policy initiative has started to address these shortcomings.

Elizabeth Reed and Dora Wheeler

Over the last decade, the medical management of metastatic breast cancer has improved, with the development of more effective and better-tolerated therapies that can be applied sequentially to a wider range of patients.1-3

Active treatment often allows women with metastatic breast cancer, even those with visceral disease, to have a prolonged illness trajectory, and for many it may become a long-term illness.

But the increase in treatment options, together with the potentially prolonged illness trajectory, means that patients are now faced with a growing number of decisions to make, obstacles to overcome and complex problems to navigate. And while advances in treatment options have raised expectations for a longer life, these women often have very limited access to the psychosocial support and information.

Not surprisingly, low levels of professional awareness and a failure to acknowledge their needs have been found to affect the well-being of women with advanced breast cancer.4 These findings are reflected in the experience of advocacy groups like the UK’s Breast Cancer Care, which reports that feedback from women with metastatic breast cancer shows they often feel unsupported and isolated.

In an effort to address the many and various needs of this growing population of women, in 2006 Breast Cancer Care set up a Secondary Breast Cancer Taskforce to improve the care, treatment and support for people with metastatic breast cancer.

A PATIENT-LED TASKFORCE

The Taskforce ran for two years as a national coalition of health care professionals, charities, policy makers and women with metastatic breast cancer.

The agenda was guided by women living with metastatic disease. Eight women formed a User Advisory Group, which met regularly, and 50 women participated in a Reference Panel, responding to surveys, taking part in focus groups, commenting on papers, attending campaigning events and doing media interviews. Two members of the User Group were included in the Taskforce.

Five priorities were identified through a process of expert consensus, driven by the needs outlined in a paper presented by the User Group, supplemented by the views and comments from the wider Reference Panel. These focused on the need for better data, access to nurse specialists, information provision, psychological support and shortcomings at the level of primary care.

COLLECTING THE DATA

Despite developments in the detection and management of breast cancer, it is estimated that approximately 50% of all those with primary operable breast cancer who receive local regional treatment alone will have micrometastases at presentation and will go on to develop metastatic disease.5 A further 5–10% will present with metastatic disease at diagnosis.6

These figures indicate that a significant number of the 550,000 women in the UK estimated to be alive with a diagnosis of breast cancer will have metastatic disease.7 However, data on the incidence of metastatic cancer are not collected in the UK. The lack of accurate data makes
it difficult for policy makers and service providers to develop services to address the needs of these women.

The Taskforce therefore drew up a policy document that highlighted the need to collect data on the incidence of metastatic breast cancer. This document recommended that data should be collected on the incidence of metastatic breast cancer and survival, and called on key stakeholders to address the lack of data. This was backed up by a campaign – ‘Stand up and be counted’ – launched at the UK Parliament in October 2007.

In June 2008, the UK’s National Cancer Intelligence Network announced that data on recurrent and metastatic breast cancer would be collected and

**A meeting of the User Advisory Group, which guided the work of the Secondary Breast Cancer Taskforce**

become mandatory for all cancer registries. A good result for one priority area of action.

**CO-ORDINATING CARE**

Access to the appropriate specialist care was another area identified as a priority. Evidence suggests that those with metastatic disease are not receiving the same levels of attention and care as those with primary disease.6

This may explain why uncontrolled symptoms such as fatigue, pain, sleeplessness and depression have been found to be a problem in this group of women.4-10

Many women on the Taskforce felt their experience of being diagnosed with metastatic breast cancer compared unfavourably to the experience they had on being diagnosed with primary breast cancer, when they had felt informed and supported.

Few of them had been offered breast care nursing support at the time they were informed that their disease had

While advances in treatment options have raised expectations for a longer life, these women often have very limited access to the psychosocial support and information
spread, and many felt they were left to navigate their way through the complex health and social care services with little formal support.

This may be related to the findings of a 2007 survey of UK breast care nurses, which found that their time is primarily dedicated to meeting the needs of women in the adjuvant setting. Indeed some felt they had neither the knowledge nor the confidence to care for women with metastatic disease. 11

The Taskforce therefore called for everyone with a diagnosis of metastatic breast cancer to have a key worker with the appropriate skills and knowledge to support and care for women with metastatic breast cancer. Breast Cancer Care is currently collating information from around the UK about the models of care that could be applied to this patient group and is planning research to investigate the impact of different follow-up models.

**APPROPRIATE INFORMATION**

Lack of appropriate information was another key issue identified by the Taskforce. Research has shown that when patients are diagnosed with recurrent cancer, treatment staff tend to assume that the experience of their initial diagnosis would have prepared them for the recurrence. Ninety per cent of patients said they had been given less attention and information and that staff simply assumed that they were coping and had sufficient support. 12 A separate study found that professionals’ engagement with metastatic breast cancer patients appears to wane as the disease progresses and the treatment options dwindle. 13

In response to this evidence and feedback from the User Group and the Reference Panel, the Taskforce recommended that all people with metastatic breast cancer have their information needs formally assessed. Breast Cancer Care, in consultation with women with metastatic breast cancer and health care professionals, has produced a pack that includes information on diagnosis and treatment along with other resources. It is designed to function as a personal record for each woman. It is free and available to anyone through their health care professional or Breast Cancer Care’s website (www.breastcancercare.org.uk).

**PSYCHOLOGICAL SUPPORT**

The Taskforce felt strongly that women with metastatic breast cancer should have their psychological needs assessed on a regular basis, and identified this as another priority area.

Given that up to 50% of women with metastatic breast cancer experience clinically significant levels of traumatic stress symptoms associated with their cancer, 14 and one-third of women with advanced breast cancer have been found to have an affective disorder – sufficiently severe and persistent to require an appropriate intervention in one in three of them 15 – the need to address the psychological health of this group of patients is of paramount importance.

The needs of family and friends were also a concern for the women in the User Group and Reference Panel. They

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**Recommendations of the Taskforce**

The Secondary Breast Cancer Taskforce drew up the following recommendations for action, based on the priorities identified by the User Advisory Group, together with comments from the Reference Panel.

- Data should be collected on the incidence and survival of patients with metastatic breast cancer
- Every patient should be given a key worker who has the appropriate knowledge to support and care for women with metastatic breast cancer
- Formal assessment should be made of the information needs of each patient
- Consideration should be given to assessing psychological well-being, using validated assessment tools, for both the patient and family members
- Management of women with metastatic breast cancer at the primary care level should be improved

To find out more about the Taskforce’s achievements and further work, please go to http://www.breastcancercare.org.uk/server/show/nav.728
felt health care professionals failed to acknowledge these needs.

Their experience is supported by evidence which suggests that health care professionals appear to underestimate the support needed by those with metastatic cancer, and this unmet need is associated with high levels of burden on the caregiver, including poor health.15 Those caring for people with metastatic breast cancer can have similar levels of depression to those they care for.15

The Taskforce therefore called for initiatives on the part of government to consider the assessment of psychological well-being, using validated assessment tools for both the patient and family members, at key points – such as disease progression – and regularly throughout their illness trajectory.

**BEETR PRIMARY CARE**

Primary care services have an important role to play in the care of patients with metastatic breast cancer. But the Taskforce found many primary care providers have poor levels of awareness and are ill-equipped to fulfil this role. Addressing this shortcoming was identified as the fifth priority area for action.

The Taskforce identified three main concerns:

- Poor awareness among general practitioners (GPs) of the signs and symptoms of metastatic breast cancer
- Inadequate knowledge about managing metastatic breast cancer among primary care clinicians
- A lack of communication between primary and hospital care providers.

These concerns are mirrored by research which has found that the involvement of GPs and palliative care services in the management of metastatic breast cancer is limited, with care provided predominantly through outpatient clinics by hospital specialists, with little or no community-based support.17

A survey undertaken by the Taskforce found that 64% of women presented their symptoms to their GP first, and 66% had more than one appointment with their GP before being referred to a breast cancer specialist.18

Women in the User Group and the Reference Panel said they felt that their GPs were not up to date with the medical management of metastatic breast cancer, and the communication between primary and hospital care was fragmented.

In consultation with users and primary care clinicians, the Taskforce therefore developed a tool to support primary health care teams in the management of women with metastatic breast cancer,18 and recommends each GP is sent a copy at the time they are sent a letter confirming a patient’s metastatic diagnosis.

**FROM RESEARCH TO PRACTICE**

The multidimensional needs of patients with metastatic breast cancer have been highlighted by a significant body of international research. However, the Taskforce found little evidence to show that this translates into assessment of needs in clinical practice in the UK. Nor is it reflected in the level of provision of services offering ongoing support. The development of support services appears to lag behind the development of life-prolonging treatment.

The Taskforce came to an end in November 2008, but its work continues. Breast Cancer Care continues to influence and improve the care of those with metastatic breast cancer in all of the areas identified, through collaboration with government initiatives such as the National Cancer Survivorship Initiative and campaigning work.

Details of the references cited in this article can be accessed at www.cancerwise.eu/communication/econs_newsletter.html
Boosting adherence to adjuvant endocrine therapy

Five years can be a long time to keep taking a medication, particularly if you are bothered by side-effects, can feel no benefit, and don’t understand why your doctor has recommended it. Nurses are well placed to help address some of these problems and can help women stick with their prescribed therapy.

Yvonne Wengström and Eva Gustafsson

Adjuvant endocrine treatment (AET) is used to reduce the risk of recurrence in women with hormone-responsive breast cancer. Women generally remain on AET for five years, and emerging evidence now suggests that it may be beneficial to extend the treatment duration even further.

Failure to take the medication as prescribed is known to jeopardise the efficacy of the treatment. However, adherence to medication cannot be assumed, even in the face of a potentially life-threatening disease such as breast cancer. Finding ways to help women stick with their prescribed therapy is becoming increasingly important, and cancer nurses have a valuable role to play.

SHARED DECISION-MAKING
Research into adherence has consistently highlighted the importance of the way treatment decisions are made. Shared decision-making has been suggested to be the patients’ preferred approach and to have a positive impact on outcome. But as treatment options for breast cancer become ever more numerous and complex, with varying types of side-effects, women are finding it increasingly difficult to weigh up their relative advantages and disadvantages.
Recent research looking at predictors of adherence to tamoxifen in breast cancer patients has demonstrated an association between long-term adherence and the right amount of involvement in decision-making and patient-centred care.4

This research suggests that non-adherence to treatment is the result of three factors:
- lack of information about the advantages and disadvantages
- lack of visible benefits
- need for psychological adaptation in order to realise the necessity for treatment.

**COMMUNICATING AT THE RIGHT LEVEL**

The decision-making process needs to include health care professionals working with patients to ensure that they have the information they need to make difficult decisions.

An understanding of the patient’s choice of degree of partnership is also essential in patient-centred care. It is important to communicate information about different treatment options and their advantages and disadvantages, due to the complexity of the side-effects of different therapies. The treatment choices are complicated for these women, as they are mainly in the form of recommendations rather than clear-cut options.

Doctors have been found to underestimate the need for this information, and the trend in recent years is that patients with a cancer want more counselling, information and influence over treatment.5,6

Perceived control over illness also has an influence on adherence to medication.7 Socio-demographic factors such as gender, level of education and race have not been found to influence adherence; however, some research suggests that non-adherence to AET is more likely at a more advanced age8 and that adherence to long-term medication often declines over time.9 It is also a well-known fact that patients are less likely to adhere to complex therapies or those with adverse side-effects.2,4,5

**COMMUNICATING ABOUT SIDE-EFFECTS**

The benefits of AET are well documented and it is often well-tolerated; however, its many side-effects have not been sufficiently recognised. Symptoms and side-effects are often related to menopausal symptoms, which can have a severe impact on quality of life, although women who have had previous treatment with chemotherapy may describe the side-effects of AET as less severe.

Information concerning side-effects is often perceived as unsystematic, and many think that the information leaflet in the medication box is frightening. Although patients are often willing to tolerate side-effects when faced with a life-threatening illness such as breast cancer, it cannot be assumed that they will actually adhere to medication, and there is research evidence to show that unpleasant side-effects of medication may impede adherence.2,5,6

Our clinical experience indicates that sometimes the side-effects may be diminished by adjusting the time of day at which the pill is taken. This is supported by a finding that women who take tamoxifen may have a different diurnal pattern of flushing than those who are not taking tamoxifen.10 Complementary therapies, such as acupuncture, may also be helpful.

**COMMUNICATING ABOUT BENEFITS AND RISKS**

It seems obvious that it is important to know why AET is recommended, along with information about the benefits and risks of the treatment. However, it is not uncommon for women to lack this information and to have a poor understanding of the purpose and preventative aim of AET.

Research shows that adherence requires that patients understand their illness and the need for the medications prescribed.21 Information about risks and benefits influences adherence and enables patients to make an informed choice. Belief in the necessity of taking a prescribed medicine is an important factor in adherence; there is evidence that those who adhere to treatment experience benefits whereas non-adherers are more likely to report no benefit.22

If we are to achieve optimal adherence, effective communication between patients and health care professionals is essential. This may well be a challenge in the adjuvant situation if the need for, or benefit of, the AET is not clear to the patient.

Some factors and experiences have been identified that will have an impact on whether treatment will be continued or not. Nurses in cancer care are in a central position to support patients and hence need to develop better strategies to educate women with breast cancer about treatment choices, in order to help them to function better in their preferred decision role and to enhance adherence to long-term adjuvant treatment.

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**Compliance or adherence?**

The increase in patient autonomy has led to the term ‘adherence’ replacing the more authority-laden term ‘compliance’ in the literature. ‘Compliance’ implies an imbalance in the doctor–patient relationship: the patient must do as they are told. ‘Adherence’, in contrast, can be defined as “the extent to which a person’s behaviour coincides with medical or health advice”. This highlights the importance of ensuring women have the information they need about risks, benefits and side-effects and why the medical advice is important.

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Details of the references cited in this article can be accessed at [www.cancernurse.eu/communication/eons_newsletter.html](http://www.cancernurse.eu/communication/eons_newsletter.html)
A one-size-fits-all strategy for providing information and support to breast cancer patients is bound to leave certain groups with unmet needs. The Better Access Better Services project, which focused on reaching older women, and those from black and minority ethnic groups, recommends a more tailored and flexible approach.

How to engage with hard-to-reach groups in the UK

Emma Blows, Karen Scanlon, Alison Richardson and Emma Ream

The outcome of cancer treatment, in terms of survival and quality of life, is known to vary significantly not just between countries, but within countries. Outcomes may be better in some geographical regions than others. Certain socio-economic groups may do worse than others. In the UK it is clear that there are inequalities in cancer outcomes experienced by a range of different groups, including those from black and minority ethnic groups and older people.

Enhancing the quality and experience of care for these groups was prioritised as a key aim of the Department of Health’s 2007 Cancer Reform Strategy. Equitable provision of information and support is seen as fundamental to meeting this aim. With this in mind, the UK charity Breast Cancer Care, in collaboration with King’s College London, set out to explore the barriers to the uptake of Breast Cancer Care’s services, and develop a strategy for enhancing uptake of services by people affected by breast cancer.

The Better Access Better Services (BABS) project had a specific remit to
Breast care nurses were considered an important source of information and support, but were inconsistent in signposting to services appropriate to the needs of women from these communities

**HARD-TO-REACH GROUPS**

Compared to women from the general population, women from black and ethnic minority groups tend to have more limited knowledge of breast cancer.

- Women from some communities believe that breast cancer is a ‘white woman’s disease’ and thus perceive themselves to be at a low risk of developing the disease.
- Cultural and health beliefs, and fears about breast cancer, prevent women from seeking advice and treatment.
- Women from black and ethnic minority groups have many similar information needs; however, their access to culturally appropriate written and verbal sources to meet these needs is very limited. When it comes to the needs and behaviour of older women, the literature suggests that they prefer their information to come from the hospital specialist and, in contrast to younger women, they tend not to seek alternative sources of information.

- They place faith in health care professionals, adopting a ‘doctor knows best’ approach and, on the whole, accept passive roles in decision-making and management of their illness.

- However, there is concern that the quality of communication and interaction between older women and health care professionals declines with age. In particular, studies have found that specialists often spend less time in consultations with patients the older they are.

- This may contribute to older women not receiving appropriate levels of information and support.

**ACCESSIBILITY OF SERVICES**

How well do the services provided for women with breast cancer by UK statutory and voluntary sectors fit the needs of older women and those from black and ethnic minority communities? To answer this question, focus groups were held with Asian and African Caribbean women, and semi-structured telephone interviews were conducted with older women, in order to explore their information and support needs, to find out what role, if any, was played by voluntary organisations in meeting their needs and to try to identify barriers and facilitators influencing uptake of services provided by the statutory and voluntary sectors.

**Lack of relevance**

Both Asian and African Caribbean women had unmet information and support needs, particularly relating to skin and hair care, and dietary concerns.

Breast care nurses were considered an important source of information and support, but were inconsistent in signposting to services appropriate to the needs of women from these communities.

- Breast care nurses were considered an important source of information and support, but were inconsistent in signposting to services appropriate to the needs of women from these communities.
- However, women also felt services provided by both the statutory and voluntary sectors were often not relevant to, or representative of, their needs. As a result, women from Asian and African Caribbean communities were often dissatisfied with services used.

**Poor communication**

Health care professionals were the most important source of information and support for the older women in this study.

- However, many experienced poor communication, and a lack of
involvement in decision-making regarding treatment and care.

There seemed to be great variability in the level of support provided by health care professionals, particularly after treatment ended. Some women reported that they had felt ‘cast adrift’ and had been apprehensive about life after treatment. However, others felt reassured, trusted the information provided and felt health care professionals were looking after them.

**WHAT THEY SAID**

The BABS project documented a wide variety of experiences and views among older women and those from black and minority ethnic communities, a selection of which are presented below.

“The nurse should sit down with you, tell you certain things and make a connection, they know who you are and what you’re all about.”

“Lady, do not direct me upstairs because the wigs you’ve got up there do not cater for a Black woman.”

“I had a breast cancer nurse and she gave me information and ... kept in touch with me. Not as much as perhaps... she was a very busy lady...”

“(I) received very short shift. She seemed to think I was a stupid old woman who was making a fuss about nothing...”

“I didn’t know what I needed to know, I didn’t know what help I needed to have or what I was entitled to or whatever... you don’t know what’s out there.”

“Issues relating to skin that are quite apart from Caucasian women – that is the level of information I wanted to hear but you don’t get it.”

**Women from different black and minority ethnic communities and different age groups have specific concerns that should be considered, and cannot be addressed with a ‘one-size fits all’ approach to service delivery**

Particular importance was placed on the role of consultants and breast care nurses, who clearly play a crucial role in providing information and support to these women.

**HOW BREAST CARE NURSES CAN HELP**

The Better Access Better Services project used a variety of research and evaluation techniques to obtain a comprehensive picture of the information and support needs of breast cancer patients, in particular among older women and those from black and minority ethnic communities.

The findings repeatedly highlighted the important role played by breast care nurses in providing information and support to women from hard-to-reach groups.

However, it is clear that much more needs to be done if older women and those from black and ethnic minority communities are to receive the information and support services that they need, and if progress is to be made in reducing disparities in the outcomes of cancer treatment.

The BABS project made a number of specific recommendations covering individual assessment of information and support needs, improving access to specialist nurses, training in communication and better signposting to culturally appropriate services.

**Assessment of needs**

Breast care nurses should continue to be aware of the changing needs and preferences of individuals. The type and timing of information giving should be continually assessed, to ensure each patient receives information support specific to their individual needs.

**Specialist nurses**

Breast care nurses play a pivotal role in the provision of information. Greater provision should be made for the hiring and training of specialist breast care nurses and/or cancer-specific information specialists, who can devote their time and expertise to providing each patient with the information they require.

**Communication skills training**

Health care professionals need to be responsive and adaptable to patient information and support needs. This is especially important when consulting patients from black and minority ethnic groups and older women.

Some health care professionals may need training in cultural awareness and diversity issues. Specific training on communicating with older women should also be considered, to ensure they are encouraged to engage in the decision-making process, if they wish.

**Signposting**

The development and delivery of services that are culturally appropriate to patients from a diverse range of backgrounds is important. Women from different black and minority ethnic communities and different age groups have specific concerns that should be considered, and cannot be addressed with a ‘one-size fits all’ approach to service delivery.

In addition, better signposting by breast care nurses to culturally appropriate statutory and voluntary support services is needed.

Details of the references cited in this article can be accessed at www.cancernurse.eu/communication/eons_newsletter.html
The World Health Organization has identified new models and practices of care appropriate for the rising number of patients with chronic conditions. With the emphasis on patient-centred care and partnering, well-trained breast care nurses will be perfectly placed to play a central role.

The breast care nurse
a 21st century concept

The recent rapid development of treatment modalities has changed perceptions of breast cancer. Breast cancer is now understood to be a heterogeneous, highly variable disease, requiring individualised treatment.

More than 80% of breast cancer patients survive their disease and are confronted with the challenges of cancer survivorship. Due to its long-lasting nature and risk of recurrence, breast cancer should be considered a chronic disease. Women diagnosed with breast cancer develop specific emotional, informational and physical needs that have been analysed in oncology nursing over the last decade. Many of these studies conclude that, while expressing a general satisfaction with the care provided, many women also report a number of unmet supportive care needs, especially in later phases of treatment and during survivorship.

Manuela Eicher

The WHO report “Preparing a health care workforce for the 21st century: the challenge of chronic conditions” criticises current models of care for emphasising diagnosis and treatment of acute diseases. Such outdated models of care, it argues, are inadequate for a growing population of patients with health problems that persist over decades or even a lifetime. Patients are forced to consult multiple health care providers who lack coordination among themselves and across settings, resulting in care being expensive, confusing, or even harmful to patients.

In this report the WHO defines five basic competencies needed when caring for patients with chronic conditions: patient-centred care, partnering, quality improvement, information and communication technology and a public health perspective.
When fully implemented, the EONS curriculum puts breast care nurses in a promising position to realise the WHO’s plea for more patient-centred care

Competencies

The WHO defines competencies as the skills, abilities, knowledge, behaviours and attitudes that are instrumental in the delivery of desired results and, consequently, of job performance. Patient-centred care and partnering are two of the five core competencies defined by the WHO.

The particular needs of women with breast cancer, the heterogeneity of this chronic disease, as well as the development of diagnostic and treatment modalities, have led to the development of multidisciplinary teams. Such teams tend to improve consistency, continuity, coordination and cost-effectiveness of care by coordinating a team of specialists in this particular field. Since 2000 the European Society of Breast Cancer Specialists (EUSOMA) has required breast care nurses (BCNs) to be part of these teams. Whereas in some countries (such as the UK, the Netherlands, the Scandinavian countries) BCNs are an integral part of specialist breast units, other countries (such as France) tend to continue traditional models of care, without offering BCN services. To date, all over Europe, the competencies, roles and training of BCNs vary considerably between different settings and countries.

TOWARDS A CONSISTENT MODEL OF BREAST CARE NURSING

In the future, BCNs should have more consistent roles, competencies and training. This would enable patients to better understand what needs could be addressed to BCNs. One particular benefit could be a standardised patient-centred, cooperative approach including an overall improvement of coordination among health care providers and settings. This would enable nursing science to better analyse the efficacy and cost-effectiveness of BCNs.

With their particular role within multidisciplinary teams, BCNs are well positioned to take on a prominent position for the implementation of new models of care in breast cancer care all over Europe. To see why, you only have to examine the similarities between two of the basic competencies defined by the WHO (patient-centred care and partnering) and the competencies for BCNs specified in EONS Breast Care Nursing Post Basic Curriculum.

Being equipped with these particular competencies, BCNs can make major contributions to the required changes of models of care. They can therefore be considered as key players to promote a shift from acute care towards models of care in chronic conditions for people affected by breast cancer.

PATIENT-CENTRED CARE

The WHO suggests a shift from health professional-centred care towards patient-centred care. The essence of patient-centred care is an understanding of the illness experience from the patient’s perspective. Central elements in such a shift include:

- being responsive to and respectful of the needs, values, differences, and preferences of the patient
- aiming at coordinating continuous and timely care
- relieving pain and emotional suffering
- listening and communicating
- providing education and information
- sharing decision making and management
- preventing disease, disabilities, and impairments
- promoting wellness and healthy behaviour.

The EONS Breast Care Nursing Post Basic Curriculum requires BCNs to identify, validate and prioritise potential and actual physical, psychological, social, sexual and spiritual health, coping strategies and consequent support needs of people affected by breast cancer across the continuum of care.

They should demonstrate an ability to integrate contemporary knowledge and evidence about breast cancer and its impact, to effectively promote self-management strategies and provide a range of supportive care interventions to meet the multiple health needs of people with breast cancer, in the context of a multidisciplinary approach to care.

BCNs should also be able to provide education to enable patients and their significant others to achieve optimal self-management strategies, and information to assist them to achieve optimal health outcomes, reduce distress and make informed decisions about treatment options and support available within the community. When fully implemented, the EONS curriculum puts BCNs in a promising position to realise the WHO’s plea for more patient-centred care.

Partnering

The WHO defines partnering as the ability to join with patients, other providers and communities for effective care of patients with chronic conditions. The workforce need skills that allow them to share power and involve patients in all aspects of decision-making in their health care. They need the ability to work in teams and collaborate with other providers: those who care for the patient across
time, in different settings, from different disciplines, and for different diseases that might coexist in the same patient.

According to the EONS curriculum, BCNs should develop collaborative therapeutic relationships with people affected by cancer and their significant others to anticipate and meet their multiple care needs across the continuum of breast cancer care. They should be aware of the variety of healthcare resources relevant to the needs of clients with breast cancer and utilise them appropriately. They are responsible for facilitating a coordinated and efficient approach to the delivery of health and support services and care interventions that are responsive to individual clinical and social circumstances across the continuum of breast cancer care.

Furthermore BCN’s should be able to collaborate with the person receiving care, their significant others, other nurses and members of the health care team, to optimise health outcomes for people with breast cancer. Equally here, the EONS curriculum enables BCNs to take a leading role in realising the WHO’s plea for partnering within and beyond a multidisciplinary team and its institutional context.

Taken as a whole, BCNs trained and acting in accordance with the competencies defined in the EONS curriculum are well positioned to realise the core competencies the WHO has identified as essential for health care providers in the 21st century. They can and should be key players in the much-needed shift from acute to more chronic oriented models and practices of care across Europe.

Enabling BCNs to play this role will require more consistency in the training of BCNs and in the extent to which they are able to play a full and integrated role within multidisciplinary breast care teams.

Functioning as a fully integrated member of a multidisciplinary breast care team, such as this one at the European Institute of Oncology in Milan, is essential to the partnering role of the breast care nurse.

Details of the references cited in this article can be accessed at www.cancernurse.eu/communication/eons_newsletter.html
The triple negative phenotype
what is it and how do we treat it?

The treatment of breast cancer is increasingly dictated by the status of receptors. The relatively new triple negative phenotype – negative for ER, PR and HER2 – has a particularly poor prognosis, and the search is on to find the most effective therapy options.

Kay Townsend

The receptors that indicate treatment and prognosis of breast cancer have become well known to public and health care professionals alike, although the implications of diagnosis are not always clear to the patient (“Thank heavens I’m HER2 positive and I can have Herceptin”). These subtypes are becoming more distinct, if more complicated.

Oestrogen receptor (ER), progesterone receptor (PR), and human epidermal growth factor receptor 2 (HER2) have become well-known terms in the common parlance in breast cancer care. The combination of the presence (positive) or absence (negative) of receptors is an indicator of the disease response to treatment. One receptor alone is not sufficient to make a treatment decision and, as a result, subtypes are classified according to the combination of receptors, giving rise to new terms such as the relatively new triple negative phenotype (TNP) cancer, which is ER negative, PR negative and HER negative. This subtype is further distinguished by whether it also has over-expression of the basal markers CK5/6 and epidermal growth factor receptors (EGFR), so that within the TNP subtype there is further classification: those TNP in the majority with the
markers – the ‘basal-like’ TNP – and those without the markers – the ‘non-basal-like’ or ‘normal breast-like’ TNP. ¹

Unfortunately it is not quite as clear-cut as the table below suggests, because some cancers that are basal do not appear to be TNP cancers. The debate between researchers continues as methods of distinguishing between the basal cancers and the TNP ‘basal-like’ cancers develop.² For now, the treatment decisions should be based upon the receptor status of the cancer, and with those that have the triple negative result, chemotherapy is recognised as the first line of treatment.³

It is known that patients with an ER-negative status gain greater benefit from intensive chemotherapies than those with an ER-positive status,⁴ but TNP is a relatively new subtype, and the ideal approach is far from certain. Studies have shown a predominance of the BRCA1 mutation in these cancers, which is sensitive to both cross-linking agents (e.g. platinum salts) and the poly ADP-ribose polymerase (PARP) enzyme inhibitor.⁵ Trials (TNT trial, BRCA trial) are currently recruiting to see if this can be taken advantage of. The key points, however, remain that this subtype of breast cancer needs research, that the systemic therapy option is chemotherapy and that phase III trials are currently recruiting.

Future treatments may involve monoclonal antibodies such as bevacizumab. This antibody affects the growth of tumour blood vessels by targeting the vascular endothelial growth factor (VEGF) to inhibit its action. Although it is hoped that affecting angiogenesis in these TNP cancers will be successful, the UK National Institute of Health and Clinical Excellence (NICE) has suspended the technology appraisal of its use in first-line treatment of metastatic breast cancer with paclitaxel, acting on manufacturer’s advice that it is unlikely to be cost-effective when compared with paclitaxel alone.⁶ A further technology appraisal of bevacizumab with non-taxane chemotherapy is planned.

This relatively new subtype of breast cancer has poor prognosis, as the treatment options are limited at this time. Systemic therapy option is chemotherapy, and research for the ideal regimen is being investigated with trials that are currently recruiting.

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### Classifying breast cancer

Breast cancers testing negative for oestrogen, progesterone and HER2 receptors (triple negative) are now further classified into ‘basal-like’ and ‘non-basal-like’ subtypes. The implications of the latter subtyping for treatment are not yet clear.

IHC immunohistochemistry, FISH, fluorescent in situ hybridisation

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### What subtypes tell us about a breast cancer

<table>
<thead>
<tr>
<th>Luminal A</th>
<th>Luminal B</th>
<th>HER2 ER- HER2+</th>
<th>‘Basal-like’ TNP</th>
<th>‘Non-basal’ TNP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most common subtype</td>
<td>Similar to luminal A</td>
<td>Less common, highly aggressive subtype</td>
<td>Aggressive subtype</td>
<td>Similar to basal-like</td>
</tr>
<tr>
<td>Less aggressive</td>
<td>More frequently ER+/PR-</td>
<td>High-grade histology</td>
<td>High-grade histology, high rate</td>
<td>Better prognosis than basal-like triple negative</td>
</tr>
<tr>
<td>Lower histological grade</td>
<td>Worse prognosis</td>
<td>Risk increased in younger age (&lt;40)</td>
<td>Risk increased in younger age &lt;40</td>
<td></td>
</tr>
<tr>
<td>Good prognosis</td>
<td>Outcome improved with HER2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: This table and the graphic above were adapted from Lyman et al (2006).⁷

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Details of the references cited in this article can be accessed at www.cancernurse.eu/communication/eons_newsletter.html
Training and education
setting the standards for the next generation

Breast care nurses play an increasingly central role in the care of women with breast cancer. Their qualifications, however, vary widely across Europe, and their training lacks uniformity and common minimum standards.

Ilana Kadmon

Breast care nursing first began as a specialty in the early 1980s. Some of the first descriptions of its role and importance in supporting and counselling women with breast cancer originated in the UK.1-4 Maguire and his colleagues5 emphasised the importance of monitoring the psychosocial well-being of women with breast cancer, and the role of the nurse counsellor in providing such a service.

Later, during the 1990s, these reports started to make an impact in other countries such as the US, Australia, Scandinavia and Israel.5-8 In Israel, for instance, breast care nursing began its development as a recognised specialty in 1996, thanks to the generous support of the Israel Cancer Association. The position was established first at the Hadassah Medical Organisation in Jerusalem. Since then, most clinics in the country have followed suit, providing a nurse (some have two) dedicated to the care of women with breast cancer. Today there are around 25 breast care nurses employed across the country.

However, the role carried out by these specialist nurses working in various Western countries lacks standardised practice, and most importantly a uniform standard of curriculum. As stated by Amir et al,9 who explored the role of the breast care nurse (BCNs) in the UK, “…there is evidence that the BCN practices in advanced level of practice. However, there is a severe lack of evidence-based description of that advanced practice.”

UNEVEN EDUCATION

The training of breast care nurses remains variable and falls short of agreed standards of education for the profession in a number of ways.

- Different types of qualification. Some nurses may have a diploma, others a first degree or a postgraduate academic grade in nursing.
- Different levels of training in oncology nursing in general, and in breast care nursing in particular. Some nurses may have taken up post-basic oncology training and education as well as a special training in nursing patients with breast cancer. Others may not.
- Different professional background and skills. Some nurses may chose to become a breast care nurse after spending many years working in oncology, surgery or plastic surgery, and some have a long experience in nursing women with breast cancer, whereas others may come from a totally different working background, and with little experience in this area.
- Different personal experience, in particular with breast cancer. This is of great importance and may have a
No national or recognised curriculum exists for this specialist training, nor is there any recognised European training to provide a standard in this area of care

- Diverse national, cultural and political variations in the status of nursing and nursing practice and education. In some countries, nursing is well recognised as an academic profession with various specialties, while in others it is not established at all, and nurses receive no formal education. This may obviously create a large diversity in the educational level of this sub-profession.

**APPROPRIATE STANDARD OF TRAINING**

Many studies – mainly originating from Australia – have examined the importance of the role of the breast cancer nurse to women diagnosed with cancer. However, no research, to date, has examined the education of these nurses and its influence on the standard of care.

In the UK and Australia, there are a range of structured courses for the training of nurses in the area of breast cancer. The Royal College of Nursing, the professional body representing nurses in the UK, has developed various modules of education for breast care nursing.

Writing about the developing role of the nurse specialist in breast cancer in Britain, Burnet et al.\(^\text{1}\) say that: “They [the RCN] have identified three stages in breast care nurse’s career development: breast care nurse, clinical nurse specialist and nurse consultant. They recommended a structured educational preparation, including specific qualifications in breast care nursing, teaching, assessing and counselling, as well as a higher level degree.”

However, apart from the British and the Australian experience, no national or recognised curriculum exists for this specialist training, nor is there any recognised European training to provide a standard in this area of care.

Moreover, when searching the literature, no article was found that addressed the issue of the special education needed for breast care nurses.

Given the lack of standards, it is important to set minimum educational and background competencies that the nurse should have prior to enrolling in an educational and training course to become a breast care nurse. These should include:

- At least a first degree in nursing, preferably a Masters
- Post-basic education in cancer nursing
- Professional experience working for a few years with cancer, and preferably breast cancer patients
- Some form of experience in nursing research.

It should be emphasised that many nurses throughout Europe do not have the right educational background to be employed in such an occupation. These nurses started their job either through their own initiative, or thanks to the entreprenurial efforts of nursing management, or the goodwill of a doctor working with women with breast cancer.

These nurses may be referred to as the first generation of breast care nurses. It remains our challenge and responsibility to think about the future and the next generation of breast care nurses in Europe, and to ensure that they receive the appropriate standard of training, with a strong background experience before taking up this most important and exciting occupation.

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Details of the references cited in this article can be accessed at www.cancer.nurse.eu/communication/econs_newsletter.html
Minimising the risk of lymphoedema
early information is key

Lymphoedema affects one-third of women whose treatment for breast cancer involved lymph node intervention. The condition can be kept to a minimum if timely, balanced and precise information and advice, tailored to individual circumstances, are given at the right time.
Lymphoedema can develop at any time following breast cancer treatment and women carry a life-long risk of its development.

It is estimated that one-third of women will develop lymphoedema at some time following treatment for breast cancer.¹

As women undergo treatment for breast cancer, they come into contact with many health care professionals, all of whom can play an important part in education about lymphoedema.

It is at this time that information about the risk of lymphoedema should be provided, along with advice concerning care of the ‘at risk’ arm.

If information is provided at this early stage, women can be encouraged to adopt healthy activities that promote lymph drainage, so minimising the risk of lymphoedema developing in the future.

Knowledge of which women are at risk, why they are at risk and what can be done to minimise the risk is therefore essential.

THE ROOT OF THE PROBLEM
Following breast cancer treatment, lymphoedema can develop in all or part of a limb, and is termed secondary lymphoedema because it arises as a result of disruption or obliteration of lymph vessels at the time of surgery, or during radiotherapy. As drainage routes for the lymph reduce, lymphatic fluid can accumulate in the tissues giving the appearance of swelling.

It is usually the woman who first discovers the swelling, which may initially be mild and uncomplicated. However, if left untreated, it can progress to become severe and eventually lead to skin and tissues complications.

Swelling can also develop within the breast tissue following breast conserving treatment. Among women with larger breasts and those who have had a combination of surgery and radiotherapy,² breast oedema can result in breast heaviness and pain. It can also influence body image and the fitting of a bra and clothing.

Physical signs
The International Society of Lymphology³ has described the successive stages by which lymphoedema develops according to the physical signs that evolve in the limb once swelling appears.

Foldi and Foldi⁴ describe the time between lymph node intervention and the first appearance of swelling, during which period the woman is ‘at risk’ of developing lymphoedema, but the condition is in a subclinical or latency period where swelling is not present.

They found that this stage may last for many years, during which the transport capacity of the lymphatics is reduced, but they can still transport the lymph load.

Knowledge of which women are at risk, why they are at risk and what can be done to minimise the risk is therefore essential.

Who is at risk of breast cancer related lymphoedema?
Any woman who has received breast cancer treatment involving surgery or radiotherapy to lymph node areas is at risk of developing lymphoedema. The lymph nodes most commonly involved in breast cancer treatment include the axillary lymph nodes, and the supraclavicular lymph nodes.

Any patient who has a tumour obstructing the lymph node areas will also be at risk of developing lymphoedema.

Armer⁵ suggests that lymphoedema may be under-recognised and under-diagnosed, because of a failure to recognise symptoms such as changes in feel and function as early indicators of developing lymphoedema.

This view is supported by Moffatt et al.,⁶ who suggest the true prevalence of lymphoedema may be underestimated because many women may not be receiving care for the condition or the symptoms they are experiencing.

Risk factors
Lymphoedema may develop early or after a delayed time period, and it is not always possible to predict which women will go on to develop the condition.

Among the most important factors involved in its development is surgery in which lymph nodes are removed and fail to regenerate, and radiotherapy to lymph node areas that leads to scarring and decreased lymph drainage.

Deo et al.⁷ suggest a link between postoperative swelling that persists for more than two weeks and the development of lymphoedema. Other postoperative events that are considered to be clinically relevant to the risk of developing lymphoedema include seroma formation, cording and postoperative infection, although there is limited research to support these associations.

In other studies of signs and symptoms of lymphoedema, Armer and Fui⁸ found that younger women are more at risk of the development of lymphoedema, and Deo et al.⁷ observed that women with an increased body mass index were also at greater risk.

MINIMISING THE RISK
Lawenda et al.⁹ argue that the management of lymphoedema should begin with efforts to prevent its development. Two main principles are involved in achieving this: minimising the production of lymph, and minimising obstructions to its transport. Women should be advised as early as possible about how to take them into account in their daily life.
Minimising lymph production
The production of lymph is directly proportional to blood flow. Consequently, any activities that involve an increase in blood flow can lead to increased lymph production and should therefore be minimised.

These include exposure to extremes of heat such as saunas, hot baths and sunbathing. The inflammatory response to injury or trauma can also lead to increased blood flow and lymph production, and women should be advised to take great care of their skin in order to minimise the risk of infection.

Prolonged, vigorous and repetitive activities or sports that increase blood flow constitute an important risk, particularly if these activities have not been taken up previously.

A return to any previous activities should be slow and controlled, with special attention paid to any symptoms of pain, aching or heaviness in the arm.

Minimising obstruction of lymph transport
The obstruction of small lymph vessels responsible for lymph transport can occur when wearing tight clothing or jewellery. Women should therefore dress only in clothes that do not restrict movement, and should wear jewellery on the other arm or hand if it is too tight.

Clinical activities such as monitoring blood pressure and using a tourniquet can also damage superficial lymph vessels and should be avoided on the arm that is at risk of lymphoedema.

Piller\(^1\) and Armer et al.\(^2\) observe that the development of early lymphoedema can only be truly confirmed if baseline measurements of the arm have been taken pre-operatively and are available for comparison.

These may be recorded as circumferential measurements using a tape measure or with a bio-impedance analyser. Before an increase in arm measurements can be considered as indicative of lymphoedema, Armer et al.\(^3\) suggests that all women should be advised to observe and be alert to early symptoms of developing lymphoedema, such as a heaviness, tightness or aching of the arm. By acknowledging such symptoms and seeking early advice, it may still be possible to reverse any developing lymphoedema.

A non-randomised study by Campisi et al.\(^4\) advocated a three-month preventative treatment regimen for women at risk of lymphoedema following breast cancer treatment. The study group underwent manual lymph drainage (MLD) every day for two weeks every month, for a three-month duration, and wore a compression garment daily whilst the control group underwent only clinical observation.

The results suggested that the programme was of benefit, but the clinical, practical and financial implications of such an intensive treatment to prevent secondary lymphoedema is questionable.

Well-balanced advice, tailored to the individual’s circumstances, will ensure that women... gain an awareness of why they are at risk and what they can do to minimise that risk

Managing lymphoedema
If lymphoedema develops, a combination of approaches can be used to reduce and control the swelling (see box). Emphasis is placed on the patient’s active participation in managing the swelling on a daily basis. Above all, it is crucial that strategies to minimise the risk of developing lymphoedema should be discussed as early as possible, in a sensitive manner. Lymphoedema can have physical, psychological and psychosocial implications for women following breast cancer treatment. Well-balanced advice, tailored to the individual’s circumstances, will ensure that women do not develop a fear of the onset of lymphoedema and are able to maintain their quality of life whilst gaining an awareness of why they are at risk and what they can do to minimise that risk.

All health care professionals caring for this group of women should be able to monitor routinely for lymphoedema following breast cancer treatment, and practice an approach of risk reduction, rather than waiting for the swelling to appear before taking action.

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Based on a presentation at the Interconference Breast Cancer Meeting IBCN2, Sarajevo, Bosnia and Herzegovina, April 2009

Details of the references cited in this article can be accessed at www.cancernurse.eu/communication/eons_newsletter.html

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Four ways to manage lymphoedema
Dougherty and Lister\(^5\) have outlined the four aspects of lymphoedema management which are used following a full assessment of the patients needs:

- A skin care regime to minimise the risks of infection
- An exercise regime to promote lymph drainage
- Simple lymph drainage, based on the principles of manual lymph drainage
- Compression therapy to reduce and control the swelling
15-16 April 2010
THE HAGUE, THE NETHERLANDS

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**mCRC: metastatic colorectal cancer**

**Vectibix®** is indicated as monotherapy for the treatment of patients with EGFR-expressing, metastatic colorectal carcinoma with nonmutated (wild-type) **KRAS** after failure of fluoropyrimidine-, oxaliplatin-, and irinotecan-containing chemotherapy regimens.

**INDICATION:** Vectibix® is indicated as monotherapy for patients with mCRC* with nonmutated (wild type) **KRAS** after failure of fluoropyrimidine-, oxaliplatin-, and irinotecan-containing chemotherapy regimens.

**STABILITY AND STORAGE:** Vectibix® should not be administered in combination with 5-FU chemotherapy or with bevacizumab-containing chemotherapy. A high incidence of severe diarrhoea was observed when panitumumab was administered in combination with 5-FU, and increased toxicity and deaths were seen when panitumumab was combined with bevacizumab and chemotherapy.

**INTERACTIONS:** Vectibix® should not be administered in combination with 5-FU chemotherapy or with bevacizumab-containing chemotherapy. A high incidence of severe diarrhoea was observed when panitumumab was administered in combination with 5-FU, and increased toxicity and deaths were seen when panitumumab was combined with bevacizumab and chemotherapy.

**UNDESIRABLE EFFECTS:** Very common (≥1/10): Rash, dermatologic reactions (erythema, skin inflammation, pruritus), dry skin, skin lesions, paronychia, dermatitis, fatigue. Common (≥1/100 to <1/10): Infusion reactions (pyrexia, infusion reactions, dyshidrosis, dermatitis), conjunctivitis, growth of eyelashes, increased lacrimation, hypokalaemia, hypomagnesaemia, hypophosphataemia, hypertrichosis, hyperpigmentation, increased sweating, hypokalaemia, hypomagnesaemia, dry mouth, pulmonary embolism.

**References:** 1. Volumedix® Summary of Product Characteristics 2008