

Secondary Breast Cancer Taskforce



Guide for commissioners
Meeting the nursing needs of
metastatic breast cancer patients



November 2008

This guide is aimed at commissioners and providers of care for people with metastatic breast cancer to help them offer the optimal nursing service to meet the needs of this patient group. It contains recommendations to improve nursing provision for people with metastatic breast cancer and examples of best practice. The guide illustrates the key interventions undertaken by nurse specialists who care for metastatic breast cancer patients and explains how they meet health service targets and standards.

Data for this guide was collected through a mixture of qualitative and quantitative research. This involved the use of the Pandora database developed by UCLH NHS Foundation Trust and NHS Innovations, which articulates the work of clinical nurse specialists, and qualitative data from eight in-depth interviews with metastatic breast cancer patients.

The guide was developed by Breast Cancer Care's Secondary Breast Cancer Taskforce, a national coalition of healthcare professionals, representatives from cancer charities, people living with metastatic breast cancer and health service representatives, all with expertise and interest in the area of metastatic breast cancer. The aim of the Taskforce was to improve the treatment, support and care of people living with metastatic breast cancer. To learn more about the Taskforce's work and its calls to action, read the final report *Improving the care of metastatic breast cancer patients* (November 2008), available from www.breastcancercare.org.uk

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1. Metastatic breast cancer

Metastatic breast cancer occurs when cancer cells break away from the breast and travel through the blood or lymph system to settle in other parts of the body, most commonly the bones, liver, lung or brain. Metastatic breast cancer cannot be cured but it can be controlled, sometimes for years. It is also known as secondary or advanced breast cancer.

In the UK today, 550,000 people are alive who have had or have a diagnosis of breast cancer. Of these, it is not known how many have or will develop metastatic breast cancer as this data is not collected. Various estimates exist for the percentage of people with early breast cancer who will go on to develop metastases, which range from between 40-50% (NICE, 2002) and 20-70% (Johnston and Swanton, 2006). Treatments for metastatic breast cancer include systemic drug treatments such as chemotherapy, endocrine therapy, biological targeted therapy and supportive therapies. Median survival from the time of diagnosis is approximately 2-3 years, but this will vary according to the site of the disease (Johnston and Swanton, 2006). However, the advancement in targeted biological therapies has seen increases in survival for this patient group and as a result it is envisaged that many patients will live considerably longer with their metastatic disease under control. Some patients with more indolent disease may live up to 10-15 years (Johnston and Swanton, 2006).

A diagnosis of metastatic breast cancer has been found to be more traumatic than a primary diagnosis (Cella, 1990). There is a growing body of evidence that this group of patients has a high degree of unmet social and psychological need (Parle et al 2001, Coristine et al 2003). Quality of life is significantly poorer in those with a cancer recurrence than those with primary breast cancer or those with a serious medical illness, with poorer physical, functional and emotional health (Northouse et al, 2002).

Patients with metastatic breast cancer can suffer from depression, anxiety and traumatic stress (Hopwood et al, 1991, Pinder et al 1992). Research examining coping and emotional distress in primary and secondary breast cancer patients found that those with a secondary diagnosis exhibited higher emotional distress (Cohen, 2002). Pain, sleeplessness and fatigue have also been identified as problems for this patient group (Aranda et al, 2005).

In addition, it has been found that at a time when the patients were most in need of direction and support, the treatment staff assumed that their previous experience of initial diagnosis prepared them for the recurrence. Ninety per cent of patients report less attention and information giving at a metastatic diagnosis and an assumption that they were coping and had sufficient support (Cella et al, 1990). Optimal care for metastatic breast cancer patients needs to combine treating and managing the disease and meeting the psychosocial needs of the patient. Specialist knowledge and skills are required to be able to manage this patient group successfully.

2. Lack of access to clinical nurse specialists

'I was immediately put into contact with the breast care nurses first time round, but it's as if they expect you to know the ropes second time round! I was a mess and wanted a breast care nurse specialising in secondaries – I expected it really and was amazed that I was just sent home to cope with my family.'

Within the NHS, systems have been put in place to support patients diagnosed with primary breast cancer and to support the needs of patients nearing end of life through the provision of breast care nurses (BCNs) and specialist palliative care services. However, feedback from metastatic breast cancer patients suggests that when a patient is diagnosed with metastatic breast cancer they fall through a gap and the same level of care and support is often not available. In particular they do not have access to a healthcare professional who can act as their 'key worker', who has expert knowledge and skills in managing metastatic breast cancer and who is able to co-ordinate their care, provide and/or signpost to information and support and act as their advocate.



'I have no time or capacity to be involved in oncology clinics. I am rarely informed of metastatic breast cancer – unless they come through our follow-up clinic.'

A survey of breast care nurses (272 responses) carried out by Breast Cancer Care and the Royal College of Nursing (RCN) in 2004, found that over 50% of the nurses surveyed indicated they would like training on working with metastatic breast cancer patients. The survey also found that many nurses had large caseloads of primary breast cancer patients and some did not have enough time to support the needs of metastatic breast cancer patients.

'I am only able to provide care for the newly diagnosed, I would like to be able to follow patients up at the end of adjuvant treatment and offer care and support to metastatic breast cancer patients.'

'The remit of the expectations of the role of the BCN within the trust is too broad; it would be beneficial to employ a BCN who can give more time to metastatic patients.'

A further survey of breast care nurses (149 responses), carried out by Breakthrough Breast Cancer, Breast Cancer Care and the RCN in 2007, echoed these findings, with almost 50% of nurses feeling unable to provide the quality of care to all breast cancer patients that they would like to. A variety of reasons was given, including increased workload due to new, additional duties, staff shortages, and redeployment to other areas, e.g. general wards. Specific issues were raised around not being able to provide care for metastatic breast cancer patients.

Traditionally breast care nurses sit within screening and surgical units therefore they do not necessarily have a presence in oncology follow-up. This means if metastatic breast cancer patients are attending oncology clinics, breast cancer nurses may not be aware of them. Surgery is not commonly needed in the management of metastatic disease, so it is more likely these patients are being cared for in the oncology unit. A lack of presence of breast care nurses in oncology could be one explanation as to why this patient group lacks access to a clinical nurse specialist (CNS).

'Because there is only me, and with 140 new diagnoses I usually leave the patients with metastatic breast cancer to the palliative care team.'

'We need a metastatic CNS, however with financial deficits, no plans are being made for recruitment or to identify the post.'



3. Recommendations

The Taskforce recommends that within every patient's clinical team there is a CNS who has the skills and knowledge to manage metastatic breast cancer. This person will act as the patient's 'key worker', co-ordinating their care, acting as their advocate and providing and/or signposting them to support and information.

The gold standard would be the creation of a metastatic breast care nurse within every breast care team. However, CNSs in breast care, oncology or palliative care may possess the skills and knowledge to manage metastatic breast cancer patients but services may need reconfiguring to allow them to take on this role.

The Taskforce calls on cancer networks to review the availability of nurse specialists within their network who have the skills and knowledge to manage metastatic breast cancer patients. The Taskforce has developed a set of core competencies (see page 5) needed to be able to undertake this role and recommends cancer networks use these to assist with this review.

Where there are gaps in the provision of nurse specialists who have the appropriate skills and knowledge to care for metastatic breast cancer patients the Taskforce calls for cancer networks to reconfigure their workforce to ensure this gap is filled. Reconfiguring the workforce could involve creating a new post within the breast care team which would take the lead on caring for metastatic breast cancer patients, although it should be emphasised that the whole team would benefit from additional training in metastatic disease.

Different models may suit different settings: what is most important is that every patient diagnosed with metastatic breast cancer has access to a CNS who has the skills and knowledge to be able to manage them effectively.

Service providers should be able to demonstrate to commissioners that every metastatic breast cancer patient has access to a skilled and knowledgeable CNS. Commissioners should only contract for services that can demonstrate this.

For every patient diagnosed with metastatic breast cancer to have access to a specialist CNS, the Taskforce believes specialist training will be needed. Bodies with an interest in CNS training, such as Skills for Health, the RCN and charities, should consider how training needs can be met. Innovative methods of providing training, support and professional development should also be piloted.

4. Core competencies

The Secondary Breast Cancer Taskforce has defined the core competencies needed for a key worker caring for metastatic breast cancer patients.

Knowledge

- Specialist knowledge of metastatic breast cancer, treatment and the disease trajectory*
- Specialist oncology knowledge
- Understanding of the implications of living with a long-term illness
- Understanding of the psychosocial, spiritual/existential impact of metastatic breast cancer on the patient and their family*
- Palliative care knowledge*
- Knowledge of local and national support services for metastatic breast cancer patients*
- Knowledge of current clinical research and clinical trials
- Knowledge of end of life care tools (Preferred priorities of care, Gold Standards framework, Liverpool care pathway)

Skills

- Ability to assist in decision-making
- Ability to case manage – act as co-ordinator for patients' care and liaise with all health/social care and other professionals involved in patients' care
- Advanced assessment skills
- Advanced communication skills
- Ability to discuss end of life issues and palliative care*
- Ability to offer information to the patient

- Ability to offer (or be able to signpost to) national and local information and support to patients' families
- Ability to be the patient's advocate
- Ability to identify need for personal support

The key worker must also:

- be available to talk to the patient as soon as possible after diagnosis of metastatic breast cancer* (patients must be given contact details of key worker at diagnosis)
- have access to relevant information about the patient.

Supporting guidelines

- In addition to these core competencies the Taskforce fully supports the RCN guidance for nursing staff *Clinical standards for working in a breast specialty (2007)*. The standards contain essential knowledge and skills which are the requisites for competent nursing practice.
- The Taskforce also recommends that the key worker must be competent at levels 3 or 4 within the NHS Knowledge and Skills Framework.

* The Taskforce recognises that taking on this role may mean some healthcare professionals will need additional training in the areas marked.

5. Best practice case studies

Palliative Breast Care Nurse, Huntingdonshire

My role was created to provide specialist care for this very complex group of patients. Their needs were seen as diverse with constantly changing symptom control issues. It was felt that there should be one person with a good knowledge base who could co-ordinate care and be a named person. Generic Macmillan Nurses were finding the patients too demanding, time consuming and complex. I was appointed six years ago – initially my post was pump primed by Macmillan but is now funded by trust from the breast budget. I feel my role is unique as I have a specialist interest and knowledge base of these patients and an understanding of the complex issues that they present with.

I see all metastatic breast cancer patients in the area, even patients not treated at the hospital where I'm based. The contact is decided by need and I am always available to see them at home, in clinics, in the support groups or in the unit, or on my mobile during my working hours. I also do cover for the primary breast cancer patients when my colleague is on leave.

I attend MDT meetings, both palliative and breast; I work very closely with the palliative care team and in the oncology clinic. I see patients having treatments in the unit, check on results of tests and imaging. I refer to other allied health professionals – physiotherapy, occupational therapy, dietitians, hospice at home and other volunteer organisations. I also complete referrals to obtain continuing care in the community grants and attend their meetings to present cases.

I attend End of Life meetings and Gold Standards framework meetings. I also offer educational sessions to other healthcare professionals to increase the awareness of the potential for psychological morbidity with these patients.

For patients I offer whatever support is needed – emotional, psychological or spiritual. Most have to deal with changes to their body image, unpredictable health status, treatment side effects, psychosexual issues and adjustment to their role in the family. Many women feel isolated and alone and all experience their bereavement prior to their death – loss of their and their families' future. I have worked with loss and grief and have a clear understanding of the process.

I visit patients in their own homes to provide a full range of services, from medication reviews to symptom control, and support for children, family and friends. I provide resources and information for patients, family members and children. I attend community support groups and manage the complementary therapy service and psychological support service. I offer financial advice – applying for and completing grant forms, disability forms and badges.

CNS Secondary Breast Cancer, The Royal Marsden NHS Foundation Trust, London

This role was created as the Trust recognised that there was a gap in the care and support provided to women with breast cancer once metastatic disease occurred. Funded by the trust, the post has been in place for 2.5 years. After a year, a part-time (.6) post was added to meet demand.

We provide expert nursing care to all the Trust's metastatic breast cancer patients, including running a metastatic breast cancer clinic. It is of great benefit working with a consultant oncologist and a team that specialises in metastatic breast cancer and having specific clinics for patients with metastatic breast cancer. We are active members of the metastatic breast cancer MDT and liaise and have good working relationships with colleagues and other allied health professionals in house and in the community.

Our specialist knowledge means we are able to provide active symptom control and reduce statutory emergency admissions. We can use our knowledge and experience to be proactive and not reactive when identifying potential problems.

By assessing patients' needs and managing their disease, patients are reassured and their anxieties reduced. We provide information, clinical and psychosocial support and can also provide practical support and financial advice. We have a good understanding of the emotional impact of metastatic disease – lack of cure, family dynamics etc. – and are able to refer on to further support if necessary, such as in-house psychologists and psychiatrists, community-based GP and palliative care teams, and independent outside agencies. We can also provide psychosocial support for spouses/partners/carers/children and refer on where appropriate.

Part of my role is also about being the patient's advocate, there may be times when more treatment may be an option but they do not wish to take it but do not have the confidence to say so. Questioning medical colleagues on the appropriateness of continuing treatment in certain cases is also part of the role.

We also provide training to other healthcare professionals on metastatic breast cancer and are actively engaged in auditing and research.

6. Meeting healthcare targets and standards

England

The *Improving Supportive and Palliative Care for Adults with Cancer* guidance (NICE, 2004) defines the service models needed to ensure patients, their families and carers receive support to help them cope with their cancer and its treatment. The guidelines contain recommendations about needs assessment, information provision, access to support services including specialist psychological support, and communication guidelines. Implementation of these guidelines would significantly improve the support and care received by metastatic breast cancer patients.

However, meeting many of the recommendations in the supportive and palliative care guidelines hinges on patients having access to a healthcare professional who can provide or signpost to the required support and information. The guidelines include a specific recommendation that all patients are allocated a 'key worker' who would co-ordinate the patient's care and who they could contact at any time. This recommendation is echoed in the draft *Advanced breast cancer: Diagnosis and treatment* guidelines (NICE, draft 2008 – publication date 2009).

Improving Outcomes in Breast Cancer (NICE, 2002) also recommends that patients 'should have the name and contact number of a particular nurse, and should, wherever possible, see and speak to the same nurse.'

The importance of the CNS in improving the experience of people living with cancer was recognised in the Cancer Reform Strategy (CRS) 2007, which identifies the CNS's core functions as providing information and support and co-ordinating care. The CRS recommends that commissioners should give particular consideration to their role.

The CRS recognises the need to improve the care of those living with cancer and sets out a framework to improve their experience relating to:

- information and communication
- decision-making and choice
- co-ordination and continuity of care
- psychosocial support
- supportive and palliative care.

CNSs with skills and knowledge in managing metastatic breast cancer are able to improve the experience of those with a metastatic breast cancer diagnosis in all these areas.

To ensure the aims of the CRS are met, commissioners are recommended to:

- ensure that NICE guidance on supportive and palliative care is implemented as planned by December 2008
- work with providers to ensure they have robust systems in place to ensure patients experience a good continuity of care
- work collaboratively to ensure that good psychological support services are available throughout the cancer journey.

The specialist knowledge and skills of nurses caring for metastatic breast cancer patients means that they will be able to contribute to meeting all the recommendations above.

The CRS also places an emphasis on measuring patients' experience through surveys. Again, ensuring there is a CNS in place for metastatic breast cancer patients will ensure experiences of this patient group are greatly improved.

Scotland

Scottish guidelines recommend, 'All women with a potential or known diagnosis of breast cancer should have access to a breast care nurse specialist for information and support at every stage of diagnosis and treatment. Contact details and information about the role of the breast care nurse should be available to the patients, their families and all members of the disciplinary team.' (*Management of breast cancer in women – A national clinical guideline*, Scottish Intercollegiate Guidelines Network (SIGN) 2005)

'At every stage' can be interpreted to mean at the point of a metastatic diagnosis of breast cancer, therefore it is imperative that skilled and knowledgeable CNSs who can manage the complexity of metastatic breast cancer are in post.

Better Cancer Care, A Discussion launched by the Scottish Government (February 2008) outlines future priorities for cancer care in Scotland. It identifies the importance of self-supported care management particularly around how patients navigate the system and access information and support – both core functions of CNSs. *Better Cancer Care* questions what service approaches should be considered for patients living with cancer to achieve better integration and continuity of care. CNSs with skills and expertise in managing metastatic breast cancer will play a vital role in meeting these goals.

Wales

Both the NICE guidance on *Improving Supportive and Palliative Care* and *Advanced breast cancer* were commissioned jointly by the Welsh Assembly Government and therefore also apply to health services in Wales.

The *National Standards for Breast Cancer Services in Wales* (2005) recommends that:

- care provided by teams should be well co-ordinated to provide an efficient, effective service to patients
- patients and/or their carers have support and all the information they require regarding their diagnosis, treatment options and treatment, and care plan.

CNSs with skills and knowledge in managing metastatic breast cancer are able to ensure effective co-ordination of patients' care and provide information based on patients' needs.

In *Designed to Tackle Cancer* the Welsh Assembly set out its three year vision to improve cancer services in Wales by 2011. A core aim is to provide diagnosis, treatment and palliative care services for people with cancer that match or surpass the best in Europe in terms of both quality and access. It also examines the importance of assessing the ongoing needs of cancer survivors: by definition this includes those living with progressive cancer and thus applies to metastatic breast cancer patients.

CNSs caring for metastatic breast cancer patients will play an integral role in delivering these aims.

7. Nursing interventions

The Taskforce commissioned research to explore the complexity and value of the metastatic (secondary) breast care specialist nursing role. The clinical, emotional and financial benefits of the role were examined.

A combination of qualitative and quantitative research was used. A focus group of 12 nurses who predominately care for metastatic breast cancer patients was held where the nurses articulated the attributes of nursing required to manage this patient group. Following this, the nurses entered data into the Pandora inter-relational database, developed by UCLH NHS Foundation Trust and NHS Innovations, which articulates the work of CNSs.

The data from this research is used here to demonstrate the benefits of metastatic breast cancer nursing.

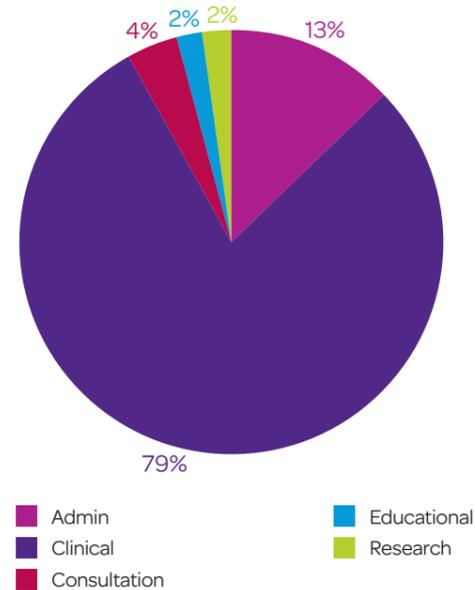
Clinical nurse specialists who care for metastatic breast cancer patients are able to:

1. be a 'key worker' for patients and families with skills and knowledge in managing metastatic breast cancer and providing good co-ordination and continuity of care
2. apply specialist knowledge of metastatic breast cancer and skill to manage physical, psychological and social morbidity
3. co-ordinate complex care – making services more efficient and resolving unsatisfactory experience
4. meet unmet information needs and empower patients
5. prevent unscheduled admission to hospital
6. support patients in clinical decision-making.

1. Be a 'key worker' for patients and families with skills and knowledge in managing metastatic breast cancer and providing good co-ordination and continuity of care

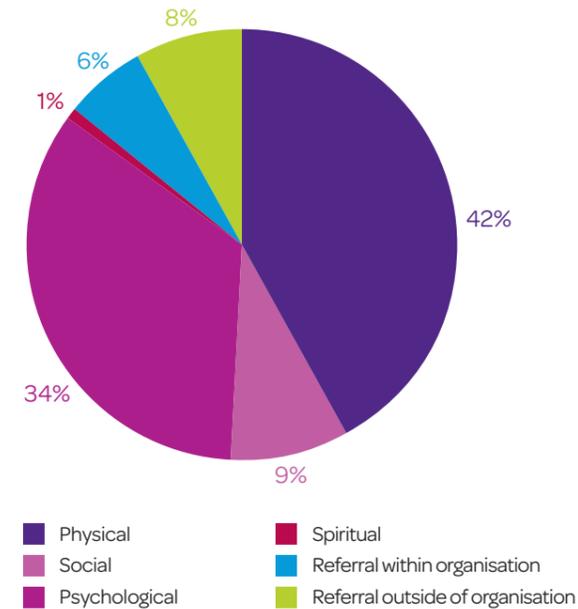
Clinical nurse specialists working with patients with metastatic breast cancer spend almost 80% of their time engaged in clinical work. This can be seen in Figure 1. This work involves: providing direct clinical care to patients, meeting clinical needs such as symptom control or supporting patients in clinical choice, using professional judgement to co-ordinate care or providing other clinical staff such as GPs and hospital staff with expert clinical advice in this area of care. The range of work undertaken highlights the wide range of skills needed to undertake this role.

Figure 1 Type of intervention



The range of clinical work is very varied but a large proportion (43%) consists of providing psychological and social interventions. Forty-two per cent is physical interventions for patients and 14% are referrals. This can be seen in Figure 2.

Figure 2 Breakdown of clinical work



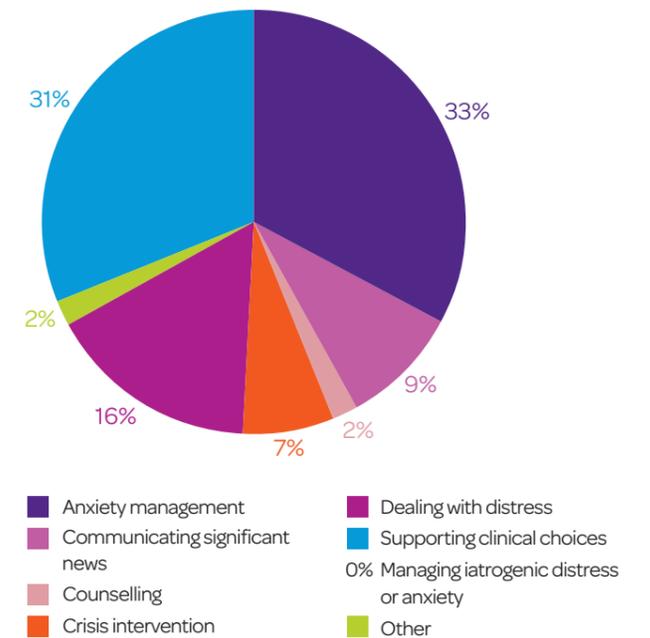
This emphasises the need for CNSs caring for metastatic breast cancer patients to have the combination of skills required to manage both the physical and the psychological impact of a diagnosis.

2. Apply specialist knowledge of metastatic breast cancer and skill to manage physical, psychological and social morbidity

Metastatic breast cancer carries a considerable psychosocial morbidity (Classen et al 2001). CNSs working with patients with metastatic breast cancer focus much of their clinical work on providing specialist psychosocial support.

The types of psychological care/interventions can be seen in Figure 3. This support is primarily in the form of anxiety management around disease progression/prognosis and supporting clinical choices. The poorer prognosis of metastatic breast cancer patients can mean higher risk of psychosocial distress (Anderson 1994). This may also mean that the pattern and natural course of distress is different from those diagnosed with early stage disease. This has implications for the management of care and the differences in support required by this group of patients.

Figure 3 Psychological care interventions



7. Nursing interventions (Continued)

Assessment of need is a core recommendation in the supportive and palliative care guidance and is also recommended in the draft advanced breast cancer guidance (NICE, 2004 and 2009). Nurse specialists who have an understanding of the emotional impact of metastatic breast cancer are better placed to be able to assess the needs of this patient group and provide them with or refer them to appropriate support services.

Providing such specialist and specific advice means that patients and families can enjoy a better quality of life.

A unique understanding of the patient experience, technical knowledge and professional experience in metastatic breast disease means that CNSs are able to broker on behalf of patients. They use highly developed co-ordination strategies to make pathways more efficient, applying local knowledge to speed up cancer journeys.

CNSs working with metastatic breast cancer patients are often responsible for developing and leading their own service in providing care for this patient group. The range of clinical-physical work they undertake can be seen in Figure 4.

Patients with metastatic breast cancer experience a range of symptoms relating to their disease and treatment such as pain, fatigue and sleeplessness. CNSs working with these patients spend 46% of their clinical time directly managing patients' symptoms. Almost a quarter of their time is spent offering specialist symptom management and a further 15% recommending specialist and specific care to the multi-professional team. Research has shown that many patients with metastatic breast cancer do not receive adequate symptom relief, particularly in alleviating pain (Lebel et al, 2007). This highlights the importance for CNSs of having expert knowledge of metastatic breast cancer be able to provide adequate symptom relief for patients.

'When I was diagnosed with secondaries my GP tried to help with my pain but it was like, try this, try that, try the other, then I was allocated a specialist nurse and she is right on the ball. Twice now when my pain has become more severe she has assessed my needs at home and changed my pain control and I haven't needed to go into the hospice.'

Patient

'I spent time discussing with the patient how she and her family were coping with the diagnosis and the future.'

CNS narrative

'She (CNS) referred my son to counselling which has really helped him. She also arranged counselling for me, but she will also sit and listen when I'm bawling my eyes out – she will come right over. She also told me about the local support group in my hospice. Without her I don't think I would be able to cope, she's taken stress off me, without her I think I would have been a nervous wreck.'

Patient

3. Co-ordinate complex care – making services more efficient and resolving unsatisfactory experience

CNSs working with patients with metastatic breast cancer also apply their unique understanding of the disease to manage complex pathways and ensure continuity of care. Their knowledge base includes knowledge of signs and symptoms of oncological emergencies which can be a risk for patients with metastatic breast cancer. They can ensure that the patients see the most appropriate members of the multi-professional team at the right time. This can be of particular importance in the prevention of morbidity:

'I was concerned about symptoms described by a patient on the telephone – I arranged immediate review and MRI as the patient had the symptoms of spinal cord compression.'

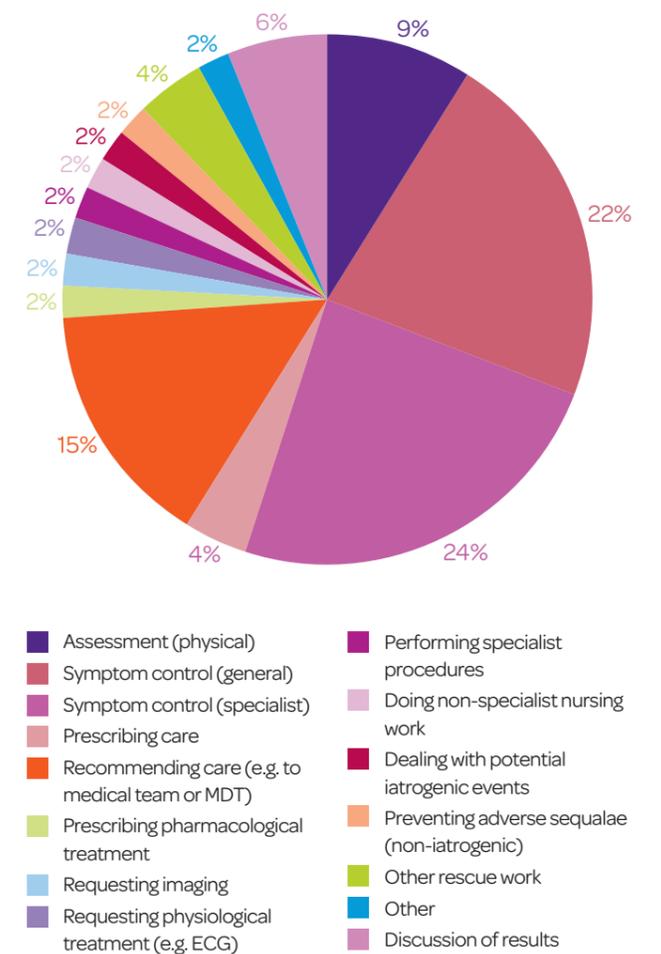
CNS narrative

An in-depth knowledge of services allows CNSs to play a strategic part in evaluation. They are exposed to patient opinion and perception every day and are able to inform instruments such as patient satisfaction questionnaires or support patients in partnership working. CNSs working with metastatic breast cancer patients regularly (at least weekly) resolve unsatisfactory patient experiences before the formal complaints process is used; they use local knowledge to achieve the best outcome, which is often in the sphere of enhancing communication or mediation.

'The PALS office say they always know when I am away.'

CNS narrative

Figure 4 The physical dimension of clinical care by CNSs working with patients with metastatic breast cancer



7. Nursing interventions (Continued)

4. Meet unmet information needs and empower patients

It has been recognised that there are gaps in the information provided to those with advanced cancer (CRS, 2007). Information needs are high in patients with metastatic breast cancer and it is essential that these are addressed (Sanson-Fisher et al 2002, Aranda 2005, 2006). Research has shown that patients with metastatic breast cancer who have their information needs met have lower feelings of anxiety and are less likely to be depressed (Mayer, 2006).

CNSs working with patients with metastatic breast cancer have the expertise in metastatic breast disease needed to be able to provide appropriate information to patients.

'The questions about my treatment, my doctor (GP) wouldn't have been able to answer those and my consultant doesn't give you enough time to ask those questions, so I wouldn't have had anyone to go and talk to had it not been for my nurse.'

Patient

It is vital that support is provided alongside information given to patients to ensure the patient fully understands about their cancer and its management.

'I spent time discussing the secondary breast cancer and aims of treatment with a new inpatient.'

CNS narrative

Nurse specialists with expertise in metastatic breast cancer are able to assess the information needs of patients and their families and provide timely and accurate information.

'Sometimes you need to have several conversations about recurrence with patients and families – they sometimes just don't take it in the first time.'

CNS narrative

Assessment of information need is a key recommendation in the forthcoming NICE *Advanced breast cancer* guidelines – CNSs with skills and knowledge of metastatic breast disease are the ideal people for this role.

The expertise of CNSs caring for this patient group means they are aware of the range of issues people face and can provide information around it. This experience also allows CNSs to be at the forefront of information development and to assess the need for information where there may be gaps in provision.

'My nurse has helped sort out the benefits I am entitled to and got me a grant via Macmillan.'

Patient

'The nurse sorted me out with a disabled badge.'

Patient

Not having access to a CNS in metastatic breast cancer means that supportive, specific information is difficult to access and makes the cancer experience even more challenging for patients.

'The only advice we get, or the chance to ask questions, is when something is wrong, and then when we do ask we're not always given the explanation of what to expect or how it's going to affect us. There are times you want to know something and there is no-one there to ask – we can cope at the hospital, but when we come away we've got nothing.'

Husband of patient

5. Prevent unscheduled admission to hospital

Clinical nurse specialists working in metastatic breast cancer use their expertise to facilitate appropriate admission, discharge and referral to other teams such as palliative care.

'The patient was due to go to a hospice but was in hospital as a brace had not been fitted. I arranged for the local clinicians to be involved and the brace to be delivered to the hospice where a local clinician agreed to fit it; the patient was able to go to the hospice and did not have to stay in hospital.'

CNS narrative

CNSs working in metastatic breast cancer prevent emergency admissions to hospital. They provide an alternative to unscheduled care by helping keep patients in the community. They do this by working with community teams and GPs to provide clinical solutions to complex problems. Sixty per cent of the CNS's work is dealing with community-based issues. Specialised nurses prevent an unscheduled care episode approximately 26 times per year.

CNSs working with metastatic breast cancer patients reduce new to follow-up ratios in cancer units, releasing clinic and outpatient time for new patients. A CNS specialising in metastatic breast cancer will see an average of 13 follow-up patients per week in an outpatient setting. Matched against the Department of Health (DH) tariff this represents £53,040 in income and the potential release of 13 slots to new patients (new medical oncology £159,120 per 48 week year) This means CNSs working with metastatic breast cancer patients can speed up pathways, helping trusts meet targets and allowing new patients to be seen which allows for generation of income.

6. Support patients in clinical decision-making

People with metastatic breast cancer can face many difficult decisions around management of treatment, such as which treatment to have or whether to continue treatment. CNSs in metastatic breast cancer provide expert information at the appropriate level and time to assist with these decisions. Having a trusted relationship with the patient also ensures they and their family can make these difficult decisions in a supportive environment. The CNS can facilitate choice, particularly where patients are facing difficult decisions, for example about whether to continue with treatment.

7. Nursing interventions (Continued)

'I might need to have chemo again, if I said I didn't want it, I think she [CNS] would support me and listen.'

Patient

Supporting patients with metastatic disease through choice and decision-making is a key component of the role of the CNS in metastatic breast cancer. This is emphasised by the CRS which recommends patient involvement in decision-making. The experience and expertise of this group of nurses can ensure that partnership working becomes a reality. One-third of psychosocial support interventions given by the CNS are around supporting patients to make these clinical choices. To make informed choices, patients with metastatic breast cancer need access to knowledgeable, professional and accessible support.

'I spent time with a patient advising on possible treatment options if current treatment is failing, and how to cope with this, i.e. side effects of treatment on a daily basis and how to cope with family life.'

CNS narrative

8. Conclusion

CNSs in metastatic breast cancer are highly skilled professionals providing a wide variety of interventions and applying specialist knowledge to ensure this patient group receives optimum care and support.

This guide demonstrates how they can assist in meeting government targets and standards; in particular how their specialist knowledge and skills can enable patients to fully understand their cancer and its treatment, be involved in decision-making as they wish and make choices about their care as they see fit.

The Taskforce urges cancer networks and trusts to review the nursing service they offer to metastatic breast cancer patients and reconfigure it as appropriate to ensure every such patient has access to an appropriately skilled and knowledgeable CNS.

References

- Anderson, BL. (1994) *Surviving cancer*. Cancer 74: 1484-95
- Aranda, S, Schofield, P, Weih, L, Yates, P, Milne, D, Faulkner, R & Voudouris, N. (2005) *Mapping the quality of life and unmet needs of urban women with metastatic breast cancer*. European Journal of Cancer Care, 14, 211-222
- Aranda, S, Schofield, P, Weih, L, Yates, P, Milne, D & Faulkner, R. (2006) *Meeting the support and information needs of women with advanced breast cancer: a randomised controlled trial*. British Journal of Cancer, 95, 667-673
- Breakthrough Breast Cancer, Breast Cancer Care, Royal College of Nursing. (2007) *Survey of breast care nurses*.
- Breast Cancer Care, Secondary Breast Cancer Taskforce. (November 2008) *Improving the care of metastatic breast cancer patients*.
- Breast Cancer Care. (2007) *Access to a key worker for all secondary breast cancer patients – Setting the scene*.
- Breast Cancer Care and the Royal College of Nursing. (2004) *Time to care: maintaining access to breast care nurses*.
- Department of Health (DH). (2007) *Cancer Reform Strategy*.
- Cancer Research UK, Prevalence (numbers of cancer survivors) UK. (2008) (cited 10.10.2008) Available at <http://info.cancerresearchuk.org/cancerstats/incidence/prevalence>
- Cella, DF, Mahon, SM & Donovan, ML. (1990) *Cancer recurrence as a traumatic event*. Behavioural Medicine 16: 15-22
- Classen, C, Butler, LD, Koopman, C, Miller, E, DiMiceli, S, Giese-Davis, J, Fobair, P, Carlson, RW, Kraemer, HC, Spiegel, D. (2001) *Supportive expressive group therapy and distress in patients with metastatic breast cancer; a randomised clinical interventional*. Archives of General Psychiatry 38 (May) 494-499
- Corestine, M, Crooks, D, Grunfield, E, Stonebridge, C. & Christie, S. (2003) *Caregiving for women with advanced breast cancer*. Psycho-oncology 12, 709-719
- Department of Health (DH). (2004) *The NHS knowledge and Skills Framework (NHS KSF)*.
- Department of Health (2007) *The Cancer Reform Strategy*. HMSO
- Hopwood, P, Howell, P & Maguire, P. (1991) *Psychiatric morbidity in patients with advanced cancer of the breast: prevalence measured by two self-rating questionnaires*. British Journal of Cancer 64, pp349-352
- Johnston, SRD, & Swanton, C. (2006) *Handbook of Metastatic Breast Cancer*. Informa Healthcare
- Lebel, S, Rosberger, Z, Edgar, L & Devins, GM. (2007) *Comparison of four common stressors across the breast cancer trajectory*. Journal of Psychosomatic Research 63(3);225-32
- Meyer, M & Grober, SE. (2006) *Silent voices: Women with advanced (metastatic) breast cancer share their needs and preferences for information, support and practical resources*. Living Beyond Breast Cancer
- National Institute for Health and Clinical Excellence (NICE). (2002) *The clinical effectiveness and cost effectiveness of trastuzumab for breast cancer*.
- NICE. (2002) *Guidance on cancer services – Improving Outcomes in Breast Cancer*.
- NICE. (2004) *Guidance on cancer services – Improving Supportive and Palliative Care for Adults with Cancer*.
- NICE. (draft 2008) *Clinical Guideline – Advanced breast cancer: Diagnosis and treatment. Draft for consultation*.
- Parle, M, Gallagher, J, Gray, C, Akers, G, Liebert, B. (2001) *From evidence to practice, factors affecting the specialist breast care nurse's detection of psychosocial morbidity in women with breast cancer*. Psycho-oncology 10, 503-510
- Pinder, KL, Ramirez, AJ & Black, ME. (1993) *Psychiatric disorders in patients with advanced breast cancer: prevalence and associated factors*. European Journal of Cancer, Volume 29A, No.4, pp524-527
- Royal College of Nursing. (2007) *Clinical standards for working in a breast speciality: RCN guidance for nursing staff*.
- Sanson-Fisher, R, Grgis, A, Boyes, A, Bonevski, B, Burton, L & Cook, P. (2000) *The unmet supportive care needs of patients with cancer*. Cancer 88, 226-237
- Scottish Intercollegiate Guidelines Network (SIGN). (2005) *Management of breast cancer in women: A national clinical guideline*.
- The Scottish Government (2008) *Better Cancer Care – a discussion*.
- Welsh Assembly Government. (2005) *National standards for breast cancer services*.
- Welsh Assembly Government. (2006) *Designed for Life: creating world class health and social care for Wales in the 21st century. Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement*.
- World Health Organisation. (2008) *International classification of diseases (ICD)* on <http://www.who.int/classifications/icd/en/> accessed May 2008

Breast Cancer Care set up the Secondary Breast Cancer Taskforce in May 2006 to improve the treatment, support and care of people living with metastatic breast cancer by influencing policy, raising awareness of good practice and promoting optimum services. It is a national coalition of healthcare professionals, government representatives and, most importantly, people living with metastatic breast cancer.

Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our professional expertise in everything we do. Visit **www.breastcancercare.org.uk** or call our free helpline on **0808 800 6000**.

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