

5th International Congress
of Breast Disease Centers 2015

“MULTIDISCIPLINARITY IN THE BREAST CENTER”

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The Metastatic Breast Cancer Patient

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What does metastatic mean?

- This is cancer that has spread from the original site to another place in the body
- Metastatic cancer has the same name and the same type of cancer cells as the original (primary) cancer
- E.g. breast cancer that spreads to the lung and forms a metastatic tumour is metastatic breast cancer, not lung cancer
- The goal of treatments is to control the growth of the cancer or to relieve symptoms caused by it



All these terms are interchangeable

- Advanced breast cancer
- Secondary breast cancer
- Metastatic breast cancer



Early Breast Cancer Epidemiology

- Breast cancer is the most frequently diagnosed cancer and a leading cause of cancer death among females in the world¹
- Almost 49,000 women were newly diagnosed with breast cancer in the UK in 2009²
- 1 in 8 women in the UK will develop breast cancer at some point in their lifetime
- Around 400 men are diagnosed with breast cancer every year in the UK
- More women than ever in the UK are surviving breast cancer thanks to better awareness, better screening and better treatments



European Breast Cancer Statistics

- 450,000 new cases annually in Europe
- Estimated 3,600,000 by 2020
- Every 2 minutes someone in the EU is diagnosed with breast cancer
- Every 6 minutes someone in the EU dies from breast cancer
- 1/3rd of these could be prevented by lifestyle changes



Advanced Breast Cancer Epidemiology - UK

- Around 1,000 women die of breast cancer every month in the UK
- Around 2,500 women will have detectable metastatic disease at presentation³
- In the order of 25, 000 women with early oestrogen receptor positive (ER+) disease subsequently develop disseminated disease³
- Average life expectancy after diagnosis of advanced breast cancer is approximately 18 to 24 months⁴



Worldwide data

- In 2008, 1 380 000 new cases and 458 000 breast cancer deaths were noted in the world and 332 000 new cases/89 000 deaths in the European Union
- Approximately 5% to 10% of breast cancers are metastatic at diagnosis; of these, approximately one-fifth will survive 5 years
- Depending on prognostic factors, up to 30% of node-negative and up to 70% of node-positive breast cancers will relapse
- The prevalence of metastatic disease is high because many women live with this disease for several years;
- There is a major lack of accurate data on this prevalence in the great majority of countries since most cancer registries do not capture relapses

innovate respect
care
achievement
pride



But what is the size of the problem..?

- Estimated that around 550,000 people are alive in the UK after a diagnosis of breast cancer (1)
- Unknown how many have recurrent or metastatic disease
- Lack of information on recurrence and metastasis of breast cancer means
 - effectiveness of treatments for primary cancers cannot be adequately assessed
 - care of patients with recurrent and metastatic cancer cannot be fully evaluated
- This makes it difficult to plan and resource services for this group of patients (2)
- Welcome the announcement in *Improving Outcomes: a Strategy for Cancer* in January 2011 that during 2011/12 data on recurrence/metastasis in patients with breast cancer would be piloted with the aim of undertaking full collection from April 2012 (3)

1 Cancer prevalence in the United Kingdom: estimates for 2008. Maddams, J. Brewster, D. Gavin, A. et al (2009). *British Journal of Cancer* 101: 541-547

2. *An Intelligence Framework for Cancer*. Department of Health, December 2011
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_132385.pdf

3. *Improving Outcomes: a Strategy for Cancer*. Department of Health, January 2011.
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf



How people present to our clinics

- 30% of people who have early breast cancer will develop secondary breast cancer
- 5% of people who are first diagnosed with breast cancer have metastatic disease



The Cinderella subject?

- Worldwide about 1/3rd of those with early breast cancer will develop ABC
- Little is known about
 - the personal
 - psychological
 - emotional experiences of these women
- Early breast cancer is highly-visible in the media and within advocacy groups
- Metastatic breast cancer is rarely mentioned
- Women with ABC feel isolated and alone



“People tend to shy away from me when they find out about my disease.” Lynn

“When I explain what ‘metastatic’ means, I see the look of pity or sadness and a complete lack of understanding that one can live quite normally with metastatic breast cancer for many years.” Robin



BRIDGE (Bridging gaps, expanding outreach) Survey (2008) Pfizer

- International survey; 13 countries (Argentina, Australia, Belgium, Brazil, Canada, Egypt, France, Mexico, Poland, Spain, UK, USA, Venezuela)
- To understand attitudes of those living with ABC
- To determine gaps in resources, info & psychological support
- To identify perceived barriers to clinical trials enrolment and participation
- 1,342 women with ABC
- Face to face, via the telephone or postal service



BRIDGE Survey - results

- Women thought less attention was given to them compared to those with EBC
 - 52% reported ABC given too little consideration
- 51-69% reported negative emotions e.g. fear of dying, fear of future, unknown
- 74% state they still enjoy life (great!)
- 61% did not like to be called 'survivor'



BRIDGE Survey - results

- 98% felt they receive sufficient support from at least one person (family/friends)
- 83% & 81% stated enough support from oncologist and nurse
- 48% said family and friends were uneasy talking about ABC
- 76% took active role in searching for information on ABC
- HCP gave written info (63%), but only 13% of women felt these were most helpful
- 23% of patients thought internet most helpful



Here & Now Campaign (Novartis Oncology)

- A Pan-European disease awareness campaign for ABC
- To improve understanding and raise awareness of high unmet social and psychological needs of patients with ABC
- To generate richer picture of the current ABC landscape on a personal and societal level through survey findings
- To bring together breast cancer community to drive the relevant call to action
- To generate a tangible change in support and care available to ABC patients



Here & Now Patient and Carer Survey

- Supplied new and in-depth insights into real impact of ABC
- Nine countries (France, Italy, Spain, Netherlands, Greece, Austria, Poland, Denmark, Sweden)
- 304 respondents (158 patients and 146 carers)
- Looked at:
 - Personal impact
 - Socio-economic impact
 - Support needs



Here & Now Survey- Personal Impact of ABC

- Negative feelings are at the forefront of their minds
- Following a diagnosis of ABC over 50% of patients surveyed are worried
- 41% claim to be depressed
- Less than 1/3rd feel 'strong' or are 'looking forward'
- 50% of patients experience pain and discomfort that affects their daily life



Here & Now Survey- Socio-economic Impact of ABC

- 51% of patients believe they are perceived negatively by society
- 56% of patients experienced a decline in household income as a result of ABC
- 87% said their expenditure had to increase to cover treatment



Here & Now Survey- Support needs of ABC Patients

- Only 36% of women living with ABC have received support from patient groups following a diagnosis
- Only 37% have received support from fellow breast cancer patients (ABC or EBC)
- 79% state the importance of improving personal well-being/QoL
- 72% wish for improved access to treatment
- 68% wish for improved access to HCPs



Pan-European Consumer Survey

- Survey conducted in 11 European countries
- There is a poor understanding of ABC within the public
- Nearly 8 in 10 of public do not know that ABC means incurable
- It seems there is work to be done in creating public awareness





‘Count Us, Know Us, Join Us’ (Novartis Oncology)

- Global survey illustrated a high degree of unmet social and psychological need among those with ABC
- 41% of respondents stated support from friends/family were not as strong as when they were diagnosed with primary disease
- 70% stated there was difficulty in finding appropriate support groups
- Implications of ABC are far-reaching



'Count Us, Know Us, Join Us'..2

- Could be more practical issues due to associated financial worries (medication costs, travel to hospital)
- Significant social roles these people play in the community decreases after the cancer spreads.
- Implications of ABC are far-reaching



Here & Now HCP survey (2014)

- Pan-European survey
- Aim to uncover what unmet need in ABC is for the HCP and identify gaps
- Sample (n=327)
- 8 countries across Europe
- 20 closed questions
- 50% oncologists
- 50% breast cancer nurses



Here & Now HCP survey- identified challenges

- 38% believe greatest unmet need for pts is availability of emotional support
- HCPs surveyed think 41-60% of pts do not understand implications of their ABC diagnosis



Here & Now HCP survey-HCP needs

- 82% say treating ABC pts impacts on them emotionally
 - 58% of nurses feel sadness
 - 53% feel helplessness
 - 51% feel motivated
- 88% of HCPs in Europe would like further training
- 96% agree that a MDT approach improves the level of care for those with ABC
(74% worked as part of a MDT)



Breast Cancer Care's (BCC) Secondary Breast Cancer Taskforce (2006-2008)

- BCC stated this group of patients have specific needs and requirements that are not being met (e.g. access to a CNS to act as advocate and provide support and information)
- The Taskforce was a national coalition of HCPs, charities, policymakers and people with secondary breast cancer
- The Taskforce was user-led – guided by people living with secondary breast cancer
- Through surveys, research and expert consensus, the Taskforce identified gaps in
 - treatment
 - support
 - care for this patient group



Taskforce outputs

- *Improving the care of people with metastatic breast cancer* is the final report written by BCC's Secondary Breast Cancer Taskforce
- The report is aimed at HCPs and policy makers involved in the care of people with secondary breast cancer
- It identifies core issues and makes recommendations for those facing people with secondary breast cancer
- It sets out recommendations for improving patient care in these areas
- Designed to complement this report, came the Standards of Care for people living with secondary breast cancer



Taskforce – priority issues:

- Lack of data on the incidence of secondary breast cancer and the survival of these patients
- Lack of access to CNS's with the skills and knowledge to manage secondary breast cancer
- Gaps in access to accurate and appropriate information from the point of secondary diagnosis onwards for patients and families
- Gaps in the provision of psychosocial support for patients with secondary breast cancer and their families
- The need for improved management of secondary breast cancer by doctors within the community
- The Taskforce was the first of its kind in the U.K.



Distilled to 3 aims to improve care

- For every breast cancer unit in UK to collect accurate data on the number of people with secondary breast cancer
- For all HCPs to support BCC Standards of Care for people with secondary breast cancer
- For healthcare professionals to have enough training and support so that they can meet the needs of their patients who are living with secondary breast cancer



BCC's Standards of Care Standards of Care for people with secondary breast cancer (2009)

- Developed in conjunction with people with people with secondary breast cancer and healthcare professionals with expertise in caring for people with secondary breast cancer
- They aim to empower patients by making them aware of the level of care they should be receiving



Standards of Care - a person with secondary breast cancer should:

1. Have access to a CNS at and from the point of diagnosis of secondary breast cancer
2. Receive a multidisciplinary team approach to their care
3. Experience continuity of care between the hospital and community services
4. Be given timely information on all aspects of treatment and care (verbally and in writing) and be clear on the purpose of treatment, side effects and potential impact on wellbeing. Information needs should be assessed regularly and support provided
5. Have their emotional wellbeing assessed regularly and access to the appropriate level of psychological support



Standards of Care continued....

6. Have access to information on support services (nationally and locally)
7. Have access to expertise in palliative care, symptom control and on going management of troublesome symptoms
8. Have access to support and guidance on talking to partners, family, friends and children, about the experience of living with secondary breast cancer and it's impact on others
9. Have access to expert financial and employment advice
10. Have access to appropriate treatments and be made aware of clinical trials they may be eligible before treatment is started or changed



Nursing input is vital

- Potential and realistic treatment goals should be discussed
- Told the disease is incurable but treatable
- Informed many live for extended periods of time
- Give realistic hope
- Transparency
- Discussed with caregivers/family as wished
- Encouraged to actively participate in all decisions re care
- Promote patients to have a healthy lifestyle to increase chance of good outcomes



BCC Nursing Toolkit

- One of the 'standards of care' is every person with secondary breast cancer should have access to a CNS
- This CNS should be knowledgeable about the disease, treatment and support needs of people with secondary breast cancer
- BCC produced a toolkit which covers a range of issues;
 - developing your nursing service to reflect current policy and national guidelines
 - suggestions about changing your service
 - case studies from nurses in practice where work can be shared and learnt from
- The toolkit is available as one document or as separate modules, downloadable as PDFs



6 Modules

- Module one - The case for change
- Module two – Excellence in practice
- Module three – Making the change
- Module four – Promoting the change in the nursing service
- Module five – Case studies
- Module six – Useful reading



A recent change in service – the birth of the metastatic MDT

- Large unit with 3 hour MDT
- Felt cases discussing those with metastatic disease were not utilising all clinicians
- Felt cases could be discussed for longer
- Scoped availability of relevant clinicians
- Sourced a room
- Sourced sponsored breakfast – vital!
- Was once a month, soon going twice a month



The Future is bright....

- Treatment of metastatic breast cancer has substantially changed in the last decades
- There has been a significant improvement in both survival and patients quality of life due to
 - Availability of new cytotoxics and targeted therapies
 - Changes in treatment philosophy and strategy
- There has been a new treatment paradigm which encompasses
 - The MDT approach
 - personalised treatments based on tumour characteristics
 - patient's and disease history
 - re-definition of treatment goals (aimed at lowest possible impact on patients' life)
- More recently the development of the international advanced breast cancer (ABC) consensus guidelines have further contributed to this improvement



Our focus

- With insight and strategy, we can not only attempt to improve the care for women with ABC and improve understanding of this group of people
- We should work together to find solutions to support these women and accelerate change
- Ensure this 'Cinderella' subject gets the arena and focus it deserves



The Challenge

- More in our armoury – palliative no longer means death and dying
- Nurses upskilling and advanced practice roles are undertaken in order we provide more pathway care, continuity and a better holistic service
- Financial constraints and having to prove our worth
- Work differently
- Push our frontiers – be pioneering
- Be more creative
- Communication vital in acute and community setting and when crossing boundaries and integrate care



Communication

- Our communication is vital in order the patient understands about their
 - Disease (transparency re where they are)
 - Treatment (clinical impact)
 - Goals (personal understanding and actions)
 - Future (understanding and realistic hope)
- Effective communication crosses the boundaries between home and hospital (clinical and family life)



I wish to leave you with Ismena and some of her experiences of advanced breast cancer (from the Here & Now campaign)

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General discussion

