Driving High Standards of Nursing Care for Metastatic Patients
The Role of an MBC CNS in the Management of MBC Patients

Karen Verrill
CNS and Centre Head, Maggie’s Newcastle
• There are 550,000 people alive in the UK today who have, or have had, a diagnosis of breast cancer

• Breast cancer patients are the largest population of cancer survivors
  – More than \( \frac{1}{4} \) of the 2 million cancer survivors

• No-one knows exactly how many of the 550,000 are living with secondary breast cancer

What is different about MBC?

• EBC – treatment aim is cure
  – Treatment may seem interminable but the end is in sight

• MBC – cure is unrealistic
  – Treatment aim is to control, manage, stabilise, “keep a lid on it”
  – The end is also in sight – death from MBC
EBC Pathway

- Diagnosis
- Surgery +/- Reconstruction
- Adjuvant Chemotherapy*, RT, Herceptin, Hormones**
- Follow up
- Discharge

*EC/TC
FEC
FEC-T

** Al’s Tamoxifen
MBC Pathway

Diagnosis

DEATH
The pathway from symptoms to MBC diagnosis can have many twists and turns.
Survival with MBC

• Median survival time for MBC is now 3 years\textsuperscript{1}
  – Advances in medical management continue to extend survival\textsuperscript{2}
  – The range is very wide
  – not unusual for patients to live for $>10$ years\textsuperscript{2}

• MBC can be like a chronic disease

• Requires long–term specialist care

---

…yet there is less or sometimes no specific CNS support

“It was pretty awful. I was immediately put into contact with the BCN’s first time around but it’s as if they expect you to know the ropes the second time!

I wanted a BCN specialising in secondaries – I expected it really and was amazed that I was sent home to cope with my family.”
Support needs of MBC patients

• For many women, the impact of the diagnosis of MBC is even more devastating than their initial diagnosis with EBC
Breast NS’s in England

EBC

520

MBC

20
BCC Secondary BC Taskforce

- Lack of support/CNS’s highlighted by number of calls to BCC helpline from women with MBC
- 2 year initiative set up in 2006 – coalition of HCP’s, charities, policy makers, people with MBC
- Identified gaps in treatment, support and care of people with MBC through surveys, research and expert consensus
- Final report set out ‘Standards of Care for People with Secondary Breast Cancer’
  - Access to a CNS with time, skills, expertise . . .
  - Information on Clinical Trials

Breast Cancer Care, Nov 2008
Access to MBC nursing specialists

- Many BCN’s sit within screening or surgical units – do not have a presence in oncology clinics
- Breast surgery uncommon in the management of MBC
- Most MBC patients are managed by oncologists, not breast surgeons
- BCN’s may not be aware of the MBC diagnosis if not discussed at MDTM

Breast Cancer Care, Nov 2008
Newcastle BCN’s to Feb. 2011

- Screening centre, c. 450 new breast cancer diagnoses per year
- BCN’s originally in breast screening, part of radiology directorate at RVI
- Focus on diagnosis and surgical options
- 70 New patients/week – 3.5k pa.
  - 50% through NHS BSP
  - Every patient having biopsy sees a BCN
- Opportunity for support beyond surgical results limited by time and distance – oncology is in NCCC at Freeman
The Stimulus

• Breast Cancer CNS for HaH – private and NHS contracts. Provided service from diagnosis to end of life
• Awareness/Experience of local and national service provision – recognition of need for service improvement
• Meetings with Cancer Directorate Manager – no CNS support for people with MBC in NCCC
• Proposed secondment – business plan referencing BCC’s Taskforce findings
Business Case for Secondary Breast Cancer CNS post

- Unmet need recognised and quantified
- Directorate Manager/Clinicians enthusiastic about post
- Business case put forward
- Reluctance to agree secondment from 3rd party provider
- Concerns about financial risk – 51 week post identified as only acceptable option
- Part funding agreed by NCCC cancer charity
What Happened Next
Could a Clinical Trials & MBC NS Role be combined?
YES!!!

- Proposal to combine MBC CNS role with NCRN clinical trials recruitment

- Funding obtained from regional NCRN for 0.5 WTE CNS

- Renewable if demonstration of increased recruitment NCRN and ECMC trials
Charlie Bear MBC CNS Post

- Interviews November 2010
  - “What new initiatives can be put in place to generate income to take the post past 51 weeks?”
- Post Started 28/2/2011
- 51 week contract
- Blank Canvas?!
Gestation of the post

- 4 weeks induction
- 5 weeks AL
- Bank Holidays

= 40 Weeks
February 2011 – Charlie Bear MBC NS and the challenges!

< 51 weeks to make the job work

- Contract “temporary” in 2\textsuperscript{nd} year
- Constant pressure to deliver
  - quality for patients
  - revenue for trust
  - accrual to clinical trials
- Documentation of every single chargeable interaction and ensuring it goes on the system

- CODING, CODING, CODING
And more!

- Time
- Initial publicising of service
- Rapidly increasing patient caseload
- Rapidly increasing patient expectation
- Increasing expectations of Clinicians
- Clinic/Support Group rooms?
- No cross cover
- Admin support
- CODING, CODING, CODING
Income

Quality
NCCC MBC NS Service February 2011 – February 2013

• Chemo. day unit & inpatient visits
  – Link to acute oncology (off site)
• “Planned” Nurse led clinics including
  – “Drop-in”, new patient, follow up, rapid access, telephone, clinical trials
• Unplanned activity
  – Unexpected “drop ins”, out of clinic attendances, telephone calls +++
• MBC support group
• Support to Consultant led oncology clinics
Clinical Trials

- Patients potentially eligible for open trials identified before clinic
- CNS saw new patients first in oncology clinics and discussed treatment plan.
- Further Nurse led appointment for 1–2 days later for further discussion +/- consent
- Information giving continued after medical consultations with “decision support”
- Streamlined handover to trials unit
Charges for CNS activity:

- New MPC (311) £ +59*
- FU MPC(116) £ +2*
- Nurse led New £ 252
- Nurse led FU £ 114
- Seroma asp. £ 249
- Dressing £ 140
- Telephone cl. £ 23
- Ward/CDU visits £ 0

* = additional income for CNS presence
Annual income >£66,000
The MBC Nurse Specialist Role:

- Co-ordination of complex multidisciplinary care, ensuring continuity
- Addressing patient information needs for the myriad treatments
  - Decision support
- Recognising the signs and symptoms of oncological emergencies
- Managing the transition from active anticancer treatment to end of life care
The MBC Nurse Specialist Role:

• Support through the challenges faced
  – Symptoms of disease
  – Shock of the diagnosis
  – Comprehending multiple treatment options
  – Side effects of treatment
  – Limitation of life span/loss of future

• Supporting and respecting each person throughout their cancer journey whatever choices they make
Day to day challenges

• Clinic content, frequent bad news
• All interactions are with people who will ultimately die from cancer
• Constantly trying to make them feel better takes a huge toll on the NS
  – Picking up the pieces
  – Young patients with young children
Tea and Sympathy
Compassion Fatigue
Measures of Success

- Service valued by users and Breast Cancer MDT
- Nurse led, new, review, rapid access, and drop-in clinics set up
- Revenue streams identified and income generation demonstrated
  - Clinic Tariff
  - Chemotherapy waste
  - Nursing contribution to trials costed
- Increased recruitment to clinical trials
  - D-CARE, SafeHer
Patient satisfaction

- Completed patient satisfaction audit in year 1
- 100% of patients replied to postal survey
- All valued the service
Comments

“Being diagnosed a 2nd time is a whole different ball game to the 1st diagnosis. Having a Secondary Breast Cancer CNS act as guide is confidence building”

“I am surprised that CNS support is much more widely available for primary breast cancer than secondary as the latter is clearly a more serious clinical condition with more unstable treatment pathways and potentially devastating emotional consequences”
“I think it is absolutely crucial to have a Secondary Breast Cancer CNS available to offer support. Her positive outlook and constant caring support have kept me going through some very dark days (and nights)”

“A fantastic support. She has co-ordinated appointments so visits to hospital are kept to a minimum”

“Please don’t stop the service. Without a secondary CNS there is a glaring gap in care”
“Having thought you were getting over your breast cancer successfully and then to be told it is back in another part of your body is devastating. Knowing that there is one person who knows your medical situation and who is there for you is absolutely priceless”

“The lynchpin between Specialist and patient, extremely important to a vulnerable patient”
What now for MBC CNS?

- Year 3, confirmed as substantive post on the basis of successful first 2 years
  - KV took up Maggie’s Centre Head role knowing the MBC NS role would continue
- F/T post advertised April 2013 – no applicants
- Re-advertised F/T or P/T May 2013
  - 1 applicant interviewed but unappointable
- Due to be re-re-advertised soon
  - Concern that there are no suitably qualified candidates “out there”
• My EBC and MBC support groups are now run in Maggie’s
• Many other support groups
• Cancer Centre patients visit for advice/support
• Maggie’s is working collaboratively with NCCC and other hospitals in the region to enhance care provision for all people affected by cancer not just patients
Ongoing MBC CNS Leadership role

• Regional
  – MBC Support Group in Maggie’s
  – NECN – Lead role development
  – NCCC – continue to attend and link to clinics
  – Continue to work with private patients

• National work
  – Joint working with BCC – MBC Nursing forum
  – Working party – NS/MBC pathway
  – UKONS Board – Joint lead on Survivorship Forum, including metastatic disease
  – C4C workshops
Dedicated MBC NS’s?
Does one size fit all?

• Where are the MBC NS’s we need?
  – Are there individuals out there with the necessary skills and experience?
  – How many have absorbed it into their ‘day job’? All stages of the disease
  – Ageing workforce!!!!
  – Do we need to train a new breed of NS?
    • Oncology nurses training in breast care
    • Breast care nurses training in [non–surgical] oncology
    • Planned succession planning?
Final Reflections

• However challenging it may seem to us, these women are living it every day and need and deserve support:
  – Over long periods of time.
  – Through many treatments
  – For the rest of their lives
  – For the symptoms of cancer
  – For side effects of treatment
  – Psychological support
  – To achieve their goals

• Support to live with cancer, not just die of it