Assessing symptomatic, supportive, social & psychological care in metastatic breast cancer:

A review of options for the National Audit of Metastatic Breast Cancer (NAoMe)

We set up a small working group within the NAoMe project team/audit advisory committee to assess the feasibility of this ambition.

We recognized that information to support the assessment of symptom control, social support and psychological care is likely to be less available and thus more difficult to obtain than that concerning medical care, initial presentation and the 'harder' outcomes including hospital admissions, recurrence and survival. The latter are routinely collected in national cancer datasets we have experience in using.

Nevertheless, given the appropriate and widespread acceptance that these outcomes are important it was necessary to explore this.

Palliative Care Services

Community and secondary care based palliative care services, funded in part or fully by the NHS and/or by charities, linked to hospices (themselves commonly charitably funded) are routinely available within England and Wales but have variable organisational structures. They provide services based on local need and availability of resources, but these services may differ considerably according to geography. End of life (EOL) care is recognised to be of key importance.

Hospices have bespoke local data collection arrangements, but do not routinely collect standardised data on services provided, admissions or care episodes in the way that NHS trusts do. Some have conducted surveys to examine types of service provision and/or interviews with patients and carers to identify needs and resources required. There are in addition, likely to have been local or regional projects to address service needs care quality or other matters, but to our knowledge, there is no long-term systematic data collection process in place at national level to allow an assessment of the elements of care as defined above, provided to patients with metastatic breast cancer.

End of Life Care

There is an ongoing audit in EOL care (National Audit of Care at the End of Life – NACEL)[1] although this is generic and not confined to patients dying from cancer. It provides benchmark information, surveys and case note review information and suggests standards for communication, care planning, family needs and workforce requirements and support. A recent report produced from the Royal College of Physicians (London) reinforced the need for these standards.[2]

Other related guidelines are available from the GMC[3] and NICE.[4] In addition NHS England recently published 'Palliative and End of Life Care Profiles'[5] This is factual with emphasis on cause and place of death and some other metrics including preceding hospital admissions but doesn't directly address quality of care. Emeka et al[6] identified marked regional variations in England in proportions of patients dying in hospices, home to hospice distance and in access to hospice in-patient care. Of note place of death information will be available to the NAoMe.

Clinical Nurse Specialists (CNS) – Breast Cancer Now

There is an existing network of CNSs with expertise in metastatic breast cancer in clinical practice, co-ordinated by Breast Cancer Now. This Secondary Breast Cancer Nursing Group brings together nurses working with people with secondary breast cancer, enabling them to share expertise and learn and share best practice in order influence positive changes in care and help improve standards for people with secondary breast cancer. This has recently included collation of patient caseloads of Metastatic Breast Cancer CNS's.

The Breast Cancer Now 'service pledge' programme brings together patients, healthcare professionals, NHS Trusts and Cancer Alliances, to deliver improvements for everybody's experience of breast cancer and is the only breast cancer specific patient involvement and service improvement programme in the UK.

The programme uses surveys to collate patient and staff views on the service provided and to analyse and discuss feedback, in order to co-design and implement improvements following the production of a formal report for each NHS Trust and Cancer Alliance who take part in the programme.

Maggie's[7] (and other voluntary patient support services)

It was agreed that it was unlikely that these services would be able to provide usable information for NAoMe.

Other relevant publication identified

A publication entitled '*National End of Life Care Intelligence Network, Palliative care clinical data set, Evaluation report*'[8] was identified. Of interest, it discusses a palliative care clinical data set and the pros and cons of such data collection. Not all trusts have the IT functionality for this dataset, and currently there is no national minimum dataset for England.

Conclusions

There are serious challenges in addressing how to assess symptomatic, supportive, social & psychological care in metastatic breast cancer at national level. We agreed to explore the possible use of CPES (Cancer Patient Experience Survey) national data and await the results of the BCN 'service pledge' survey, as well as seek input from the national breast cancer audits advisory committees in March.

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References

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