Communicating a Diagnosis of Advanced/Metastatic Breast Cancer

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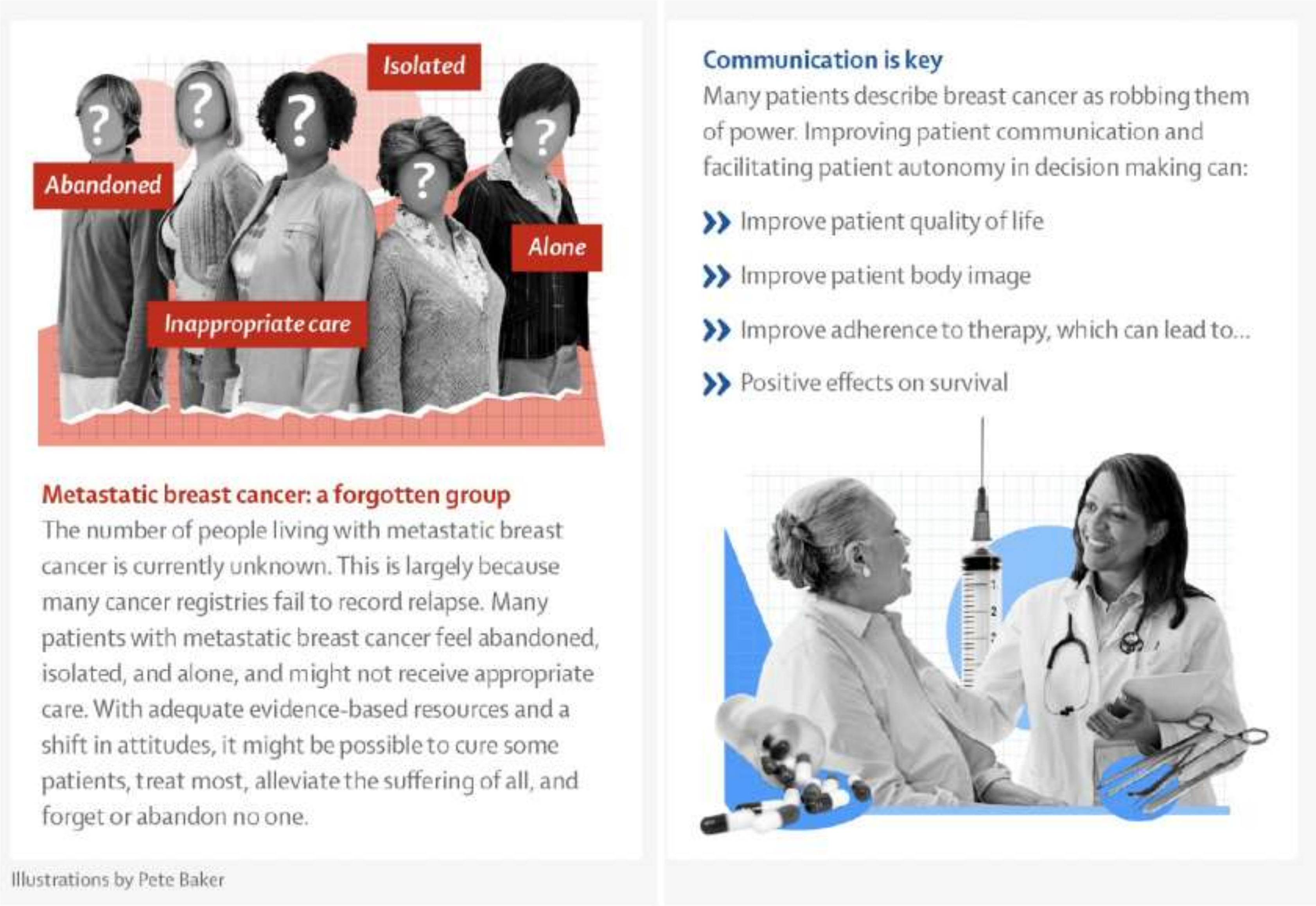

Metastatic breast cancer: a forgotten group

The number of people living with metastatic breast cancer is currently unknown. This is largely because many cancer registries fail to record relapse. Many patients with metastatic breast cancer feel abandoned, isolated, and alone, and might not receive appropriate care. With adequate evidence-based resources and a shift in attitudes, it might be possible to cure some patients, treat most, alleviate the suffering of all, and forget or abandon no one.

Illustrations by Pete Baker

Communication is key

Many patients describe breast cancer as robbing them of power. Improving patient communication and facilitating patient autonomy in decision making can:

- Improve patient quality of life
- Improve patient body image
- Improve adherence to therapy, which can lead to...
- Positive effects on survival

Patient Empowerment

- Patient empowerment should be defined as being fully informed and supported to confidently participate in decisions about personal health and wellbeing to the desired extent
- Patient-centered communication must acknowledge the unique background and need for information of each individual, consider their situation holistically, and work with the patient to define and achieve shared goals in their care

Patients Don’t Fail: But We Do Fail to Prevent the Development of Metastatic Disease for Many

- Outcomes of metastatic breast cancer have improved considerably in the past decade
  - median overall survival of metastatic breast cancer has remained at around 2–3 years for decades
  - but within the past 5 years, median overall survival has reached 5 years for 2/3 main subtypes (HER2-positive and ER-positive/HER2-negative), which account for approximately 85% of people with MBC
- Some patients can now live 10 years or longer with metastatic disease
  - and some subgroups are beginning to be considered as having a chronic disease
- Metastatic breast cancer is a spectrum of disease, both at a molecular level and in terms of disease burden
  - including potentially curable oligometastatic disease, long-term remissions or stabilizations, and more rapidly progressive disease (often the triple-negative subtype)
- Therefore, both the management of metastatic breast cancer and communication about the meaning of a diagnosis of metastatic disease must be individualized
  - not just on the basis of tumour biology, but also on patient characteristics

Challenging Conversations

- The balance between efficacy and toxicity of treatments and between the focus on survival, quality of life, and relief of serious health-related suffering is delicate and very personal for each individual in the metastatic setting
- Supportive care and palliative care are crucial parts of the management of metastatic breast cancer and should be incorporated from diagnosis
  - In a survey of 240 US oncologists, only 17% said that they refer patients to palliative care upon diagnosis of metastatic disease, despite two-thirds of respondents agreeing that earlier introduction of palliative care leads to better outcomes
  - Resistance from patients and their families is also a problem, often due to stigma and the perception that palliative care only means end-of-life care

The Concept of MBC & Goals of Treatment: What Providers Must Accomplish

- Explain that although MBC is usually incurable, it is treatable & can often be controlled for years
- Explain that treatment aims to slow cancer progression, reduce symptoms, improve quality of life, and prolong survival
- Understand how a patient prioritizes longevity, comfort, and independence
- Help patients make the treatment decisions that are best for them
  - requires the patient to understand the goals, logistics, and side-effects of treatment
  - requires the clinician to understand the patient's individual preferences, values, and life goals
    - (e.g., wanting to attend a loved one's wedding, travel, meet a grandchild, or avoid any change in appearance)
- Give realistic hopes and expectations: extremely challenging but also essential
  - Patients who want prognostic information might not always ask for it, so it is recommended that doctors ask explicitly if, when, and how patients want to talk about prognosis
    - It is best not to confront patients with information they do not want
    - Many patients still find it helpful to know the truth, and there is no evidence that increased information about prognosis with sensitive communication is harmful to patients, or that it increases anxiety or distress
    - For patients wanting quantitative information on life expectancy, providing ranges for worstcase, typical, and best-case scenarios is helpful and conveys more hope than providing a single point estimate of median survival—Dr. Kiely is the world expert who has done research on this and speaking next!

Principles & Best Practices of Communication for Providers

- Build rapport
- Convey respect for the patient and understand their preferences regarding decision-making
  - Set the agenda for the visit in collaboration with the patient
  - Specifically ask about the patient’s priorities for the consultation and their preferences for information and decision involvement (both their own and that of others)
- Share information
- Check understanding
- Empathize
- Review and make recommendations
- Come to mutual understanding about next steps

Examples of Language

- With these recent tests, we now have some new information about the disease that I would like to discuss with you.
- Unfortunately, the cancer has spread to…
- We can talk through what this means and what options there are.
- I know this is hard to hear. I am here to support you and will work with you and your other doctors to get a plan in place that works best for you and your priorities.
- Here’s what we know about this cancer so far.…
- Sometimes, the hardest thing is knowing you have metastatic cancer and not yet knowing what your next steps are going to be. Once you have a plan, and you understand how to put that plan into action with your team, I really do think it will feel so much better. Here are the options for how we might treat this.
- What is your understanding of what we’ve discussed so far?
- Is there anything else I should know about you that will help me take the best possible care of you?
- Based on everything we’ve discussed, I think this would be the best option for you. Does that sound like the right path to you?

Complicating Factors

- 21st Century Cures Act prohibits EMR information blocking
- This means that many health systems provide immediate release of results (including radiology and pathology) to patients, who may receive the news of new metastatic disease late at night, when no one is available to convey this information
- This is pretty clearly not patient-centered or ethical but is also viewed by most hospital lawyers as legally mandatory

Future Work

- Developing an accessible tool to provide information and resources to patients diagnosed with metastatic breast cancer with the goal of mitigating worry and facilitating choices that align with individuals' values and preferences
  - Modeled on the SharES tool developed with the support of NCI P01 and R01 grants and the Alliance A231901CD trial

- Collaborators:
  - Sarah Hawley, Director, Center for Health Communications Research, University of Michigan
  - Rohini Bhatia, Radiation Oncologist, Emory University School of Medicine
  - Jane Meisel, Medical Oncologist, Emory University School of Medicine; Chair, ASCO Communication Committee

Above all what matters
is not to lose
the joy of living
in the fear of dying

--Maggie Jencks, founder of Maggie’s centres in the UK

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THE LANCET

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BREAST CANCER NOW The research & care charity