



Original article

Putting words into practice

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ABSTRACT

Many ABC/MBC (advanced or metastatic breast cancer) patients describe feelings of isolation and lack of support [1], often exacerbated by inadequate and insensitive communication. To examine these issues and the changing landscape of the wider breast cancer (BC) community, eight BC patients from across Europe took part in an advisory board. Each patient generously gave up their time to discuss how communication could be enhanced; driven by a desire to improve the experience and bolster support for future ABC/MBC patients. The most powerful and touching message emerged; maintaining the feeling of hope was vitally important as was the knowledge they were not alone in their diagnosis, with patient-to-patient communication representing an important 'lifeline'. It transpired that patients found certain language difficult, confusing and shocking to deal with, particularly as their disease journey was very much an emotional rather than clinical one. For those communicating with ABC/MBC patients, adopting an empathic, patient and personalized language and approach was considered invaluable. Here we examine further the key findings of the advisory board to help shape how, step-by-step, we can change the language we use in practice to effectively and sensitively communicate with ABC/MBC patients.

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1. Introduction

The diagnosis of Breast Cancer could be a devastating experience for patients [1], despite the fact that Public breast cancer awareness, sharpened community focus and advances in imaging (both technologically and via improved service provision) has had a positive impact on the recognition and screening of breast cancer [2]. Nonetheless BC remains a life-threatening disease for men and women and one of the leading causes of mortality among the female population aged 20–59 years worldwide [3].

Around 30% of those treated for early breast cancer can progress

to recurrent advanced or metastatic breast cancer (ABC/MBC) [4], nonetheless, a previous global analysis [5] showed definite gaps in care, resources and support available for ABC/MBC patients. While improvements have been seen in ABC/MBC outcomes from 2005 to 2015, a need for better communication with patients and caregivers in ABC/MBC is apparent [5]. However, the landscape is changing as is public perception, often driven by ABC/MBC patients, who are urging the public to go beyond awareness campaigns and push for actual research into the real killer. One such activist is metastatic breast cancer patient and METUP co-founder Susan Rahn, who says, "it's okay if something's pink, as long as the money is going to the right place. We want to bring the ugliness and the things that people don't want to talk about into the light. It's not all pink and fun, and it's not a sorority. The narrative needs to change."

The cultural focus on 'survivorship' can mean that patients with ABC/MBC (who will be in treatment for the rest of their lives) often feel isolated from society [4] and overwhelmed with the unique

Abbreviations: MBC, Metastatic Breast Cancer; ABC, Advanced Breast Cancer; HCP, Healthcare Professional.

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challenges they face. It is important that while acknowledging that life will be different for ABC/MBC patients from now onwards, both healthcare professionals (HCPs) and non-HCPs reflect that it can still be full of hope.

To examine the language used around ABC/MBC an advisory board supported by Novartis was organized with ABC/MBC patients from across Europe. The aims were to explore how people living with ABC/MBC would like others - HCPs, family and friends, to communicate with them, to improve that dialogue and ensure the needs of those with ABC/MBC are central to any interactions. The findings are intended to both drive linguistic and attitudinal changes in practice and form a communications guidance for people involved in ABC/MBC, articulated by the women living with the disease. For those living with ABC/MBC with limited time ahead, any improvements to their quality of life are worth making.

2. Communicating about coming to terms with ABC/MBC

Undoubtedly, when a patient receives a diagnosis of ABC/MBC it is traumatic and overwhelming. Whilst processing this incredibly difficult news, the impact of poor or insensitive communication can be crippling. Words such as 'terminal' should be used with the utmost care and giving ABC/MBC patients an estimate of how long they have to live can also be too difficult to digest, particularly during the initial period of shock participants described. However, they found it helpful to be told that although their ABC/MBC cannot be cured, there are many excellent new treatments available to improve their symptoms and slow progression.

Inevitably, HCPs use clinical phases to define the ABC/MBC patient pathway, whereas for patients, the journey is very much an emotional one. It was advised that these emotional stages (disappointment, understanding, acceptance and ownership, support-seeking, coping and relapse) should form the basis of educational materials for healthcare professionals to allow them to understand how a patient perceives their pathway.

Complicated medical jargon which facilitates communications between the medical fraternity can however be unfamiliar, confusing and alienating to patients – especially during an emotionally charged consultation. Members thought that HCPs who explained the biology of what was happening during metastasis in a clear and simple way (pictures were ideal) gave them power to understand their condition and the therapy of it. The use of the word tumor also requires delicate handling. Our ABC/MBC patients explained that conversations which centered solely on the tumor rather than the patient made them feel invisible; that the tumor had become their identity. However, when discussing progression, it is more helpful to explain that the patient's *tumor* has progressed, rather than *they* have progressed, dissociating personal identity away from the tumor so the progression is not deemed their 'fault'.

3. Communicating in a way that brings hope: lifting the shadow on ABC/MBC

When asked what makes a conversation feel much better for people with ABC/MBC, the resounding response was that hope must be kept alive. They need to feel hope for better treatments, for living well in the time they have left and that ultimately, that life isn't all bad from this point onwards. Allowing patients the space to express their feelings whether positive or negative is also helpful. Finding a carefully worded balance between giving bad news and good, honesty and optimism, without reverting to platitudes or trivialization, can make all the difference.

4. Communicating to their individual and their community: context is important

People and patients differ greatly in the way they cope with bad news and information. Some prefer to know all the details of their condition and treatment, others are happier with the bare minimum. What one person finds empowering; another will be overwhelmed by. HCPs are advised that they can improve the patient's ability to cope by tailoring their language during conversations about treatment to reflect this and avoid patients feeling as though they're on a conveyor belt. Granted, this is not a simple task. Sufficient time should be allowed for consultations so HCPs are able to ask patients the right questions, heed their responses and body language, and understand what would be most helpful for that individual.

As with diagnosis at any stage, ABC/MBC can be a lonely place, and for many participants, 'you are not alone' was the first thing they wanted to hear after being diagnosed. For many with ABC/MBC, patient-to-patient communication was very beneficial, and HCPs can facilitate this by signposting support materials and ways in which to connect with other metastatic patients. Many advisory board members found that writing down their experiences, or in one case, writing a blog, helped them come to terms with their disease, voice their emotions and gave them back a feeling of control and empowerment.

Certain terms which have been championed by the wider breast cancer community can land completely differently for those with ABC/MBC. When examining specific terminology, the words 'survivor, battle, war and fight' evoked a negative reaction from participants. One member explained the implication that if an ABC/MBC patient does not 'survive their battle' against cancer it is somehow due to a failure, lack of effort or weakness on their part, which is undoubtedly not the case. The word 'survivor' also indicates that following diagnosis patients could return to life as normal, which for ABC/MBC patients is an impossibility. This finding corresponds with the recent 'Missed Opportunities' report from Macmillan Cancer Support [6], which advises against urging cancer patients to 'fight' their disease as it puts them under exceptional pressure. Relying on the frequently used terminology of cancer patients being 'fighters' or viewing cancer as a 'battle' can actually increase patient's stress, rather than keep their spirits high.

Our panel were more divided on the use of the word journey, dependent on their native language and its inherent meaning. For some, the word captured the ups and downs of an ABC/MBC diagnosis, however for others the word implied a predominantly pleasant experience not relevant to ABC/MBC. Other terms such as pathway, road or experience, more aptly described the arduous highs and lows involved.

Nonetheless, a unanimous decision was reached by the panel who all preferred their condition to be referred to as metastatic breast cancer, rather than advanced. This makes clear the Stage distinction; as advanced breast cancer comprises or includes locally advanced as well as metastatic disease. The specificity of the language was important to help the patients and those around them know what their terminal condition entailed without shying away from the facts.

5. Concluding remarks and recommendations

Above all, hope needs to flow through every communication. Open, informative and empathic dialogue between patients and HCPs is incredibly important. Although difficult, adopting a step-by-step approach to tailor the language, tone, behavior, eye contact and body language to each ABC/MBC patient can have a radical impact on their quality of life. Taking the time to clearly and simply

explain the disease, the treatment options and what to expect is invaluable and can empower an ABC/MBC patient who now must deal with grave news. By successfully crafting a nuanced, personalized approach we can avoid ABC/MBC patients feeling like they are 'just a number'.

Ultimately, the language we use and the way we communicate can shift a patient's perception of ABC/MBC and improve their experience of living with the condition. As one ABC/MBC patient beautifully put it, "My wish is to take the shadow from metastatic breast cancer and bring light to us patients. Life will never be the same, we all know that. We can never be cured, but life is still colorful."

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