

Understanding the perceptions and unmet needs of advanced breast cancer patients

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SUMMARY

It is estimated that up to one third of all breast cancer cases will become metastatic, as early as a few months and up to 15 years or longer after initially being diagnosed, with a median survival rate of 3 years and a 5-year survival rate of only 26 %. At this stage, complete responses remain uncommon, and progression of disease is often inevitable. Additionally, one in 10 women will already be at an advanced stage when first diagnosed, with a 5-year survival rate of less than 20 %.

Advanced breast cancer has a wider social and economic impact and must be seen as a different disease than early stage breast cancer. In addition to the emotional impact (isolation, depression and fear for the future), 50 % of patients experience pain and discomfort that affects their daily life. Many women are forced to give up paid employment or reduce the hours that they work and are also less able to look after their families.

Beyond medical advances it is vital to advocate political and

Breast cancer is a malignant tumor starting in the cells of the breast. It is the most common cancer in women worldwide, with 1,676,633 new cases diagnosed in 2012 [1]. Breast cancer accounts for about a quarter of all cancers diagnosed in women [2] and is the most common cause of death from cancer in women worldwide [3].

Across Europe, the age-standardized incidence for 2012 was 62.8 per 100,000 women and the mortality was 16.7 per 100,000 women per year [4]. Globally, breast cancer remains the leading cause of cancer death in women in both developing (269,000 deaths, 12.7 % of total) and developed (189,000 deaths, 15.5 % of total) regions [4]. The number of breast cancer cases worldwide has significantly increased since the 1970s, a phenomenon that has partly been attributed to modern lifestyles [5] but also to early detection through screening and public awareness. Breast cancer is strongly related to age with only 5 % of all breast cancers occurring in women under 40 years old [6]. There were more than 41,000 newly diagnosed cases of breast cancer registered in England

in 2011, around 80 % of these cases were in women aged 50 or older [7].

Risk factors for developing breast cancer include obesity (body mass index, BMI ≥ 30), lack of physical exercise, drinking alcohol, hormone replacement therapy during menopause, ionizing radiation, early age at first menstruation, not breastfeeding and having children late or not at all [8, 9].

Advanced breast cancer

Compared to other diseases or other cancers, breast cancer receives a proportionately greater share of resources and attention [10]. Breast cancer is typically portrayed in the media with an optimistic message that emphasizes the positive effect of early detection and the high likelihood of a cure. The disease is typically illustrated as having nearly been “beaten”, and the concept of long-term survival is stressed. However, there is hardly any public discussion of advanced breast cancer (ABC). It is estimated that up to one third of all breast cancer cases will become metastatic,

societal advances and to keep this highly vulnerable group in the eye of the public as well as of policy-makers. Through increasing awareness and education about the disease and advancing policy and strategic coordination of research funding specifically focused on metastasis, the lives of and outcomes for those living with advanced breast cancer and their families must be improved. Payers, regulators and commissioners should try to advance their understanding of advanced breast cancer and consider their responsibilities when making decisions about access to care. By working closely together, we have immense potential to improve the level of care and support for women living with advanced breast cancer, both today and in the future.

Keywords: advanced breast cancer, metastatic breast cancer, unmet need, perceptions, societal contribution, work contribution

as early as a few months and up to 15 years or longer after initially being diagnosed, with a median survival rate of 3 years and a 5-year survival rate of only 26 % [4, 11, 12]. At this stage, complete responses remain uncommon, and progression of disease is often inevitable. In spite of advances in treatment possibilities and better chances of survival, the death rate is likely to rise with an aging population [13].

Additionally, one in 10 women will already be at an advanced stage when first diagnosed, with a 5-year survival rate of less than 20 % [4]. Shame, silence, and isolation are often hallmarks of advanced breast cancer [14]. However, we know from what has happened with other life-threatening illnesses (such as AIDS/HIV) that this can change. Whereas 3 in 5 people in the “Here and Now Consumer Poll” knew someone that has had breast cancer, 43 % had not heard of advanced breast cancer or were not able to define it correctly [15]. 88 % of people were aware, that early breast cancer could be cured but only 23 % were aware, that ABC could not be treated so that patients were disease free [15].

The actual prevalence of advanced breast cancer across Europe is currently not known, since in almost all countries cancer registries include diagnosis and death but unfortunately not disease relapse. Because women with ABC live for several years and every year new cases occur, the overall prevalence is unknown.

In the past few years, several surveys and publications have been conducted which clearly show the suffering that this group of patients has to endure. This “forgotten population” – as a social worker at Memorial Sloan Kettering Cancer

Center referred to her advanced breast cancer patients [16] – must be remembered, not only after they die, but now, while they are still alive.

The emotional and practical impact of advanced breast cancer

In the survey “Count us, Know us, Join us” done by Harris Interactive among women living with ABC, 1,273 women were recruited across 12 countries [17]. The women were from the US (n=349), Canada (n=55), Mexico (n=102), Brazil (n= 100), Argentina (n=100), UK (n=66), Germany (n=100), Russia (n=100), India (n=100), Taiwan (n=99), Hong Kong (n=52), and Lebanon (n=50).

The survey confirmed that many women with advanced breast cancer (comprising stage III and stage IV) feel left out of the “breast cancer movement”, with 40 % of women stating that they felt isolated from the broader breast cancer awareness movement. Approximately two thirds of the participants felt like no one understood what they were going through. Following the diagnosis of ABC, over half of patients were worried and 41 % claimed to be depressed. Less than a third of patients felt “strong”, were “looking forward” or felt they were “surviving” since their diagnosis. 50 % of patients had experienced pain and discomfort that affected their daily life. The majority of women (77 %) considered that they took an active role in seeking out information, however many (45 %) found it difficult to find information about ABC or said that the available information did not address their needs (55 %). Many women (41 %) experienced that support

from family and friends decreased over time.

45 % of participants said that being diagnosed with ABC had led them to volunteer or give back to the ABC community. Regarding relationship and marriage, the diagnosis had a negative impact on their relationship for 40 % of women. However, 87 % of women confirmed to receive sufficient support from their spouse or partner [17].

The large international BRIDGE (Bridging Gaps, Expanding Outreach) survey including 1,342 women with ABC from 13 countries was one of the first large-scale attempts to address the unmet needs of these patients and was conducted in 2009 [14]. In this survey, 55–80 % of women reported feeling scared, confused, depressed, angry and alone at the time of ABC diagnosis. 51–69 % reported serious concerns related to ABC, such as fear of dying. 59 % said most aspects of their life had changed in a negative way [14].

These results are also supported by the online survey “METAvivor” conducted in 2011 to learn about the lifestyle and support issues of patients with ABC. There were 789 responders from 22 countries with the participants considered typical of Internet users in terms of their demographic profile. In this survey, 40 % of patients felt outcast and isolated [18].

In the “Here & Now European patient and carer survey”, one in two women living with ABC suffered from daily pain and only 22 % rated their health as “good” or better [15]. The “Here & Now European patient and carer survey” was conducted in 2013 by the Insight Research Group, interviewing 158 patients and 146 carers in nine European countries.

The special group of young women diagnosed with advanced breast cancer was surveyed via an online survey in 2012 [19]. Inclusion criteria were women diagnosed with any stage of breast cancer before the age of 41, who either had ABC at initial diagnosis or developed it thereafter. The emotional wellbeing of these women was heavily impacted by the disease as they suffered from anxiety (72 %), trouble sleeping (62 %), depression (46 %), withdrawal from enjoyable activities (33 %) and withdrawal from friends (26 %). 90 % indicated that their diagnosis impacted their sexuality, femininity, or body image. Over 90 % believed that public awareness should be raised about ABC especially in young women [19].

Work and societal contributions of women living with advanced breast cancer

The “Here & Now European patient and carer survey” showed that 40 % of the surveyed European women with ABC were working [15]. Of this group, a quarter was working full-time. After their ABC diagnosis, 50 % of patients had to make some change to their employment status, the most common state reducing their work (56 %). Most patients (56 %) had experienced a decline in their household income as a direct result of their illness. The majority indicated that their income had fallen by 30 % or more. 87 % of women said their expenditure had to increase to cover treatment and further medication. As a result of this, 39 % had experienced psychological or physical problems.

Many European households are dependent on women aged over

50 years for social and economic support. Women over the age of 50 play an important role, cooking as well as cleaning for their families, looking after elderly relatives, children and grandchildren while the parents are working [20]. In the 11 European countries included in the survey, the value of the unpaid care work of women aged over 50 is an estimated €876.5 billion a year ranging from 4.7 billion in Denmark to 110 billion in Italy – €8,767 for every woman aged 50+ living in the 11 countries [15].

After the diagnosis for ABC women’s ability to fulfill an active role in their private life falls significantly. Before the diagnosis, 74 % of women were responsible for the housework, 25 % responsible for childcare and 17 % looked after their grandchildren on a regular basis. After the ABC diagnosis, only 35 % were able to conduct their housework, 11 % were responsible for childcare and just 9 % were able to look after their grandchildren [15].

The patients’ role to fulfill an active role in the wider community outside their home is affected heavily by the ABC diagnosis. This parameter falls by 29 % as a direct result of their illness [15]. Interestingly, over half (51 %) of ABC patients believe they are perceived negatively by society [15]. This clearly shows the urgent need to improve the level of support for these women so they feel included and valued by society.

These results are supported by another survey, the “METAvivor” online survey conducted in 2011 to learn about the lifestyle and support issues of patients with ABC [18]. 75 % of women were employed (58 % full time), at diagnosis. Half of women stopped

working, most within a year. Although the majority returned to work, almost all stopped again thereafter. 31 % reported that they struggled financially [18].

In the survey “Count us, Know us, Join us “ done by Harris Interactive, women reported that regarding their workspace, most or all of their coworkers were aware of the status of the disease. Seven in ten women said that their ABC has interfered with their ability to work such that they suffered a loss of personal income [17].

Every cancer-related death in someone of working age represents an economic loss to society. In a study recently published in the *International Journal of Cancer* it was estimated that lost productivity costs due to premature cancer-related mortality in Europe in 2008 were €75 billion. The most costly sites were lung (€17 billion; 23 % of total costs), breast (€7 billion; 9 %) and colorectum (€6 billion; 8 %) [21].

Conclusion

Advanced breast cancer should not be seen as only a personal tragedy – it is a social problem for the people concerned, their families and friends, and society as a whole. In addition to the emotional impact (isolation, depression and fear for the future), 50 % of patients experience pain and discomfort that affects their daily life. Many women are forced to give up paid employment or reduce the hours that they work and are also less able to look after their families. Advanced breast cancer has a wider social and economic impact and must be seen as a different disease than early stage breast cancer. The prevalence of

the disease and the unmet needs of patients must be measured and quantified in further research.

It is of great importance for women with advanced breast cancer to feel that they are not alone. Beyond medical advances it is vital to advocate political and societal advances and to keep this highly vulnerable group in the eye of the public as well as of policy-makers. Through increasing awareness and education about the disease and advancing policy and strategic coordination of research funding specifically focused on metastasis, the lives of and outcomes for those living with advanced breast cancer and their families must be improved. The role of close collaboration between the medical, research and advocacy worlds continues to be highlighted. Payers, regulators and commissioners should try to advance their understanding of advanced breast cancer and consider their responsibilities when making decisions about access to care.

By working closely together, we have immense potential to improve the level of care and support for women living with advanced breast cancer, both today and in the future. □

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