



## Original article

# Evolving psychosocial, emotional, functional, and support needs of women with advanced breast cancer: Results from the Count Us, Know Us, Join Us and Here & Now surveys<sup>☆</sup>



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## ABSTRACT

Although medical advances have marginally improved survival of women with advanced breast cancer, their psychosocial, emotional, and functional needs remain unmet. Two surveys, Count Us, Know Us, Join Us (Count Us) and Here & Now (H&N), were conducted to understand the unique challenges faced by women with advanced breast cancer and to identify ways of addressing these issues. A total of 1577 women with advanced breast cancer (Count Us,  $N = 1273$ ; H&N,  $N = 304$ ) participated in the two surveys, which revealed several previously unreported challenges. Nearly half the women felt isolated and worried, and slightly more than half experienced declines in income because of change in employment; 41% of women felt that support from family and friends decreased over time, and many patients believed information about advanced breast cancer was inadequate and difficult to find. Concerted efforts by people who care for and support women with advanced breast cancer are urgently needed to address these issues.

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## Introduction

Breast cancer is the most frequently reported cancer in women, with an estimated 1.67 million new cases diagnosed worldwide in 2012 [1]. It is also the most common cause of cancer-related death among women, accounting for 522,000 deaths in 2012 [1]. Compared with 2008 statistics [2], the most recent global statistics

(for 2012) reveal a 20% increase in breast cancer incidence and a 14% increase in breast cancer-related deaths [3]. Approximately 5–10% of breast cancers in Western countries are locally advanced or metastatic (collectively termed advanced breast cancer [ABC<sup>1</sup>]) at diagnosis [4], but this number can reach up to 60% in developing countries. The exact number of women with ABC is unknown, and only estimates can be made as most cancer registries record only primary diagnosis and death but not recurrence [5–7]. The true prevalence of ABC is likely to be higher because, even with the best treatment options, about one-third of patients with early breast cancer (EBC) eventually relapse [8].

Improved understanding of the clinical and biologic aspects of ABC has resulted in several recent advances in treatment [9]. However, currently, ABC essentially remains incurable, albeit well treatable [8,10]. The main goals of therapy for ABC are prolonging survival, improving or maintaining quality of life, and symptom control [8]. However, the emotional, social, and spiritual needs of women with ABC often remain unaddressed [11]. The psychosocial challenges faced by these women are also different from those of women with EBC [11,12]. Breast cancer awareness programs and advocacy groups predominantly focus on EBC, with messages about

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<sup>1</sup> ABC, advanced breast cancer; ASCO, American Society of Clinical Oncology; Count Us, Count Us, Know Us, Join Us survey; EBC, early breast cancer; ESMO, European Society for Medical Oncology; HCP, healthcare provider; H&N, Here & Now survey; mBC, metastatic breast cancer; NA, not applicable.

the importance of prevention, early detection, and likelihood of cure [11,12]. The reality of ABC is rarely mentioned [11] and very few programs have been dedicated to address the unique concerns of women with ABC [12]. As a result, these women often feel excluded and isolated [10–12]. Gaps in availability of information and resources, medical and psychosocial support, as well as barriers to enrollment in clinical trials, prevent a holistic approach to ABC management [10,13].

Very few large-scale studies have focused on evaluating the effect of ABC on women and their families. Although previous international surveys (BRIDGE and Silent Voices) and several smaller surveys have provided some insight into the unique needs of women living with ABC [11,12,14,15], information regarding several aspects, such as support needs, effect on relationships, and financial challenges, is still lacking.

Two surveys, the global Count Us, Know Us, Join Us (Count Us) survey and the European Here & Now (H&N) patient and carer (caregiver) survey, aimed to identify challenges faced by women with ABC, assess the real-life effect of ABC, and find new approaches to satisfy the needs of these women. This publication presents key observations from these two surveys regarding the psychosocial and functional effects of ABC; the emotional, support, and information needs of patients and caregivers; and evolution of the patient experience since the previous large-scale surveys. Furthermore, the roles of various stakeholders in the breast cancer community in improving the experience of women with ABC are discussed.

## Methods

### *Count Us survey*

The Count Us survey, which included women with ABC more than 21 years of age, was conducted between October 2012 and March 2013 by Harris Poll on behalf of Novartis Oncology and the global advocacy community. Survey participants self-reported by completing an online questionnaire designed to provide a detailed assessment of their experiences with ABC, especially the effect of the disease on their emotional well-being, relationships, work and home life, and economic situation. The information and support needs of women with ABC were also assessed in the Count Us survey. The survey methodology is presented in greater detail in the [Supplementary Information](#) section.

### *Here & Now patient and caregiver survey*

The H&N survey included women with ABC more than 18 years of age and caregivers for women with ABC. Combined results for patients and caregivers are presented here. Most women were recruited by healthcare providers (HCPs). Consumer recruiters and recruiting agencies assisted in patient recruitment in some countries. In most countries, patients were reimbursed with an incentive or a charitable donation made on their behalf. The H&N survey was commissioned by Novartis Oncology and administered by Insight Research Group (now Cello Health Insight) between November 2012 and September 2013.

Key details of the Count Us and H&N Surveys are outlined in [Table 1](#).

## Results

The survey was initiated by 3072 women, of whom 1495 were disqualified during screening ([Table 2](#)). The remaining 1577 women completed the surveys. Total of 1273 women with ABC in 12 countries worldwide participated in the Count Us survey, whereas

the H&N survey included 304 respondents (158 women and 146 caregivers) from nine European countries. The [Supplementary Information](#) section contains details on the number of respondents by country.

### *Psychosocial effect of ABC*

Results of the Count Us and H&N surveys revealed that women with ABC felt a sense of isolation from society in general and more specifically from the non-ABC community. More than 6 in 10 women said that no one understood what they were going through, and half of the women felt that society viewed them negatively after their ABC diagnosis. More than half found it difficult to find support groups for patients with ABC ([Fig. 1A](#)). Negative emotions dominated the thoughts of women with ABC when asked how they viewed life after their diagnosis. More than half of the women surveyed were worried. More than four in 10 were “living in the moment” or were depressed, and about a quarter admitted that they were simply “surviving.” Fewer than three in 10 women felt strong and were looking forward to life after their ABC diagnosis, with less than a quarter of women feeling hopeful or optimistic about their life ([Fig. 1B](#)).

The sense of isolation and the overall negative feelings about their own lives put a strain on their relationships with their families and friends. Nearly one-third of women reported that relationships with their spouse/partner were negatively affected a lot or a moderate amount by ABC. Similar proportions of women said that their relationships with other family members/friends were also strained because of their disease. Approximately one-quarter of women said their relationships with co-workers were likewise affected ([Fig. 2A](#)). Despite the negative effect of ABC on relationships, most women reported receiving sufficient support from family, friends, and their HCPs. Almost nine in 10 women received support from their family, and a similar proportion received support from their HCPs. Friends were a source of support for almost six in 10 women. However, women received little support from support groups (one in three women) and social services (fewer than one in 10 women) ([Fig. 2B](#)).

The level of satisfaction with the support received from family and society was generally high. Two-thirds of women felt that they received enough support from their spouse/partner. Seven in 10 women were satisfied with the support they received from their children. More than half of the women expressed satisfaction with the support they received from their parents, and more than seven in 10 received enough support from their friends and neighbors ([Fig. 2C](#)). However, four in 10 women felt that the support they received from family and friends was not as strong as when they were first diagnosed with ABC ([Fig. 2D](#)).

### *Functional effect of ABC*

The various challenges associated with living with ABC negatively affected women's employment and income. Nearly half of the women responded that all or most of their managers/supervisors/co-workers knew about their diagnosis, whereas approximately 40% responded “not applicable” to each (presumably because they were not employed; [Fig. 3A](#) and B). Approximately half of the employed women had to change their employment due to ABC ([Fig. 3C](#)), with 41% of them having to give up work temporarily, 34% giving up work altogether, 21% taking days off from work, and 17% reducing work hours ([Fig. 3D](#)). One in 10 women transitioned into a less senior role at work.

Changes in employment adversely affected the income of women with ABC. More than half experienced a decline in income, with the decline being more than 50% for approximately one in 10

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