

Published on Thursday 6 November 2025

First global survey highlights challenges faced by young women with advanced breast cancer

Nearly half have children aged under 18 years, and many experience hardship

Lisbon, Portugal: Nearly half of all women aged younger than 40 who live with advanced breast cancer have children under the age of 18, according to the first global survey to investigate the challenges these women face. Results from the survey were presented to the Advanced Breast Cancer Eighth International Consensus Conference (ABC8) today (Thursday).

Jennifer Merschdorf, chief executive officer of [Young Survival Coalition](#), which conducted the [Project 528 survey](#), told the conference: “We launched Project 528 to fill a critical gap – the voices of young adults living with advanced breast cancer are often under-represented in clinical discussions and policy dialogues.

“For the first time, we now have global data that reflect the voices of young women with advanced breast cancer. This survey gives us the evidence we need to understand their unique challenges and to ensure that research, services and policies are shaped by their lived experiences – not by assumptions.”

Of 3,881 women living in 67 different countries around the world who responded to the survey, 385 were under the age of 40 and living with advanced breast cancer. Results presented today relate to these younger women.

They showed that, in addition to the 48% of women with young children, 64% said their employment had been disrupted after they were diagnosed with advanced breast cancer (ABC), 40% incurred medical debts and their financial security plummeted from 51% before diagnosis, to just 3% after their treatment.

Despite 84% feeling able to ask questions at diagnosis, 40% delayed seeking care, often because their primary care physicians dismissed their concerns, or due to lack of awareness or fear. Only 14% were diagnosed through clinical screening or routine care, while 85% were diagnosed after self-detection of symptoms.

“This highlights gaps in early detection for younger adults,” said Ms Merschdorf.

The burden of ABC extended to all areas of women’s lives. Eighty percent reported psychological distress; body image, fertility and sexual health concerns were widespread but rarely addressed; practical challenges, including childcare, housekeeping and transportation, were common, with many patients reporting unmet needs.

Access to precision diagnostics varied: 90% had genetic testing to see if they had any inherited mutations, yet only 59% had genomic testing of the tumour to see if there were any genetic

mutations in the cancer itself, how active the cancer was and how likely it was to recur. Genomic testing of the tumour gives cancer doctors extra information on which to base treatment decisions, such as chemotherapy, radiotherapy and hormonal therapy.

While 77% understood the reasons for their treatment, 25% lacked clarity and only 46% of young women were offered more than one treatment option. Targeted therapies had the lowest levels of patient understanding. Online communities of women with ABC were a vital source of information and empowerment, but only 43% of patients were referred to these by their care team.

“Our analysis of young women living with ABC underscores a consistent theme,” said Ms Merschdorf. “The current standard of care, while medically advanced, remains deeply fragmented when it comes to the lived realities of younger ABC patients. From diagnosis delays to unmet psychosocial needs, patients face a system that too often demands self-advocacy in the face of fatigue, fear and financial strain.”

Young Survival Coalition plans further studies to explore the unique needs of patients with ABC.

Ms Merschdorf concluded: “Advanced breast cancer poses a complex set of challenges for younger adults, whose experiences with this incurable illness intersects with critical phases of career, parenting and identity development. Project 528 provides a roadmap for researchers to investigate the issues that respondents identified as the most pressing, while also guiding supportive services and advocacy organisations to align their programmes with those needs.

“Beyond research and services, these findings can inform the development of health policies that better reflect and support the lived experiences of young adults facing breast cancer. Ultimately, the goal is for these data to drive meaningful improvements in research, care, and policy that truly serve this community.”

Strengths of this survey include that the respondents were from many different countries and cultural backgrounds, but a limitation is that a significant number of responses came from the USA, which limits its global applicability. Other limitations include: the data were self-reported, which may introduce a potential for recall bias; and the accuracy of information regarding diagnosis details, treatment experiences and timeline of events may vary depending on the women’s memories and the time elapsed since their diagnosis.

Professor Fatima Cardoso, medical oncologist and President of the ABC Global Alliance, said: “This is an important study that shows, for the first time, the experiences of young patients living with advanced breast cancer and the challenges they face in their daily lives. It is concerning that not all of the women in this study were offered tests to see whether or not they had inherited cancer-causing genetic mutations, and to understand the biology of the tumour itself. In an age of precision medicine, all breast cancer patients should have access to these tests as they have a crucial role in treatment decision-making and hence impact on survival and quality of life. I hope that policymakers

will take note of the results of this study and address the many gaps that it highlights in terms of diagnosis, treatment and supportive care, but also psychosocial and financial support.”

ABC is cancer that has spread from the site of the first tumour to other parts of the body. Currently, it is incurable, although treatments can slow the progression of the cancer, often for many years. The prevalence of people living with ABC is unknown (see note below) and has never been quantified in young women.

Christina Thammasen: her story

Christina, 45, lives in California with her spouse and three children. She was diagnosed with breast cancer at the age of 38. She has been living with metastatic breast cancer for over seven years and is doing well on her current treatment. She enjoys reading, exercising, spending time with her family and volunteering in her local community. She is also a Licensed Clinical Social Worker and co-facilitates the [YSC Virtual Hangout](#). Christina is especially passionate about mental health awareness and support for cancer patients.

She said: “There is a distinct line in my life before being diagnosed with advanced breast cancer and my life after. I have worked hard to reclaim my identity as a breast cancer thriver, someone who isn’t just keeping their head above water but is trying to savour every moment of their life. I want to teach my children that even when life is unfair, because it is, you don’t give up, you have to keep fighting, you have to keep moving forward, you have to keep living your life.”

(ends)

[1] **Abstract no: OR36**, ‘Living with Advanced/Metastatic Breast Cancer under 40: global insights into diagnostic delays, treatment gaps, psychosocial burdens, and policy solutions from the project 528 patient experience survey’, by Jennifer Merschdorf and Mary Ajango, in ‘Best abstracts’ session, 15.10-15.55 hrs GMT, Auditorium 1, Thursday 6 November.

Funding: The study was funded by Young Survival Coalition with support from Daiichi-Sankyo, AstraZeneca, Exact Sciences, Lilly, Pfizer and Gilead.

About ABC8 and advanced breast cancer

Around 1,300 participants from approximately 90 countries around the world will join the [Advanced Breast Cancer Eighth International Consensus Conference \(ABC8\)](#), including health professionals and patient advocates.

Advanced breast cancer is defined as cancer that has spread beyond the site of the first (primary) tumour to other sites either within the same breast such as the skin, chest wall and some lymph nodes (locally advanced) or other parts of the body (metastatic cancer). There are no reliable figures for the numbers of women and men living with advanced breast cancer. However, there are over two million new cases of breast cancer a year in the world and 0.7 million deaths. In high-income countries about 10-15% of cases are metastatic at diagnosis, but these figures can reach 80% in low-middle income countries. About 25-30% of breast cancer cases detected early will become metastatic even with the best care, and the average overall survival for these patients is around five years if access is available to the best treatments.