

First in-depth study of secondary breast cancer patients finds current care inadequate

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A qualitative study following the experiences of 10 women living with secondary breast cancer in the UK has identified evidence of poor care for this much overlooked group.

Carried out by the University of Southampton and Breast Cancer Care, and published online in *BMJ Supportive & Palliative Care*, the examination of women between 40 and 78 found their lives to be dominated by trying to manage the disease and treatment.

Whilst [secondary breast cancer](#) patients are surviving longer thanks to better treatments, their problems are becoming more complex.

Around 36,000 women are now estimated to be living with advanced disease in the UK which can be controlled but cannot be cured. Of these, around 12,000 are in the last year of life. Little evidence exists as to the course of metastatic disease and whether current models of palliative care services, presently focused on high levels of support at the end of life, are delivering what these patients need.

The collaborative study, part of a previously published survey of 235 women by Dr Elizabeth Reed for Breast Cancer Care, Professor Jessica Corner of the University of Southampton and funded by leading research charity Breast Cancer Campaign, revealed that patients seemed unsure and unclear as to how to re-enter the healthcare system in contrast to the clear path at the point of primary [breast cancer](#) diagnosis. Even once seen, there was no structured pathway to help ensure they received

appropriate care and support. Breast Cancer Care is campaigning to change this through its Spotlight on Secondary Breast Cancer campaign.

Co- author Dr Liz Reed commented: "We found very few of the women had any access to formal support. There have been great strides in clinical treatment but with little or no support, these patients are faced with a constant cycle of illness, treatment and recovery and particularly for those with more aggressive disease, there was little let-up. They had an uphill struggle in trying to adapt to constant change whilst trying to manage pain in the present and a future reduced life expectancy. "

The way that diagnosis and the future were explained to patients was found to be crucial to how those participating coped. When limitations of treatment were emphasised, this had a significant impact.

Professor Jessica Corner, Dean of Health Sciences, said: "The emphasis on the next treatment seemed to mean that for these patients few had any support services in place until the very end stage of their lives. Few had any established relationship with palliative care services, often managing chronic pain themselves and there seemed little awareness of where to seek information about end of life care."

The study questions the configuration of current [palliative care](#) services when an increasing number of people with metastatic breast cancer may live for years with advanced disease.

Liz Carroll, Breast Cancer Care's Head of Policy and Campaigns said: "We know from our work with this patient group that people living with secondary breast cancer have very specific needs that aren't being met. This qualitative study importantly highlights how progress in treatment is simply failing to keep pace with what patients need. That's why our Spotlight campaign is calling for named support by specially trained professionals for each and every person diagnosed with metastatic

disease."

Katherine Woods, Research Information Manager at Breast Cancer Campaign which funded the study added: "With research leading to new and improved treatments for secondary breast cancer, women are now living longer with the disease than ever before. We need to ensure that they not only have access to the best treatments but that their care and support needs are fully recognised and met, for the remainder of their lives - research like this is a crucial part of developing a gold standard of support for everyone."

More information: [spcare.bmj.com/content/early/2012-07-28/spcare-2012-000415.full](https://spcare.bmj.com/content/early/2012/07/28/spcare-2012-000415.full)

Provided by University of Southampton

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