

A changing identity: A focus group study of the experiences of women diagnosed with secondary breast cancer and their psychosocial support needs.



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Background

Approximately 36,000 women are living with incurable secondary breast cancer in the United Kingdom. With significant advances in its treatment and management, a diagnosis of secondary breast cancer now reflects a chronic potentially long-term condition. Women with this diagnosis have complex and often unmet needs, reporting a higher level of psychological distress compared to that at receiving a primary diagnosis and higher levels of psychosocial morbidity (Breast Cancer Care, 2009; Reed et al. 2010)

Study Design

This focus group study set out to explore how such women make sense of their experience of being diagnosed with secondary breast cancer and to gain understanding of their needs for psychosocial support and information. Data was analysed using thematic analysis. Ethical approval was obtained from the South West Wales NHS REC.

Participants

12 women with secondary breast cancer were recruited from the Breast Care Centre at Singleton Hospital Swansea and participated in one of two focus groups (6 women in each group). The women had secondaries in bone, brain, liver and lung. Ages ranged between 29 & 70 years.

Findings

"I don't want it to be this frightening demon, but its like this big black cloud that hangs over you all the time, you never get away from it".

Living with no cure

"I want to know how much time I've got to tidy my house, before someone says why has mother kept this? Like I did with mine".

The findings indicated the women felt unsupported by the care system in comparison to the levels of support received as primary breast cancer patients. Participants talked about the lack of formal support, the self-stigma experienced as a secondary breast cancer patient, the impact of being informed that their cancer was not curable and the resilience needed to manage an uncertain future. The role of the secondary breast cancer nurse was seen as helping bridge these gaps.

"So I feel that nobody is treating me holistically because you can't separate parts of my body".

A changing identity

"I had loads of support and everything but when we were given to oncology I feel I was treated like a statistic not as a person, and you do feel lost."

A loss of support

"Once you find out they leave you. You don't know nothing about it. You gets told and then you just walk out of there and you think well where do I go from here?"

Conclusions, implications and next steps

- Women with a secondary breast cancer diagnosis need to be assessed regularly for their emotional wellbeing
- A monthly "Breast of Friends" support group was established as a direct consequence of this study, with lead author (AB) becoming Wales' first Secondary Breast Oncology Clinical Nurse Specialist.
- Healthcare professionals in oncology need to be made more aware of effective communication strategies for engaging in difficult conversations surrounding a diagnosis of secondary breast cancer
- The power of the patient voice in driving change and shaping services needs to be better recognised and embedded into the co-design and co-development of future secondary breast cancer services.
- Funding is now being sought to work with secondary breast patients to co-produce a communication skills training intervention with oncology professionals.