

"They... Kept Saying There's Nothing There": British Women's Accounts of Delayed Lobular Breast Cancer Diagnosis



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Lay Summary Objective: To examine the experience of women with lobular breast cancer who had a delayed diagnosis because their cancer was not visible on mammograms.
Methodologies: One to one interviews were carried out with 12 women with a lobular diagnosis and their tumours were not visible on mammograms. The data was analysed using IPA, which focuses on the experience of participants, and themes were generated which conveyed their experience. **Results:** The main themes were the distress of a tumours not being visible on mammogram, delayed diagnosis, the lack of faith in future screening and the importance of charities and support groups to help people advocate for themselves.
What this means for patients: This is the first time that the experience of delayed diagnoses due to inaccurate screening has been researched. More work is needed on education about breast cancer screening for patients and health professionals, as well as psychological support when cancers are not visible.

Introduction and Aim

- Lobular breast cancer is a common cancer accounting for 15% of all breast cancer diagnoses.
- A lack of the protein e-cadherin causes a distinctive linear growth pattern, meaning that tumours rarely form a palpable lump and up to 30% are not identified on mammograms (Porter et al., 2014).
- The effects of false positive screening are well researched and have found that it causes anxiety despite individuals subsequently receiving no diagnosis of breast cancer (Brodersen & Siersma, 2013).
- There is a lack of research on the experience of having a false negative test (receiving a clear screening result when breast cancer is actually present) though it is established that this is a regular occurrence in screening (Ciriello et al., 2015)

The main aim of the present study was to examine the experience of women who had received a clear mammogram shortly before a diagnosis of lobular breast cancer, resulting in a delay in their diagnosis.

Method

- Full ethical approval was granted by De Montfort University.
- Eligible participants were English-speaking, UK-based women who had all received a lobular breast cancer diagnosis, initially missed by mammography screening, 12 months+ prior to their participation. Participants were recruited via social media platforms.
- In-depth, semi-structured interviews were conducted with 12 women (age range= 51-64 years). The questions that formed the interview schedule were discussed with and reviewed by a patient advocate from the charity Lobular Breast Cancer UK prior to data collection.
- Interviews were carried out by two researchers (VR and BL) online via Microsoft Teams and, in most cases, lasted for approx. 50 minutes.
- Interviews were recorded, anonymised, transcribed and later analysed using Interpretative Phenomenological Analysis (Smith et al., 2022), with three interrelated themes were identified.

Findings

Previous Diagnostic Delay and Distress

Lobular breast cancer of many woman was not visible on initial cancer screenings which left several having to push and persevere for a diagnosis over the course of months; repeatedly asking for more tests to assess various symptoms, such as irregular discharge etc.

When individuals finally received a diagnosis, they were immensely shocked by the size and number of lobular tumours that had grown. As a result, multiple woman voiced feelings of anger and disappointment with healthcare staff, who they felt had let them down.

"I had about five mammograms over the next three years [...] and I think I had two ultrasounds, and I had biopsies as well, and they just kept saying there's nothing there" (Louise)

"The bit I'm still most cross about is ... those months of not being listened to... I'm thinking if you've done that [an MRI scan] initially we might have caught this before it had gone everywhere else.. I might have had a better chance" (Debra)

Ongoing Screening Doubts and Future Fears

Due to the failures of initial mammograms to detect their lobular cancer, various woman viewed them as a waste of time and resources as part of their annual check-up and voiced further scepticism and doubt of cancer screening practices more generally.

Moreover, a number of women discussed feelings of chronic anxiety as they feared possible reoccurrence of the lobular breast cancer that might go undetected again for an extended period, and thus threaten their future health and long-term survival.

"I am still called back for annual mammograms... I can honestly see no point at all in turning up religiously—I don't have any faith in the in the [mammogram screening] process... I don't trust it" (Alice)

"I'm... more questioning now... People need to be vigilant for other things [cancer signs and symptoms] and not rely entirely on the screening... I don't think people know that it misses things" (Eva)

Developing Knowledge, Support and Confidence

In view of previous false negatives at screening and limited information provided by care providers, many women sort to educate themselves and provide peer support to others living with lobular breast cancer as part of a budding online lobular patient community.

This community appeared to help women advocate for themselves and others, particularly in navigating the healthcare system and in encouraging the use of Magnetic Resonance Imaging at annual check-up to better check for possible lobular cancer reoccurrence.

"I wasn't given any information [about lobular breast cancer], so I like to do research myself, and so I've joined two lobular breast cancer Facebook sites" (Sally)

"I'm insisting on an MRI [...] because he was saying, "no you can't get an MRI, we have to follow NHS guidelines" and I said, "if you don't approve it then I'm going to have to go further and go and get a second opinion" (Holly)

Discussion and References

- The experience of having a clear mammogram shortly before a lobular breast cancer diagnosis was a difficult experience for the participants**, which had an impact on all aspects of their treatment, particularly trust in mammography as a method of follow-up screening and detection of recurrence.
- Mammogram is currently the standard of care for all of those who have had a diagnosis of breast cancer**, regardless of whether or not their cancer was visible on initial mammograms.
- Clinical implications.** The psychological well-being of individuals who have had false negative screens should be taken into account by health professionals, and should be addressed in the surveillance plans of those affected. There is a strong case that those women whose initial cancers were not visible on mammogram should be offered additional surveillance methods such as MRI (Johnson et al., 2015).
- Future research** should examine the psychological experience of individuals who are later diagnosed with secondary breast cancer after a false negative mammogram. In addition the possibility of liquid biopsies for false negative breast cancers should be explored.