Is there misdiagnosis and/or late diagnosis of metastatic ILC? A quantitative and qualitative patient-reported analysis

M. E. Cody[1], H. C. Chang[2], J. Foldi[3], R. C. Jankowitz[4], M. Balic[3], T. Cushing[5], C. Donnelly[6], S. Freeney[7], J. Levine[8], L. Petitti[9], N. Ryan[10], K. Spencer[11], C. Turner[11], G. C. Tseng[2,12], C. Desmedt[13], S. Oesterreich[14,15], A. V. Lee[14,15,16]

[1]School of Medicine, University of Pittsburgh, Pittsburgh, PA, USA, [2]Biostatistics, University of Pittsburgh, Pittsburgh, PA, USA, [3]UPMC Hillman Cancer Center, University of Pittsburgh Medical Center, Pittsburgh, PA, USA,[4]Abramson Cancer Center, University of Pennsylvania, Philadelphia, PA, USA, [5]Independent Patient Advocate, Boulder, CO, USA, [6]Independent Patient Advocate, Pittsburgh, PA, USA, [7]Non-profit organization, Lobular Ireland, IRELAND, [8]Non-profit organization, Lobular Breast Cancer Alliance, Delaware, DE, [9]Independent Patient Advocate, Los Angeles, CA, USA,[10]Independent Patient Advocate, Portland, ME, USA, [11] Non-profit organization, Lobular Breast Cancer UK, Manchester, UNITED KINGDOM, [12]Computational & Systems Biology, University of Pittsburgh School of Public Health, Pittsburgh, PA, USA, [13]Laboratory for Translational Breast Cancer Research, Department of Oncology, KU Leuven, BELGIUM, [14]Women's Cancer Research Center UPMC Hillman Cancer Center and Magee Women's Research Institute, University of Pittsburgh Medical Center, Pittsburgh, PA, USA,[15]Department of Pharmacology and Chemical Biology, University of Pittsburgh School of Medicine, Pittsburgh, PA, USA, [16]Institute for Precision Medicine, University of Pittsburgh and UPMC, Pittsburgh, PA, USA.

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Abstract

Given its unique tumor biology, invasive lobular carcinoma (ILC) can be difficult to detect and diagnose, especially when it spreads to distant sites within the body. Given the limitations in accurate and timely diagnosis of metastatic ILC (mILC), we developed a patient survey to:

1. Assess the prevalence and impact of misdiagnosis or delays in patients with mILC.
2. Use the findings from this self-report data to inform strategies to improve earlier detection and treatment.

Survey results revealed patients were diagnosed as de novo mILC, often misdiagnosed initially, leading to unnecessary treatments, and waited up to one year or longer for an accurate diagnosis.

Introduction

- ILC is the second most common special subtype of breast cancer (BC) in women.
- ILC's diffuse growth pattern makes it harder to detect with standard imaging, and mILC often has low glucose uptake, reducing sensitivity to FDG-PET scans.
- mILC frequently metastasizes to unusual sites that may remain undetected for long periods (Figure 1).
- These atypical metastatic sites and nonspecific symptoms often cause late or incorrect diagnoses, delaying effective treatment.

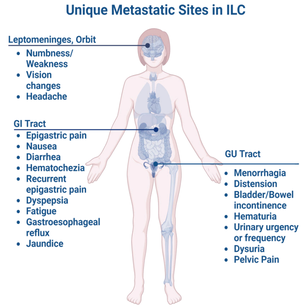


Figure 1. *Metastatic sites in ILC.*

Methods and Materials

1. A 45-question survey, reviewed by breast cancer researchers, oncologists, and patient advocates, was developed.
2. The IRB-approved survey was sent to patients with mILC using numerous distribution channels (Figure 2).
3. Data were cleaned to remove incomplete or inconsistent responses. Analyses in R used descriptive statistics, and summary statistics were stratified by four common mILC metastatic sites (Gastrointestinal (GI), Genitourinary (GU), Neurology, Hematology) to identify subgroup patterns.

Figure 2*. ILC patient survey distribution methods.*

Results

- Of the 520 total responses, 321 patients had mILC (61.7%). Of those with mILC, 33.3% were diagnosed as de novo mILC, 26.2% reported misdiagnosis, 31% reported ≥2 misdiagnoses, and 42.9% reported symptoms before diagnosis (Figure 3).
- 44.5% of the mILC patients waited ≥1 year for an accurate diagnosis, with inconclusive imaging and low provider awareness as major delay factors (Figure 4).

Figure 3*. Patient survey demographics.*

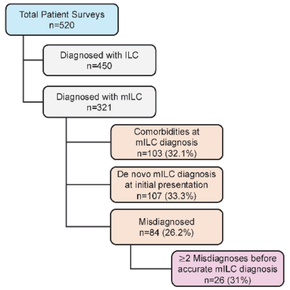
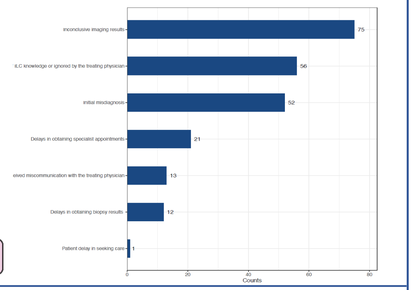


Figure 4*. Patient-reported reasons for the delay in accurate diagnosis.*



- 38% of patients underwent unnecessary treatments; 6 patients received unnecessary cancer treatments (Figure 5).
- 40% had mammography during initial misdiagnosis work-up, which detected ILC in only 20.5% of cases, and only 5 (25%) of 20 de novo mILC (Figure 6).

Figure 5. *Types of Treatment Misdiagnosed Patients Received.*

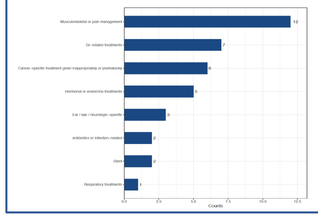
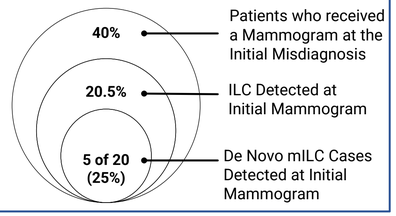


Figure 6. *Mammographic Findings for Patients Initially Misdiagnosed.*



Discussion

1. ILC exhibits a unique pattern of metastatic invasion, causing misleading symptoms, such as bowel obstruction or abdominal bloating, that are not typically associated with breast cancer.
2. In our survey, 138 (42.9%) of the 321 patients with mILC reported experiencing symptoms before diagnosis (Figure 7).
3. Vague symptoms like persistent abdominal pain, bloating, or changes in bowel habits should prompt additional diagnostic testing for mILC.
4. Addressing delays and diagnostic errors in mILC, along with improving provider education and knowledge of the disease, is critical to optimizing treatment strategies and improving patient outcomes.

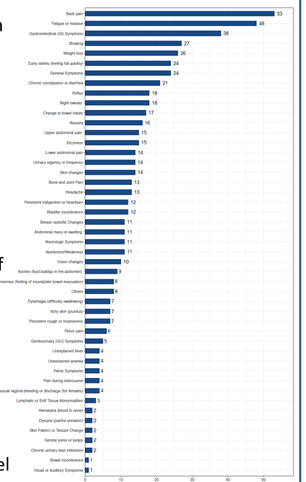


Figure 7. *Most common patient-reported symptoms before diagnosis.*

Conclusions

Patient-reported survey results underscore the need to address delays and diagnostic errors in mILC to optimize treatment strategies and improve patient outcomes.

Contact:
Morgan Elizabeth Cody, MS3, School of Medicine, University of Pittsburgh
Email: cody.morgan@medstudent.pitt.edu

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