

BREAST CANCER SUBTYPES: A PATIENT SURVEY WITH A SPECIAL FOCUS ON LOBULAR BREAST CANCER

Gueroult-Accolas Laure, Coutier Claude, Borval Hélène, Dolbeault Sylvie, Bouleuc Carole, Cottu Paul, Vincent-Salomon Anne, Leygues Jessica, Bredart Anne, Grandin Jonathan

BACKGROUND

Despite representing 15% of all breast cancers, invasive lobular breast cancer (ILC) remains unknown to the general public. It differs from other types of breast cancer in terms of its biological characteristics and metastatic profile, with no specific treatment implications identified to date. Due to its special characteristics, the diagnosis and the subsequent course of treatment can happen to be particularly distressing for the patient.

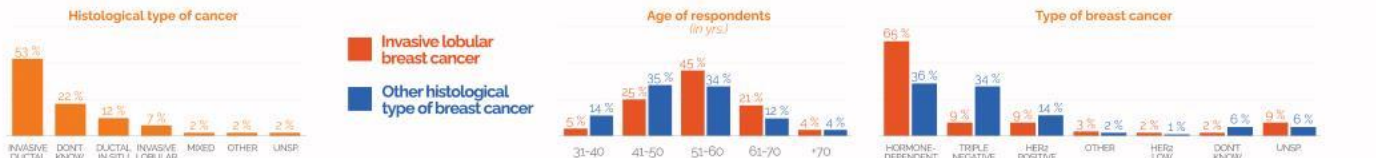
METHODS

A survey was proposed to patients with various types of breast cancer with two primary objectives: first, to ascertain the respondents' knowledge of the different phenotypes and histological types; second, to determine their perception of the impact of their disease on their daily lives and to identify their information needs. A comparative analysis was conducted between the 'lobular cancer' subgroup and the remainder of the survey population.

The anonymous online survey was conducted in June 2024 by two patient associations, 'Patients en Réseau' via its 'Mon Réseau Cancer du Sein' platform and 'Collectif Triplettes Roses' via their private and public social networks. The questionnaire, developed by a multidisciplinary team comprising patient advocates (The ELBCC, Patients en Réseau, Collectif Triplettes Roses), clinicians, and researchers, consisted of 23 questions investigating the knowledge of breast cancer, one's own diagnosis, and patient needs.

RESULTS

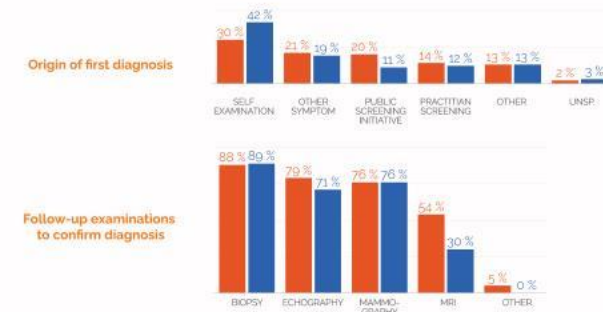
RESPONDENTS PROFILE



A total of 1,220 individuals (779% of the 1,568 total accesses to the survey page) provided a response, of which 1,193 were deemed usable. 6.6% of the respondents indicated that they were undergoing treatment for ILC, while 2.3% reported a diagnosis of mixed cancer (i.e. **107 patients in orange** versus **1,086 individuals in blue** with a different type of breast cancer).

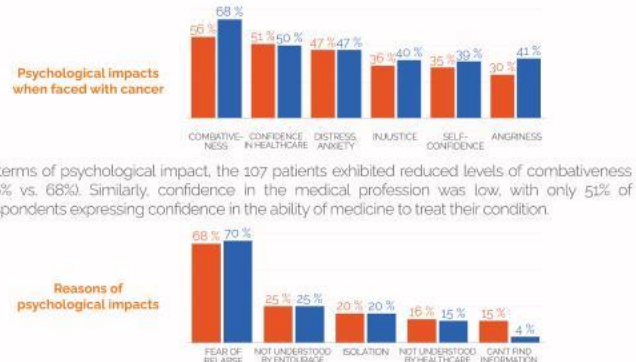
Among these 107 ILC patients 45% were between 51 and 60 years old, while 43% had been diagnosed with breast cancer for less than two years. 65% of the patients had hormone-dependent cancer, 42% had lymph node involvement, and 16% had metastasis to another organ.

DIAGNOSIS



Similar to other forms of breast cancer, ILC is initially identified through self-examination in approximately 30% of cases. However, the diagnosis is more often substantiated by magnetic resonance imaging (MRI), with a higher proportion of cases (54% vs. 30%) undergoing this confirmation method. Thirteen patients (42% vs. 18%) reported longer waiting times for treatment due to the necessity of additional diagnostic procedures.

PSYCHOLOGICAL IMPACTS

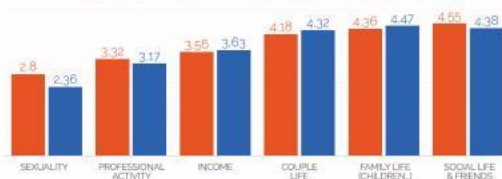


In terms of psychological impact, the 107 patients exhibited reduced levels of combativeness (56% vs. 68%). Similarly, confidence in the medical profession was low, with only 51% of respondents expressing confidence in the ability of medicine to treat their condition.

A total of 15% of the 107 patients surveyed indicated that they encountered difficulties in locating sufficient information about their cancer in French, a proportion significantly higher than the 4% observed among all respondents.

NEGATIVE IMPACTS OF ILC

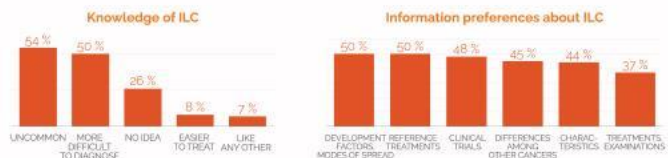
Daily-life impacts of cancer (most negative impact: 0, no impact: 5)



As with other types of breast cancer, the most negative impact reported by these 107 patients was related to sexuality, followed by professional activity and loss of income.

KNOWLEDGE & INFORMATION PREFERENCES

While these patients indicated that they had a good understanding of their ILC, only 7% of them felt that it was a breast cancer "like any other" and only 43% claimed to know which organs were most frequently affected by metastases.



To enhance their understanding of ILC, respondents indicated a preference for information on its development factors and modes of spread (50%), reference treatments (50%), and clinical trials (48%).

DISCUSSION

Although the survey's representativeness is limited due to its reliance on patient advocate's group social network data, the findings highlight areas for improvement in medical information on lobular cancers. The therapeutic and psychological burden associated with lobular cancers is comparable to that observed in other breast cancer subtypes.

BIBLIOGRAPHY

Wilson N, Ironside A, Diana A, Oikonomidou O. *Lobular breast cancer: a review*. Front Oncol. 2021;10:591399.

Pate L, Desmedt C, Metzger O, Burgess Hutcheson L, Turner C, Freney S, et al. *How Researchers, Clinicians and Patient Advocates Can Accelerate Lobular Breast Cancer Research*. Cancers (Basel). 2021;13(13).