

Understanding Cholangiocarcinoma—perspectives from three European advocacy groups

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Cholangiocarcinoma (CCA; bile duct cancer), one of the biliary tract cancers, is a complex and challenging type of cancer. In the Western world, most cases are sporadic, they occur without a known cause or identifiable risk factors. In other parts of the world, particularly Southeast Asia, the majority of cases are liver fluke induced.¹

CCA, the second most common primary liver cancer globally, is increasingly diagnosed in working age adults. Despite advancements in cancer care, CCA remains one of the deadliest cancers. The 5-year survival rate is just 6–9% in the UK² and approximately 15% in Spain³ and Italy⁴, in stark contrast to the average 5-year survival rates for all cancers, which stand at 54% in England, 55.3% for men and 61.7% in women in Spain and 59% for men and 64% for women in Italy. Early diagnosis is crucial, as late-stage diagnosis often rules out liver resection, the only potential curative treatment. Low awareness of CCA among primary care providers leads to missed early diagnosis opportunities. Additionally, the lack of standardized screening guidelines for CCA further delays diagnosis and limits access to potentially curative treatments.

For those diagnosed with an inoperable CCA increasing treatment options can help control symptoms, delay cancer progression and, in some cases, make resection possible after reassessment. Each CCA patient should have their case reviewed by a specialist Multidisciplinary Team (MDT) with knowledge and experience, including understanding the growing importance of molecular profiling. In this way, each patient will have access to the most appropriate and current treatments and clinical trials⁵ in the timeliest way possible.

AMMF maintains an up-to-date list of clinical trials currently open and recruiting in the UK, along with

several in Europe, including the pivotal first-line SAFIR ABC-10 study. In Spain, numerous clinical trials involving new drugs and innovative therapeutic strategies are expected to be open, in progress, or under follow-up.

Those with CCA face many challenges and unmet needs, across the UK^{6,7} and Europe, with geographic disparities exacerbating these. In rural areas and smaller hospitals, especially in some areas in Spain and Southern Italy, access to advanced diagnostic tools and specialized care is often delayed. For many patients, receiving care at tertiary centers, often located in major cities, requires extensive travel, adding financial and logistical burdens for patients and their families. All CCA patients should have access to clinical nurse specialists, nutritional and psychological support, and patient groups. A dedicated clinical nurse specialist should guide patients throughout their treatment, offering advice before, during, and after. Physicians should encourage patients and families to join reputable support groups and connect with relevant agencies. Psychooncology services, counseling, and peer support can help manage fear, anxiety, and depression, and should be integrated into treatment plans for comprehensive care.

Sonia Carreras, a patient from Spain, shares: “When you start this journey, fear takes over due to the grim prognosis. No one prepares us for the uncertainty, and medicine doesn’t have all the answers. Living in the present and sharing the path with others brings relief. Hope is the only thing we truly own.” Her story highlights the emotional toll of CCA and the importance of support networks for patients and families.

Across the world, patient organizations such as the Cholangiocarcinoma Foundation in the US, AMMF in the UK, APiC in Italy, Cholangiocarcinoma Australia, and ATUVIBI in Spain are vital in offering community support, accurate information, and advocacy. These organizations can also alleviate feelings of isolation by connecting patients with others who share similar experiences. Kevin Rodger, diagnosed with CCA aged 44, comments on the help AMMF offered him: “AMMF is a gateway to specialists, clinical trials and to others in the same situation. All of a sudden, I had the confidence to challenge the opinion of local doctors who had little experience with this cancer and who appeared to have written me off. I’m now under one of the best medical



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Panel 1: Recommendations

From patient groups AMMF, APiC and ATUVIBI, adapted from The BSG (British Society of Gastroenterology) Guidelines for the Diagnosis and Management of Cholangiocarcinoma.⁸

- 1 At the earliest opportunity, each CCA patient should have their case reviewed by a specialist Multidisciplinary Team (MDT) with knowledge and expertise in CCA.
- 2 Develop standardized screening protocols and increase awareness among general practitioners to reduce diagnostic delays.
- 3 Molecular profiling should be conducted at the earliest opportunity for all patients diagnosed with CCA.
- 4 All patients with incurable CCA should have access to a comprehensive palliative care assessment to evaluate their holistic care needs.
- 5 Investment in clinical trials is critical to evaluate the pharmacological management of symptoms and the effectiveness of different models of care for CCA patients.
- 6 All patients diagnosed with CCA should have access to a hepatobiliary cancer nurse specialist.
- 7 Ensure all patients have access to dietitians and tailored exercise programs to improve physical well-being.
- 8 Incorporate psycho-oncology services, counselling, and peer support groups into standard care plans.
- 9 Timely access to high-quality information should be guaranteed for all CCA patients.
- 10 Patients should have the opportunity to seek a second specialist clinical opinion to gain reassurance about their diagnosis or treatment options.

teams in the UK, I have a treatment plan and the cancer is retreating.”

Blerita Sylá, whose father was diagnosed with CCA, sought help from APiC. A year later, she ran for its Executive Committee, declaring: “I would do anything for APiC.”

The guidelines on the use of diagnosis and treatment methods should be addressed at a European, UK, and global level by negotiating with pharmaceutical companies for the availability of drugs, as seen with COVID-19, yielding benefits in research and treatment costs. Drug approval times must be shortened, prioritizing patient needs.

Despite the European Medicines Agency (EMA) approval, patients in countries like Spain and Italy experience significantly longer wait times than other European countries before these treatments are reimbursed and made accessible to them. Addressing these delays is critical for ensuring equitable access for all patients.

As patient group representatives, we stress the need for faster access to innovative drugs during the experimental phase for those with serious diseases. Agnostic drug trials must be more agile, targeting multiple tumors and earlier treatment lines, especially for patients with limited life expectancy.

This piece, on behalf of European patient organizations, calls for improved treatment access, amplifying patient voices to enhance outcomes.

Contributors

The first drafts were written by EB, HM, and PL, based on ideas jointly developed by all three. Each of the three authors contributed to the editing and approved the final version.

Declaration of interests

We declare no competing interests.

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