

Global Patient Interviews Exploring the Journey from Symptoms to Diagnosis and Treatment Initiation in Biliary Tract Cancer

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Background

- Biliary tract cancers (BTCs) are a fast paced and diverse group of gastrointestinal cancers.¹
- BTC has shown a significant rise in both global incidence and mortality rates in recent years.²
- Diagnosis is frequently delayed because of non-specific symptoms, differences in how the condition presents, rarity of occurrence, lack of routine screening tests, and complex diagnostic approaches.^{1,3}

Objective

To describe the patient journey from initial symptom presentation through to diagnosis and treatment initiation for BTC with a particular focus on the barriers and challenges that contribute to delays along the pathway.

Methodology

61 qualitative semi-structured 60 minute remotely-conducted interviews by phone or video with patients from 5 countries world-wide from July 2025-March 2026. Because people volunteered to take part in the interviews, the findings may not reflect everyone's experience.



Table 1. Characteristics of the Study Population

Demographics and Clinical Characteristics	Overall N = 61
Age at diagnosis, years	
Mean ± SD	54.7 ± 11.0
Gender, n (%)	
Female	38 (62.3%)
Race/ethnicity, n (%)	
White or Caucasian	44 (72.1%)
Asian or Pacific Islander	9 (14.8%)
Black or African	3 (4.9%)
Latino or Hispanic	2 (3.3%)
Prefer not to answer	3 (4.9%)
Geographic setting, n (%)	
Urban	25 (41.0%)
Suburban	27 (44.3%)
Rural	9 (14.8%)
Health insurance status/provision, n (%)	
Private	28 (45.9%)
Public	33 (54.1%)
Patient-reported time since diagnosis, months	
Mean ± SD	26.9 ± 26.0
BTC stage at diagnosis, n (%)	
Early	32 (52.5%)
Late	29 (47.5%)
BTC subtype, n (%)	
iCCA – Intrahepatic cholangiocarcinoma	30 (49.2%)
eCCA – Extrahepatic cholangiocarcinoma	20 (32.8%)
GC – Gallbladder cancer	7 (11.5%)
Unknown	4 (6.6%)



Initial Presentation and Symptoms

Most patients experienced no symptoms or vague, non-specific symptoms easily mistaken for less serious conditions, delaying recognition and help-seeking.

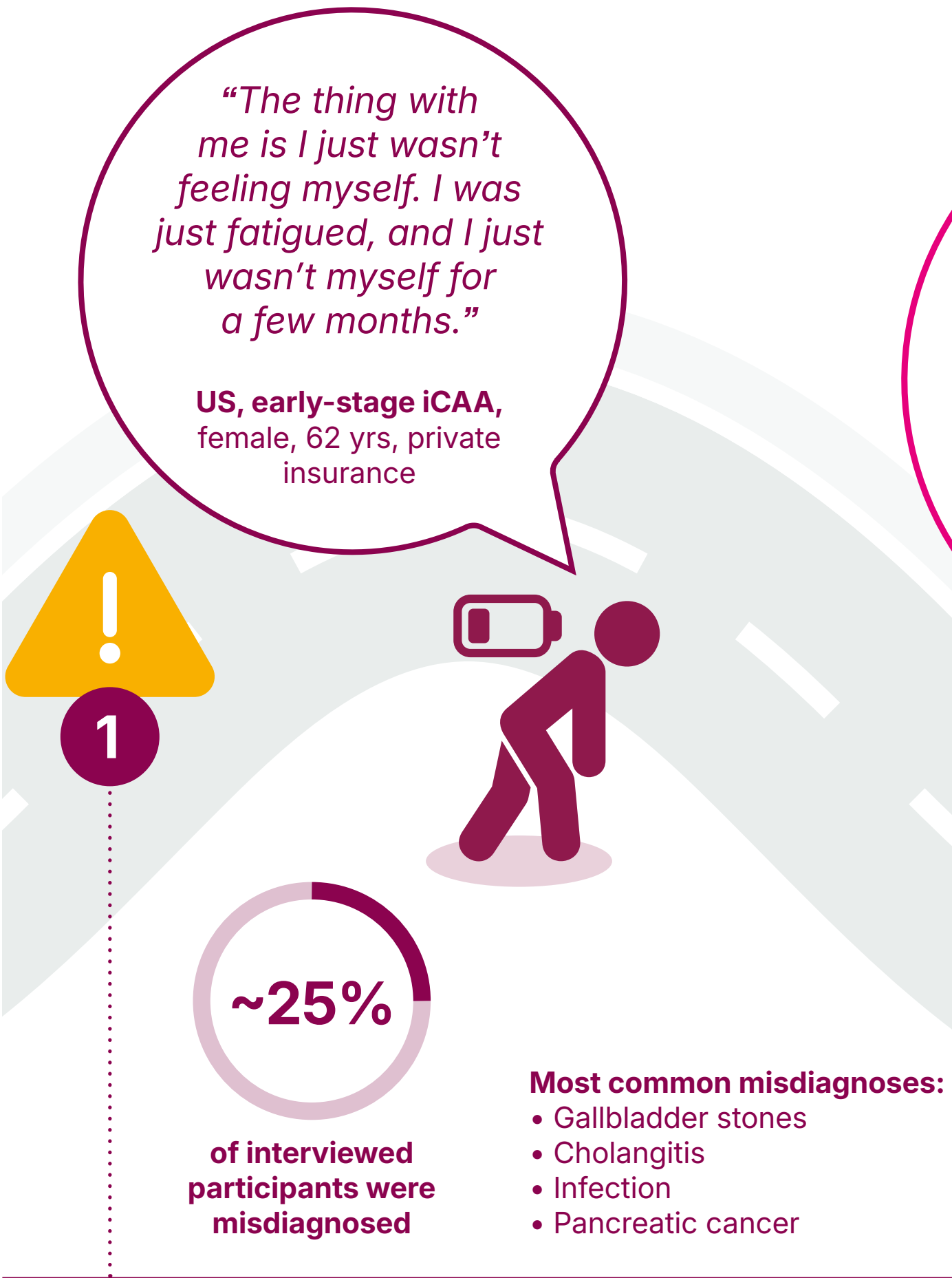


Table 2. The most common three reported symptoms at initial presentation

Symptoms	Overall N=61	US N=22	Canada N=14	UK N=5	Germany N=12	Japan N=8
Gastrointestinal issues	22 (36.1%)	6 (27.3%)	9 (64.3%)	3 (60.0%)	4 (33.3%)	0 (0.0%)
Abdominal pain or pressure	21 (34.4%)	5 (22.7%)	4 (28.6%)	3 (60.0%)	6 (50.0%)	3 (37.5%)
Jaundice	15 (24.6%)	2 (9.1%)	5 (35.7%)	1 (20.0%)	5 (41.7%)	2 (25.0%)

Seeking Care

Delayed presentation was common. Action was typically prompted by worsening symptoms, family encouragement or found by chance during routine check-ups.

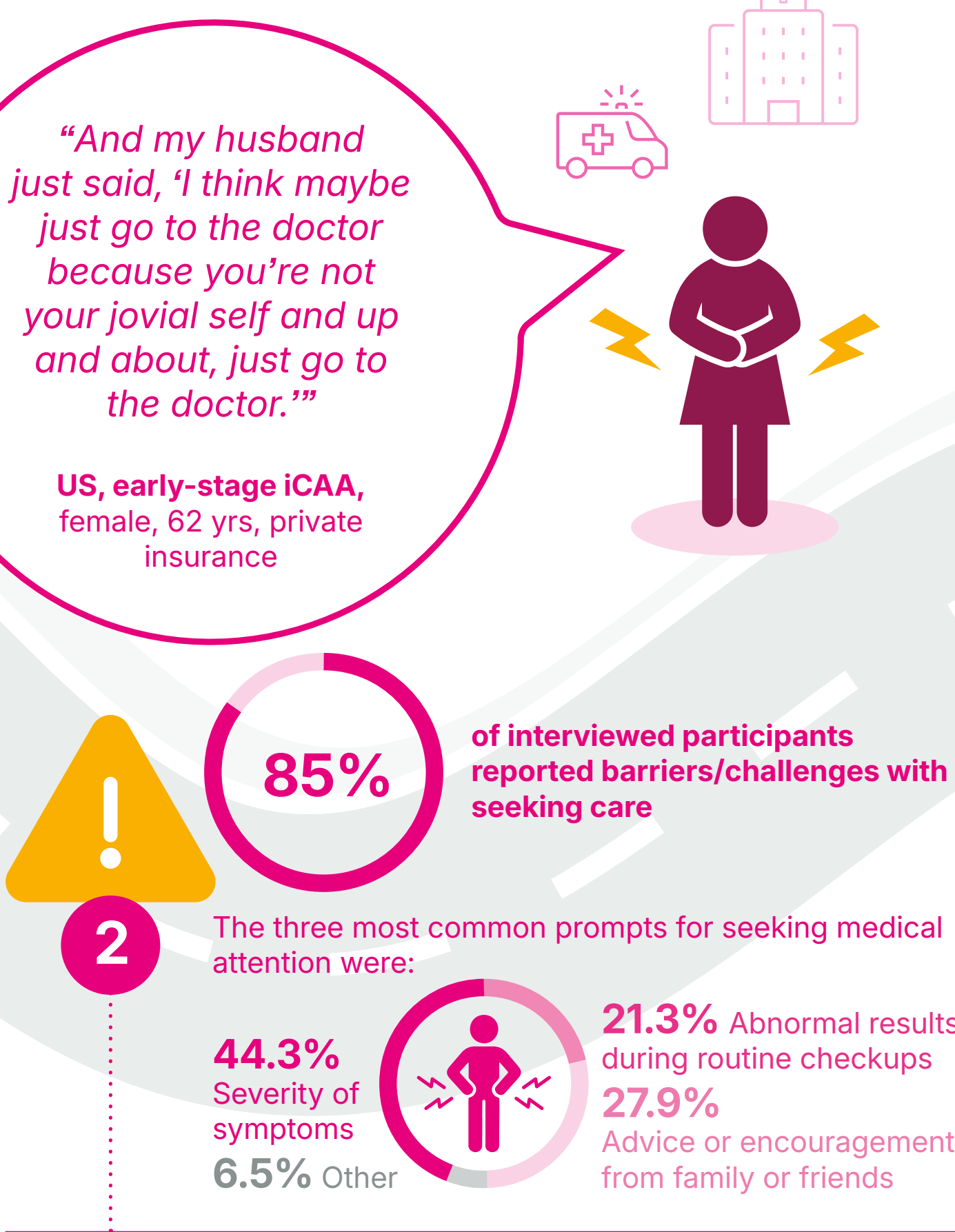


Table 3. The most common three reported barriers / challenges in seeking care

Barriers / Challenges	Overall N=61	US N=22	Canada N=14	UK N=5	Germany N=12	Japan N=8
Patients perceive symptoms as less serious	21 (34.4%)	6 (27.3%)	5 (35.7%)	2 (40.0%)	5 (41.7%)	3 (37.5%)
Patients are asymptomatic	13 (21.3%)	7 (31.8%)	1 (7.1%)	1 (20.0%)	1 (8.3%)	3 (37.5%)
Time-related burden*	12 (19.7%)	5 (22.7%)	3 (21.4%)	0 (0.0%)	1 (8.3%)	3 (37.5%)

(e.g., long travel time, anticipated wait times, or competing work obligations)

Receiving Care

Patients described a complex journey involving multiple appointments across several providers. Most reported at least three visits – spanning GPs, gastroenterologists and oncologists – before reaching the appropriate primary care physician or a specialist.

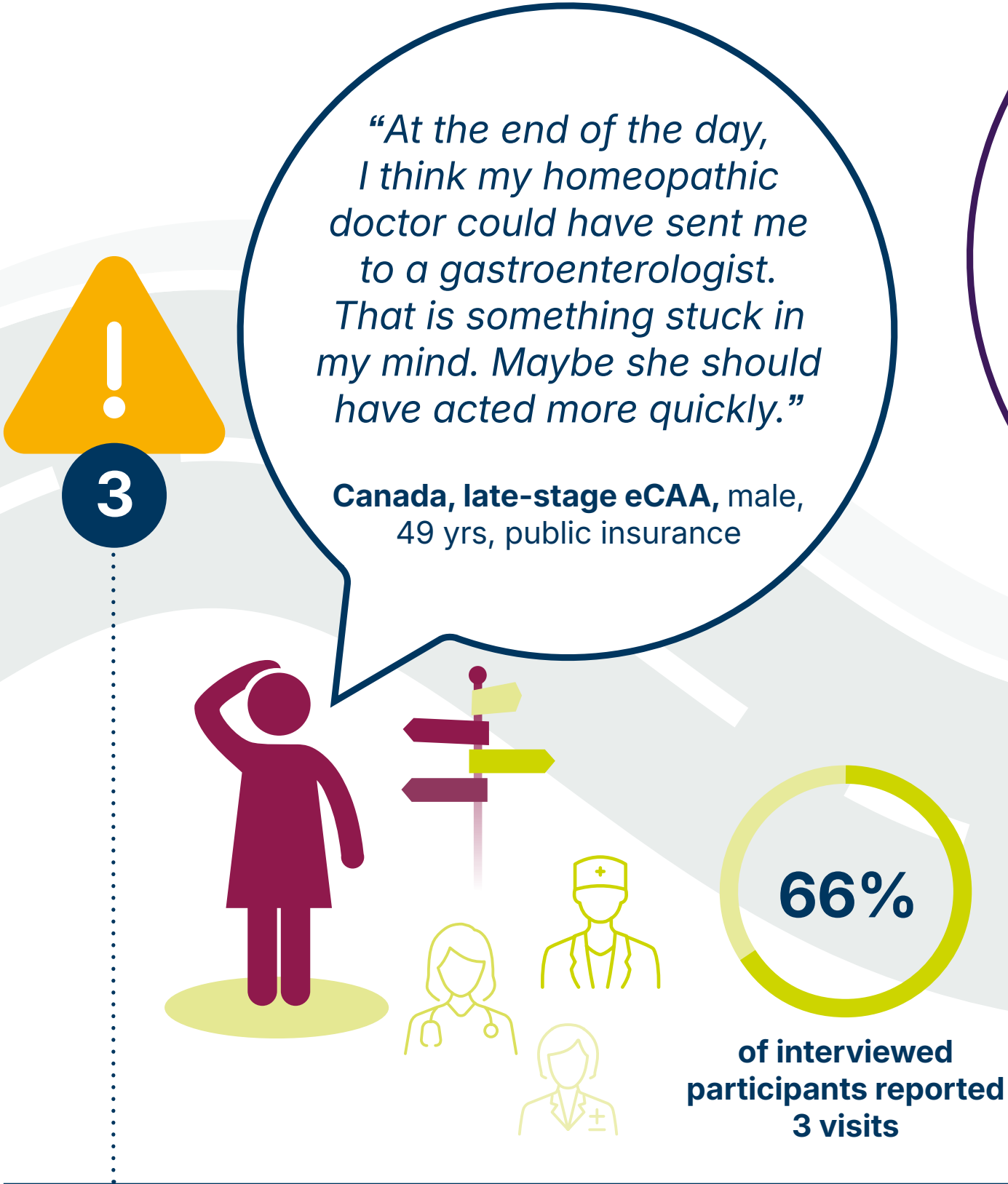


Table 4. The most common three reported barriers / challenges in receiving care

Barriers / Challenges	Overall N=61	US N=22	Canada N=14	UK N=5	Germany N=12	Japan N=8
Long wait times	24 (39.3%)	6 (27.3%)	8 (57.1%)	4 (80.0%)	5 (41.7%)	1 (12.5%)
Providers dismissing concerns*	13 (21.3%)	3 (13.6%)	4 (28.6%)	2 (40.0%)	3 (25.0%)	1 (12.5%)
Lack of care coordination	4 (6.6%)	0 (0.0%)	3 (21.4%)	1 (20.0%)	0 (0.0%)	0 (0.0%)

*not responding with urgency

Diagnostic Testing

Nearly all patients underwent multimodal diagnostic workups combining imaging (MRI, PET, CT), laboratory tests and biopsy. Pathways were frequently lengthy and involved repeated procedures.

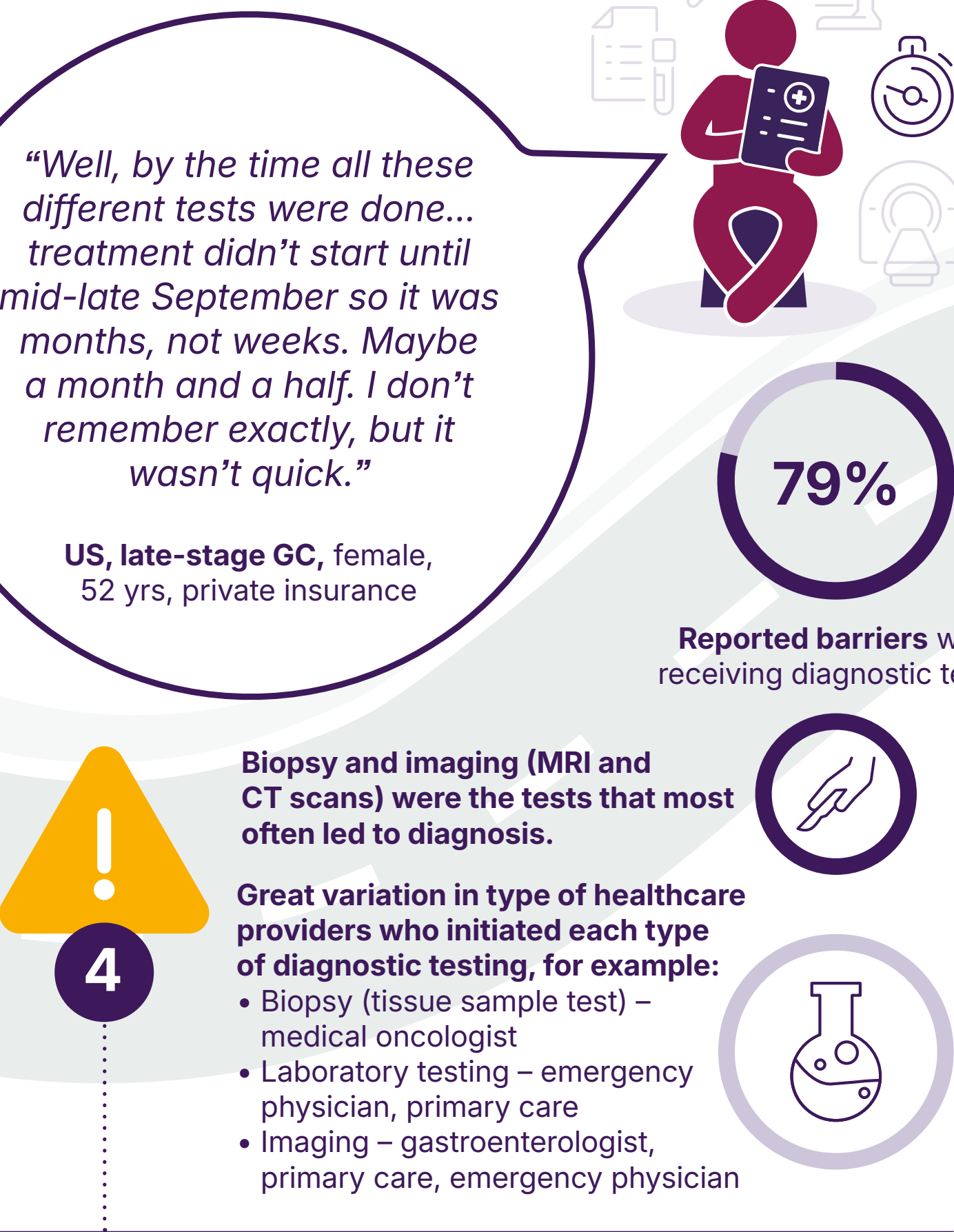


Table 5. The most common three reported barriers / challenges in diagnostic testing

Barriers / Challenges	Overall N=61	US N=22	Canada N=14	UK N=5	Germany N=12	Japan N=8
Physical discomfort or pain during testing	18 (29.5%)	6 (27.3%)	5 (35.7%)	0 (0.0%)	4 (33.3%)	3 (37.5%)
Long wait times	17 (27.9%)	3 (13.6%)	6 (42.9%)	2 (40.0%)	4 (33.3%)	2 (25.0%)
Scheduling or referral difficulties	7 (11.5%)	1 (4.5%)	4 (28.6%)	0 (0.0%)	1 (8.3%)	1 (12.5%)

Treatment Initiation

Diagnosis was typically delivered by a medical oncologist or surgeon, often with family present, and while many patients appreciated clear, direct communication and received support information, others reported emotional distress, difficulty processing information, or dissatisfaction with how diagnosis was conveyed.

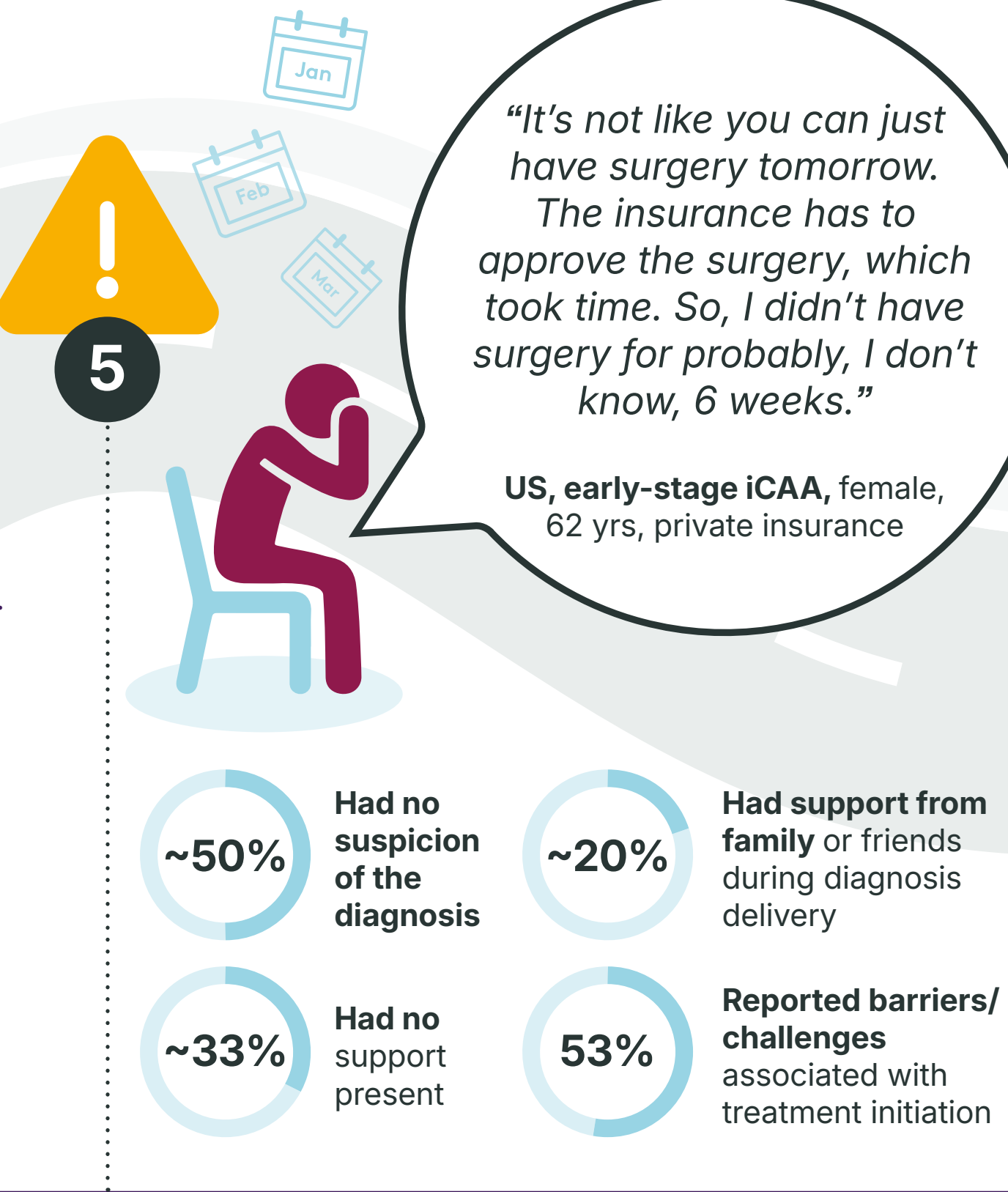


Table 6. The most common three reported barriers / challenges in treatment initiation

Barriers / Challenges	Overall N=61	US N=22	Canada N=14	UK N=5	Germany N=12	Japan N=8
Difficulty scheduling appointments	8 (13.1%)	2 (9.1%)	2 (14.3%)	1 (20.0%)	2 (16.7%)	1 (12.5%)
Delay due to post-surgical complications	6 (9.8%)	0 (0.0%)	4 (28.6%)	0 (0.0%)	1 (8.3%)	1 (12.5%)
Fear or anxiety about starting treatment	4 (6.6%)	4 (18.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Calls to Action 5 actions with potential to improve timely BTC diagnosis

- 1 Raising awareness of BTC symptoms
- 2 Supporting earlier recognition of BTC in primary care
- 3 Reducing waiting times and improving co-ordination or referrals
- 4 Streamlining diagnostic pathways
- 5 Improving holistic support at diagnosis

Conclusion

People with BTC often experience a range of barriers and challenges throughout their diagnostic journey, some of which can lead to delays in receiving a diagnosis.

Across countries, patients reported similar challenges. At initial disease presentation and when first seeking care, symptoms are often vague and not recognised or associated with BTC by either patients or healthcare providers, and are frequently misattributed to more common, benign conditions.

After seeking care, patients encountered a range of healthcare system related barriers and challenges, including difficulty securing appointments, long waiting times, and delays in referrals or test scheduling. These issues were reported more often in countries with publicly funded healthcare systems.

Alongside these system-level challenges, patients also described interpersonal and procedural difficulties. Some felt dismissed by healthcare professionals, while others experienced poor coordination between

services, adding complexity to navigating the diagnostic process. Patients also reported challenges with diagnostic procedures, including discomfort and the need for repeated tests.

Many patients described a sense of losing control during their journey, particularly due to unclear communication and a lack of coordination. In some cases, starting treatment was delayed due to logistical factors such as appointment availability and recovery from procedures. Emotional factors, including anxiety about treatment, also contributed to delays for some patients.

Overall, the findings highlight the need to improve awareness of early symptoms, support earlier help-seeking, and address barriers across the diagnostic pathway. Improving access to care, streamlining referrals and diagnostic processes, and providing more coordinated, patient-centred support could help people receive a diagnosis and start treatment sooner.

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Susanne Radke, Young Jung, and Mufiza Farid-Kapadia are employees and stock owners of AstraZeneca. Jennifer Knox received consulting fees from AstraZeneca, Incyte, Ipsen, Roche, and Astellas. Raphael Mohr did not receive a consultation fee for this study. Maral DerSarkissian is an employee of Analysis Group, a consulting company that received funding from AstraZeneca to conduct this study.

References

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*MRI stands for Magnetic Resonance Imaging – a scan that uses magnetic fields and radio waves to create detailed images of the body's organs and tissues. PET stands for Positron Emission Tomography – a scan that uses a small amount of radioactive tracer to show how tissues and organs are functioning, often used to detect cancer activity and metabolism. CT stands for Computed Tomography - a scan that uses X-rays and computer processing to produce cross-sectional images of the body.

