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

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Objective

- **The objective of this study was to describe the journey from initial symptom presentation to diagnosis and initiation of treatment for biliary tract cancer (BTC) from the patients' perspective, focusing on barriers and challenges across the US, Canada, UK, Germany, and Japan**

Introduction

- Biliary tract cancers are a highly aggressive and heterogeneous group of gastrointestinal cancers associated with long diagnostic delays, poor prognosis due to late-stage diagnosis, and limited curative treatment options,[1-3] with a notable rise in global incidence and mortality rates in recent years[4]
- Diagnosis is frequently delayed because of non-specific symptoms, clinical heterogeneity, rarity of occurrence, lack of routine screening tests, and complex diagnostic approaches[1,2]
- Qualitative interviews uniquely capture patients' lived experiences and provide depth of understanding often missed by quantitative methods
- Mapping the diagnostic journey and identifying barriers can inform targeted interventions to improve early detection, patient outcomes, and healthcare delivery

Methods

Study Design

- Qualitative semi-structured 60-minute interviews were remotely conducted from July 2025 to March 2026 with 61 adults diagnosed with early- or late-stage BTC across five countries: US (n=22), Canada (n=14), Germany (n=12), Japan (n=8), and UK (n=5)
- Patients were recruited through patient organization networks and patient panels
- Ethics approval for this study was obtained in each country per requirements for research, and patient informed consent was obtained before all interviews

Study Population

- Adult patients (age ≥18 years) with self-reported diagnosis of BTC who resided in a country of interest, were fluent in the language in which the interview was conducted, and were **not** diagnosed with another cancer on or before BTC diagnosis
- Recruitment was stratified to include a higher proportion of early stage BTC patients than the real-world distribution of BTC, to ensure insights from these patients' diagnostic journeys were captured meaningfully

Approach

- A semi-structured interview guide containing open-ended questions and concept elicitation methods was used by an experienced interviewer to explore different domains of the patients' diagnostic journey, including: initial disease presentation, seeking care to diagnosis, healthcare encounters, diagnostic testing, diagnostic delivery, and transition to treatment
- Inductive and deductive coding was applied by two independent reviewers to identify overarching themes
- Quantitative demographic data were descriptively summarized

Results

Characteristics of the Study Population

- N=61 adult patients with BTC participated in this study, with mean age of 54 years; the majority were female (62%) and White (72%)
- At the time of interview, the mean patient-reported time since diagnosis was 27 months, with 52% of patients diagnosed at early stage and 48% at late stage
- iCCA was the most common BTC subtype reported (49%), followed by eCCA (33%) and GC (12%)

Table 1. Characteristics of the Study Population

Demographics and Clinical Characteristics	Overall N=61
Age at diagnosis, years	
Median [IQR]	55.1 [49.3, 62.0]
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	
Median [IQR]	20.5 [8.7, 37.9]
Mean ± SD	26.9 ± 26.0
BTC stage at diagnosis, n (%)	
Early	32 (52.5%)
Late	29 (47.5%)
BTC subtype, n (%)	
iCCA	30 (49.2%)
eCCA	20 (32.8%)
GC	7 (11.5%)
Unknown	4 (6.6%)

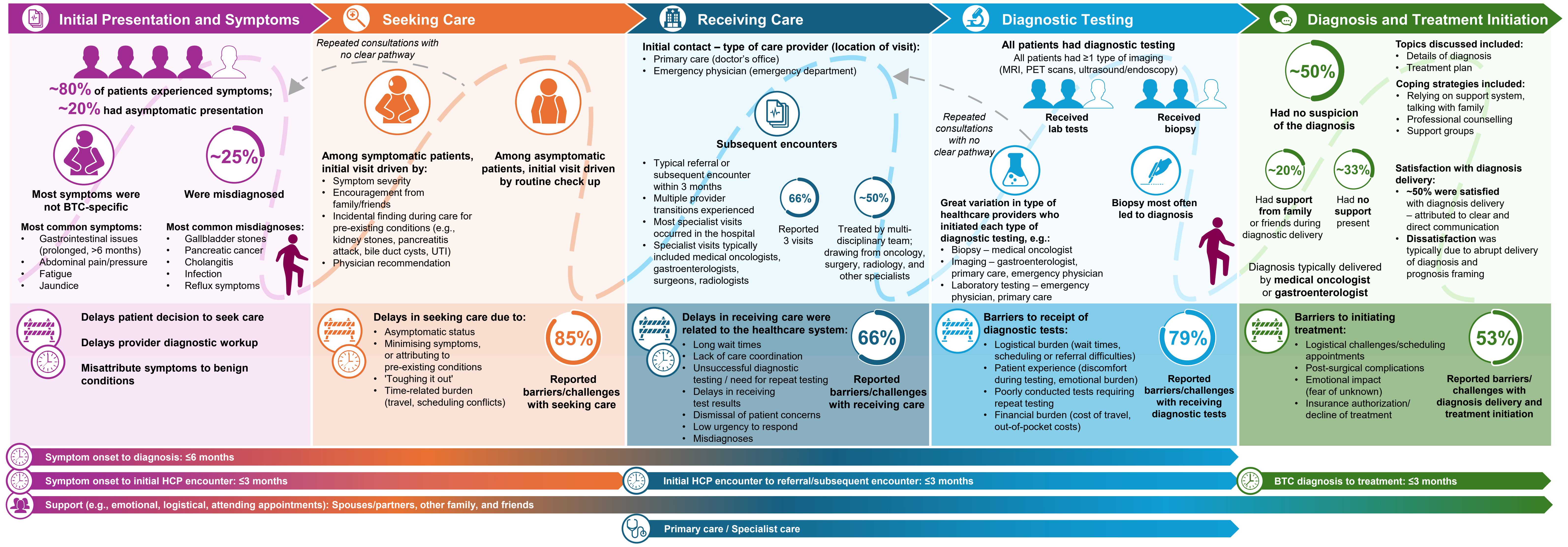
BTC: biliary tract cancer; eCCA: extrahepatic cholangiocarcinoma; GC: gallbladder cancer; iCCA: intrahepatic cholangiocarcinoma; IQR: interquartile range; SD: standard deviation.

Results (continued)

Patient Journey to Diagnosis

- **Figure 1** presents the journey map for patients with BTC, from initial symptom presentation through diagnosis and treatment initiation. It provides a chronological overview of symptoms experienced by patients with BTC, prompts for seeking care, healthcare encounters, diagnostic testing and result delivery, as well as the challenges and barriers experienced across each stage

Figure 1. Patient Journey Map



Initial Presentation and Symptoms

~80% of patients experienced symptoms; ~20% had asymptomatic presentation

Most symptoms were not BTC-specific

~25% Were misdiagnosed

Most common symptoms:
- Gastrointestinal issues (prolonged, >6 months)
- Abdominal pain/pressure
- Fatigue
- Jaundice

Most common misdiagnoses:
- Gallbladder stones
- Pancreatic cancer
- Cholangitis
- Infection
- Reflux symptoms

Delays patient decision to seek care

Delays provider diagnostic workup

Misattribute symptoms to benign conditions

Seeking Care

Repeated consultations with no clear pathway

Among symptomatic patients, initial visit driven by:
- Symptom severity
- Encouragement from family/friends
- Incidental finding during care for pre-existing conditions (e.g., kidney stones, pancreatitis attack, bile duct cysts, UTI)
- Physician recommendation

Among asymptomatic patients, initial visit driven by routine check up

Delays in seeking care due to:
- Asymptomatic status
- Minimising symptoms, or attributing to pre-existing conditions
- 'Toughing it out'
- Time-related burden (travel, scheduling conflicts)

85% Reported barriers/challenges with seeking care

Receiving Care

Initial contact – type of care provider (location of visit):
- Primary care (doctor's office)
- Emergency physician (emergency department)

Subsequent encounters
- Typical referral or subsequent encounter within 3 months
- Multiple provider transitions experienced
- Most specialist visits occurred in the hospital
- Specialist visits typically included medical oncologists, gastroenterologists, surgeons, radiologists

66% Reported 3 visits

~50% Treated by multi-disciplinary team; drawing from oncology, surgery, radiology, and other specialists

Delays in receiving care were related to the healthcare system:
- Long wait times
- Lack of care coordination
- Unsuccessful diagnostic testing / need for repeat testing
- Delays in receiving test results
- Dismissal of patient concerns
- Low urgency to respond
- Misdiagnoses

66% Reported barriers/challenges with receiving care

Diagnostic Testing

All patients had diagnostic testing

All patients had ≥1 type of imaging (MRI, PET scans, ultrasound/endoscopy)

Repeated consultations with no clear pathway

Received lab tests

Received biopsy

Great variation in type of healthcare providers who initiated each type of diagnostic testing, e.g.:
- Biopsy – medical oncologist
- Imaging – gastroenterologist, primary care, emergency physician
- Laboratory testing – emergency physician, primary care

Biopsy most often led to diagnosis

Barriers to receipt of diagnostic tests:
- Logistical burden (wait times, scheduling or referral difficulties)
- Patient experience (discomfort during testing, emotional burden)
- Poorly conducted tests requiring repeat testing
- Financial burden (cost of travel, out-of-pocket costs)

79% Reported barriers/challenges with receiving diagnostic tests

Diagnosis and Treatment Initiation

~50% Had no suspicion of the diagnosis

~20% Had **support from family** or friends during diagnostic delivery

~33% Had **no support** present

Diagnosis typically delivered by **medical oncologist** or **gastroenterologist**

Topics discussed included:
- Details of diagnosis
- Treatment plan

Coping strategies included:
- Relying on support system, talking with family
- Professional counselling
- Support groups

Satisfaction with diagnosis delivery:
- **~50% were satisfied** with diagnosis delivery – attributed to clear and direct communication
- **Dissatisfaction** was typically due to abrupt delivery of diagnosis and prognosis framing

Barriers to initiating treatment:
- Logistical challenges/scheduling appointments
- Post-surgical complications
- Emotional impact (fear of unknown)
- Insurance authorization/ decline of treatment

53% Reported barriers/ challenges with diagnosis delivery and treatment initiation

Symptom onset to diagnosis: ≤6 months

Symptom onset to initial HCP encounter: ≤3 months

Initial HCP encounter to referral/subsequent encounter: ≤3 months

BTC diagnosis to treatment: ≤3 months

Support (e.g., emotional, logistical, attending appointments): Spouses/partners, other family, and friends

Primary care / Specialist care

Barriers and Challenges

Initial Presentation and Symptoms

- Many patients initially reported no or non-BTC-specific symptoms, such as fatigue or abdominal pain, that overlapped with benign gastrointestinal conditions. These symptoms may be more likely to be misattributed to benign conditions by providers or patients and more prone to minimization or normalization. This contributes to delays in diagnostic work-up or misdiagnosis and necessitates multiple healthcare visits before receiving a diagnosis, with approximately two-thirds of patients reporting ≥3 visits.

> *"So, I just pushed it off, but then finally went back in. It was really just fairly mild, basically just acid reflux and heartburn and, and very odd belches or burps, just not normal…it felt like I drank a soda when I hadn't. That kind of feeling."*
> **— US, early-stage iCCA, female, 48 yrs, public insurance**

Seeking Care

- Patients delayed seeking care due to attitudinal barriers, including symptom minimization due to perceiving symptoms as less serious, attributing symptoms to pre-existing conditions, or being asymptomatic. Because symptoms were nonspecific and often normalized, care-seeking was delayed until a trigger, such as worsening symptoms, external prompting by family and friends, or an incidental finding during a routine check up (among asymptomatic patients specifically) prompted escalation to seek further care
- Time-related burden, such as long travel time, anticipated wait times, or competing work obligations were also drivers of delays in seeking care

> *"My age and being young and overall healthy and having no medical history just causes you to think, I'm sure everything's fine…I'm sure I'm just sort of bloated, or…maybe it's just like an ovarian cyst and people get those all the time."*
> **— US, late-stage eCCA, female, 33 yrs, private insurance**

Receiving Care

- Delays in seeking care were compounded by challenges experienced by patients while receiving care. Patients navigated a multi-step care pathway, characterized by multiple visits and provider transitions (often within ~3 months, with approximately 34%, 34%, 18%, and 3% of patients seeing a second provider within one week, 1–4 weeks, 1–3 months, and ≥3 months, respectively) before reaching specialty care (e.g., medical oncologists). Delays were driven by structural and operational barriers within the healthcare system, including long wait times, scheduling constraints, limited appointment availability, and lack of care coordination. Additional delays arose from unsuccessful or inconclusive diagnostic testing and slow return of results, as well as provider-level factors, such as low clinical urgency or dismissal of patient concerns

> *"I was…on the waitlist for the NHS gastro…At some point, finally, I did get a letter to say, months and months later, that my time had finally come up for an appointment."*
> **— UK, late-stage iCCA, female, 33 yrs, private insurance**

Diagnostic Testing

- Diagnostic testing was observed universally, with a multimodal approach that involved at least one imaging modality (i.e., MRI or PET scan), laboratory testing, and biopsy. Barriers to diagnostic testing included logistical challenges, such as long wait times and scheduling and referral difficulties, as well as the patients' perception or experience of physical discomfort or pain and emotional distress; in some cases, inconclusive diagnostic tests required repeat testing

> *"Big factor I found was that between May of 2002, when the doctor said do it right away, till they were able to squeeze me in for the diagnostic imaging, it passed almost a year."*
> **— Canada, early-stage iCCA, female, 60 yrs, private insurance**

Diagnosis and Treatment Initiation

- Most patients were diagnosed within 6 months of symptom onset (15% in ≤1 month, 25% in 1–3 months, 16% in 3–6 months, 13% in 6 months–2years, and 10% in ≥2 years), reflecting the cumulative impact of earlier barriers in the diagnostic pathway. Diagnosis was typically delivered by a medical oncologist or surgeon, often with family present, and while many patients appreciated clear, direct communication and received informational resources, others reported emotional distress, difficulty processing information, or dissatisfaction with how the diagnosis was conveyed. Nearly half of patients had no prior suspicion of BTC, contributing to the shock of the diagnostic experience. Following diagnosis, treatment was generally initiated within 3 months; however, some patients experienced additional delays due to scheduling challenges, post-surgical complications, or anxiety-related hesitancy

> *"The difficult part was just scheduling and getting started. I really didn't want to do it. I didn't want to kill myself because I'd heard so many bad stories about it...It kills your whole body and, you know. So, I wasn't really looking forward to that."*
> **— US, late-stage iCCA, male, 76 yrs, public insurance**

Discussion

- Delays in BTC diagnosis were cumulative and multi-level, beginning with nonspecific symptom presentation and continuing through care-seeking, clinical evaluation or receipt of care, and diagnostic testing
- Barriers and challenges experienced by patients were largely consistent across countries, with attitudinal and informational barriers resulting in delays in seeking care and structural and logistic barriers resulting in delays in receiving care. Notably, patients in publicly funded healthcare systems (UK [80%], Canada [57%], Germany [42%]) more frequently reported delays in receiving care due to structural constraints (e.g., longer wait times, scheduling and referral processes), compared to those in the US (27%)
- Limitations of the study include recall bias (time elapsed since diagnosis may impact the accuracy of patients' responses) and selection bias, as patients who elect to participate in the study may differ from those who decline

Conclusions

- **Patients with BTC identified a range of attitudinal, logistical, and structural barriers to diagnosis, underscoring the need to increase awareness for early work up of symptoms to facilitate diagnosis and to address systemic obstacles to timely care – such as limited appointment availability, scheduling constraints, and insufficient coordination among providers**
- **Trends were largely consistent across countries**

Disclosures

Jennifer Knox received consulting fees from AstraZeneca, Incyte, Ipsen, Roche, and Astellas. Susanne Radke, Young Jung, and Mufiza Farid-Kapadia are employees and stock owners of AstraZeneca.
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.

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Plain language summary

Background

- This study identified and described barriers and challenges faced by patients with BTC – a rare cancer that starts in the bile ducts – from first experiencing symptoms to diagnosis and treatment

Methods

- In-depth interviews with 61 patients with early- or late-stage BTC were conducted to understand their journey from initial symptom presentation through diagnosis and treatment initiation, and identify common themes and experiences

Results

- Many patients had no or non-BTC-specific symptoms at initial presentation, which often led to delays or misdiagnosis and required multiple healthcare visits before receiving a diagnosis
- Attitudinal (e.g., perceiving symptoms as less serious) and time-related barriers (e.g., long travel times or competing schedule obligations) were the primary drivers of delays in seeking care, while structural and logistical system-level barriers (e.g., long wait times) were commonly cited as reasons for delays in receiving care

Conclusion

- Improving awareness of biliary tract symptoms among patients and providers, earlier diagnostic testing, and smoother referrals may help patients receive timely diagnosis and treatment with the potential to improve outcomes

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Poster

Supplementary material

Poster presented at the Cholangiocarcinoma Foundation (CCF) 2026 Annual Conference, Salt Lake City, UT, USA, May 1–3, 2026

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