

# Patient and caregiver perspectives in hepatobiliary cancer

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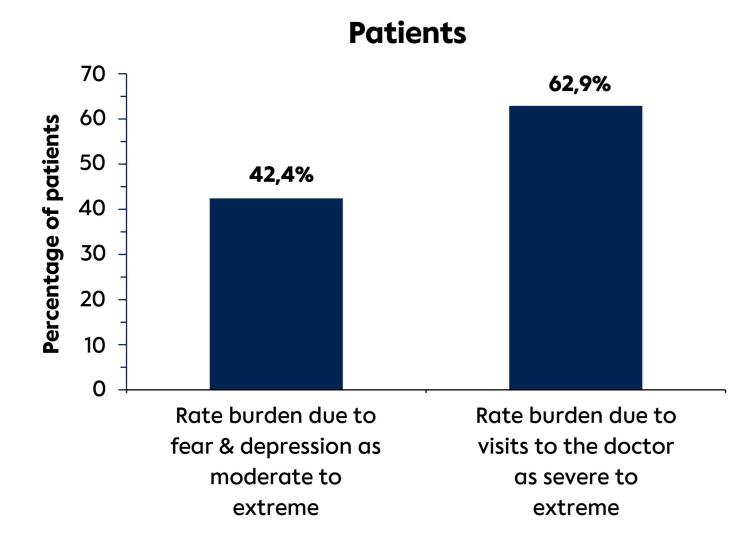
# Background

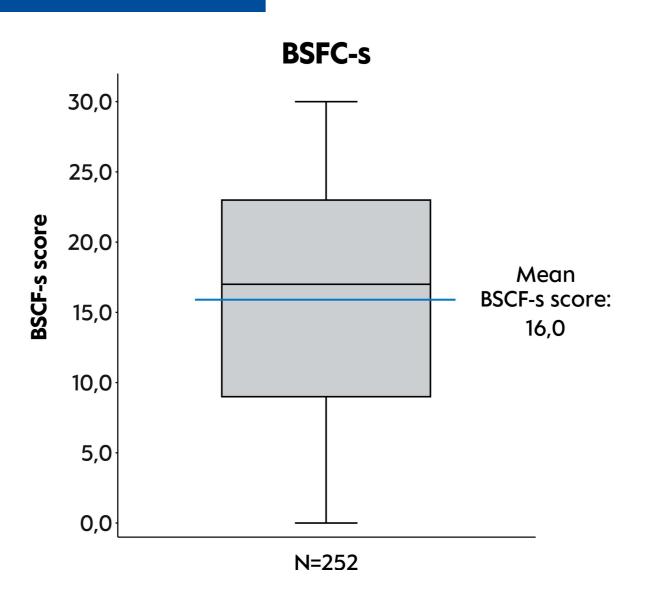
- In cancer therapy, perspectives of patients and caregivers are highly important and should be included in treatment decisions
- For hepatocellular carcinoma (HCC) and biliary tract cancer (BTC), these data are largely missing
- New approaches to collect reliable data on patient and caregiver perspectives are urgently needed to improve care of hepatobiliary cancer
- We aimed to gain better insight into the needs and expectations of HCC / BTC patients and their caregivers

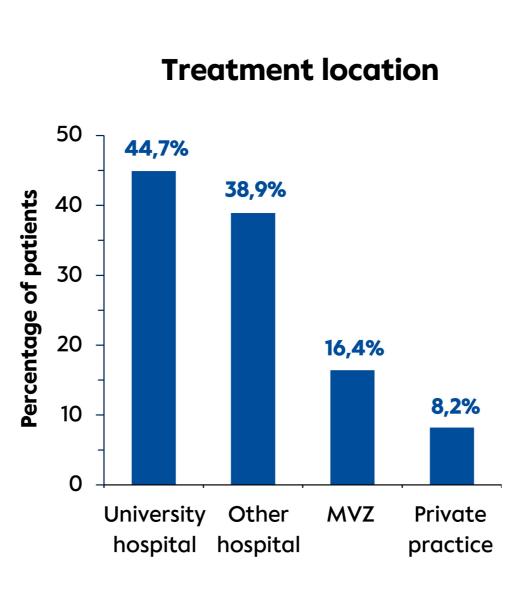
## Methods

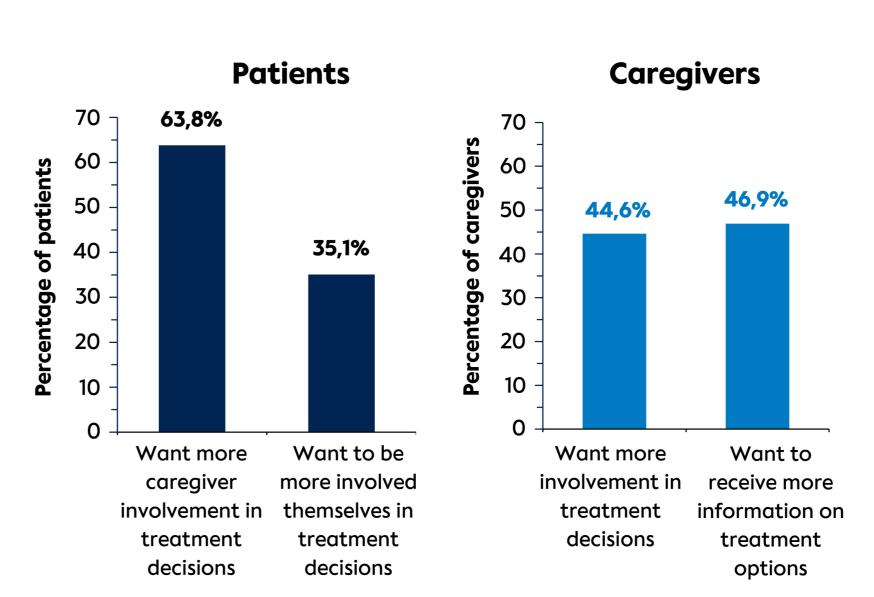
- We conducted an online survey distributed via social media with a detailed questionnaire for HCC/BTC patients and caregivers, assessing, among others:
- The diagnostic and therapeutic journeys as well as disease characteristics
- Quality of life (QoL) parameters (e.g., via EQ-5D-5L score)
- Involvement of patients and caregivers in therapeutic decision-making
- Psychological burden on patients and burden on caregivers (e.g., via BSFC-s score)
- Informational/educational requirements of patients/caregivers and possible knowledge gaps
- 340 people completed the survey, 80 patients and 260 caregivers

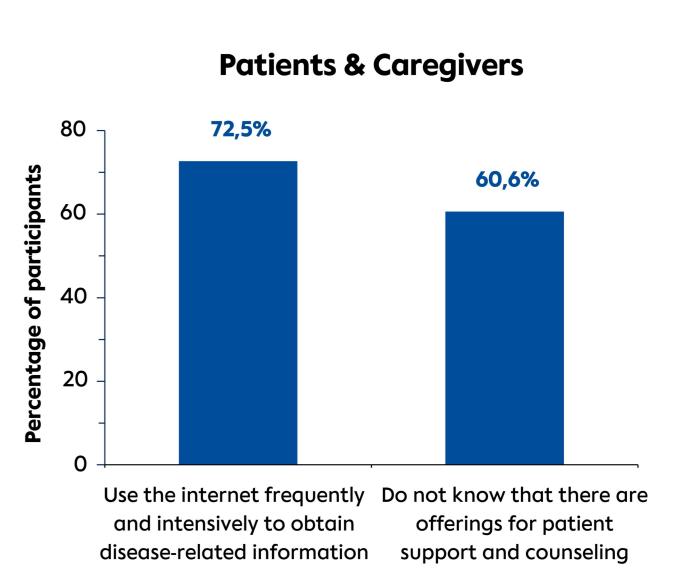
## Results











### **Quality of life for patients**

Referenzen

- Among EQ-5D-5L subscales, fear/depression was rated as most burdensome
- Burden due to visits to the doctor was rated higher than symptoms of the disease
- 61,3% of patients considered QoL and longterm survival as equally important

### Burden on caregivers (BSFC-s)

- With a mean BSFC-s score of 16, there was a high burden on caregivers
- A score between 5 and 14 constitutes a moderate subjective burden, a score ≥ 15 is considered a high subjective burden<sup>1</sup>

#### **Treatment location**

- Most patients were treated in university hospitals
- The majority of patients and caregivers (55,85%) stated that they do not have a main contact at the hospital

#### Involvement in therapeutic decision-making

- 63,8% of patients wish that their relatives/caregivers are involved in treatment decisions
- 44,6% of caregivers want to be involved to a greater extend into therapeutic decisions

#### Informational requirements

- 72,5% of participants use the internet intensively to obtain disease-related information
- 60,6% of participants did not know that there are offerings for patient support and counseling

# Discussion and Conclusion

- Our results highlight the importance of patient and caregiver perspectives for implementing a modern and patient-centered care in hepatobiliary cancer
- Due to the heterogeneity of the analyzed population and the small sample size, interpretation of data should be done with caution. In a next step, these data should therefore be complemented with

additional real-world data, e.g., from routine care

- In conclusion, comprehensive data from this survey on patient and caregiver perspectives point to a medical need to improve QoL and reduce the burden on caregivers
- There is a high demand for more patient/caregiver information, education, and involvement

In cooperation with 1. Pendergrass A. et al. BMC Health Serv Res. 2018 Apr 2;18(1):229.

