

# Caregiver Burden and Socioeconomic Impact of Cirrhosis, HE and OHE Among Individuals Caring for Patients With Cirrhosis

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## STUDY OBJECTIVE

This study aimed to characterize the burden on caregivers of patients with cirrhosis, hepatic encephalopathy (HE), and overt HE (OHE), including impacts on finances, work productivity, and quality of life (QoL).

## KEY MESSAGES

- Caregivers of patients with cirrhosis provide substantial, multifaceted support, spanning medical management, daily activities, and care coordination.
- These caregiving demands result in significant burden, including employment disruptions, reduced productivity, and financial strain.
- Progression to HE/OHE is associated with increased caregiver burden, including greater time demands, financial strain, and work disruption.

## CONCLUSION

Caregiving for cirrhosis imposes a substantial, multidimensional burden that extends beyond health into economic and social domains and is further amplified with progression to HE/OHE.

These findings highlight the need for earlier recognition of caregiver strain and targeted support strategies. Interventions that delay or prevent progression to HE/OHE may reduce caregiver burden and improve wellbeing and productivity.

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## BACKGROUND

- Cirrhosis is a common and growing public health concern in the United States (US), placing substantial burden on patients and caregivers, including quality of life and financial impacts<sup>1</sup>
- Hepatic encephalopathy (HE) and its more severe form, overt HE (OHE), are serious complications of cirrhosis that impair daily functioning and often require significant caregiver support<sup>2,3</sup>
- Despite known clinical impacts, comprehensive assessments of socioeconomic, and caregiver burden of cirrhosis, as well as HE and OHE, remain limited

## METHODS

- An online survey was conducted among 200 US adults who provide unpaid care to adult patients with cirrhosis with or without HE, including a subgroup caring for patients with OHE
- Participants were classified into the following cohorts based on the self-reported disease status of the care recipient:
  - Cirrhosis cohort**: Caregivers of patients with cirrhosis without HE/OHE
  - HE cohort**: Caregivers of patients with HE
  - OHE cohort**: A subgroup of caregivers of patients with OHE
- Data collection took place between September and November 2025

- The following information was collected:
  - Demographic and clinical characteristics of care recipients and caregivers
  - Characteristics related to caregiving
  - Employment status and changes in employment
  - Financial difficulties experienced
  - Work productivity and activity impairment (WPAl)
  - Caregiving burden (Zarit Burden Interview [ZBI-12])

## RESULTS

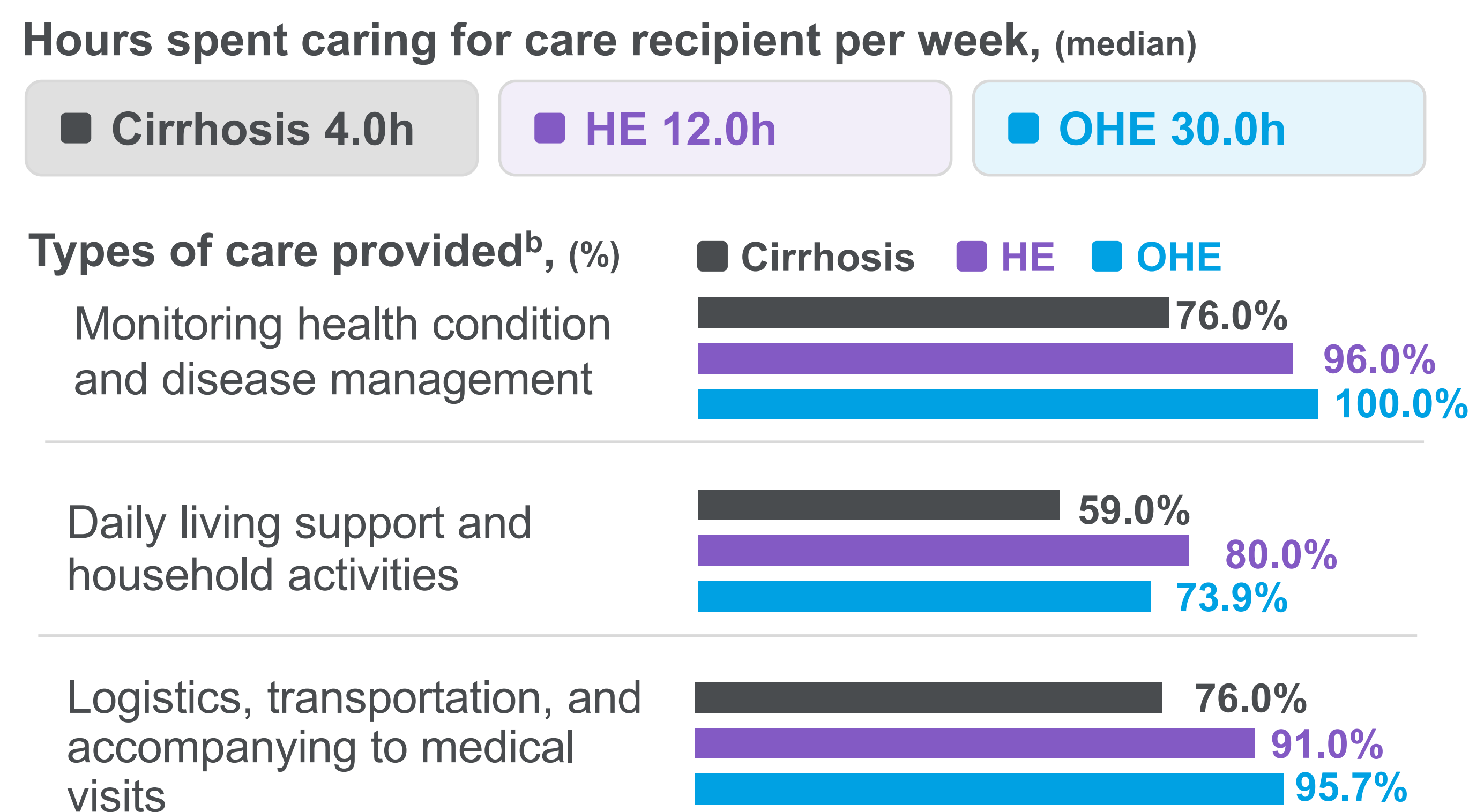
Table 1. Caregiver characteristics

	Cirrhosis N = 100	HE N = 100	OHE N = 23
Age, years (median)	60	63	62
Female, (%)	54.0%	67.0%	73.9%
Relationship to care recipient, (%)			
Spouses or partners	61.0%	73.0%	78.3%
Siblings or children	27.0%	24.0%	21.7%
Friends or neighbors	12.0%	3.0%	0.0%
Duration of care, (%)			
<1 year	36.0%	12.0%	4.3%
1-2 years	53.0%	45.0%	47.8%
3-5 years	11.0%	43.0%	47.8%
Current employment status in the working age (18-64) <sup>a</sup> , (%)			
Not Employed	15.8%	18.5%	38.9%
Employed	84.2%	81.5%	61.1%
Full-time	65.8%	49.2%	27.8%
Part-time	13.2%	18.5%	11.1%
Flexible	5.3%	13.8%	22.2%

Caregivers were primarily spouses and older adults. Employment rates of caregivers decreased as cirrhosis severity increased.

HE: hepatic encephalopathy; N: number; OHE: overt hepatic encephalopathy  
 a. Employment was assessed among caregivers in the working age population (18-64) at the time of data collection (cirrhosis: N = 76, HE: N = 65, OHE: N = 18).

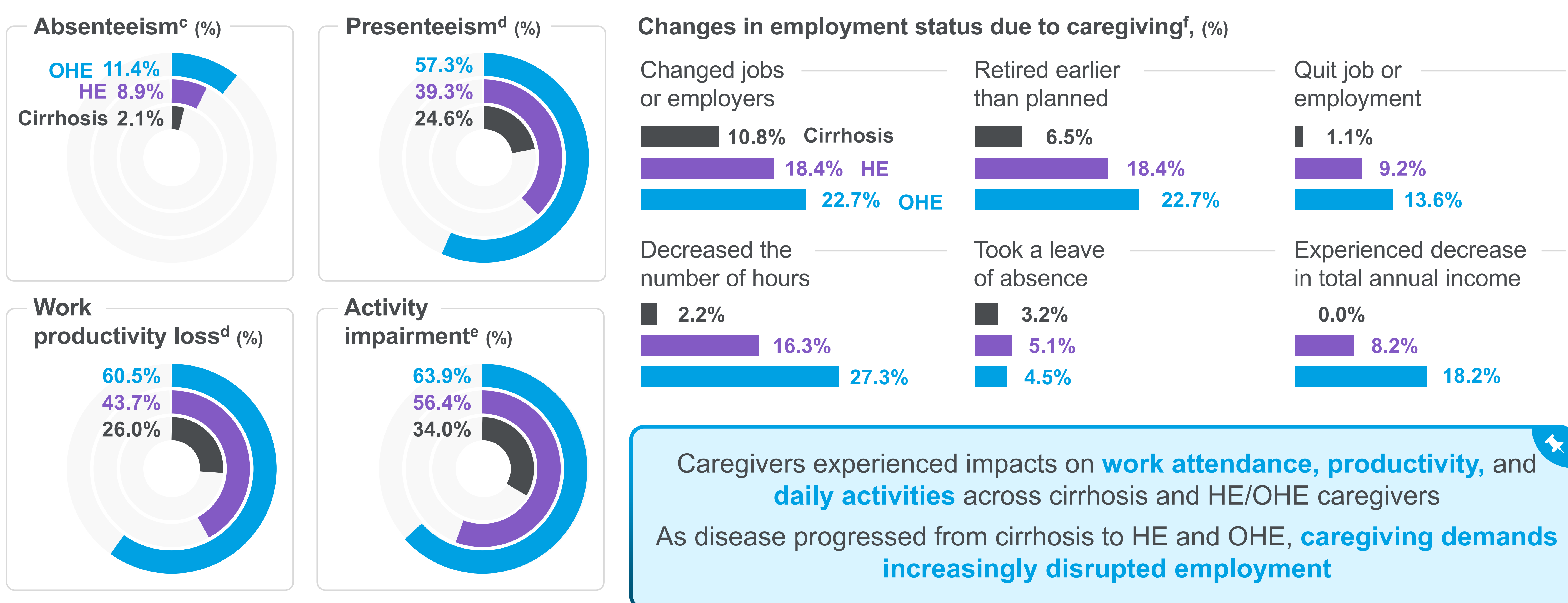
Figure 1. Caregiving characteristics



Caregivers provide substantial support, including medical care, daily activities, and coordination of care. Caregiver demands tended to increase with disease severity.

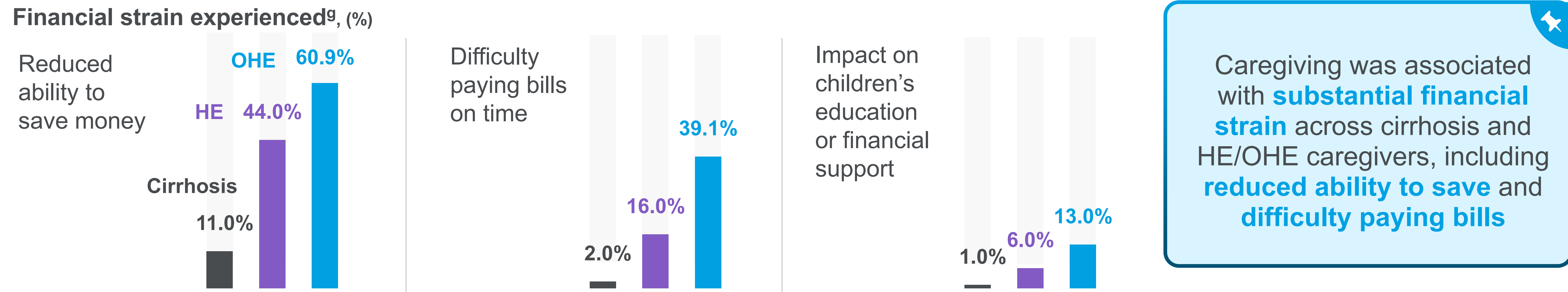
h: hour; HE: hepatic encephalopathy; N: number; OHE: overt hepatic encephalopathy  
 b. Categories are not mutually exclusive.

Figure 2. Work productivity and activity impairment (WPAl) and impact on employment status



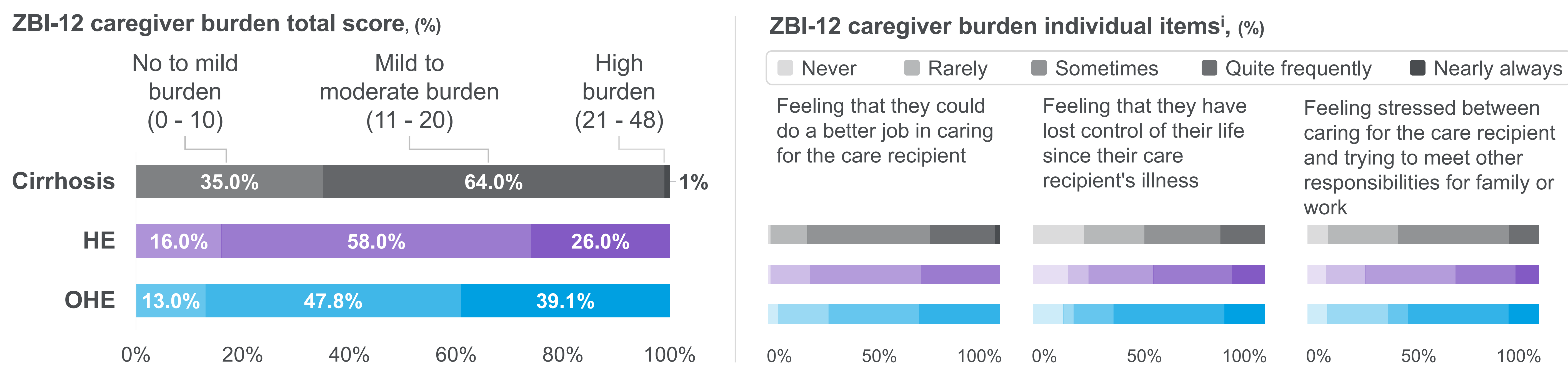
HE: hepatic encephalopathy; N: number; OHE: overt hepatic encephalopathy  
 c. Absenteeism was assessed among caregivers that were employed at the time of data collection (cirrhosis: N = 70, HE: N = 56, OHE: N = 11); d. Presenteeism and work productivity loss were assessed among caregivers that were employed and worked >0 hours in the last 7 days from the time of data collection (cirrhosis: N = 70, HE: N = 56, OHE: N = 11); e. Activity impairment was assessed among all caregivers regardless of employment status (cirrhosis: N = 100, HE: N = 100, OHE: N = 23); f. Changes in employment were assessed among caregivers that were employed prior to caregiving (cirrhosis: N = 93, HE: N = 98, OHE: N = 22); categories are not mutually exclusive.

Figure 3. Financial strain due to caregiving



HE: hepatic encephalopathy; OHE: overt hepatic encephalopathy  
 g. Categories are not mutually exclusive.

Figure 5. Caregiver burden (ZBI-12<sup>h</sup>)



Caregiver burden was substantial across cirrhosis and increased with disease severity, with many caregivers reporting loss of control, unmet caregiving needs, and stress balancing responsibilities.

HE: hepatic encephalopathy; OHE: overt hepatic encephalopathy; ZBI-12: 12-item Zarit Burden Interview  
 h. Source: ZBI © Steven H. Zarit and Judy M. Zarit, 1980-2008. All rights reserved. Thresholds were defined based on the Wisconsin Alzheimer's Institute. Source: Wisconsin Alzheimer's Institute. Zarit Caregiver Burden Assessment Instruments. University of Wisconsin-Madison; 2021. Available at: Zarit Caregiver Burden Assessment Instruments. i. ZBI-12 includes 12 items in total; the 3 most burdensome items reported are shown in this figure.

References

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Limitations

Caregiver-reported HE/OHE status of care recipients and self-reported outcomes may be subject to misclassification and recall bias. Findings may be influenced by non-response and self-selection bias, and results may not be fully representative of all caregivers of patients with cirrhosis in the US.

Disclosure

ABJ has provided paid consulting services to Salix/BHC, Mallinckrodt Pharmaceuticals, and Madrigal Pharmaceuticals. Other authors: DG, PGS, AS, KY, SS, and AG are employees of Analysis Group ULC, a consulting company that has provided paid consulting services to Bausch Health. LPC and OO are employed by Bausch Health. This study was undertaken by Analysis Group ULC sponsored by Bausch Health.