Real-World Evidence of the Impact of Dravet Syndrome and Lennox-Gastaut Syndrome on Patient and Caregiver Quality of Life

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Lin J,[1] Kothare SV,[2,3] Salpekar JA,[4] Connolly H,[5] Gillespie A,[5] Vyas K,[6] Simontacchi K,[1] Thomas SM,[1] Viswanathan HN,[1] Chin R[7,8]

[1]Jazz Pharmaceuticals, Inc., Palo Alto, CA, USA; [2]Cohen Children's Medical Center, Lake Success, NY, USA; [3]Northwell Health, Lake Success, NY, USA; [4]Kennedy Krieger Institute, Baltimore, MD, USA; [5]Adelphi Real World, Bollington, UK; [6]Jazz Pharmaceuticals UK Ltd., London, UK; [7]The University of Edinburgh, UK; [8]Royal Hospital for Children and Young People, Edinburgh, UK.

Introduction

- Dravet syndrome (DS) and Lennox-Gastaut syndrome (LGS) are rare developmental and epileptic encephalopathies characterised by treatment-resistant seizures, and associated with cognitive and behavioural impairments.[1]
- Patients with DS or LGS and their caregivers face a range of challenges that negatively impact their quality of life (QoL), including concerns about seizures and potential physical injury, difficulties in maintaining social and personal relationships, sleep deprivation and fatigue, as well as obstacles related to education, career development, and financial stability.[1,2]
- The complex nature of these conditions places a significant physical and mental burden on caregivers and can greatly affect their emotional well-being.[1,2]
  - Understanding the disease burden in patients with LGS or DS and how these conditions impact the health-related quality of life (HRQoL) of their caregivers is therefore essential

Objective

- To describe the real-world impact of disease burden of DS or LGS on patients and caregivers' HRQoL.

Methods

- The Adelphi DS and LGS Disease Specific Programme™ was a real-world, multi-country, cross-sectional study comprising patient record forms abstracted from medical records, as well as from caregiver and physician surveys, conducted between July 2022 and August 2023.
- Caregivers of a patient whose information was collected were invited to complete a caregiver self-completion (CSC) record, independent of the physician, and immediately after consultation.
- The CSC captured the caregiver's perspective on the patient's seizures burden and QoL, as well as the caregiver's own QoL and perceptions of treatment satisfaction.
- This analysis comprises descriptive statistics of caregiver-reported demographics for patients and caregivers, and caregiver HRQoL.

Results

Table 1. Caregiver characteristics

	Overall (n=327)	DS (n=146)	LGS (n=181)
Age, years	**n=323[a]**	**n=144**	**n=179**
Mean (SD)	39.3 (10.3)	37.7 (9.7)	40.5 (10.6)
Median (Q1–Q3)	37.0 (32–44)	35.0 (31–40)	37.0 (33–46)
Sex, n (%)	**n=327**	**n=146**	**n=181**
Female	263 (80)	122 (84)	141 (78)
Number of caregivers/patient	**n=322[b]**	**n=146**	**n=176**
Mean (SD)	2.6 (0.8)	2.5 (0.8)	2.7 (0.8)
Caregiving (hours/week)	**n=287**	**n=126**	**n=161**
Mean (SD)	55.7 (38.8)	58.1 (41.8)	53.8 (36.2)
Caregiver type, n (%)	**n=327**	**n=146**	**n=181**
Parent	325 (99)	144 (99)	181 (100)
Other family member	194 (59)	78 (53)	116 (64)
Non-family caregivers	25 (8)	14 (10)	11 (6)
Others	9 (3)	2 (1)	7 (4)

[a]Four caregivers reported their patients' ages in error. [b]Five caregivers did not complete the question 'Who else, apart from yourself, helps with caring for the patient?'. DS, Dravet syndrome; LGS, Lennox-Gastaut syndrome; Q1–Q3, interquartile range; SD, standard deviation.

Table 2. Patient characteristics

	Overall (n=327)	DS (n=146)	LGS (n=181)
Age, years			
Mean (SD)	6.9 (5.5)	6.3 (5.3)	7.3 (5.7)
Median (Q1–Q3)	6.0 (4.0–8.0)	5.0 (3.0–8.0)	6.0 (4.0–8.0)
Age group, years, n (%)			
0–12	294 (90)	131 (90)	163 (90)
13–17	13 (4)	6 (4)	7 (4)
18+	20 (6)	9 (6)	11 (6)
Sex, n (%)			
Female	113 (35)	57 (39)	56 (31)
Caregiver-reported patients' physical impairment, n (%)			
None	40/326 (12)	7/146 (5)	33/180 (18)
Mild	143/326 (44)	68/146 (47)	75/180 (42)
Moderate–very severe	143/326 (44)	71/146 (49)	72/180 (40)
Caregiver-reported patients' mental impairment, n (%)			
None	51/326 (16)	24/146 (16)	27/180 (15)
Mild	140/326 (43)	63/146 (43)	77/180 (43)
Moderate–very severe	135/326 (41)	59/146 (40)	76/180 (42)

DS, Dravet syndrome; LGS, Lennox-Gastaut syndrome; Q1–Q3, interquartile range; SD, standard deviation.

Top activity of daily living (ADL) requiring caregiver assistance

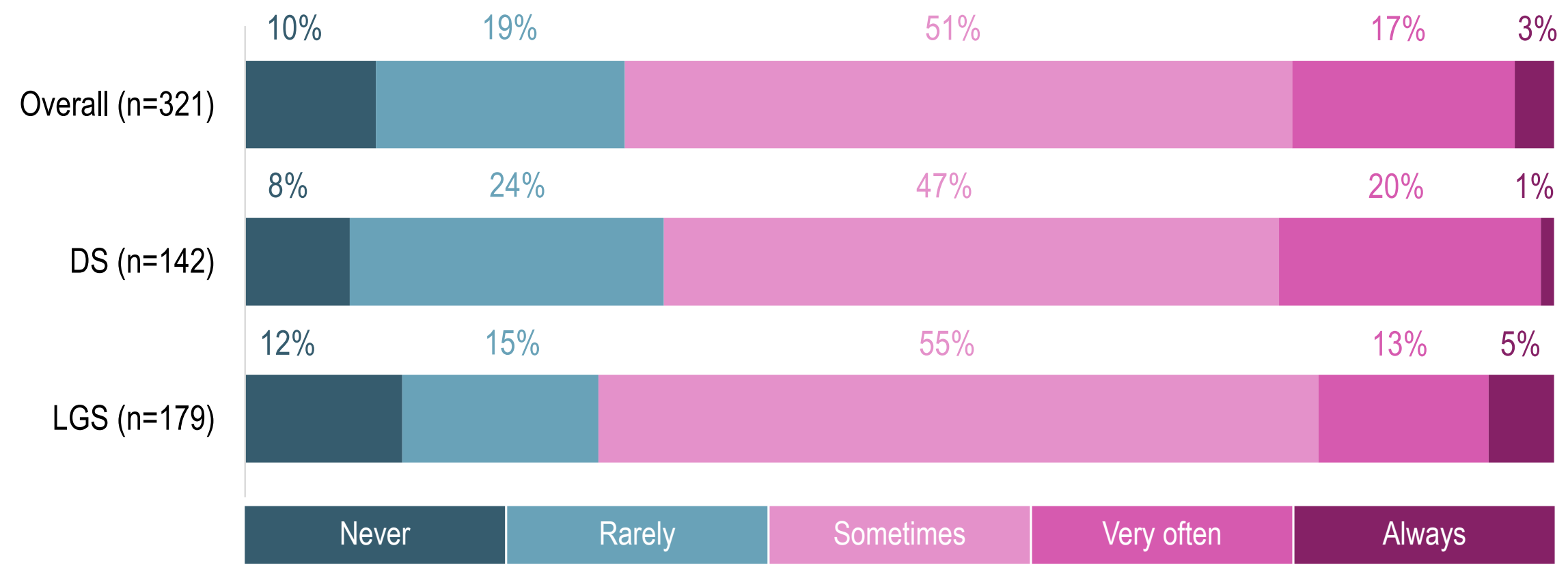
- The top ADL requiring caregiver assistance was supporting patients with taking their medication when required (93%; see **Supplementary Material** via the QR code for more details on top ADLs).

Impact of caring for a patient with DS or LGS on caregivers' employment

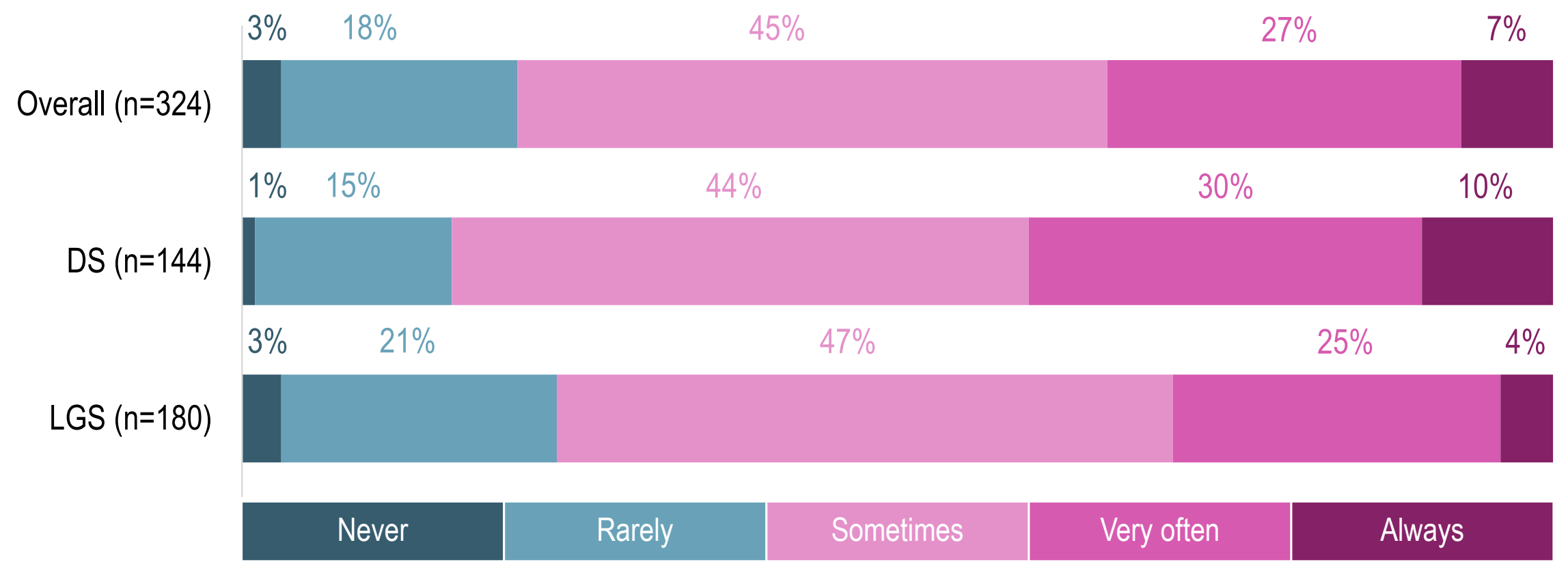
- Owing to caring for a patient, 11% of caregivers reported being unemployed.
- Additionally, 62% of employed caregivers overall reduced their working hours (see **Supplementary Material** via the QR code for more details on employment status).

Figure 1. Impact on caregivers' QoL

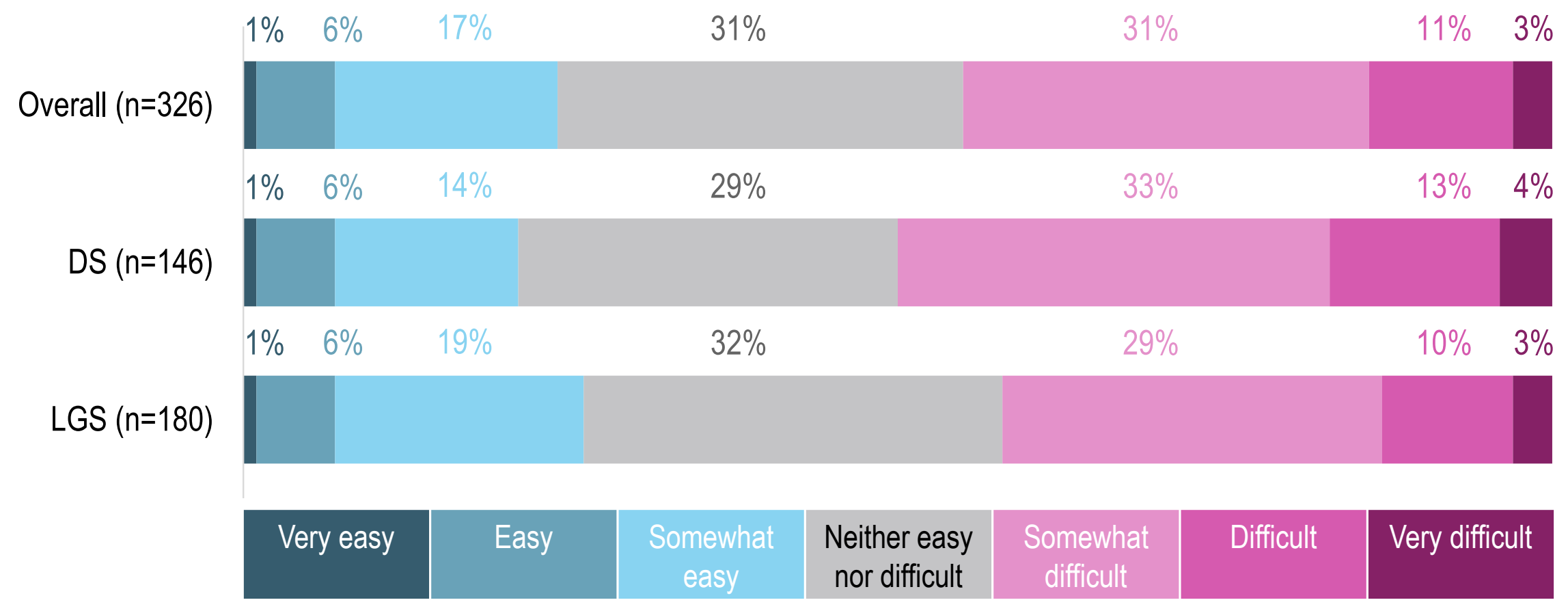
A How often did the patient's nighttime disturbances disrupt the caregiver's sleep in the last 4 weeks?



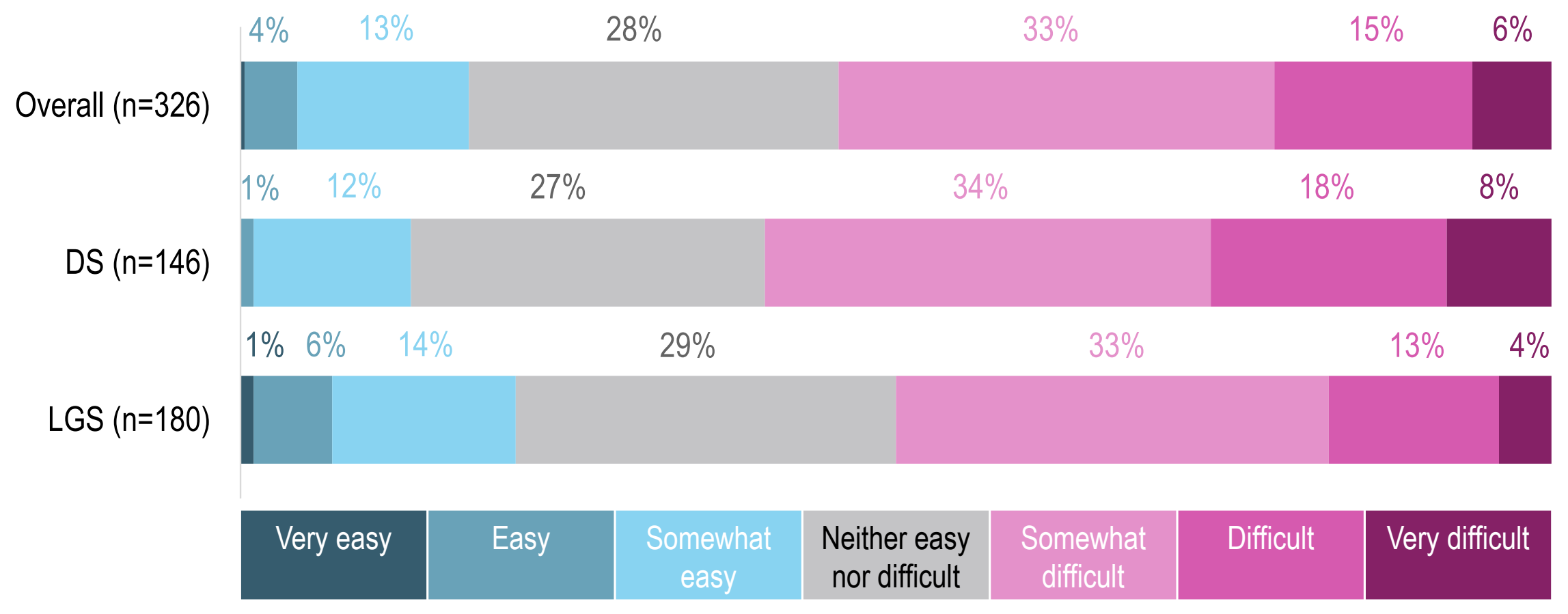
B How often did caring for the patient impact the caregiver's other responsibilities, such as household chores in the last 4 weeks?



C How easy or difficult has it been for the caregiver to care for the patient in the last 4 weeks?

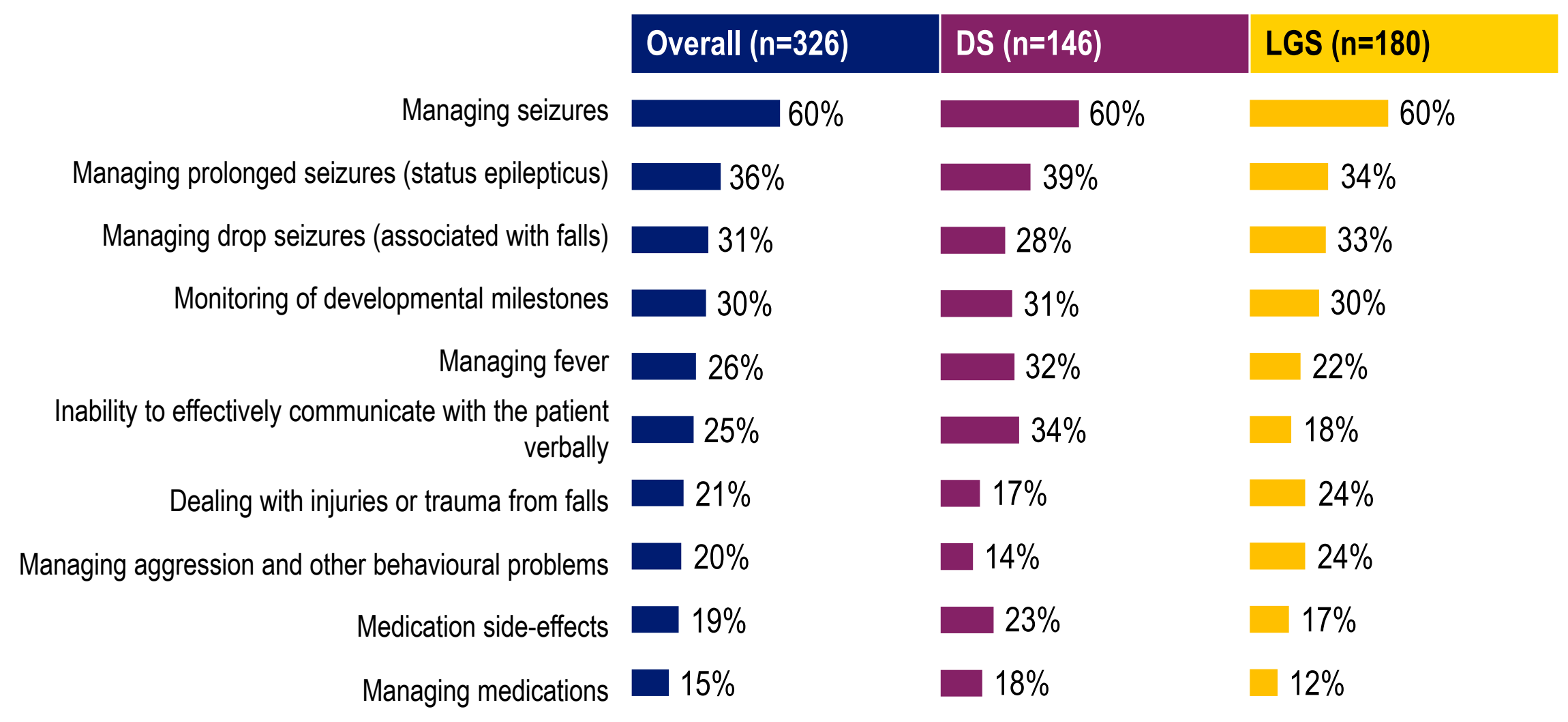


D How easy or difficult has it been for the caregiver to find time for their own needs and interests in the last 4 weeks?



- Approximately 71% of caregivers' nighttime sleep was sometimes, very often, or always impacted due to caring for patients; 28% (mean) of seizures occurred during patients' sleep, as reported by physicians.
- More than 50% of caregivers found it hard to find time for their own needs and interests, and 79% reported that caring for patients impacted their other family responsibilities.

Figure 2. Most difficult aspects of managing DS or LGS



- Most caregivers reported that the management of seizures (60%), particularly prolonged seizures (36%) and drop seizures (31%), were the most difficult aspects of caring for a patient with DS or LGS.

Figure 3. Conditions developed by caregivers since caring for patients with DS or LGS

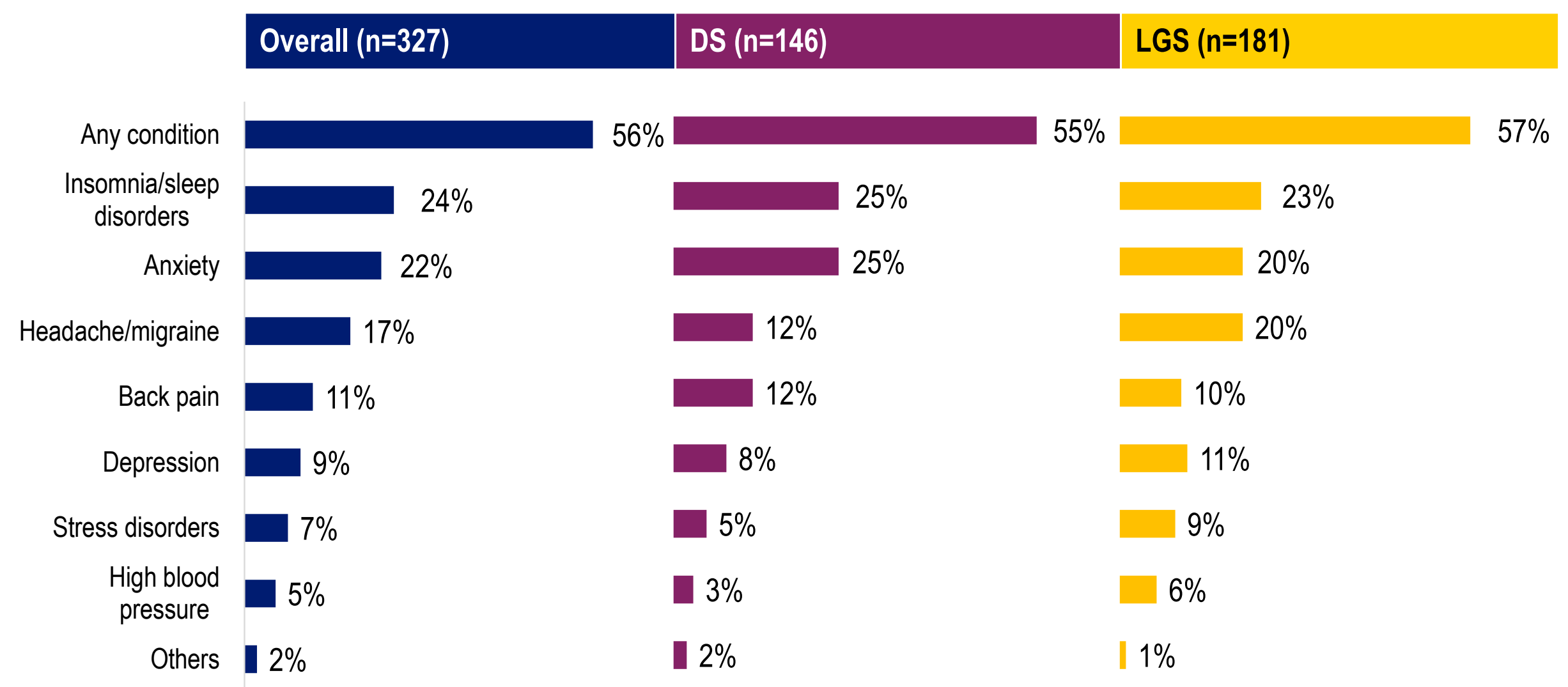
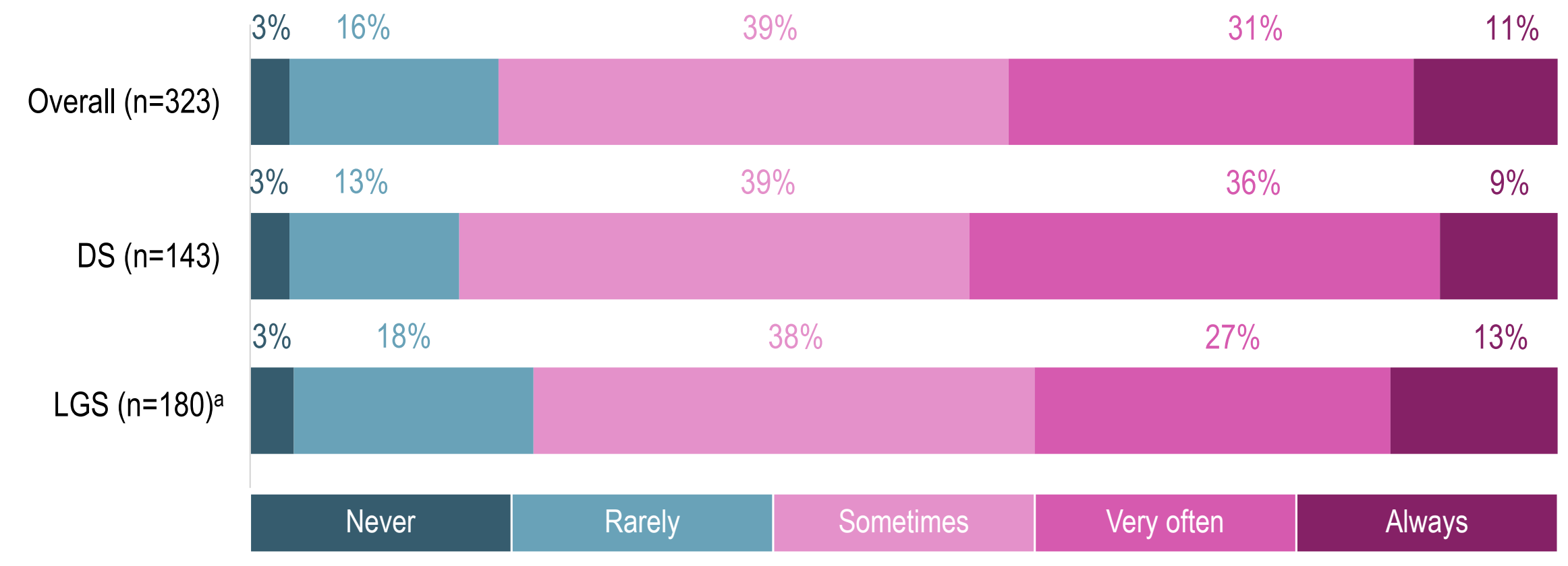
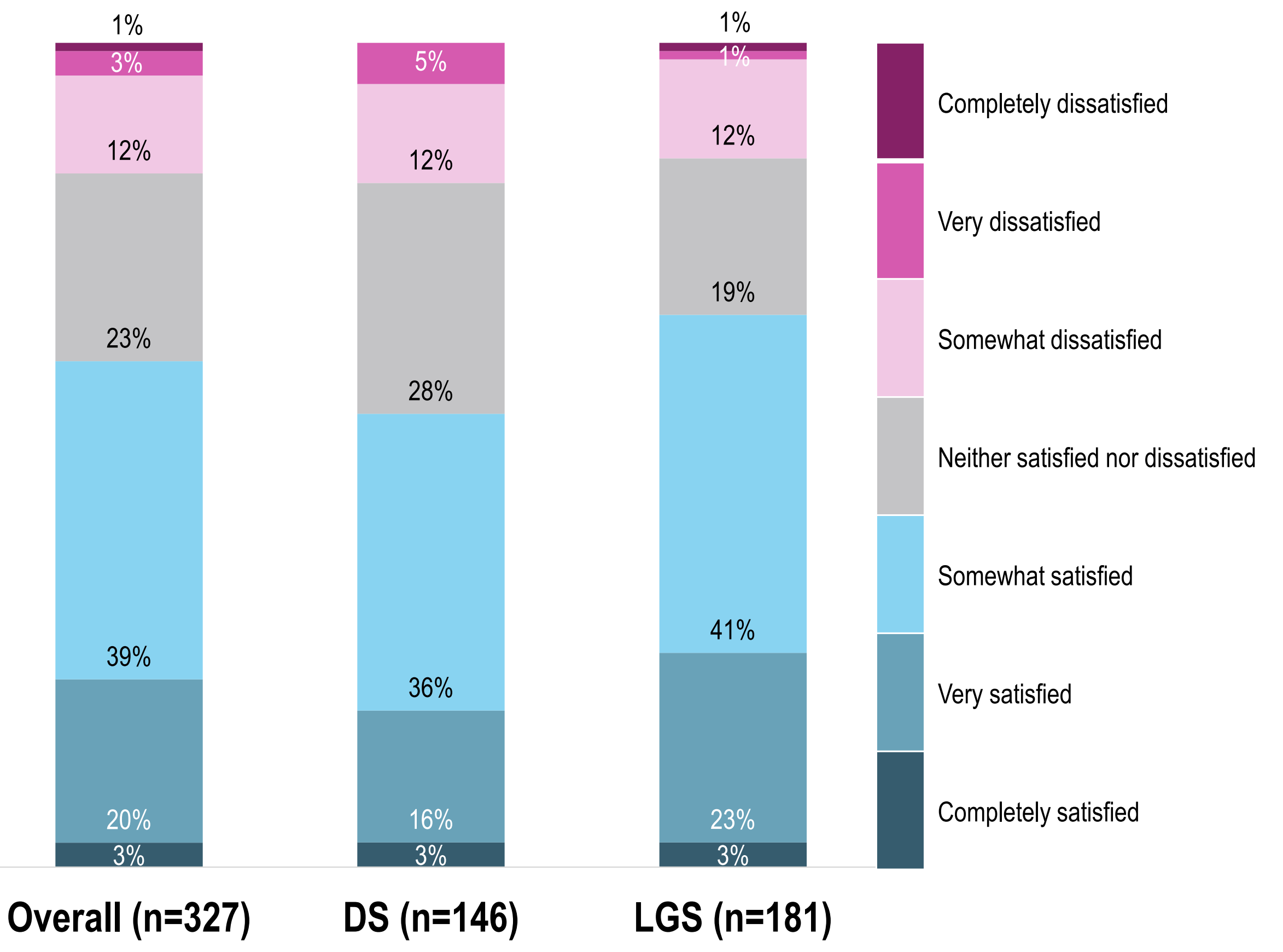


Figure 4. Proportion and level of caregiver worry about the emotional impact of patients with DS or LGS on other family members in the last 4 weeks



[a]Percentages shown add up to 99% due to rounding of data to whole integers.

Figure 5. Caregiver satisfaction rate with current treatment



- Although 55–67% of caregivers reported being satisfied with the current treatment, most (36–41%) of them reported that they were only somewhat satisfied.

Conclusions

- Caregiving places a substantial burden on the family, with the primary caregiver typically being a parent or family member.
- Most caregivers reported that supporting patients in taking their medication when required (93%) and managing seizures (60%) were the most challenging aspects of caring for patients with DS or LGS.
- Most caregivers' nighttime sleep (~70%) was affected due to caring for patients.
- Caring for patients with DS or LGS substantially affected caregivers' work status, family responsibilities, and overall QoL.
  - More than 50% of caregivers developed conditions such as anxiety, sleep disorders, headaches, or migraines
- Data presented herein demonstrate the substantial disease burden of DS and LGS, and associated impact on caregiver HRQoL, highlighting unmet needs for improved disease management and support with alleviating the impact on caregiver HRQoL.

References: **1.** LoPresti M, et al. *Epilepsy Behav.* 2024;158:109932. **2.** Auvin S, et al. *Epilepsy Behav.* 2021;123:108239.

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