

Burden Among Caregivers of Adult Patients with Neurofibromatosis Type 1 and Plexiform Neurofibroma in the United States: A Cross-Sectional Survey Study

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1 **SUPPLEMENTARY MATERIALS**

2 **Supplementary Table S1. Health Conditions of Caregivers of Adults with NF1-PN**

	All caregivers (N = 100)
Anxiety	19 (19.0)
Obesity	14 (14.0)
Depression	13 (13.0)
Diabetes	13 (13.0)
Cancer	2 (2.0)
None of the above	55 (55.0)

3 **Abbreviations:** NF1-PN, Neurofibromatosis Type 1 and Plexiform Neurofibroma.

4 **Supplementary Table S2. Demographic Characteristics of Adult Dependents with NF1-PN**

	All dependents (N = 100)
Age, years	
Mean $\pm$ SD	39.6 $\pm$ 16.0
Median (IQR)	41.5 (24.4, 51.5)
Sex, n (%)	
Male	59 (59.0)
Female	41 (41.0)
Race, n (%)	
White	53 (53.0)
Black or African American	17 (17.0)
Asian or Pacific Islander	3 (3.0)
Native American/American Indian or Alaska Native	2 (2.0)
Multiple races or other	7 (7.0)
Declined to answer	18 (18.0)
Ethnicity, n (%)	
Not Hispanic or Latino	65 (65.0)
Hispanic or Latino	17 (17.0)
Declined to answer	18 (18.0)
US Census Region, n (%)	
West	44 (44.0)
South	29 (29.0)
Midwest	16 (16.0)
Northeast	11 (11.0)
Employment status, n (%)	
Disabled	44 (44.0)
Unemployed and not looking	30 (30.0)
Housemaker	10 (10.0)
Self-employed	7 (7.0)
Student	6 (6.0)
Paid full time (40 hours/week) employee	2 (2.0)
Paid part-time (temporary or seasonal) employee	0 (0.0)
Unemployed and looking	1 (1.0)
Marital status, n (%)	
Single, never married	46 (46.0)
Married or in a domestic partnership	37 (37.0)
Widowed	6 (6.0)
Divorced or separated	2 (2.0)
Other	5 (5.0)
Declined to answer	4 (4.0)

5 **Abbreviations:** IQR, interquartile range; NF1-PN, Neurofibromatosis Type 1 and Plexiform Neurofibroma; PN,
6 Plexiform Neurofibroma; SD, standard deviation.

7 **Supplementary Table S3. Clinical Characteristics of Adult Dependents with NF1-PN**

All dependents (N = 100)	
Age at NF1 diagnosis, years	
Mean $\pm$ SD	17.4 $\pm$ 8.8
Median (IQR)	15.6 (11.3, 20.6)
Age at PN diagnosis, years	
Mean $\pm$ SD	30.0 $\pm$ 12.0
Median (IQR)	28.9 (21.2, 40.0)
Café-au-lait spots, n (%)	
≥ 1 café-au-lait spots	96 (96.0)
<6	16 (16.0)
6-20	66 (66.0)
>20	14 (14.0)
None	4 (4.0)
Number of PN tumor(s), n (%)	
<3	41 (41.0)
1	12 (12.0)
2	29 (29.0)
≥ 3	59 (59.0)
3	18 (18.0)
4	11 (11.0)
5	5 (5.0)
>5	24 (24.0)
Location of PN tumor(s)¹, n (%)	
Neck	54 (54.0)
Abdomen	44 (44.0)
Head	39 (39.0)
Back	34 (34.0)
Legs	32 (32.0)
Spine	30 (30.0)
Arms	25 (25.0)
Chest	15 (15.0)
NF1-PN related symptoms¹, n (%)	
Pain	84 (84.0)
Fatigue	80 (80.0)
Disfigurement	61 (61.0)
Chronic itching	24 (24.0)
Depression	25 (25.0)
Bowel or bladder dysfunction	23 (23.0)
Vision loss	22 (22.0)
Cognitive and learning problems	22 (22.0)

Anxiety	24 (24.0)
Motor dysfunction	19 (19.0)
Difficulty swallowing	19 (19.0)
Airway obstruction	3 (3.0)
Other	6 (6.0)
Ever received any treatment for NF1-PN¹, n (%)	97 (97.0)
Debulking surgery	89 (89.0)
Opioid pain relievers	74 (74.0)
Non-opioid pain relievers	70 (70.0)
Radiation therapy	43 (43.0)
Oncology medication	22 (22.0)
MEK inhibitor treatment for <1 month	0 (0.0)
Other	43 (43.0)
None	3 (3.0)
Debulking Surgery for PN tumor(s), n (%)	
Received ≥1 debulking surgery	89 (89.0)
1	23 (23.0)
2	17 (17.0)
3	21 (21.0)
4	11 (11.0)
5	6 (6.0)
>5	10 (10.0)
Unknown number of surgeries	1 (1.0)
NF1-PN related conditions¹, n (%)	
Attention-deficit disorder	57 (57.0)
Headaches	31 (31.0)
Hypertension	23 (23.0)
Autism	19 (19.0)
Epilepsy	18 (18.0)
Spinal problems	15 (15.0)
Deformities	6 (6.0)
Vasculopathy	4 (4.0)
Congenital heart disease	1 (1.0)
Other	5 (5.0)
None of the above	5 (5.0)

Abbreviations: IQR, interquartile range; NF1-PN, Neurofibromatosis Type 1 and Plexiform Neurofibroma; SD, standard deviation.

Notes:

[1] Categories are not mutually exclusive. Therefore, percentages may not sum up to 100%.