

An invisible rare patient population: Idiopathic hypersomnia (IH)

Discovering the key discrepancies with support for patients with IH in the U.S. and 5EU compared to other rare diseases

(Featuring data collected from the National Health and Wellness Survey, one of the largest patient-reported studies)

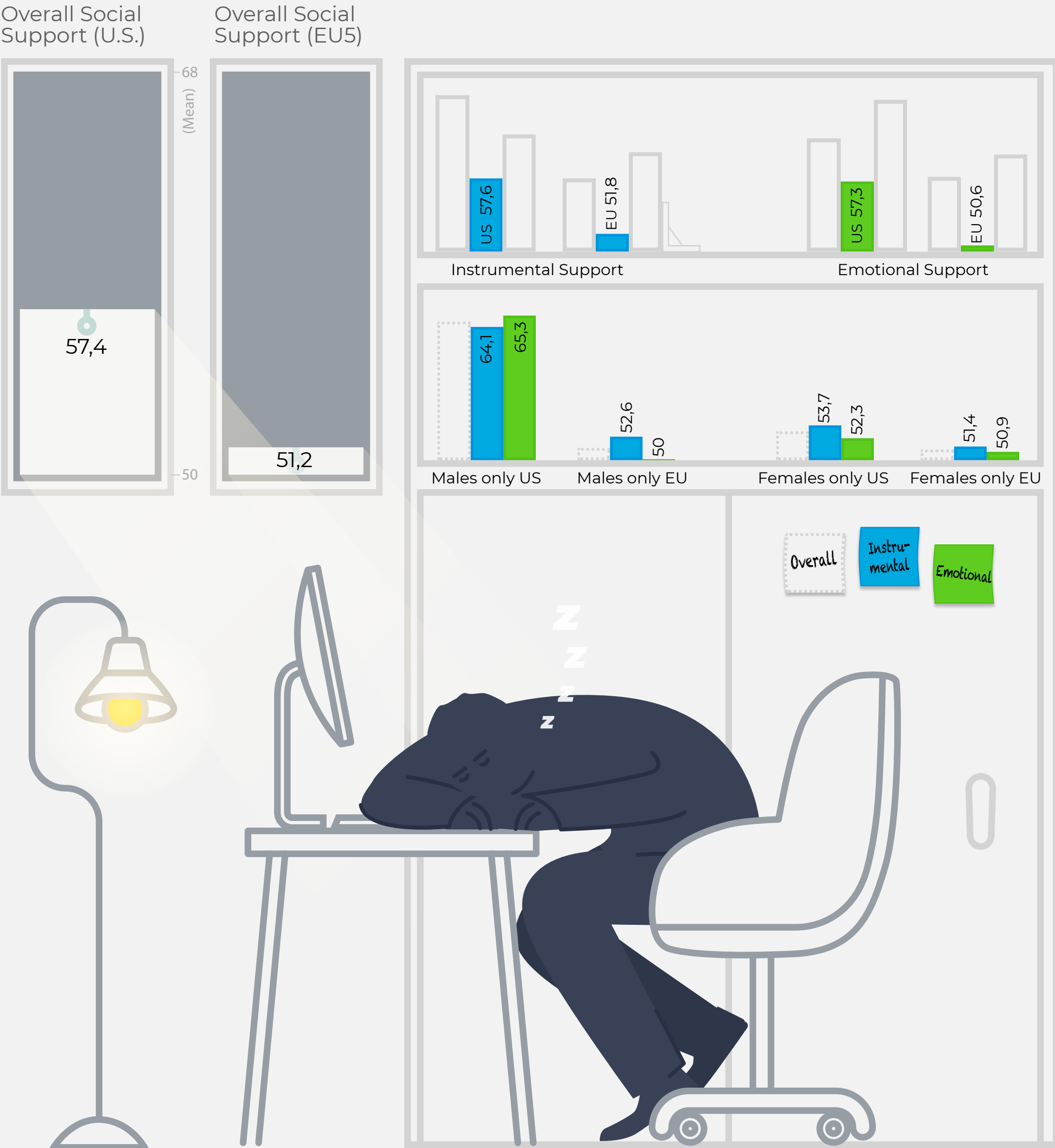
Sickle cell disease

Sickle cell disease (SCD) is a rare blood disorder that is inherited in an autosomal recessive manner. It is characterized by the presence of sickle, or crescent-shaped, red blood cells (erythrocytes) in the bloodstream.¹ Sickle cell disease is caused by a change in genes that are involved in producing hemoglobin, an iron-rich compound found in RBCs.² While SCD may be invisible to the naked eye, healthcare providers can identify the condition using a number of tests, including newborn and prenatal screening, blood tests, and genetic tests.



Idiopathic hypersomnia

IH is a complex diagnosis, with clinical manifestations often being nonspecific.³ Overall, IH patients receive significantly lower social support in the U.S. and 5EU compared to other rare diseases. Our findings conclude that although there is no gender disparity differentiating IH support in 5EU, there is a vast different between men and women in the U.S.; women receive over 10% less social support than men, often due to factors such as delayed or incorrect diagnoses.⁴



Alopecia

Alopecia areata is a disorder characterized by loss of hair. Sometimes, this means simply a few bare patches on the scalp. In other cases, hair loss is more extensive. The exact cause of alopecia areata is not known. An autoimmune mechanism is suspected in this disorder.⁵



Key findings: Social support for women in the U.S.

Why do women receive less social support than men?

Confusion at diagnosis with other disorders⁶

Dismissal or lack of trust from physician⁶

Symptoms are confused with laziness or misunderstanding

Lack of female representation in research⁷

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2. National Human Genome Research Institute. Available at: Sickle Cell Disease (genome.gov)
3. Self-reported symptoms and objective measures in idiopathic hypersomnia and hypersomnia associated with psychiatric disorders: a prospective cross-sectional study - PubMed (nih.gov)
4. Orphanet: Idiopathic hypersomnia
5. National Organization for Rare Disorders (NORD). Available at: Alopecia Areata - NORD (National Organization for Rare Disorders) (rarediseases.org)
6. Gaslighting in women's health: when doctors dismiss symptoms | Northwell Health
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