

Revealing overlooked Symptoms of Myasthenia Gravis in France: findings from patient national survey

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INTRODUCTION

- Myasthenia gravis is an autoimmune disorder characterized by the presence of antibodies that induce dysfunction in neuromuscular transmission. It manifests as excessive fatigue of the striated muscles with exertion.
- The initial symptoms are most often ocular (ptosis, diplopia), then generalize to the entire body, which in some cases can lead to respiratory failure. However, myasthenia gravis often includes less visible symptoms like cognitive fatigue and fluctuating energy levels, which can significantly affect daily life. These hidden symptoms are frequently overlooked, leading to underestimation of the disease's impact.
- While primary symptoms are well-documented, urinary-sphincter and sexual difficulties remain notably underexplored^{1,2}. In collaboration with French Patient Advocacy Groups (PAG) and a neurologist with sexology expertise, this study aimed to assess the patients' experience with myasthenia, with particular focus on overlooked symptoms.

OBJECTIVE

- To evaluate the overall impact of myasthenia gravis and its symptoms on patients' daily lives.
- To reveal the lived experience of myasthenia gravis from the patient perspective in France.

CONCLUSIONS

- This study revealed that myasthenia gravis can significantly affect intimate and urinary functions, aspects that are often neglected, yet they have a substantial impact on patient physical and emotional well-being.
- Although a significant proportion of myasthenic patients experience sphincter dysfunction and sexual difficulties as confirmed in this study, it is often overlooked and not discussed with HCPs. Therefore, this study highlights the need for further exploration of these symptoms in the future during clinical assessment to improve patient care and address these invisible symptoms effectively.
- Collaborating with PAGs played a crucial role in raising awareness about these difficulties in France. Implementing systematic screening protocols and facilitating referral to urologist and sexologist could greatly improve patient care and support.

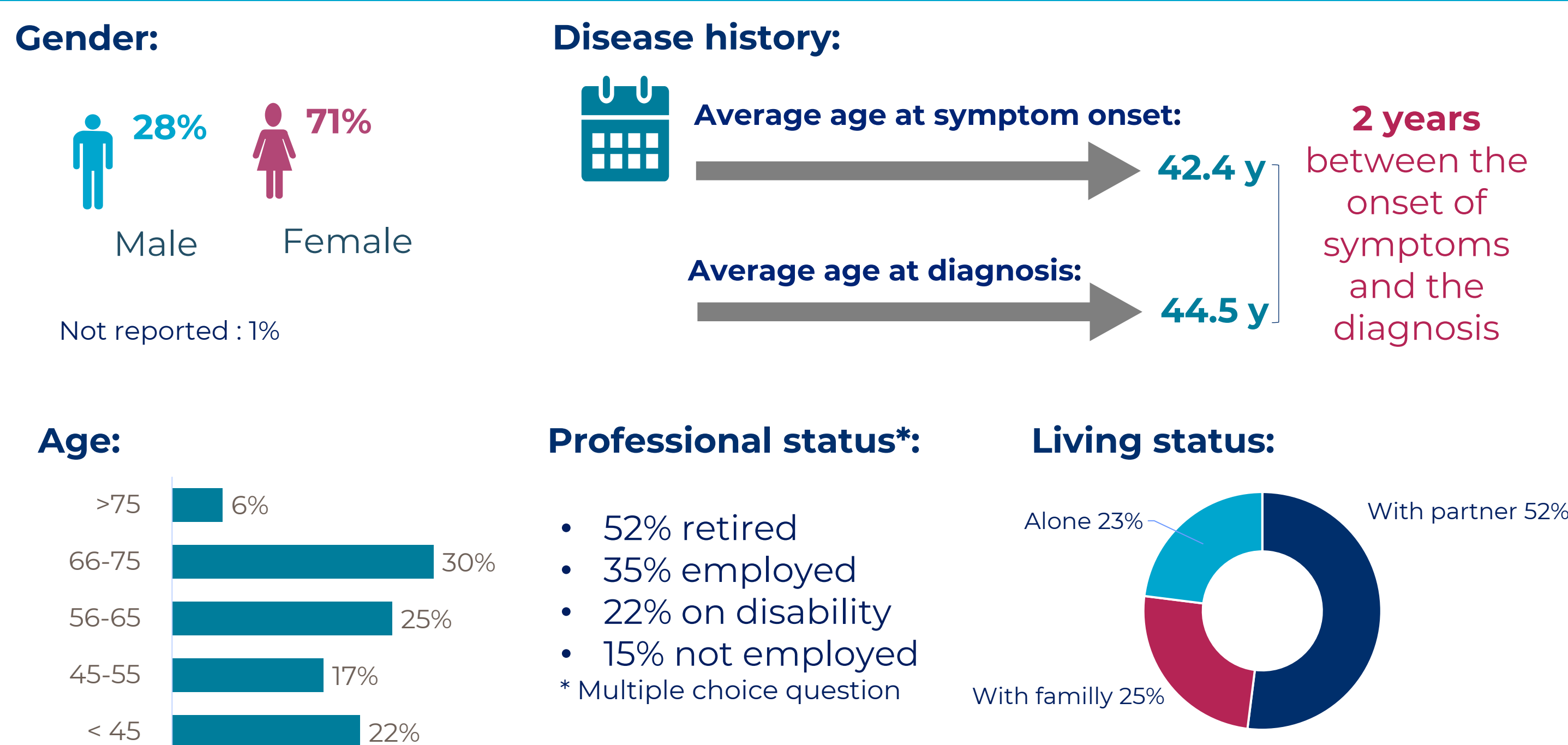
METHODS

This a cross-sectional national survey, launched by Alexion Pharma France- AstraZeneca Rare Disease, in collaboration with expert patients from the *Association des Myasthéniques Isolés et Solidaires (AMIS)*, the Myasthenia Interest Group of *AFM-Téléthon*, and Dr. Bresch.

- Qualitative phase:** Eight in-depth interviews were conducted within a focus group setting.
- Development of the questionnaire :** developed in collaboration with expert patients and a neurologist with sexology expertise.
- Recruitment and data collection for the quantitative phase:**
 - Eligibility criteria:** Adults diagnosed with myasthenia gravis.
 - Period:** from December 8, 2022, to February 15, 2023.
 - Participants were recruited through the websites and social media channels of the 2 PAGs, as well as through a distributed flyer.
- Statistical analysis and summary of findings:** mainly descriptive manner with the Chi-square test to compare percentages and the Student's t-test to compare means.

RESULTS AND INTERPRETATION

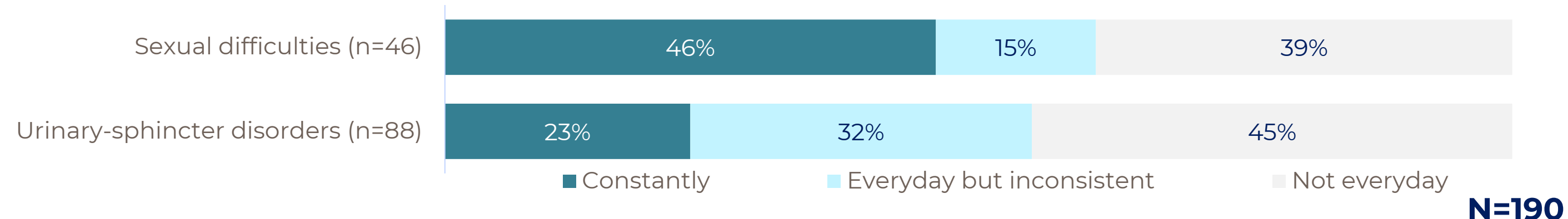
Description of respondents (N=190)



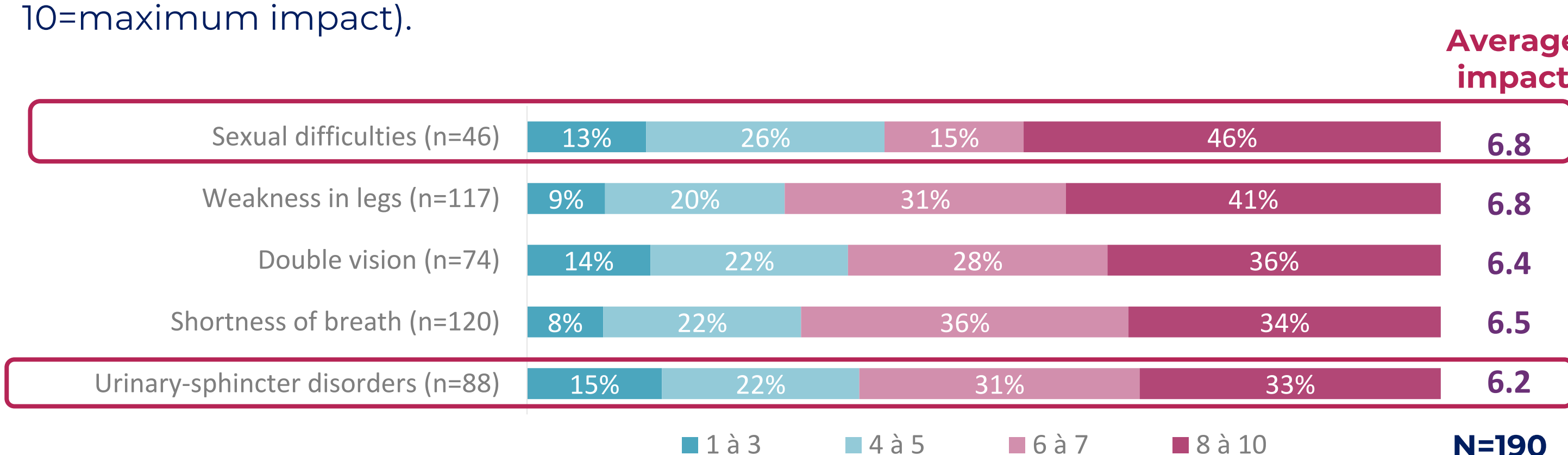
Manifestation of symptoms in daily life (N=190)

The survey showed that among 88 respondents, 23% constantly experienced urinary sphincter difficulties, while 45% faced these difficulties intermittently, which reflects the fluctuating nature of myasthenia gravis symptoms. Additionally, 46% of 46 respondents reported consistently experiencing sexual difficulties and 39% intermittently.

Frequency of symptoms manifestations at the time of survey

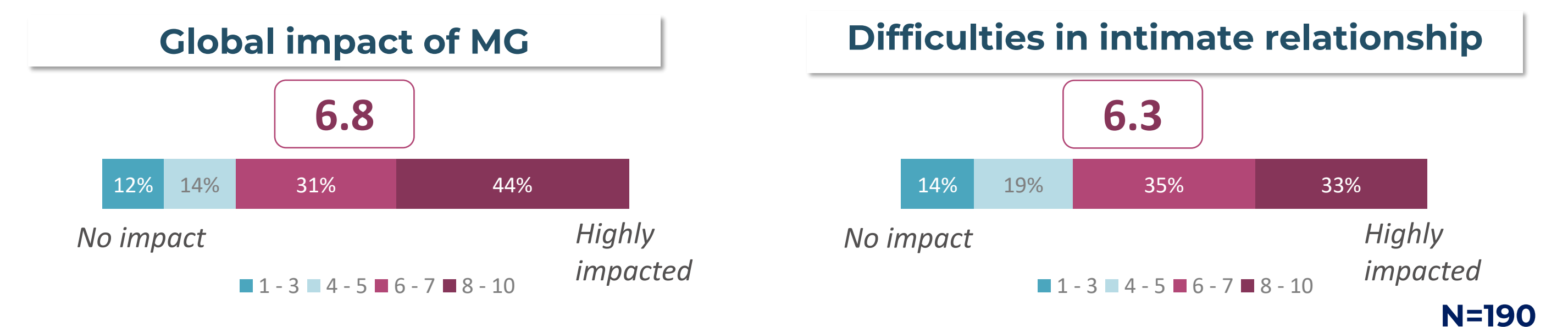


Among the 16 symptoms/difficulties, sexual disorders are the most impactful disorders for patients (n=46), with urinary-sphincter disorders ranking fifth. These disorders affect the daily lives of patients, as 46% and 33% of them respectively rate their sexual disorders and urinary-sphincter disorders between 8 and 10 (on a scale from 0 to 10, 0=no impact; 10=maximum impact).



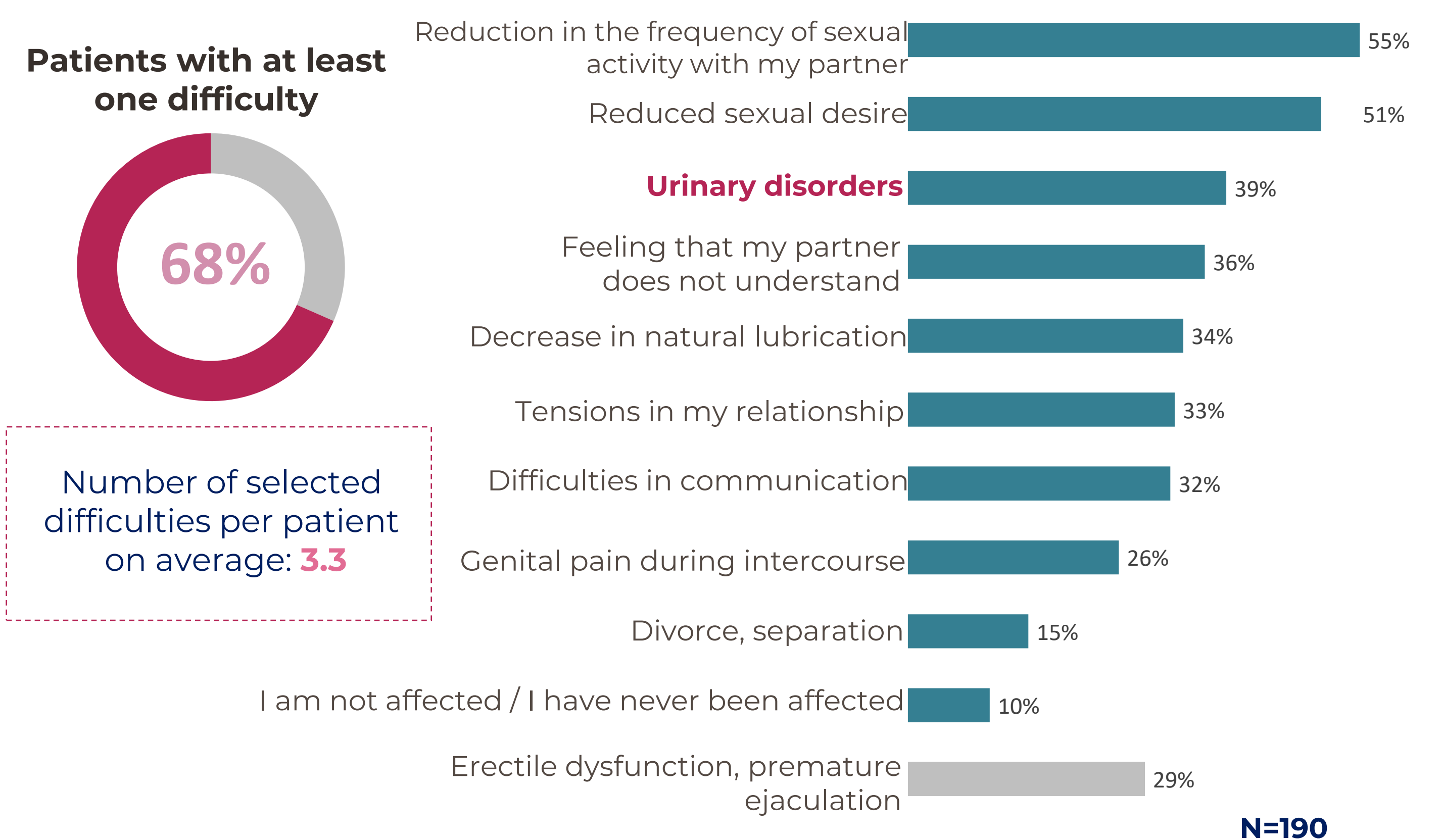
Impact of myasthenia gravis on Intimate and/or Couple Life (N=190)

Patients rated the overall impact of myasthenia gravis on a scale from 0 to 10 (0 indicating no impact, and 10 representing the maximum impact), with an average score of 6.8. The average impact on relationships and intimate life was slightly lower at 6.3.



Difficulties encountered in couple and/or intimate life (N=190)

Among the most commonly reported difficulties in couple and/or intimate life, over half of patients report a decrease in the frequency of sexual relations with their partner (55%), a decrease in desire (51%) and urinary disorders (33%).



Qualitative summary of patient' perspectives – Focus group (N=8)

The focus group included 6 females and 3 males. Three patients were living alone and 5 were with partner or family. The perspectives of patients on their difficulties in their intimate relationships are summarized below:

Changes in Intimacy: Patients struggle with physical symptoms or emotional changes that impact their desire or ability to engage in intimate activities.

Emotional and Social Barriers: The stigma and emotional impact of the illness can create barriers, making it difficult for patients to find a supportive and understanding partner.

Challenge in Finding a Partner: Single patients at diagnosis may struggle to find a partner later, as the diagnosis can be unsettling or frightening to potential partners.

Caregiver Role: The partner taking on the caregiver role can significantly shift relationship dynamics, leading to caregiver fatigue and strain.

Disruption of Relationship Balance: The illness often upsets the equilibrium within the relationship, impacting daily life and interactions. This might include changes in how responsibilities are managed, and difficulties to plan outings

Altered Self-Image: Patients may experience changes in their self-image and relationship with their body, which can affect their partner's perception of them and their sexual life.

Acknowledgment:

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References :

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