

Health-Related Quality of Life in a Large Cohort of Adult Patients with Sickle Cell Disease in France (THE DREPAntient study)

Issifou Yaya^{1,2}, Adrien Pourageaud^{1,2}, Benjamin Derbez³, Marie-Hélène Odièvre^{4,5}, Damien Oudin Doglioni⁶, Marieke Podevin⁷, Gaëlle Thomas⁷, Lisa Yombo Kokule^{1,2}, Frederic Galacteros⁸, Olivier Chassany^{1,2}, DREPAntient study group

1- Patient-Reported Outcomes Research (PROQOL), Unité de Recherche Clinique en Economie de la Santé (URC-ECO), Hôpital Hôtel-Dieu, AP-HP, Paris, France; 2- ECEVE, UMR-S 1123, Université Paris Cité, Inserm, Paris, France; 3- Université Paris 8, Cresppa-CSU59, Paris, France; 4- Department of General Pediatrics, Sickle Cell Center, Trousseau Hospital, Assistance Publique - Hôpitaux de Paris (AP-HP), Sorbonne Université; 5- INSERM U1134, Integrated Red Globule Biology, Paris, France; 6- Université Grenoble Alpes, Université Savoie Mont-Blanc, Laboratoire Interuniversitaire de Psychologie / Personnalité, Cognition, Changement Social (LIP/PC2S), Grenoble, France; 7- ARGO Santé, Orléans, France; 8- Sickle Cell Referral Center, Internal Medicine Unit, Henri Mondor Hospital, Assistance Publique-Hôpitaux de Paris, U-PEC; INSERM-U955, Institut Mondor, Université Paris-Est Créteil, Team 2 Transfusion et Maladies du Globule Rouge, Créteil, France,

Context

Sickle cell disease (SCD) is an inherited autosomal recessive disorder, affecting millions of people worldwide.

It causes a range of symptoms and acute and/or chronic complications that may impact the health-related quality of life (HRQoL).

In France, over 500 newborns are born with the SCD each year, with almost 32,400 people living with SCD.

Despite the challenges that may face many individuals with SCD, little is known about the HRQoL in that population.

Aim

To assess HRQoL and to identify associated factors in adult patients with SCD in France.

Methods

- **Cross-sectional, multicenter study** conducted from June 2020 to April 2021 in France, and in certain French overseas territories where SCD is highly prevalent.
- **Sociodemographic, and clinical data** collected online.
- **Outcomes** : HRQoL assessed by SF-36 French version, with 8 domains :
 - General health (GH, 5 items)
 - Physical functioning (PF, 10 items)
 - Physical role functioning (RP, 4 items)
 - Bodily pain (BP, 2 items)
 - Mental health (MH, 5 items)
 - Vitality (VT, 4 items)
 - Emotional role functioning (RE, 3 items)
 - Social role functioning (SF, 2 items)
- **and 2 summary scores** :
 - **Physical component summary (PCS)**
 - **Mental component summary (MCS)**
- **Scores from 0 (worst) to 100 (best).**
- **Statistical analysis**
 - Descriptive analysis
 - Multivariable linear regression analysis to identify factors associated with HRQoL (PCS and MCS)

Contact: Dr Issifou YAYA, E-mail: drissifouyaya@gmail.com



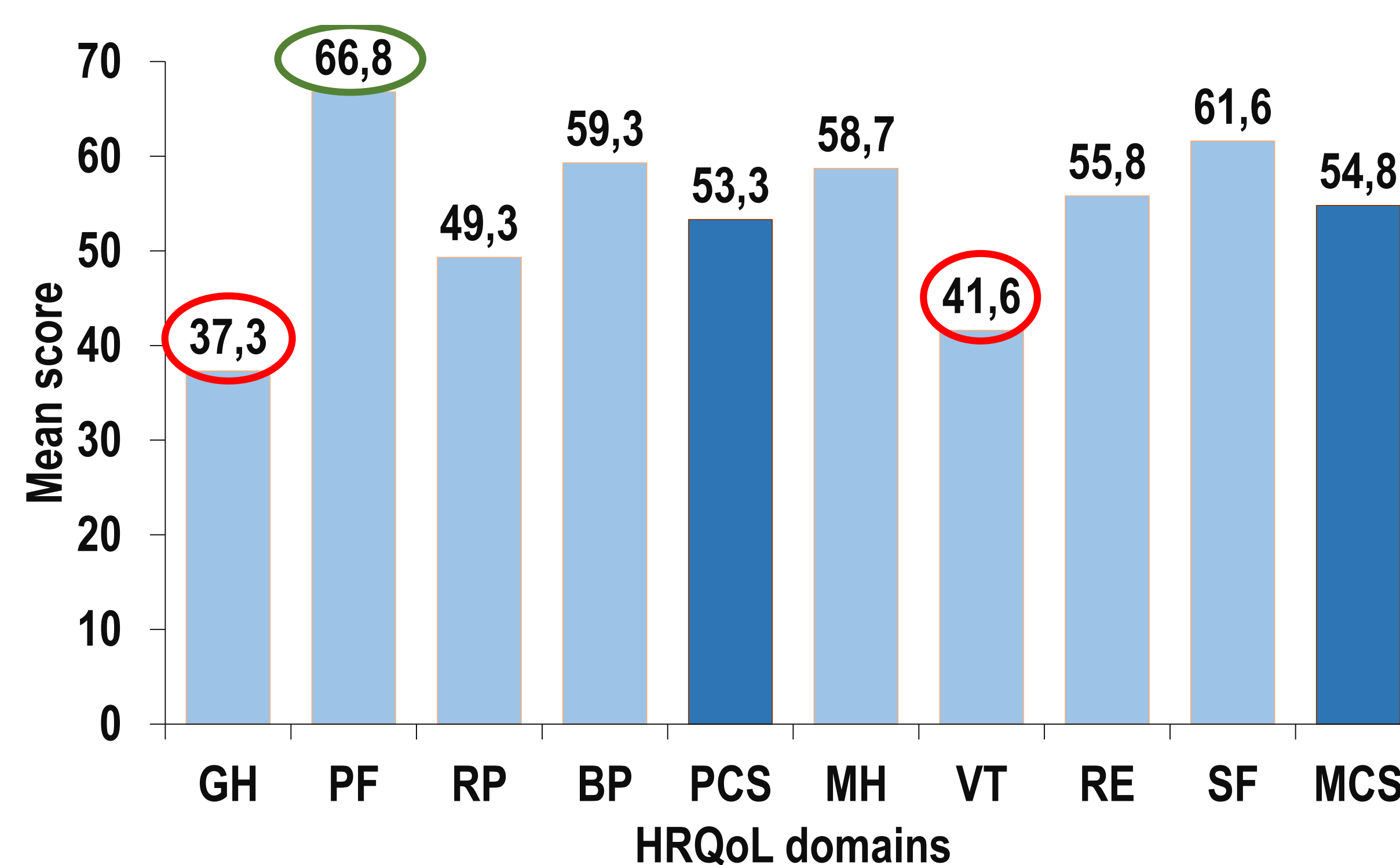
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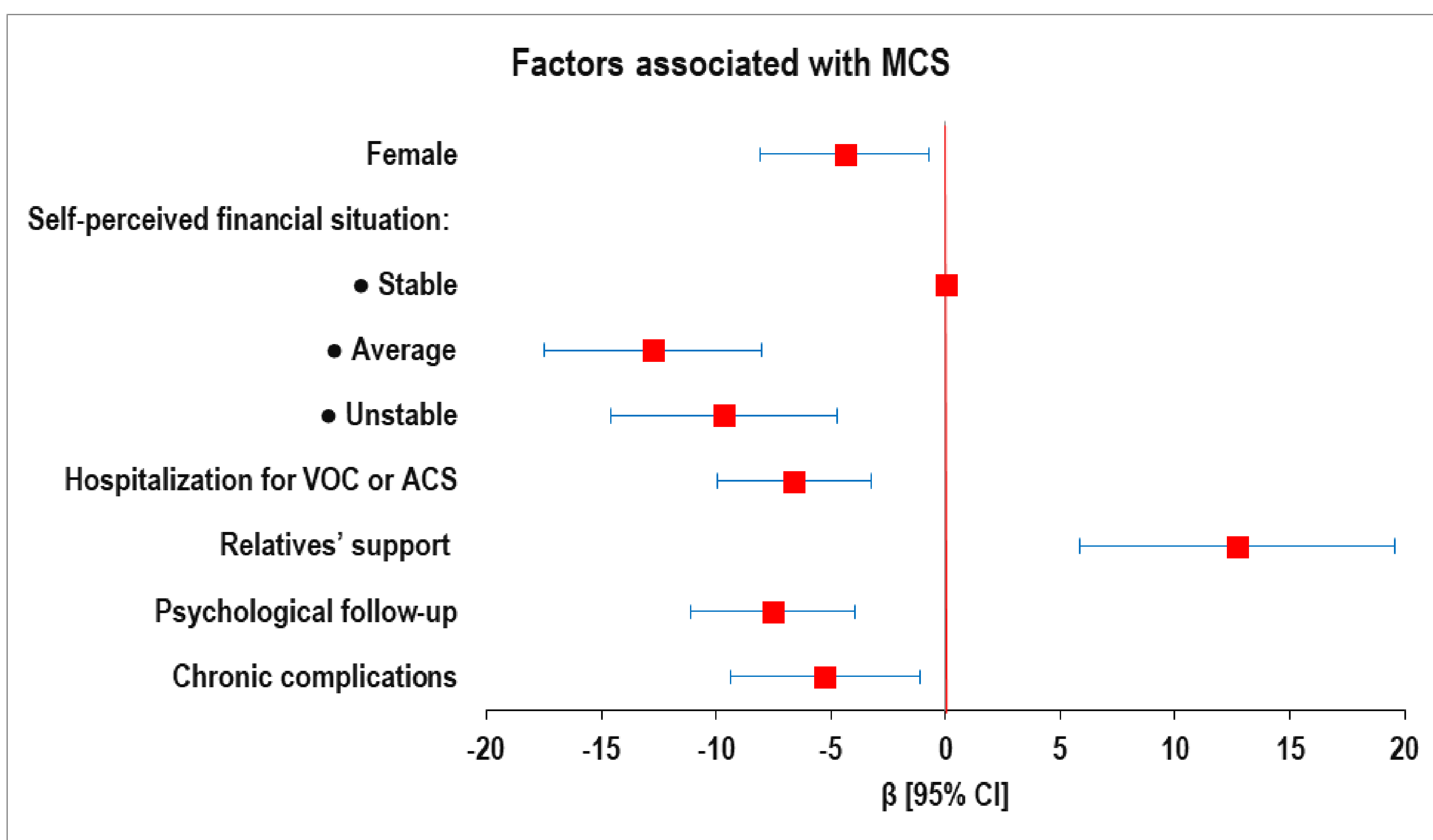
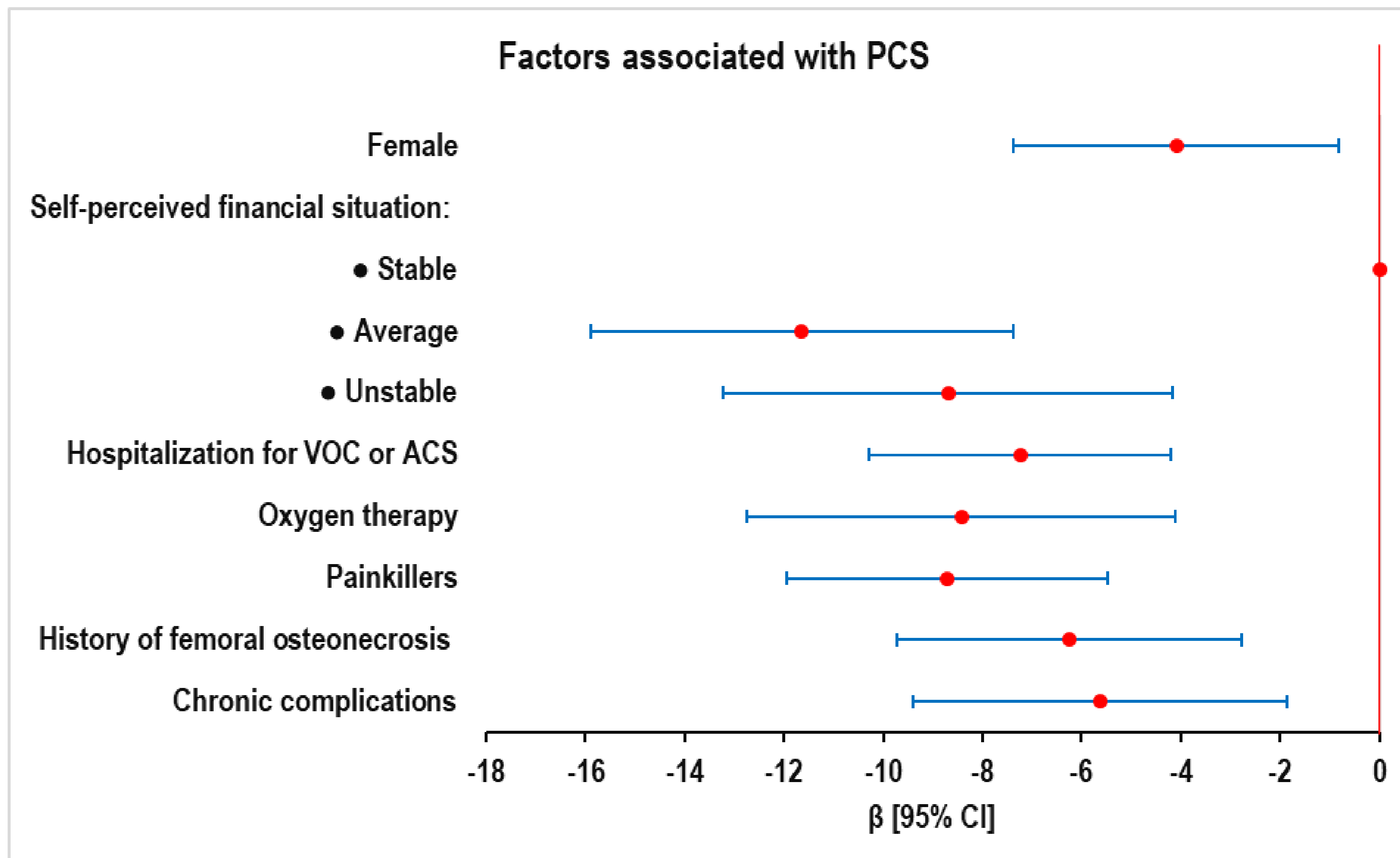
Results

- 570 participants, 33 yrs (median), sex ratio (M/F): 0.45

HRQoL domain scores



Factors associated with physical (PCS) and mental (MCS) health outcomes (multivariable linear regression):



Conclusion

Adults with SCD have poor HRQoL, especially women, those with unstable financial situation, chronic complications and those hospitalized for vaso-occlusive crisis (VOC) or acute chest syndrome (ACS).

This suggests that greater attention should be paid to HRQoL in adults with SCD, in terms of management strategies.

