

# Caregiver-proxy EQ-5D ratings of children with Gaucher Disease: a comparison of 5 domains between genders

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## 1 Objective

- ◆ The huge expenses and complications of Gaucher disease are associated with lower health-related quality of life (HRQoL), yet few studies comprehensively assessed the **gender-specific HRQoL among children patients**. This study aimed to assess the caregiver-proxy HRQoL on children patients with Gaucher disease, and explore the gender differences in the 5 domains of HRQoL.

## 2 Method

- ◆ Participants were recruited from the **China Gaucher Disease Association**, a national level NGO formed by Gaucher patients and their families. People taking care of **children aged 5-18** years old were eligible for this study. HRQoL was measured by EuroQoL Five-Dimension Questionnaire (**EQ-5D**) containing Mobility, Self-Care, Usual Activities, Pain/Discomfort, and Anxiety/Depression of the patients. Descriptive analyses of each domain were performed with STATA 14.0.

## 3 Result

- ◆ Among the 52 male patients and 26 female patients, over 70.5% (55 subjects) were reported as 'suffering Pain/Discomfort'. 43 subjects (55.1%) reported 'some or extreme problems' with the patients' usual activities. 36 (46.2%) subjects reported 'moderately or extremely Anxiety/Depression' of their kids. 35 subjects (44.8%) reported 'some or extreme problems with the patients' Self-Care ability'.
- ◆ Although male and female patients on average had **similar EQ-5D utility scores**, gender differences were observed in Mobility, Self-Care, Usual Activities, and Anxiety/Depression domains.
- ◆ Comparing to female child patients, **males** had a significantly higher change of having problems in **Usual Activities** (male: 59.6% vs. female: 46.2%,  $p < 0.05$ ) and **Anxiety/Depression** conditions (57.7% vs 45.2%,  $p < 0.05$ ), yet better **Self-Care Ability** (42.2% males had problems vs 49.9% females,  $p < 0.05$ ).

## 4 Conclusion

- ◆ The high proportion of children patients with problems in self-care, mobility, usual activities and mental health status implied huge physical and psychological burdens of patients' caregivers. Comparing the situation between genders, **male patients' usual activities and depression/anxiety conditions**, as well as **female patients' self-care ability**, may be the concern of further studies.

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