

Health-related Quality of Life of Patients with Epidermolysis Bullosa in Hungary: Results with the EQ-5D-5L and EQ-5D-Y-3L Preference-based Measurement Tools

Márta Péntek^{1,2}, Márta Medvecz³, László Gulácsi^{1,2}, Zsombor Zrubka^{1,2}, Renata Linertová^{3,4}, Áron Hölgyesi^{1,2}, BUR-EB Study Group

1 Health Economics Research Center, University Research and Innovation Center, Obuda University, Budapest, Hungary
 2 Doctoral School of Innovation Management, Obuda University, Budapest, Hungary
 3 Department of Dermatology, Venereology and Dermatocology, Faculty of Medicine, Semmelweis University, Budapest, Hungary
 4 Canary Islands Health Research Institute Foundation (FIISC), Las Palmas de Gran Canaria, Spain
 5 Red de Investigación en Servicios de Salud en Enfermedades Crónicas (REDISSEC), Madrid, Spain

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 Correspondence: pentek.marta@uni-obuda.hu

OBJECTIVES

As part of the BUR-EB project (<https://www.bur-eb.com/>) on the social and economic impact of epidermolysis bullosa (EB), we aimed to assess the health status utility values of the EB patients in Hungary to feed health economic evaluations of new innovative therapies with country-specific data.

METHODS

Study design: cross-sectional online survey conducted in 2024 in Hungary

Participants: patients suffering from EB without age restrictions

Recruitment: DEBRA Hungary (patient organization) and an University Hospital-based EB center

Data collection (self-reported survey):

- Direct medical, direct non-medical and indirect resource utilization due to EB
- Health-related quality of life was measured with standard questionnaires
 - EQ-5D-5L¹ → adults
 - EQ-5D-Y-3L² → children
- Hungarian value sets were used to calculate the index scores^{3,4}

Ethical approval was obtained from Medical Research Council, Hungary (BM/26385-3/2023)

References: 1 Herdman M. et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res.* 2011 Dec;20(10):1727-36. doi: 10.1007/s11136-011-9903-x. Epub 2011 Apr 9. | 2 Wille N. et al. Development of the EQ-5D-Y: a child-friendly version of the EQ-5D. *Qual Life Res.* 2010 Aug;19(6):875-86. doi: 10.1007/s11136-010-9648-y. Epub 2010 Apr 20. | 3 Rencz F. et al. Parallel Valuation of the EQ-5D-3L and EQ-5D-5L by Time Trade-Off in Hungary. *Value Health.* 2020 Sep;23(9):1235-1245. doi: 10.1016/j.jval.2020.03.019. Epub 2020 Aug 12. | 4 Rencz F. et al. Value Set for the EQ-5D-Y-3L in Hungary. *Pharmacoeconomics.* 2022 Dec;40(Suppl 2):205-215. doi: 10.1007/s40273-022-01190-2. Epub 2022 Sep 20.

CONCLUSIONS

This first EB study with the EQ-5D instruments in Hungary show a significant burden of EB on patients' health-related quality of life. Our data can be used to estimate utility scores but further studies involving larger samples of different EB subtypes are encouraged to confirm and refine our results.

RESULTS

- Altogether, 9 adults (female 44.4%) participated in the survey and out of the 13 child (female 53.8%) participants EQ-5D-Y-3L was applicable for 7 children.
- Adults' mean EQ-5D-5L index value was 0.47 (±0.5) and children's mean EQ-5D-Y-3L was 0.71 (±0.2).
- Figure 1 and Figure 2 show the reported problem levels on each instruments.

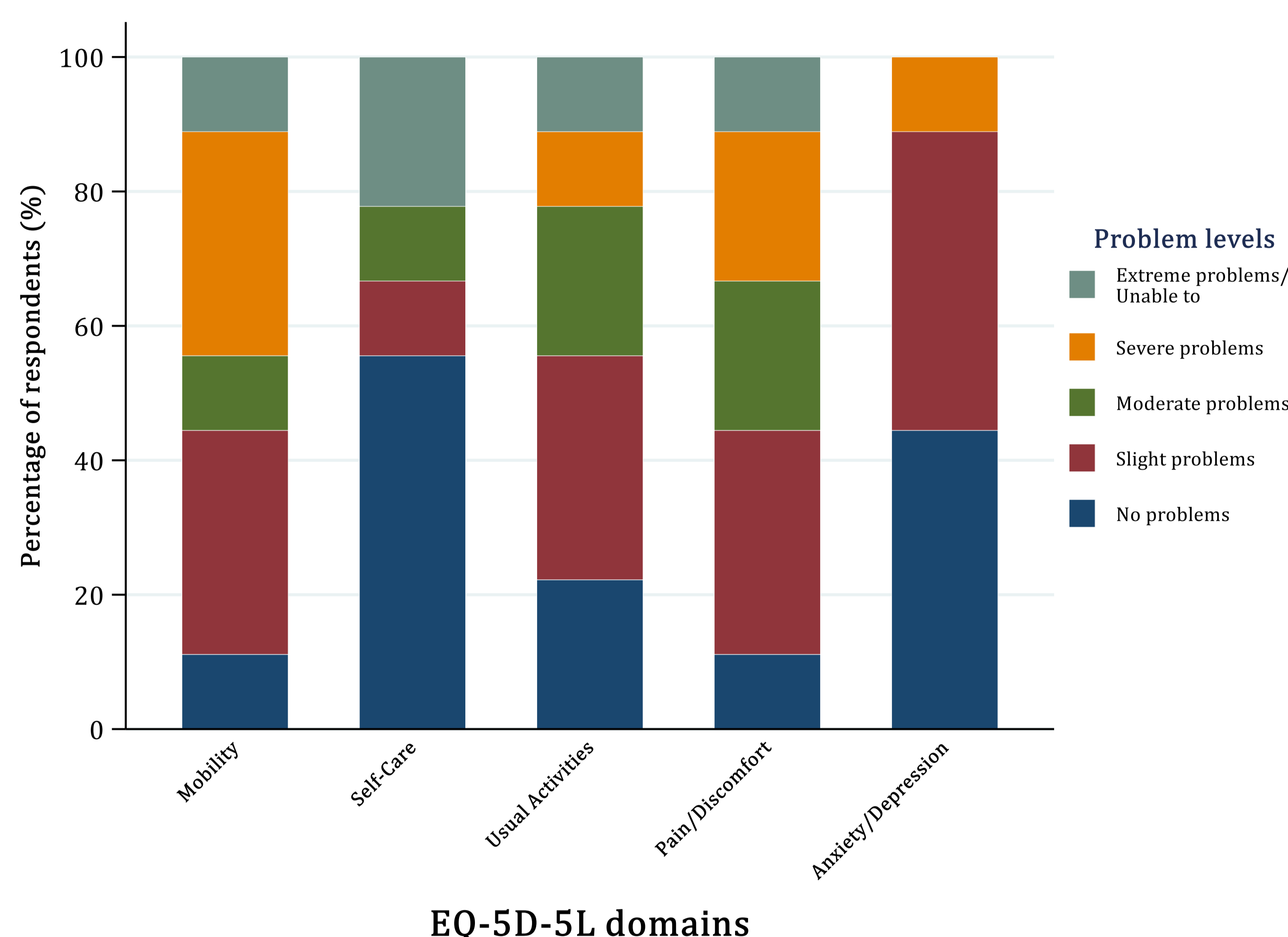


Figure 1. Adult patients' reported problems by EQ-5D-5L domains (N=9)

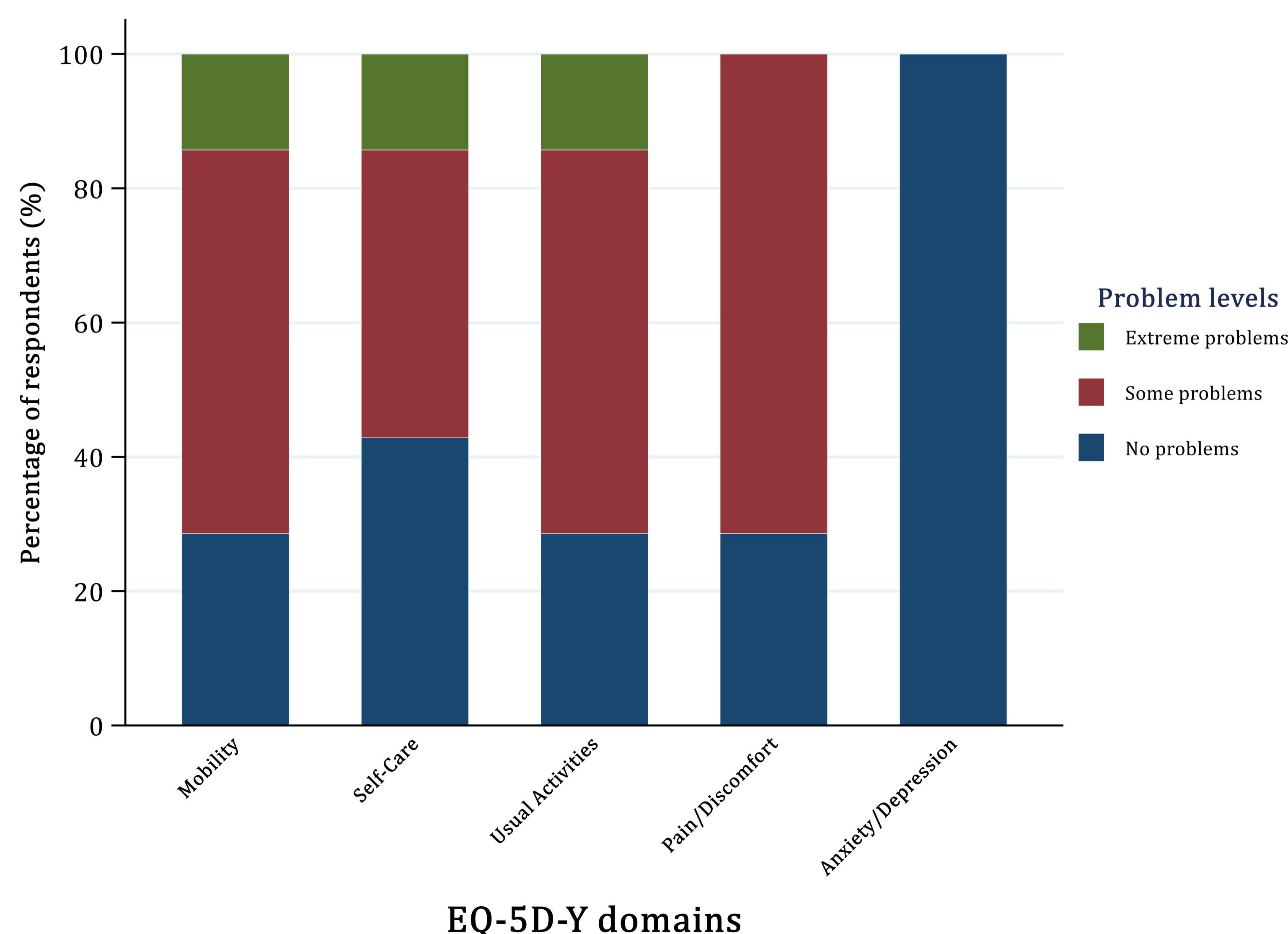


Figure 2. Pediatric patients' reported problems by EQ-5D-Y-3L domains (N=7)