

# Less Ready for Adulthood? —

## Turner syndrome has an impact on transition readiness

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### Objective

For girls diagnosed with Turner syndrome (TS) health care transition (HCT) is particularly challenging. Young women with TS are known to be especially at risk for loss to follow-up. Standardized processes for HCT are often lacking. A growing body of literature recommends the assessment of readiness for transition before releasing patients from pediatric care. Assessing differences in transition readiness might be crucial for identifying special needs in specific patient cohorts. Autonomy, sufficient health literacy and adherence to therapy regimen are essential parameters for successful transition.

### Patients and Methods

#### Comparison of TS patients and controls:

- n=52, three study sites
- Comparison of age-matched (14 to 23 years) female patients with TS (n=26) and control group (n=26) regarding transition readiness scores
- **Control group:** girls diagnosed with type 1 diabetes or with rheumatic conditions
- **Data obtained:**
  - transition readiness score (TRAQ-GV-15)
  - "fill-in time", "help needed", "consultation time"
  - first language, number of hospital visits/year

Fig.1: Description of the cohort of tested adolescents

#### Description of patient cohort

Average age at the time of the assessment was 17.2 (±2.1) years for the TS group and 17.4 (±2.4) years for the control group. 4/26 (15.4%) TS patients were not treated with growth hormones, 4/26 (15%) had spontaneous puberty. One participant was diagnosed in her country of origin and detailed information on history of oestrogen substitution or spontaneous puberty was not obtained. The rest of the TS patients received oestrogen substitution for induction of puberty at a mean age of 13.1 years. Pubertal status has not been assessed in the control group.

#### TRAQ-GV-15

TRAQ-GV-15 (Culen et al. 2019), the recently cross-culturally adapted German version of the Transition Readiness Assessment Questionnaire TRAQ 5.0 (Wood et al. 2014) was applied to assess transition readiness. This disease neutral instrument comprises 15 items, assigned to three domains (domain 1 "Autonomy", domain 2 "Health Literacy", domain 3 "Adherence"). It yields an overall sum score as well as subscores for the three domains.

Link for download:

[https://www.degruyter.com/view/j/jtm.2019.1.issue-1/jtm-2018-0005/suppl/j\\_jtm-2018-0005\\_suppl.pdf](https://www.degruyter.com/view/j/jtm.2019.1.issue-1/jtm-2018-0005/suppl/j_jtm-2018-0005_suppl.pdf)

#### References

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### Results

#### Handling of the questionnaire (TRAQ-GV-15)

Patients of the TS group needed significantly more time to fill in the questionnaire as well as significantly more consultation time than controls. (Fig.1)

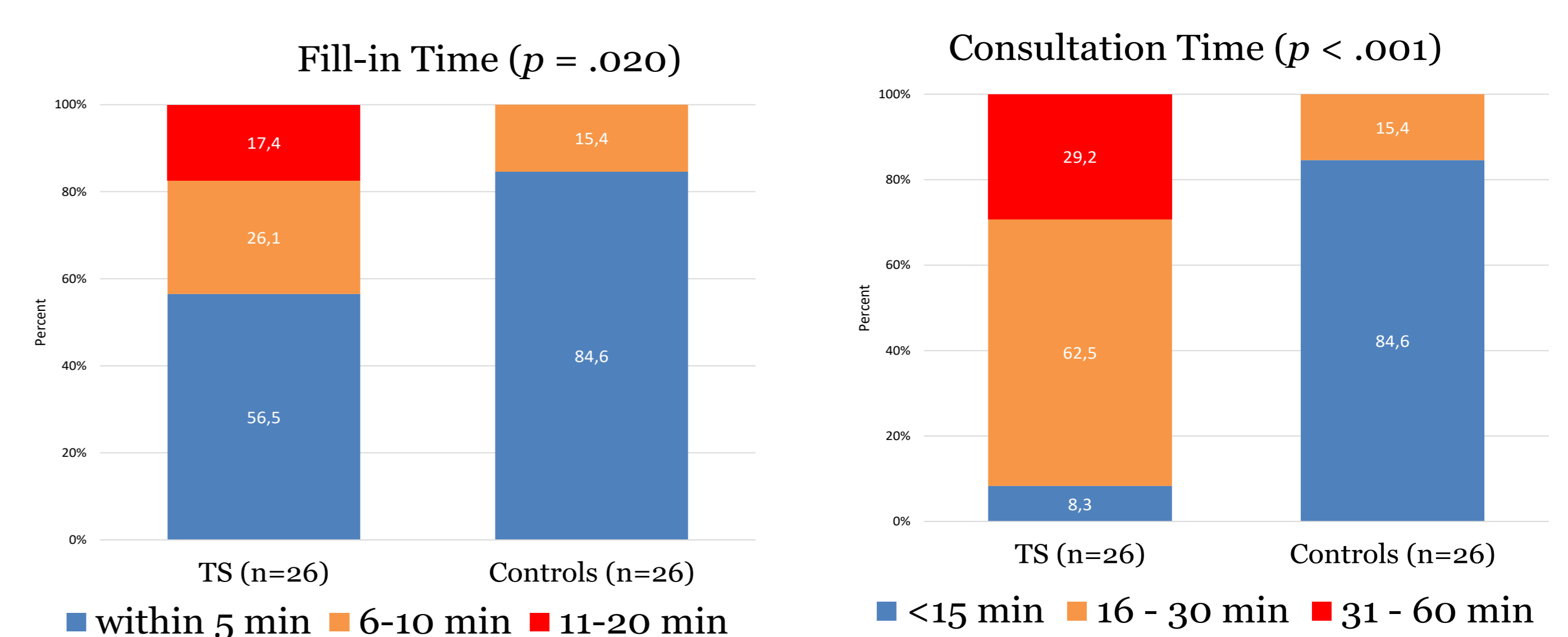


Fig.2: Comparison of TS and controls regarding handling the TRAQ-GV-15

#### Differences in TRAQ-GV-15 scores

TS patients scored significantly lower for the overall TRAQ-GV-15 sum scores and for the domain 1 "autonomy" (Fig.2). Scores for the domains „Health Literacy“ and „Adherence“ showed no significant difference when compared to the control group (Fig.2).

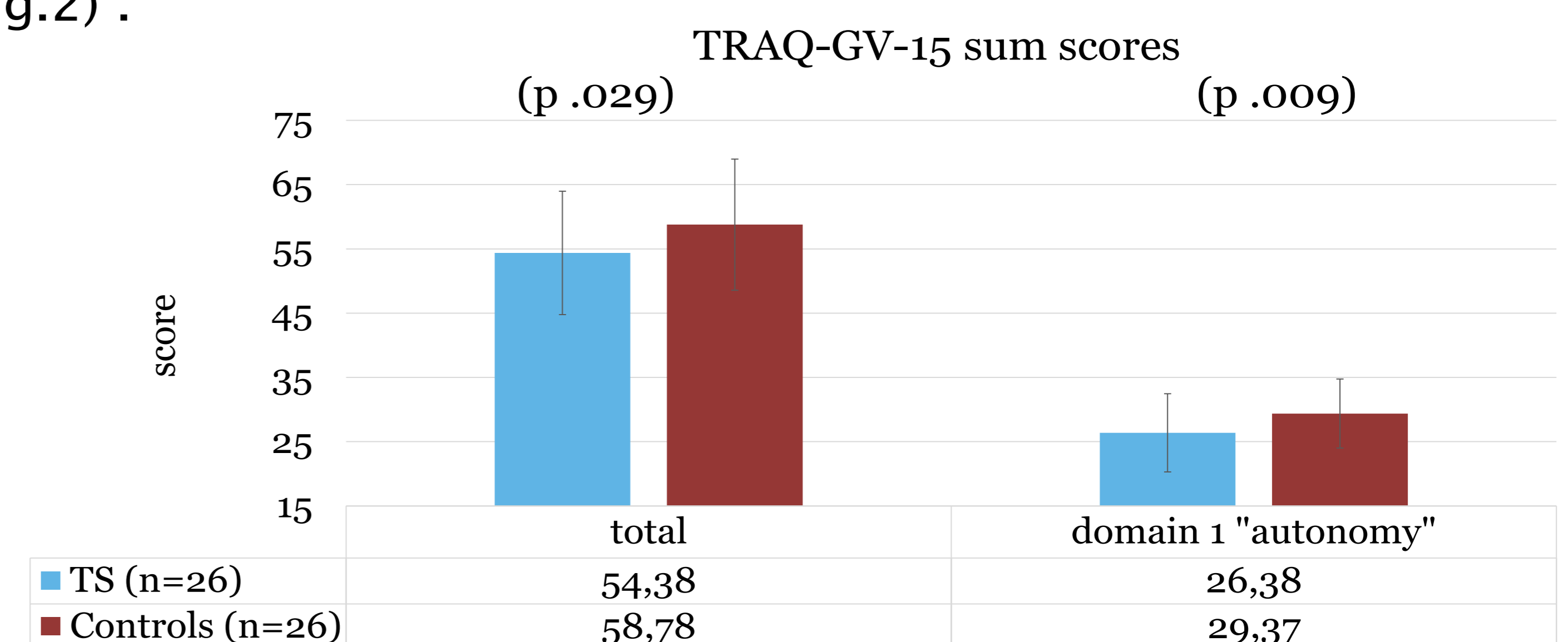


Fig.3: Comparison of TS and controls regarding TRAQ-GV-15 scores

### Conclusion

Patients with TS are less ready for transition than age-matched patients with less impairing chronic condition. Thus, special attention should be given to improvement of health autonomy in young women with TS. Moreover, sufficient time for consultation should be scheduled, as in our study more time was needed by the TS patients. Assessment of transition readiness in the clinical setting helps to identify areas for improvement in TS patients' skills and knowledge regarding their condition.

### Future research

Studies on the assessment of transition readiness with larger patient cohorts could potentially help to differentiate structural, individual and conditional influences on outcome. This would facilitate the development of targeted interventions.