

Health Status in Women with Turner Syndrome

– a questionnaire study on health status, education and work participation

Eva Elisabeth Næss, Frambu Resource Centre for Rare Disorders, Norway

David Bahr, Frambu Resource Centre for Rare Disorders, Norway

Claus H.Gravholt, Medical Department M (Endocrinology and Diabetes) and Medical Research Laboratories, Århus sygehus, Aarhus University Hospital, Denmark



Objective

To explore level of education, work participation, medical conditions and health status in adult women with Turner syndrome (TS) and compare with a control group (C) matched for age and place of residence of the TS group.

Methods

A questionnaire study where the Turner syndrome group was recruited from Frambu Resource Centre for Rare Disorders and the Norwegian Turner Syndrome Association. The control group was established by The Norwegian National Registry.

Participants

80 women with Turner syndrome from 19 to 63 years (34±12). Control group with 214 women from 18 to 63 years (33±11), (p=0.3).

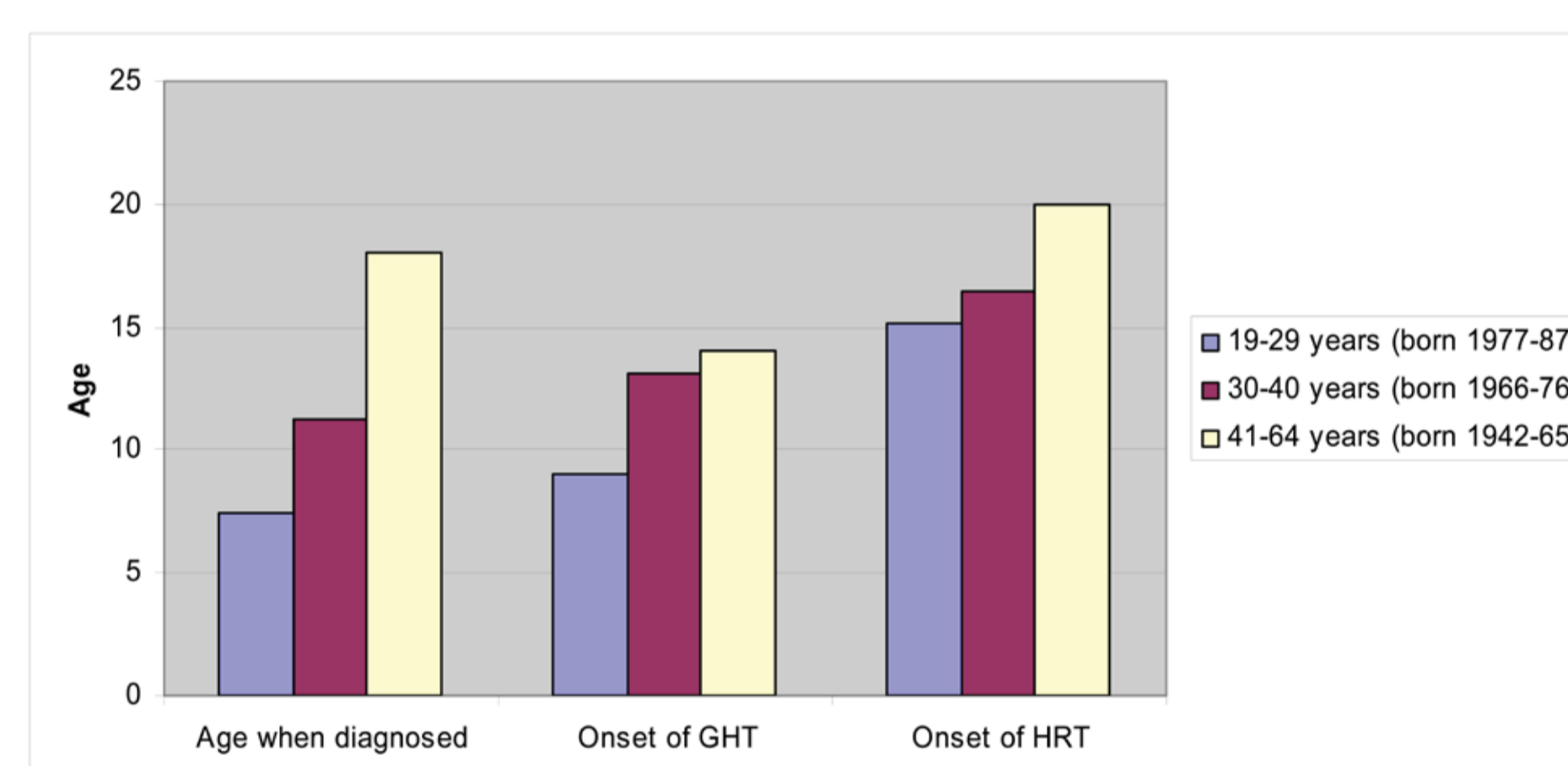
Results

Self Reported Health Complaints

Health complaints	TS n (%)	Control n (%)	P value
Hearing loss	52 (64)	14 (7)	<0.0001
Strabismus	27 (34)	8 (4)	<0.0001
Shortsightedness	44 (55)	74 (35)	<0.0001
Longsightedness	22 (28)	35 (16)	0.01
Kidney problems	3 (4)	2 (1)	0.1*
Hypothyreosis	9 (11)	4 (2)	0.0008*
Osteoporosis	6 (8)	1 (1)	0.001*
Scoliosis	12 (15)	6 (3)	<0.0001
Kyphosis	3 (4)	2 (1)	0.1*
Oedema of the legs	15 (19)	12 (6)	0.0005
Type 1 diabetes	1 (1)	1 (1)	0.4*
Type 2 diabetes	6 (8)	0 (0)	0.0002*
Bowel disease	12 (16)	9 (4)	0.0004
High blood pressure	15 (19)	4 (2)	<0.0001*
Myocardial infarction	3 (4)	1 (1)	0.05*
Coarction of the aorta	5 (6)	1 (1)	0.004*
Dissection of aorta	0 (0)	0 (0)	¶
Dental malalignment	20 (25)	8 (4)	<0.0001
Disease of the gingiva	8 (10)	8 (4)	0.04*
Underbite, undershot jaw	3 (4)	3 (1)	0.2*
Overbite, receding jaw	19 (24)	23 (11)	0.002
Overlapping molars	6 (8)	2 (1)	0.004*

Data are presented as the number (percentage) of patients reporting a specific health complaint. P-value calculated using the χ^2 statistic unless otherwise stated. *Fishers exact test. ¶ Not possible to compute a p-value.

Age when diagnosed, onset of treatment with growth hormone therapy (GHT) and hormone replacement therapy (HRT) shown in age groups



Note that older women in the two oldest cohort born before 1976 reporting receiving GH treatment, have probably been given other growth promoting therapy in the form of oxandrolone or other steroid therapies as neither recombinant nor pituitary GH were available at the time they report starting GHT.

Health Status. Data from the questionnaire Short Form 36 (SF 36)

	n	Turner syndrome Median (Range)	n	Controls Median (Range)	p-value
Mental health	75	80.0 (10-100)	214	80.0 (0-100)	0.5
Vitality	75	55.0 (10-90)	214	60.0 (10-90)	0.4
Bodily pain	76	84.0 (22-100)	214	84.0 (0-100)	0.4
General health	76	68.5 (10-100)	214	87.0 (5-100)	<0.001
Social functioning	78	100.0 (0-100)	214	100.0 (0-100)	1.0
Physical functioning	76	95.0 (15-100)	214	100.0 (20-100)	<0.001
Role physical	76	100.0 (0-100)	214	100.0 (0-100)	0.3
Role emotional	74	100.0 (0-100)	214	100.0 (0-100)	0.3

Data are presented as median and range for both groups. Best health status score is 100. The Mann-Whitney test was used to test data.

Level of education

Years of education	TS n (%)	Controls n (%)	p-value
up to 12 years	44 (55)	94 (44)	0.2
up to 15 years	23 (29)	77 (36)	
more than 15 years	13 (16)	43 (20)	

Work participation

Work participation	TS n (%)	Controls n (%)	p-value
Employed or under education	71 (89)	186 (91)	0.096
Disability pension	7 (9)	10 (5)	
Out of work and domestic work	2 (2)	18 (7)	

Conclusion

Women with Turner syndrome attain the same level of education and employment as controls. They report more frequent occurrence of medical conditions, but scored lower on only two subscales in the SF-36. Despite considerable medical morbidity, women with Turner syndrome seem to cope well with life.