

Attitudes of parents of Klinefelter boys and Flemish pediatricians towards neonatal screening and fertility preservation techniques in Klinefelter syndrome.



Gies I¹, Tournaye H², De Schepper J¹.

¹ Dept of Pediatrics, UZ Brussels, Brussels, Belgium; ² Centre for Reproductive Medicine, UZ Brussel, Vrije Universiteit Brussel, Laarbeeklaan 101, 1090 Brussels, Belgium.



BACKGROUND

Until recently, Klinefelter syndrome (KS) boys were considered to be infertile. Recent studies however show a 50-60% success rate of spermatozoa and/or spermatogonial stem cell (SSC) recovery by using the newest fertility preservation techniques in both KS adults and adolescents. Cryopreservation and transplantation of SSC's is currently only successful in animals.

OBJECTIVES AND METHODS

To evaluate the attitude of the parents of KS boys as well as of the Flemish pediatricians with regard to early detection of KS and fertility preservation options in pubertal KS boys. The written response to a specifically designed questionnaire investigating the acceptability towards neonatal screening for KS and the use of testicular biopsy and sperm collection in 49 pediatricians and 18 parents of KS boys was studied.

RESULTS

In total 18 responses from parents of KS boys (37.5 % response rate) were retrieved and 49 pediatricians (11% response rate) returned the questionnaires.

All parents and 67% of the responding pediatricians consider neonatal screening for KS to be a good option, in view of early detection and treatment of medical and psychosocial complications.

All parents stated that they were counseled on the expected infertility of their son at diagnosis. However in only 55.6% information on the use and outcome of TESE in adult KS patients was given.

83.3% of the parents agree on performing a testicular biopsy in their pubertal KS boy, 72.2% are in favor of spermatozoa banking after masturbation, and 77.7% agree on spermatozoa banking after penile vibrostimulation or rectal electrostimulation (PVS/RES) under general anesthesia.

The presence of behavioral/mental problems generated a significantly ($p=0.03$) more frequent negative attitude towards fertility preservation. No effect of the studied parental socio-demographic characteristics on the responses to the questionnaires was seen.

69% of Flemish pediatricians would counsel their KS patient in favor of detection and cryopreservation of spermatozoa after masturbation, and 71.2% agreed on testicular biopsy to detect and isolate spermatozoa or SSC's for cryopreservation in minor KS patients.

Table 1. Socio-demographic characteristics of KS

	KS parents (n=18)
Median age (range) (yr)	45 (31-56)
Median number of children	2
Infertility requiring ART (number)	3
Higher education level (number)	10

Table 2. Number of KS patients with comorbidities

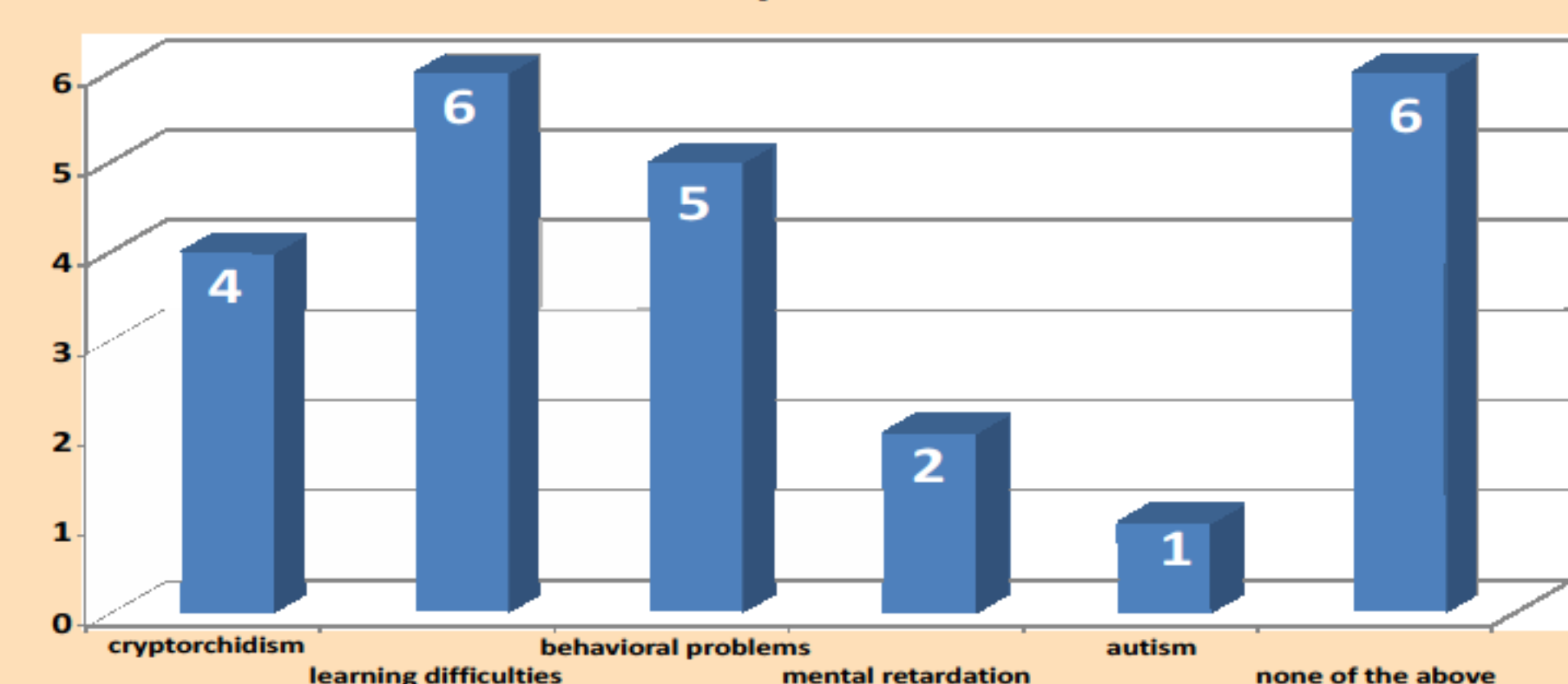
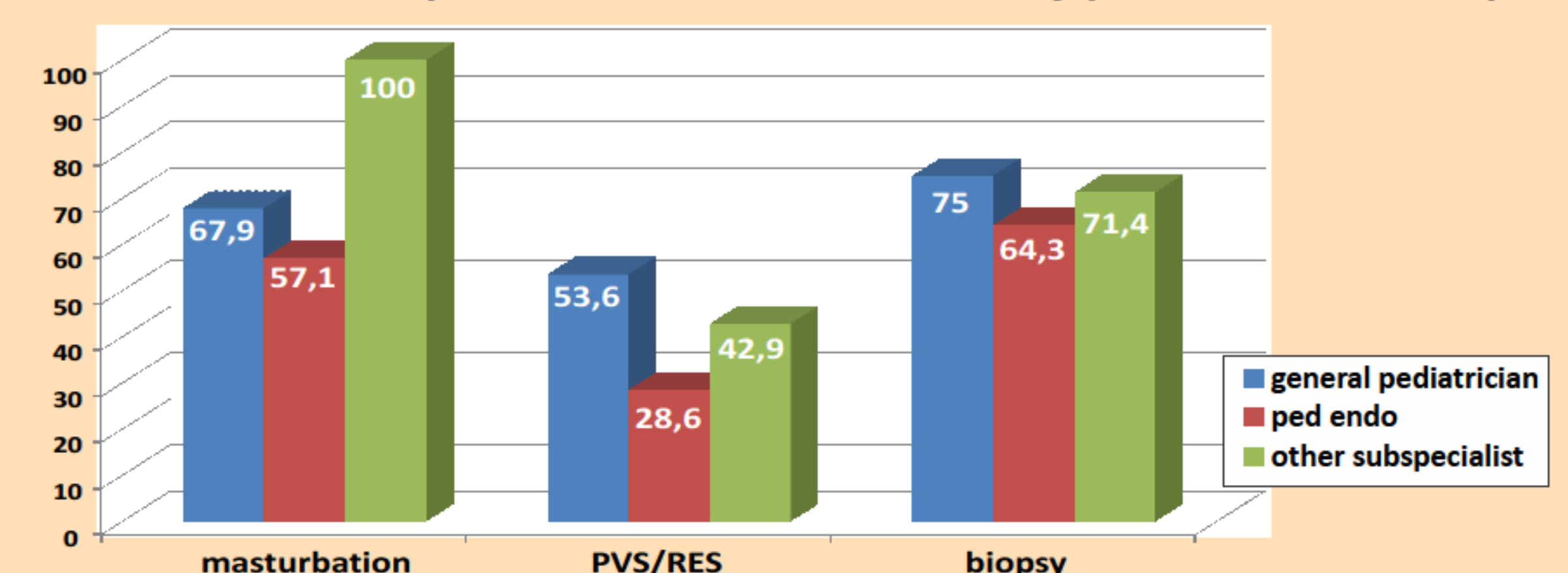


Table 3. Socio-demographic characteristics of the pediatricians

	General Pediatricians	Pediatric Endocrinologists	Other subspecialists	All
N (%)	28 (57.1)	14 (28.6)	7 (14.3)	49
Median age (range) (yr)	40.5 (29-66)	36 (25-46)	44.5 (30-53)	36 (25-66)
Gender (♂:♀) (% ♂)	8:20 (40)	4:10 (40)	1:6 (17)	13:36 (36.1)
Working in university setting (yes:no) (% yes)	15:28 (53.6)	8:14 (57.1)	1:7 (14.3)	24(49)
Children of your own (yes:no) (%yes)	23:5 (82.1)	12:2 (85.7)	5:2 (71.4)	40:9 (81.6)
Relatives with infertility (yes:no) (%yes)	11:17 (39.3)	7:7 (50)	4:3 (57.1)	22:27 (44.9)

Table 4: Attitudes of pediatricians on different fertility preservation techniques



CONCLUSIONS

The majority of KS parents and Flemish pediatricians who completed the questionnaire were in favor of neonatal screening of the syndrome. Furthermore, both sperm collection and SSC collection are highly appreciated by parents and pediatricians, even when success rates of fertility preservation techniques are still low.

Correspondence to : Inge.Gies@uzbrussel.be

