



Clinical Practice and Therapeutics

Down syndrome is not disappearing in Taiwan

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Trisomy 21 [Down syndrome (DS)] is the most common chromosome anomaly in live births and the most frequent form of intellectual disability caused by a numeric chromosomal disorder. In 1985, Taiwan started a prenatal DS screening program by means of amniocentesis for pregnant women more than 35 years old. Tests of maternal serum alpha-fetoprotein and human chorionic gonadotropin during the second trimester were begun in 1994. During the past 10 years, the rate of babies with DS born alive has decreased from 76% to 32.2%, and the rate of those stillborn by therapeutic abortion has increased from 23.1% to 73%. Most pregnant women in Taiwan select therapeutic abortion when DS is diagnosed prenatally.

The mother of our patient was a 36-year-old woman, gravida 3 previa 3, who gave birth at full term with no known perinatal insult. The woman had received maternal serum screening at 18 weeks gestational age, and the risk was 1:87. The woman was also found to have a thick nuchal fold on prenatal fetal ultrasonography, and refused amniocentesis for religious reasons. The mother was looking forward to the birth and the parents said that the baby was one of nature's gifts and they respected and were willing to follow the diversity of life. The peripheral blood chromosome count was 47, XX, +21; a female infant with DS was thus confirmed. (Fig. 1).

Our patient is now 3 years 6 months old. The patient's parents have become active lifelong learners and public educators. They learned the techniques of an early infant stimulation program, and are very familiar with health care systems from different

professions and social resource allocation. They have organized a family support group locally, created a system for a friendly DS living environment, initiated a destigmatization movement, and executed an individual educational system. They are generating



Fig. 1. Our patient has a facial appearance typical of children with Down syndrome (with parent's permission for scientific publication).

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Items / Age (years old)	0-3	3-6	6-12	12-22	22-40	40-65	>65
Infant stimulation program							
Individual education system							
Occupational/physical training							
Sheltered occupation or employment							
Life long elderly care and rehabilitation center							
Self care ability							
Patient and family association							
Health care	1 *	2 *	3 *	4 *	5 *		
1. New born screening, cardiac echography, hearing and ophthalmologic assessment, vigilance for leukemia 2. Vigilance for cervical spine instability and leukemia, dental care, evaluation of developmental, behavior, and psychiatric issues, intelligence quotient (IQ) test 3. Programs for a healthy life style and regular exercise, follow-up of developmental, behavior, and psychiatric issues and IQ test 4. Sexuality and reproductive health, prevention of obesity and periodontal disease 5. Recognition of dementia and psychiatric problems * Annual thyroid function test and survey other healthcare issues.							

Fig. 2. Gradational and holistic care of people with Down syndrome.

lifelong elderly care for people with DS, and are actively communicating their care experiences with people with DS through public education.

DS does not disappear at maturity and the rights of people with DS must be valued by society. Stereotypical perceptions from the public should be changed. Keeping pace with medical advances and generating a holistic health care team through evaluation, prevention, monitoring, and vigilance are mandatory for medical personnel (Fig. 2).

Further reading

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