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Title (type in CAPITAL LETTERS, leave one blank line before the text) THE SOCIAL ACTIVITIES AND QUALITY OF LIFE IN YOUNG ADULT MYELOMENINGOCELE: QUESTIONNAIRE ANALYSIS.

Aims of Study

Recent multidisciplinary care since immediately after birth had significantly impacted on the long-term survival of children with myelomeningocele. Clean intermittent catheterization (CIC), which has been a central core of the urinary management at the last quarter of the 20th century, is undoubtedly one of the major contributors to the survival and the social abilities. The quality of life of myelomeningocele in adulthood is supposed to be improved, however, there has been little information regarding the long-term social activities in these individuals. Herein, we report the long-term urological status and the social activities of adult myelomeningocele in northern part of Japan.

<u>Methods</u>

Of 224 patients with myelomeningocele who are registered in our hospital records, questionnaire was mailed to 66 patients older than 18 years to examine educational achievement, employment, living arrangement and interpersonal relationship as well as genitourinary status and bowel control.

<u>Results</u>

Forty-one (62%) responded the questionnaire (21 female and 20 male, 18 to 40 years, median 26 years). Thirty-two (78%) were walking with or without devices in this study population. Thirty-three (81%) had been treated with CIC without urinary tract infection. Previous surgery included augmentation (6), antireflux procedure (4), and sling procedure (4). Renal deterioration was noted in one (2.4%) with late institution of CIC, who subsequently underwent renal transplantation. Two patients underwent intestinal urinary diversion in the childhood. There were 33 patients (81%) who completed high school (97% in general population). Eleven (27%) had some education beyond high school (31% in general population) (table 1). Twelve female (63%) and 15 male (79%) had been employed (table 2). Living status revealed 22% of

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independence (10% married). Both erection and ejaculation were present in 9 of 17 men (53%), while only 5 of them had sexual partner. In total, 31% (33% in female, 29% in male) had a partner. Although amount of urinary leakage was considerable only in a third, 85% was never satisfied with the current urinary control regardless the incontinence grade. Thirty-nine percent of the patients had unacceptable fecal incontinence (20% in female, 58% in male, P<0.05).

<u>Conclusions</u>

Adult myelomeningocele achieved comparable level of education as general population, whereas other social activities were not. Despite urinary leakage was not severe under CIC, majority of them was eager to have " dry life" for further activities including sexual life. Fecal control was another serious concern, especially, in male.

Table	1:	Educational	achivement
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2	-junior high school(%)	high school(%)	college-(%)	
	8 pts. (20)	22 pts.(54)	11 pts. (27)	
Urinary leaka	ge*			
Negligible(%)	28	27	30	
Minimal(%)	28	47	50	
Severe(%)	44	26	20	

*Two diverted patients were excluded.

Table 2: Employment

unemployed(%)	employed(%)	
11 pts. (29)	27 pts. (71)	
4 pts.(21)/ 7 pts.(37)	15 pts.(79)/ 12 pts.(63)	
	,	
36	30	
36	37	
28	33	
	11 pts. (29) 4 pts.(21)/ 7 pts.(37) 36 36	