

Oral presentation

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Bridging health care gaps for new survivors – a total population study of young persons with MMC

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Background

Since the number of newborns with myelomeningocele (MMC) is decreasing a national network of neuropaediatricians with long experience of MMC has been founded in Sweden. Our first task was to identify the areas of medical concern in adolescents with MMC.

Materials and methods

A total national population study has been performed. The first analysis concerns those born 1986 – 89 and is based on review of medical records.

Results

175 adolescents born 1986–89 were living in Sweden on July 1st 2004, 86 females and 89 males. Their special medical characteristics are presented in Table I. Single symp-

toms and signs specifically/not specifically related to the MMC were recorded but not presented here.

Conclusion

In Sweden approximately 40 adolescents with MMC will yearly reach adulthood the next decennium. A majority of them will have medical problems with need for a multi-disciplinary team approach in order to supply the best care in adulthood.

Table I

Individuals with MMC	No	%		No	%
Mental retardation (MR)	46	26	Recurrent urinary tract infections	27	15
Active epilepsy	24	14	CIC	149	85
Hydrocephalus	150	86	Anticholinergic medication	70	40
- Shunts	145		Surgery (eg Mitrofanoff)	42	24
- Ventriculocisternostomi	5		Incontinence pads	125	71
Tethered cord syndrome (Op)	62	36	Reduced kidney function	3	1,7
No independent walking indoors	92	53	Anal water irrigation	103	59
Walking with aids	35	20	MACE	17	10
Walking independently indoors	47	27	Gastrostomy	6	3,5
Orthopedic surgery/ortoses	128	73	Respiratory aids	5	3
Scoliosis (operated 44)	74	42	Recurrent bedsores	34	19