Adults with myelomeningocele living in southern Sweden How are we doing?

MMCUP

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BACKGROUND

- In Sweden, children with myelomeningocele (MMC) are eligble for coordinated multidisciplinary care through pediatric habilitation services
- The same coordinated care is less available in adulthood
  - Problems related to transition from pediatric-adult healthcare are common
  - How these challenges manifest socially & medically in adulthood are not known

OBJECTIVES

To investigate health, medical status, physical functioning, health-related quality of life (HRQoL), and social outcomes in adults with MMC
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METHODS

- Semi-structured interviews & medical records review
- The assessments lasted approximately 3 hrs & were performed by physical therapists, uro-therapists or physicians. A neuropediatrician performed the medical records reviews.

3 structured questionnaires were used to assess:

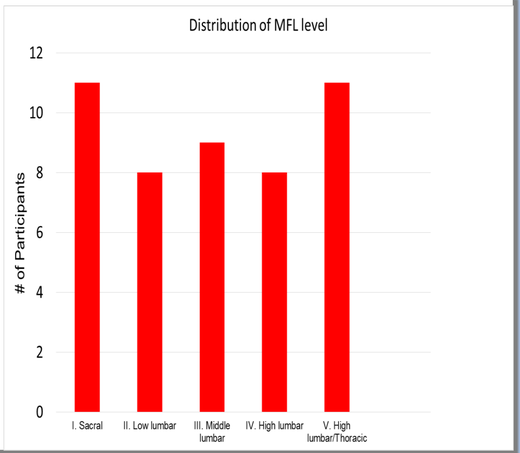
- Medical status,
- Physical functioning,
- Social outcomes,

HRQoL was measured with the EQ5D-5L

Convenience sample (pilot) of adults with MMC recruited from 4 Swedish healthcare regions

METHODS CONT'D

-N = 51, males 53%, median age 29 years (range 19-56 years)
-11 had intellectual disability, 36 did not, 4 = ?
- 41 (80%) had shunted hydrocephalus,
- 11 were "walkers"
-Muscle Function Level* (MFL) was used to classify level of lesion
*Bartonek et al DMCN 1999



RESULTS

Social-

- 14 (27%) were still enrolled in school
- 16 (31%) were working
- 7 (14%) participated in government sponsored activities
- 14 (27%) reported no activity (i.e. school, work) at all

Medical-

- 2 (4%) had normal voiding (80% CIC, 16% urinary diversion)
- Renal function not investigated in 20% (57% had normal eGFR)
  - 2 had undergone kidney transplant
- 53% reported at least one urinary tract infection in the past year
  - 44% with fever present
- 33 (65%) reported urinary leakage
- 28 (55%) reported fecal leakage
  - Only 9 reported no leakage at all (urinary- or fecal)

RESULTS CONT'D

Medical-

How does the participant perceive the medical-, motor-, and uro/bowel function?

	Stable (3 years)	Worse (past 3 years)	Better (past 3 years)	Do not know	Intervention warranted* following assessment
Medical function (n = 48)	32 (67%)	13 (27%)	2 (4%)	1 (2%)	14 (29%)
Motor Function (n = 47)	30 (64%)	13 (28%)	3 (6%)	1 (2%)	26 (55%)
Uro/bowel function (n = 43)	25 (58%)	11 (26%)	3 (7%)	4 (9%)	17 (40%)

*the principal investigator referred/suggested medical follow-up of some sort, -in some cases old questionnaires were used that did not contain all items (i.e. not all 51 answered these questions)

DISCUSSION & CONCLUSION

- Based on self-report-, assessments-, and medical records reviews, many (51%) of the participants had medical problems or concerns related to motor function or uro-bowel function that required follow-up.
  - In many cases, follow-up was deemed urgent by physician.
- The sample size was small. It is possible that it is not representative of the "general adult MMC population" (i.e. recruited those who were generally worse/better off).
- Much work still remains to be done to maximize health and participation in adults with MMC.

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