MMCUP –
The National MMC Follow-Up Program and Quality of Care Registry

ERN ITHACA Spina Bifida clinicians workshop
Stockholm, 25 Nov 2017

Swedish professionals and users network for MMC /
Lena Westbom
MMCUP registry holder
Aims MMCUP

- to prevent complications and loss of function
- to increase knowledge
- to improve cooperation
- to boost high quality of care
  - effective interventions at the right time
  - skip in-effective treatments
Methods

Follow-up according to the Swedish national guidelines in MMC/HC

Guidelines for medical follow-up
Swedish neuropaediatric society

Guidelines PT, OT, Psychol follow-up
See links from mmcup.se

Investigations and measurements on body structure and function (Drs, UT, PT, OT, Pslg)
Recording of interventions/operations, indications, complications
Reports on function, activites and HRQoL (PROM)
Methods

standardised follow-up →
   early detection →
      early intervention →
         standardised evaluation →
            standardised follow-up →

Comparisons
…maybe a little more stiff

…probably no difference

…unclear if new symptom

…have not met him before, don’t know previous function

MEASURE
RECORD
COMMON LANGUAGE
Tertiary care university hospitals
MMC-specialized:
Neuropediatrician
Neurosurgeons
Paediatric surgeons
Urologists
Urotherapists
Orthopaedics
Obstetrics
Neonatal dpt
…

Primary care
General care physicians, nurses, OTs, PTs, ….

Local hospitals
Emergency, medicine & general surgery dpts
Orthopaedic dpt
Urology dpt

Local rehab units
PT, OT, psychol, social workers, drs, nurses
A computerised registry

Longitudinal data

Abduktion hö resp vä höftled

0
10
20
30
40
50
60
70
80
950201 950903 960305 960927 970415 971010 980304 981022 990215
Support in the choice of treatment for each person with SB/HC

Support process of care – lists of planned investigations, treatments, visits to the clinic

National quality of care registry - comparisons of results of medical care and surgical interventions

Research Health care improvements

Bladder... Age (years)

e.g. functional bladder volume and detrusor pressure over time

<table>
<thead>
<tr>
<th>Senaste us</th>
<th>Nästa us</th>
<th>Pnr Namn</th>
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Sweden

10 000 000 inhabitants

110 000 births/year

Taxes include health care insurance fee for all citizens

Multiprofessional habilitation teams in each municipality (290)

21 counties – health care responsibility

6 tertiary health care regions
MMCUP – organisation

**National steering group**
Representatives from:
- patient org - 2 adults with MMC, 2 parents each professional organization (FT, OT, UT, psychol rehabdr, neuroped, neurosurg, orthop)

**Local habilitation centres**
The university hospital in each region (6)

**Regional MMCUP-teams (6)**
Coordinator (UT, nurses)
Nped/rehab dr, Nsurg, Ort, Child surg/urologist

**Central team (Lund)**
Registry holder + registry coordinator (PT)
Psychol-fundraiser, UT coordinator, secr.

All working only few hours with MMCUP
MMCUP – organisation

RCSYD – Registry centre southern region – Registry development and support, data managing, IT platforms

"Personal integrity responsible authority" (CPUA) - Region Skåne

Funding – Swedish government and SALAR (Swedish Assoc of Local Authorities and Regions)
National working groups for MMCUP:

Patients/relatives
UTs/Urol
PTs
OTs
Ort
Nsurg
Nped/Neurol/Rehab drs
Pslg,
Special teachers
MMC/"lipoMMC" – prio 1
Born ≥ 2007 – 100% coverage

Older children and adults – prio 2
other spinal NTDs – prio 3
Cong or early aq. hydrocephalus without NTD
Number of participants in MMCUP database per birth cohort since start Nov 2013

- 1945-1996
- 1997-2000
- 2001-2006
- 2007-2017

- 2013: 50
- 2014: 100
- 2015: 200
- 1/8 2016: 350
- 1/8 2017: 450
MMCUP - Degree of covering
Participating persons with MMC 31/12 2016

Children 0-9 yrs 97%
Teenagers 15-18 yrs 94%
Adults 19-30 yrs 16%
Adults > 30 yrs ??

Participating units 1/8 2017

County regions – 21/21
Tertiary care university hospitals - 6/6
Habilitation units from 16/21 counties
...
> 200 professionals log in and contribute with assessments/data
Examples results:

Children born 2007-2016 with MMC/”lipoMMC”

<table>
<thead>
<tr>
<th>0-9 years of age</th>
<th>160</th>
</tr>
</thead>
<tbody>
<tr>
<td>Born in Sweden</td>
<td>132</td>
</tr>
<tr>
<td>Moved in</td>
<td>28  (18 %)</td>
</tr>
<tr>
<td>Moved out</td>
<td>1</td>
</tr>
<tr>
<td>Died</td>
<td>6   (4 neon)</td>
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</table>

Prevalence 1.44/10 000 (95% CI 1.22-1.66)
Incidence 1.24/10 000

Termination of pregnancies MMC 65%
Children born 2007-2016 with MMC/”lipo-MMC”
(n=60, PT latest assessment)

- Orthoses LE 45 (75%)
- Spinal orthosis 7 (12%)
- Pressure sores 0
- Pressure marks hindering orthosis use 8 (13%)
- Pressure marks hindering spinal orthosis 1
- Pain now 10 (17%)
- Pain every day or often last 4 weeks 9 (15%)
- Leading pain sites spine/back (9) and lower legs/feet (7)
- Most often pain both in activity and during rest/night (11)
Number of children born 2007-2015 in Sweden starting CIC neonatally (MMC/"lipo-MMC" n=114)
Number of children born 2007-2015 in Sweden starting CIC neonatally
(MMC/”lipo-MMC” n=114)

Skin covered

Open cele

Regional differences

From 2015: Almost all start CIC neonatally

No CIC neon  CIC neon
**Operations**  
(Children born 2007-2016 with MMC/"lipo-MMC", n=160)

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Count</th>
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<tbody>
<tr>
<td>Primary op cele</td>
<td>134</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>198</td>
</tr>
<tr>
<td>Untethering</td>
<td>47</td>
</tr>
<tr>
<td>OC decompression</td>
<td>7</td>
</tr>
<tr>
<td>Urologic (incl BxA)</td>
<td>95</td>
</tr>
<tr>
<td>Orthopaedic</td>
<td>114</td>
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**Regional differences**  
(6 regions)

- One region larger proportion shunted although a higher proportion of skin covered cele
- One region higher proportion of shunt re-operations than the others
- 5/6 deaths occurred in one region

*Project 2017. All six neurosurgeon units perform retrospective review of cases in MMCUP-forms*
Quality of care indicators in MMCUP –

Number and proportion of persons without

- pain interfering with sleep or activities
- pressure sores
- urine- or bowel incontinence interfering with activities
- severe obesity and/or malnutrition
- perioperative complications
- hospitalizations for preventable health problems
- loss of function (ex. motor f, kidney f, continence, growth, respiration, vision, cognition)
- preventable mortality causes
Quality of care indicators in MMCUP – planned – but not easy to find validated reliable instruments…..

PREM (Patient-Reported Experience Measures)
Self reported QoL (EQ5D-5L used now)
Participation, Activity, and Function
Quality indicator 1 – Process item: Coordinated care?

Ex adults with MMC
IMPROVEMENTS 2012-2017

KNOWLEDGE
- Inter- and multiprofessional networking in creating guidelines and the registry

STATUS
- Appointment of MMCUP as a national quality of care registry

COMMON LANGUAGE
- Definition of terms used, classification of spinal NTDs,

IMPLEMENTED FOLLOW UP
Almost all children born > 2007 with MMC/”lipoMMC” included

COMPARISONS for improved management started
FUTURE

- More habilitation units need to start with PT, OT and psychol assessments

- Continue….and go on include adults and teenagers;


- Improved IT; no double registration MMCUP ↔ medical records
secondary prevention
life-span perspective

for all persons with SB

Thank you!