## Slide 1

Forekomst av barn med nevrologisk tilstand som har fått hostemaskin til langtidsbruk

Samtidig bruk av LTMV

Brit Hov
Spesialfysioterapeut, MSc
Barnefysioterapiseksjonen
BAR, OUS HF

PhD student, UiO

NKH-seminar
21.April 2021

Oslo University Hospital   UiO : University of Oslo

Slide 2
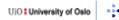
Original Article   Open Access

Prevalence of long-term mechanical insufflation-exsufflation in children with neurological conditions: a population-based study

Brit Hov ✉, Tiina Andersen, Michel Toussaint, Maria Vollsæter, Ingvild B Mikalsen, Solfrid Indrekvam, Vegard Hovland ... See fewer authors ⋀

- Datainnsamling: NKHs nettverk med ressurspersoner
- Finansiering:
  - NKH forskningsstipend
  - Forskningsfondet om nevromuskulære sykdommer
  - Erik Allums legat
  - Bredo og Renee Grimsgaards stiftelse

Oslo University Hospital   UiO : University of Oslo

Slide 3
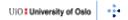
Mechanical insufflation-exsufflation in children with NMD

⬆Peak cough flow to aid mucus clearance.
Bach-93, Chatwin-03

⬆Thorax shape.
Bach-03, Chatwin-11

⬆ Vital capacity.
Stehling-15

Safe in post-op setting.
Miske-13

⬆Physiologic short term benefits.
Fauroux-08

Avoid intubation.
Chen-19

⬇ Pneumonia and respiratory failure.
Bach-97, Tzeng-00, Miske-04

⬇ Hospital admissions.
Veldhoen-20, Mahede-15

⬇ Treatment time.
Chatwin-09, Siriwat-18.

⬆Self-reported respiratory health.
Mehede-15

Foto: Lene Linnerud

Oslo University Hospital   UiO : University of Oslo

Slide 4
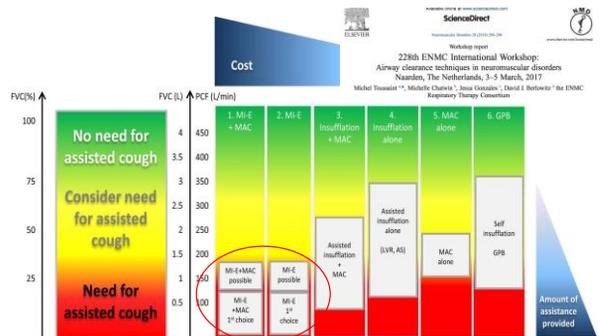
Mål:

- **Beskrive forekomsten av barn med nevrologiske tilstander som har fått hostemaskin til langtids bruk.**

- **Beskrive samtidig bruk av LTMV**

- **Oppstart:**
  - **Undersøkelser gjennomført.**
 - **Selvrapporterte begrunnelser til å starte.**

Metode

Prevalence by:
- Age
- Diagnose
- Regional residency
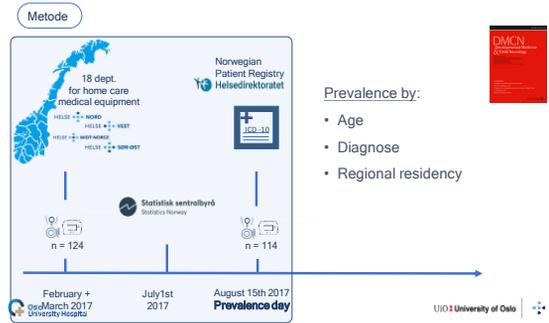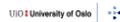
The Norwegian neuropaediatric population using long-term MI-E treatment
Sex (male/female): 69/45
Age median (min–max) 10y 8mo (1y 5mo–18y)

Age group (y)	n	MI-E users	Prev. per 1000
0–2	570	5	8
3–6	2834	22	7
7–12	7164	44	5
13–17	8696	43	4

Diagnosis (ICD-10)	n	MI-E users	Prev. per 1000
Encephalitis (G00-09)	1512	3	2
Systemic atrophies (G10-11, G13-14)	145	0	0
SMA/SMARD (G12)	70	24	343
Degenerative CNS (G30-32)	154	4	26
Nerve/nerve root, plexus (G50-59)	1800	0	0
Peripheral nerve (G60-64)	350	2	6
In muscle (G70-72)	523	36	69
Cerebral palsy (G80-83)	2938	27	9
Other in nervous system (G90-99)	11 772	11	1
ICD-10 G: Nervous system	19 264	107	6
ICD-10 E: Metabolic disorder	na	7	na
Overall	19 264	114	6
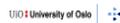
The Norwegian paediatric population: 1 129 007 [a]
The Norwegian neuropaediatric population: 19 264 [b]

North:
8 MIE-users
Age: 11y 5mo
(9y 4mo–15y 8mo)
Neuropaediatric population: n=964
Prevalence of MI-E: 8.3 per 1000

Middle:
19 MI-E users
Age: 6y 10mo
(1y 8mo–17y 10mo)
Neuropaediatric population: n=1578
Prevalence of MI-E: 12.0 per 1000

West:
16 MI-E users
Age: 9y 1mo
(1y 7mo–18y)
Neuropaediatric population: n=7437
Prevalence of MI-E: 2.2 per 1000

South-East:
71 MI-E users
Age: 11y 2mo
(1y 5mo–18y)
Neuropaediatric population: n=9285
Prevalence of MI-E: 7.6 per 1000
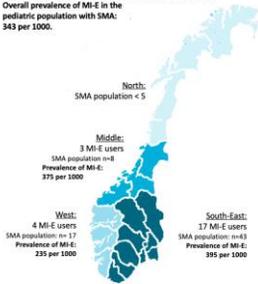
[a] Statistics Norway
[b] Norwegian Patient Register – (ICD-10 diagnose G 00_99)
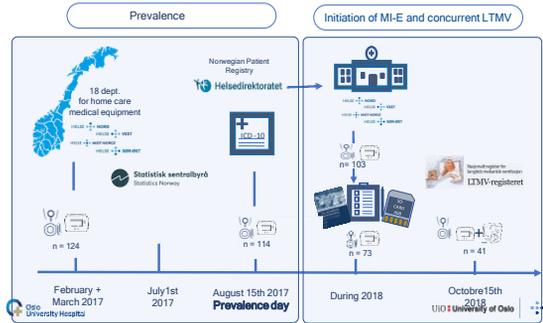
Diagnosis	n	Overall	Neuro Muscular Disorders 47		Central Nervous System 26	P-value
			Spinal muscular atrophy 24	Muscular 23		
Study-population 2 (n)		73	24	23	26	
Age median (min-max)	73	10 y 2 mo (1 y 6 mo -17 y 9 mo)	9 y 11 mo (1 y 5 mo -17 y 10 mo)	11 y 4 mo (4 y 3 mo -17 y 1 mo)	9 y 3 mo (1 y 7 mo -16 y 9 mo)	0.544
Age at MI-E initiation*	70	5 y (0 – 15)	3 y (0 – 14)	5 y (1 – 14)	6 y (0 – 15)	0.041
MI-E use duration at study*	70	2 y 6 mo	3y 1 mo (0-14)	3 y (0 -10)	2 y (0 – 12)	0.120
Gender	73					
Male /Female		42; 58% /31; 42%	13; 54% /11; 46%	17; 74% / 6; 26%	12; 46% /14; 54%	
Comorbidity	73					
Sleep disorder		28; 38%	9; 38%	8; 35%	11; 42%	0.859
Epilepsy		19; 26%	1; 4%	3; 13%	15; 58%	<0.001#
Additional treatment						
CPAP for Airway Clearance*	69	15; 22%	0	2; 9%	13; 50%	<0.001#
Long-term Mechanical Ventilation**	41	41; 56%	20; 83%	13; 57%	8; 31%	<0.001

Variable	Overall	SMA	Muscular dystrophies/ myopathies	CNS	p
Study population 2	73	24	23	26	
LTMV users	41 (56)	20 (83)	13 (57)	8 (31)	<0.001
Sex					
Male	24 (59)	11 (55)	8 (62)	5 (63)	0.025*
Female	17 (41)	9 (45)	5 (38)	3 (38)	
Ventilatory mode					
CPAP	5 (12)	0	1 (8)	4 (50)	0.002*
Bi-level PAP	33 (81)	19 (95)	11 (84)	3 (38)	
Respirator	3 (7)	1 (5)	1 (8)	1 (12)	
At LTMV initiation					
Age, median (min–max)	2 (0–18)	2.6 (0–13)	2 (0–18)	1 (0–12)	0.544
Hospitalization days, median (min–max)	7 (1–199)	3 (1–83)	22 (2–105)	56 (5–199)	0.016
Nocturnal capillary PCO_2, kPh, n; median (min–max)	30; 5.5 (4.4–8.9)	17; 5.3 (4.4–8.4)	7; 6.6 (4.4–7.1)	6; 5.6 (4.4–8.9)	0.257
Nocturnal average SpO_2, %; n; median (min–max)	34; 96 (91–99)	17; 96 (92.5–99)	10; 97 (94.6–99)	7; 96 (91–97)	0.103
Part of night with SpO_2 <90%, n; median (min–max)	18; 1 (0–36)	9; 2.6 (0–5)	5; 0.3 (0–36)	4; 0.8 (0–10)	0.098

Diagnosis "Study population 2" (n)	Total	Neuro Muscular Disorders - 47		Central Nervous System	P-value
		Spinal muscular atrophy	Muscular dystrophies/ myopathies		
	73	24	23	26	
Q: Hvorfor startet du MI-E? Svar (n; %)	70	23	22	25	0.011
- Forebygge luftveisinfeksjoner	17; 24%	5; 22%	10; 45%	2; 8%	
- Svak hoste, problemer med å fjerne slim, hyppige luftveisinfeksjoner.	53; 76%	18; 78%	12; 55%	23; 92%	
Q: I hvilken forbindelse startet du MI-E? Svar(n; %)	69	23	22	24	0.037
- Ved innleggelse med luftveisinfeksjon	29; 42%	13; 57%	8; 36%	8; 33%	
- Ved innleggelse for andre årsaker	21; 31%	4; 17%	10; 45%	7; 29%	
- Elektivt på poliklinikken	14; 20%	2; 9%	4; 18%	8; 33%	
- Husker ikke	5; 7%	4; 17%	0	1; 4%	
Ikke regionale forskjeller					

Health-region	n	Overall	South-East n=57	West n=9	Middle n=5	North n=2	p-value
Continuous data: median (min-max) Age (years months)	73	10y 2 mo (1y6m-17y9m)	10y 4 mo (1y5m-17y1m)	10y 6 mo (1y7m-17y11m)	4y 1mo (1y8m-6y9m)	10y 5mo (9y4m-11y6m)	0.047
Age at MI-E initiation*	70	5y (0 – 15)	6 (0-15)	4 (0-12)	1.5 (0-3.5)	3 (1 – 5)	0.202
MI-E use duration at study*	70	2y 6 mo	3y 6 mo	5y 2mo	2y 2mo	7y 5mo	0.268
Categorical data; n Diagnosis-group	73						0.082
NMD		47				0	
CNS		26				2	
Gender	73						0.851
Male		42				1	
Female		31				1	
Q: Why did you start MI-E? *	70						0.779
- To prevent respiratory infections		17				0	
- Weak cough resulting in problems removing secretions/frequent RTIs		53				2	
Q: In what context did you initiate the long-term MI-E treatment? *	69						0.517
- During admission for RTI		29				1	
- During admission for other		21				0	
- Elective in outpatient clinic		14				1	
- Do not remember		5	3	2	0	1	
Long-term Mechanical ventilation **	73						0.561
User		41	30	7	3	1	
Non-user		32	27	2	2	1	

Non-responders n=30
Age (yrs): median (min-max) 11.5 (3-18)
Gender (male/female) 22/8
Diagnosis (n):
Neuromuscular disorders 14
Central nervous system 13
Metabolic condition 3
Health-region : N: 6, M: 11, W: 4, SE: 9

University Hospital

Mekanisk hostestøtte

- 6 pr 1 000 barn med diagnose i ICD-10 kapittel G har behandlingen.
- Hyppigst forekommende ved spinal muskel atrofi – 1/3.
  - Følger guidelines
- 1 av 3 maskiner utlevert i Norge var gitt til barn med tilstand i CNS.
  - Ikke et bevis på effekt – kun beskrivelse av tilstand – uttrykk for få behandlingsalternativer?
- Ingen studie av insidens – tall fra 2017 – høyere i dag?
- Samtidig bruk av LTMV var 56% overall.
  - Forskjell mellom diagnosegrupper.
  - Hyppigst hos SMA.
- Rapportert indikasjon –
  - 76% behandling,
  - 24% forebygging – i hovedsak NMD

Oslo University Hospital   UiO : University of Oslo

Takk for oppmerksomheten

Oslo University Hospital   UiO : University of Oslo