

ORIGINAL ARTICLE

Pressure injuries are common in children with myelomeningocele: Results from a follow-up programme and register

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Funding information

This research was supported by Stiftelsen för Bistånd åt Rörelsehindrade i Skåne and by Forte and the Swedish Research Council under grant number 218-01468. The funders did not have a role in the design, collection, analysis or interpretation of data, in the writing of the report, or in the decision to submit the article for publication.

Abstract

Aim: To investigate the occurrence of pressure injuries (PIs) in children with myelomeningocele (MMC) and to investigate the association between PIs and orthoses use by disability-specific variables.

Methods: Population-based registry study including participants in the Swedish multidisciplinary follow-up programme for MMC. Risks of PIs were investigated by birth cohort, country of birth, sex, type of MMC, muscle function level (MFL), and continence status.

Results: Of 180 participants, 29% had PIs recorded. Of the 132 participants with >1 assessment records, 17.4% reported multiple PI occasions. More assessments increased the likelihood of PIs (Odds Ratio [OR] = 1.33, 95% CI 1.15–1.54) and participants born 2015–2018 had a lower OR of PIs than those born 2007–2010 (OR = 0.08, 95% CI = 0.01–0.74). Those at MFL I had lower OR of PIs than those at MFL V (OR = 0.06, 95% CI 0.01–0.64). Of the 73 participants with orthoses on the lower extremities, 47% reported skin irritations/injuries in the last 4 weeks; 30% reported that it made them stop using orthoses.

Conclusion: Pressure injuries are common even in young children with MMC. Many have recurring skin irritations. Inspecting for PIs should be part of a daily routine and tools to increase compliance are needed.

KEYWORDS

children, MMCUP, myelomeningocele, orthoses, pressure injury

1 | INTRODUCTION

Spina bifida (SB) is an umbrella term for spinal neural tube defects including myelomeningocele (MMC). MMC is the most severe and frequent type of SB that is compatible with life.¹ The prevalence rate of MMC in Sweden has been reported at 3.8 per 10,000 in those

born 1986–1989 and resided in Sweden in 2004.² This is similar to prevalence rates reported elsewhere,³ although geographical location,⁴ standards of health care, and variations in pregnancy termination rates⁵ affect incidence rates. Comorbidities and secondary conditions occur frequently and primarily affect the urological/renal, neurological, and musculoskeletal body systems. Examples include

Abbreviations: ICPG, International Clinical Practice Guidelines; MFL, Muscle Function Level; MMC, Myelomeningocele; MMCUP, Myelomeningocele Follow-Up Programme; PIs, Pressure Injuries.

† Deceased, April, 2021.

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neurogenic bladder/bowel, hydrocephalus, brain stem dysfunctions/Arnold Chiari malformation type II, respiratory difficulties, and spinal deformities.^{6–11} Research has shown that individuals with MMC tend to have a specific neurocognitive profile, with executive dysfunctions^{12,13} being highly prevalent. This means that planning, initiating, and carrying out tasks are likely affected in this group of individuals with complex medical issues who require ongoing care and self-management to stay healthy.

Sensation and mobility are compromised to different degrees in individuals with MMC. Reduced sensation, in particular in combination with immobility and incontinence, put these individuals at increased risk of pressure injuries (PIs).¹⁴ PIs are defined as localised injuries in the skin or underlying tissue, caused by pressure or shear. The pressure leads to oxygen/nutrient deficiency in the tissue, consequently damaging the cells. The risk of PIs increases with reduced sensation in the pressure-exposed area and skin exposure to moisture or increased temperature. PIs are therefore more common in the lower extremities, pelvic area, and perineum¹⁴ and have been associated with pain, depression, reduced participation, and can lead to sepsis, amputation, and death.^{15,16} Moreover, healthcare expenditures associated with PIs are high. American researchers have reported that the average cost associated with treatment of stage IV PIs was approximately USD 130,000 over 29 months for hospital-acquired PIs and USD 125,000 for community-acquired PIs.¹⁶ Furthermore, individuals with SB who are hospitalised and have PIs have been reported to increase their lengths of stay by, on average, close to 25%.¹⁷

Studies on PIs in individuals with MMC specifically are scarce and most have focused on adults.^{11,18,19} In the largest, clinic-based, study on PIs to date – which included data on >3000 individuals with SB at 19 clinics in the United States – 19% had experienced PIs in the past 12 months.²⁰ Most (82%) of the participants were younger than 20 years of age. Similarly, in an older Swedish population-based study on teenagers with MMC, 19% had recurrent PIs.² Known risk factors of PIs include sensory impairment, which is associated with a higher level of lesion, executive dysfunction, Arnold Chiari II malformation, incontinence, male sex, obesity, and the presence of previous PIs.^{20–22}

The overall purpose was to study PIs in children/ adolescents with MMC. We investigated (1) how many of the participants experienced/had experienced PIs, (2) what factors (country of birth, sex, type of MMC, continence status, and muscle function level (MFL)) were associated with PIs, and (3) the occurrence of PIs in participants who used orthoses on the lower extremities.

2 | METHODS

2.1 | Participants and procedure

This was a registry study including all children/adolescents with MMC, myeloschisis, or lipo-MMC, born during 2007–2018, who participated in the Swedish registry and multidisciplinary follow-up programme for MMC (MMCUP), and who resided in Sweden as of

Key Notes

- Pressure injuries are frequent even at young ages in children with myelomeningocele.
- Almost half of the study participants with pressure injuries had repeated pressure injuries reported.
- Multidisciplinary follow-up programmes can detect pressure injuries at an early stage.

31 December 2018. Numerous healthcare disciplines participate in MMCUP including paediatric neurology, urology, neurosurgery, orthopaedic surgery, urotherapy, occupational therapy, physical therapy, and psychology. Depending on the healthcare discipline and the participant's age, prospective assessment schedules are followed.²³ Consequently, data are collected at different occasions.

Children born during 2007–2018 were selected because this is a priority cohort in MMCUP, and it is known how many children in Sweden are living with MMC for those particular birth years. This cohort has been prospectively followed since information is available concerning the neonatal period and surgical interventions. Children born abroad have been followed since their arrival in Sweden. Because the data included were extracted from three separate MMCUP assessment records (physical therapy, urotherapy, and the neuropediatric assessments), the total number of participants available for the study aims vary. To be included in the statistical analyses, participants had to have data in the physical therapy or the urotherapy assessment records – or both – because that is where the information pertaining to PIs is recorded (Figure 1). Data from all assessments since the participant joined the MMCUP until 31 December 2018 were included.

2.2 | Variables

Information on birth year, whether the child was born in Sweden or abroad, and sex was included. Information on PIs is recorded by both urotherapists and physical therapists at different time points. In the urotherapy assessment record, the following item is included “Does the person have a skin change characteristic of a pressure injury?” with the corresponding answer anchors “No, according to patient or proxy (skin not examined);” “No, skin examined at the visit;” or “Yes.” If yes, the severity of the PI is recorded as one of four stages according to the International Clinical Practice Guidelines (ICPG) by the European Pressure Ulcer Advisory Panel and the National Pressure Ulcer Advisory Panel^{24,25} (I = Nonblanchable erythema (red remaining mark that does not fade during pressure test/relief); II = Partial-thickness skin loss with exposed dermis, III = Full-thickness skin loss. Subcutaneous fat may be visible, but bone, tendon, or muscle are *not* exposed, and IV = Full-thickness tissue loss with exposed bone, tendon, or muscle).

The item on PIs in the physical therapy assessment record reads “Have skin/pressure injuries, unrelated to the use of orthoses,

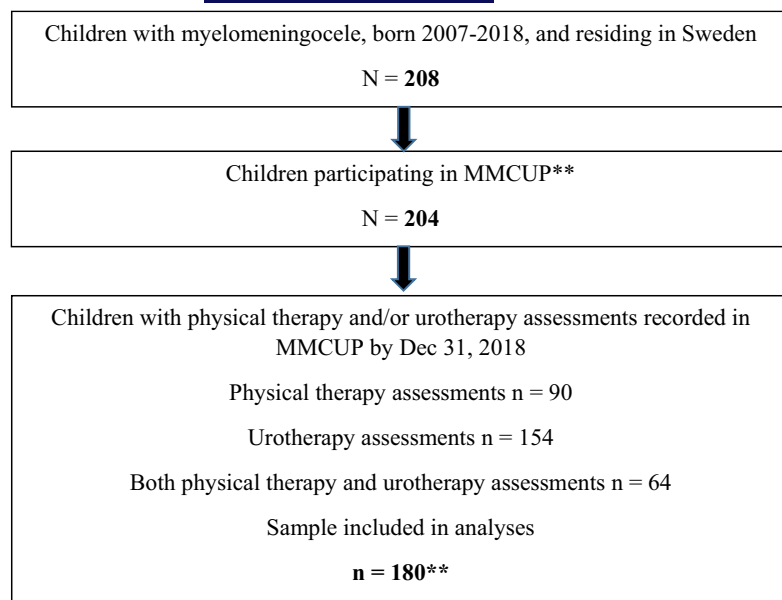


FIGURE 1 Flow chart of the inclusion of study participants

*MMCUP = Myelomeningocele Follow-Up Program. **24 participants had no physical or urological assessment registered prior to 2019.

occurred in the last 4 weeks?" with the answer anchors "No, according to patient or proxy (skin not examined);" "No, skin examined at the visit;" or "Yes." Grading of the PI was not performed. Participants who used orthoses on the lower extremities at their last MMCUP assessment were asked an additional item "Have skin irritations/injuries on the lower extremities occurred in the last 4 weeks?" with the corresponding answer anchors "No;" "Yes, but does not prevent use of orthoses;" and "Yes, and does prevent use of orthoses." An affirmative answer on any of the three items above on any of the participant's assessments was coded as if PIs had occurred. Data from all assessment records available for each participant were included.

Myelomeningocele was divided into open (one child with prenatal closure was included), skin-covered, or – for children who had immigrated to Sweden with unknown status of the lesion – nonspecific MMC. Muscle function level (MFL) was classified according to the muscle function level system developed and validated by Bartonek and colleagues.²⁶ The muscle strength of the weakest side was assessed and graded into five MFLs.

Data on use of orthoses on the lower extremities were available for the 90 participants who had data from the physical therapy assessments and were coded as yes or no. Orthosis use can change over time. For those with more than one physical therapy assessment, information on the use of orthoses from the latest assessment was used.

The urotherapy assessment record contains questions regarding bladder/bowel continence and was coded as "no leakage" (might include occasional leakage of urine), "urine leakage" (every day or numerous times per week), "bowel leakage" (every day or numerous times per week), or "both urine and bowel leakage" which was a combined variable of those who had urine/bowel leakage as defined previously.

2.3 | Statistical analyses

Descriptive data were presented as medians/interquartile range for continuous variables and absolute numbers/percentages for categorical data. Spearman's correlation was calculated between total number of assessments (physical therapy/ urotherapy assessments combined per participant) and birth year (2007–2010; 2011–2014; 2015–2018). Binary logistic regression was run to regress birth cohort, country of birth (Sweden or abroad), sex, type of MMC, MFL levels (I–V), continence, and total number of assessments on the presence of PIs. MMC was dichotomised into open or closed. Due to small numbers, "not specified" was included in closed. Urinary, bowel, or urine and bowel leakage were combined into one group creating a dichotomous variable (continent/ incontinent). Because there was a substantial amount of data missing for MFL, two separate models were run, one model including MFL and the other excluding it. The study was approved by the local Ethics Board (Regionala etikprövningsnämnden, Lund, dnr 2009/241). SPSS 26.0 was used and significance level was considered at 5% level.

3 | RESULTS

The study sample included 180 of all 208 children with MMC in the population. The median number of assessment records was three (range 1–9), two (range 1–13), and three (range 1–18) for physical therapy, urotherapy and both combined, respectively. Comparison of descriptive data between MMCUP participants who were included versus excluded in the analyses are presented in Table 1. Those included did not significantly differ on any of the variables from those excluded, with the exception of hydrocephalus status.

TABLE 1 Description of participants and non-participants, born 2007–2018 $N = 204$

Participants in the myelomeningocele follow-up programme eligible for inclusion		
	Included in analyses*	Not included
	$n = 180, n (\%)$	$n = 24, n (\%)$
Birth cohort		
2007–2010	79 (44)	14 (58)
2011–2014	61 (34)	7 (29)
2015–2018	40 (22)	3 (13)
Born		
Sweden	138 (77)	17 (71)
Abroad	42 (23)	7 (29)
Sex		
Girls	77 (43)	12 (50)
Boys	103 (57)	12 (50)
Type of myelomeningocele		
Open, including one child with prenatal closure	111 (62)	12 (50)
Skin-covered	54 (30)	7 (29)
Non-specified **	15 (8)	5 (21)
Hydrocephalus***		
Yes	102 (57)	8 (33)
No	78 (43)	16 (67)
Muscle function level		
I	26 (14)	Not applicable
II	20 (11)	
III	13 (7)	
IV	20 (11)	
V	21 (12)	
Missing	80 (44)	
Incontinence (a few times/week or more often)		
Urine leakage		
Yes	107 (59)	Not applicable
No	21 (12)	
Bowel leakage		
Yes	81 (45)	
No	70 (39)	
Both urine and bowel leakage		
Yes	63 (35)	
No	65 (36)	
Median number of assessments per birth cohort, interquartile range (IQR), (total range)		
2007–2010, $n = 79$	2, IQR 4, (1–14)	Not applicable
2011–2014, $n = 61$	3, IQR 4.5, (1–18)	
2015–2018, $n = 40$	3, IQR 3, (1–10)	

TABLE 1 (Continued)

Participants in the myelomeningocele follow-up programme eligible for inclusion		
	Included in analyses*	Not included
	$n = 180, n (\%)$	$n = 24, n (\%)$
Total number of assessment records	688	Not applicable

Note: The total number of children born in 2007–2018 with myelomeningocele residing in Sweden as of Dec 31, 2018, was 208. Four declined to participate in MMCUP and are not included. *Physical therapy and/or urotherapy assessment records. **Uncertain if lesion was covered or open at birth; ***Defined as neurosurgically treated hydrocephalus; NB. The percentage may not add up to 100 due to rounding.

MMCUP participants included in the analyses were significantly more likely to have hydrocephalus than non-participants, ($\chi^2 = 4.64$, $df = 1$, $p = 0.03$).

Of the 180 participants, 52 (29%) had PIs recorded in at least one of the assessments at least once (Aim 1). Most (68%) had no note of PIs in their assessment records, and six (3%) had missing data. For the 132 participants with more than one assessment record, 17% had PIs recorded in more than one of their records (13% of the total sample). Of the 52 participants who had PIs recorded, 42% had repeated PIs. Grading of the PIs was only available in the urotherapy assessments, and of those 154 participants, 41 (27%) had reported PIs. Ten were coded as category I; five as category II; two as category III; and one as category IV. Twenty-three participants had missing data on grading of PI.

When analysing factors associated with PIs in children/adolescents with MMC (Aim 2), Spearman's rho correlation between total number of assessment records per participant and birth cohort was non-significant ($r = 0.002$, $p = 0.98$). In the first model (MFL excluded), the OR for reporting PIs was significantly lower for the youngest participants compared to the oldest, and the odds of reporting PIs decreased by 92% compared to the oldest group. Having more assessments increased the odds of reporting PIs by 33%. Country of birth, sex, status of continence, or type of MMC (open/closed) were not significantly associated with reporting PIs. In model two, where MFL was added, the odds of reporting PIs decreased with 94% for participants with MFL I compared to participants with MFL V. There were no longer significant associations between birth cohort, country of birth, sex, type of MMC, status of continence, number of assessments and reporting PIs and the explanatory power of the model increased (Model 1 Nagelkerke $R^2 = 0.36$, Model 2 Nagelkerke $R^2 = 0.40$). The odds ratios (OR) and corresponding 95% confidence intervals for both models are presented in Table 2.

In aim 3, the occurrence of PIs in those who reported orthoses on the lower extremities was investigated. Of the 90 participants who completed the physical therapy assessment, 73 (81%) had orthoses on the lower extremities. Of those, close to half (47%, 34/73) reported having

TABLE 2 Binary logistic regression of probability of having reported some level of pressure injury at a minimum of one occasion

	Model 1	Model 2
Variables (reference)	OR (95% CI)	OR (95% CI)
Birth year (2007–2010)		
2011–2014	0.54 (0.20–1.48)	0.09 (0.01–1.19)
2015–2018	0.08 (0.01–0.74)*	0.56 (0.15–2.10)
Born (Sweden)		
Born abroad	1.19 (0.40–3.59)	0.48 (0.09–2.54)
Sex (Male)		
Female	0.86 (0.33–2.26)	0.56 (0.15–1.96)
Myelomeningocele (Closed or non-specified)		
Open	1.53 (0.56–4.24)	0.41 (0.80–2.14)
Muscle function level (V)		
I		0.06 (0.01–0.64)*
II		0.55 (0.08–3.94)
III		0.53 (0.08–3.60)
IV		0.52 (0.07–4.16)
Status of continence (Incontinent)		
Continent	1.45 (0.94–2.24)	1.66 (0.92–3.00)
Total number of assessment records	1.33 (1.15–1.54)**	1.17 (0.97–1.40)
<i>n</i>	114	63
Constant	0.05	1.01
Nagelkerke (<i>pseudo R</i> ²)	0.36	0.40

* $p < 0.05$, ** $p \leq 0.01$.

experienced skin irritations/injuries – comparable to ICPG level 1 – in the lower extremities in the last 4 weeks, and 30% (22/73) reported that it made them stop using the orthoses. Older participants (birth cohorts 2011–2014 and 2007–2010) were significantly more likely to report PIs due to the use of orthoses in the last 4 weeks than participants in birth cohort 2015–2018 ($\chi^2 = 13.55$, $df = 4$, $p < 0.001$). None of the 17 children who reported not using orthoses reported PIs in the physical assessment record. However, two of those children had PIs recorded in their urotherapy assessment records. Of those born 2007–2010, 78% used orthoses on the lower extremities compared to 94% of those born 2011–2014, and only 65% of those born 2015–2018. Those who completed versus did not complete the physical therapy assessment records did not significantly differ in terms of birth cohort, country of birth, sex, type of MMC, or hydrocephalus status. The group with physical therapy assessment records was significantly more likely to report bowel incontinence.

4 | DISCUSSION

We investigated the occurrence of PIs in children with MMC who participate in the Swedish registry and follow-up programme MMCUP. We also assessed the ORs of PIs for specific, non-modifiable (birth cohort, sex, type of MMC, MFL, born in Sweden or abroad), and

modifiable (continence, number of assessment records per participant) variables. Finally, we studied the occurrence of PIs in the last 4 weeks in participants who used orthoses on the lower extremities. The participants included in the analyses were more likely to have hydrocephalus than those who were excluded.

Close to 3 in 10 participants reported PIs during at least one of their MMCUP assessments. The definition of PI in this study was broad and less severe PIs, such as red remaining marks without skin loss, were included. Different definitions of PIs, repeated multidisciplinary assessments, and the time frame covered likely help explain the higher occurrence of PIs in this study compared to the 19% previously reported by Kim et al.²⁰ and Olsson et al.² Nevertheless, we find no support that PIs have decreased in this population in Sweden during the 15 years that have passed since this topic was last addressed.² PIs in individuals with MMC seem to remain an important area of concern. PIs need careful attention to heal and often require extended time out of the wheelchair as well as wound dressing, all of which can hamper the child's participation in everyday life activities.* Although grading of PIs was only available for a subgroup of participants, results showed that most had red remaining marks that did not fade during pressure relief as opposed to higher grades of PIs. Nevertheless, our findings confirm that PI is an issue also in young children and needs to be addressed with the family early on because signs of PIs – and in some cases, full-thickness skin loss – clearly appear at a young age in this population.

The frequency of PIs has been found to increase with age,^{20,21,27} and this was supported by our findings. However, because we could not record the exact age of the participants when PIs occurred, it is possible that some participants born during 2007–2010 with multiple assessments had PIs at one of their earlier assessments. PIs noted at any of the participants' MMCUP assessments during the study period were included. This could mean that older participants had more MMCUP assessments, and therefore more opportunities to report PIs, simply due to being older. However, the median number of assessments per birth cohort was similar. In fact, it was somewhat lower for the participants in birth cohort 2007–2010. Also, the correlation between birth cohort and total number of MMCUP assessments was weak. As participants get older, they might assume more of the responsibility to check for PIs, which might be difficult for those with executive dysfunction. Given the relatively young age of the participants herein, caregivers were probably still assuming the main responsibility of checking for PIs and of preventive measures to avoid PIs. It is also possible that the number of surgeries increases as the child grows older. It has previously been shown that, for instance, above-the-knee orthopaedic surgeries increase the odds of PIs.²⁰ Participants at MFL I had 94% lower odds of reporting PIs than participants at MFL V. This is in line with previous research^{11,20,28} and may be due to more substantial loss of sensation, and possibly also due to executive dysfunction. No significant differences

*Regarding PIs as a consequence of orthosis on lower extremities; decompression measures result in longer wheel-chair/inactivation time.

were found by sex, type of MMC, whether the participant was born in Sweden, or number of assessments. It is encouraging that there were no significant differences on PIs between those born in Sweden and those born elsewhere given that language barriers may be more frequent in those born elsewhere. Interestingly, there was no difference between those classified as continent as opposed to incontinent. It is possible that the categorisation of continence was too crude. It is also possible that as the individual ages, and the supervision of caregivers' decreases as the child is to assume more self-care responsibilities, unattended incontinence might more often lead to PIs, which increase the association between incontinence and PIs.

In participants with orthoses on the lower extremities, almost half had experienced skin irritations/injuries in the last 4 weeks. This had resulted in 30% of them having stopped using orthoses, which might reduce ambulatory function during a period, or perhaps for the rest of their lives. Those who were older were more likely to have orthoses prescribed than those who were younger and this might help explain why those in older cohorts were more likely to report PIs due to orthoses in the past 4 weeks. It is possible that those who walk and have a higher level of function might be more prone to PIs in the lower extremities due to the combination of reduced sensation and the use of orthoses.

4.1 | Limitations

This study needs to consider several limitations: MMC is a rare condition and a study sample of 180 participants is relatively large. Lack of statistical power might still have been an issue. Data were extracted from both the physical therapy and the urotherapy assessment records. Some participants only had data available in one of the assessment records, reducing the sample size for some statistical analyses. Information on sensation would have been useful, which have not yet been routinely collected in MMCUP. However, having different professionals (urotherapists and physical therapists) checking or inquiring about PIs might increase the likelihood of noticing early signs and addressing it with the families. Nevertheless, it would be beneficial, both from a clinical and research perspective, for the MMCUP registry to adapt internationally accepted nomenclature and for the physical therapists to also grade the PIs. That the study was population-based is a strength and increases the generalisability of the findings. Missing data were a concern for some variables, including the MFL. Consequently, two models were analysed, including/excluding MFL as a predictor.

5 | CONCLUSION

Pressure injuries are common even in young children with MMC. Many have recurring skin irritations and prevention should be the first line of defence. Ensuring that PIs are systematically addressed in multidisciplinary follow-up programmes or clinics from a very young age is important. This can be challenging given that executive

function is often affected in this group of individuals. Resources that are available such as the "Did you look? Skin integrity bundle materials" (<https://www.spinabifidaassociation.org/about-our-research/did-you-look/>) can be used by professionals to educate about skin integrity. In addition, the fit of the orthoses needs to be assessed continuously. Further studies on the effect of PIs on ambulatory function of children and in a lifetime perspective are needed.

CONFLICT OF INTEREST

The authors report no conflicts of interest.

DATA AVAILABILITY STATEMENT

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data are not available.

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How to cite this article: Stockman J, Westbom L, Alriksson-Schmidt AI. Pressure injuries are common in children with myelomeningocele: Results from a follow-up programme and register. *Acta Paediatr*. 2022;111:1566-1572. <https://doi.org/10.1111/apa.16406>