Original Article

Quality of life in pediatric patients with lumbosacral myelomeningocele compare to normal children

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Keywords:
Quality of life; lumbosacral; myelomeningocele; children; care giver

Abstract

Objective: The aim of this study was to assess the health-related quality of life of patients and explore the factors that are associated with the quality of life in patients with lumbosacral myelomeningocele.

Material and method: The cross-sectional design study was conducted between January 2017 and December 2017. The questionnaires were given to patients aged 13 – 18 years of age and their care givers, and to parents of patients between 2 and 12 years. A second group of age matched people were given questionnaires as a control group. Patient's health-related quality of life (HRQOL) was examined using The Pediatric Quality of Life Inventory™ (PedsQLTM) 4.0 Generic Core Scale (Thai version). The data of patients and controls were collected, compared and analysed.

Result: The mean quality of life scores of the patients with lumbosacral myelomeningocele were lower in the case of physical, emotional, social and school functioning in comparison to the scores recorded by the control group. The reductions were most marked in the factors referring to education, bladder function, bowel function, ambulation and caregiving.

Conclusion: Patients with myelomeningocele often require assistance in many aspects of their life. Caring for their physical, emotional, and social needs and their ability to function at school is important.

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นิพนธ์ต้นฉบับ

การศึกษาคุณภาพชีวิตของผู้ป่วยเด็กโรคไขสันหลังและเยื่อหุ้มโป่งออกที่กระดูกสันหลังระดับบั้นเอวและกระเบนเหน็บเปรียบเทียบกับเด็กปกติ

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คำสำคัญ:
คุณภาพชีวิต, บั้นเอวและกระเบนเหน็บ, โรคไขสันหลังและเยื่อหุ้มโป่งออก, เด็ก, ผู้ดูแล

บทคัดย่อ

วัตถุประสงค์: เพื่อประเมินคุณภาพชีวิตและศึกษาปัจจัยที่มีผลกับคุณภาพชีวิตของผู้ป่วยเด็กโรคไขสันหลังและเยื่อหุ้มโป่งออกที่กระดูกสันหลังระดับบั้นเอวและกระเบนเหน็บ

ผู้ป่วยและวิธีการศึกษา: ใช้วิธีการศึกษาแบบ Cross sectional โดยให้ตอบแบบสอบถามทั้งตัวผู้ป่วยและผู้ดูแล เทียบกับเด็กปกติ ในช่วงระหว่าง เดือนมกราคม ถึง เดือนธันวาคม พ.ศ. 2560 ซึ่งผู้ป่วยอยู่ในช่วงอายุระหว่าง 2 ถึง 18 ปี และตัวแบบสอบถามคุณภาพชีวิตใช้ฉบับสากลที่เป็นภาษาไทย และทำการวิเคราะห์ข้อมูล

ผลการศึกษา: ผู้ป่วยเด็กโรคไขสันหลังและเยื่อหุ้มโป่งออกที่กระดูกสันหลังระดับบั้นเอวและกระเบนเหน็บมีคุณภาพชีวิตลดต่ำลงในด้านร่างกาย อารมณ์ สังคม และการเรียน โดยปัจจัยที่มีผลที่สำคัญได้แก่ระดับการศึกษา การทำงานของกระเพาะปัสสาวะ การทำงานของลำไส้ การเคลื่อนไหวและปัจจัยการพึ่งพาผู้ดูแล

สรุป: ผู้ป่วยเด็กโรคไขสันหลังและเยื่อหุ้มโป่งออกที่กระดูกสันหลังระดับบั้นเอวและกระเบนเหน็บมักต้องการความช่วยเหลือหลายด้าน ดังนั้นการดูแลคุณภาพชีวิตในด้านร่างกาย อารมณ์ สังคมและการเรียนของผู้ป่วยจึงมีความสำคัญเป็นอย่างยิ่ง

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Introduction

Meningoceles (MC) and myelomeningoceles (MMC) are the most common causes of congenital neurogenic bladder, which can be classified as spina bifida abnormalities. The incidence rate was 1 case per 1,000 person-years of live birth neonates. Folic acid supplementation during pregnancy is known to decrease the incidence. Ultrasound examination during antenatal care was found to be important in the early detection of these anomalies. This allowed the termination of the pregnancy to be considered as a possible.

The risk factors are: the family history of MC and MMC; premature or elderly pregnancy; gestational diabetes mellitus; poor socio-economic status; low level of maternal education; passive smoking; stress disorder during pregnancy and poor weight gain during pregnancy[1]. Spina bifida or myelodysplasia is a birth defect arising as a result of incomplete closure of the backbone and membranes around the spinal cord during the first month of pregnancy. There are two main types: spina bifida occulta and open spina bifida (MC or MMC). Spina bifida occulta, occulta meaning hidden or closed, is a malformation of one or more of the vertebrae. The only thing to see may be a fatty dimple, or a tuft of hairs.

The more severe condition is open spina bifida, MC, in which the spinal cord is exposed and the membranes that cover the spine and parts of spinal cord protrude through a bone defect in the spinal column. If the bulging sac involves cerebrospinal fluid and meninges alone the condition is known as MC, and if the actual spinal cord is involved it is called MMC. These defects cause spinal root and cord abnormalities. The most common site is at the lumbosacral level which is found in nearly 47% of cases, 26% at the lumbar level, and 21% at the sacral level. There are small numbers at cervical and thoracic spine levels specifically 7%. The condition known as congenital neurogenic bladder is about 90% of open spina bifida[2]. The resulting uncontrollable urine voiding and incontinence caused by this condition make living what is perceived as a normal life difficult.

MC or MMC need surgical repair a short time after birth. The ventriculo-peritoneal shunt was used about 50-90%[3] can correct hydrocephalus at the fourth ventricle (Arnold-Chiari malformation type 2). Tethered cord are the delayed complications of this surgery[4]. In almost all cases MMC, open spina bifida results in continuous urinary incontinence or frequent urinary tract infection (UTI), constipation, and fecal incontinence. In this study the level of severity in these symptoms was assessed by the urologist when the correcting surgery was done. A neurosurgeon also consulted regarding the patient care. The genital examination often identified inflammation of the genitalia due to the urinary incontinence. Patients had defects in motor power ranging from grade 0 to 5, claw toes and a Cavus foot or high arch deformity[5].

The anatomical site of the MMC does not predict lower urinary tract dysfunction. Videourodynamic studies have an important role in the making of accurate diagnoses, classifying and assessing the severity of the disease and management[6].

Health-related quality of life status, HRQOL, is a useful tool in the evaluation of the physical and mental health of the patient and may be a key performance index in the specific therapy used for treatment of chronic diseases. The HRQOL evaluation form was developed to use in long term care of MC or MMC patients[7]. There are two parts: generic HRQOL instruments and disease-specific HRQOL instruments. The generic part can and will be used to compare the investigative group with the healthy population. But the disease-specific HRQOL instrument informs the relationship of disease progression that cannot be compared with the other conditions. The PedsQL 4.0 is a respected measurement model which facilitates the integration of generic HRQOL instruments;

incorporating data pertaining to quality of life in health, mental, and social areas and also as regards learning. The forms are designed to be completed by both the patients and the care takers[8-13].

The aim of this study to assess patient's health-related quality of life and to explore the factors that are associated with the quality of life in pediatric patients with lumbosacral MMC (LSMMC) compared with age-matched controls.

Material and method

The study was designed as a cross-sectional study and was carried out between January 2017 and December 2017.

Participants

Patients with LSMMC and patients who had no chronic disease aged from 2-18 years old who attended Maharaj Nakorn Chiang Mai Hospital, Thailand were enrolled onto the study.

Methods

Patients were identified as fulfilling the study criteria, i.e. had MMC and were aged from 2-18 years, and if they were 13+ they were invited to enroll onto the study and if they were from 2-12 years of age their parents or caregivers were asked if they could be included in the study. In both cases the parameters of the study were explained to all stakeholders and forms of consent were signed by the patient, if appropriate and in all cases by the parent or caregiver. An age-matched control group were selected from healthy children clinic. Following this, the study began with the use of questionnaires.

The questionnaires were divided into three sections:

1. Patient characteristics: age, sex, type of school, family structure, level of MMC, bladder function, renal function, hydrocephalus, tethered cord, ambulation, caregiver, management of neurogenic bladder, and management of defecation (Table 1).

2. Caregiver Characteristics: age, sex, relationship to patient, occupation, underlying disease, income, and education (Table 1).

3. The Pediatric Quality of Life Inventory™ (PedsQLTM) 4.0 Generic Core Scale (Thai version).

The Pediatric Quality of Life InventoryTM (PedsQLTM) 4.0 Generic Core Scale (Thai version) was used and completed by patients and/or care givers. PedsQL is a generic instrument widely used to measure health-related quality of life for children, both reported by the children or by proxy, usually parents. The instrument spans ages 2-18 with age adjusted versions. The 23-item PedsQL can be expressed as a total score or grouped into four domains: physical functioning (eight items), emotional functioning (five items), social functioning (five items), and school functioning (five items). All domains have a scale ranging from 0-100 where higher scores indicate better HRQOL.

Statistics

The data were analyzed using the STATA program version[12]. Categories variables were analyzed using Fisher's exact test and reported as numbers and percentages. Continuous variables were analyzed using Student's t-test and reported as mean and SD. Quality of life scores and factors controlling them were checked for confounding variables with a generalized linear regression. A value of $p<0.05$ was considered statistically significant.

Results

There were no significant differences in mean age, sex, family, renal function, sex of caregiver, relationship to patient, occupation of caregiver, underlying disease of caregiver, income of caregiver and education of caregiver between LSMMC and control groups (Table 1). There were significant differences in education, bladder function, bowel function, ambulation, need for a caregiver, management of a neurogenic bladder, management of defecation between the groups (Table 1).

Table 1. Characteristics of the patients with LSMMC compared to controls

Parameters	MMC N = 50 n (SD)	Control N = 50 n (SD)	P-value
Sex, n (%)			
Male	26 (52)	27 (54)	1.000
Female	24 (48)	23 (46)	
Mean age (years)	8.74 (4.02)	8.56 (3.90)	0.820
Age group (years)			
2-4	1 (12)	6 (12)	1.000
5-7	16 (32)	16 (32)	
8-12	18 (36)	18 (36)	
13-18	10 (20)	10 (20)	
Education			
None	14 (28)	2 (4)	0.001
Preschool	6 (12)	17 (34)	
Primary school	23 (46)	20 (40)	
Secondary school	7 (14)	11 (22)	
Family structure			
Full	28 (56)	20 (40)	0.200
Single	22 (44)	30 (60)	
Level of MMC			
None	0 (0.0)	50 (100)	<0.001
Lumbar	21 (42)	1 (0.0)	
Sacral	3 (6)	0 (0.0)	
Lumbosacral	26 (52)	0 (0.0)	
Bladder function			
Normal	4 (8)	50 (100)	<0.001
Storage dysfunction	12 (24)	0 (0.0)	
Voiding dysfunction	4 (8)	0 (0.0)	
Mixed	30 (60)	0 (0.0)	
Bowel function			
Normal	30 (60)	50 (100)	<0.001
Incontinence	7 (14)	0 (0.0)	
Constipation	13 (26)	0 (0.0)	
Renal function			
Normal	46 (92)	50 (100)	0.120
Insufficient	3 (6)	0 (0.0)	
ESRD	1 (2)	0 (0.0)	
Hydrocephalus			
No	35 (70)	50 (100)	<0.001
Yes	15 (30)	0 (0.0)	
Tethered cord			
None	21 (42)	50 (100)	<0.001
Had with surgery	25 (50)	0 (0.0)	
Had without surgery	4 (8)	0 (0.0)	
Ambulation			
Walker	8 (16)	0 (0.0)	<0.001
Wheelchair	11 (22)	0 (0.0)	
Self-walk	31 (62)	50 (100)	

Table 1. Characteristics of the patients with LSMMC compared to controls

Parameters	MMC N = 50 n (SD)	Control N = 50 n (SD)	P-value
Caregiver needed			
No	0 (0.0)	50 (100)	<0.001
Always	11 (22)	0 (0.0)	
Sometimes	24 (48)	0 (0.0)	
Independent	15 (30)	0 (0.0)	
Management of bladder			
None	8 (16)	50 (100)	<0.001
Antimuscarinic drug	8 (16)	0 (0.0)	
Surgery	2 (4)	0 (0.0)	
SCIC	12 (24)	0 (0.0)	
CIC assistance	20 (40)	0 (0.0)	
Management of defecation			
None	38 (76)	50 (100)	<0.001
Enema/suppository	7 (14)	0 (0.0)	
Evacuation	5 (10)	0 (0.0)	
Sex of caregivers			
Male	12 (24)	8 (16)	0.450
Female	38 (76)	42 (84)	
Relation to patients			
Father	11 (22)	8 (16)	0.560
Mother	34 (68)	34 (68)	
Cousin	5 (10)	8 (16)	
Occupation			
None	5 (10)	0 (0.0)	0.150
Labor	27 (54)	33 (66)	
Government	11 (20)	10 (20)	
Farmer	4 (8)	2 (4)	
Others	3 (6)	5 (10)	
Underlying disease			
No	41 (82)	38 (76)	0.620
Yes	9 (18)	12 (24)	
Education of caregivers			
None	3 (6)	0 (0.0)	0.210
Primary school	8 (16)	3 (6)	
Secondary school	23 (46)	32 (64)	
Higher school	16 (32)	15 (30)	
Income (Thai Baht/month)			
<20,000	38 (76)	39 (78)	0.271
20,001-40,000	11 (22)	7 (14)	
40,000-60,000	0 (0.00)	3 (6)	
>60,000	1 (2)	1 (2)	

Note: LSMMC-lumbosacral myelomeningocele; SCIC-self clean intermittent catheterization; CIC-clean intermittent catheterization; ESRD-end stage renal disease.

Table 2. Comparative QOL between LSMMC group and control group

QOL	LSMMC N = 50 n (SD)	Control N = 50 n (SD)	P-value
Mean physical	67.44 (27.26)	95.75 (8.56)	<0.001
Mean emotional	68.40 (16.02)	89.70 (10.27)	<0.001
Mean social	65.70 (24.82)	93.10 (11.51)	<0.001
Mean school	69.20 (19.07)	83.20 (11.94)	<0.001
Mean psychosocial	67.77 (15.75)	88.67 (8.62)	<0.001

Note: QOL-Quality of life; LSMMC-lumbosacral myelomeningocele.

Education in the LSMMC group: none 28%, primary school 12%, secondary school 46%. Bladder function of LSMMC group: normal 8%, storage phase 24%, voiding phase 8%, mix 60%. Bowel function of LSMMC group: normal 60%, incontinent 14%, constipation 26%. Ambulation of LSMMC group: walker 16%, wheelchair 22%, self-walk 62%. Caregiver needed by LSMMC group: always 22%, sometimes 48%, independents 30%

Management of neurogenic bladder of LSMMC group: none 16%, antimuscarinic drug 16%, surgery 4%, self clean intermittent catheterization (SCIC) 24%, clean intermittent catheterization (CIC) assistants 40%. Management of defecation of LSMMC group: none 76%, enema/suppository 14%, evacuate 10%.

The questions analyzed from The Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scale (Thai version) shows statistically significant differences in all domains (physical, emotional, social and school) (Table 2), (Figure 1). Multivariate analysis generalized linear model of QoL shows the factors that reduce the Physical domain: ambulation (p=0.044), management of bladder (p<0.001), management of defecation (p=0.004); Emotional domain: level MMC (p<0.001); Social domain: level MMC (p<0.001), management of defecation (p<0.001); School domain: management bladder (p<0.001); Total domain: level LSMMC (p=0.021), management of bladder (p=0.043), management of defecation (p=0.014) (Table 3).

Discussion

This study indicated that patients with LSMMC have a reduced perception of quality of life in all the analyzed domains compared with patients who did not have this chronic disease.

Our findings are particularly important for clinicians involved in the management of patients with LSMMC in Thailand. When a child is born with a disability, in addition to rapid adaptation, the family has to cope with stress, sadness, disappointment and challenges, which can lead to a serious crisis and can cause disruption to family life. Parents need to analyze the child's development, use regular comprehensive rehabilitation, maintain contact with a number of specialists and interact with numerous social institutions or services. They are often faced with important decisions to be made for the benefit of the disabled child and economic decisions that affect the family. A child born with a disability is always a tragedy for guardians, but early specialist intervention and adequate financial support helps in adjustment and results in positive commitment to the care and development of the child, even if the child is different and requires special treatment.

Table 3. Multivariate analysis generalized linear model of QOL

	difference	95%CI		P-value
Total QOL				
Level of MMC	-11.78	-21.70	-1.84	0.021
Management of bladder	-10.72	-21.10	-0.34	0.043
Management of defecation	-11.19	-20.10	-2.80	0.014
Physical				
Ambulation	-15.21	-0.42	-30.00	0.044
Management of bladder	-22.09	-31.12	-13.07	<0.001
Management of defecation	-19.21	-32.06	-6.35	0.004
Emotional				
Level of MMC	-21.30	-26.64	-15.96	<0.001
Social				
Level of MMC	-23.49	-31.52	-15.46	<0.001
Management of defecation	-16.27	-28.62	-3.91	<0.001
School				
Management of bladder	-15.21	-21.51	-8.90	<0.001
Psychosocial				
Level of MMC	-23.49	-31.52	-15.46	<0.001
Management of defecation	-16.27	-28.62	-3.91	<0.001

Adjusted by level MMC, hydrocephalus, tethered, education, bladder function, bowel function, ambulation, caregiver needed, management of neurogenic bladder, management of defecation.

In this study, we found that most children had problems with the level of LSMMC, hydrocephalus, tethered cord, education, bladder function, bowel function, ambulation, caregiver need, management of a neurogenic bladder and management of defecation. The HRQoL was found to be significantly lower in all domains (physical, emotional, social, school) when compared to the age-matched controls. The greatest differences found in the HRQoL scores were: Physical domain, ambulation, management of neurogenic bladder and management of defecation; Emotional domain the level of MMC; Social domain the level of MMC, and the management of defecation; School domain management of the neurogenic bladder; and in the total domain the level of MMC, management of neurogenic bladder and management of defecation.

This study also shows factors that had no significance, these included age, sex, family, renal function, sex of caregiver, relationship to patient, occupation of caregiver, underlying disease of caregiver, income of caregiver and education of caregiver.

Several studies have shown reduced quality of life in patients with myelomeningocele[14-17]. We expected a similar result for the patients in this study. Since they have diagnoses with mainly physical disabilities, we expected the most reduction in QoL on the physical scale. A physical disability may influence life for a child in many ways: it may lead to some discomfort or pain, give some extra strain and make play with other children difficult. Therefore, we expected a reduction also on the emotional scale, social scale and school scale.

Because of the different nature of the patient characteristics in this study we expected differences in reported HRQoL, and this was confirmed. The patients with LSMMC, a complex condition with several medical and cognitive challenges, had lowest scores on all PedsQL scales[18].

We also expected that the patient's functioning in different areas of life would influence the life satisfaction of their parents in different degrees. In the multiple regression analyses, the most pronounced positive associations in all domains were the level of LSMMC, management of a neurogenic bladder and management of defecation. The most frequent reasons given by patients regarding these issues is embarrassment hen other people are around. Therefore one recommendation from this study is that the caregivers should be encouraged to sympathize and support their patients and give thought to how they can ameliorate the situation surrounding these emotive issues. This may explain why the patient QoL is important. It is important to understand the perception of the patient regarding their QoL and involve them in planning strategies to improve it.

Conclusion

Patients with LSMMC had a lower quality of life in all the analyzed domains compared to patients who don't have this chronic disease. Analysis of the sub-scales showed that the quality of life of patients with LSMMC is significantly worse than patients who don't have this chronic disease. Particularly significant factors are: the level of MMC, the management of neurogenic bladder and management of defecation.

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Disclosure

The authors report no conflicts of interest in this work.

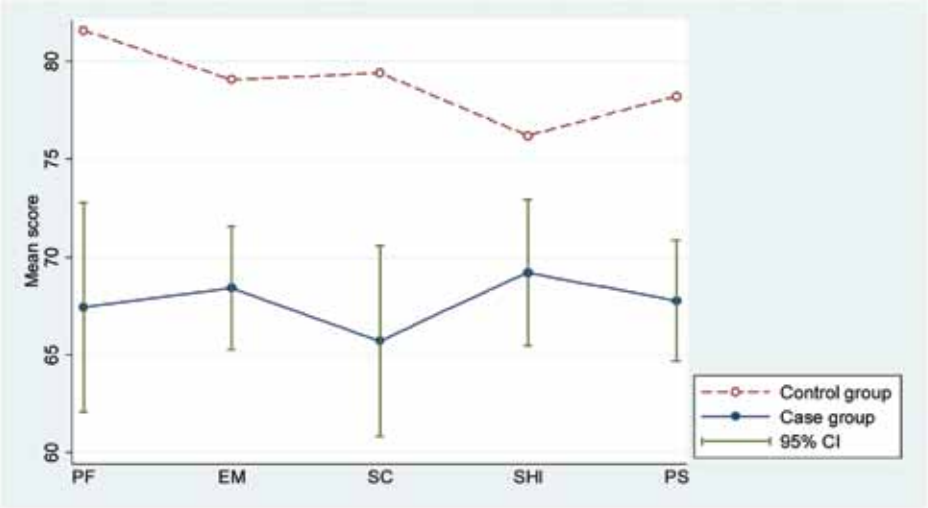

Figure 1
Comparative Quality of Life between lumbosacral myelomeningocele group and control group

Note: PF; Physical, EM; Emotional, SC; Social, SHl; School, PS; Psychosocial.

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