

Living and health conditions for adults with Spina Bifida in Sweden – a comprehensive prevalence group study

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Conclusion

This study shows the multifaceted problems adults with SB are facing and contributes to increased knowledge concerning their living and health conditions.

Increased knowledge can lead to targeted interventions and better care, thereby decreasing secondary complications, reducing costs for society and hopefully increasing quality of life for persons with SB and their families.

Introduction

Seventy-five percents of children born with Spina Bifida (SB) are expected to live into adulthood, meaning that the adults will need more attention in the future. Adulthood involves great demands for persons with SB, but also for their families, the social well-fare and healthcare systems, as the group has a persistent need for care and support.

Aim

To describe the living and health conditions for adults with SB in different ages including medical, physical, psychological, cognitive and social aspects.

Methods

A cross-sectional study conducted by a multidisciplinary team. Data collection was performed through structured interviews, questionnaires and clinical assessments. All individuals > 18 years with SB (n=219) registered at a regional outpatient clinic were offered participation; 196 persons (104 women, 92 men 18-73 years) were included.

Results

- There was a great variation in the group concerning problems related to their congenital injury.
- The most common neurological impairment level was at L3 (41%) .
- 1/3 always walked, 1/3 always used wheelchair, 1/3 combined the methods.
- Clean intermittent catheterization was the most common used method for bladder emptying, used by 52%.
- The group as a whole performed 1 SD below the general population in the cognitive tests, with a significant difference with and without hydrocephalus.
- People with SB > 45 years and especially > 61 years seems to have less problems such as less prevalence of hydrocephalus, Chiari II malformation, tethered cord syndrome and they also walked to a higher extent.
- People with SB in the older age-groups also passed elementary school to a higher extent and performed better on the tests for psychomotor speed and executive function.

| | Total | 18-30 years | 31-45 years | 46-60 years | ≥61 years |
|---------------------------------|----------|-------------|-------------|-------------|-----------|
| Participants, n (%) | 196 | 90 (46) | 60 (31) | 38 (19) | 8 (4) |
| Women, n (%) | 104 | 42 (47) | 28 (47) | 28 (74) | 6 (75) |
| Men, n (%) | 92 | 48 (53) | 32 (53) | 10 (26) | 2 (25) |
| Hydrocephalus, n (%) | 123 (63) | 68 (76) | 42 (70) | 12 (32) | 1 (13) |
| >2 shunt revisions | 48 (39) | 19 (28) | 19 (45) | 10 (83) | - |
| Tethered cord syndrome | | | | | |
| Earlier in life, n (%) | 53 (27) | 36 (40) | 11 (18) | 5 (13) | 1 (12) |
| Last year, n (%) | 5 (3) | 3 (3) | 2 (3) | - | - |
| Ambulatory function** | | | | | |
| 1 | 71 (37) | 33 (37) | 18 (30) | 15 (39) | 5 (64) |
| 2 | 13 (6) | 6 (7) | 3 (5) | 3 (8) | 1 (12) |
| 3 | 17 (9) | 10 (11) | 5 (8) | 1 (3) | 1 (12) |
| 4 | 5 (2) | 4 (4) | 1 (2) | - | - |
| 5 | 17 (9) | 10 (11) | 6 (10) | 1 (3) | - |
| Do not walk | 73 (37) | 27 (30) | 27 (45) | 18 (47) | 1 (12) |
| Passed elementary school | 135 (69) | 50 (56) | 46 (77) | 30 (81) | 8 (100) |

Ambulatory function**: 1 Community ambulation, 2 Community ambulation, and wheelchair use only for long distances outdoors, 3 Household ambulation, wheelchair outdoors, 4 Household ambulation, wheelchair both in and outdoors, 5 Non-functional ambulation, ambulation during therapy. Wheelchair use for mobility.

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