

Living conditions and level of independence of adult Spina Bifida patients in Germany

Henriette Reinhardt, Dieter Class, Raimung Firsching

ABSTRACT

Aims: Due to well organized medical and daily care for children with spina bifida (SB) in many countries the number of adult patients with SB is increasing. After reaching adulthood individuals suffering from SB have to organize their medical care and assistance in their daily life mostly on their own. The aim of this study is to illustrate living conditions of adults with SB in Germany and to find out if lesion level as well as an individual's independence influence these conditions. **Methods:** Questionnaires were sent out to adults suffering from SB living in German speaking countries. Included were questions concerning medical history, need for support in activities of daily living (ADL) in the form of the Barthel index and their current living conditions. **Non parametric statistic** was used to examine interdependencies. **Results:** In the study were 261 individuals with a median age of 26 years (range 18 to 49) included. Of the participants 92% had a neurological deficit with a lesion level mainly in the lumbar region (64%) followed by the thoracic (25%) and the sacral (11%) region.

Concerning the living conditions we found a lack of autonomy in people suffering from SB. This is reflected by e.g. their housing situation, on the one hand, with only 32% of the individuals living on their own or with a partner, and their financial situation, with only 22% of the individuals being financially self-sufficient. The Barthel index, a measuring instrument of independence in performing ADL, was significantly related to the lesion level and many aspects of daily life (e.g. communication and financial situation). **Conclusion:** It is an enormous medical success that many children with SB reach adulthood nowadays. However many of these individuals stay dependent on support in various aspects for their whole life. So it is crucial important that care and therapy in childhood and later on are optimized with respect to the functional outcome to enable adults suffering from SB to live a self-determined life within the limitations of the primary underlying disease. The Barthel index illustrates the restrictions that adults with SB face and their general influence on a self-determined life.

Keywords: Adult, Barthel index, Chronic physical illness, Spina bifida

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INTRODUCTION

Spina bifida (SB) is a spinal dysraphism caused by an incomplete closure of the neural tube in early embryonic stage. It results in diverse neural damage and is often associated with hydrocephalus, bladder and bowel incontinence, orthopedic illnesses and cognitive impairments. During the last years the number of children born with SB is declining mainly because of folic acid fortification [1] and improved prenatal diagnostics [2]. Nevertheless, it is well known that nowadays a growing number of individuals with SB reach adult age [3, 4]. Impairments in childhood may progress in adulthood and new complications may arise. Most frequent are motor and sensory deficits. They depend on the level of the primary lesion and influence individuals' ability to walk as well as the development of orthopedic diseases, especially of the hip, knee, ankle and foot [5-7]. Most of SB patients also suffer from hydrocephalus [3, 8], which influences e.g. IQ [9, 10] and often makes several operations necessary [3, 11]. Additionally, a lot of patients suffer from neurogenic bladder and bowel disease [12,13] leading to incontinence and post void residual urine [12, 14, 15] or constipation [15, 16]. Through missing social continence and necessary procedures like clean intermittent catheterization [13, 17] and the use of stomata individual's social life and independence are influenced [18, 16]. Further well known associated diseases are Arnold Chiari malformation type II and tethered cord syndrome. Both can cause an increase of existing symptoms and deterioration of neurological functions [19-22].

Over the course of a lifetime the individuals' requirements of nursing staff and attending physicians change because of a changing living situation and the development of the disease [15]. Although quality of life is known to be assessed as good by the individuals suffering from SB [23, 24] most aspects of life are influenced by the disease. Research so far has mainly focused on the development and special needs of children affected by SB, but as it is a chronic disease adults with SB also need special care. To help to improve their quality of life, it is necessary to know more about their specific medical needs and about specific difficulties they encounter during their everyday life. Through the work of Hunt et al. development of a constant cohort became traceable [25-27]. Their results reflected the considerable influence of lesion level and medical complications on individuals' outcome. Young adult SB patients from Canada have been described by Hetherington et al. [28] illustrating that physical, medical, and cognitive effects of SB impair individuals beyond childhood and impact quality of life. Some additional data came from Northern Ireland by McDonnell et al. [16]. They demonstrated patients' heterogeneity of disability and the need for well-organized medical care. However, up to now there are only few studies available focusing on the topic and most of them included only small numbers of individuals. Most studies

focus on one aspect of individuals' lives without giving an overview of the general consequences for individuals' living conditions.

This study focuses on German speaking adults suffering from SB with their medical history, their Barthel index (BI) results and their living conditions.

Aims of the study were to get an overview of different aspects of life of adult individuals with SB in German speaking countries and their level of independence in their everyday life.

MATERIALS AND METHODS

A questionnaire was developed including all questions of the BI, next to questions concerning personal data, diagnosis, medical history and living conditions. The BI is a measure of dependence concerning activities of daily living (ADL). It was introduced by Mahoney and Barthel in 1965 [29] and included a scale ranging from 0 (worst) to 100 (best). Each of the ten included variables is awarded between 0 and 10 or 15 points characterizing the dependency on nursing. The results of all questions were added up for each participant giving the BI. The BI was chosen because it is a widely used tool in Germany for patients with neurological disorders and had already successfully been applied to SB patients [30, 31]. Self-assessment is possible and valid [32].

The questionnaire comprised a total of 26 questions. It was sent out to all neurosurgical clinics in Germany (with no special focus on clinics with pediatric neurosurgical department) and all adult members of the organization of the support group "Arbeitsgemeinschaft Spina bifida und Hydrozephalus e.V." (ASBH). ASBH members were then contacted by the organization and questionnaires were submitted anonymously. Furthermore, there was an online version of the questionnaire published in a support group forum on the internet (www.sternchenforum.de). The "Gesellschaft für Spina bifida und Hydrozephalus Österreich" (SBHÖ Austria) and the "Schweizerische Vereinigung zugunsten von Personen mit Spina bifida und Hydrozephalus" (SBH Schweiz) (Switzerland) were also informed about the study. Both organisations contacted their members via email including the URL for the online questionnaire. Double submission (online and via letter) cannot be excluded. However, all individuals contacted via letter were informed about both options and their equivalence. Furthermore, a double reply could have caused similar answers in all free-text comments. This would be very obvious during transformation of answers.

Since the questionnaire is written in German, not German speaking people suffering from SB living in Germany could not be included. An informed consent following the guidelines of the ethics committee of the medical faculty of the Otto-von-Guericke University in

Magdeburg was obtained from all participants included in this study.

Answers to open questions were transformed into a standardized format and grouped. The transformation involved the digitization of all questionnaires and handwritten comments and answers were manually transferred to digital text. This was followed by a thematic grouping of the answers (e.g. regarding further operations different options were foot surgery, hip surgery, tenotomy, etc.). Next, the BI was calculated based on the given answers. Statistical analyses were conducted by the Department of Biometry and Medical Informatics of the University of Magdeburg using the SPSS. For the analysis, U tests and H tests were used. The U Test (also Mann-Whitney test) compares differences between two independent groups when the dependent variable is either ordinal or continuous but not normally distributed. The H Test (also Kruskal-Wallis test) is a rank-based nonparametric test, which is used to determine if there are statistically significant differences between two or more groups of an independent variable on a continuous or ordinal dependent variable. Nonparametric tests were used since a normal distribution could not be assumed. A p-value of <0.05 was used to determine statistical significance for all data analyzed.

RESULTS

Participants

A total of 306 individuals filled in the questionnaire. The online questionnaire was used by 47 (15.6%) individuals and 259 questionnaires were sent back via letter. Of all participants, 271 individuals agreed with the usage of their data for scientific purposes. Not included in the study were eight participants who choose a diagnosis other than “spina bifida” and 2 participants who did not choose any diagnosis. The gender distribution indicated 56% female participants and 43% male participants. Two individuals did not specify a gender. The median age was 26 years (SD = 7,0; range 18 to 49). The proportion of participants older than 40 years was 18%.

The information about participants’ diagnoses is given in Table 1.

Both diagnoses ‘SB aperta’ and ‘SB with hydrocephalus’ were chosen by 49 participants. Therefore, we concluded that 52 (19.2%) participants have SB without hydrocephalus. Moreover, diagnosis Arnold Chiari malformation was indicated by 87(32.3%) participants. All of these individuals declared to have SB with or without hydrocephalus, which makes up 33.3% in this group of participants with SB. Table 2 illustrates participants’ answers with regard to connected diseases and operations.

Participants were asked to name further operations. More than 10% of the participants listed operations

such as foot surgery, urologic surgery, tenotomy and hip surgery. In most cases participants used general names or descriptions. Unfortunately, this prevented us from a more in-depth analysis.

The distribution of lesion level is shown in Figure 1. As can be seen, 6% of the individuals stated to have no paralysis.

Barthel index

The distribution of answers to the BI’s items is shown in Table 3. Particularly low scores are reached in the categories using stairs, bathing, bladder and bowel. Especially after combining data concerning bladder and bowel issues, participant’s restrictions become apparent since only 7% of the participants are continent for both whereas 48% of the participants are complete incontinent. All other participants are occasionally incontinent for urine and/or faeces.

A total of 79% of all participants answered all questions of the BI material. The individual scores of each question were summed up leading to a BI score for each participant, which characterizes the individual’s level of dependence in everyday life (Figure 2).

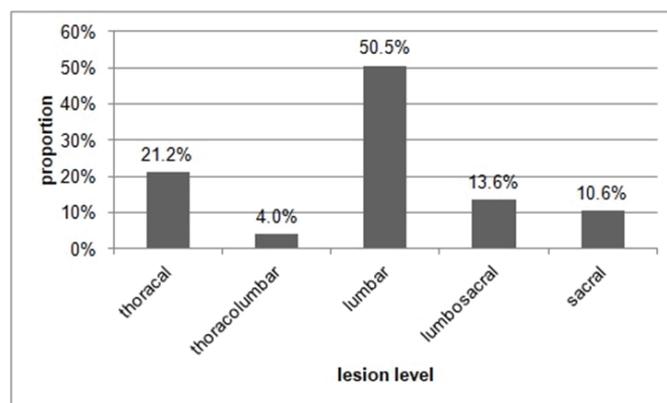


Figure 1: Distribution of lesion level.

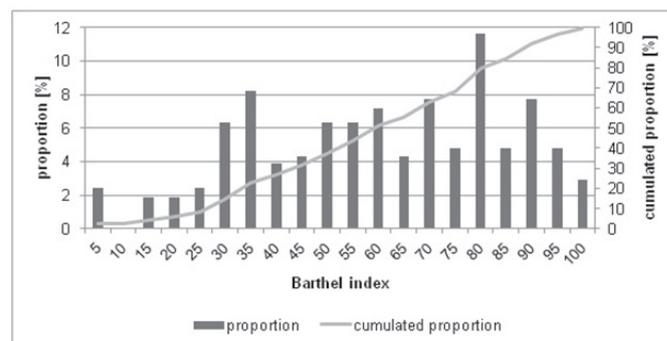


Figure 2: Barthel index score in proportion and cumulated proportion.

Table 1: Participant’s diagnoses (participants could choose various answers)

Diagnosis	Percentage	Number
Spina bifida aperta/myelomeningocele	38.7	101
Spina bifida with hydrocephalus	80.1	209
Hydrocephalus in children without spina bifida*	2.2	6
Encephalocele*	0.7	2

* Answers were included for future use of the questionnaire

Table 2: Percentage distribution of connected diseases and operations (N =261)

Disease	One operation	Various operations	No operation	No answer
hydrocephalus	17.2	62.5	19.9	0.4
Arnold Chiari malformation	15.7	1.9	77.8	4.6
Tethered cord- syndrome	21.5	6.5	67.0	5.0

Table 3: Distribution of answers to the BI’s items (deviations from 100% are due to rounding)

Item of Barthel index	Percentage	Number (sum = 261)	Score
Feeding			
Unable	2%	6	0
Needs help	15%	40	5
Independent	78%	204	10
No answer	4%	11	
Bathing			
Dependent	54%	142	0
Independent	43%	112	5
No answer	3%	7	
Grooming			
Needs to help with personal care	15%	39	0
Independent (face/hair/teeth/shaving)	82%	214	5
No answer	3%	8	
Dressing			
Dependent	7%	19	0
Needs help but can do half unaided	33%	87	5
Independent	58%	151	10
No answer	2%	4	
Toilet use			
Dependent	18%	48	0
Needs some help	26%	68	5
Independent	49%	129	10
No answer	6%	16	
Bladder			
Incontinent	63%	166	0
Occasional accident	24%	63	5
Continent	11%	29	10
No answer	1%	3	
Bowels			
Incontinent	53%	138	0
Occasional accident	29%	76	5
Continent	17%	45	10
No answer	1%	2	
Transfers (bed to chair and back)			
Unable	0%	0	0
Major help, can sit	21%	54	5
Minor help	11%	28	10
Independent (incl. wheelchair users)	63%	164	15
No answer	6%	15	

Mobility			
Immobile or < 50 m	14%	37	0
Wheelchair: independent > 50 m	42%	110	5
Walks with help of one person > 50 m	3%	7	10
Independent (but may use any aid) > 50 m	36%	93	15
No answer	5%	14	
Stairs			
Unable	53%	137	0
Needs help	7%	19	5
Independent	38%	100	10
No answer	2%	5	

BI: Barthel index

The median score was 55 (CI: 52,33-62,14; SD = 25,1). The spectrum of scores ranged from 5 (2% of the participants) to 100 (3% of the participants) and there is one peak at a BI score of 80. According to Granger et al. [33], a threshold BI value of 60 should be used to differentiate between low and high dependency with (with lower values representing higher dependency). For the data of the current study, the peak lies in the group of low dependent individuals. However, since the median is below 60, more than half of the participants are highly dependent on support every day.

Living conditions

Concerning communication, 11% of the participants indicated that their communication is impaired (in German “erschwert”). A total inability to communicate could not be found.

The answers concerning the field of education are shown in Figure 3. Most of the participants finished a vocational training, but there are also 31% of the participants, who did not answer this question. Only 2% of the participants were not able to finish their vocational training or studies.

Nearly the same proportion of individuals have either a regular job (30.3%) or work at sheltered workshop (28.4%). A total of 17.2% has not finished their education yet and another 11.9% are currently unemployed. In 5.7% of cases participants receive a pension and 1.9% said they are not able to work. The question concerning work was not answered by 4.6% of the participants.

Most participants stated to have no relationship (68%). Another 10% are married/live in a long-term relationship and another 10% chose the response option “relationship”.

The majority of participants (56%) is still living with their parents. Those who reached an independent life are either living alone (21%), with a partner (12%) or in a residential community (5%). The smallest proportion (4%) lives in a nursing home.

Especially the housing situation influences people’s perceived care situation. Most of the care needed is

carried out by the parents. Since the individuals and their parents naturally grow older, the maintenance of a certain standard of care is an important issue to be raised. In order to evaluate the current care situation in contrast with the past care situation, participants were asked to rate the development thereof. The results are shown in Figure 4.

Most of the participants rate their care situation as “good” with only small differences between the past and the present situation. However, some participants reported a shift from “good” to “improvements necessary” when comparing their present and past care situation. This could be a sign for an impending negative trend.

Finally, participants were asked to assess their life situation as a whole. Nearly two thirds of the participants are “satisfied” (64%) and another quarter is “less satisfied” (25%). Only 7% rate their situation as “dissatisfied” and a mere 1% perceived it as “very bad”.

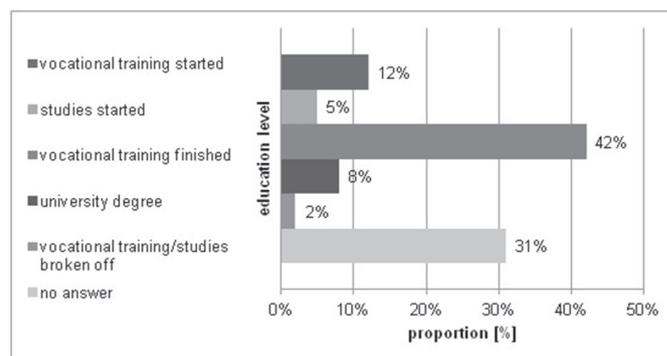


Figure 3: Distribution of education level.

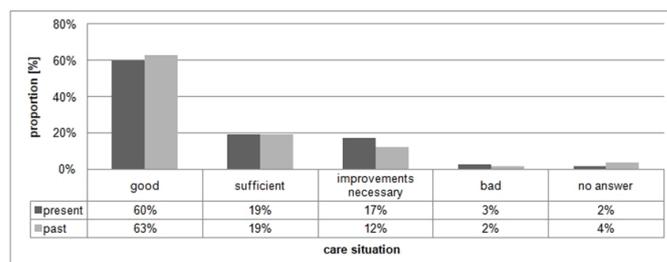


Figure 4: Current and past care situation.

Dependencies on living conditions

Since the lesion level has a big influence on peoples' physical abilities and limitations we looked for significant dependencies between living conditions and lesion level (Table 4).

Only some of the tested parameters show some dependence on lesion level. This, however, might be caused by a lot of different factors. Interrelations between lesion level and parameters depending on a participant's interaction with other people who are probably not being used to disabled people (e.g. communication, education, work) are found. That implies that it is not only the individuals' health situation but also the support by the environment which influences the living conditions of individuals suffering from SB.

To check whether the BI – next to lesion level - is an indicator for living conditions of adults with SB, statistical tests were performed. Table 5 presents the obtained results.

As can be seen, most parameters requiring autonomous planning and parameters depending on intellectual skills are interrelated with the BI (e.g. education, housing situation). The BI is not interrelated to parameters depending on support of others (like care situation or the life situation as a whole).

Table 4: Interrelations between lesion level and living conditions

Parameter	p-value	Test
Communication	0,018*	u-test
Education	0,854	h-test
Work	0,000*	h-test
Relationship	0,075	h-test
Housing situation	0,028*	h-test
Present care situation	0,038*	h-test
Past care situation	0,578	h-test
Whole life situation	0,131	h-test

* = significant; p-value <0.05

Table 5: Interrelations between Barthel Index and living conditions

Parameter	p-value	Test
Communication	0,000*	u-test
Education	0,001*	h-test
Work	0,000*	h-test
Relationship	0,057	h-test
Housing situation	0,000*	h-test
Present care situation	0,314	h-test
Past care situation	0,744	h-test
Whole life situation	0,142	h-test

* = significant; p-value <0.05

DISCUSSION

Most studies up to now focusing on adult SB patients are small-group studies [3, 34, 35]. Furthermore, there are only a few publications including individuals (no adults) from Germany [24, 36]. Another problem is that in different studies differing definitions of lesion level are used.

The current study presents the first comprehensive data collection concerning adults with SB in Germany. Following the grouping of lesion level in Bellin et al.[8] and Mahmood et al. [37] we found a slightly higher proportion of thoracic lesions and a slightl over proportion of lumbar and sacral lesions. Incidences of hydrocephalus do not differ from data reported in other publications [26, 38]. In the current study nearly two thirds of the participants (62.5%) had more than one operation due to their hydrocephalus. Numbers in other studies vary between 58.7% [11] and 95% [3]. Arnold Chiari malformation type II is known to be present in many patients with SB [39] but only a part of them develops clinical symptoms [30]. Important for future therapeutic decisions is the question of an adequate hydrocephalus management including a sufficient CSF (cerebrospinal fluid) drainage system/ shunt. In the current study, the number of participants that had to undergo an operation because of the Arnold

Chiari malformation is slightly higher than in comparable studies [3, 20]. Differences can be caused by varying therapeutic strategies between countries, neurosurgical departments or differing age compositions.

The BI is an instrument currently mostly used in the setting of neurological rehabilitation [32, 40]. However, there are some studies that have applied it to individuals with SB [30, 31]. In contrast to the results of their current study, both studies find a considerable better score. It has to be taken into account that participants in the study of Padua et al. [31] are not adults, which could have influenced the scores. Moreover, McDonnell et al. [30] used a modified version of the BI. Other studies assessed the need of assistance in daily activities without using the Barthel index [27, 41, 42]. The results of these studies vary considerably, which indicates that the best instrument for assessing dependency in activities of daily life still needs to be determined.

None of the studies using the BI listed the distribution of answers to all BI items. However, there are some studies that focus on aspects of the individual questions. Only few data is available concerning grooming. Buffart et al. [41] found a considerably higher proportion of individuals having difficulties with grooming than in the current study. But it has to be taken into account that Buffart et al. included various aspects of self-care via a standardized questionnaire.

A lot of information concerning urinary continence can be found. Reported values differ greatly among the different studies (30% [43] to 68.7% [44]). The result of the current study (11.1%) is considerably lower. Various reasons might have caused this difference. These include varying definitions of continence, a differing distribution of lesion level and heterogeneous classification of clean intermittent catheterization. Generally, it can be concluded that a substantial number of adults with SB do not reach urinal continence.

We found 35.6% of participants that reported independence with respect to mobility, which is slightly higher than in other studies [45-47]. The amount of wheelchair users tended to be higher in other studies [27, 48, 49]. Fundamental differences with respect to mobility could not be found.

SB patients' communication can be compromised by neuromotor speech deficits [50] and an impaired processing of verbal and nonverbal information [51-53]. However, most participants of the current study reported no problems with communication similar to other studies [54, 55]. The formulation of the questions in the questionnaire is very general ("impaired communication") and, therefore, lack sensitivity. As a result, impairment of communication cannot be specifically addressed. Since the aim of the current study was to get a broad overview of different aspects of participants' lives, we left a more detailed investigation of an impairment of communication for future research.

As there are a lot of participants aged between 18 and 25 years, it could be expected that some participants had not finished their education yet. The proportion of participants with a completed vocational training is slightly lower than the national average in Germany. But the proportion of participants with a university degree is only half as high as the proportion in the general population of Germany [56]. A comparison with other publications proves to be difficult because of differing educational systems and a varying age composition. With regard to university degree other publications report similar results [34, 37, 57].

The distribution of answers in the category "work" shows a great variety among different studies – values differ between 24% and 44% [26, 58, 59] for individuals with a regular job. In this study we found hardly any difference between the proportions of participants with a regular job and participants working in a sheltered workshop. The results in comparable studies differ between 9.3% [47] and 45.8% [60]. A possible reason for this might be a varying frequency and availability of sheltered workshops in different countries. While other studies found high rates of unemployment (up to 50% [8], we found 12%. However, this is still nearly twice the total unemployment rate of Germany in 2013 (7.7%) [61]. Of course there are various aspects influencing a successful job search. For example, there are some activities of daily living (here represented in the BI), which can be negative influencing factors such as transfer, mobility or using stairs.

Other studies report similar distributions of answers regarding relationship status [43, 46, 62] as the one found in the present study. However, compared with the general population of Germany there are significant differences (e.g. a larger proportion of married individuals in the general population). This confirms the known hurdles individuals with SB encounter in their social relations [63]. To make social contacts for individuals with SB easier they should be encouraged to take part in social and physical activities. Furthermore, mind set barriers should be eliminated. A positive starting point could be the implementations of inclusion schools in Germany.

The proportion of participants still living with their parents does not come as a surprise when comparing the results with other studies [38, 62] and considering the participant's respective age. Although there are not less people with a relationship in this study, the proportion of people living with a partner is lower than reported in the literature [27, 35]. It has to be taken into account that participants in these other studies are significantly fewer in number and tend to be older on average. Even when considering that there are a lot of young individuals included in the current study it is also known that SB patients often wish to live alone [49]. So it was expected that healthy young adults would have left home more frequently and individuals suffering from SB would not be able to live as independently as they wish. Most of the

participants are content with their present and past care situation and comparing the two points in time there are only small differences. It can be assumed that this care is mostly provided by the parents [23]. Usually parents are performing well – even over time - and the participants came to terms with this situation.

In the literature the life situation as a whole is often not rated as good as it is in the current study [23, 64]. Here it has to be taken into account that results of a single question tend to be higher in value than a calculated result of a questionnaire [65]. But in general most of the participants seem to reach a satisfying life situation.

We found only some of the living conditions to be significantly influenced by lesion level and BI. Interrelations between lesion level and education [66] as well as work [28, 67] have already been described in the literature. In SB patients with hydrocephalus Van Verhoef et al. described correlations between lesion level and independence. They also found an influence of lesion level on transfer, mobility and sphincter control [55]. Furthermore Valtonen et al. found an increased risk for unemployment in wheelchair users [68].

The weakness of our study is that only participants' view is represented. To get a more extensive and profound insight perspective of caregivers and doctors would be necessary.

It is obvious that compensation of neurological and possible cognitive deficits in individuals with SB via support and training do not provide full compensation. To enhance this situation, improvements in various starting points are necessary. On the one hand, a further improvement of medical outcome should be aimed at. On the other hand, individuals should be provided with mental skills to deal with difficulties they experience. More research is needed to find out which aspects influence independence most. That would allow choosing most efficient future actions. Individuals with SB themselves could look for role models such as other SB patients demonstrating which aims are achievable (e.g. in the form of self-help groups) [69].

CONCLUSION

Individuals suffering from SB are dependent on support performing most ADL. In the current study, the BI shows a broad distribution of results with a median score of 55, illustrating that half of the participants are highly dependent. Nearly a third of the participants have a normal job, but close to this number are also participants working in a sheltered workshop and a high rate is unemployed. Integration of SB patients in the normal labor market is clearly difficult. The majority of the participants still lives with their parents and has no relationship outside the family. But current and past care situations as well as the whole life situation are mostly assessed as good. Lesion level and the BI significantly

influence some living conditions, but are no good predictors for care or the whole life situation. For a better understanding of further factor that influence the life of individuals suffering from SB more detailed research on single aspects is necessary as well as taking into account the points of view of caregivers and doctors.

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Author Contributions

Henriette Reinhardt – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Critical revision of the article, Final approval of the version to be published

Dieter Class – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Critical revision of the article, Final approval of the version to be published

Raimund Firsching – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Critical revision of the article, Final approval of the version to be published

Guarantor of Submission

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Consent Statement

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Conflict of Interest

Authors declare no conflict of interest.

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APPENDIX

Questionnaire

- In which year were you born?
- What gender are you? Female / male
- Diagnoses:
 - Spina bifida aperta/Myelomeningocele
 - Spina bifida with hydrocephalus
 - Hydrocephalus in children without Spina bifida
 - Arnold Chiari malformation
 - Encephalocele
- Do you have a paralysis?
Yes / No If so, starting at which spinal segment?
- Have you ever had an operation due to hydrocephalus?
Yes / No / several times If so, when?
- Have you had an operation on the spine?
Yes / No / several times If so, when?
- Have you had an operation due to Arnold Chiari malformation?
Yes / No / several times If so, when?
- Have you had an operation due to tethered cord-symptoms?
Yes / No / several times If so, when?
- Have you had other, not yet mentioned, operations?
Yes / No If so, which ones and when?
- Feeding
Unable / need help / independent
- Bathing
Dependent / independent
- Grooming need help with personal care / independent (face/hair/teeth/shaving)
- Dressing dependent / need help but can do half unaided / independent
- Toilet use dependent / need some help / independent
- Bladder incontinent / occasional accident / continent
- Bowel incontinent / occasional accident / continent
- Transfer (bed to chair and back)
Unable / major help, can sit / minor help / independent (incl. wheelchair users)
- Mobility
Immobile or <50m / wheelchair: independent > 50m / walk with help of one person > 50m / independent (but may use any aid) > 50m
- Stairs unable / need help / independent
- Communication with other people
No difficulties / communication impaired / not able to communicate
- Education and training Vocational training started / studies started / vocational training finished / university degree / vocational training or studies broken off
- Work
Regular Job / sheltered workshop / receive a pension / currently unemployed / not able to work / education not finished yet
- Living conditions
I'm living alone / I'm living with a partner / I'm living in a residential community / I'm living with my parents / I'm living in a nursing home
- Partnership
Married/long-term relationship / relationship / no relationship
- How do you assess your care situation?
Present care situation: good / sufficient / improvements necessary / bad
Past care situation: good / sufficient / improvements necessary / bad
- How do you assess your life situation as a whole?
Satisfied / less satisfied / dissatisfied / very bad

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