Life satisfaction of young adults with spina bifida

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This study concerns life satisfaction and its determinants in Dutch young adults with spina bifida (SB). Data on life satisfaction (Life Satisfaction Questionnaire [LiSat-9]) were related to hydrocephalus, lesion level, disabilities, and demographic variables. In total, 179 young adults with SB participated (41% male, age range 16–25y; 79% SB aperta, 67% hydrocephalus [HC], 39% wheelchair-dependent). Most were satisfied with their life as a whole (24% dissatisfied). No difference was found from a population reference group (28% dissatisfied). Highest proportions of dissatisfaction were found for financial situation (44%), partnership relations (49%), and sex life (55%). Least dissatisfaction was found for contact with friends (17%) and families (15%). Young adults with SB and HC were more satisfied with their financial situation and family life but were less satisfied with self-care ability and partnership relations than those without HC and the reference group. However, except for self-care ability, relationships between life satisfaction and having SB were weak. In conclusion, self-care ability and partnership relations were rated least favourable and may need more attention from care providers. Overall, SB does not seem to be an important determinant of life satisfaction.

Spina bifida (SB) is a congenital condition that may result in a wide variety of physical and cognitive limitations.[1–7] After the initial hazardous years, the survival rate for a person with SB is near normal,[8,9] although hydrocephalus (HC), bladder management, and kidney-sparing always remain an issue.[7,9] Several authors have proposed that chronic conditions such as SB confront youngsters with additional barriers in the transition from adolescence to adulthood compared with their typically developing peers.[10–12] They may find themselves, for example, disadvantaged with regard to career opportunities or finding a partner. Better insight into the quality of life (QoL) of young adults with SB might identify support needs and might, thereby, provide a basis for improving the support system. Knowledge of the QoL of persons with SB is also relevant with regard to today's policies of aborting pregnancies early in gestation, the use of new operation techniques such as in utero closure of the neural tube,[13] and deciding whether or not to treat early after birth. Such decisions by medical professionals are based on, among other considerations, the expected long-term QoL of the patients involved. However, professionals tend to rate the QoL of their patients much lower than the patients themselves do.[14] Only limited research into the QoL of persons born with SB is available, and the results are equivocal. Some authors[15] found that the health-related QoL of their study population was below normal, whereas others concluded that QoL was good[10] and comparable to that of persons without SB.[11,16]

QoL is a notion with a rather broad meaning, but it is usually associated with well-being or life satisfaction.[17] Defining life satisfaction as an element of QoL, rather than equating it to QoL, is an effective approach.[18] This study addressed life satisfaction, the more subjective perceptions of the quality of one's own existence,[19] and focuses on the following research questions: (1) what is the life satisfaction of young adults born with SB?; (2) how does this compare with the life satisfaction of the general population?; and (3) does having SB affect life satisfaction?

Method

PARTICIPANTS

Participants were people who had SB aperta or occulta[20] who were within the age range 16 to 25 years, and who had sufficient command of the Dutch language. Participants with comorbidity that could independently induce serious physical and/or cognitive impairments were excluded. Participants were recruited by 11 of the 12 Dutch Spina Bifida Teams, in coordination with the Dutch Spina Bifida Patients Association, organizations for sheltered homes, and rehabilitation centres. The ethics and research committees of the participating institutions approved the study. Written informed consent was obtained from the participants, or their parents if applicable. Patient characteristics (age, sex, type of SB, level of lesion, presence of HC) were collected from medical records to facilitate a non-response analysis. Invitations were sent to 350 persons, of whom 179 participated in this study. There was no significant difference ($\alpha=0.05$) between the response group and the non-response group with regard to age, sex, type of SB, level of lesion, or having a shunt for HC. Participants were interviewed orally and filled in questionnaires as part of a larger project focusing on the physical and cognitive disabilities of young adults with SB.[5,7] Participants were interviewed between August 1999 and August 2001. Seven participants had the

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See end of paper for list of abbreviations.

questionnaires filled in on their behalf by their parents.

POPULATION

Data on the general population were taken from Post et al.[21] For this study a random sample of 1200 persons between 18 and 65 years of age was drawn from the municipal register of the city of Utrecht. These persons received a questionnaire by mail, which was completed and returned by 507 persons. From this reference group all 132 persons between 18 and 25 years of age were selected.

INSTRUMENTS

The Life Satisfaction Questionnaire (LiSat-9)[22,23] contains one question about satisfaction with life as a whole, and eight questions about domain-specific life satisfaction (shown in Table II). Each question was answered on a 6-point scale (1=very dissatisfied, up to 6=very satisfied). As described by Fugl-Meyer et al., persons with scores of 1 to 4 were classified as 'dissatisfied' and persons with scores of 5 and 6 as 'satisfied'.[22,23] The Dutch LiSat-9 has previously been used and showed satisfactory internal consistency reliability (Cronbach's alpha 0.74–0.85).[24,25]

Demographic variables taken into account were age and sex. Disease characteristics taken into account were type of SB (occulta or aperta), the level of the lesion (defined as the lowest completely unimpaired level on both sides with sensitivity to pin prick and light touch), and the presence of HC (defined as having been shunted early in life to reduce intracranial pressure). Ambulatory status (Hoffer scale[26]), incontinence, and intelligence (Raven standard progressive matrix[27]) were determined.

STATISTICS

Descriptive statistics were used and differences in the percentage of satisfied persons were tested with the χ^2 test or Fisher's exact test for 2×2 tables. This was followed by two series of logistic regression analyses: first, to check the impact of lesion level and having HC on life satisfaction, and second, to analyze differences in life satisfaction between persons with SB and the reference group, controlled for age and sex. Collinearity between type of SB, HC, and level of lesion on the one hand, and self-care ability, wheelchair dependence, incontinence, and intelligence on the other, unfortunately prohibited the use of all these variables in the same regression analysis. Therefore, only the disease characteristics were used. In addition to the odds ratios and their confidence intervals, Nagelkerke R^2 are reported as a proxy for percentage-explained variance. All results are taken to be significant at $p<0.05$ two-sided. For multiple testing, a Bonferroni correction was applied.

Results

Table I shows characteristics of the study group. Most participants had SB aperta and 84% of this group developed HC early in life, requiring a shunt. Participants with HC more often had a higher level of lesion than participants without HC. Mean age did not differ across the three groups. Except for the group of participants with SB aperta without HC, more females than males participated. Participants without

Table I: Descriptive characteristics of participants and population

Characteristic	*SB occulta*	*SB aperta without HC*	*SB aperta with HC*	*Reference group*
n	37	23	119	132
Age				
15–20y, %	46	48	45	22[b]
21–26y, %	54	52	55	78
Females, %	68	39	60	68
Level of lesion				
L2 or higher, %	14	9	56[a]	–
L3 to L5, %	38	30	40	–
S1 or lower, %	49	61	5	–
Ambulation: wheelchair dependent, %	5	9	56[a]	–
Continence: incontinent, %	38	57	81[a]	–
Intelligence: below average IQ (<85), %	16	25	54[a]	16
Living status				
With parent, %	57	57	50[a]	–
Sheltered home , %	3	9	45	–
Independent, %	41	35	5	–
Marital status				
Married/living together, %	22	4	3	18
Partner but not living together, %	27	39	15	47
No relationship, %	51	57	82[a]	35
Vocational status				
Unemployed, %	8	9	26[a]	2
Student, %	60	65	49	64
Paid work, %	32	26	25	32
Housekeeping, %	0	0	0	2

[a]Significant difference ($p<0.05$) between group of persons with SB with HC and merged group of persons with SB without HC. [b]Significant difference ($p<0.05$) between reference group and total group of persons with SB. SB, spina bifida; HC, shunted for hydrocephalus.

HC showed fewer disabilities and better social integration than participants with HC.

Because of the minimum age of 18 years, the reference group comprised a smaller proportion of persons younger than 21 years than the group of persons with SB (Table I). The proportion of female participants was similar in both groups. In terms of intelligence, marital status, and vocational status, the groups of persons with SB but without HC were similar to the reference group.

LIFE SATISFACTION OF PERSONS WITH SB

In Table II, the proportions of dissatisfied persons (LiSat-9 item score below 5) are displayed. Of all persons with SB, 21% were dissatisfied with their life as a whole. The highest proportions of dissatisfaction were found in the domains of financial situation (44%), partnership relations (49%), and

Table II: Proportions of dissatisfied persons (%) with spina bifida (SB) and in the population

Aspect of life	*SB total (n=179)*	*SB occulta (n=32)*	*SB aperta without HC (n=23)*	*SB aperta with HC (n=119)*	*Reference group (n=132)*
Life as a whole	21	14	17	24	28
Self-care ability	22	14	0	28[a]	5[b]
Leisure situation	25	16	4	32[a]	25
Vocational/educational situation	31	29	30	32	38
Financial situation	44	60	50	38	66[b]
Sex life	55	46	41	61	45
Partnership relations	49	35	41	56	34[b]
Family life	15	19	22	12	32[b]
Contacts friends and acquaintances	17	8	9	21	17

[a]Significant difference ($p \leq 0.003$) between persons with HC and persons without HC. [b]Significant difference ($p \leq 0.01$) between persons with spina bifida (SB) and reference group. Dissatisfaction was defined as a score below 5 on each Life Satisfaction Questionnaire item. HC, shunted for hydrocephalus.

Table III: Determinants of life satisfaction for participants with spina bifida

Determinant	*Life as a whole*	*Self-care ability*	*Leisure situation*	*Vocational/educational*	*Financial situation*	*Sex life*
Sex	1.10	0.44	1.07	0.77	1.53	**3.05**[b]
	(0.52–2.33)	(0.19–1.03)	(0.52–2.20)	(0.39–1.53)	(0.82–2.85)	**(1.53–6.10)**
Age	1.34	1.15	0.80	0.96	0.99	1.41
	(0.63–2.84)	(0.52–2.54)	(0.39–1.62)	(0.49–1.88)	(0.53–1.83)	(0.73–2.75)
Hydrocephalus	1.28	1.68	2.15	0.53	**0.45**[a]	1.11
	(0.47–3.50)	(0.53–5.29)	(0.78–5.92)	(0.22–1.28)	**(0.20–0.99)**	(0.49–2.55)
High lesion	1.73	**3.97**[b]	1.39	**2.22**[a]	1.13	**2.84**[b]
	(0.75–4.00)	**(1.65–9.53)**	(0.65–2.97)	**(1.03–4.81)**	(0.56–2.31)	**(1.31–6.15)**
Low lesion	1.28	4.49	2.55	2.27	1.09	1.64
	(0.37–4.47)	(0.50–40.15)	(0.62–10.52)	(0.75–6.83)	(0.43–2.75)	(0.62–4.35)
Nagelkerke R^2 (%)	4.4	25.4	10.7	7.7	5.2	18.3

Results are shown as odds ratios (95% confidence interval) unless otherwise defined. Condition per determinant: sex (male); age (21y or older); high lesion (L2 or higher); low lesion (L5 or higher). Results in bold are significant at the following levels: [a]$p<0.05$; [b]$p<0.01$.

Table IV: Associations between having spina bifida, age, and sex with life satisfaction

Determinant	*Life as a whole*	*Self-care ability*	*Leisure situation*	*Vocational/educational*	*Financial situation*	*Sex life*
Sex	0.88	0.52	0.98	1.25	1.61	**1.69**[a]
	(0.51–1.54)	(0.25–1.07)	(0.57–1.68)	(0.76–2.05)	(0.99–2.62)	**(1.04–2.73)**
Age	1.45	1.07	0.76	1.15	1.11	1.30
	(0.80–2.61)	(0.54–2.12)	(0.44–1.31)	(0.68–1.94)	(0.67–1.81)	(0.78–2.17)
Spina bifida	0.76	**6.27**[b]	0.94	0.74	**0.40**[b]	1.57
	(0.44–1.30)	**(2.52–15.61)**	(0.54–1.61)	(0.45–1.21)	**(0.24–0.65)**	(0.96–2.55)
Nagelkerke R^2 (%)	1.8	13.2	0.5	1.2	7.7	3.9

Results are shown as odds ratios (95% confidence interval) unless otherwise defined. Condition per determinant: sex (male); age (21y or older). Results in bold are significant at the following levels: [a]$p<0.05$; [b]$p<0.001$.

sex life (55%). The lowest proportion of dissatisfaction was found for contact with friends (17%) and families (15%).

To analyze differences between groups of persons with different types of SB, first the groups of persons with SB occulta and those with SB aperta without HC were compared. There was no difference in life satisfaction between these two groups on any item. We, therefore, merged these two groups into one group as participants without HC. Comparing the persons with and without HC, persons with HC were more often dissatisfied with their self-care ability ($p=0.002$) and leisure situation ($p=0.003$).

SB VERSUS REFERENCE GROUP

Of the reference group, 28% were dissatisfied with life as a whole (Table II). The highest proportions of dissatisfaction were found with respect to financial situation (66%) and sex life (45%), whereas the lowest proportions of dissatisfaction were found for contacts with friends (17%) and self-care ability. When compared with the reference group, persons with SB were more often dissatisfied with their self-care ability ($p<0.000$) and partnership relations ($p=0.008$). However, they were less often dissatisfied with their financial situation ($p<0.000$) and family life ($p=0.001$) than persons in the reference group. These differences can mostly be attributed to the effect of HC. The group of persons with HC differed significantly from the reference group on all four items ($p<0.001$), whereas no significant difference was found between the group of persons without HC and the reference group.

Table III: continued

Partnership relations	*Family life*	*Contacts friends*
1.93	0.71	**0.34**[a]
(0.99–3.74)	(0.29–1.73)	**(0.13–0.89)**
0.98	0.80	0.82
(0.51–1.87)	(0.34–1.86)	(0.35–1.88)
2.01	0.71	**4.70**[a]
(0.87–4.64)	(0.24–2.10)	**(1.25–17.63)**
1.25	1.18	0.85
(0.59–2.63)	(0.41–3.37)	(0.34–2.18)
0.94	0.51	0.43
(0.35–2.49)	(0.15–1.66)	(0.11–1.72)
7.4	3.9	11.7

Table IV: continued

Partnership relations	*Family life*	*Contacts friends*
1.63	1.07	**0.40**[a]
(0.99–2.68)	(0.59–1.93)	**(0.2–0.83)**
0.82	0.81	0.84
(0.49–1.37)	(0.44–1.50)	(0.44–1.59)
1.76[a]	**0.35**[b]	0.96
(1.06–2.91)	**(0.19–0.63)**	(0.52–1.80)
5.3	6.5	3.9

DETERMINANTS OF LIFE SATISFACTION OF PERSONS WITH SB

The impact of demographic and disease characteristics on life satisfaction of persons with SB is shown in Table III. No significant determinant was found between these variables and satisfaction with life as a whole, leisure situation, partnership relations, and family life. A high level of lesion was a single significant determinant for dissatisfaction with self-care ability and vocational/educational situation. HC was a single significant determinant of satisfaction with financial situation. Both sex (males) and high level of lesion predicted dissatisfaction with sex life. Finally, dissatisfaction concerning contact with friends was predicted by sex (females) and HC.

Apart from self-care ability (25.4%) and to some extent sex life (18.3%) only a minimal amount of variance was explained by the determinants used.

A series of logistic regression analyses were performed to explore the effect of having SB on life satisfaction (Table IV). Age was not a significant determinant of life satisfaction in any logistic regression analysis. Sex (male) was a significant determinant for dissatisfaction with sex life. Sex (female) was also a significant determinant for contact with friends. Group membership (SB versus reference group) was a significant determinant for dissatisfaction with self-care ability and partnership relations as well as a determinant for satisfaction with financial situation and family contact. However, except for self-care ability (13.2%), the amount of variance explained by age, sex, and having SB was again very small.

Discussion

One of the major findings of this study is that life satisfaction of young adults born with SB is more or less similar to that of their typically developing peers, and that severity of SB has only a minor impact on life satisfaction. This finding confirms the results of most of the previous smaller studies, using similar or different conceptualizations of QoL. Query et al.[10] concluded that, despite reports of physical and emotional stress, most children and adolescents with HC and SB judged the quality of their lives and family relationships to be good. Similarly, Lindstrom and Kohler[11] found only small differences in QoL between adolescents with myelomeningocoele and typically developing youths. However, self-esteem was lower in the group of persons with myelomeningocoele. Sawin et al.[16] found a moderately high QoL in families with adolescents with SB. In addition, they found no relationship between QoL and shunt status, level of lesion, and severity of the SB. Padua et al.[28] concluded from their study on adolescents with SB that there is no linear inverse correlation between disability and QoL in patients with SB and that patients with mild disabilities needed as much psychological support as patients with severe disabilities.

The finding that persons with severe disabilities are more satisfied with their lives than others might expect, is known from groups of patients with different aetiologies. For example, Bach et al. showed that professionals underestimated the QoL of persons with high tetraplegia.[14] Post et al. reported that persons with paraplegia due to spinal cord injury had an overall life satisfaction similar to that of the general population.[21,24]

Despite similar overall life satisfaction, differences in satisfaction between persons with SB and typically developing persons were found for several domains, although these differences were not always in the expected direction. The group of persons with SB and HC were more satisfied with their financial situation and family life than the general population. This might possibly be explained by different ways of living. Whereas most typically developing young adults were students, had left their parental homes to live on their own, and many of them having a low income, persons with SB and HC were mostly living with their parents or in a sheltered home. In both circumstances, financial limitations might be a burden mainly for their caregivers. In the present study, persons with SB and HC were more often dissatisfied with their sex life and partnership relations than the general population. For partnership relations, having SB was a significant factor, but for sex life the significant determinant was sex; males were less satisfied with their sex life or with not having a sex life at all. The topic of sexuality has been explored in greater detail elsewhere.[29] More persons with SB were dissatisfied with their self-care ability than persons in the general population. This was to be expected, considering the number of persons with SB being wheelchair-dependent or incontinent, and being dependent on others for help.

However, except for self-care, differences in life satisfaction between persons with and without SB were generally small and were probably more strongly related to other factors, such as living arrangements, than to having SB by itself. Thus, having SB does not in general seem to be an important determinant of life satisfaction for the persons involved.

With regard to the differences between subgroups of persons with SB, some findings are worthy of discussion. One finding is that the proportions of satisfied persons with SB aperta without HC and the persons with SB occulta were similar across all domains. In addition, these two groups taken together (SB without HC) showed a level of well-being fairly similar to that of the reference group, even though a considerable number suffered from incontinence.

Within the group of young adults with SB, those with HC were more dissatisfied with five out of eight life domains. This was most obvious for self-care ability and leisure activities. However, it must be emphasized that the large majority of persons with HC were satisfied with their lives as a whole, and with six out of eight life domains. Despite a few high odds ratios in the regression analyses, the amount of variance explained by HC and level of lesion was minimal for all domains of life, apart from self-care ability and sex life. This supports the statements by Sawin et al.[16] that conditions specific for SB, such as shunt status, level of lesion, and severity of the SB, are not major determinants of QoL. Differences in life satisfaction may be more strongly associated with factors not included in the present study, e.g. parental hope and other family factors.[16] Other factors might contribute as well, e.g. coping, social support, living status, or differences in personality.[11] More research is needed into the other determinants of life satisfaction to permit the development of interventions for those persons with SB at risk of poor life satisfaction.

Our study adds to the available evidence on several aspects. First, a large number of persons were included. Second, contrary to earlier studies,[10,15,16] we used reference data and were able to perform statistical testing of differences between both groups. Third, the standardized measure of life satisfaction used in the present study enabled us to differentiate between several important domains of life. Last, most earlier studies included children and/or adolescents,[15,16] whereas our study reports on a sample of adolescents and young adults (age 16–25y).

The study has some limitations. The cut-off point for the difference between satisfied and dissatisfied is rather strict, meaning that the proportion of satisfied persons might have been underestimated. In addition, seven parents filled in the questionnaires on behalf of their child. They were, however, instructed to fill in the questionnaire in a way they felt it would best reflect their child's own perception of life satisfaction, and not the parent's perception. The small number of parental reports most probably did not bias the results. Sawin et al.[16] showed that parents are accurate in supplying overall quality-of-life data for their adolescent. Another point is that the lack of persons aged 16 and 17 years in the population sample might have influenced the results. However, the analyses showed no relationship between age and life satisfaction, and in the regression analysis the comparisons were corrected for age. Furthermore, multiple comparisons were made, which increases the chance of false positives. Because the influence of SB on life satisfaction was positive for some domains and negative for others, adding up item scores and analyzing a total LiSat-9 score only would obscure influences of interest. To minimize the chance of false positives, the alpha coefficient was corrected with the Bonferroni method.

In general, satisfaction with life seems to be fairly similar for young adults with or without SB, which in itself is good news. However, young adults with SB are at risk for dissatisfaction with important aspects of life, such as self-care, partnership relations, and sex life, even when this does not seem to be reflected in their satisfaction with life as a whole. Professional care providers should pay special attention to issues of sexuality and autonomy.

Finally, the participants in our study are in the middle of a period of transition and integration into society. Further longitudinal research is needed to study their development of life satisfaction over time, as well as research into personal and environmental factors that might influence life satisfaction.

Conclusion

In a large group of Dutch young adults born with SB, a good to fair level of satisfaction with life was found. Self-care ability, sex life, and partnership relations were domains of life that need the attention of professional care providers. However, SB itself does not seem to be an important determinant of life satisfaction.

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List of abbreviations

HC	Hydrocephalus
LiSat-9	Life Satisfaction Questionnaire
SB	Spina bifida