Work participation among young adults with spina bifida in the Netherlands

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The aim of this study was to: (1) assess work participation among young adults with spina bifida, (2) identify problems perceived in finding employment, and (3) examine which determinants are related to work participation. This cross-sectional study was a follow-up study to the Adolescents with SPina bifida In the Netherlands (ASPINE) study. Data regarding work participation and problems finding employment were collected with questionnaire developed by the authors. Data on disease characteristics were taken from the ASPINE database. Responses of 136 participants were analyzed (77 females, 59 males; mean age 26 years 1 month [SD 3y1mo], range 21–32y). Twenty participants had spina bifida occulta and 116 had spina bifida aperta, 96 of whom also had hydrocephalus. Work participation rate was 62.5%, of which 22.4% was in a sheltered workplace. Significant determinants of having paid work for at least 1 hour a week were: level of education, level of lesion, hydrocephalus, IQ, functional independence, and ambulation. Significant determinants of full-time employment were the same, plus sex and type of spina bifida. In a multivariate backward logistic regression analysis, however, only level of education remained a significant predictor of work participation. Sex, level of education, and self-care independence were significant predictors of full-time employment. This study shows the importance of educational support and self-care independence training for children with spina bifida.

The transition from adolescence into adulthood presents major challenges to persons with spina bifida. One of these challenges is obtaining a place in the labour market. Having a job is an important aspect of societal integration, not only because it provides financial independence, but also because it provides an environment for social interaction and a sense of self-esteem.[1]

Previous research on adolescents or adults with spina bifida examined employment in the context of outcome, participation, or quality of life.[2–8] Other studies focussing on work participation showed overall employment rates varying between 19 and 38%.[9–16] Few studies have reported on determinants of work participation for persons with spina bifida.[8,9,13,14] Hurley and Bell[13] found cognitive ability to be significantly associated with work participation. In a study excluding patients with an IQ below 65, Tew et al.[14] found intelligence, highest obtained academic qualification, and independence in toileting to be significantly associated with work participation. Valtonen et al.[9] also found work participation to be associated with educational level, ambulatory status, and independence in self-care activities. This study, however, focussed on patients with traumatic spinal cord injury, and included only a minor group of patients with myelomeningocele. Loomis et al.[8] found that perceived family encouragement of achievement was positively related to employment, while perceived moral/religious emphasis in the family environment was negatively related to employment. We found no study of the work-related problems perceived by persons with spina bifida themselves. Thus, little is known about the employment status of young adults with spina bifida or its determinants. Knowledge of these factors might yield recommendations to improve the support system for persons with spina bifida, in order to improve their chances on the labour market.

The aim of this study was to assess work participation among young adults with spina bifida, to identify problems they experience in finding employment, and to examine determinants of work participation.

Method

PARTICIPANTS

Participants were young adults with spina bifida who had previously participated in the Adolescents with SPina bifida In the Netherlands (ASPINE) study between 1999 and 2001. Three hundred and fifty patients were invited to participate in the ASPINE study, of whom 179 eventually participated. This group consisted of young adults with different types of spina bifida (aperta and occulta, International Classification of Diseases, 9th revision codes 741 and 756.17), aged 16 to 25 years and living in the Netherlands.[17,18] These patients were recruited from 11 of the 12 Dutch spina bifida teams, in cooperation with the Dutch Association for Patients with Spina Bifida, organizations for sheltered homes, special schools, and rehabilitation centres. No significant difference was found between the study population and the non-participants in terms of type and level of spina bifida, hydrocephalus, or demographic variables.

PROCEDURE

In 2006, all 179 participants in the ASPINE study were sent a postal questionnaire with an invitation letter. It was stressed that participation was voluntary, that they could consent to

participate by returning the completed questionnaire to the research team, and that they were free to decline participation. Non-responders were first sent a postal reminder and were later telephoned to confirm that they had received the questionnaire. Most questionnaires were completed by the patients themselves, while a few were completed by their parents. The Medical Ethics committee of De Hoogstraat Rehabilitation Centre approved this follow-up study.

MEASURES

Follow-up data were collected using a self-developed questionnaire. Participants were asked about working in open or sheltered employment (a working facility organized by the government with specially adapted conditions, in which employees earn their own money), type of work, number of hours a week of paid work, problems related to spina bifida they had experienced when trying to find employment, experiences with professional assistance when trying to find employment, and work satisfaction.

Work was defined as having paid employment, either on the open labour market or in a sheltered workplace. Employment status was divided into: 1 to 23 hours a week, 24 to 35 hours a week, and 36 hours a week or more (full-time employment). Participants without paid work were subcategorized as: (1) attending a day centre (a facility where people perform easy tasks under supervision for part of the day or a few days a week without salary), (2) being in full-time education, (3) actively looking for employment, (4) performing volunteer work, or (5) being inactive. Education was divided into three categories: special education for persons with disabilities, lower education (lower general secondary education), and higher education (higher general secondary education, higher professional education, or university). Self-care was classified as independent if no help from other persons was required. Ambulation was divided into walkers and wheelchair users.

Data on neurological level of lesion, hydrocephalus, number of shunt revisions, urinary and/or faecal incontinence, and cognitive functioning were derived from the database of the ASPINE study.[17] Level of lesion was measured according to the International Standards for Neurological and Functional Classification of Spinal Cord Injury[19,20] and defined as the lowest completely unimpaired dermatome level on both sides, measured with sensitivity to pin prick and light touch. Participants were divided into three subgroups based on level of lesion: (1) L2 and above; (2) L3 to L5; (3) S1 and below. Hydrocephalus was defined as having a shunt either at the time of physical examination or having had one previously. Information regarding shunting was retrieved from medical files. Incontinence was defined as faecal and/or urinary spoilage requiring a change of clothes or incontinence wear at least once a month.[17] Cognitive functioning was determined using the Raven Standard Progressive Matrices,[21] with the raw score converted into an IQ score. Mean IQ of the general population is 100 (SD 15). The cut-off point for low IQ was 85. The cognitive status of nine participants was not determined, so they were excluded from the relevant analyses.

STATISTICAL ANALYSIS

Data were analyzed using SPSS (version 15.0). Possible determinants of work participation were explored using crosstabs with four categories of work participation: none, 1 to 23 hours a week, 24 to 35 hours a week, and 36 hours or more a week. To test possible determinants of work participation, odds ratios were calculated using two series of bivariate logistic regression analyses. First, respondents who did not work at all were compared with respondents who worked at least 1 hour a week. Second, respondents who did not work full-time (0–35h/wk) were compared with respondents who worked full-time (≥36h/wk or more). Finally, variables showing a bivariate relationship with work participation ($p<0.10$) were included in two multivariate backward logistic regression analyses to identify the strongest predictors of working and of working full-time; Nagelkerke's R-square was computed to estimate the predictive power of the regression models.

Results

PARTICIPANTS

A total of 179 persons with spina bifida were approached, 146 of whom participated (83%). One person was deceased, one person was untraceable, and the others failed to respond to our request to participate. No significant difference between participants and non-participants was found in terms of type of spina bifida, level of lesion, or hydrocephalus. Ten participants diagnosed with spina bifida occulta without any neurological loss were excluded afterwards.

Eventually, data for this study on work participation were available for 136 participants (77 females, 59 males; mean age 26y 1mo [SD 3y 1mo], range 21–32y). Characteristics of participants are shown in Table I.

EMPLOYMENT AND PROBLEMS FINDING EMPLOYMENT

Table II shows the employment situation or other daily activities of all participants. Most (62.5%) were employed for at least 1 hour a week, while 43.4% were employed for at least 24 hours a week, and 26.5% were employed for at least 36

Table I: Participant characteristics (n=136) n (%)

Sex	
Males	59 (43.4)
Females	77 (56.6)
Age, y	
21–26	77 (56.6)
27–32	59 (43.4)
Mean age (SD)	26 (3.1)
Type of spina bifida	
Aperta	116 (85.3)
Occulta	20 (14.7)
Level of lesion	
≥L2	59 (43.4)
L3–L5	52 (38.2)
≤S1	25 (18.4)
Hydrocephalus	
Yes	96 (70.6)
No	40 (29.4)
Incontinence of urine/faeces	
Yes	92 (67.6)
No	44 (32.4)
IQ (n=127)	
≥85	77 (60.6)
<85	50 (39.4)
Wheelchair user	
Yes	80 (58.5)
No	56 (41.5)

Table II: Work participation among young adults with spina bifida (n=136), n (%)

Paid employment	85 (62.5)
Open labour market	66 (77.6)
Sheltered workplace	19 (22.4)
No paid employment	51 (37.5)
Day centre	12 (23.5)
Looking for a job	9 (17.6)
Full-time education	5 (9.8)
Voluntary work <15h/wk	7 (13.7)
Voluntary work ≥15 h/wk	4 (7.8)
Inactive	14 (27.6)

hours a week. Fifty-one participants (37.5%) were unemployed, but the majority of these were engaged in some activity such as attending a day centre, full-time education, or volunteer work; only 14 persons were inactive. The relation between demographic characteristics and physical and cognitive impairments and work status are shown in Table III. Sixty-four percent of the working males and 24% of the working females were in full-time employment. Of the 25 patients who had a higher education qualification, two (8%) were unemployed because they were still in full-time education, while most (72%) worked for more than 24 hours a week. In contrast, of the 52 patients who had had special education, most (63.5%) were unemployed and 25% worked more than 24 hours a week.

Participants were asked about spina bifida-related difficulties they had experienced with trying to find employment. Forty-four (49%) participants did not report any problems, whereas 46 (51%) reported one or more problems. All participants who had experienced problems had paid work or attended a day centre. Reported problems included being offered work that was physically (30%) or mentally (27%) too demanding, transportation facilities (32%), accessibility of buildings (23%), and toilet space (23%). The most commonly reported problem, however, was a reluctant attitude among employers (57%).

Seventy-five participants (81.5%) who had paid work or attended a day centre said they enjoyed their work, while 17 participants (18.5%) did not. Participants were asked about assistance they had received to help them find employment.

Table III: Work participation among young adults with spina bifida in relation to demographic characteristics, characteristics of the condition, and disabilities (n=136), n (%)

	No paid work (n=51)	*< 24h/wk (n=26)*	*24–35h/wk (n=23)*	*≥36h/wk (n=36)*
Age, y				
21–26	28 (36.4)	16 (20.8)	10 (13.0)	23 (29.9)
27–32	23 (39.0)	10 (16.9)	13 (22.0)	13 (22.0)
Sex				
Males	20 (33.9)	6 (10.2)	8 (13.6)	25 (42.4)
Females	31 (40.3)	20 (26.0)	15 (19.5)	11 (14.3)
Education				
Special school	33 (63.5)	6 (11.5)	7 (13.5)	6 (11.5)
Lower general secondary	15 (26.3)	14 (24.6)	11 (19.3)	17 (29.8)
Higher general secondary/ professional/university	2 (8.0)	5 (20.0)	5 (20.0)	13 (52.0)
Type of spina bifida				
Occulta	5 (25.0)	2 (10.0)	4 (20.0)	9 (45.0)
Aperta	46 (39.7)	24 (20.7)	19 (16.4)	27 (23.3)
Lesion level				
≥L2	29 (49.2)	14 (23.7)	8 (13.6)	8 (13.6)
L3–L5	18 (34.6)	9 (17.3)	9 (17.3)	16 (30.8)
≤S1	4 (16.0)	3 (12.0)	6 (24.0)	12 (48.0)
Hydrocephalus				
No	8 (20.0)	5 (12.5)	8 (20.0)	19 (47.5)
Yes	43 (44.8)	21 (21.9)	15 (15.6)	17 (17.7)
Shunt revision (n=95)[a]				
0	7 (43.8)	2 (12.5)	3 (18.8)	4 (25.0)
1–2	16 (45.7)	8 (22.9)	4 (11.4)	7 (20.0)
≥3	20 (45.5)	11 (25.0)	7 (15.9)	6 (13.6)
IQ (n=127)				
≥85	22 (28.6)	16 (20.8)	13 (16.9)	26 (33.8)
<85	25 (50.0)	10 (20.0)	8 (16.0)	7 (14.0)
Incontinence of urine/faeces				
No	12 (27.3)	8 (18.2)	6 (13.6)	18 (40.9)
Yes	39 (42.4)	18 (19.6)	17 (18.5)	18 (19.6)
Self-care				
Independent	25 (27.2)	16 (17.4)	18 (19.5)	33 (35.9)
Dependent	25 (58.1)	9 (23.3)	5 (11.6)	3 (7.0)
Ambulation				
Walker	12 (21.4)	11 (19.6)	9 (16.1)	24 (42.9)
Wheelchair user	38 (48.1)	15 (19.0)	14 (17.7)	12 (15.2)

[a]Only for participants with hydrocephalus.

Fifty-six participants (43.3%) reported they had not received any support, while 73 participants (56.6%) had. Of those who had not had any support, 15 (25.9%) would have welcomed it.

LOGISTIC REGRESSION ANALYSIS

Two series of bivariate logistic regression analyses were performed; the results are shown in Table IV. Patients who had a higher level of education, a lower level of lesion, no hydrocephalus, an IQ over 85, who were Self-care independent, and who were walkers were more likely to have paid work (1h/wk or more). These same characteristics were also significantly related to having full-time employment (36h/wk or more). Male patients and patients with spina bifida occulta were also more likely to be in full-time employment.

Finally, two multivariate backward logistic regression analyses were performed. The first showed that level of education was the only significant predictor of having paid work. Nagelkerke's R-square for this first model was 23.8%. Significant predictors of full-time employment were sex, level of education, and Self-care independence. A trend was further found for being continent for urine and faeces ($p<0.10$). Nagelkerke's R-square for this last model was 38.6%.

Discussion

The purpose of the present study was to assess work participation and its determinants among young adults with spina bifida. We found an overall work participation rate of 62.5%, or 48.5% if work participation was restricted to work in the open labour market. Level of education was the only significant predictor of work participation in general. Significant predictors of full-time employment were level of education, being male, and being self-care independent.

Many participants without paid work were engaged in activities in activity centres, education, or voluntary work. We presume that participants who were still in full-time

Table IV: Logistic regression of work participation and demographic characteristics, characteristics of the condition, and disabilities among young adults with spina bifida (*n*=136)

	Determinant of work participation (>0h/wk)		*Determinant of full-time work participation (≥ 36h/wk)*	
	Bivariate OR (95% CI)	*Multivariate OR (95% CI; n=125)*	*Bivariate OR (95% CI)*	*Multivariate OR (95% CI; n=125)*
Age, y				
21–26	0.89 (0.44–1.80)	Not included	0.66 (0.30–1.46)	Not included
27–32	[d]		[d]	
Sex				
Males	1.31 (0.65–2.67)	Not included	4.41 (1.94–10.03)[a]	6.17 (2.24–16.97)[a]
Females	[d]		[d]	[d]
Education				
Special	0.05 (0.01–0.24)[a]	0.06 (0.01–0.28)[a]	0.12 (0.04–0.38)[a]	0.18 (0.04–0.76)[b]
Lower	0.24 (0.05–1.16)[c]	0.25 (0.05–1.22)[c]	0.39 (0.15–1.03)[c]	0.37 (0.12–1.15)[c]
Higher	[d]		[d]	[d]
Type of spina bifida				
Occulta	1.97 (0.67–5.8)	Not included	2.70 (1.01–7.19)[b]	$p>0.10$
Aperta	[d]		[d]	
Lesion level				
≥L2	0.20 (0.06–0.64)[a]	$p>0.10$	0.17 (0.06–0.50)[a]	$p>0.10$
L3–L5	0.36 (0.11–1.21)[c]		0.48 (0.18–1.28)	
≤S1	[d]		[d]	
Hydrocephalus				
No	3.25 (1.36–7.77)[a]	$p>0.10$	4.20 (1.87–9.47)[a]	$p>0.10$
Yes	[d]		[d]	
Shunt revision (n=95)[e]				
0	1.07 (0.34–3.39)	Not included	1.86 (0.57–6.04)	Not included
1–2	0.99 (0.41–2.41)		1.09 (0.42–2.97)	
≥ 3	[d]		[d]	
IQ (n=127)				
≥ 85	2.50 (1.19–5.26)[b]	$p>0.10$	2.40 (1.13–5.08)[b]	$p>0.10$
< 85	[d]		[d]	
Incontinence of urine/faeces				
No	1.96 (0.91–4.35)[c]	$p>0.10$	1.96 (0.94–4.00)[c]	2.48 (0.91–6.76)[c]
Yes	[d]		[d]	[d]
Self-care				
Independent	3.72 (1.74–7.96)[a]	$p>0.10$	7.46 (2.14–25.98)[a]	6.44 (1.22–34.08)[b]
Dependent	[d]		[d]	[d]
Ambulation				
Walker	3.40 (1.56–7.38)[a]	$p>0.10$	4.19 (1.86–9.42)[a]	$p>0.10$
Wheelchair user	[d]		[d]	

[a]$p<0.01$; [b]$p<0.05$; [c]$p<0.10$; [d]$p>0.10$; [e]only shunted participants. Final model of backward binary logistic regression analysis: 1: Nagelkerke's R-square model >0h/w: 23.8%; 2: Nagelkerke's R-square model >35 h/w: 38.6%. OR, odds ratio; CI, confidence interval.

education will join the labour market in the future. In fact, only a few participants had no activity at all.

The work participation rate of 62.5% found in this study was higher than the percentages reported in earlier studies. Smith[16] found an employment rate (including sheltered work) of 45% among 126 participants with spina bifida with an age range of 16 to 73 years (mean 24y 5mo). Lonton et al.[15] found a much lower employment rate of 19% (including sheltered work) in a group of 157 patients with spina bifida aperta, but their population had a lower age range of 16 to 24 years (mean 22y 4mo). The low age bracket of this group makes the low percentage having paid work less significant because most participants were probably still in full-time education, as was found in the earlier ASPINE study.[18] Moreover, both studies date from 23 years ago, making comparisons difficult.

More recent studies[9–11,13,14] showed work participation rates of between 29 and 38% in study groups with a mean age of between 25 years 5 months and 30 years 2 months. If sheltered work had been included, as it was in our definition of work, Tew et al.[14] and Hurley and Bell[13] would have found work participation rates of 52% and 75% respectively. These figures resemble our work participation rates. Other studies only included participants with hydrocephalus,[10,13] participants with myelomeningocele,[9,11] or participants with an IQ of 65 or above.[14] The added value of the present study is the inclusion of all persons with spina bifida, including persons with a high functional level (those having spina bifida occulta with neurological deficits and those without hydrocephalus), as well as persons with a low IQ.

Although work participation was relatively high in our study, finding employment does not seem to be without problems. The most commonly experienced problem in finding work was a reluctant attitude among employers, based on the assumption that a disabled person would be less productive and take more sick leave. However, the survey by Smith[16] revealed that employees with spina bifida were regular attendees at work and took sick leave relatively rarely. In their article about the needs of adults with spina bifida, Stellman-Ward et al.[2] stated that certain facilities at the workplace could be improved, such as wider doors, bigger washbasins, and more room to move in toilets, as well as better transportation and accessibility of buildings. These items were also mentioned by our participants as problems in their work situations.

Level of education, level of lesion, hydrocephalus, IQ, self-care independence, and ambulation were significant determinants of work participation in general. The same determinants, plus sex and type of spina bifida, were significantly related to full-time employment. Only four studies have reported on determinants of work participation. Two of these studies also found significant relationships between level of education, independence in self-care, and work participation.[9,14] Valtonen et al.[9] found ambulation to be a determinant of work participation, while Tew et al.[14] found intelligence to be so. Hurley and Bell[13] found that cognitive abilities represented a determinant of work participation. These three studies only included patients with hydrocephalus, and did not make a distinction between levels of lesion. In these three studies, patients were divided into those who had found work on the open labour market (part-time or full-time), those who worked at a sheltered workplace, and those who were unemployed, making it difficult to compare our results with theirs. Loomis et al.[8] found that perceived family encouragement of achievement was positively related to employment, while perceived moral/religious emphasis in the family environment was negatively related to employment. As far as we are aware, our study is the first to report on the relation between work participation and level of lesion, hydrocephalus, sex, and type of spina bifida.

A higher level of education was an important and significant predictor in our logistic regression analysis. Apparently, requirements for a successful educational career resemble those for success on the labour market. This is not surprising, since the qualities required to attend regular (higher) education successfully are also necessary for many types of employment. Professions require physical rather than intellectual demands are often less suitable for persons with spina bifida, because of their physical disabilities. It is, therefore, important to ensure that adolescents with spina bifida, are encouraged to pursue the highest level of education their ability can allow in order to improve their chances in the labour market. It is worth investing in the highest level of education that suits their intellectual abilities. Barf et al.[18] found that a large proportion of children with hydrocephalus who started off in regular primary school were forced to transfer to a special school. These children had lower intelligence and were less ambulant. A below-average IQ is a strong predictor of a requiring special education;[22] however, wheelchair dependence should not be a reason to leave regular education for those with normal intelligence.

The most effective time to help patients find a job is immediately after they finish their education. Although many participants in our study had been assisted in finding employment (56%), there was still a group who would have liked help, but did not receive it. When people are unable to find employment immediately after completing their education and have to accept welfare benefits, there is a danger that their motivation to work will gradually decrease.[14]

The number of patients in paid work did not differ between the 21 to 26 and 27 to 32 year age groups, probably because very few patients in these age brackets were still in full-time education. Since self-care independence was a predictor of being employed, it is important to train patients in this respect. Sex was another predictor of full-time employment. Although in the healthy population, males are also more likely to be in full-time employment than females, the difference in work participation between the sexes appears to be higher in spina bifida patients. Therefore female patients should be encouraged to find full-time employment. Although the difference was not significant ($p<0.10$), urinary and faecal continence made it 2.48 times more likely for the spina bifida patients in our study to be employed. It is, therefore, also important to train patients in this respect.

Currently, little is known about factors restricting work participation by patients with spina bifida, and further research on this subject is required. This study included a large group of young adults with all types of spina bifida, aged between 21 and 32 years, and all but five of them had completed their education. This allowed us to gather reliable data about work participation and to perform a multivariate analysis of determinants of work participation.

This study included participants of the earlier ASPINE study. A limitation of that study was the low response rate

(179 out of 350), although there was no significant difference in terms of age, sex, level of lesion, hydrocephalus, or type of spina bifida between responders and non-responders. A further limitation of the present follow-up study was the use of a written questionnaire, which means that the quality of the response might be related to the participants' cognitive situation. Fortunately, parents were willing to help participants fill in the forms. Finally, this study focussed on work participation only. Further research could focus on other important domains of social participation.

Conclusion

This study among young adults with spina bifida in the Netherlands found a work participation rate of 62.5%. About half of this group experienced spina bifida related problems with trying to find employment. Highest attained educational level was the main predictor of employment outcome, while the main predictors of full-time employment outcome were sex, highest attained educational level, and self-care independence.

The challenges in terms of increasing employment opportunities for this group are to help create conditions allowing patients with spina bifida to achieve the highest possible educational level matching their cognitive status, to improve the support they receive in finding employment, and to encourage them to achieve self-care independence.

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