

THE SELF-CONCEPT OF YOUNG PEOPLE WITH SPINA BIFIDA: A POPULATION-BASED STUDY

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This paper reports a study of self-concept in young people with spina bifida. Previous studies are briefly described, followed by an account of the relevance to physical disability of findings in the developmental psychology of self-concept.

Interventions by professionals for physically disabled young people will need increasingly to take account of young people's views of themselves, and their wishes and plans for the future (Department of Health 1989). It follows that the scientific study of self-concept and self-worth in those with a physical disability is an essential component of the knowledge that professionals should be using for designing multi-agency interventions. Young people's overall sense of self-worth, their motivation to develop and change, the value they place on various aspects of personal functioning, and their sense of social identity, are all factors which are central to an understanding of how best to intervene to help young people with physical disabilities (Thomas *et al.* 1989) and how to provide more appropriate developmental opportunities (Rutter 1987).

To date, the reported studies of global self-worth (or self-esteem) in spina bifida subjects find mean differences between spina bifida and control samples to be marginal (Campbell *et al.* 1977) or non-existent (Spaulding and Morgan 1986).

However, samples have tended to be small (Campbell *et al.* 1977, Spaulding and Morgan 1986, Lavigne *et al.* 1988); hospital out-patient clinic lists have been the predominant source of samples; there have been IQ selection biases in some studies (Campbell *et al.* 1977, Spaulding and Morgan 1986, Murch and Cohen 1989); and theoretical models of self-concept development and disability have not been employed (Harper 1991). Thus, for instance, while it is known that able-bodied teenagers are concerned with their own physical appearance and that this factor is linked very closely to their global self-worth (Harter 1986), no study has identified the exact association between feelings about the body and feelings about the self-as-a-whole of young people with spina bifida. Until recently one problem has been the lack of appropriate measuring instruments.

It is now known that self-concept can be broken down into dimensions (or 'domains'), and that children and teenagers can accurately assess what they feel about themselves in relation to these different domains (Harter 1986, Marsh 1989).

We would expect that children with spina bifida, like able-bodied children, would have individual areas of difficulty and individual areas of success in the various domains of self-concept. In general it would be expected that, because

of difficulties with mobility, continence and intellectual performance, young people with spina bifida would evaluate themselves relatively poorly in the domains of athletic, physical and scholastic self-concept. Harter (1985a, 1986, 1990) used the term 'perceived competence' to refer to the evaluation the young person makes of performance in each domain. It would be useful to know whether perceived competence in these key areas is indeed lower among physically disabled than among able-bodied young people.

However, the evaluation placed on experience or performance in a particular domain of self-concept will depend on how important that area is to the individual personally: not being good at mathematics may not affect your self-esteem if it is not important to you (Harter 1986).

It is essential, therefore, that self-concept instruments incorporate a method of ascertaining the importance that a child places on each domain, as well as a self-rated measure of competence. If children feel competent in a domain which is important to them, then self-worth is likely to be boosted. On the other hand, competence may be irrelevant for self-worth if the domain is not important or personally valued. Using instruments developed by Harter (1985a), and Renick and Harter (1988), it is possible to measure both competence and importance for each domain. The relation between these two measures can then be examined. Following William James' notion of the ratio of pretension (aspiration or importance) to success (competence), Harter calculated a 'discrepancy' score (competence minus importance) to convey the size and direction of disparity for each domain. Harter (1986) demonstrated a linear relationship between discrepancies and global self-worth, negative domain discrepancies being associated with lower global self-worth.

How would a child with several areas of difficulty cope with a range of potentially stressful discrepancies between competence and importance? If the child feels less competent than peers, but experiences similar aspirations, there is a risk of low self-worth. In order to regulate this, competence could be overestimated or

importance reduced.

Harter (1986) and Crocker and Major (1989) summarised evidence that actively reducing the importance of domains in which people perceive themselves to be less able, *i.e.* 'discounting', optimises global self-worth. By placing less importance on (or discounting) a particular aspect of self-development, performance failures in an identified area are no longer a threat to self-worth. However, this cognitive process could result in decreased motivation for change and development (Crocker and Major 1989).

One of the most robust findings in the literature of self-esteem is the correlation between a person's evaluation of their physical appearance and their global self-worth. Harter (1986) showed that self-rated physical appearance, as one domain of self-concept, correlates more highly (0.6 to 0.8) with global self-worth than does any other domain. There is also evidence that this correlation is higher for girls (Harter 1986). So how do young people with a physical disability cope with the socio-cultural emphasis, especially for adolescent girls, on the value of physical appearance?

From early adolescence onwards, able-bodied girls are at greater risk for low self-esteem and depression than boys (Harter 1985a, Petersen *et al.* 1991). Studies of self-concept in those with a physical disability have rarely examined gender, perhaps because of sample-size problems. It may be a salient variable, acting as an effect modifier, protecting or making the disabled child more vulnerable. For instance, being female and being adolescent (as distinct from being in middle childhood) might render the physically disabled young person more susceptible to socio-cultural norms concerning the importance of physical appearance.

One cognitive process that could be protective of self-worth is the young person's choice of a model for comparison (Renick and Harter 1989). In a study by Harter (1986), there was evidence to suggest that mentally disabled children chose to compare themselves primarily with other mentally disabled children.

Global self-worth is also governed by the extent to which a young person feels

supported and accepted by parents, teachers and peers (particularly classmates). For able-bodied children, these associations are independent of the associations between domain-specific self-evaluations and global self-worth (Harter 1986). For children with congenital/acquired limb deficiencies, low classmate support is a significant predictor of low self-worth and depressive symptomatology (Varni *et al.* 1992).

This study tested a number of theoretical predictions, all of which are relevant to the design of interventions. In doing so, we attempted to overcome some of the methodological problems of previous studies. The objectives and hypotheses were as follows.

(1) To examine the multidimensional structure of self-concept in young people with spina bifida (SB) and to compare it with that of able-bodied (AB) young people who have no known learning difficulties.

(2) To study and compare young people's self-rated competence in each of nine self-concept domains and in global self-worth, and to examine the effects of age and gender on the above measures. In line with the preceding discussion, it was hypothesised that there would be group ($AB > SB$), gender ($M > F$), and age ($Y > O$) main effects for social acceptance, athletic competence, physical appearance and global self-worth. We expected older girls with spina bifida to have the very lowest scores in these domains and in overall self-worth.

(3) To study the personal importance or value which young people place on each self-concept domain, comparing groups, and examining the effect of age and gender. In order to examine the possibility of discounting, it was hypothesised that group would be a main effect ($SB < AB$) in all academic, physical appearance and athletic domains, with the exception of older girls with spina bifida, among whom the importance of physical appearance and athletic competence would be at the same mean levels as AB.

(4) To study the discrepancies between importance and self-rated competence in each domain by group, age and gender, and to investigate the degree to which these discrepancies determine global self-

worth. It was hypothesised that, while the relationship between discrepancies and global self-worth would, in general, hold across groups, the physical appearance discrepancy would be less strongly associated with global self-worth in young people with spina bifida.

(5) To explore whether young people with SB are more likely to compare themselves with other physically disabled young people or with able-bodied young people when assessing their own competencies in self-concept domains.

(6) To study the impact of the choice of social comparison group on self-rated competence and global self-worth among young people with SB. It was hypothesised that comparing oneself with other physically disabled young people would be associated with higher competence scores than when comparing oneself with AB peers.

(7) To study young people's perceived social support as a function of group, age and gender; to investigate the association between social support and global self-worth.

Method

For the purposes of this study, spina bifida was defined as open or closed myelomeningocele, with or without associated hydrocephalus, with or without ventricular drainage. All patients had measurable functional impairment of locomotion, continence, intellect or physical parameters associated with the spina bifida. They were aged between seven years and 18 years 11 months. The diagnosis was confirmed in all cases with the young person's own medical advisers and/or by review of the medical notes. Case notes were obtained in order to clarify points in the history and on cases not seen clinically.

Subjects

Recruitment for the study was from the adjoining health authority catchment areas of Clwyd, Wirral, Chester and Crewe. In order to get as complete a sample as possible, extensive investigations were made with consultant paediatricians, clinical medical officers, the Association for Spina Bifida and Hydrocephalus (ASBAH), and the Family Fund (a UK

TABLE I
Demographic characteristics of study sample

	Controls (N = 79)	Spina bifida (N = 79)	Refusals (N = 17)
Age (yrs:mths)			
Mean	13:3	13:7	12:11
SD	47	38	21
Gender			
Male	38	38	7
Female	41	41	10
Education/work status			
Mainstream	63	49	7
Special school	0	17	8
Residential college	0	4	0
Mainstream college	9	1	1
College (SND) ¹	0	3	0
Not in education	7	5	1

¹SND = special needs department.

national register of families with a disabled child claiming a specific benefit). All eligible subjects were approached in the first three areas from which ascertainment data were available; in the final area, subjects were approached on the basis of random selection to complete our sample. A total of 104 subjects were approached.

Seventeen families indicated that they did not wish to participate in the research, and a further eight children were excluded due to either apparent severe cognitive impairment or severe family distress. This left 79 cases in the sample.

For each subject with spina bifida we obtained a comparison subject, matched for age (plus or minus six months), gender, classroom and housing neighbourhood. Comparison subjects were selected from the same mainstream classroom as that attended by the student with spina bifida or, in the case of older subjects, from the same/similar workplace, college or employment training scheme. If the child with spina bifida was not in mainstream education, the comparison subject was chosen from an appropriate local school. The comparison subjects had no known chronic illness, disability or special educational need (Table I).

Medical assessment

The sample comprised 79 pairs of subjects. Six subjects chose not to have

the medical interview, and three further subjects did not receive the medical interview for administrative reasons, but in all these cases the medical records enabled a disability severity score (Wallander *et al.* 1989) to be calculated. The remaining 70 received detailed clinical assessment.

Medical assessments were performed by five assessors (P.E.M., G.C., V.K., R.P., R.B.), in a clinical setting rather than at home.

If there was doubt about details in the history, these details were verified from medical notes. Generally, parental recall proved accurate. For those nine patients not examined clinically, as much information as possible was collated from their hospital and community medical records.

The medical assessment comprised a detailed medical history, questions on aspects of physical ability and independence (including continence and mobility), a full physical examination and neurological assessment, and vision and hearing screening.

DISABILITY SEVERITY SCORE

Clinical severity for thoracic, lumbar and sacral lesions was quantified following the criteria of Wallander *et al.* (1989), who defined the degree of severity of spina bifida according to six medical parameters (Table II). The score was not designed to include cervical lesions, and therefore the three cervical cases have been excluded.

TABLE II
Medical parameters assessed for Wallander and colleagues' severity score

Parameter	Disability score	Clinically evaluated (N = 70) N (%)	Total sample (N = 79) N (%)
<i>Level of lesion</i>			
Sacral	0	11 (16)	11 (14)
Lumbar	1	26 (37)	32 (41)
Thoracic	2	30 (43)	33 (42)
Cervical	*	3 (4)	3 (4)
<i>Operations for ventricular valve</i>			
None	0	18 (26)	23 (29)
1	1	11 (16)	12 (15)
≥ 2	2	41 (59)	44 (56)
<i>Operations for skin ulcer below waist</i>			
None	0	61 (87)	69 (87)
≥ 1	2	9 (13)	10 (13)
<i>Total surgical operations required</i>			
None	0	1 (1)	1 (1)
1-2	1	3 (4)	5 (6)
≥ 3	2	66 (94)	73 (92)
<i>Level of independent ambulation</i>			
No aids	0	16 (23)	18 (23)
Braces	1	31 (44)	36 (46)
Wheelchair or carried	2	23 (33)	25 (32)
<i>Bladder function</i>			
Continent	0	14 (20)	16 (20)
Catheterised	1	43 (61)	48 (61)
Collection device	2	13 (19)	15 (19)

*Not applicable to cervical lesions.

MULTIBECED SEVERITY SCORE

This functional severity assessment, originally devised by Lindon (1963), was used in the modified form described by Thomas *et al.* (1989). It is not specific to spina bifida. It uses a scoring of 12 items (Table III), scored from 1 to 4 according to defined degrees of severity.

The disability can be graded in a number of ways, according to (a) the total number of problems across the scales, (b) whether the main disabilities relate to physical function (items 1 to 5, 11 and 12) or behavioural or communication difficulties (items 6 to 10), and (c) the functional severity of the problem.

Psychological interview

As part of an interview, we used the revised versions of the Wechsler Intelligence Scale for Children (WISC-R) and the Wechsler Adult Intelligence Scale (WAIS-R).

All children received a four-subtest short form of the age-appropriate test: up to 16 years 11 months, the WISC-R; and

between 17 years and 18 years 11 months, the WAIS-R. The short form comprised Arithmetic, Vocabulary, Picture Arrangement and Block Design for both the WISC-R (Kaufman 1976, 1979) and the WAIS-R (Silverstein 1982, 1987). In addition, all children were administered Digit Span.

THE REY AUDITORY LEARNING TEST

This test (Rey 1958, Lezak 1983), administered to all children, involved presentation of a 15-word list for five trials with free recall after each trial. A second 15-word (interference) list was then presented once for free recall, immediately followed by an unprompted recall trial and a recognition trial for the first list. Recorded responses were scored for words correctly recalled, repeats and intrusions.

THE SELF-PERCEPTION PROFILE FOR LEARNING DISABLED STUDENTS (HSPPLDS)
This self-report instrument (Renick and

TABLE III
Capacity assessed for Multibed Severity of Disability Score (N = 70)

	Severity Grade			
	1 N (%)	2 N (%)	3 N (%)	4 N (%)
Physical capacity	24 (34)	23 (33)	20 (29)	3 (4)
Upper limbs—arms	49 (70)	17 (24)	4 (6)	0 (0)
Upper limbs—hands	36 (15)	33 (47)	1 (1)	0 (0)
Locomotion	4 (6)	15 (21)	15 (21)	36 (51)
Toileting	10 (14)	4 (6)	34 (49)	22 (31)
Intellectual function	5 (7)	43 (61)	16 (23)	6 (9)
Behaviour	41 (59)	8 (11)	21 (30)	0 (0)
Eyesight/vision	41 (59)	14 (20)	10 (14)	5 (7)
Communication—speech	61 (87)	9 (13)	0 (0)	0 (0)
Communication—hearing	65 (93)	3 (4)	1 (1)	1 (1)
Eating and feeding	66 (94)	4 (6)	0 (0)	0 (0)
Dressing	36 (51)	5 (7)	26 (37)	3 (4)

Harter 1988) is based on the Self-Perception Profile for Children (Harter 1985a). It is designed for the assessment of learning-disabled and normally achieving children's domain-specific judgements of their competence or adequacy in nine self-concept domains, and their feelings of global self-worth. The instruments have well established validity and reliability (Harter 1985a, Renick and Harter 1988). The 10 subscales independently tap children's self-perceptions in the following areas: (1) general intellectual ability, (2) reading competence, (3) spelling competence, (4) writing competence, (5) mathematics competence, (6) social acceptance, (7) athletic competence, (8) behavioural conduct, (9) physical appearance, and (10) global self-worth. The separate domains for specific academic areas have been found to be useful for children with specific learning difficulties. Children were asked to evaluate their perceived competence by completing three separate questionnaires entitled, 'What I am like—first presentation' (self-ratings of competence in each self-concept domain), 'Who I am like' (specification of chosen comparison group for each domain), and 'What I am like—second presentation' (repeated competence ratings based on the comparison group not used in the first presentation of the scale).

A questionnaire entitled, 'How important are these things to how you feel about yourself as a person?' was then adminis-

tered to young people aged nine years and over. This questionnaire asks children to identify how important each of the nine domains of self-concept is to them personally. Items are scored on a four-point rating scale; high scores indicating greater perceived importance and low scores representing lesser perceived importance.

For calculation of importance/competence discrepancy scores, Renick and Harter (1988) advised a cut-off of 3 on the four-point importance scale. Discrepancy scores (both domain-specific and overall discrepancy) therefore represent data solely on those domains in which individual children place special personal importance. Discrepancy scores were calculated by subtracting importance ratings from their respective competence scores. In most cases this value was negative, since importance ratings tend to be higher than competence scores. A mean discrepancy score was calculated by taking the sum of the discrepancy scores and dividing by the number of domains rated as important.

THE SOCIAL SUPPORT SCALE FOR CHILDREN (SSSC)

This scale (Harter 1985b), of well established reliability and validity, measures the degree to which others like the child the way he or she is, treat the child like a person, care about his or her feelings, and act as if they feel that the child matters. The four sources of social support or

positive regard in this instrument are parents, teachers, classmates and close friends. Each item is scored on a scale of 1 to 4, 1 representing the lowest level of support and 4 representing the highest. The format is similar to the HSPPLDS.

Other measures and interviews

The psychological interview also involved quantitative measures of depression and coping not reported here. A qualitative section allowed young people to reflect on the development of their relationships. Separate interviews were conducted with parents or carers, and an occupational therapy assessment was offered to a subsample of young people. These data will be the subject of further papers.

Procedure

The research was agreed by the Research Ethics Committees of all participating health districts, and directors of education gave their consent to the research being conducted in participating schools. If the family indicated that they were willing to take part in the study, written consent was then obtained from both the young person and the parent or guardian.

Psychological data were collected by four graduate research assistants, specially trained in interviewing skills. Extensive training was given to the interviewers on the administration and scoring of the WISC-R and WAIS-R under the supervision of C.E.E. Practice interviews (using video cameras and one-way mirrors) were completed with volunteer subjects before the interviewing of research subjects took place. Interviews were carried out in a confidential setting within the school/college/workplace. Four older subjects who were living in a residential college for young people with special needs preferred a home-based interview.

Results

Physical findings

An outline of the medical findings, levels of mobility and continence is shown in Table II.

INITIAL MANAGEMENT

In only two cases had there been an antenatal diagnosis of SB. In 66 cases there had been no diagnosis before birth, and

information was not available in two cases. At birth, six of the lesions were covered by skin. 47 of the open lesions were operated on within the first week of life. Hydrocephalus was present in 56 cases, of whom 52 had valves *in situ*. Three patients with hydrocephalus had not had valves inserted, and one had had the valve removed.

SUBSEQUENT SURGERY

Details of orthopaedic, urological and other surgery were collected. Patients had a total number of surgical procedures ranging from 0 to 36 (mean 8.2), with 53 having five operations or more and 21 having 10 operations or more.

SUBSEQUENT MEDICAL PROBLEMS

A variety of medical problems were recorded. 11 patients had had seizures at some stage and four were currently regarded as epileptic. Elevated blood pressure was noted in three patients.

MOBILITY

Sixteen walked independently and required no bracing. 23 were dependent on wheelchairs. 52 young people required a manual wheelchair for at least part of the time, and six had the use of electric wheelchairs. 20 of the wheelchair users were unable to transfer independently.

URINARY CONTINENCE

Sixteen cases were fully continent and 15 totally incontinent. The majority, 41, appeared to be managing their continence independently. Intermittent catheterisation was used by 39 and long-term catheterisation by five. Six patients had artificial urinary sphincters. Four had urinary diversions.

BOWEL CONTINENCE

Twenty-four cases were fully continent, with 36 soiling intermittently and 10 totally incontinent. 29 managed their bowels independently.

CLINICAL FINDINGS

Problems relating to the skin (ulceration, oedema, poor circulation) were found in 48 patients.

Spinal deformity was present in 47 cases. Though most spinal scars were

TABLE IV
Mean short-form IQ scores for both groups

Score	Controls Mean (SD)	Spina bifida Mean (SD)	p
Estimated IQ	100.8 (14.9)	78.9 (17.9)	<0.0001
Arithmetic	10.1 (3.1)	6.9 (3.2)	<0.0001
Vocabulary	9.5 (2.9)	6.9 (3.2)	<0.0001
Picture Arrangement	10.2 (3.3)	6.4 (3.3)	<0.0001
Block Design	11.0 (3.2)	6.8 (3.4)	<0.0001
Digit Span	9.2 (2.8)	7.2 (3.2)	<0.0001

well healed, in seven cases the scar was considered still unstable.

CLINICAL AND FUNCTIONAL SEVERITY

Details of medical and functional severity, as defined by the severity score and the Pultibeced assessment, are shown in Tables II and III, respectively. The distribution of the disability severity scores (Wallander *et al.* 1989) is shown in Figure 1.

Psychological Findings

INTELLECTUAL FUNCTION

The mean estimated IQs and subtest scaled scores for both groups are given in Table IV. As a group, the controls performed at a level equivalent to the average of the WISC-R normative population (mean 100, SD 15). Mean estimated IQ for the spina bifida group was significantly lower than for the controls, reflecting lower scores on all subtests administered.

Table V displays the numbers and percentages of each group falling into particular IQ ranges. Almost exactly half of the able-bodied controls were classified within the average range, compared with 19 per cent of the spina bifida group, in which, as expected, there was a greater proportion of scores falling within the lower IQ bands.

RELIABILITY OF HSPPLDS AND SSSC

For the total sample, Cronbach alphas were 0.91 (HSPPLDS—'What I am like', 0.90 (HSPPLDS—importance) and 0.85 (SSSC). Homogeneity of these instruments was stable across groups (spina bifida and controls) and across IQ (greater or less than 75).

TABLE V
Classification of short-form IQ scores for both groups

Short-form IQ classification	Standard score range	Controls N (%)	Spina bifida N (%)
Extremely high	130+	2 (3)	0 (0)
High	120-130	6 (8)	1 (2)
High average	110-119	12 (15)	3 (4)
Average	90-109	39 (49)	15 (19)
Low average	80-89	16 (20)	21 (27)
Low	70-79	1 (1)	16 (20)
Extremely low	<70	3 (4)	22 (28)

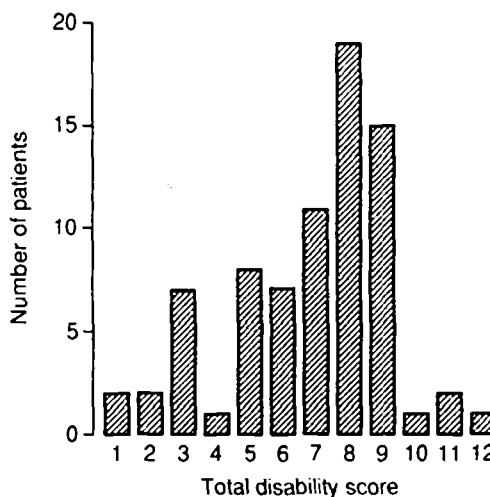


Fig. 1. Distribution of disability severity scores (Wallander *et al.* 1989).

STRUCTURE OF SELF-CONCEPT (HSPPLDS)

Factor analyses of the HSPPLDS demonstrated factor structures equivalent to those found by Renick and Harter (1988),

TABLE VI
Self-rated competence measures (Harter Self-Perception Profile for Learning-Disabled Students)

Competence domain	Controls Mean (SD)	Spina bifida Mean (SD)	Paired-t test t (df)	p
General intellectual ability	2.87 (0.56)	2.66 (0.71)	2.12 (78)	0.04
Reading competence	3.28 (0.72)	2.92 (0.86)	3.00 (78)	0.004
Writing competence	2.05 (0.83)	2.55 (0.88)	2.99 (78)	0.004
Spelling competence	3.03 (0.80)	3.00 (0.97)	0.22 (78)	0.83
Maths competence	2.85 (0.83)	2.36 (0.94)	3.42 (78)	0.001
Social acceptance	3.30 (0.57)	3.03 (0.80)	2.39 (78)	0.02
Athletic competence	2.70 (0.76)	2.27 (0.84)	3.39 (78)	0.001
Behavioural conduct	3.06 (0.63)	2.95 (0.78)	1.06 (78)	0.29
Physical appearance	2.74 (0.67)	2.65 (0.91)	0.82 (78)	0.42
Global self-worth	3.17 (0.58)	2.98 (0.78)	1.69 (78)	0.10

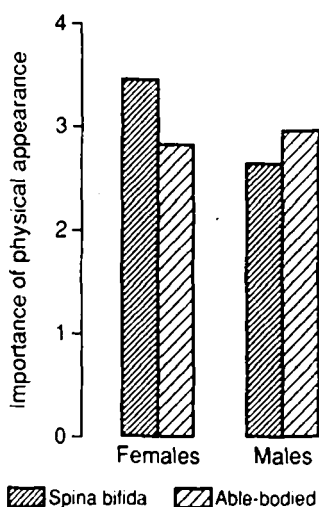


Fig. 2. Importance of physical appearance as a function of group and gender (HSSPLDS).

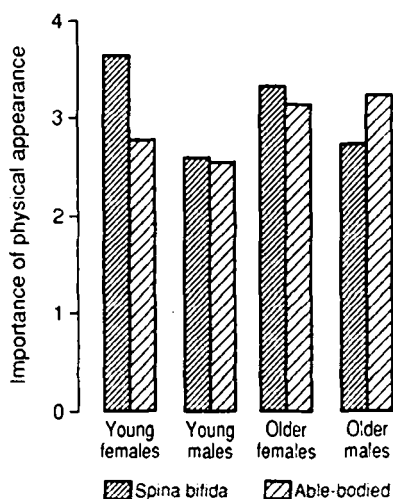


Fig. 3. Importance of physical appearance as a function of group, age and gender (HSSPLDS).

and stable across groups. The scales were therefore appropriate for this study population, and the scoring system recommended by Harter to derive subscale scores was also appropriate.

COMPETENCE (HSPPLDS)

We conducted *t* tests for related samples, comparing groups. As can be seen from Table VI, young people with spina bifida regarded themselves as less competent than did controls in four of five academic domains. Mathematics competence was regarded as low, both when compared with control scores and when compared with other domains. Young people with spina bifida also regarded themselves as less socially accepted and less athletically competent than did controls. At this level of analysis there were no group differences evident in the domains of behavioural conduct, physical appearance or global self-worth.

ANOVAS were conducted for each domain, allowing us to study the impact of gender and age (greater vs. less than 160 months), as well as group. In addition to the group effects there were gender main effects (M>F) for athletic competence ($F(1,150) = 13.75, p < 0.001$), physical appearance (M>F) ($F(1,150) = 13.01, p < 0.001$), behavioural conduct (F>M) ($F(1,150) = 7.77, p < 0.01$) and global self-worth ($F(1,150) = 5.19, p < 0.05$). In the area of global self-worth, not only did gender appear as a main effect—girls demonstrating lower self-worth than boys—but a significant three-

TABLE VII
Self-rated importance measures (Harter Self-Perception Profile for Learning-Disabled Students)

Competence domain	Controls Mean (SD)	Spina bifida Mean (SD)	Paired <i>t</i> test <i>t</i> (df)	<i>p</i>
General intellectual ability	2.93 (0.86)	3.03 (0.92)	0.66 (71)	0.51
Reading competence	2.92 (0.81)	3.03 (1.00)	0.70 (71)	0.48
Writing competence	2.72 (0.78)	2.85 (1.01)	0.88 (71)	0.38
Spelling competence	2.83 (0.91)	3.11 (0.89)	1.91 (71)	0.06
Maths competence	2.81 (0.91)	3.03 (0.97)	1.39 (71)	0.17
Social acceptance	2.87 (0.81)	3.07 (0.89)	1.51 (71)	0.14
Athletic competence	2.51 (0.96)	2.34 (1.05)	1.25 (71)	0.22
Behavioural conduct	3.35 (0.68)	3.42 (0.71)	0.56 (71)	0.58
Physical appearance	2.90 (0.81)	3.03 (1.07)	0.96 (71)	0.34

way interaction was also evident between group, age and gender ($F(1,150) = 3.75$, $p = 0.055$). Examination of the tabulated three-way ANOVA interaction indicated that older girls with spina bifida had the lowest mean self-worth scores and young able-bodied boys had the highest mean self-worth scores.

Hypothesis 2 was partially confirmed in the group and gender effects, but no age effects were evident except in the interaction term for global self-worth. In addition to the hypothesised effects, most academic domains emerged as areas in which young people with spina bifida feel less competent than do able-bodied peers. The hypothesis that older girls with spina bifida would experience relatively low scores in global self-worth was confirmed in the marginally significant three-way ANOVA interaction.

IMPORTANCE (HSPPLDS)

Using *t* tests for related samples, no group differences were evident in the personal importance or value that the young people placed on different domains of self-concept (Table VII). In fact, across all but one domain, young people with spina bifida placed importance higher than did able-bodied peers. There was no evidence for the first part of hypothesis 3, *i.e.* that physically disabled young people, as a group, will devalue the importance of most domains of self-concept.

ANOVAS were also conducted with importance data, allowing us to explore the influence of age and gender as well as group. For the importance assigned to

athletic competence, there was a highly significant age effect ($F(1,137) = 14.75$, $p < 0.001$), older children feeling that this area was less important to them. In addition, there was a gender \times age effect ($F(1,137) = 4.80$, $p < 0.05$), older girls attributing less importance to athletic competence. Group did not enter either as a main effect or as an interaction. For physical appearance, there was a gender main effect ($F(1,138) = 8.68$, $p < 0.005$), girls giving this domain greater importance than boys. There were also two-way interactions of group \times sex ($F(1,138) = 6.38$, $p < 0.05$) and group \times age ($F(1,138) = 3.98$, $p < 0.05$).

As can be seen in Figures 2 and 3, girls with spina bifida assigned more importance to physical appearance than did able-bodied children (regardless of gender), who in turn thought it more important than did boys with spina bifida. In hypothesis 3, we predicted an SB < AB group 'baseline' in most domains, and that this would be qualified by an upward shift in importance of physical appearance and athletics among older girls with spina bifida (*i.e.* a failure to 'discount' as these girls mature). The findings for physical appearance among girls (Fig. 3) were the precise opposite of the hypothesis, namely that younger girls with spina bifida placed a relatively high level of importance on physical appearance, which reduced for the older girls. It has yet to be ascertained whether early pubertal onset in girls with spina bifida may be associated with assigning such importance to physical appearance so

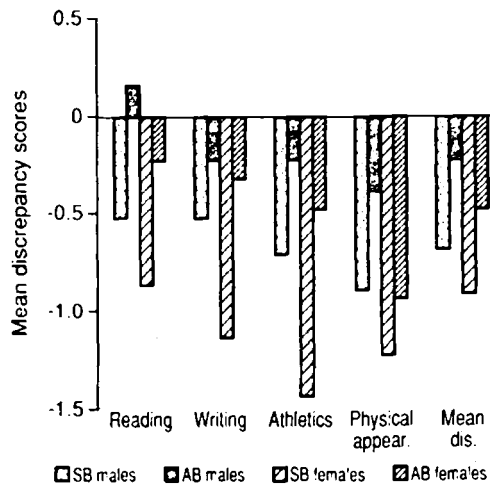


Fig. 4. Discrepancy scores by group and gender.

early in their lives.

In summary, despite feeling less competent than their able-bodied peers in six out of nine domains, young people with spina bifida did not devalue the importance of any domain. Older children, especially girls, felt that athletic competence was less important than other domains. This effect applied independently of whether the child was disabled or not. In contrast to our hypothesis, physical appearance was of especial importance to the disabled girls.

DISCREPANCIES BETWEEN IMPORTANCE AND COMPETENCE

Individual discrepancy scores, as discussed in the Method, were calculated for the domains to which each young person assigned special personal importance. Therefore there were a significant number of missing values, precluding the use of statistics for related samples. Higher negative discrepancy scores, signifying a larger gap between competence and importance, have been associated in previous research with lower self-worth (Harter 1986).

ANOVAS were conducted by group, age and gender. There were significant main effects of group (SB > AB) for reading ($F(1,88) = 13.14, p < 0.001$), writing ($F(1,73) = 9.30, p < 0.005$), mathematics ($F(1,89) = 10.67, p < 0.005$), social acceptance ($F(1,85) = 21.50, p < 0.001$), athletic competence ($F(1,52) = 12.15,$

$p < 0.005$) and physical appearance ($F(1,92) = 6.01, p < 0.05$). Group differences between the behavioural conduct and general intellectual ability discrepancy scores approached significance.

There were gender main effects (F > M) for physical appearance ($F(1,92) = 8.12, p < 0.01$), reading ($F(1,88) = 4.35, p < 0.05$), writing ($F(1,73) = 3.99, p = 0.05$) and athletics ($F(1,52) = 4.21, p < 0.05$).

No consistent picture emerged from marginally significant age main effects and no interactions were evident in the discrepancy ANOVAS.

In summary, for those self-concept domains on which individual young people placed personal importance, young people with spina bifida experienced considerably large discrepancies between the level of importance and level of competence than did the able-bodied controls. These highly significant effects were evident in certain academic areas, social acceptance, athletic competence and physical appearance. Larger discrepancies were evident for girls across groups creating additive effects in physical appearance, reading, writing, and athletics for physically disabled girls (Fig. 4). The summary discrepancy score for physically disabled girls ($-0.90, N = 38$) was four times as large as that of able-bodied boys ($-0.22, N = 34$).

DISCREPANCIES AND GLOBAL SELF-WORTH

Table VIII shows that many of the domain discrepancy scores were correlated with global self-worth. Physical appearance was a very strong predictor. For young people with spina bifida the strongest associations were, in turn, physical appearance, social acceptance, behavioural conduct and intellectual ability. Further analyses of these correlations for the spina bifida group, broken down by age and sex, showed that the physical appearance association was highly significant for girls ($r(34) = 0.82, p < 0.001$) and younger boys ($r(8) = 0.91, p < 0.005$), and the social acceptance association was significant for girls only ($r(25) = 0.54, p < 0.01$). These latter correlations must be interpreted with caution because of the small cell numbers and multiple correlations.

TABLE VIII
Spearman rho correlations between domain discrepancy scores and global self-worth

Domain	All subjects	Control group	Spina bifida group
General intellectual ability	0.34 (96)* $p < 0.001$	0.31 (46) $p = 0.019$	0.35 (50) $p = 0.007$
Reading competence	0.19 (96) $p = 0.031$	0.33 (47) $p = 0.011$	0.07 (49) $p = 0.326$
Writing competence	0.30 (81) $p = 0.004$	0.33 (39) $p = 0.021$	0.21 (42) $p = 0.094$
Spelling competence	0.12 (100) $p = 0.115$	0.17 (45) $p = 0.132$	0.09 (55) $p = 0.251$
Maths competence	0.30 (97) $p = 0.002$	0.23 (45) $p = 0.065$	0.27 (52) $p = 0.026$
Social acceptance	0.38 (93) $p < 0.001$	0.17 (46) $p = 0.131$	0.39 (47) $p = 0.003$
Athletic competence	0.29 (60) $p = 0.013$	0.30 (34) $p = 0.041$	0.26 (26) $p = 0.096$
Behavioural conduct	0.31 (121) $p < 0.001$	0.19 (58) $p = 0.072$	0.36 (63) $p = 0.002$
Physical appearance	0.63 (100) $p < 0.001$	0.45 (48) $p = 0.001$	0.73 (52) $p < 0.001$

*Values in parentheses are Ns.

TABLE IX
Young people with spina bifida who compared themselves with physically disabled, not disabled, or 'other' comparison group by domain

Domain	Chosen comparison group		
	Physically disabled N (%)	Non-disabled N (%)	Other N (%)
General intellectual ability	20 (26)	57 (73)	1 (1)
Reading competence	20 (26)	58 (74)	0 (0)
Maths competence	18 (23)	60 (77)	0 (0)
Social acceptance	20 (26)	55 (71)	3 (4)
Athletic competence	31 (40)	46 (59)	1 (1)
Behavioural conduct	15 (19)	59 (76)	4 (5)
Physical appearance	20 (26)	58 (74)	0 (0)
Global self-worth	23 (30)	53 (68)	2 (3)

There was no evidence for hypothesis 4, *i.e.* that physical appearance would be less highly correlated with global self-worth in young people with spina bifida. In fact the opposite appeared to be the case, this correlation being the highest in the family

of associations between discrepancies and global self-worth.

SOCIAL COMPARISON

Table IX shows that the majority of young people with spina bifida compared

TABLE X
Effects of different comparison groups on competence scores (HSPPLDS) of young people with spina bifida

Domain	Non-disabled Mean (SD)	Disabled Mean (SD)	<i>d</i>	Paired <i>t</i> test <i>t</i> (df)	<i>p</i>
General intellectual ability	2.59 (0.82)	3.04 (0.89)	0.45	4.60 (76)	0.0001
Reading competence	2.87 (0.95)	3.12 (0.97)	0.25	2.06 (77)	0.04
Maths competence	2.34 (1.00)	2.70 (1.08)	0.36	3.07 (75)	0.003
Social acceptance	2.96 (0.83)	3.10 (0.83)	0.14	1.46 (74)	0.15
Athletic competence	2.07 (0.81)	2.70 (0.93)	0.63	7.13 (76)	0.001
Behavioural conduct	2.94 (0.84)	2.95 (0.83)	0.01	0.17 (73)	0.86
Physical appearance	2.61 (0.91)	3.06 (0.88)	0.45	5.12 (77)	0.001
Global self-worth	2.88 (0.77)	3.17 (0.73)	0.28	4.36 (75)	0.001

TABLE XI
Scores on Harter Social Support Scale for Children

	Controls Mean (SD)	Spina bifida Mean (SD)	Paired <i>t</i> test <i>t</i> (df)	<i>p</i>
Parental support/regard	3.55 (0.56)	3.49 (0.61)	0.69 (78)	0.49
Classmate support/regard	3.38 (0.44)	3.05 (0.66)	3.41 (78)	0.001
Teacher support/regard	3.27 (0.56)	3.46 (0.59)	2.18 (78)	0.03
Close friend support/regard	3.53 (0.61)	3.57 (0.58)	0.53 (78)	0.59

themselves with able-bodied peers across all domains. This finding may well reflect the fact that 74 per cent of the physically disabled subjects were in mainstream schools. An analysis by school placement shows that those young people who were in a special school were much more likely to compare themselves with physically disabled peers, whereas those in mainstream schools were very much more likely to compare themselves with able-bodied peers. For instance, in the domain of general intellectual ability, 43 of 49 young people in mainstream schools compared themselves with able-bodied peers, in contrast to four out of 16 in special schools ($\chi^2(2) = 26.26, p < 0.001$).

The mean scores for the non-disabled controls were close to the mean competence scores shown in Table VI, a further indication of the reliability of response in the spina bifida group. Young people with spina bifida were asked to rate themselves again on the HSPPLDS using a comparison group which they had not chosen on the first occasion. The second presentation tapped all domains

except spelling and writing. The data in Table X show that the subjects felt relatively less competent in academic, athletic and physical appearance domains when comparing themselves with able-bodied peers than when comparisons were made with other disabled young people. The same effect was evident in global self-worth. No significant differences were found in the areas of social acceptance and behavioural conduct.

In summary, hypothesis 6—that comparison with other physically disabled young people would be associated with higher competence scores—was largely confirmed. However, the majority of the disabled group spontaneously compared themselves with able-bodied peers, an effect associated with being in mainstream school.

SOCIAL SUPPORT (SSSC)

We conducted *t* tests for related samples, comparing the groups for different aspects of social support. As can be seen from Table XI, young people with spina bifida felt equally as supported by parents

and friends as did their able-bodied peers. This contrasted with the finding for classmate support ($SB < AB$). A significant difference in the opposite direction was found for teacher support ($SB > AB$).

Three-factor ANOVAs were conducted to investigate the effects of group, gender and age. For parental support there was a main effect for age ($Y > O$) ($F(1,150) = 5.72$, $p < 0.05$) and an interaction of group \times gender ($F(1,150) = 5.69$, $p < 0.05$), girls with spina bifida reporting significantly less parental support than others. For teacher support, there was a main effect for age ($Y > O$) ($F(1,150) = 5.53$, $p < 0.05$).

SOCIAL SUPPORT AND GLOBAL SELF-WORTH
For each group, Spearman correlations were computed between each of the social support variables and global self-worth (Table XII). For able-bodied young people only parental support was significantly associated, whereas for young people with spina bifida three of the sources of support (parent, teacher and classmate) were significantly associated with global self-worth.

Discussion

Reliability and factor analyses showed that young people with spina bifida, irrespective of age or IQ, made clear and consistent discriminations between different domains of their personal functioning and the social support system. It has therefore been possible to isolate those aspects of personal-social experience that are most closely associated with global self-worth.

The present study demonstrates that, because they usually compare themselves with able-bodied peers, physically disabled children in mainstream schools are in a difficult position: identifying with the able-bodied peer group, but at the same time feeling less competent and less accepted than matched able-bodied controls. The academic and athletic self-perceptions were accurate in one sense, since the comparison group consisted mainly of peers without intellectual or physical impairment. The findings on social acceptance and classmate support are in line with other studies which have found disabled children to be isolated

TABLE XII
Spearman rho correlations between sources of social support and global self-worth

	<i>Spina bifida</i> (<i>N</i> = 79)	<i>Controls</i> (<i>N</i> = 79)
Parental support	0.42 $p < 0.001$	0.26 $p = 0.022$
Classmate support	0.28 $p = 0.014$	0.15 $p = 0.175$
Teacher support	0.30 $p = 0.006$	0.05 $p = 0.686$
Close friend support	0.20 $p = 0.083$	-0.12 $p = 0.283$

from their peers (e.g. Lord *et al.* 1990).

Gender exerted a powerful influence, both independently of, and in interaction with, the disability. Girls felt less competent than boys in domains that were important to them. There was evidence for an interaction effect between gender, age and disability in the global self-worth data, and there were additive effects in the discrepancy data. There were suggestions in the correlational data that physical appearance and social acceptance discrepancies were more strongly associated with global self-worth for girls than boys. One process by which gender exerted its influence was through self-perception of physical appearance. Disabled girls assigned greater importance to physical appearance than did able-bodied children and boys with spina bifida. Therefore, they experienced higher negative discrepancies in this domain.

In simple group-comparison terms, young people with spina bifida did not show lower global self-worth than able-bodied peers. Other studies have obtained comparable results, measuring self-esteem with different instruments (Campbell *et al.* 1977, Pearson 1985, Spaulding and Morgan 1986). Varni *et al.* (1989), in their study of children with congenital/acquired limb deficiencies, using the Harter Self-Perception Profile for Children, found no differences in global self-worth compared with norms for healthy children.

In our own study, the maintenance of reasonable self-worth was clearly not accounted for by any of the cognitive defences we examined. In fact, given the

defences we examined. In fact, given the group differences in discrepancies, and the correlations between discrepancies and global self-worth, it is surprising that global self-worth was not lower in the young people with spina bifida. Several points are relevant. First, as noted above, the most powerful disability effects in this study were those that emerged in interaction with gender, rather than main effects. Second, Harter (1986) viewed global self-worth as a 'core variable', influenced by (and presumably influencing) a wide range of component parts of the person's psychosocial experience. Unmeasured compensatory factors in the experience of the physically disabled group may have been important, and possibly would have emerged in a qualitative study. Third, an over-emphasis on group difference methodology precludes investigation of factors within the spina bifida group that promote or impede the development of optimum self-esteem. A series of studies of psychosocial adjustment in physical disability by Wallander and others (see review by Varni and Wallander 1988) has used a within-group design.

It is encouraging that, on a simple group-comparison basis, the young people with spina bifida felt equally as supported by friends and parents as their able-bodied peers. The disabled group felt more supported by teachers, perhaps an effect associated with the special classes and greater amount of individual attention required by a physically disabled child. It is of concern that disabled girls appeared to feel less supported by parents than did able-bodied children and disabled boys. This finding requires replication, but is another indication of the importance of gender as a potential effect modifier in psychosocial aspects of physical disability. If the finding is not spurious, then at least two causal interpretations are possible. First, disabled girls may objectively be more difficult to care for in adolescence because of their relatively low self-esteem and associated factors, leading to a relative reduction in received parental support. Second, because of low self-esteem, the disabled girls may perceive themselves as receiving less support from the most important close

relationship, *i.e.* that with a parent. This perception could be based on feelings of 'not being worthy of love'. It is not possible to discriminate between these possibilities with the current data set.

It is not at all clear why correlations between social support and global self-worth were attenuated for able-bodied children. These findings are different from published data on US samples (Harter 1985b). Support from parents, teachers and classmates were significantly correlated with global self-worth in the disabled group.

Harter (1986) regarded self-concept domains and social support areas as independent variables, predictive of global self-worth. It seems to us that, with current information, it is equally plausible that global self-worth has reciprocal influence on specific domains and perceived support. For instance, low support may indeed cause a lowering of self-worth, but low self-worth may in turn cause the disabled young person to attend selectively to negative aspects of experience (Gotlib and Hammen 1992) such as scholastic problems and problems of physical appearance, thereby setting in motion cognitive-interpersonal negative chain-reactions (Rutter 1987). Longitudinal and intervention research designs are required to address these questions.

What are the implications for practitioners? First, that the use of instruments such as the HSPPLDS can be useful as part of multidisciplinary assessment. The primary focus of assessment, around which other assessments are built, must now be the young person's own view of his or her life situation, wishes, interests and plans (Department of Health 1989). Tools such as the HSPPLDS allow practitioners to plan management, and evaluate change and outcome, using variables that are relevant to the young person. Treatment plans failing to take account of these fundamental sources of motivation are likely to prove less fruitful (Harter 1991).

Second, peer social acceptance and social comparison appear to be key issues. Work with the able-bodied peer-group itself can be valuable (*e.g.* Armstrong *et al.* 1987). Work with disabled young people on social skills (Inderbitzen-

Pisaruk and Foster 1990) must recognise the distinction between individual friendship-making skills, and the experience of feeling 'part of' a peer group (Parker and Asher 1993). Our data, and Harter's data (1986) on able-bodied children, suggest that the latter set of group processes is as important as individual friendships, if not more so. Much is known about the cognitive and social aspects of group integration (see Turner 1991); application of this knowledge to special-needs settings is important. By the time children reach adolescence, peer group identities and the feeling of being part of a larger community are very important aspects of the young person's life (Widdicombe 1988, Parker and Asher 1993).

Finally, it is clear that the young person's self-perception of physical appearance may need addressing as part of an overall intervention programme. While it may be true that physically disabled young people find other sources of reward in their lives, there is little doubt that many (especially girls) are distressed by their physical disabilities and appearance. This will have specific implications for attitudes towards developing continence and other self-care skills. If young people have negative perceptions of their physical appearance, and this is closely tied to their overall view of themselves, motivation for self-care programmes is likely to be low. Therapists' attention should therefore focus, in partnership with the young person

(Department of Health 1989), on self-perceptions of the body and how these are linked, in each case, to overall self-esteem. Such cognitive-behavioural work (Harter 1991, Gotlib and Hammen 1992) may be viewed as a first stage, or foundation stage, out of which the young person may wish to engage in specific pieces of collaborative work on self-care.

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SUMMARY

Seventy-nine young people with spina bifida were given a psychological, medical, carer and occupational therapy assessment. 79 matched able-bodied young people received the psychosocial interview. The disabled group felt themselves to be less competent in academic, athletic and social aspects of self-concept, less supported by classmates, equally supported by parents and friends and more supported by teachers than the able-bodied group. Disabled subjects did not discount the importance of any area of personal-social functioning, and experienced greater discrepancies between competence and importance in most academic, athletic, social and physical appearance aspects of self-concept. Disabled girls assigned very high importance to physical appearance. Physical appearance was more strongly associated with general self-esteem than any other area of self-concept.

RÉSUMÉ

L'appréciation de soi de jeunes spina bifida: une étude de population

Une entrevue concernant les aspects psychologiques, médicaux de prise en charge de soins et de rééducation a été proposée à 79 jeunes spina bifida. La même entrevue psychosociale fut proposée à 79 jeunes sujets valides appariés. Les membres du groupe avec incapacités, se sentaient moins compétents dans une auto-évaluation sur les aspects scolaires, athlétiques et sociaux, moins aidés par leurs camarades de classes, également aidés par leurs parents et amis, et mieux aidés par leurs professeurs que les jeunes du groupe de valides. Les sujets avec incapacités en minimisaient l'importance d'aucun aspect de l'activité individuelle et sociale, et faisaient une plus grande

distinction entre compétence et importance dans la plupart des aspects d'auto-évaluation sur les domaines scolaires, sportifs, sociaux et d'apparence physique. Les filles avec incapacités attribuaient une très grande importance à l'apparence physique. L'apparence physique était plus fortement associée avec l'estime de soi générale qu'à n'importe quelle autre aspect d'auto-évaluation.

ZUSAMMENFASSUNG

Die Selbsteinschätzung junger Leute mit Spina bifida: eine Populationsstudie

79 junge Leute mit Spina bifida wurden anhand von Interviews bezüglich ihrer psychologischen, medizinischen, pflegerischen und beschäftigungstherapeutischen Situation befragt. 79 gesunde Kontrollen wurden mit einem psychosozialen Interview untersucht. Die behinderten Probanden fühlten sich in akademischen, sportlichen und sozialen Bereichen weniger kompetent, durch Klassenkameraden weniger, durch Eltern und Freunde gleich und durch Lehrer mehr unterstützt als die gesunden Kindern. Die behinderten Patienten waren sich der Bedeutung der allgemeinen psychosozialen Eingliederung bewußt und machten die Erfahrung größerer Diskrepanzen zwischen ihren Fähigkeiten und der Bedeutung, die sie den meisten akademischen, sportlichen, sozialen und körperlichen Erscheinungsbildern in ihrer Selbsteinschätzung zuschrieben. Behinderte Mädchen legten sehr grossen Wert auf die körperliche Erscheinung. Umgekehrt war die körperliche Erscheinung stärker mit dem allgemeinen Selbstwertgefühl verknüpft als irgendein anderer Bereich der Selbsteinschätzung.

RESUMEN

Autoconcepto de jóvenes con espina bífida. Estudio de población

Setenta y nueve jóvenes con espina bífida pasaron una entrevista psicológica, médica, de cuidador y de terapia ocupacional. Otro grupo de 79 jóvenes sin minusvalencia física pasaron por una entrevista psicosocial. El grupo con minusvalencia se sentía menos competente en los conceptos académico, atlético y social de su autoconcepto menos apoyados por los compañeros de clase, igualmente apoyados por padres y amigos y más apoyados por los profesores, que el grupo sin minusvalencia. Los individuos minusválidos no descontaban la importancia de ninguna área del funcionamiento personal y social y experimentaban grandes discrepancias entre la competencia y la importancia de la mayoría de los aspectos académicos, atléticos, sociales y aspecto físico del autoconcepto. Las chicas minusválidas daban una muy gran importancia al aspecto físico. El aspecto físico estaba más fuertemente asociado con la autoestima en general, que con cualquier otra área del autoconcepto.

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