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Impact of functional severity on self concept in young people with spina bifida

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Abstract

This study examines the relationship between medical and functional severity of disability and levels of self esteem and self concept in 79 young people with spina bifida. Greater feelings of global self worth and of self esteem in physical appearance were associated with greater severity of disability. This was only in part an effect of lower IQ among the most disabled young people. Many of the least disabled had marked impairment of self esteem. Analysis of the impact of individual aspects of disability confirmed the association between increased self esteem in physical appearance and global self worth, and diminished functional ability. Academic self ratings, however, were higher in the less disabled. Hydrocephalus and continence appeared to have minimal effect on self esteem.

The relationship between severity of disability in spina bifida and self concept is complex and mediated by a range of factors. It is incorrect to assume that the psychological impact is less in the mildly disabled young person.

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Table 1 Numbers of spina bifida subjects by age

Age (years)	*No*
7·0–7·9	3
8·0–8·9	3
9·0–9·9	3
10·0–10·9	10
11·0–11·9	9
12·0–12·9	9
13·0–13·9	8
14·0–14·9	6
15·0–15·9	6
16·0–16·9	4
17·0–17·9	11
18·0–18·9	7

The perceptions, self esteem, and relative values of young people with physical disability are difficult to assess. Some studies suggest they have low levels of self esteem while others fail to demonstrate any differences between the physically disabled and controls.[1 2]

Spina bifida presents a complex pattern of disability with a variable impact on mobility, continence, and intelligence. Previous studies have shown little or no difference from controls in measures of self esteem[3 4] or psychosocial adjustment.[5] We have reported evidence of specific areas of diminished self esteem.[6]

Although the correlation between medical aspects of physical disability and functional impairment is well recognised, the relative psychological impact associated with different levels of severity is unclear. Two studies of spina bifida found no association between severity and psychosocial adjustment.[7 8] In rheumatoid arthritis, research appears to indicate a diminution in psychosocial adjustment in those with *milder* disability.[9]

We carried out a multidisciplinary study of the self image of children and adolescents with spina bifida, including medical and psychological assessment. This paper assesses the impact of severity of disability on self esteem.

Methods

STUDY POPULATION

The study group, aged 7·0 to 18·9 years (table 1), had spina bifida, with or without hydrocephalus. There was a measurable impairment of sensation, motor skills, continence, or intellect in all cases. Of 104 families approached, 17 (16%) refused and eight children were excluded on grounds of severely limited intellect or because of major current family stresses. The ascertainment method and description of the study group has been fully reported.[6]

MEDICAL ASSESSMENT

Medical assessment was carried out in 70 cases. Of the remainder, six refused and three were omitted for administrative reasons. Where clinical assessment was not possible information on history, physical findings, and function was acquired from medical notes. Details relating to mobility, continence, and independent function were recorded.

When a full clinical assessment was carried out the Pultibeced assessment of disability was completed. This comprises 12 items covering details of physical ability, independent function, communication, and intellect and has been used in both children and adolescents.[10 11] It is not specific to spina bifida but defines functional disability.

In all cases, except for those with cervical lesions for whom it is not valid, a disability severity score as described by Wallander *et al* was completed. This measure was devised and standardised on children and young people.[5] It is specific to spina bifida, defining severity on medical and functional parameters.

ASSESSMENT OF SELF CONCEPT

Self concept may be assessed in distinct academic, physical, and social domains. The Harter self perception profile for learning disabled students is designed to delineate this structure. The measure has been validated in children and young people with and without specific learning difficulties.[12] The young people are asked to rate themselves in domains of self concept, including general intellect, academic skills, social acceptance, athletic competence, behavioural conduct, physical appearance, and global self worth (overall self esteem). Of the domains, that of physical appearance has been shown to be most closely correlated with global self worth.[6 13] They are

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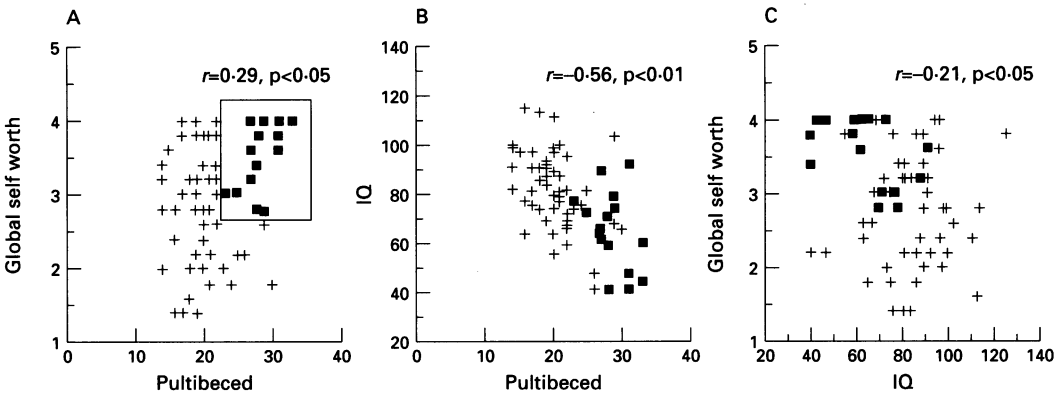

(A) Global self worth as a function of severity; (B) IQ as a function of severity; and (C) global self worth as a function of IQ; ■=individuals (n=16) with high severity and high global self worth (in (A) two points overlap).

then asked to rate the importance of each domain to themselves. The difference between the importance ascribed to a domain and one's self rated competence in it is then calculated as a discrepancy score. It is calculated only for those domains rated highly in importance. Where there is a discrepancy between self rated competence and personal aspiration, self worth is also diminished. In order to protect self worth Harter postulated that individuals would diminish or 'discount' the importance of self concept domains to themselves. Appleton *et al* found no evidence of discounting in this spina bifida group.[6]

Psychological assessment included the Wechsler intelligence scale for children-revised or the Wechsler adult intelligence scale-revised as appropriate.[14 15]

STATISTICS

Test and questionnaire data were field coded by trained interviewers. All statistical analyses were performed using SPSS-X.

Results

STUDY SAMPLE CHARACTERISTICS

Complete details of the disabilities as defined by the Pultibeced and disability severity scores have been published.[6]

There were 79 patients in the study (38 male, 41 female). Three had cervical lesions, 33 thoracic, 32 lumbar, and 11 sacral. Seventy were evaluated clinically (34 male, 36 female) of whom three had cervical, 30 thoracic, 26 lumbar, and 11 sacral lesions. Hydrocephalus was present in 56 cases. Intraventricular valves were present in 52. Three with hydrocephalus had no valve and one had a valve inserted and subsequently removed.

The mean IQ in the spina bifida group was 78·9 compared with 100·8 in an able bodied control group ($p<0·0001$). IQ was significantly lower in those with hydrocephalus (75·8) than without (90·3) ($p<0·01$).[6]

GENDER AND SEVERITY

There was no significant difference between the sexes in the measures of severity of disability.

RELATIONSHIP OF SEVERITY OF DISABILITY TO PSYCHOLOGICAL FINDINGS

When severity, defined by Pultibeced, is plotted against global self worth (fig A) there is a wide scatter and this is also evident when severity is assessed by disability severity score. However, there is a significant correlation with increased severity being associated with *increased* global self worth ($r=0·29$, $p<0·05$). This is also true for severity measured by the disability severity score ($r=0·23$, $p<0·05$).

It was postulated that this effect may be related to a limitation in IQ in those most severely affected individuals with high global self worth (highlighted on the figures). Not unexpectedly IQ is inversely related to severity (fig B) and the severely affected individuals highlighted in fig A have the lowest IQs. When global self worth is plotted against IQ (fig C) it is evident that decreased IQ is associated with high levels of global self worth ($r=-0·21$, $p<0·05$).

It is clear that severity of disability and associated lowering of cognitive function are interacting in affecting global self worth. In order to determine their independent effects subsequent analyses investigate: (1) which aspects of self concept are most affected by severity of disability, both as a general association and also disentangled from the confounding effect of IQ; (2) which aspects of physical disability most affect global self worth; and (3) the general associations of IQ and global self worth in this population and the specific effects of IQ on global self worth controlling for degree of physical disability.

EFFECTS OF SEVERITY AND IQ ON GLOBAL SELF WORTH AND DOMAINS OF SELF ESTEEM

To investigate the impact of severity and IQ on self esteem, the psychological parameters were assessed for their correlation with severity measures and reassessed when controlled for IQ (table 2). For the purposes of this analysis the academic domains were pooled to create a composite score of general academic ability.

Higher global self worth ratings were associated with higher severity as defined by either severity measure. When controlled for IQ, the Pultibeced association diminished but remained significant. The greater the severity by either measure the greater the physical

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Table 2 Correlations of competence and importance ratings and of discrepancy scores with measures of severity of disability and correlations controlled for IQ

Domain	Raw correlation coefficients		Correlations controlling for IQ	
	Pultibeced (n=70)	Disability severity score (n=76)	Pultibeced (n)	Disability severity score (n)
Global self worth	0·29*	0·23*	0·22 (67)*	0·18 (72)
Competence:				
General intellectual ability	0·05	−0·00	0·19 (67)	0·07 (72)
General academic ability	−0·23	−0·22	−0·02 (67)	−0·11 (72)
Social acceptance	−0·05	−0·02	0·00 (67)	0·01 (72)
Athletics	0·11	0·16	0·16 (67)	0·18 (72)
Behaviour	0·15	0·11	0·07 (67)	0·05 (72)
Physical appearance	0·44**	0·26*	0·36 (67)**	0·20 (72)*
Importance:				
General intellectual ability	−0·02	0·03	−0·01 (62)	0·04 (67)
General academic ability	0·01	0·03	−0·05 (63)	0·01 (68)
Social acceptance	0·09	0·24*	0·16 (62)	0·27 (67)*
Athletics	0·15	0·02	0·20 (62)	0·03 (67)
Behaviour	0·07	0·15	0·07 (62)	0·15 (67)
Physical appearance	−0·09	0·11	−0·13 (63)	0·11 (68)
Discrepancy:				
General intellectual ability	−0·14	−0·22	0·09 (40)	−0·11 (43)
General academic ability	−0·36**	−0·32*	−0·10 (56)	−0·08 (61)
Social acceptance	−0·12	−0·02	−0·07 (38)	0·02 (41)
Athletics	−0·02	−0·14	0·08 (20)	−0·10 (72)
Behaviour	−0·03	−0·02	−0·07 (54)	−0·04 (57)
Physical appearance	0·40**	0·12	0·22 (44)	−0·02 (47)

Significance: *p<0·05; **p<0·01.

appearance self ratings. This consistent association was preserved after controlling for IQ, indicating that the mediating effect of intelligence is only partial.

Discrepancy findings for physical appearance were significantly associated with the Pultibeced measure. The pattern of correlations suggests that this association is largely accounted for by high competence ratings as there is no diminution of importance ratings. Where discrepancy of academic self ratings showed an association with severity it was in the reversed direction with the less disabled rating themselves relatively highly.

INFLUENCE OF INDIVIDUAL ASPECTS OF DISABILITY ON DOMAINS OF SELF ESTEEM

Table 2 demonstrates that global self worth and self rated competence relating to physical appearance show the most consistent correlation with severity. These variables were therefore analysed for associations between specific aspects of functional impairment and these measures (table 3). Small cell numbers limited the possible analyses of the findings and some functional levels were grouped.

In each case, evidence of significant association between severity and self concept was in the direction of increased self worth in the more disabled. High levels of global self worth and physical appearance competence ratings are seen among those young people with higher lesion levels, more restricted mobility, poorer upper limb function, and less functional independence as judged by dressing skills. Surprisingly there was no apparent correlation between the self esteem measures and continence.

THE EFFECTS OF IQ ON SELF CONCEPT AND GLOBAL SELF WORTH

The correlations between IQ and domains of self concept with and without control for severity are shown in table 4. There is a marginal association whereby the lower the IQ the higher the self worth. This diminishes to total insignificance once severity of disability is controlled. However, once we look at the details of these relationships following Harter's conceptual model, various aspects of process become clear. There is a relationship whereby the lower the intelligence the larger the discrepancy score for physical appearance ($r=-0{\cdot}423$, $p<0{\cdot}01$), and this remains once severity of disability is partialled out. As was the case for severity, this association between IQ and physical appearance discrepancy comes from lower IQ individuals having a higher evaluation of their own physical appearance rather than a lowering of its perceived importance to them.

Table 4 also demonstrates the positive associations whereby higher IQ individuals see themselves to be more competent in general academic and general intellectual domains.

SELF ESTEEM AND THE PRESENCE OF HYDROCEPHALUS

Specific effects of hydrocephalus were sought on the psychological findings. In spite of the impact of hydrocephalus on IQ there was no evident effect on global self worth. No pattern emerged from analysis of domains of self concept.

Table 3 Means of global self worth and competence ratings for physical appearance as a function of physical status. Parameters with significant correlations only; functional categories grouped for smaller numbers

	Global self worth	Physical appearance (competence)	No
Pultibeced measures			
Physical capacity:		*	
Good/exceptional	2·93	2·42	24
Low to average	2·77	2·43	23
Poor	3·14	3·05	23
Upper limbs (arms):	**	**	
Normal	2·77	2·42	49
Loss of skill	3·35	3·12	21
Upper limbs (hands):	*	**	
Normal	2·73	2·32	36
Loss of skill	3·18	2·95	34
Locomotion:			
Normal/slight difficulty	2·77	2·33	19
Moderate difficulty	2·79	2·20	15
Severe difficulty	3·11	2·96	36
Toileting:			
Normal/nocturnal enuresis	2·69	2·33	14
Continent with aid	3·08	2·75	34
Incontinent	2·90	2·62	22
Behaviour:			
Normal	2·90	2·45	41
Behaviour problems	3·01	2·88	29
Dressing:	**	**	
Normal	2·71	2·31	36
Requires help	3·19	2·96	34
Disability severity score			
Lesion level:	**	**	
Sacral	2·64	2·16	11
Lumbar	2·79	2·42	32
Thoracic	3·32	3·09	33
Shunt operations:			
None	2·99	2·56	23
1	2·97	2·50	12
⩾2	2·97	2·73	44
Ambulation:	*	*	
No acids	2·64	2·21	18
Braces	2·94	2·60	36
Wheelchair	3·26	3·03	25
Bladder function:			
Continent	2·78	2·49	16
Catheterisation	2·96	2·61	48
Collection device	3·25	2·92	15

Contrast significant on one way analysis of variance: *p<0·05; **p<0·01.

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Table 4 Correlations of IQ with competence ratings, importance ratings, and discrepancy scores. Controlled for Pultibeced and disability severity scores

Domain	*Correlation coefficient (n=79)*	*Correlations controlled for Pultibeced (n)*	*Correlations controlled for disability severity score (n)*
Global self worth	−0·21	−0·05 (67)	−0·14 (72)
Competence:			
General intellectual ability	0·19	0·26 (67)*	0·20 (72)*
General academic ability	0·38**	0·32 (67)**	0·34 (72)**
Social acceptance	0·09	0·08 (67)	0·09 (72)
Athletics	0·04	0·13 (67)	0·10 (72)
Behaviour	−0·17	−0·10 (67)	−0·14 (72)
Physical appearance	−0·26*	−0·03 (67)	−0·20 (72)*
Importance:			
General intellectual ability	0·03	0·02 (62)	0·04 (67)
General academic ability	−0·09	−0·11 (63)	−0·09 (68)
Social acceptance	0·07	0·14 (62)	0·16 (67)
Athletics	0·03	0·14 (62)	0·04 (67)
Behaviour	−0·02	0·03 (62)	0·03 (67)
Physical appearance	−0·04	−0·11 (63)	−0·00 (68)
Discrepancy scores:			
General intellectual ability	0·39**	0·37 (40)**	0·34 (45)**
General academic ability	0·45**	0·33 (56)**	0·40 (61)**
Social acceptance	0·12	0·06 (38)	−0·12 (41)
Athletics	0·15	0·17 (20)	0·11 (22)
Behaviour	−0·05	−0·09 (54)	−0·06 (57)
Physical appearance	−0·42**	−0·26 (44)*	−0·41 (47)**

Significance: *p<0·05; **p<0·01.

Discussion

The impact of the severity of disability on feelings of self worth is clearly not a simple relationship and no single medical or functional description of disability is likely to give a complete model of the mechanisms involved. Meaningful definition of severity of disability is problematic.[16] Medical parameters may be clearly recognised, for example spinal level, which link to aspects of function such as mobility. However, no single factor or collection of factors can illuminate every facet of 'severity' (medical, functional, social, financial, emotional, etc). In order to go some way to resolving this we have used two measures. One measure looks at the medical definition of disability and the other at functional limitations so it is not surprising that some associations between psychological findings and severity measures achieve statistical significance with one measure and not with the other.

Comparing this group of young people with able bodied controls showed areas of low self-rating in competence and greater discrepancy scores with no evidence of 'discounting' as hypothesised by Harter.[6] In this study the relationship between severity and global self worth indicated that the greater the severity of disability the greater the individual's global self worth. Conversely, those with lesser degrees of disability actually showed lower feelings of self esteem. Physical appearance self ratings follow a similar pattern with the most severely disabled young people demonstrating the highest ratings in this domain of self esteem. That the young people are expressing objective views of their self concept is indicated by the higher self ratings in academic domains by less disabled individuals with higher IQs and, presumably, greater academic ability. These findings parallel those of McAnarney *et al* where social adjustment in juvenile arthritis was found to be worse in those with milder disorder.[9] In our study group this is in part an effect of the high self esteem of the most disabled, who have significantly lower IQs than the rest of the group. For the most disabled, a lower IQ would appear to have a protective effect on global self worth. However, even when the effect of IQ is controlled for, the more disabled individuals still have greater self esteem in terms of global self worth and physical appearance. Thus low IQ has an additive, independent, protective effect whereby the lower the IQ, the greater the self rating of physical appearance and the greater the global self worth.

It is evident from the scattergrams (figure) that some young people with lesser degrees of disability show low self worth. Evidently some young people, superficially less in need of counselling and support, are at particular risk. Therefore, directing resources in relationship to physical severity may be misplaced. Moreover many of the mildly disabled individuals will be attending mainstream schools where the particular problems of spina bifida may be less well recognised.

In looking for evidence of the impact of specific aspects of disability, the findings of diminished self esteem with more normal functional ability is repeated. The most severely disabled individuals with high spinal lesions, poor mobility, and evidence of diminished upper limb function show higher self esteem in their physical appearance and global self worth.

Mobility[11] and urinary continence[1 7 11] might be expected to have a major negative impact on self esteem, though Wallander *et al* found no relationship between continence and psychosocial adjustment.[5] Our findings fail to demonstrate an association.

The effect of hydrocephalus on intellect has been described elsewhere.[17] Given the evidence from the severely disabled group it might have been expected to affect self esteem in the present sample as IQ was significantly lower in those with hydrocephalus than without. Yet there was no apparent relationship between levels of global self worth and the presence or absence of hydrocephalus as judged by their history of valve insertion.

Varni and Wallander suggested that parameters of physical disorder are major risk factors in the differential adjustment of handicapped children and are associated with greater psychosocial stress.[18] Though we find relationships between physical parameters and self esteem, the severity of disability is a poor indicator of the degree of impact which disability has on young people with spina bifida. The relative lack of evidence of association between specific parameters of disability and self esteem would suggest that it is psychosocial and other factors compounded by the total impact of the disability which modifies these aspects of self concept. Bleck has emphasised the importance of family, social, and cultural considerations in the success, or otherwise, of rehabilitation programs.[19]

Medical, social, and educational interventions to promote the health, developmental progress, and independence of young people with physical disability may appear to be hampered by a failure to align the process with the young person's own expectations and

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attitudes. Though the more severely disabled person with spina bifida may have more clearly definable problems, the mildly affected individual may well be more vulnerable and in greater need of appropriately structured support.

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