The Role of Pain in Reduced Quality of Life and Depressive Symptomology in Children With Spina Bifida

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Objectives: Children with spina bifida report both chronic and acute pain caused by both their condition and the treatments they undergo regularly. This research provides a description of the impact of this pain on their quality of life.

Methods: A sample of 68 children (56% female) between the ages of 8 and 19 completed the Varni/Thompson Pediatric Pain Questionnaire, a supplementary questionnaire on pain, the Children's Depression Inventory, the Nowicki-Strickland Locus of Control Scale for Children, and a pediatric measure of health related quality of life.

Results: Health related quality of life was shown to be systematically low in this group as compared with a reference sample of chronically ill children. It was negatively impacted by high reported frequency of pain and high ratings of current pain. Both pain and low quality of life were strongly associated with Children's Depression Inventory scores. Locus of control scores was not associated with quality of life or reported pain.

Conclusion: The unmanaged pain in children with spina bifida can have a substantial negative impact on quality of life. Better treatment and surveillance of pain and depression symptoms may significantly improve quality of life.

Key Words: pain, children, spina bifida, quality of life, depression

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Children and adolescents with spina bifida face a variety of challenges to quality of life. They report significant episodes of pain,[1] limited mobility, and both social and psychologic barriers to participation in activities with peers.[2–6] A recent study by Cate et al[7] showed that quality of life, as rated by parents, is dramatically impaired in this population. We wished to focus on the extent to which better management of pain might improve quality of life.

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Chronic and recurrent pain can affect nearly every aspect of a child's daily functioning.[8] For example, problems with peer relationships, general health (ie, sleep and appetite), and family functioning have been linked with pediatric pain.[9,10] As well, children who experience chronic pain may be frequently absent from school, resulting in poorer academic performance[11] and limited opportunity to participate in social and athletic activities.[10–14] Pain has been associated with reduced quality of life using broad quality of life measures in children with cerebral palsy[15,16] (although the measures used may not have been ideal[17,18]). Therefore, no single health related quality of life (HRQoL) measure could be expected to capture the relationship between pain, lack of function, and ability to participate in society. As well, acute pain, that which is currently experienced, may have both immediate and temporary effects, but acute pain may be judged in the context of chronic pain as well. Thus both pain and quality of life are multifaceted concepts, which can only be measured in limited ways.

General health HRQoL measures rate children with spina bifida as having low quality of life simply because of their reduced physical functioning.[19] This can be problematic because it does not reflect the quality of life as experienced by the children.[20] To supplement this measure we therefore included a child specific measure of depressive symptomology [Children's Depression Inventory (CDI)[21]], and a measure of locus of control (LOC) (Nowicki-Strickland Locus of Control Scale[22]), both of which relate to children's own constructions of their situation without regard to physical functioning per se.

Previous studies have shown a link between pain, anxiety, and depression in both children[23,24] and adults.[25–28] Clinical observations reveal that many patients with spina bifida who report multiple pain sites also exhibit depressive symptomatology and poor social and emotional adjustment. Given that pain seems to be undertreated and under-recognized in children with spina bifida,[1] we hypothesized that pain could be a significant factor in poor quality of life. There is also some support for the hypothesis that a history of recurrent pain episodes in children could lead to long-term changes, such as either acclimatization or sensitization, in their pain perception and tolerance.[29]

Pediatric pain has also been associated with a sense of personal helplessness or external LOC,[24,30] resulting in an over dependence upon parents, health care professionals, and health services.[12] LOC can play a mediating

role between pain and quality of life for a variety of reasons.[31,32] For example, the development of coping strategies may depend on the perception that one is able to make a difference, however, this link may not be critical or useful in children. Sawyer et al[33] found no relations between pain and LOC in children with arthritis. Lack of control and dependence on others also represent challenges to quality of life in their own right.[34,35] The goal of the present study was to demonstrate the direct and indirect impact of pain on various aspects of well-being to highlight the importance of pain management.

MATERIAL AND METHODS

Participants

A convenience sample of children and adolescents attending the Spina Bifida/Spinal Cord Clinic at the Bloorview MacMillan Children's Centre were approached with their parents' consent. Children were excluded from participating in the study if they: (1) were under 8 years of age, (2) had a physical disability other than spina bifida (eg, spinal tumor, spinal cord injury), (3) were non-English speaking or nonverbal, and (4) had significant cognitive limitations (as reported by clinic staff). Data were collected between January and June 2001. Bloorview MacMillan is a regional referral centre and may represent a referral bias towards the more severely impaired than some community samples.

Seventy-seven children and their parents were approached. Sixty-eight provided written consent or verbal assent along with consent from their guardians, (with 9 declining participation after assent due to time constraints). The mean age of the children who participated was 12 years, 8 months. Forty-four percent were male. For additional information about this sample please consult Clancy et al.[1] This study was approved by the ethics review board at the Bloorview MacMillan Children's Centre and the University of Toronto (Table 1).

Using a categorization based on diagnosis and ambulatory status, 28% of children would be classified as severe—a diagnosis of myelomeningocele and a lesion level of L4 or higher. This reflects a rough division between those children whose mobility will be dependant on wheelchairs and other devices and those who can walk with or without assistive devices.

Measures

We summarized pain using the child version of the Varni/Thompson Pediatric Pain Questionnaire (PPQ),[11] and a supplemental questionnaire that we designed. The PPQ provides ratings of current pain and worst pain in the preceding week; each rated on a separate 10 cm visual analog scale (1 for current pain, 1 for worst pain). Each scale was anchored by a smiley face (no hurting/no discomfort/no pain) on one end and a sad face (hurting a whole lot/very uncomfortable/severe pain). The PPQ offers face validity but work to establish its validity in children with complex conditions is limited.[36] Using a supplemental questionnaire we also asked about the frequency of pain using a 7-point scale (every day, a few times each week, once a week, a few times each month, once a month, every couple of months, once a year, never).

TABLE 1. Frequency and Percentage Distributions for Child Demographic Characteristics

Medical Information	Frequency (N = 68)	Percentage
Diagnosis		
Myelomeningocele (MMC)	59	86.8
Lipomyelomeningocele (LipoMMC)	6	8.8
Lipomeningocele (LipoMC)	3	4.4
Spina bifida and hydrocephalus	48	72.1
Spina bifida alone	20	27.9
Lesion level		
L4 to T12	44	64
L5 to S2	24	36

Reproduced from *Dev Med Child Neurol.* 2005;47:27–34.

The CDI[21] was administered to assess depressive symptomatology in the children, Although it has been used extensively in research, there are some concerns about its validity and specificity on an individual basis.[37]

LOC was measured using the Nowicki-Strickland Locus of Control Scale for Children.[22] This is a scale widely used in research but with no known data available on use with children who have complex needs.

A pediatric quality of life measure (PedsQL) was used to measure quality of life. All analyses were carried out using *z*-scores based on the reference sample for chronically ill children.[38] The PedsQL has been shown to have acceptable reliability and validity across a large sample of children.[39]

Procedure

The investigator approached children and parents who met the selection criteria while they waited for their clinic appointments. The study was explained verbally and in an information letter detailing the rationale and procedures of the study. Informed consent and assent was then obtained from parents and children who agreed to participate. Measures were administered to children by 1 of the 2 trained Masters level volunteer research assistants in a separate, quiet area. For children who demonstrated or indicated that they had difficulty with reading, the research assistant read items aloud and provided time for the child to record their responses. Note that the CDI was not administered to the 8 young adults of 18 or 19 years old, thus some analyses are based on a smaller sample.

Statistical Analysis

All correlations involving the frequency or magnitude of pain were assessed using Spearman correlation coefficients (indicated r_s). Group differences on the pain scores were assessed using Mann-Whitney tests. Scores from CDI and LOC standardized tests were assumed to be interval scaled. Relationships between these scores were evaluated using Pearson and group differences using

t tests as appropriate. Linear regression was used to assess the independent contribution of all variables to predict quality of life. Where analyses are carried out on fewer than 68 participants, either due to missing data or to restriction to a particular subgroup, the number involved is reported.

RESULTS

Quality of Life

The quality of life subscales formed a highly cohesive measure, such that the 5 chronic subscale scores had a high internal consistency, Cronbach $\alpha = 0.93$ (Table 2). In summary, there was little to discriminate the subscales from each other. Therefore, we took the overall quality of life z-score referenced to children with chronic illness as a proxy for quality of life in the subsequent analyses.

The association between PedsQL total z-scores and lesion level, $r_s = 0.20$, $P = 0.11$, was no stronger than expected by chance; this result was supported by a Mann-Whitney U conducted on total z-scores grouped by severity, $Z = -1.43$, $P = 0.15$. PedsQL scores were not influenced by age, $r_s = 0.13$, $P = 0.29$, or sex, $t = 1.15$, $P = 0.25$. Children using wheelchairs reported lower quality of life than full time ambulators, $t = 1.94$, $P = 0.05$, n = 46. This effect was concentrated in the physical subscale of the PEDS-QL, $t = 2.92$, $P < 0.01$, showed a trend on the emotional subscale, $t = 1.85$, $P = 0.08$, and was not significant on the psychologic, $t = -1.21$, $P = 0.52$, social, $t = -0.01$, $P = 0.99$, or school, $t = -1.07$, $P = 0.31$ subscales.

LOC

There was a trend towards external LOC in this sample, $t = -1.98$, $P = 0.05$. Lesion level and LOC z-score did not have a linear association, $r_s = 0.09$, $P = 0.47$; and there was no systematic difference between severe and nonsevere groups, $Z = -0.95$, $P = 0.34$.

Depressive Mood

CDI scores were available for 60 children. The mean score, M = 45.6, SD = 6.89, is within the accepted normal range, although the average score in this sample shows more depressive symptomology in this sample than was found in the normative group of healthy children, $t = -4.95$, $P < 0.01$, n = 60. According to the standard cutoff scores, about 5 children would be considered "below average." CDI scores were not associated with lesion level, $r_s = 0.15$, $P = 0.25$, n = 60; and there was no impact of severity grouping, $Z = -1.60$, $P = 0.11$.

Pain

The Supplementary Pain Questionnaire was used to collect information about how often children in this sample experienced pain. Fifty-six percent (n = 38) of children reported that they had experienced pain once a week or more often, and 82% (n = 56) of children reported having had pain a few times a month or more often. A Mann-Whitney U test found no significant age effect in reported frequency of pain ($z = -0.75$, $P > 0.05$). Mann-Whitney U tests were calculated because the pain frequency was reported in ordered categories from "everyday" to "once a year;" these have discrete rather than continuous distributions, and they do not meet the assumptions of normal distribution and equal population variances for parametric statistics. According to the PPQ (10 cm visual analog scale), children in this sample reported relatively little pain at the time of interview (current pain—M = 1.55, SD = 2.56) and reported substantial worst pain in the last week (M = 4.03, SD = 3.36).

Frequency, current pain and worst pain are correlated. The pain reported at the time of the survey (current pain) is correlated with the worst pain experienced in the last week, $r_s = 0.53$, $P < 0.01$, and with the frequency of pain, $r_s = -0.48$, $P < 0.01$. Frequency of pain is also associated with worst pain, $r_s = -0.61$, $P < 0.01$. None of these pain measures were associated with lesion level levels unexpected by chance.

TABLE 2. PedsQL Mean z-scores by Subscale (n = 64)

	Subscale Mean z-score	t	P
Physical	−1.02	−7.26	< 0.001
Psychologic	−0.82	−5.81	< 0.001
Emotional	−0.39	−2.90	0.005
Social	−0.70	−4.99	< 0.001
School	−0.85	−6.22	< 0.001
Total	−1.01	−7.00	< 0.001

The Relationship Between Pain and Quality of Life

PedsQL total z-scores were correlated with both frequency of pain, $r_s = 0.41$, $P < 0.01$, n = 64, and with the amount of current pain, $r_s = -0.28$, $P = 0.03$, n = 65. It was only marginally associated with the rating of worst pain in the last week, $r_s = -0.24$, $P = 0.06$, n = 65. Depression as measured by the CDI was associated with frequency of pain, $r_s = -0.47$, $P < 0.01$, n = 60, and with reported worst pain, $r_s = 0.51$, $P < 0.01$, n = 60. CDI scores were not associated with current pain at a level greater than that expected by chance, $r_s = 0.20$, $P = 0.12$, n = 60. LOC did not seem to be associated with frequency of pain, $r_s = 0.17$, $P = 0.17$, current pain, $r_s = -0.16$, $P = 0.21$, or reported worst pain, $r_s = -0.12$, $P = 0.34$.

CDI scores had a negative association with quality of life, $r = -0.57$, $P < 0.01$, n = 56. This does not primarily reflect a relationship mediated by pain as the partial correlation, removing variation attributed to frequency of pain, current pain, and worst pain, is very similar, $r = -0.52$, $P < 0.01$, n = 51.

The comparative roles of depressive symptomology, pain, and LOC in predicting quality of life was investigated through a linear regression. CDI, worst pain, and current pain scores all made independent contributions to predicted quality of life. LOC and frequency of pain did not (Table 3).

TABLE 3. Regression Coefficients for Selected Variables on PedsQL *z*-scores, (n = 55)

	β	*t*	*P*
CDI	−0.517	4.16	< 0.001
Worst pain	0.285	2.04	0.047
Current pain	−0.265	1.98	0.053
LOC	0.160	1.37	0.178
Pain frequency	0.158	1.18	0.245

DISCUSSION

The PedsQL is a HRQoL measure comprised of 5 subscales: Physical, Emotional, Social, Psychological, and School. For each subscale, there are 2 possible comparison groups: healthy children or children with chronic illness. The children in this sample showed seriously impaired HRQoL compared with both reference groups on every subscale. Furthermore, the scores were highly consistent across subscales, suggesting that no single type of problem characterizes this population and that individual variation on this scale is relatively low.

Assessing quality of life is always difficult and might be additionally complicated by some of the other factors in this sample. For example, the development of children with spina bifida can differ from that of children without disability. This makes it difficult to compare against children of a similar chronologic age. Disparate physical and intellectual functioning may potentially lead to different importance being attributed to particular activities. It is also important to consider the extent to which the PedsQL may be too focused at the level of impairment.[38–40] The PedsQL contains questions that implicate physical function, and the majority of children in this sample had physical impairments that would lead to a measured reduction in quality of life based on this definition. However, the PedsQL is based on 5 subscales of which 4 are intended capture levels of function and participation beyond simple impairment per se. A very low quality of life was recorded on each of these suggesting that our findings do not only reflect physical impairment.

Tests of LOC determine whether or not a person feels capable of accomplishment and participation in the world or whether they feel that most things result from outside influence. Variability amongst our sample was high and no significant trend on the basis of physical disability (ie, lesion level) was found. LOC also seems to play no part in mediating the impact of pain on HRQoL. This may be due to the fact that the change of LOC with age in the reference group for which the measure was designed does not correspond to the developmental sequence of children with spina bifida. It may also be the case that other variables such as acceptance are more relevant than LOC per se.[41]

The CDI is a measure of depressive symptomology. The overall trend (as compared with the reference population of the test) is towards more depressive symptoms than a normative sample, with 85% scoring below average. However, only 18% scored more than one standard deviation below average, and given the nature of the sample, none would be automatically considered to be demonstrating clinically significant depressive symptomatology on the basis of these scores. We would recommend additional caution in interpreting this as evidence of depression because of the differences between this population and the reference sample of children. Validity and norms have not been established for the population of children with spina bifida.

High CDI scores were strongly associated with poor quality of life. It should be clear that although depression as a construct is distinct from reduced quality of life; the extent to which our findings also indicate that children reporting frequent or severe pain and reduced quality of life were also depressed is subject to interpretation. Our results are consistent with the possibility that pain is causing severe and important emotional consequences, which reflect the observed quality of life. They are also consistent with the possibility that the willingness to endorse certain items on the CDI is more reflective of a response bias based on negative outlook than an independent quality of life issue. This important issue demands future research.

Given that nearly all the children experienced more current, frequent, and worst pain than would be expected in a broader sample of children, we have focused on this issue. Pain was associated with impaired quality of life. In particular, the frequency of pain and the ratings of severity of current pain were each associated with lower than average HRQoL, and the first 2 were associated with depressive symptoms. Pain was not associated with LOC on either an individual or group level.

An advantage of this study is its foundation in child self-report measures. The previous work by Cate et al[7] relied on parent report, and although this is adequate for some aspects of HRQoL, it is encouraging that their primary conclusion is echoed here. The primary weakness in all studies of this type is that it is not possible to summarize the experience of chronic pain using just 3 variables; almost every measure other than the rating of current pain is in some sense retrospective and depending on the memory rather than actual experience. Logically, we would expect that chronic pain, rather than current pain, would have the largest influence on quality of life. However, young children's reports of history and frequency of pain are subject to the biases of memory, which may or may not be accurate.[42] Their expression of and honesty about pain may also be influenced by other people in their environment; for example, they may be motivated to conceal pain for fear of being sent back to the doctor and undergoing invasive treatments.[43] The present study focused on current pain and current quality of life to reduce the impact of this problem, but future research might replace this approach with a long-term diary of both pain and quality of life issues.

There are several avenues by which pain enters the lives of children with spina bifida. There are specific physical symptoms, conditions, and manifestations, which themselves cause pain. For example, hydrocephalus often

leads to headaches and neck pain, as do shunt malfunctions.[44–46] There is also pain caused during the management of the disability, for example during recovery from operations or in therapy to promote flexibility and strength.[47–49] Pain has both direct (eg, "I cannot play because it hurts too much") and indirect (eg, "I do not have as many friends because pain makes me too tired to go out") effects, and seems to have an important and negative impact on long term well-being.

On the basis of other work,[1] there seems to be a substantial amount of untreated or under-treated pain in this population. Like limitations of physical function,[19] this seems to have an impact on quality of life. We conclude that improving pain management in this population is a priority because of its potential to substantially impact quality of life and well-being. The observer relationship between pain and depressive symptomology also suggests that this may require management in children reporting or predicted to have significant pain.

The key relationship between pain and quality of life is that the frequency of pain is the most strongly associated with lower overall quality of life. Reduction of pain frequency from daily to weekly, or from weekly to monthly could be expected to make a substantial improvement in quality of life. Therefore, children whose pain recurs frequently should be aggressively treated for pain and be presented with a maximum of treatment options. However, the present study did not undertake the study of other relevant factors that may contribute to well-being in the presence of pain. We conclude that additional effort in pain management is likely to have a substantial benefit in terms of quality of life, but that the best strategies for management could not be identified within the present, retrospective study.

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