

The Incidence of Pain in Children With Severe Cognitive Impairments

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Background: Children with severe cognitive impairments are believed to suffer pain frequently.

Objective: To document the frequency, duration, and intensity of pain experienced by children with severe cognitive impairments.

Design: Cohort study using surveys during 1 year.

Setting: Tertiary-care pediatric center for 3 provinces in eastern Canada.

Participants: Caregivers of 94 children and adolescents with moderate to profound mental retardation, aged 3 to 18 years (mean age, 10.1 years [SD, 4.3 years]). Forty-four children had cerebral palsy and 59 had a seizure disorder; 83 lived with family, and 11 in group homes.

Main Outcome Measure: Caregivers completed 4 semi-structured telephone surveys, reporting the cause, duration (in minutes), and intensity (on a scale of 0-10) of children's pain during the previous week.

Results: A total of 406 episodes of pain occurred. During a 4-week period, 73 children (78%) experienced pain at least once, and 58 (62%) had nonaccidental pain. Accidental pain was most frequent ($n=28$ [30%]), followed by gastrointestinal tract ($n=21$ [22%]), infection ($n=19$ [20%]), and musculoskeletal ($n=18$ [19%]) pain. Each week, 33 to 49 children (35%-52%) had pain. Mean pain duration was longer than 9 hours per week (SD, 1.7-2.4 hours). Mean intensity was 6.1 (SD, 2.2) for nonaccidental pain and 3.8 (SD, 2.1) for accidental pain. Children with the fewest abilities had more nonaccidental pain ($F_{4,89}=3.7$; $P=.007$), and children with greater motor abilities had more accidental pain ($F_{4,89}=2.8$; $P=.03$). Pain did not vary with demographic characteristics.

Conclusions: Children with severe cognitive impairments experience pain frequently, mostly not due to accidental injury. Children with the fewest abilities experience the most pain.

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ALL CHILDREN have pain, from bumps and bruises to needle pain and headaches. However, little research details that pain. Most childhood epidemiological studies are retrospective, examining only the occurrence of pain,¹ and focusing on specific conditions such as migraine,² back pain,³ and recurrent abdominal pain.⁴

Only 1 large-scale study of children's pain exists. Perquin et al⁵ collected information concerning pain experienced in the previous 3 months from 1001 parents of preschool children and 4459 children and adolescents aged 4 to 18 years in the Netherlands. They reported that 53.7% of children had pain during that time. Of these, 25% had pain that had been recurrent or continuous for more than 3 months. Approximately half of the children experienced pain in more than 1 location, most commonly the com-

bination of headache and abdominal pain. The percentage of children reporting pain also differed by body location and age. We could also locate only 1 study examining pain due to injury in the home setting.⁶ In that study, children were interviewed every 2 weeks for a 6-month period about injuries. They recalled approximately 10 injuries for each 2-week period (SD, 3.1 injuries).

Neither study included children with severe cognitive impairments. This omission is significant because this group is believed to experience more pain than most children.⁷ They may also experience pain from sources other children do not.⁸⁻¹⁰ For example, pain is frequently due to medical interventions, such as intravenous insertions, irritations caused by prostheses, and surgeries.⁸ They also experience pain due to chronic conditions associated with their syndromes or disorders, such as muscle spasms due to spasticity.⁹

Table 1. Items of the Non-Communicating Children's Pain Checklist-Revised

Vocal subscale
Moaning, whining, whimpering (fairly soft)
Crying (moderately loud)
Screaming/yelling (very loud)
A specific sound or word for pain (eg, a word, a cry, or a type of laugh)
Eating/sleeping subscale
Eating less, not interested in food
Increase in sleep
Decrease in sleep
Social subscale
Not cooperating, cranky, irritable, unhappy
Less interaction with others, withdrawn
Seeking comfort or physical closeness
Being difficult to distract, not able to satisfy or pacify
Facial subscale
A furrowed brow
A change in eyes, including squinching of eyes, eyes opened wide, eyes frowning
Turning down of mouth, not smiling
Lips puckering up, tight, pouting, or quivering
Clenching or grinding teeth, chewing or thrusting out tongue
Activity subscale
Not moving, less active, quiet
Jumping around, agitated, fidgety
Body/limb subscale
Floppy
Stiff, spastic, tense, rigid
Gesturing to or touching part of the body that hurts
Protecting, favoring, or guarding part of the body that hurts
Flinching or moving the body part away, being sensitive to touch
Moving the body in specific way to show pain (eg, head back, arms down, curls up, etc)
Physiological signs subscale
Shivering
Change in color, pallor
Sweating, perspiring
Tears
Sharp intake of breath, gasping
Breath holding

Their injuries may also differ. A study of ambulatory children with cognitive impairments at a day care found that 72% had at least 1 injury, compared with only 25% of children without impairments.¹⁰ Children with cognitive impairments were also more likely to have experienced a purposive injury by another person.

These studies suggest that children with cognitive impairments may experience pain that differs from that of children without cognitive impairments. We set out to document the cause, intensity, and duration of pain in this group of children and also explored whether the pain experienced differed as a result of child and family characteristics.

METHODS

PARTICIPANTS

Participants included 101 children and adolescents with severe cognitive impairments, aged 3 to 18 years (hereafter referred to as children), and their caregivers. Caregivers com-

pleted the measures described during participation in a larger longitudinal study of pain in children with severe cognitive impairments.¹¹⁻¹³ Each provided informed consent, and the study was approved by the Research Ethics Board of IWK Health Centre, Halifax, Nova Scotia.

Caregivers were recruited through physicians of the Division of Child Neurology at the IWK Health Centre. This is a tertiary pediatric care center for the provinces of Nova Scotia, New Brunswick, and Prince Edward Island. Physicians follow up virtually all children with cognitive impairments residing in these provinces, and all pediatric neurologists in this region are located at this center. In January 1999, the Medical Records Department, Division of Child Neurology, and Occupational Therapy Department identified children with mental disabilities or who were seen for adaptive seating equipment from January 1996 through January 1999. A physician in the Division of Neurology (C.S.C.) then reviewed the children's medical charts to select those with moderate to profound mental retardation for recruitment.

A total of 143 children were eligible for recruitment, and 101 caregivers (71%) agreed to participate. Three children died before completion, and 3 withdrew due to life-threatening child or parent illness or family move. One caregiver completed only 2 of the 4 pain surveys and was excluded from analyses. One additional caregiver completed 3 of the 4 pain surveys. This child's data were retained. Because her caregiver reported she had experienced no pain during the first 3 pain surveys, she was given that score for the fourth survey. Thus, 94 children (41 girls and 53 boys) formed the final sample for this study. Because of the small number of exclusions (n=7), it was not possible to conduct statistical comparisons of those children who were and were not included in these analyses.

MEASURES

Demographic Information and Medical History

Caregivers provided demographic information at entry. This was not available for children in group homes. The children's neurological diagnoses (cerebral palsy or general or focal seizures), time of onset of the neurological condition (prenatal, neonatal, or postnatal), and level of diagnosed mental retardation were obtained from the medical records.

Vineland Adaptive Behavior Scales

The Vineland Adaptive Behavior Scales (VABS)¹⁴ constitute a standardized measure of functional adaptation that is administered as a semistructured interview. This interview was administered to caregivers when they entered the 2-year study. It generates age equivalents describing the children's adaptive abilities in areas of communication, daily living skills, socialization, and motor skills.

Non-Communicating Children's Pain Checklist-Revised

The Non-Communicating Children's Pain Checklist-Revised (NCCPC-R)¹³ was designed for children with cognitive impairments. It consists of 30 items (**Table 1**) in 7 classes (vocal, eating/sleeping, social, facial, activity, body/limb, and physiological signs). It displays very good psychometric properties, with a score of 7 of 90 showing 77% specificity and 84% sensitivity to pain. Children's scores on the NCCPC-R are also consistent over time, even when pain due to different causes is experienced. A postoperative version of the tool has also been developed.¹¹ It also displays very good psychometric properties when used by a caregiver or another observer who is un-

Table 2. Pain Reported Each Week*

Pain Type	Week 1		Week 2		Week 3		Week 4	
	No. (%) of Children	No. of Episodes	No. (%) of Children	No. of Episodes	No. (%) of Children	No. of Episodes	No. (%) of Children	No. of Episodes
Accidental	14 (15)	16	15 (16)	21	10 (11)	14	7 (7)	10
Immediate	13 (14)	15	14 (15)	17	9 (10)	13	6 (6)	9
Postaccident†	1 (1)	1	1 (1)	4	1 (1)	1	1 (1)	1
Gastrointestinal tract	11 (11)	25	13 (14)	35	9 (10)	20	5 (5)	21
Digestive‡	5 (5)	12	5 (5)	21	5 (5)	12	4 (4)	15
Reflux	1 (1)	2	1 (1)	1	0	0	0	0
Bowels§	3 (3)	9	4 (4)	10	4 (4)	8	1 (1)	6
Constipation	2 (2)	2	3 (3)	3	0	0	0	0
Musculoskeletal	6 (6)	12	5 (5)	11	7 (7)	11	3 (3)	19
Muscle	3 (3)	3	2 (2)	2	1 (1)	1	1 (1)	5
Orthopedic	3 (3)	9	3 (3)	9	6 (6)	10	2 (2)	14
Everyday	6 (6)	12	3 (3)	9	4 (4)	6	5 (5)	6
Teething	5 (5)	11	0	0	1 (1)	2	0	0
Menstruation	1 (1)	1	3 (3)	9	3 (3)	4	4 (4)	5
Headache	0	0	0	0	0	0	1 (1)	1
Infection	7 (7)	9	7 (7)	11	5 (5)	22	7 (7)	21
Chest	2 (2)	2	1 (1)	1	1 (1)	7	0	0
Throat	2 (2)	2	1 (1)	1	0	0	0	0
Other	3 (30)	5	5 (5)	9	4 (4)	15	7 (7)	21
Recurrent	4 (4)	4	3 (3)	15	5 (5)	6	6 (6)	8
Ears¶	3 (3)	3	3 (3)	15	2 (2)	2	5 (5)	7
Seizures	1 (1)	1	0	0	2 (2)	3	1 (1)	1
Diaper rash	0	0	0	0	1 (1)	1	0	0
Medical	5 (5)	11	0	0	7 (7)	13	2 (2)	7
Needle	1 (1)	1	0	0	4 (4)	4	0	0
Postoperative	1 (1)	1	0	0	0	0	1 (1)	3
Feeding-tube irritation	3 (3)	9	0	0	3 (3)	9	1 (1)	4
Other#	4 (4)	4	0	0	0	0	1 (1)	7
Unknown	1 (1)	9	4 (4)	9	0	0	1 (1)	2
Total per Week	49 (52)	102	44 (47)	111	38 (40)	92	33 (35)	101

*N = 94. Percentages have been rounded and may not total 100. Some children are listed more than once in different categories.

†Due to an injury on a previous day.

‡Due to gas or gastrointestinal tract pain without elaboration of the cause or the location.

§Described as being bowels, but not specifically described as due to constipation.

||Includes pain due to viral or bacterial infections not in the throat or the chest.

¶Described as pain in the ears with no physician-indicated infection.

#Includes pain due to a cast, tumor, chemical burn, or self-injurious behavior.

familiar with the child. Correspondence between caregivers and other observers is very good. The NCCPC-R was completed at entry by caregivers to assess the pain behavior children typically display while in pain so that the relation between pain behavior and pain experienced could be examined.

Pain Surveys

For the 1-year study period, 4 semistructured telephone surveys were administered to caregivers. To facilitate caregivers' recall, they were systematically questioned regarding pain episodes that had occurred, day by day, beginning with 6 days before the call and moving forward to the day of the call. For each episode, they were asked to describe (1) pain cause, (2) pain intensity from 0 (none at all) to 10 (worst pain ever), and (3) duration of pain in minutes.

PROCEDURE

Caregivers completed the demographic questionnaire, the VABS,¹⁴ and the NCCPC-R by telephone. Four pain surveys were completed at 3-month intervals beginning 1 month after entry (survey 1, a mean of 4.8 weeks after entry [SD, 3.3 weeks]; survey 2, a mean of 13.4 weeks [SD, 4.2 weeks] after survey 1; survey 3, a

mean of 13.1 weeks [SD, 2.7 weeks] after survey 2; survey 4, a mean of 13.6 weeks [SD, 2.7 weeks] after survey 3).

STATISTICAL ANALYSES

Coding of the Pain Episodes

Some children had pain more than once on a specific day or had pain that lasted more than 1 day. Thus, *episode* was used as the unit of analysis, defined as of 1 continuous period of pain. These episodes lasted from a few minutes to several days. Caregivers' descriptions of the cause of the pain were used to classify episodes (**Table 2**). Pain was also grouped into 2 categories for some analyses. Accidental pain included pain immediately after an accident or later (eg, pain due to tenderness the day after a fall). Nonaccidental pain included all pain except that due to accident or medical procedures.

Missing Data

Of the 406 episodes of pain described by caregivers, intensity ratings on the intensity scale of 0 to 10 were not provided for 22 (5%), and duration was not provided for 68 (17%). These were not replaced.

Table 3. Chronological and Adaptive Ages of the Children*

Measure	Range	Mean (SD)
Chronological age, y	3.0-18.7	10.1 y (4.3)
VABS age equivalents, mo†		
Communicative	<1-56	13.8 (10.0)
Daily living skills	<1-83	14.0 (11.7)
Socialization	<1-90	14.0 (12.9)
Motor skills	<1-44	8.7 (9.5)

Abbreviation: VABS, Vineland Adaptive Behavior Scales.¹⁴

*N = 94.

†Age equivalents computed according to VABS guidelines based on VABS scores obtained.

Statistical Procedures

We analyzed data using SPSS for Windows, version 10.0.7.¹⁵ The α was set at .05 for all analyses, and Bonferroni corrections were applied. Power computations were conducted using SamplePower¹⁶ or based on Stevens,¹⁷ using large effect sizes as defined by Cohen,¹⁸ as these would be considered clinically significant. Multivariate Fs were tested using Wilks Λ .

Descriptive statistics were generated for each pain survey and for the 4 pain surveys combined. Because all children were under observation for the same period, incidence rates were the ratio of children who experienced at least 1 episode of pain to the total number of children.¹⁹ Comparisons of the total number of pain episodes, number of accidental pain episodes, and number of nonaccidental pain episodes experienced by sex were made using independent *t* tests and by age group (3-7, 8-12, and ≥ 13 years) using 1-way analyses of variance (ANOVAs). Power for *t* tests and ANOVAs exceeded 0.90. Analysis of the amount of time spent in pain during the 4 weeks by sex and age group were made using a multivariate ANOVA (MANOVA).

Comparisons of demographic factors of children who experienced accidental or nonaccidental pain with those who did not were made using independent *t*, Mann-Whitney, and χ^2 tests. Power for these ranged from 0.92 to 0.97. The χ^2 tests were used to examine differences in the proportion of children who experienced categories of pain by sex and age group. Power ranged from 0.87 to 0.97.

Comparisons of adaptive age equivalents between children who had or had not experienced accidental or nonaccidental pain were made using MANOVAs on the 4 age equivalents from the VABS.¹⁴ Power exceeded 0.90 for multivariate effects and was approximately 0.82 for univariate effects. Pearson correlations were also used to examine the relations among the children's score on the NCCPC-R, adaptive age equivalents on the VABS,¹⁴ number of episodes, and number of types of pain episodes during the 4 weeks. Power exceeded 0.90.

RESULTS

CHARACTERISTICS OF THE SAMPLE

Children

The children's chronological and adaptive ages are displayed in **Table 3**. They had neurological impairments of prenatal (n=67), perinatal (n=11), postnatal onset (n=13), and unknown (n=3). The cause of the 94 children's cognitive impairments included dysmorphic syndromes (n=28), chromosomal syndromes (n=7), extreme prematurity (n=11), asphyxia at birth (n=10),

traumatic brain injury (n=9), neurodegenerative disorders (n=6), intrauterine acquired conditions (n=6), infection (n=4), and epileptic syndromes (n=2). The cause of impairment was unknown for 7 children and unavailable for 4.

The children were diagnosed as having moderate (n=9), severe (n=61), or profound (n=16) mental retardation. No diagnosis was available for 8. Forty-four children had cerebral palsy and most had a seizure disorder (generalized in 31 and focal in 28). The children also had physical limitations. Only 43 had full use of their arms, 39 had some use, and 12 had none. Twenty-one children had full use of their legs, 42 had some use, and 31 had none. Vision was also fully impaired in 23 children and partially in 18. Eight children had no hearing, and 7 had a partial hearing impairment. Twenty-five of the children were tube fed.

The children required frequent medical monitoring, 43 on a monthly, 10 on a weekly, and 19 on a daily basis. Only 22 received a single medication on a regular basis. Fifty-three received 2 or more medications regularly.

Families

Eighty-three children lived with their families. Sixty-nine (83%) of their caregivers were married. Of the 83, 38 families (46%) had 3 or more children, 28 (34%) had 2 children, and 17 (20%) had only the child with cognitive impairments. Fifty-three families (64%) earned between Can \$10 000 and \$50 000, 18 (22%) earned greater than Can \$50 000, and 7 families earned less than Can \$10 000. Five families did not provide this information. Mothers ranged in age from 20 to 66 years (mean age, 38.7 years [SD, 7.7 years]; n=83) and 40 (48%) had post-secondary or a university education (high school, n=23 [28%]; less than high school, n=18 [22%]). Fathers ranged in age from 28 to 70 years (mean age, 40.8 years [SD, 8.2 years]; n=75). Thirty-one fathers (37%) had post-secondary or university training, whereas 20 (24%) had completed high school and 19 (23%) had not. Two mothers did not provide information about education (total of categories=81) and 13 fathers did not supply information about education (total of categories=70).

DESCRIPTIVE STATISTICS OF CHILDREN'S PAIN

The pain reported by the caregivers is depicted in **Table 2**. Twenty-one children (22%) experienced no pain during the 4 weeks surveyed. The remaining 73 children (78%) experienced at least 1 pain episode, with a total of 406 episodes reported. Of the 2632 days surveyed, children had pain on 470 (18%). Each week, 35% to 52% of children had pain. Accidental pain occurred most often, in 7% to 16% of children, followed by gastrointestinal tract pain (5%-14%).

PAIN BY WEEK OF SURVEY

Table 4 displays the number of days on which children experienced pain and time in pain by week. There was little variability. On average, children had pain once per week and it lasted longer than 9 hours.

PAIN INCIDENCE, INTENSITY, AND DURATION FOR 4 WEEKS

During the 4 weeks, accidental pain happened at least once for 30% of children, whereas 62% had nonaccidental pain (**Table 5**). Pain of unknown cause was the most intense, followed by pain attributed to the bowels and gastrointestinal tract and digestive pain. Accidental pain and medical pain were the least intense. The longest lasting pain was due to throat infections, constipation, or teething. Accidental pain had the shortest duration, usually less than 1 hour.

PAIN BY SEX AND AGE

The amount of time spent in pain during the 4 weeks did not differ significantly by sex ($F_{4,89}=0.2$) or age group ($F_{8,176}=0.6$). The total number of pain episodes ($t_{92}=1.6$), number of accidental pain episodes ($t_{92}=0.1$), and number of nonaccidental pain episodes ($t_{92}=1.4$) also did not differ by sex. The total number of pain episodes ($F_{2,91}=0.3$), number of accidental pain episodes ($F_{2,91}=1.3$), and number of nonaccidental pain episodes ($F_{2,91}=0.5$) did not differ by age group. Results of χ^2 tests indicated that the proportion of children experiencing each category of pain also did not differ significantly by sex or age.

PAIN BY FAMILY DEMOGRAPHIC CHARACTERISTICS

Accidental Pain

Children who experienced at least 1 episode of accidental pain during the 4 weeks ($n=28$) did not differ from those who did not have accidental pain ($n=66$) in the proportion who lived with their family. Parents of the 2 groups also did not differ in terms of education or age, and their families did not differ in income or in number of children.

Nonaccidental Pain

Children who experienced at least 1 episode of nonaccidental pain during the 4 weeks ($n=58$) did not differ from those who experienced none ($n=36$) in the proportion who lived with their family, the education level or age of their parents, family income, or number of children in the family.

DIFFERENCES IN ADAPTIVE ABILITIES IN RELATION TO PAIN EXPERIENCED

Accidental Pain

A MANOVA comparing the adaptive abilities of children who had any accidental pain with those who had none disclosed a significant multivariate effect ($F_{4,89}=2.8$; $P=.03$). Univariate tests indicated that children who had any accidental pain had significantly higher age equivalents for motor skills (mean, 12.5 [SD, 8.4]) than children who did not (mean, 7.0 [SD, 9.5]; $F_{1,92}=7.0$; $P=.009$),

Table 4. Mean Number of Days With Pain and Mean Time Spent With Pain per Week*

Study Week	Days With Pain		Time in Pain†	
	Mean (SD)	Range	Mean (SD)	Range
1	1.1 (1.7)	0-7	9:54 (32:01)	0:00-168:00
2	1.3 (2.1)	0-7	9:12 (27:15)	0:00-168:00
3	1.1 (1.9)	0-7	10:06 (32:30)	0:00-168:00
4	1.3 (2.4)	0-7	10:30 (35:24)	0:00-168:00

*N = 94.

†Expressed as number of hours:minutes and does not include episodes for which duration was not provided.

but did not differ in age equivalents for communication (mean, 13.8 [SD, 10.8] vs 13.8 [SD, 8.0]), daily living skills (mean, 13.1 [SD, 12.9] vs 16.0 [SD, 8.0]), or socialization (mean, 14.2 [SD, 14.0] vs 13.7 [SD, 10.1]). Thus, children who had at least 1 episode of accidental pain during the 4 weeks had higher overall adaptive abilities, due primarily to their greater motor skills.

Nonaccidental Pain

A second MANOVA compared the adaptive abilities of children who had any nonaccidental pain with those who had none during the 4 weeks. The multivariate effect was significant ($F_{4,89}=3.7$; $P=.007$). Univariate tests indicated children who had any nonaccidental pain had significantly lower age equivalents than those who had none for communication (mean, 11.5 [SD, 8.5] vs 17.6 [SD, 11.5]; $F_{1,92}=9.0$; $P=.004$), daily living skills (mean, 10.8 [SD, 7.9] vs 19.1 [SD, 14.8]; $F_{1,92}=12.3$; $P=.001$), socialization (mean, 11.5 [SD, 10.3] vs 18.2 [SD, 15.6]; $F_{1,92}=6.3$; $P=.01$), and motor skills (mean, 6.2 [SD, 7.5] vs 12.7 [SD, 11.0]; $F_{1,92}=11.5$; $P=.001$). Thus, children who experienced nonaccidental pain had lower adaptive abilities in all areas.

Relation Between Adaptive Ability and Amount of Pain

Four of the Pearson correlations between children's adaptive age equivalents, number of pain episodes, and number of types of pain episodes were significant (**Table 6**). Having a lower age equivalent for communication was associated with more episodes of pain of all types. A lower age equivalent for daily living skills was also associated with more episodes of pain of all types, more types of pain, and more episodes of nonaccidental pain.

PAIN AND NCCPC-R SCORE

Pearson correlations indicated that children's scores on the NCCPC-R, a measure of typical pain behavior, were not related to the overall number of pain episodes or the number of types of pain they experienced. However, children's scores on the NCCPC-R were related to the number of accidental ($r=-0.23$; $P=.03$) and nonaccidental types of pain they experienced ($r=0.23$; $P=.03$). As the number of typical pain behaviors increased, the number

Table 5. Incidence, Mean Intensity, and Mean Duration of Pain by Type*

Pain Category	No. (%) of Children (N = 94)	No. (%) of Episodes (N = 406)	Intensity†		Duration, Hours:Minutes	
			Mean (SD)	Range	Mean (SD)	Range
Accidental	28 (30)	61 (15)	3.8 (2.1)	1-10	0:46 (3:30)	0:01-24:00
Immediate	26 (28)	54 (13)	3.8 (2.1)	1-10	0:06 (0:11)	0:01-1:00
Postaccident‡	3 (3)	7 (2)	3.9 (1.7)	1-5	4:36 (8:36)	0:01-24:00
Nonaccidental	58 (62)	333 (82)	6.1 (2.2)	1-10	6:06 (16:11)	0:01-168:00
Gastrointestinal tract	21 (22)	101 (25)	7.5 (2.0)	1-10	3:48 (9:03)	0:02-72:00
Digestive§	11 (12)	60 (15)	7.5 (2.3)	1-10	2:01 (2:12)	0:05-9:00
Reflux	2 (2)	3 (0.7)	6.7 (1.2)	6-8	2:54 (18:48)	0:45-4:00
Bowels	9 (10)	33 (8)	7.6 (1.2)	5-10	4:42 (7:54)	0:15-24:00
Constipation	5 (5)	5 (1)	6.2 (0.8)	5-7	24:30 (33:30)	0:02-72:00
Musculoskeletal	18 (19)	53 (13)	5.1 (1.7)	2-10	1:06 (3:42)	0:01-24:00
Muscle	6 (6)	11 (3)	5.2 (1.0)	4-8	0:44 (0:22)	0:02-60:00
Orthopedic	12 (13)	42 (10)	5.0 (1.8)	2-10	1:04 (4:24)	0:01-24:00
Recurrent	12 (13)	33 (8)	6.0 (1.4)	4-8	7:05 (14:24)	0:01-72:00
Ears¶	8 (9)	27 (7)	6.2 (1.3)	4-8	6:30 (15:12)	0:03-72:00
Seizures	3 (3)	5 (1)	5.4 (1.5)	4-8	6:00 (10:12)	0:01-24:00
Diaper rash	1 (1)	1 (0.2)				
Common childhood	10 (11)	33 (8)	5.0 (1.7)	2-8	9:01 (19:15)	0:01-96:00
Teething	5 (5)	13 (3)	5.2 (1.9)	2-8	18:30 (35:20)	0:13-96:00
Menstruation	4 (4)	19 (5)	4.7 (1.6)	2-7	5:54 (8:30)	0:01-24:00
Headache	1 (1)	1 (0.2)				
Infection	19 (20)	63 (16)	5.6 (2.4)	2-10	11:42 (25:42)	0:01-168:00
Chest	3 (3)	10 (2)	4.6 (2.3)	2-9	4:24 (9:42)	0:01-24:00
Throat	3 (3)	3 (0.7)	5.3 (1.5)	4-7	32:00 (13:54)	24:00-48:00
Other#	14 (15)	50 (12)	5.8 (2.5)	2-10	11:20 (27:12)	1:00-168:00
Other**	5 (5)	11 (3)	6.8 (0.7)	5-8	3:20 (8:24)	0:20-24:00
Unknown	5 (5)	20 (5)	8.7 (1.1)	6-10	11:30 (10:36)	0:30-24:00
Medical	12 (13)	31 (8)	3.8 (2.1)	1-10	0:46 (3:30)	0:01-24:00
Needle	5 (5)	5 (1)	4.4 (0.9)	3-5	16:00 (13:48)	0:02-24:00
Postoperative	2 (2)	4 (1)	5.0 (0.0)	5-5	12:45 (23:30)	1:00-48:00
Feeding-tube irritation	5 (5)	22 (5)	4.4 (1.5)	2-7	0:58 (1:09)	0:00-2:30

*Percentages have been rounded, and may not total 100. Some children are listed more than once in different categories.

†Calculated on a scale of 0 to 10, where 0 indicates none at all and 10, worst pain ever.

‡Due to an injury on a previous day.

§Due to gas or gastrointestinal tract pain without elaboration of the cause or the location.

||Described as being bowels, but not specifically described as due to constipation.

¶Includes pain in the ears with no physician-indicated infection.

#Includes pain due to viral or bacterial infections not in the throat or the chest.

**Includes pain due to a cast, tumor, chemical burn, or self-injurious behavior.

Table 6. Pearson Correlations Between Children's Adaptive Age Equivalents and Amount of Pain Experienced*

	VABS Age Equivalents							
	Communication		Daily Living Skills		Socialization		Motor Skills	
	r	P Value	r	P Value	r	P Value	r	P Value
No. of pain episodes	-0.27	.009	-0.33	.001†	-0.20	.049	-0.23	.03
No. of types of pain	-0.34	.001†	-0.33	.001†	-0.29	.005	-0.24	.02
No. of accidental pain episodes	0.02	.82	0.12	.24	0.01	.92	0.22	.04
No. of nonaccidental pain episodes	-0.26	.01	-0.33	.001†	-0.20	.054	-0.28	.007

Abbreviation: VABS, Vineland Adaptive Behavior Scales.¹⁴

*N = 94. Age equivalents computed according to VABS guidelines based on VABS scores obtained.

†Significant after correlations for multiple tests.

of episodes of accidental pain decreased, whereas the number of episodes of nonaccidental pain increased.

COMMENT

To our knowledge, this is the first study to document the incidence and characteristics of pain experienced by chil-

dren with severe cognitive impairments. Our results indicate that pain is frequent for these children, experienced on 18% of days during the 4 weeks surveyed over 1 year and by 35% to 52% of children each week. This is much higher than the rates reported in the study by Perquin et al³ of unimpaired children, in which just more than 50% experienced pain during a longer 3-month pe-

What This Study Adds

Children with severe cognitive impairments are believed to experience pain frequently, most often due to chronic medical conditions associated with their physical disabilities or medical procedures aimed at managing those conditions. However, no study has documented the nature or frequency of their pain.

This study indicates that more than one third of children with severe cognitive impairments experience pain that lasts hours each week. Most is due to chronic medical conditions, whereas relatively little is due to medical interventions. The severity of this situation highlights the need for better clinical management strategies to address these chronic painful conditions. These strategies could lead to substantial reductions in pain, improved quality of life, and better long-term outcomes for a very vulnerable group.

riod. However, caution must be taken in comparing these 2 studies, as different methods of measuring pain were used. The present study also did not include a control group of children without cognitive impairments, so that no direct comparison of the nature of the pain experienced by these 2 groups could be conducted. Confirmation that children with cognitive impairments experience pain more frequently than children without must be provided by further studies that include both groups of children and that monitor their pain using the same methods.

The pain experienced by the cognitively impaired children was also significant in nature. Only postaccidental pain received a mean rating below 4 on the pain intensity scale. The average intensity for accidental pain was 3.8; for nonaccidental, 6.1. Given that a score of 30 of 100 is considered clinically significant (equivalent to 3 of 10 in this study), and a level at which many parents give medication, it is clear that the pain these children are suffering is not minor.²⁰

Pain was also not brief; children spent an average of 9 to 10 hours per week in pain and had pain at least 1 day each week. Most pain was not due to accidental injury or medical procedures, but due to medical conditions, illnesses, or chronic painful conditions. Of the 94 children, 62% had at least 1 episode of pain that was not due to accident or medical procedures, and 82% of pain episodes were not due to injury or medical procedures. Nonaccidental pain was also more intense and lasted longer (approximately 6 hours on average) compared with 46 minutes for accidental pain. Although it has been suggested that children with cognitive impairments suffer a great deal of pain due to medical procedures such as surgery and injections,⁷ only 13% of these children had such pain, representing only 8% of pain episodes. Most medical pain was due to ongoing problems at feeding-tube sites and not to procedures or surgery.

These data were based on caregivers' judgments of the cause of their children's pain, and further research should be conducted to verify these results with medical examinations. Nevertheless, 72 (77%) of the children in the study were seen by a physician on a regular

basis. Thus, caregivers' judgments would have incorporated information they had been given by those professionals. Together, these results suggest that pain is a frequent and substantial problem for children with cognitive impairments, and that pain due to causes other than injury or medical procedures is most severe in frequency, intensity, and duration.

Family demographic characteristics did not differ between children who had accidental or nonaccidental pain, suggesting that the environment did not play a significant role in the amount or type of pain. Pain also did not differ by sex or age. This most likely reflects the fact that all of the children had severe limitations. For example, pain due to sports activities differs between girls and boys and by age group.²¹ These differences would be less likely in this group because all have severe impairments. Cognitively impaired children with greater motor skills were found to be more likely to have accidental pain. These children were not more advanced in other areas of adaptive functioning, suggesting that a combination of greater mobility without a concomitant increase in other abilities may underlie this difference.

The findings regarding the children's amount of pain, typical pain behaviors, and adaptive abilities are intriguing. The number of pain behaviors typically displayed by children decreased with the number of accidental pain episodes experienced, but increased with the number of nonaccidental pain episodes. This could reflect 2 coexisting phenomena. First, children experiencing multiple injuries may reduce their pain behavior over time, as they become accustomed to daily bumps and bruises. Second, children experiencing more nonaccidental pain may display more pain behavior over time, because they become increasingly sensitized to pain.^{22,23}

Adaptive abilities, especially in communication and daily living skills, decreased with the number of types of pain and the number of nonaccidental pain episodes experienced, although the relations appear to be only moderate in nature. This finding suggests that children who experienced more pain in this study had greater physical and cognitive impairments. This coincides with recent research indicating that daily pain in elderly persons who are institutionalized is greater with increasing dependency.²⁴ Because these correlational analyses do not indicate the direction of causality, it is also possible that more pain contributed to the reduced abilities of these children, as recent studies suggest that repeated pain may have long-term consequences for children's behavior.²⁵⁻²⁷

One weakness of this study is that the information was based on caregivers' reports rather than on direct observation of the children in a structured way by caregivers or another observer. Previous research with this population suggests that caregivers' judgments of the children's pain made by direct observation in a hospital setting correspond to those of other observers,¹¹ indicating that caregivers' judgments are valid. The information provided by caregivers in this study was also elicited in a structured way that facilitated recall. Nevertheless, caregivers had to recall events several days in the past. Future studies should incorporate diaries in which caregivers record the specifics of their children's pain as it occurs to confirm these findings.

CONCLUSIONS

Our results indicate that children with cognitive impairments experience pain weekly, and that most of that pain is not due to injury, but to illness or comorbid conditions. Studies to uncover possible risk factors for pain are needed to help caregivers and health care professionals diagnose pain when it occurs. Research into treatment and management strategies is also crucial, as these children often present with multiple, complex conditions that are occurring with increased frequency due to the higher rate of survival for children born with severe disabilities.^{28,29} Science is now challenged with developing ways of making the lives of those who survive more acceptable.

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