

Decreased access to health care and social isolation among young adults with cerebral palsy after leaving school

SY Ng, SK Dinesh

Faculty of Medicine, National University of Singapore, Singapore

SKH Tay

Department of Paediatrics, Faculty of Medicine, National University of Singapore, Singapore

EH Lee

Department of Orthopaedic Surgery, Faculty of Medicine, National University of Singapore, Singapore

ABSTRACT

Objective. To examine if leaving special schools has a negative impact on the health care and social isolation of young adults with cerebral palsy.

Methods. Young adults with cerebral palsy, aged between 15 and 22 years, were divided into 2 cohorts: current students, who were still receiving services from special schools, and school-leavers, who had since been discharged from care. A questionnaire and physical examination were administered to assess the extent of disability, health care received by, and social isolation of these young adults.

Results. School-leavers had a greater degree of disability than did students, although the results were not statistically significant. Health care exposure to

specialists, general practitioners, therapists (physiotherapists, occupational therapists, and/or speech therapists), and medical social workers decreased after leaving school; with the exception of contact with general practitioners, these results were significant ($p < 0.05$). The entire cohort was more socially isolated than a control cohort. School-leavers participated in fewer activities outside their homes, but showed less concern about their disability than did current students.

Conclusions. Young adults with cerebral palsy continue to have health care and lifestyle needs after leaving school, which are currently not being adequately met.

Key words: cerebral palsy; delivery of health care; disabled persons; health services

INTRODUCTION

The prevalence of cerebral palsy at birth¹ and life expectancy of children with cerebral palsy² are increasing worldwide. These trends have been attributed to improved obstetric and neonatal care, and hence increased survival of infants with low birth weight.³ When these individuals reach adulthood, they still require special medical attention. Young adults with physical disabilities may have severe problems left untreated due to diminished contact with health services after leaving special schools.⁴ In addition, they can have considerable continuing impairment and disability. Thus, the lack of contact with health services after leaving school may adversely affect their health status.⁵

In addition, young disabled adults face difficulties in integrating into society.⁶ Although relationships with parents are described as positive and friends are viewed as very important, most disabled people have extremely limited out-of-school contacts, negligible participation with organised social activities, and a predisposition towards sedentary activities. Dating is rare for these adults, but most of them hope to marry.⁷ In a case series focusing specifically on adolescents with cerebral palsy, young adults with cerebral palsy were found to be socially less active than a control population; the older age-group was socially less active than the younger.⁸

In Singapore, disabled young adults with cerebral palsy are cared for mainly by organisations that are funded by a combination of public and private funds, and staffed by professionals and volunteers. Examples include the Spastic Children Association of Singapore, Asian Women's Welfare Association, and the Rainbow Centre. These organisations offer a spectrum of subsidised special education and therapy for disabled children, ranging from early intervention programmes right after birth, to open and sheltered workshop employment training until the age of 18 years. However, there is no structured care programme for these adults after the age of 18 years. Some individuals are eligible for open employment or sheltered workshops, which provide a supervised environment for disabled individuals to earn a basic pay by performing simple tasks. Others remain at day-care centres. The rest inevitably become homebound. Furthermore, there is no central organisation that manages referrals and follow-ups for these individuals. Instead, care is mainly co-ordinated by health care professionals with a special interest in disability.

We aimed to investigate the health care and social integration of young adults with cerebral palsy in Singapore, both while they are in school and after leaving school. In the context of increasing prevalence

and survival of children with cerebral palsy, this study has implications for demands on medical resources in the near future.

METHODS

In 1999, young adults with cerebral palsy who were born between 1977 and 1984 and aged 15 to 22 years were identified from school records of the special schools that provide special education and therapy for the majority of children with cerebral palsy in Singapore. The participants were divided into 2 cohorts—the current student cohort, which consisted of young adults who were receiving services from the schools, and the school-leaver cohort, which consisted of those who had left school at the time of the study. Verbal permission was sought from both the schools and parents, and a visit was made to the participants' homes by 2 fourth-year medical undergraduates.

A standardised questionnaire and clinical examination were administered. The questionnaire sought to elicit data about the individual's degree of disability, the amount of health care received, and the degree of social isolation. Measures of disability were identified and adapted from those described by Hutton et al.,² Evans et al.,⁹ and Pharoah et al.¹⁰ Participants were examined and scored on the following aspects of disability: ambulation, intelligence, vision, hearing, communication skills, and manual dexterity.

The health care received by the participants was assessed using measures that were derived from those described by Cathels and Reddihough⁵ and by Stevenson et al.⁸ Participants in both groups were questioned on the amount of contact they had with various medical practitioners, therapists, and social workers in the preceding year. School-leavers were also asked to recall the amount of health care they had received in their last 2 years of school.

In addition, a social isolation questionnaire was adapted from that used by Stevenson et al.⁸ (Appendix) and administered concurrently to the 2 cohorts of study subjects, and a group of control subjects, consisting of age- and sex-matched healthy young adults studying in government schools in Singapore. This questionnaire assessed the level of social activity, concerns about socialising, and accessibility of social leisure activities.

Finally, a clinical examination was performed to look for pre-existing medical conditions. Statistical analysis using chi-square and Student's *t* tests were performed using Statistical Package for the Social Sciences (Windows version 10.0; SPSS Inc., Chicago, United States).

RESULTS

Participants

149 subjects were identified from the school records of the 4 centres; 74 were allocated to the school-leaver cohort, and 75 to the current student cohort.

Of the school-leavers, 31 were untraceable, 6 declined to participate, and 5 were deceased. The number of participants remaining in this group was 32, generating a response rate of 43%.

Of the current students, 49 agreed to participate, 19 were untraceable, and 7 declined. The response rate of this group was 65%. The overall response rate was 54%. The high overall untraceable rate was possibly because the families of the young adults had moved

since the initial registration, and the records had not been updated. We attempted to improve the response rate by tracing some of the parents using the telephone directory.

There were 51 males and 30 females in total. The overall mean age was 17.9 years (range, 15–22 years), that of the school leavers was 19.8 years (range, 17–22 years), and that of the current students was 16.7 years (range, 15–18 years).

Disability

Table 1 shows the degree of the various aspects of disability of the 2 cohorts, as well as for the cohorts combined. In total, 30 (37%) participants either had serious ambulatory disability that required a wheel-

Table 1
Aspects of disability among participants

Disability	No. (%)		
	School-leavers	Current students	Total*
Ambulation			
Fluent	6 (19)	6 (12)	12 (15)
Non-fluent	5 (16)	21 (43)	26 (32)
With walking aids	7 (22)	6 (12)	13 (16)
With wheelchair	10 (3)	15 (31)	25 (31)
Unable to move	4 (13)	1 (2)	5 (6)
Intelligence			
Normal school	3 (9)	8 (16)	11 (14)
Special school, takes exams	7 (22)	16 (33)	23 (28)
Special school, does not take exams	22 (69)	25 (51)	47 (58)
Vision			
Cannot assess	3 (9)	2 (4)	5 (6)
No aids needed	17 (53)	22 (45)	39 (48)
Correctable with aids	6 (19)	23 (47)	29 (36)
Not correctable with aids	6 (19)	2 (4)	8 (10)
Hearing			
Cannot assess	1 (3)	1 (2)	2 (2)
None	29 (91)	45 (92)	74 (91)
Correctable with aids	0 (0)	3 (6)	3 (4)
Not correctable with aids	2 (6)	0 (0)	2 (2)
Communication			
None	9 (28)	14 (29)	23 (28)
Intelligible with some difficulty	3 (9)	10 (20)	13 (16)
Intelligible with great difficulty	7 (22)	15 (31)	22 (27)
No communication	13 (41)	10 (20)	23 (28)
Manual dexterity			
No problem	10 (31)	10 (20)	20 (25)
Some difficulty	6 (19)	18 (37)	24 (30)
Considerable difficulty	2 (6)	9 (18)	11 (14)
Only with assistance	14 (44)	12 (25)	26 (32)

* Because of rounding, not all percentages total 100.

chair, or were unable to move at all. Assessment of manual dexterity showed that 26 (32%) participants were dependent on carers and could feed and dress only with assistance. On analysing current and past school attendance for current students and school-leavers respectively, 70 (86%) participants had attended special school. Of these, 67% (n=47) of the combined cohort did not take any form of regular academic lessons. Instead, their regular classes consisted of lessons focused on therapy and skills of self-care. Overall, 8 (10%) participants had uncorrectable vision problems, while 2 (2%) had uncorrectable hearing problems. 28% (n=23) of participants were unable to communicate at all or did so with great difficulty, usually being comprehensible to their parents only (n=22).

Table 2 shows the mean scores for the various aspects of disability, with a higher score depicting higher extent of disability. Although the mature cohort was more disabled in every aspect of disability, the difference between cohorts was not statistically significant in any area.

Pre-existing medical conditions

Table 3 shows the distribution of the subjects by the type of cerebral palsy. Nearly 80% participants had

spastic cerebral palsy (n=64), of which diplegia and quadriplegia were the main variants.

The pre-existing medical conditions found on clinical examination are shown in Table 4. The most common conditions were kyphoscoliosis (43%), lower limb contractures (41%), constipation (36%), squint (35%), and visual impairment (33%). Medical conditions continued to persist after these individuals had left school. Conditions such as malnutrition, respiratory infections, constipation, seizures, incontinence, kyphoscoliosis, and dental caries were more prevalent among school-leavers than among the current students.

Health care access

The access to health care among the school-leavers declined markedly after leaving school in terms of both medical care and therapy (physiotherapy, occupational therapy, and speech therapy). Three quarters of this cohort (n=24) visited a specialist at least once a year when they were in school, compared with one quarter (n=8) of the current students (p<0.001). Of those who had left school, 14 (44%) were in contact with a general practitioner, compared with 17 (53%) before leaving school. However, this difference was not statistically significant (p=0.55).

Table 2
Comparison of mean disability scores between school-leavers and current students

Disability	School-leavers	Current students	p value
Ambulation	3.03	2.67	0.212
Intelligence	2.59	2.35	0.126
Vision	1.62	1.57	0.775
Hearing	1.13	1.06	0.494
Communication	2.75	2.43	0.248
Manual dexterity	2.63	2.47	0.566

Table 3
Types of cerebral palsy

Type	No.(%)
Spastic	
Hemiplegia	8 (10)
Diplegia	29 (36)
Triplegia	4 (5)
Quadriplegia	23 (28)
Choreoathetotic	1 (1)
Ataxic	1 (1)
Mixed	5 (6)
Unknown	10 (12)

Table 4
Pre-existing medical conditions found on clinical examination

Systemic and medical condition	No.(%)		
	School-leavers	Current students	Total
Growth and nutrition			
Poor nutrition	10 (31)	13 (27)	23 (28)
Respiratory system			
Chest infection	4 (13)	6 (12)	10 (12)
Rhonchi and crepitations	7 (22)	6 (12)	13 (16)
Gastrointestinal system			
Regurgitation	1 (3)	5 (10)	6 (7)
Constipation	13 (41)	16 (33)	29 (36)
Neurological system			
Seizures	11 (34)	10 (20)	21 (26)
Incontinence	11 (34)	13 (27)	24 (30)
Visual impairment	7 (22)	20 (4)	27 (33)
Squint	11 (34)	17 (35)	28 (35)
Visual field loss	1 (3)	2 (4)	3 (4)
Hearing loss	3 (9)	6 (12)	9 (11)
Poor gag reflex	4 (13)	7 (14)	11 (14)
Ataxia	2 (6)	4 (8)	6 (7)
Musculoskeletal system			
Previous orthopaedic operations	16 (50)	27 (55)	43 (53)
Kyphoscoliosis	16 (50)	19 (39)	35 (43)
Upper limb contractures	7 (22)	12 (25)	19 (24)
Lower limb contractures	12 (38)	21 (43)	33 (41)
Dental			
Caries	11 (34)	14 (29)	25 (31)

Table 5
Mean annual frequency of school-leavers' contact with health care professionals

Health care provider	While at school	Currently	p value
General practitioners	2.10	1.76	0.468
Specialists	1.64	0.75	0.020
Physiotherapists	55.16	15.12	<0.001
Occupational therapists	48.28	6.36	<0.001
Speech therapists	22.56	0.00	<0.001
Medical social workers	1.68	0.71	0.021

Table 6
Mean annual frequency of contact with health care professionals

Health care provider	School-leavers	Current students	p value
General practitioners	1.76	2.20	0.518
Specialists	0.75	2.45	0.015
Physiotherapists	15.12	39.68	<0.001
Occupational therapists	6.36	32.32	<0.001
Speech therapists	0.00	19.36	<0.001
Medical social workers	0.71	1.84	0.311

Table 7
Case-control comparisons of mean social index scores

	Cerebral palsy*	Controls	p value
Activities outside home	4.85	15.38	<0.001
Personal concerns	33.19	37.81	0.003
Access	10.09	13.38	<0.001
Total	48.12	66.57	<0.001

* Including school-leavers and current students.

Table 8
Mean social index scores

	School-leavers	Current students	p value
Activities outside home	2.80	5.33	0.129
Personal concerns	39.00	31.81	0.002
Access	12.20	9.57	0.138
Total	54.00	46.71	0.047

The frequency of contact also decreased correspondingly, but the difference was statistically significant only for frequency of contact with specialists (Table 5).

The majority of consultations with specialists while the school-leavers were still in school occurred in the premises of the special schools by way of visiting volunteer specialists. After leaving school, most participants in this cohort had to seek specialist care at hospitals, which may account for the decline in specialist care.

In contrast, most school-leavers continued to visit their general practitioner at private clinics and polyclinics for minor ailments. School-leavers also had less contact with physiotherapists—an average of 55 times annually while at school, but only 15 times after leaving school ($p < 0.001$) [Table 5]. There were similar statistically significant declines in contact with occupational and speech therapists. Reasons behind such findings are likely because schools are a main provider of therapy. School-leavers received therapy mainly from the sheltered workshops and day-care centres. Nobody in this study was receiving care from private therapists.

Contact with medical social workers declined from an average of 1.68 times annually to 0.71 times ($p = 0.02$). While participants were in schools, it was common for medical social workers to make regular phone calls to their parents, or home visits. This service was not available after leaving school: many parents confessed to not knowing the appropriate avenues to

seeking medical social workers, and many admitted still going to the social workers in the old schools.

The current types of health care received by current students were also compared to those of school-leavers (Table 6). More than 60% of school students had seen a specialist in the preceding year, compared with 25% of school-leavers ($n = 8$; $p = 0.03$). While more current students than school-leavers consulted their general practitioners (63% versus 44%), the difference was not statistically significant ($p = 0.24$).

As expected, subjects currently still in school had more contact with the therapists, compared with those who had left school. However, while they had more contact with medical social workers, the difference was not statistically significant ($p = 0.31$).

Social index scores

The questionnaire (Appendix) was administered to all 81 participants and to the control cohort. The overall response rate was 32%, with 21 of the 49 current students (43%) and 5 of the 32 school-leavers (16%) participating. Those who did not respond were unable to communicate or did not understand the questions.

The questionnaire was used to score activities outside home, personal concerns about socialisation, and accessibility of social activities; a lower score indicated decreased activity, increased concern, and decreased accessibility, respectively. The scores of the cerebral

palsy cohort showed statistically significant differences from those of the control cohort in all three areas (Table 7). The cerebral palsy cohort was socially more isolated, especially regarding participation in activities outside home. This finding was expected, given the limitations imposed by their disabilities on social integration.

Compared with school-leavers, current students exhibited more concerns about socialisation and had decreased accessibility. Only the difference in personal concerns was statistically significant. On the other hand, school-leavers participated in less activity outside home, although this difference was not statistically significant ($p=0.129$) [Table 8].

DISCUSSION

Significant medical conditions and disability exist among young adults with cerebral palsy during and after their schooling. However, most of them experience a decrease in specialist care and therapy after leaving the coordinated care of special schools, which play an important role in providing regular and heavily subsidised specialist consultations and therapy. Bax et al.⁴ has noted in young adults that although the primary handicaps may not be progressive, many show signs of physical deterioration with time. Children with physical disabilities also have rates of psychological disturbance 2 to 5 times that of a normal school-aged population.⁶

The decrease in contact with general practitioners after leaving school was not statistically significant in our study. This suggests that general practitioners should be involved in regular care of the disabled young adults. However, the complexity of the conditions encountered will still require frequent specialist consultations. Further training should be offered to general practitioners with an interest in disability and rehabilitation, so that they can co-manage these children with the support of specialists. Special organisations could refer school-leavers to these practitioners for regular follow-up.

The most drastic drop in the health care received by school-leavers with cerebral palsy is in their contact with physiotherapists (Table 6). Therapists outside the special schools are rare, and often the regular consultations that are required on a long-term basis impose a financial and logistical hurdle for the patients and their family. In this aspect, family members should be motivated and trained to provide regular exercises for the young adults.

The cost of hospital and family practitioners' care from birth to the age of 8 to 9 years are, on average,

approximately 6 times greater for disabled children than for normal children, and 9 times greater if the disabled child has a low birth weight.⁷ Therefore, the continuity of care, which is often threatened when the child leaves school, should be continued to maintain the health and social integration that has already been acquired at a high price.

Young adults with cerebral palsy are more socially isolated than their able-bodied peers in all aspects. In addition, despite participating in fewer social activities than school students, school-leavers have less personal concern. Using a similar instrument, Stevenson et al.⁸ found that young adults with cerebral palsy tend to become less socially active and more isolated when they leave school. The special schools provide a wide spectrum of social activities for these young adults—from a venue of interaction with similarly disabled-peers to regular outings and school trips. On leaving school, access to this resource is diminished for most, which would be most drastically among those who are homebound. It is worrying that school-leavers exhibit less concern about their social isolation despite a reduction in activities outside home, reflecting possibly a resignation and scaling down of expectations of social integration that they once had in school.

Hirst¹¹ concluded that poor psychological adjustment and extreme social isolation are not direct consequences of any impairment or disability, but arise from severe functional loss and were shaped by dependency on others, restricted choices, physical barriers, and the adverse reactions of others. Hence, improved social integration of disabled people in Singapore is an achievable goal through increased education of the public to remove stigma and bias, improved infrastructure to increase accessibility, and concerted efforts to integrate the needs and requirements of the disabled population into national policy.

Many authors have proposed that handicapped adult teams should provide health care for both physically and mentally handicapped people after the age of 18 years, with the teams functioning in the framework of existing community medical resources.^{3,12,13}

The issue of appropriate distribution of limited health care resources to groups that require them most, and society's valuation of a disabled person's life will undoubtedly arise. However, young adults with cerebral palsy will continue to have needs after leaving school, and their needs are not met adequately.

It is likely that a small increase in health care resources and proper planning will bring about a significant improvement in the quality of life for disabled

young adults. Thus, there exists a need at the end of school life, for all involved in the care of the disabled, including the young adults themselves, to cooperate and communicate more closely to bring about a smooth transition and to reduce the social isolation and medical sequelae in late adolescence and beyond.

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Appendix
Questionnaire in social support (schooling cohort)

Activities outside home

When did you last do any of the following?

	Within last week (2)	Within a month (2)	Within 3 months (1)	Within a year (0)	Never (0)
1. Have a friend to visit					
2. Visit friends					
3. Spend a night away from home					
4. Go shopping on your own					
5. Go to the cinema, theatre or concert					
6. Go to a hawker centre or restaurant					
7. Go to a club or disco					
8. Go out alone					
9. Use sports facilities (e.g. swimming, football, snooker)					
10. Go to a religious place of worship					

Personal concerns

How do you feel about the following?

	Not worried (2)	A bit worried (2)	Worried (1)	Very worried (0)	Try to avoid (0)
11. Getting enough privacy at home					
12. Going into a shop to buy something					
13. Going into a hawker centre/restaurant					
14. Using public transport					
15. Going into a room full of people					
16. Meeting strangers or people you don't know					
17. Mixing with people at school or college					
18. Making friends of your own age					
19. Making first move in starting a friendship					
20. Going out with someone you are attracted to					
21. Making a close intimate friendship					
22. Making ordinary decisions on your own					
23. People looking at you					
24. Asking strangers for help					
25. Getting served in cafés and pubs					
26. How you look (clothes etc.)					
27. Not having enough money					
28. Helping around the house					
29. Being alone					
30. Feeling different from other people					
31. Your family					

Getting out and about

Please tick yes or no

	Yes (1)	No (0)
32. Do you have plenty of friends?		
33. Do you feel there are enough things to do with friends in your spare time?		
34. Do you think you are a shy person?*		
35. Do you think that most people like you?		
36. Do you have friends who live near you?		
37. Do responsibilities at home stop you from going out as much as you would like?*		
38. Do you have your own car, motorbike or bicycle?		
39. Do your parents have a car?		
40. Do friends ever take you out in their car?		
41. Do you use public transport?		
42. Do you ever travel by taxi?		
43. Do you go out as much as you would like?		
44. Is travel / transport a problem when you want to meet friends or to go out with them?*		
45. Does it cost so much to do things with your friends that sometimes you can't see them?*		
46. Are there enough places to go to with friends?		
47. Do you have any problems getting someone else to join you when you want to go out?*		
48. Do you ever go out with your parents?		
49. Do you belong to any clubs?		

* These items score as 0 point for Yes, and 1 point for No.