编者按(Leaderette):Mrs. Vicki McManus 是欧洲脑瘫监测组织(Surveillance of Cerebral Palsy in Europe, SCPE)成员,南爱尔兰地区的负责人。该文介绍了 SCPE 的概况、宗旨、工作模式和成效。该组织的宗旨是建立一个脑瘫病例的中央数据库,用于监控脑瘫的流行病学发展趋势,指导协作人员如何提高脑瘫病人的生活质量。这无论对于从事脑瘫工作的医护人员还是从事相关职业的人员来说都是十分有用的。做好登记工作是关键,有助于了解脑瘫流行病学的特征。这一组织也能为有关部门制订计划提供信息。此文值得我国从事脑瘫的工作人员借鉴。

· Original Article in English ·

SCPE work, standardization and definition — An overview of the activities of SCPE: a collaboration of European CP Registers

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Abstract: The main aim of the Surveillance of Cerebral Palsy in Europe (SCPE) network was to develop a central database of cerebral palsy (CP) cases across Europe. Monitoring trends in prevalence rates of CP should contribute to collaborative studies on risk factors or quality of life for children living with CP. A multi-centre collaboration of CP registries used a clear definition of CP to accurately and consistently identify cases of CP. The rate of CP within the collaboration varied from 1.5 to 3 per 1 000 live births. For the birth cohort 1980 to 1996 (n = 9 128), 53.9% of the CP children had a bilateral spastic cerebral palsy, 31.0% had unilateral spastic CP, 6.6% were dyskinetic and 4.1% ataxic. Among CP children, 20.4% had a birth weight less than 1 500g and 25.5% were born before 32 weeks gestational age. Intellectual impairment corresponding to an IQ < 50 was found in 29.5% of CP children. The proportion of CP children unable to walk, even with aids, was 30.3%. Twelve and a half percent of CP children were known to have a severe visual impairment. It was concluded that registers are the best means to implement epidemiological research into CP.

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Key words: Cerebral palsy; Collaboration; Epidemiology

SCPE 的工作、标准化和定义—SCPE 活动概貌:欧洲脑瘫登记协作网

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[**摘 要**] 欧洲脑瘫监测组织(Surveillance of Cerebral Palsy in Europe, SCPE)协作网络的主要目的是建立欧洲脑瘫病例的中央数据库。对脑瘫患病率变化趋势的监控有利于对脑瘫危险因素的研究以及提高脑瘫患儿的生活质量。在脑瘫多中心协作登记工作中,为了准确一致地鉴定脑瘫病例,研究人员采用明确、统一的脑瘫定义。SCPE 协作组发现每 1 000 个存活儿中脑瘫的患病例为 1.5 ~ 3 例。在 1980 至 1996 年间的出生组群中(n = 9 128),53.9% 的脑瘫患儿为双侧痉挛性脑瘫,31.0% 的为单侧痉挛性脑瘫,6.6% 为运动障碍,4.1% 为共济失调。在脑

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瘫患儿中，20.4% 患儿出生体重不足 1 500 g，而 25.5% 的孕龄不足 32 周。29.5% 的脑瘫患儿出现了智力障碍（IQ < 50）。不能步行（甚至在协助下）的脑瘫患儿比例为 30.3%。12.5% 的脑瘫患儿出现了严重的视力缺损。做好登记工作有助于了解脑瘫流行病学的特征，是进行脑瘫流行病学研究的一种最佳方式。

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SCPE work, standardization and definition

Cerebral palsy (CP) is the most common cause of motor deficiency in young children but it occurs in only 2 to 3 per 1 000 live births, thereby it is necessary to study large populations in order to monitor prevalence rates in the condition [1]. In 1998 a collaborative network of CP registers and surveys, Surveillance of Cerebral Palsy in Europe (SCPE) was formed [2]. The aim of the network was to develop a central database of CP cases in order to monitor trends in prevalence rates of CP, and to conduct collaborative research studies, e.g. on the quality of life of children living with CP. These aims make the collaboration useful to all medical and associated professionals working in the CP field. Registers are appropriate tools to answer questions on the prevalence rates and characteristics of CP.

This project should also provide information on the planning of services. Details of the population base and ascertainment sources can be found elsewhere [2]. This paper reports findings concerning 1980-1996 birth cohorts of the database.

Methods

Definition of CP

A clear definition of CP, with inclusion and exclusion criteria, is necessary to accurately and consistently identify cases. Drawing on published work [3], participating centers are now using a consensus definition of cerebral palsy: '*cerebral palsy is a group of disorders; it is permanent but not unchanging; it involves a disorder of movement and/or posture and of motor function; it is due to a non-progressive interference/lesion/abnormality in the developing/immature brain.*' [2]. The definition specifically excludes progressive disorders of motor function.

CP classification

The SCPE classification systems, based on clinical findings, are widely used for epidemiological research. SCPE classified the cerebral palsies into three main categories: Spastic (unilateral or bilateral), Ataxic and Dyskinetic cerebral palsy. When CP is of mixed type, the predominant type, spastic or dyskinetic, is retained. The diversity and expertise within the working groups of SCPE has led to many discussions over the years, which, in turn, has led to the evolution of three tools:

- Decision and Classification trees (Figure 1, Figure 2)
- Reference & Training Manual: this is a 'teaching' CD-ROM which contains video pieces describing and classifying children with different types of CP. It can be requested directly from Prof. Ingeborg (Kraegeloh-Mann@ med. uni-tuebingen. de).
- The recommended data collection form for CP cases which is directly available on the SCPE web site (http://www-rheop. ujf-grenoble. fr/scpe2/site_scpe/index. php).

Inclusion/exclusion criteria of CP

The inclusion/exclusion criteria for SCPE were: 1) children should be at least 4 years old when meeting criteria for the definition of CP; 2) if the definition criteria are met and the neurological signs of one of the subtypes of CP are present, children with recognized syndromes, brain abnormalities or chromosome abnormalities are included. A range of sources was used for case ascertainment and all centers used more than one source.

Statistical analysis

Proportions are presented with 95% confidence intervals (CI).

Results

The prevalence rate of CP within the collaboration varied from 1.5 to 3 per 1 000 live births. Among children born 1980 to 1996 in the area covered by the SCPE network, 9 128 children had CP. One center recruited only spactic diplegic CP children ($n = 149$). Among the remaining 8 979 children, 53.9% (52.8-54.9, 95% CI) had bilateral spastic CP, 31.0% (30.0-32.0) had unilateral spastic CP, 1.2% (0.09-0.1) had spastic

CP subtype unknown, 6.6% (6.1-7.2) had dyskinetic CP (dystonic or choreo-athetotic), and 4.1% (4.0-4.9) had ataxic CP (Figure 3). Among CP children, 20.4% (19.6-21.3) had a birthweight less than 1 500 g and 25.5% (24.5-26.2) were born before 32 weeks of gestation (Table 1).

Intellectual impairment corresponding to an IQ < 50 was observed in 29.5% (28.5-30.5) of children with CP. The proportion of children with CP unable to walk, even with aids, was 30.3% (29.3-31.2) and 12.4% (11.7-13.1) were known to have a severe visual impairment.

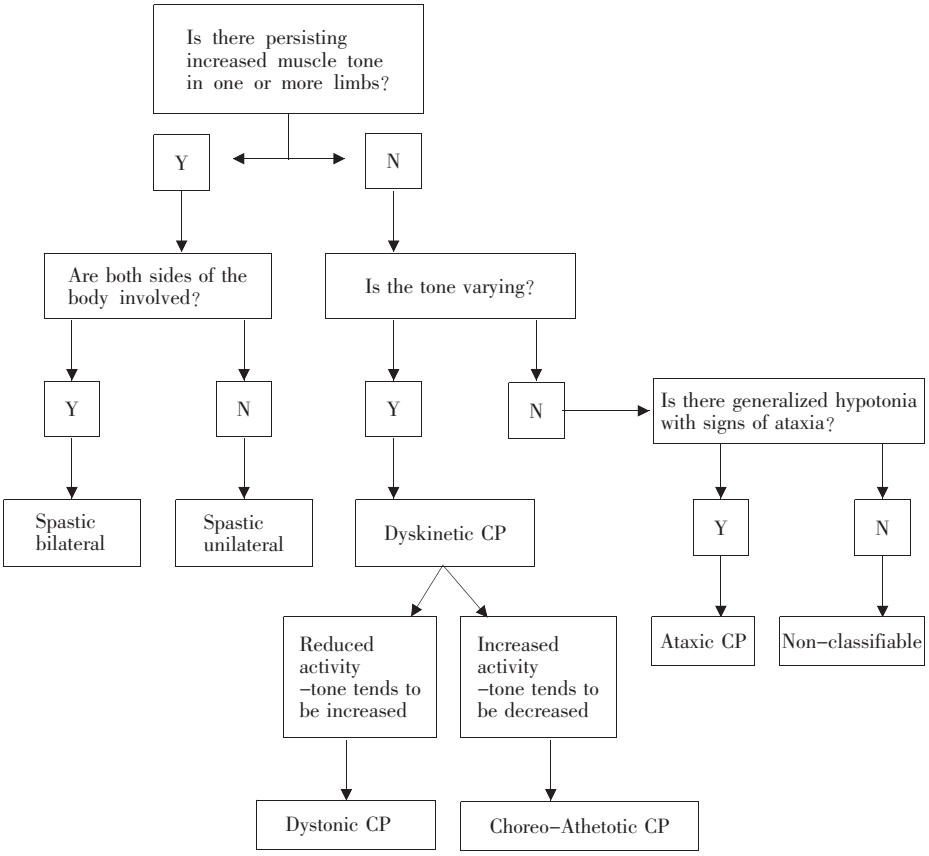

Figure 1 Classification tree for sub-types of CP

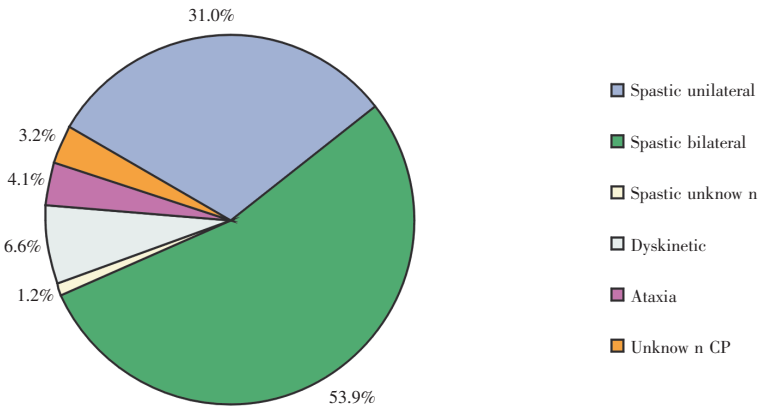

Figure 3 Distribution of different types of CP, birth years 1980-1996 (n = 8 979)

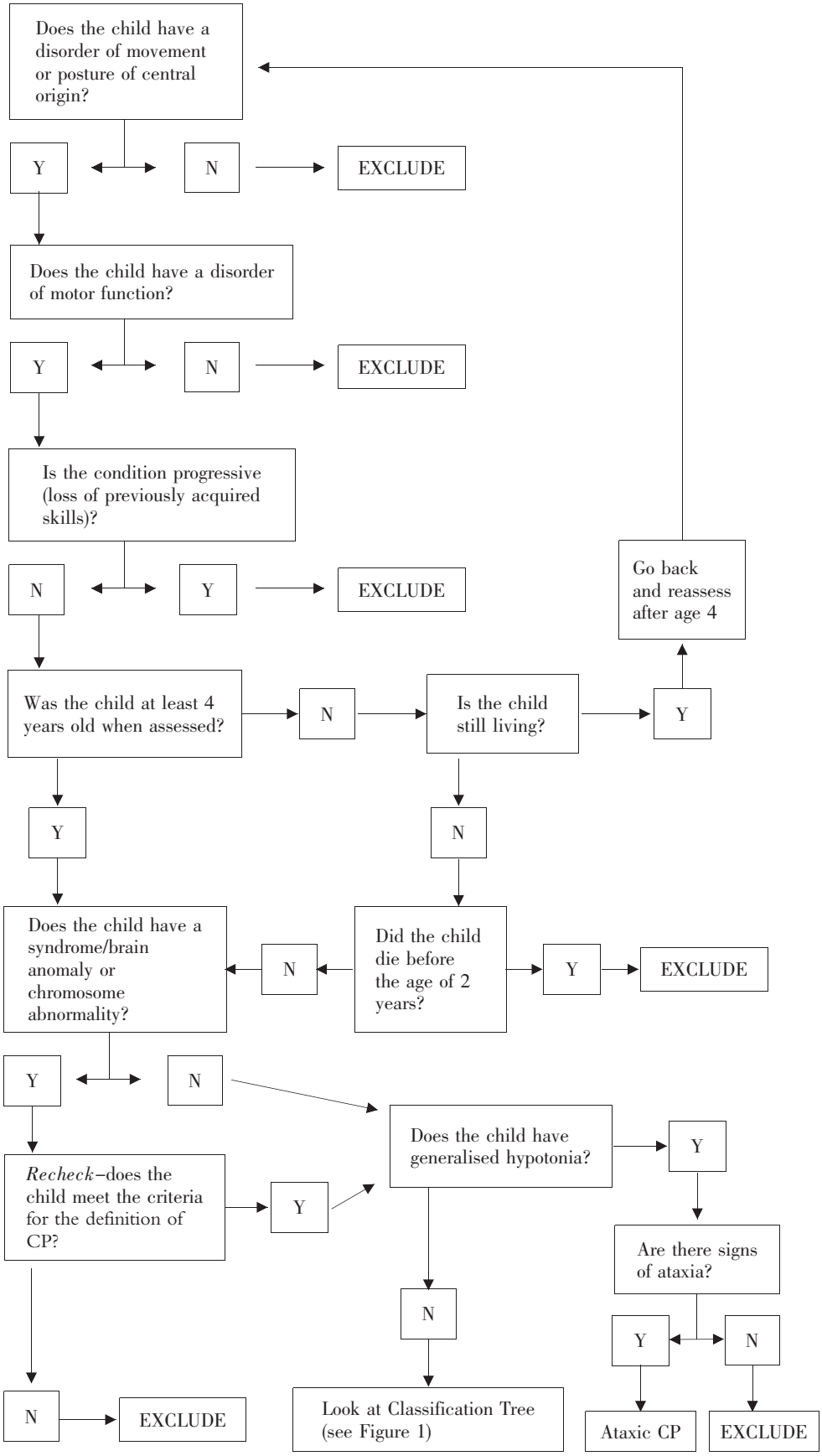

Figure 2　Decision tree for CP（Reference：Developmental Medicine & Child Neurology，2000，42：816-824）

Table 1 Prevalence rate of CP in Birth weight groups (BW) and Gestational age (GA) groups by CP type (birth years 1980-1996) [*n*, (%)]

Group	CP type					
	Unilateral spastic	Bilateral spastic	Unknown spastic	Dyskinetic	Ataxia	Total ※
BW						
<1 000 g	117 (4.5)	302 (6.4)	3 (3.1)	19 (3.4)	10 (3.1)	451 (5.4)
1 000-1 499 g	240 (9.2)	936 (19.8)	9 (9.2)	55 (9.7)	13 (4.1)	1 253 (15.0)
1 500-1 999 g	224 (8.6)	800 (16.9)	8 (8.2)	51 9.0)	10 (3.1)	1 093 (13.1)
2 000-2 499 g	269 (10.3)	582 (12.3)	10 (10.2)	44 (7.8)	26 (8.1)	931 (11.2)
2 500-3 499 g	1 074 (41.1)	1 409 (29.7)	41 (41.8)	232 (41.0)	164 (51.1)	2 920 (35.0)
3 500-4 499 g	605 (23.1)	633 (13.4)	26 (26.5)	144 (25.4)	87 (27.1)	1 495 (17.3)
≥ 4 500 g	85 (3.3)	76 (1.6)	1 (1.0)	21 (3.7)	11 (3.0)	194 (2.2)
GA						
< 32 weeks	401 (15.7)	1 565 (33.5)	13 (13.4)	86 (15.3)	24 (7.7)	2 089 (25.5)
32-36 weeks	441 (17.2)	982 (21.0)	18 (18.6)	87 (15.5)	34 (11.0)	1 562 (19.0)
≥ 37 weeks	1 720 (67.1)	2 125 (45.5)	66 (68.0)	389 (69.2)	252 (81.3)	4 552 (55.5)

※ Totals do not sum to 9 128 because of unknown values for CP type and birth weight (9.1%) or CP type and gestational age (8.9%).

Discussion & conclusions

Registers record details on children born with CP that other health/ medical records do not. They are invaluable sources of detailed information for the planning of services, monitoring trends in rates and characteristics of CP internationally. They are useful in the continuing search for etiologies and causal pathways of CP. The registers also provide a sampling frame for recruitment to various studies [4, 5]. According to Cans et al[6, 7] registers should never be an endpoint in themselves, but rather serve as a useful resource to the community, children with CP and their families. Use of the Reference & Training Manual and the recommended data collection form maximizes input from expertise across a variety of disciplines. The way forward for CP registers is to continue to collect comprehensive data from multiple sources using variables common to CP registers worldwide.

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