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The prevalence of mental retardation: a critical review of recent literature

Mental retardation (MR) is a serious and lifelong disability that places heavy demands on society and the health system. Since the first publication on this topic¹, the prevalence of MR has been thoroughly studied for different purposes. Most prevalence studies are designed for the planning of services and establish an 'ascertained' prevalence rate, which is the number of cases officially recorded by the authorities². The 'true' prevalence rate is the total number of mentally retarded people in a population, whether or not they require services, and is defined by the prevalence of MR at birth and the mortality rate. For mild mental retardation (MMR, IQ 50-70) the true prevalence rate is more difficult to estimate than for severe mental retardation (SMR, IQ <50). Very often ascertained prevalence rates are mistaken for true prevalence rates. Moreover, the estimates of both rates are influenced by the design of the study, the assessment criteria used, and the method applied for the identification of cases³⁻⁸.

As a result, differences in prevalence rates might partly reflect the true variation over populations and partly reveal discrepancies between studies and in the interpretation of the prevalence measure used. For instance, different frequencies are yielded by uses of the organic, psychological and social WHO criteria, which are reflected in impairment, disability and handicap⁹. The prevalence rates observed range from two to 85 per 1000. According to the WHO, the true prevalence rate of total MR in industrialised countries comes close to 3%¹⁰, but in the United States controversy exists over whether the rate is 1% versus 3%^{5,7,10,11}, whereas the Scandinavian countries claim that the 1% figure is their true prevalence^{9,12,13}.

The aim of this annotation is to establish valid estimates of the true prevalence rates for SMR and MMR in children of school age and to elucidate the variation in prevalence rates. Therefore the methodology of prevalence studies performed since 1960 was critically evaluated and a distinction was made between ascertained and true prevalence estimates.

Methods of selection

A computerised literature search was conducted on MEDLINE regarding publications from 1981 to 1995, using the keywords 'MR' and 'occurrence'. Only a few original articles and reviews were found; most papers were traced through references listed in these reviews^{6,7,14-17} and by browsing through relevant journals. Thirteen papers were unobtainable and 31 studies were excluded in accordance with the following criteria: 1) the study was restricted to institutionalised cases; 2) the population size was not given; 3) the age group studied exceeded the age range 5-19 years (school age) and no age structure was specified; 4) the IQ levels studied were not specified; 5) MR could not be distinguished from other disabilities. If rates for a specific population were described more than once, only the most recent publication was selected. As a result, 43 original articles were included in this review. These are summarised in Table I,¹⁸⁻⁵⁶ with the exception of four studies performed in developing countries. The validity of the studies was evaluated by: 1) the aim of the study (planning of services versus research purposes); 2) the prevalence rate estimated (ascertained versus true prevalence); 3) the method of case ascertainment (registers, other sources such as schools and agencies for the mentally retard-

Table I: Short description of selected studies on the prevalence of mental retardation

Ref	Author and year of publication	Year of study	Country and specification	Method of case ascertainment	Validity (+, good; -, poor)	Extra information	Size of study population	Age (years)	SMR per 1000	MMR per 1000
18	Goodman and Tizard (1962)	1960	England, Middlesex	Local registers + other sources	SMR +	"True" SMR (ascertained SMR)	297100	5-14	3.3 (2.8)*	-
19	Kushlick	1961	England, Salford	Regional register	SMR ± MMR -		38750	5-19	2.6	×
20	Birch et al. (1970)	1962	Scotland, Aberdeen	Local register + school IQ test	SMR + MMR +	Cohort 1952-54 MMR IQ 50-75 (ascertained MMR)	8274	8-10	3.7	23.7 (8.9*)
21	Drillen et al. (1966)	1962-64	Scotland, Edinburgh	Local registers + schools	SMR + MMR -	Cohort 1950-56 (ascertained MMR)	39498	7-14	4.9	5.3*)
22	Sedly and MacKay (1964)	1963	Northern Ireland	National register	SMR ± MMR -	Years 1953-62	358850	5-19	3.7	×

Table I: Continued

Ref	Author and year of publication	Year of study	Country and specification	Method of case ascertainment	Validity (+, good; -, poor)	Extra information	Size of study population	Age (years)	SMR per 1000	MMR per 1000
23	Brask (1972)	1963	Denmark, Aarhus county	National register	SMR±	(ascertained MMR SMR IQ < 52)	35183	5 14	3.3	3.2)*
24	Akesson (1967)	1964	Sweden, islands; high emigration	Local register + survey	SMR+		4937	0 20	4.4	
25	Rutter et al. (1970)	1964	England, Isle of Wight	Screening by school IQ test	Total MR+	Cohort 1953-55 MMR = MR 3.8	2334	9 11		21.5
26	Sorel (1972)	1966	Netherlands, Amsterdam	Local registers + agencies	SMR+ MMR±	MMR IQ 50-70	11970	10 13	7.3	8.9
27	McDonald (1973)	1966-69	Canada, Quebec	All possible sources	SMR+	Cohort 1958	141500	8 12	3.8	
28	Lemkau and Imre (1969)	1968	United States, southeast	Household survey + IQ test	Total MR+	MMR = MR 3.8	5170	6 19		79.3
29	Wallin (1975)	1969	Sweden, urban community	Local register + survey	SMR+	SMR IQ < 52	±8350	5 19	4.2	
30	MacKay (1971)	1969	Northern Ireland	National register	SMR± MMR-		±375500	5 19	4.1	×
31	Granat and Granat (1973)	1970	Sweden (male population)	Examination for military service	Total MR+	MMR = MR 3.8 (ascertained MMR)	2000	19		18.3 3.4)*
32	Gould (1976)	1970-71	England, London area	Local register	SMR+		23500	5 14	4.0	
33	Bernsen (1976)	1970-75	Denmark, Aarhus county	National register + other sources	SMR+		31457	5 14	3.9	
34	Reynolds (1976)	1972	Australia, Queensland	Regional register	SMR±	SMR IQ < 55	396200	5 16	3.4	
35	Laxona et al. (1977)	1972-74	England, Hertfordshire	Regional register + services	SMR+	Cohort 1965-67	46960	7 9	3.1	
36	Stein et al. (1967)	1974	Netherlands (male population)	Examination for military service	SMR+ MMR+	Cohort 1944-47 MMR IQ 50-75 (schools for MMR)	408015	19	3.7	57.6 30.5)*
38	Frost (1977)	1974-75	Ireland, west	Regional register	SMR± MMR-	Cohort 1956-70 (ascertained MMR)	60361	7 10	3.8	5.9)*
39	Gustavson et al. (1977)	1975	Sweden, south	National register + services	SMR+	Cohort 1959-70	16779	11 16	2.8	
40	Gustavson et al. (1977)	1975-76	Sweden, north	National register + services	SMR+	Cohort 1959-70	40871	5 16	3.5	
42	Blomquist et al. (1981)	1975-79	Sweden, north	National register + services	MMR±	Cohort 1957-58 (cohort 1959-70)	40871	19 8 19		12.0 3.8)*
43	Hagberg et al. (1987)	1984	Sweden, Gothenburg	National register + services	SMR+ MMR±	Cohort 1966-70	23544	14 18	3.3	3.9
44	Mitchell and Woodthorpe (1981)	1978-80	England, London	Local register + services	SMR+ MMR-	Cohort 1958-63	56140	15 20	3.6	×
45	Kääriäinen, (1987)	1978-81	Finland, Kuopio Province	Screening by school IQ tests	SMR+ MMR±	Cohort 1969-72 SMR IQ < 56 (registered MMR)	12882	7 9	6.3	7.5 0.7)*
46	Elliott et al. (1981)	1980	England, Oxfordshire	Regional register + survey	SMR+		81401	5 14	4.1	
47	Elwood and Darragh (1981)	1980	Northern Ireland	Regional registers + services	SMR±	Cohort 1961-69	298433	11 19	3.6	
48	McQueen et al. (1986)	1980	Canada, Maritime region	School records + agencies	SMR+	Cohort 1969-72 SMR IQ < 56	84109	7 10	3.7	
49	Rantakallio and von Wendt (1985, 1986)	1980-81	Finland, north	Hospital records + questionnaires	SMR+ MMR±	Cohort 1966	11766	14	6.3	5.6
51	McDermott (1994)	1980-81	USA, South Carolina	School records (mandatory)	SMR+ MMR+	Children of school age	616713		4.4	37.4
52	Shiotsuki et al. (1984)	1981	Japan, urban area	Institute + school records	SMR+ MMR-	Cohort 1969-74	21622	7 12	4.9	×
53	Díaz-Fernández (1988)	1983	Spain, Galicia	Regional registers	SMR+ MMR-	Years 1965-82	652671	5 19	3.9	×
54	Wellesley et al. (1992)	1984	Australia, west	State register + agencies	SMR+ MMR-	Cohort 1967-76 SMR IQ < 55	210789	6	3.9	×
55	Murphy et al. (1995)	1985-87	USA, Atlanta, metropolitan	School records + other sources	SMR+ MMR±	(ascertained MMR)	89534	10	3.6	
56	Benassi et al. (1990)	1986	Italy, Bologna	School records + services	SMR+		24494	6 13	3.4	8.4)*

Key: *, underestimated prevalence rate; -, SMR or MMR figure not reported; x, total MR or MMR figure unreliable.

ed, population surveys); 4) the clinical and/or psychometric research performed to classify cases into grades of MR (in accordance with IQ level).

For SMR, register-based case ascertainment followed by the re-evaluation of IQ levels was considered sufficient to render reliable figures for the prevalence.⁶ As most registers are virtually complete for SMR, the ascertained prevalence rates can be interpreted as estimates of the true prevalence rate. The precision of the prevalence estimates is expressed by the 95% confidence intervals (CI) in Figure 1. The average SMR prevalence rate was calculated by using the inverse variance of the rates as a weighting factor.

The prevalence rates of MMR are judged to be valid only in studies in which register-based case ascertainment was supplemented with additional research, or a population survey was performed, including extended psychometric and diagnostic evaluation⁸. In three studies, only the overall MR prevalence rates were given, but the rates for MMR were calculated by subtracting the average SMR prevalence rate^{25,28,31}. The ascertained prevalence rates of MMR were considered to be underestimates of the true prevalence rate. These rates were therefore not included in the calculation of the average MMR prevalence rate and are presented separately in Figure 3.

Concerning the quality of the material, several authors stated that it is difficult to find two single studies that are comparable in methodology^{3,7,8,14}. The selection criteria described above increased the comparability of the studies considerably but differences still remained (Table I), for instance in the upper IQ limits^{20,24,29,34,37,45,48,54}. In some studies the method of case ascertainment was definitely more thorough than in others^{20,25,28,31,36,37}. As the ascertainment of cases is best in children of school age up to 19 years old, the age range was confined to ages 5 to 19, on the basis of recalculation of the prevalence rates from 14 studies while

omitting the age-specific rates for the youngest and older age groups. A substantial variation in age range was left, however. Table I also shows a huge variation in population size, which is reflected in the 95% confidence intervals of the prevalence rates in Figures 1 and 3.

Prevalence of SMR

As shown in Figure 1, the prevalence rate for SMR in children of school age is relatively stable, varying around an average value of 3.8 per 1000. This agrees well with the SMR prevalence rates mentioned in studies conducted before 1960 and with the WHO, which considers a rate of 3 to 4 per 1000 to be a good estimate of the true SMR prevalence rate in Western countries^{9,57}. Markedly higher rates were observed in only five studies, owing to a better method of case ascertainment^{21,26,45,49,52}.

Comprehensive reviews have been written by Fryers¹⁴ and Dupont⁵⁸ on the dynamics of the prevalence of MR, revealing patterns of temporal change. In Figure 1 no time trend is observed for SMR, but Figure 2 clearly shows that the prevalence rate for SMR is age dependent. The age-specific rates show an increasing prevalence up to the age of 15, which indicates that SMR is not fully assessed in the first few years of life. This is a reflection of the way in which developmentally disabled children become known to service providers and can be traced through schools^{5,7,16,57,58}. The decreasing prevalence rates in the older age groups can be explained by a higher than average mortality among the severely mentally retarded and by flaws in registers and research methods.

Gender-specific rates were presented in approximately half of the studies. For SMR the male-to-female ratio is remarkably constant and indicates a 20% excess of males, probably due to sex-linked genetic factors. Obvious geographical differences were not observed. Only a few studies mentioned higher rates in rural compared with urban areas.

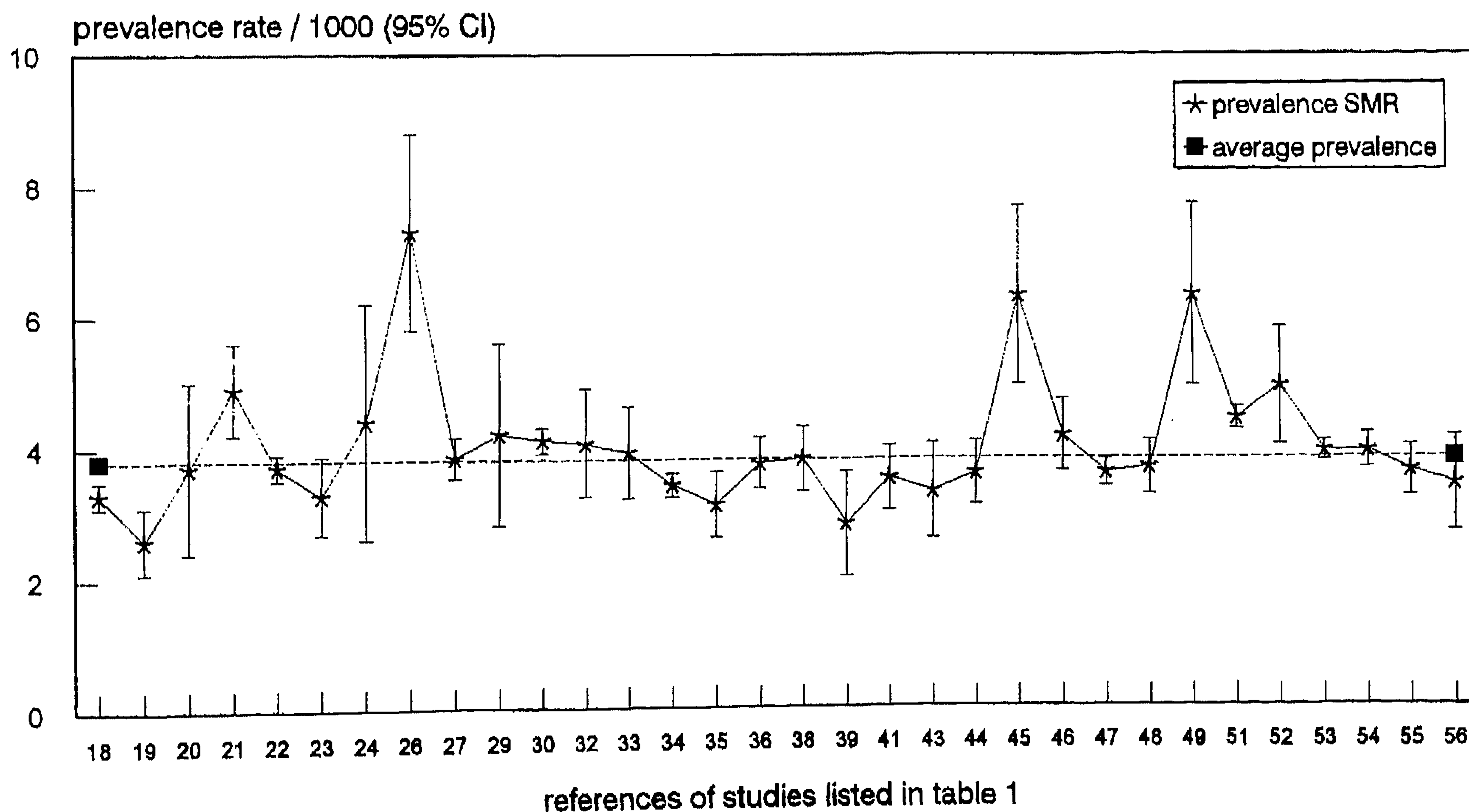


Figure 1: Prevalence of SMR in children of school age (chronological order 1960-87).

These differences were explained by a higher maternal age in the country, selective migration, religious affiliation, a high degree of endogamy, endemic meningitis and poor antenatal, perinatal and postnatal care^{24,34,36,54,59}.

Apparently there is little variation between populations concerning the prevalence of SMR. This indicates that the aetiological process of SMR is not influenced greatly by exogenous factors.

Prevalence of MMR

The prevalence figures for MMR exceed those for the severely retarded and the variation in rates is enormous (Figure 3). It is not clear whether this is a reflection of the non-comparability of studies or of real differences between populations. The identification of cases is virtually complete in the lower IQ ranges, but as long as children with an IQ of less than 70 are able to cope with the school system they will not become known to the authorities. Although the identification of

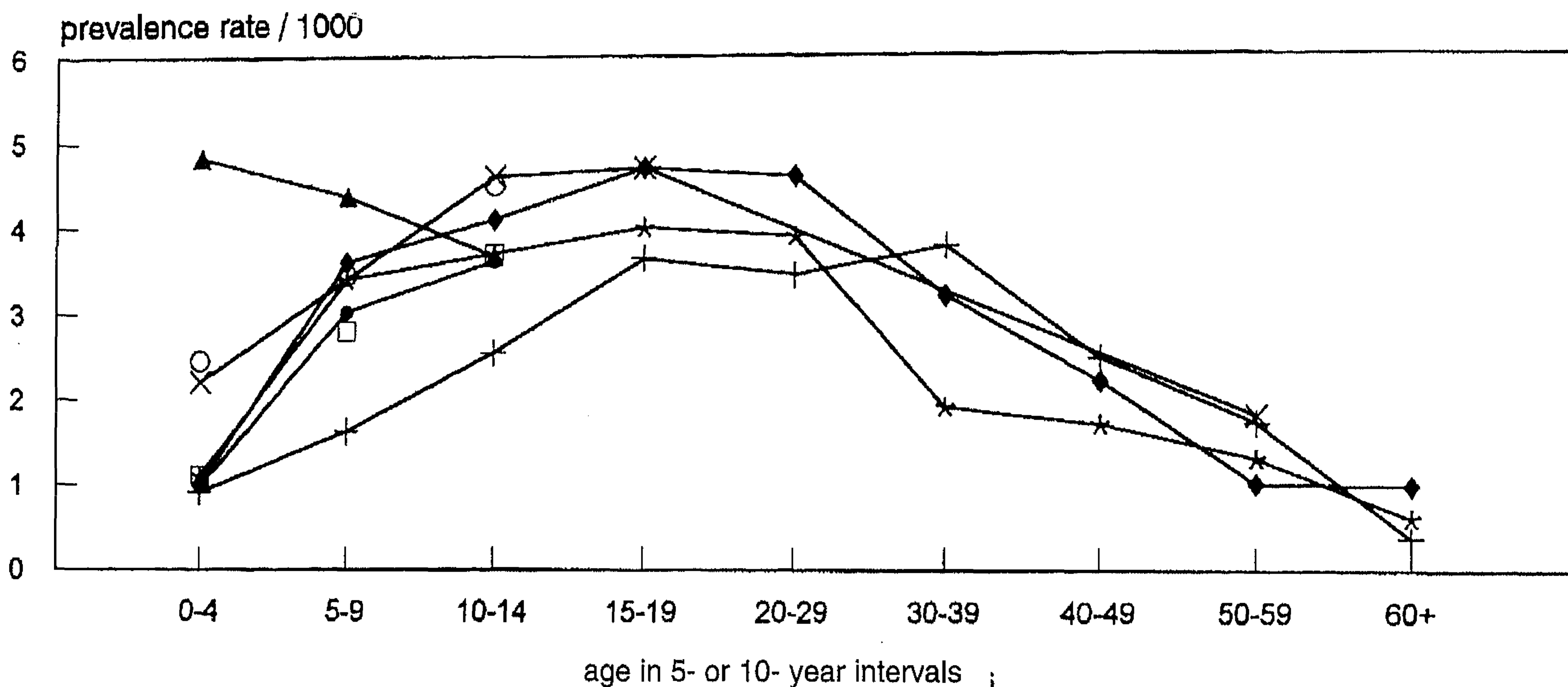


Figure 2: Age-specific prevalence rates of SMR: ●, Goodman and Tizard¹⁸; +, Kushlick¹⁹; *, Scally and MacKay²²; □, Brask²¹; x, Wallin²⁹; ◆, MacKay³⁰; ▲, Gould³²; ○, Bernsen³³.

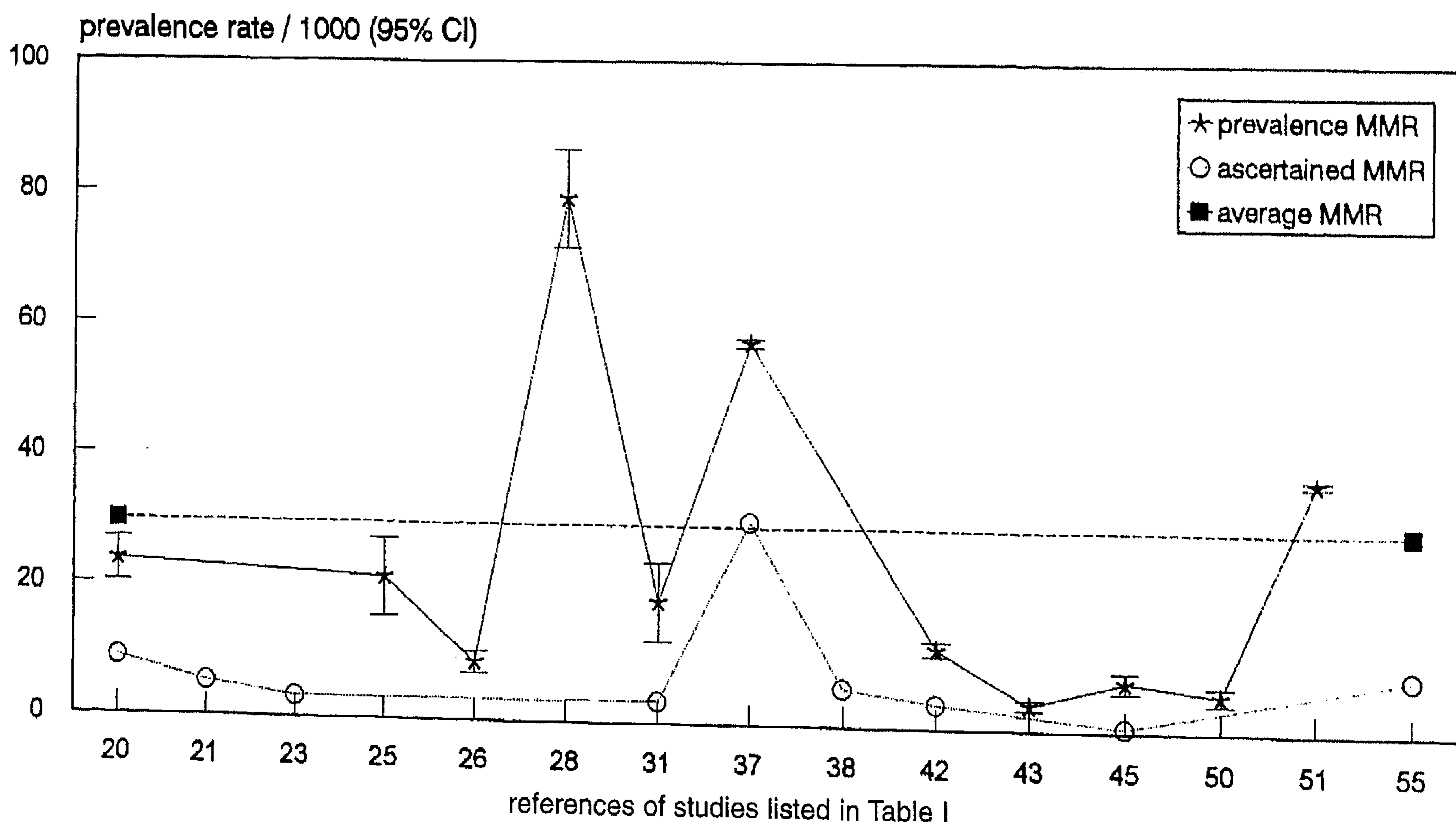


Figure 3: Prevalence of MMR in children of school age (chronological order 1962-87).

MMR is most pronounced at school age^{7,8,16}, complete assessment cannot be achieved before maturity. Therefore register-based case ascertainment, particularly in the younger age groups, leads to a gross underestimation of the true MMR prevalence rate.

This was clearly shown in five studies in which true and ascertained prevalence rates were compared^{20,31,37,42,45}. As the rates presented by Sorel²⁶, Hagberg et al.⁴³, Kääriäinen⁴⁵ and Rantakallio and von Wendt⁵⁰ have not been assessed by population surveys and fall into the range of ascertained prevalence rates, it is very likely that these rates underestimate the true MMR prevalence rate as well. However, these lower rates might also reflect the influences of improved environments and increased mean IQs in those populations^{13,43,60}. In contrast, Lemkau and Imre²⁸ and Stein et al.³⁷ found extraordinarily high MMR prevalence rates in profound screening of the population with individual IQ tests. Over-reporting could be the case here. The former study was conducted in a low socioeconomic area, with little stimulation to perform well in IQ testing. In Stein's study on 19-year-old males it is not unlikely that some tried to be labelled mentally retarded (IQ <75) in an attempt to escape military service. The high ascertained prevalence rate in this study was due to referral to special schools at an IQ of less than 80. All other ascertained MMR prevalence rates varied around 5 per 1000 children.

Because of the wide range of prevalence rates and the above-mentioned methodological problems, the calculation of a reliable average MMR prevalence rate was virtually impossible. Excluding the ascertained prevalence rates, a tentative 'true' average prevalence rate for MMR in children of school age was calculated to be 29.8 per 1000. This value agrees well with the 3% figure for overall MR given by the

WHO^{4,9} and with Penrose's theoretical value of 2.3% for children in the IQ range 50-70.⁶¹

Some studies presented useful male-to-female ratios for MMR, ranging from a 40% excess of males in the Netherlands²⁶ to an 80% excess in Sweden^{12,42}. This might reflect a difference in registration and case ascertainment or a greater susceptibility of the male central nervous system^{3,6,7,17}. Stein et al.³⁷ found a higher ascertained prevalence rate for MMR in urban areas, whereas the application of an IQ test revealed an excess of MMR cases in rural and mixed areas. Better access to special schools or the higher demands placed on children living in cities might explain this discrepancy.

A striking association was found between MMR and social class, race and/or parental occupation^{6-9,16,20,51,60,62-66}. The American Association on Mental Deficiency (AAMD) even stated that in poor rural areas and urban ghettos, 10-30% of children of school age function in the retarded range.⁵ The higher rates in the lower socioeconomic classes might be due to poor living conditions, migration, cultural difficulties, poor intellectual stimulation and the absence of reluctance against labelling children as mentally retarded. Therefore an improvement of the social environment might lead to a decline in MMR prevalence rates^{51,60,62}. It should be noted, however, that specific aetiological factors might prevail in the lower social classes, such as endemic diseases, deficiencies, intoxications, suboptimal obstetric care and parental occupations with exposure to chemical agents and radiation. These external factors might explain part of the variation in the prevalence rates of MMR.

Prevalence of MR in developing countries

Estimating the true prevalence rates of MR in developing

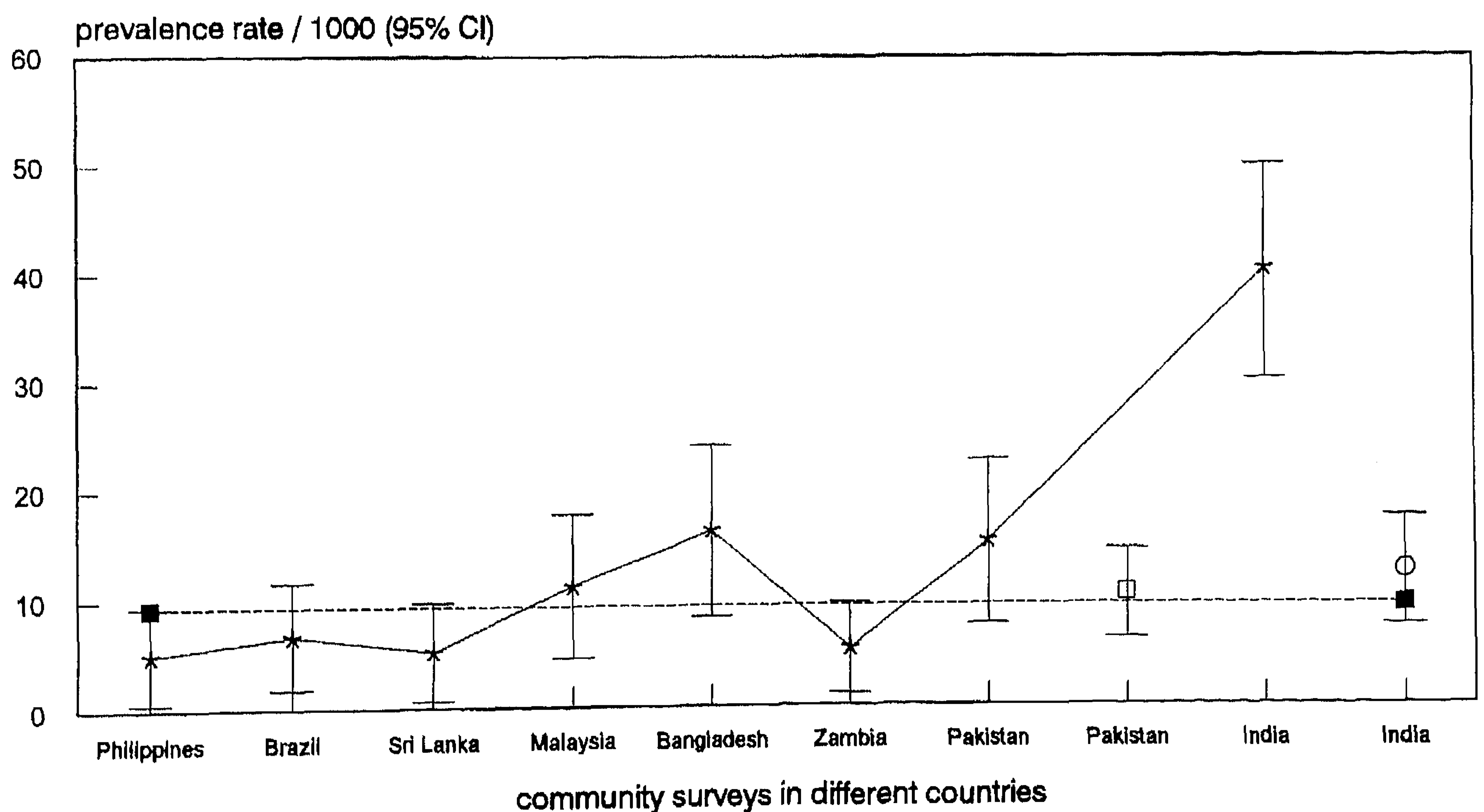


Figure 4: Prevalence of SMR in children; community surveys in eight developing countries: *, rate, Stein et al.⁶⁸; □, rate, Hasan and Hasan⁶⁹; ○, rate, Narayanan⁶⁷; ■, average prevalence.

countries is more complex than in the Western world. Registers are not available or are extremely incomplete, and population surveys also pose a lot of problems. In cities the mobility of the population is usually high and many languages are spoken. Rural communities are often characterised by a large proportion of illiterate inhabitants, the non-existence of birth registers and a lack of cooperation⁶⁷. In these less demanding communities a large percentage of MMR may go unrecognised. However, the use of IQ tests can lead to extremely high prevalence estimates because the tests are often far from adequate for non-Western populations^{4,5,9}. This can result in underestimation or overestimation of the true prevalence rates for MR.

In Figure 4 the SMR prevalence rates (IQ 55 or less) from population surveys in eight developing countries are presented⁶⁸. The rates for children 3 to 9 years old in rural communities with approximately 1000 inhabitants varied between 5 and 16 per 1000, with the exception of India, where a rate of 40 per 1000 was found. Narayanan⁶⁷ and Hasan and Hasan⁶⁹ reported similar SMR prevalence rates. Therefore the average prevalence rate for SMR in developing countries was calculated to be 9.3 per 1000, which is 2.5 times higher than the average rate in Western countries. This rate might be artificially elevated or it might be explained by a higher prevalence of SMR at birth or postnatally due to, for instance, malnutrition, consanguinity, infections and inadequate perinatal care. The AAMD⁵ and the WHO⁹ suggested that a high prevalence rate at birth will be counterbalanced by a relatively high mortality among mentally retarded children, resulting in SMR prevalence rates similar to those in the Western world. On the available evidence this does not seem to be so.

Stein et al.⁷⁰ also reported prevalence rates for MMR from the eight community surveys, which ranged from 4 per 1000 in the Philippines to 138 per 1000 in Bangladesh. Hasan and Hasan⁶⁹ found an MMR prevalence rate of 28 per 1000 for children aged 0 to 10 years in Pakistan and 92 per 1000 for 11 to 20-year-olds. In an Indian survey an overall MR prevalence rate (IQ <80) of 10.4 per 1000 was found for children under 14 years of age⁷¹. This is a very low figure compared with the SMR rates found in India^{67,68}.

Because of the extremely large variation in prevalence rates and the high probability of methodological problems, it cannot be concluded that the prevalence rates reported for SMR and MMR represent true prevalence rates for MR in developing countries. Nevertheless they point in the direction of partly preventable exogenous influences.

Conclusions

The literature study for this annotation revealed an enormous gap in our knowledge about MR. Many studies are hampered by imperfections in study methodology, and valid estimates of prevalence rates are scarce. There seems to be a strong need for standardisation of definitions and research methods in this area. Moreover, insight in the variability of the IQ distribution over time and between populations would greatly enhance the interpretation of the prevalence rates found. The SMR prevalence rates seem to centre on the 'true' average value of 3.8 per 1000, but the range in MMR prevalence rates is too large to allow valid conclusions. However, there is enough reason to presume that, even today, approximately 3% of children of school age are mentally retarded, of which a considerable proportion could have been prevented. A

change in attitude towards the causative background of MR is justified and ought to constitute a challenge to a more active preventive approach¹³. Possibilities for the prevention of SMR are marginal, but the prevalence of MMR could be reduced by improving the biological and psychosocial environment.

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