

Acknowledgements. Baseline data collection in this study was funded by grants provided by the Trustees of the Fletcher Challenge Welfare Fund, the National Heart Foundation of New Zealand and the Health Research Council of New Zealand. The important role of all the study nurses who participated in the collection of data for this project is gratefully acknowledged, as is the support of Fletcher Challenge Group management at the workplaces at which the study was performed. The help of Kathy Bos in the preparation of this manuscript and the study questionnaire is also acknowledged. The authors are grateful to Dennis Reilly from Diagnostic Lab and to Charles Small and Sue Trotman from Green Lane Hospital department of biochemistry for their assistance in the processing and storage of blood samples.

Members of the Study Management Committee. John Bloom (to August 1993) Jane Boyd, Jacinta Calverley (from August 1993), Rod Jackson, Rob Keen (to August 1993), Gary Key, Robyn Langley, Mary-Jean Mackie (to November 1993), Robyn Norton, Stephen MacMahon, Ron Stone, David Thomas.

Correspondence. Associate Professor Stephen MacMahon, Clinical Trials Research Unit, Department of Medicine, University of Auckland School of Medicine, Private Bag 92019, Auckland 1.

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IN PRACTICE

The prevalence of fetal alcohol syndrome in New Zealand

Alison M Laversha, MB ChB, Paediatric Registrar, Rosemary E Marks, FRACP, Developmental Paediatrician
Starship Children's Health, Auckland.

Abstract

Aims. To obtain an estimate of the prevalence of fetal alcohol syndrome in New Zealand and to report information on paediatrician surveillance for alcohol related birth defects.

Methods. New Zealand paediatricians were asked to complete a postal survey. Questions recorded the number of children with alcohol related birth defects under their care, and examined the respondents' surveillance for alcohol related birth defects.

Results. There were 63 children under 10 years of age with fetal alcohol syndrome under paediatric care in 1993. The majority of paediatricians considered the diagnosis only when risk features were identified: the most frequent being children of high risk mothers and children with dysmorphic features.

Conclusions. Fetal alcohol syndrome exists in New Zealand.

Zealand. The prevalence of fetal alcohol syndrome as estimated in this study is lower than would be expected from international prevalence reports and is likely to be an underestimate. Current surveillance for alcohol related birth defects depends on an individual paediatrician considering the diagnosis only when faced with a perceived at risk infant or child, and there is likely under recognition. An increased awareness of the risks of alcohol consumption in pregnancy and the full spectrum of alcohol related birth defects is required.

NZ Med J 1995; 108: 502-5

bring forth children like unto themselves, morose and languid".¹ However, it was not until 1973 that the specific constellation of findings in fetal alcohol syndrome was described² and the adverse effects of alcohol were recognised by the medical community. It is now clear that the effects of alcohol exposure to the developing fetus exist on a continuum from very subtle to very extreme abnormalities.³ At the severe end of this spectrum is fetal alcohol syndrome, a specific birth defect comprising mental retardation, prenatal and postnatal growth retardation, and classical facial features (Figure 1) (Table 1).³⁻⁶ Fetal alcohol syndrome is recognised as one of the leading causes of mental retardation in the western world.^{7,8} At the mild end of the spectrum are children with a developmental and behavioural disorder, who lack the growth retardation and classical facial features of fetal alcohol syndrome, but who have a history of prenatal alcohol exposure. These children have previously been referred to as having fetal alcohol effects, however the term alcohol related birth defects encompassing the whole spectrum is now preferred.

Table 1. - Diagnostic criteria for fetal alcohol syndrome.

1. Prenatal and/or postnatal growth retardation weight and/or height <10th centile
 2. CNS involvement
 - neurological abnormality
 - developmental delay
 - behavioural dysfunction or deficit
 - intellectual impairment
 - structural abnormalities, eg, microcephaly
 - or brain malformations found on imaging studies or autopsy
 3. Characteristic facial features
 - short palpebral fissures
 - elongated midface
 - long and flattened philtrum
 - thin upper lip
 - flattened maxilla
- Abnormalities in all three categories are required to secure the diagnosis of fetal alcohol syndrome. A relationship to prenatal alcohol exposure should be sought but is not necessary for the diagnosis.

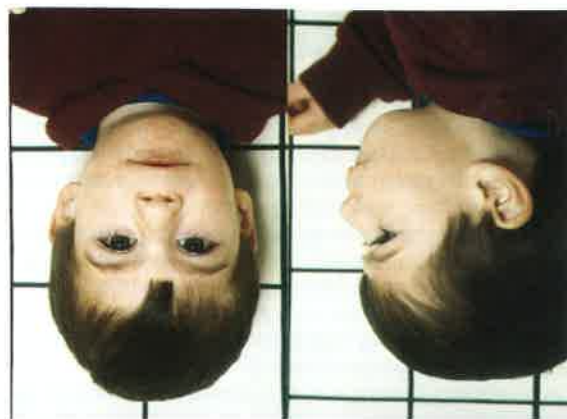


Figure 1. - Child with fetal alcohol syndrome (Age 2 years 11 months). Note the elongated midface, long and flattened philtrum, thin upper lip, and flattened maxilla. (The guardians of this boy have given written permission for these photographs to appear without alteration).

Studies from North America and Europe have reported the incidence of fetal alcohol syndrome as 0.33-5.9 per 1000 live births.^{7,8} Based on these overseas statistics one could predict between 20 and 354 children with fetal alcohol syndrome are born each year in New Zealand. However, to date there have been no reported cases and there are no available statistics on the prevalence of fetal alcohol syndrome in New Zealand.

Results

Response rate. One hundred and twenty-four of the 137 questionnaires were returned, ie, a response rate of 91%. Twelve were returned blank (5 paediatricians on sabbatical and 7 retired) thus leaving 112 questionnaires for analysis.

Prevalence of fetal alcohol syndrome. Sixty-three cases of definite fetal alcohol syndrome less than 10 years of age were under paediatric care in New Zealand in 1993. This reported prevalence of fetal alcohol syndrome is at best 30% of the predicted rate using overseas estimates. The children with fetal alcohol syndrome were cared for by 36 paediatricians with the majority reporting having only one affected child under their care. Ten paediatricians had two cases whilst only two had three cases. Less than one third of the respondents were able to provide date of birth or initials of the index cases.

An additional 78 children with fetal alcohol syndrome had been assessed but were no longer under paediatric care. These children have not been included in the prevalence data as we were unable to cross reference former cases. Including the children with the more subtle defects, there was a total of 130 children with recognised alcohol related birth defects under paediatric care in 1993. These children were under the follow up of 48 paediatricians.

Surveillance for alcohol related birth defects. Eighty-one percent of paediatricians had seen a child with alcohol related birth defects at some stage during their training or clinical practice, however less than one third had actually made the diagnosis.

Surveillance for alcohol related birth defects varied; only 13 paediatricians (11.6%) actively looked for the diagnosis at each consultation, and four paediatricians reported they never considered the diagnosis. Paediatricians caring for children with fetal alcohol syndrome were more likely to look

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The accuracy of the information obtained will depend on the accuracy of the paediatricians' reporting. Although most paediatricians were able to provide the number of affected children under their care at the time of the survey, less than one third were clear as to the exact number and details. Very few paediatricians were able to report how many children had been under their care in the past but were no longer receiving paediatric follow up. Many as a reason for being unable to provide accurate data, this study clearly has limitations with regard to its accuracy of numbers due to the above factors. However, at present there is no better way of trying to provide an estimate of the prevalence of fetal alcohol syndrome in New Zealand. Fetal alcohol syndrome and alcohol related birth defects are not notifiable conditions, and there is no national database. Monitoring for alcohol related birth defects via a national database of birth defects is recommended to provide accurate data on the incidence, to identify the extent of the problem, and to guide future resource planning.

Current surveillance for alcohol related birth defects depends on an individual paediatrician considering the diagnosis when faced with a perceived at risk infant or child. The most common clinical feature that prompted New Zealand paediatricians to consider the diagnosis of alcohol related birth defects was having a high risk mother. For this study a high risk mother was not specifically defined and the paediatricians responded according to their own opinion about what constitutes high risk. It is well established that children of alcohol dependent women are at high risk of alcohol related birth defects, however, the risks associated with lower levels of alcohol consumption and binge drinking are uncertain.³ Therefore, accurate maternal drinking histories should be recorded for every child who is being assessed for neurodevelopmental problems, growth retardation or dysmorphic features.

The presence of dysmorphic features is one of the most frequent clinical features that prompted paediatricians to consider the diagnosis of alcohol related birth defects. However, the characteristic craniofacial malformations of fetal alcohol syndrome diminish with time and it is often more difficult to diagnose fetal alcohol syndrome, in older children and adolescents.¹² In addition, children with more subtle forms of alcohol related birth defects have few or no characteristic dysmorphic features.^{3,12} If one relies on dysmorphic features as a key clinical feature, one is less likely to diagnose children at this end of the spectrum. This concept is confirmed in the current study where the group of paediatricians who placed the most emphasis on dysmorphic features were the group least likely to have children with the more subtle forms of alcohol related birth defects under their care. In contrast, paediatricians who placed relatively less emphasis on dysmorphic features and relatively greater emphasis on learning, behavioural and growth disturbances, were more likely to have children with subtle abnormalities under their care. Paediatricians' experience and exposure to alcohol related birth defects clearly affects the threshold for consideration of the diagnosis. It is surprising 19% of paediatricians reported they had never seen a child with alcohol related birth defects when the condition is likely to occur at least as often as Down's syndrome or cystic fibrosis (National Testing Centre, personal communication). This suggests under recognition and under diagnosis of the condition.

Although the diagnostic criteria for fetal alcohol syndrome are clear (Table 1),⁶ the diagnosis is elusive to many clinicians as the signs are not specific to alcohol exposure and there are no confirming laboratory tests. The neonatal period is one of the most difficult times to recognise alcohol related birth defects as the markers of the central nervous system dysfunction are sparse, and facial features may be obscured by facial oedema.¹³ Failure to recognise fetal alcohol syndrome and alcohol related birth defects is well documented in overseas studies.¹³ Australian researchers have commented on the clinical

routinely for the diagnosis than those not (17% vs 8%), as were paediatricians caring for children with alcohol related birth defects (14.6% vs 9.4%). The majority of paediatricians considered the diagnosis of alcohol related birth defects only when certain clinical features were identified, the most frequent being children of high risk mothers and children with dysmorphic features (Figure 2). Paediatricians caring for affected children (either fetal alcohol syndrome or alcohol related birth defects) were more likely to consider the diagnosis when assessing children with all clinical features, with the exception of intrauterine growth retardation than paediatricians with no affected children under their care. Paediatricians caring for children with the more subtle forms of alcohol related birth defects were more likely to consider the diagnosis when assessing a child with learning difficulties, behavioural problems, and failure to thrive, than those caring for children with the classical signs of fetal alcohol syndrome.

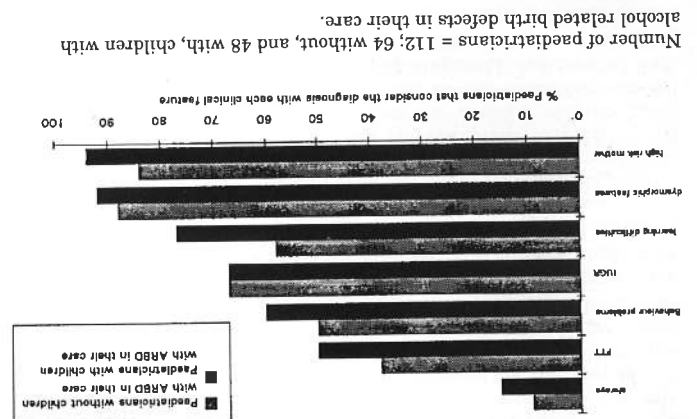


Figure 2. - Clinical features that prompt paediatricians to look for alcohol related birth defects.

In 1993, 63 children less than 10 years of age with recognised fetal alcohol syndrome were under paediatric care in New Zealand. Based on overseas estimates and an annual birth rate of 60 000, one would predict the number to be much higher: 200-3540.^{7,8} The reasons for this apparent discrepancy are unclear, however, several factors may be involved.

Eighty percent of New Zealand women drink alcohol, and 12% do so daily.⁹ Although women usually decrease their alcohol consumption during pregnancy, 41.6% of women continue to drink alcohol while pregnant, and 18.7% report drinking more than once a week.¹⁰ These figures are consistent with overseas rates of alcohol consumption,¹¹ thus it is unlikely the lower reported prevalence is due to different levels of maternal drinking. There is also no reason to suspect that New Zealand women and their fetuses are genetically less susceptible to the adverse effects of alcohol than their Australian, British or American counterparts. These points suggest the apparently lower prevalence rate is due to other reasons.

Prevalence figures obtained using this sampling method will be an underestimate as not all children with fetal alcohol syndrome will be under paediatric care. However, as affected children have multiple problems with growth, development, learning and behaviour, one would expect the majority to be under paediatric care or have been assessed by a paediatrician at some stage. Even when considering the children with recognised fetal alcohol syndrome who had seen a paediatrician in the past, but were no longer under paediatric follow up, the reported rate is still much lower than the predicted rate. The prevalence of children with alcohol related birth defects has not been calculated as it is likely to be a gross underestimate. Children with the more subtle forms of alcohol related birth defects have learning or behavioural problems, and it is likely that many are never assessed by a paediatrician and so would not be included in this sampling method.

A community's attitudes towards the mentally ill

Sonya L Ng, BSc, Research Fellow; Judith L Martin, MA, Research Fellow; Sarah E Romans, MD, FRANZCP, Professor, Department of Psychological Medicine, University of Otago, Dunedin.

underdiagnosis, referring to alcohol related birth defects as the "great paediatric imitator" implying true alcohol related birth defects may often be diagnosed as another condition for which the symptoms are similar.¹⁴ In addition, there may be a reluctance to formally label an affected child. In a recent survey in the United States, 56% of paediatricians reported having suspected fetal alcohol syndrome at one time but not formally diagnosing it.¹⁵ An additional 9% were convinced of the diagnosis but did not record it. These attitudes in part reflect societies view on alcohol consumption and in particular the stigma attached to a diagnosis of alcohol related health problems.

In conclusion fetal alcohol syndrome exists in New Zealand. The reported prevalence is likely to be an underestimate. More accurate data is needed to identify the extent of the problem in New Zealand. Current surveillance depends on an individual paediatrician considering the diagnosis when faced with a perceived at risk infant or child and there is likely under recognition. Doctors need to consider the diagnosis of alcohol related birth defects whenever they are faced with a child with neurodevelopmental problems, growth retardation or dysmorphic features, and need to enquire routinely about maternal alcohol consumption during pregnancy. An increased awareness of the adverse effects of alcohol consumption on the developing fetus is required in order to detect the full spectrum of alcohol related birth defects.

- Acknowledgements.** We wish to thank the paediatricians involved in this study for their participation and support.
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factors associated with discriminatory attitudes and behaviour towards the mentally ill. At what point is the odd behaviour of a person accepted as normal, or seen as reflecting mental illness and requiring professional help? Forty years ago, after a 6 year long study into the public attitudes towards mental illness, Nunnally and his associates² observed that the mentally ill were 'regarded with fear, distrust, and dislike' as well as having the undesirable traits of 'dangerousness, being dirty, unpredictable and worthless'; a statement that is often quoted today.

When Green and her colleagues³ reviewed several New Zealand studies in 1987 with a similar methodology, they concluded that attitudes towards people with mental illnesses had not significantly changed over a period of 22 years.

These studies illustrate research that portrays a disheartening picture of the community's acceptance of the mentally ill. However, two physicians Lemkau and Crockett⁴ disagreed. These authors in 1962 described the public as being 'fairly well informed' and expressing understanding and tolerance. An optimistic outlook as this one, stimulated a series of studies from the disciplines of sociology, psychology, psychiatry and nursing. Sociologists and social psychologists view mental illness as one form of deviance defined by society. By contrast, the professions of psychiatry and nursing are concerned with the impact of community attitudes on the prognosis of mental illness.

Also disheartening are studies showing a lack of significant improvement in public attitudes over time. From a reevaluation of 22 studies from 1954-77, Brockman and his colleagues⁵ noted how the positive optimism of mental health researchers contrasted with more negative conclusions reached by social scientists. Many of the inconsistencies in reported findings can be explained by the methodological differences, particularly by the use of different instruments to measure attitudes and by the different conceptual frameworks used in each discipline.

Aim. To assess the general community's knowledge of mental illness and personal experience of people with mental illness.

Method. Three hundred randomly selected Dunedin residents were surveyed by a postal questionnaire. The instruments used to measure attitudes towards mental illness (CAMI scale)⁶ and a social distance scale. In addition, questions were asked about the respondents age, gender, marital status, level of education, their main source of opinion, their experience with the mentally ill, and their beliefs about the causes and types of mental illness.

Results. Having known a person with mental illness facilitates more intimate relationships with people with a mental illness. Sociodemographic variables did not predict attitudes on the CAMI scale. Most respondents who had been in contact with the mentally ill held informed and enlightened views.

Conclusion. The community needs and welcomes information on the subject of mental illness and has a positive outlook for the future planning of the rehabilitation of people with mental illness.

The management of the mentally ill has changed radically over the last 50 years. The development of modern psychopharmacology and the growing awareness of the detrimental effects of institutionalisation has resulted in policies designed to encourage people with mental illness to live independently in the community. Often the plans for the relocation of psychiatric services are met with public opposition. People with mental illnesses, the primary users of these services, are regarded as a threat to the neighbourhood. Such deinstitutionalisation has prompted a number of investigations both overseas and in New Zealand to identify