



Establishing a twin register in Sri Lanka

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Nearly all twin registers are based in developed countries and there is no twin register in the developing world. Our objectives were to initiate the process of establishing a nationwide twin register in Sri Lanka by starting a volunteer register first and working towards a population-based register. Regular newspaper advertisements, feature articles, radio talks, and television programmes were used to publicise a competition for twins, their parents/relatives and friends requesting them to participate by sending in details of twins. The competition ran from 28 March 1997 for a period of 3 months. It offered prizes for three winners selected by drawing lots. Advertisements highlighted the objective of the competition as establishing a twin register for future research and emphasised that informed consent would be obtained for individual research projects. Those who registered comprise 4602 twin pairs (same sex: male – 1564, female – 1885; different sex – 1153), 80 sets of triplets (same sex: male – 17, female – 31; different sex – 42) and two sets of quadruplets (different sex). The oldest twins, triplets, quadruplets are 85, 46, and 5 years old, respectively; 88.0% of twins are less than 30 years old. Although others have previously used media publicity to enrol twins in twin registers, we believe this to be the first time that twins have been enrolled through competition. We have more young twins, and our gender and zygosity proportions after applying Weinburg's rule do not match the proportions expected from a volunteer twin sample. Establishing a twin register for research purposes has proved possible in a developing country. *Twin Research* (2000) 3, 202–204.

Keywords: volunteer register, competition for twins, newspaper advertisements, Weinberg differential method

Introduction

There is a global divide in health research. 'Although more than 90% of the world's potential years of life loss belong to the developing world, only 5% of global research funds are devoted to studying the developing world's health problems. High quality collaborative research conducted in developing countries can provide evidence of relevance and value to the developed world'.¹

As an advanced and powerful research tool, the 'twin method' can contribute to the understanding of genetic, environmental and developmental influence on human variation and disease, thereby helping prevention and treatment of diseases. Twin studies

can also provide a base for using comparable measures in illness traits and to examine cross-cultural differences. Whenever genetic and environmental variation occurs across cultures, collaborative twin studies will further increase our understanding of human variation and disease.

Nearly all twin registers have been based in highly industrialised developed countries. Consequently, the research carried out was largely in white populations.² We decided to look into the feasibility of establishing a volunteer twin registry with a view to expanding it into a population-based registry.

Sri Lanka is an island situated close to the southern tip of the Indian sub-continent with a land area of 65 654 square kilometres. The estimated mid-year population in 1997 was 18.6 million with a growth rate of 1.3%.³ Sri Lanka, has considerable genetic diversity due to the contribution of ancestors and immigrants of European and Asian origin.⁴ In this report we describe the process and outcome of establishing a volunteer twin register in Sri Lanka.

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Methods

To establish the volunteer register, we launched a campaign through the media to recruit twins. Regular advertisements in Sinhala and English in the national newspapers (once a month for three months), feature articles, radio talks, and television programmes were used to publicise a competition. The competition was to encourage registration of twins in the registry. The twins, their parents, relatives and friends were requested to participate by sending in details of twins. The twins themselves (if over the age of 16 years) or their parents (if twins were under 16 years) were asked to complete a form included in the advertisement, containing their names, gender, date of birth, and the address of the twins. They were also asked to send a copy of the twins' birth certificates. The competition ran from 28/3/97 for a period of three months. It offered prizes for three twin pairs who had registered during the competition, selected by drawing lots. Advertisements highlighted the objective of the competition as establishing a twin register for future research. The advertisements made clear that joining the register did not imply consent to any further studies. Consent will be sought individually for each study.

Ethical clearance for this project was obtained from the local ethics committees of the Faculty of Medicine, Colombo and the Institute of Psychiatry, University of London.

Results

The breakdown of the number of twins and of higher multiple births is shown in Table 1. Breakdown of twins by age is shown in Table 2. The oldest twins, triplets and quadruplets are 85, 46, and 5 years old respectively; 88.0% of twins are less than 30 years old although 55.37% of the population is in this age group.

Discussion

Although others have previously used publicity in the mass media^{6,7} to enrol twins for twin registers, we believe this to be first time that twins have been

Table 1 Total number of twins and higher births according to gender in the Sri Lankan Twin Registry

	Twin	Triplets	Quadruplets
Same sex – male	1564	17	
Same sex – females	1885	31	
Different sex	1153	42	02
Total	4602	90	02

Table 2 Breakdown of twins by age in the Sri Lankan Twin Registry

Age	Twins		Each group as a percentage of Sri Lankan population
	No.	%	
0–09	1795	39.0	17.65
10–19	1425	30.96	20.35
20–29	830	18.04	17.37
30–39	327	7.11	15.38
40–49	133	2.89	12.33
50–59	59	1.28	7.90
60–69	25	0.54	5.28
70–79	07	0.13	2.86
≥ 80	01	0.02	0.87

enrolled through a competition. The entries were mainly from younger twins. This may have been due to the word 'twin' generating a mental image of a younger age. Ascertainment bias is a recognised problem with volunteer twin samples. However, to our knowledge, ascertainment of younger twins is not a recognised bias in volunteer samples. Therefore we decided to explore further by comparing recognised features of the volunteer twin samples with those in our competition.

Studies conducted among twin volunteers show a consistent excess of females and monozygotic twins in a ratio of 2:1.⁸ This means that a volunteer sample of adult same-sex twins consists of about two-thirds females (rule 1) and two-thirds MZ pairs (rule 2). This 'rule of two-thirds' is amply illustrated in studies done between 1928 and 1977.⁹ However in a population-based sample, of same-sex twin pairs who survive the first year of life, about 50% are male, and 46–51% of each sex will be MZ.¹⁰ Therefore in an adult population-based twin registry one should expect to find equal numbers of male and female MZ and DZ pairs. Hence the ratio between MZF: MZM: DZF: DZM: should be 1:1:1:1. However, because of the two-thirds rule one will obtain MZ female, DZ female, MZ male and DZ male pairs in the approximate proportions 4:2:2:1 in a volunteer sample instead of 1:1:1:1 expected from a population-based sample.

When we applied the second rule of two-thirds to the same-sex twins in our volunteer sample the ratios between MZF, MZM, DZF and DZM pairs were 2.4:2.0:1.2:1 (MZ females 1257: MZ males 1043: DZ females 628: DZ males 521). Our gender and zygosity proportions do not match the proportions expected from a volunteer twin sample, ie 4:2:2:1. However, we cannot draw any further conclusions from this finding – even if we apply the 'first rule of two-thirds', a female-to-male ratio of 2:1 is not evident. The estimate of gender ratio in the Sri Lankan twin register of same sex females to same sex males was 1.21:1. (same sex females 1885, same sex males 1564).

Once we had recruited the initial volunteers, we tested the feasibility of using these twins for specific research projects. We selected three different random samples and invited them for different tasks in the adaptation and validation of the zygosity questionnaire. All the twins and family members who were invited agreed to participate.

With the success of the initiation of the volunteer registry, we are now considering the feasibility of using different approaches for recruiting twins to establish a population-based register in Sri Lanka. Population-based twin studies have a number of advantages over volunteer registers in reducing bias and improving generalisability of results. However, population-based registers are rare outside Scandinavia and North America and this will be the only one in a developing country. Because Sri Lanka has 98.8% completeness of birth registrations,³ tracing twins through birth records is a possibility. However, because of migration within and outside the country due to continuing internal conflict, tracing twins through birth records may be difficult. House-to-house survey may be more suitable but is expensive in terms of resources.

We also intend to encourage international collaboration for cross-cultural comparisons and to expand the local resources in this field in terms of training, skills and equipment. We aim to develop local expertise in the areas such as methodology on twin research, statistical genetics, genetic epidemiology, molecular genetics, population genetics, developmental psychology and social sciences. We will also extend our efforts to try and establish laboratory facilities for genetic aspects of twin research.

In conclusion, establishing a twin register for research purposes is feasible in a developing country. It will open up many opportunities for valuable research in Sri Lanka.

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