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Short Report

Willingness to donate blood samples for genetic research: a survey from a community in Singapore

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Studies on the public's willingness to donate blood specimens for genetic research are few and are conducted mainly among Western countries. Little is known about the Asian community's willingness to participate in genetic research. A community-based survey was conducted on 548 adult Singaporeans to examine their willingness to donate blood samples for genetic research and its associated factors. The response rate was 70.3%. About 49.3% (95% CI, 45.1–53.5%) were willing to donate blood for genetic research. In the multivariable Cox regression analysis, willingness was significantly associated with belief in the benefits of genetic research; intention to participate in government studies; having no fear of pain, blood, injections, and needles; and non-concern about the loss of confidentiality. Reasons against donating blood were fear of pain, blood, injections, and needles (38.1%); no self-benefits (24.8%); fear of finding out about having a disease (22.3%); fear of discrimination (18.7%); and concerns about weakness (15.1%) and weight gain (9.4%). Public education programs to promote participation in genetic research should stress its benefits and address people's fears and concerns.

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The success of genetic studies depends on the public's willingness to donate blood for genetic research. Studies carried out mainly among Western populations (1–10) reported a high level of willingness to donate blood specimens or have them stored for future research or genetic testing. Those who believed that genetics determine a person's health more than environment or behavior, and that genetic research prevents future disease; and those who indicated their intention to participate in government research were significantly more willing to donate blood specimens. The general population was also more willing to participate in research on physical medical or mental illnesses as opposed to stereotypical or potentially stigmatizing traits such as homosexuality and frugality (9). Other associated factors included white race, higher education, and a positive family history of a genetic disorder (7–10).

There is paucity of data on the attitudes and willingness of Asians, regarding the donation and storage of blood specimens for genetic research. Studies in Japan (11–13) have examined the individual's willingness to donate residual or additional blood for medical research in situations when blood samples have already been taken for check-up examinations, but they did not look into the individual's willingness to donate blood specifically for genetic research. Hence, we conducted a survey among the general population in Singapore to determine their willingness to donate blood specimens for genetic research and to assess factors associated with their willingness.

Methods

Singapore's population of 3.26 million is comprised mainly of Chinese (77.8%) followed by

Malays (14.0%) and Indians (7.9%) (14). A central constituency was selected for our survey because of its mixed ethnic distribution and varied socio-economic status. A random sample of 780 individuals was drawn from an electoral register of 6841 voters from this area. This sample size was needed to determine a prevalence (of willingness to give blood) of 55% with a maximum acceptable difference of 5% between sample and true prevalence (margin of error), at the 95% confidence level. A non-response rate of 52% was factored in the estimation of the sample size. The estimated prevalence and non-response rate were derived from an earlier pilot study carried out on a random sample of 40 persons from the same area. Trained medical students conducted the household interviews over 1 week in February 2002, using a structured questionnaire translated into local languages.

Questionnaire design

To ensure the cultural relevance of the questions, focus group sessions were conducted separately with three groups of seven participants each to explore their views and concerns about giving blood samples for genetic research. We purposively selected participants of varying ages and educational levels from the three main ethnic groups (Chinese, Indians, and Malays) in the study area so that a broad representation of views would be obtained. The group moderator first presented a hypothetical scenario requesting participants to donate blood specimens for genetic research. She then asked each group the same open-ended questions on their concerns and reasons, regarding their willingness to donate blood specimens for genetic research or have them stored for future research. These findings, together with some questions from previous research (2, 6–9), were used in our questionnaire.

The dependent variable was willingness to donate blood for genetic research. The following hypothetical scenario was presented to simulate the key message that will be used to recruit Singaporeans for genetic research: 'Singapore plans to carry out a research study in the community to find out more about how genes affect a person's chances of getting diseases such as cancer and heart disease. We hope to find a cure for these diseases, as they are the top killers in Singapore.' The respondent was asked to indicate his willingness to give 20 cm^3 of blood (equivalent to two tablespoons), for genetic research using a 5-point Likert scale ranging from strongly disagree to strongly agree. A pictorial representation of the scale, using flash cards, was presented to the respondents. We did not ask participants about giving mouthwash samples, as the use of alcohol in mouthwash would be culturally unacceptable to Malay Muslims. As only about half of the respondents in our pilot study have heard about genes, the meaning of a gene was explained in simple terms as something in our body that is passed down from one generation to another, for example, people from the same family 'inheriting' some diseases. It was further explained that genes make one person different from another, for example, the color of our eyes. Genetic test was explained as a test that provided information about a person's chance of getting a disease.

Independent variables that were studied with regard to the public's willingness to donate blood specimens for genetic research included sociodemographic characteristics; self-reported personal and family history of chronic illnesses such as diabetes, hypertension, heart disease, stroke, and cancer; and attitudinal characteristics. Type of housing was used as an indicator of economic status, as most respondents from our pilot study were reluctant to report their household income. The majority (88%) of Singaporeans lived in public high-rise apartments comprising one to five rooms (14). The lower income groups usually lived in apartments with one to two rooms.

Independent variables derived and adapted from literature review (6, 7) included the following statements. Respondents were asked to rate their agreement on a 5-point Likert scale ranging from strongly disagree to strongly agree to the statement 'People will benefit greatly from advances in genetic research and genetic testing'. Awareness of genetic testing was assessed by whether they have heard of it. They were also asked whether they would participate in research organized by the government.

Independent variables derived from our focus groups included the following:

Concerns about giving blood.
The most commonly cited concerns about giving blood for genetic research identified from our focus groups were fear of pain, injections, needles, and blood; concern about the loss of confidentiality and being too sick to give blood. These were incorporated into the questionnaire and rated on a 5-point Likert scale. Self-perceived health was rated as poor, fair, or good.

Respondents were asked to give a 'yes' or 'no' response to each item in a list of reasons (identified from focus groups) for and against their willingness to donate blood for genetic research.

Statistical analysis

We categorized the 'willingness' response of agree or strongly agree as willing, and all other responses: strongly disagree, disagree, and neither

agree nor disagree as not willing. The association of willingness with sociodemographic and other attitudinal and behavioral factors were determined by comparing proportions and prevalence ratios. χ^2-tests were performed to compare proportions in willingness to donate blood for independent nominal variables and χ^2 trend for independent categorical variables ranked on an ordinal scale (15).

To identify factors significantly associated with willingness to donate blood specimens after controlling for potential confounders, multivariable analysis, using a modification of Cox proportional hazards regression model (16, 17) for cross-sectional data was used. All independent sociodemographic, attitudinal, and behavioral variables with a level of statistical significance of 0.1 or less in univariate analysis (Table 1) were entered into the regression model with willingness to donate blood as the dependent dichotomous variable (yes *vs* no). This multivariable statistical analysis yields the adjusted prevalence ratios of willingness to give blood by independent variables, simultaneously adjusted for all other confounding variables included in the regression analysis. Although statistical adjustment for confounding in the comparison of proportions derived from a dichotomous-dependent variable is usually carried out by multiple logistic regression, this method has a drawback, particularly in cross-sectional studies, in that it yields the odds ratio as a measure of association. The odds ratio is less interpretable, and it only approximates the rate ratio well provided the dependent variable is a rare event (18) As willingness to donate blood is not a rare event in our study, we needed a model that can directly estimate the prevalence ratio, yet allow for adjustment of confounding. Breslow (19) has shown that by assuming constant risk period, namely the 'persons at risk' cohort, the conditional hazard ratio estimated by Cox model is equal to the cumulative incidence ratio. Thus, by assuming a constant risk or time to event period, the Cox model can be adapted to estimate prevalence ratios for cross-sectional data (17). The adjusted prevalence ratios of willingness and the 95% CI were calculated based on the estimated coefficients from the regression model. All tests were two-tailed, and $p < 0.05$ were considered significant. All data analyses were performed with use of the Statistical Package for Social Science (SPSS), version 11.0 (SPSS, Chicago, IL, USA).

Results

Characteristics of sample

The response rate was 70.3% (548 of 708); 19.2% refused to respond; and 10.5% were not contactable after three attempts. Respondents were similar to non-respondents with regard to race, gender, or housing type. The majority were Chinese (86.9%), with the others being Malay or Indian. About half (43.8%) were males, and the median age was 45 years (range 21–91 years). The majority (70%) had received more than six years of formal schooling with 16.6% having attained tertiary education.

Awareness of genes and genetic testing

Slightly more than two-thirds (69.3%) have heard of genes, and about half (47.8%) have heard of genetic tests. Those with tertiary education were significantly more likely to have heard of genetic tests compared to those with no education (43.5% *vs* 1.1%, $p < 0.001$). Of those who have heard about genes, the majority felt that lifestyles (66.3%) were the most important causes of heart diseases and cancer; smaller proportions believed in genes (18.9%) and fate (12.6%) as the most important causes.

Willingness to donate blood by sociodemographic and other variables

About 49.3% (95% CI, 45.1–53.5%) of the respondents were willing to donate blood specimens for genetic research, and 39.2% (95% CI, 35.1–43.3%) among them were willing to have their blood stored for future research. Among willing donors only, the majority (80.4%) were willing to have their blood stored for research.

Table 1 summarizes the univariate analysis of willingness to donate blood for research by sociodemographic, attitudinal, and behavioral characteristics. Respondents who were non-Chinese, resided in better housing and who had a family history of chronic illnesses were significantly more willing to donate blood for genetic research. Willingness did not differ significantly by gender, marital status, educational level, age, and personal medical history. Willingness to donate blood samples increased significantly with better self-perceived health status; awareness of genetic testing; increasing belief in benefit on genetic research; decreasing fear of pain, blood, injections, and needles; decreasing concern about the loss of confidentiality; and intention to participate in government organized studies on health. The findings were similar when we analyzed willingness to have blood stored for research by the same independent variables (not summarized in Table).

Multivariable analysis

After controlling for confounders, the variables that remained significantly associated with willingness to donate blood samples for genetic

Table 1. Percentage who are willing to donate blood for genetic research according to sociodemographic, attitudinal, and behavioral factors, 2002

Independent variable	% willing to donate blood	Number	p value
Race			
Chinese	47.1	224/476	
Non-Chinese[a]	63.9	46/72	<0.01
Gender			
Female	46.8	144/308	
Male	52.5	126/240	0.182
Marital status			
Single	49.7	75/151	
Married	49.7	180/362	
Divorced/separated/widowed	45.5	15/33	0.894[b]
Educational level (years of schooling)			
None	35.7	15/42	
1–6	51.2	62/121	
>6	50.1	193/385	0.335[b]
Housing type			
One to two rooms	33.3	6/18	
Three to four rooms	47.1	179/380	
Five rooms and executive flats	57.4	85/148	<0.05[b]
Age group			
21–39	47.2	94/199	
40–59	48.9	110/225	
≥60	53.2	66/124	0.571[b]
Personal history of chronic illness[c]			
No	49.9	211/423	
Yes	47.2	59/125	0.612
Family history of chronic illness[c]			
No	42.1	118/280	
Yes	56.7	152/268	0.001
Self-perceived health status			
Poor	36.0	9/25	
Fair	41.8	81/194	
Good	54.7	180/329	<0.01[b]
Heard of genetic test			
No	44.4	127/286	
Yes	69.4	143/262	<0.05
Genes are more important than lifestyle and environment in causing disease[d]			
No	48.3	207/429	
Yes	55.2	53/96	0.218
I believe people will benefit from genetic research			
Strongly disagree	14.3	1/7	
Disagree	25.0	7/28	
Neither agree or disagree	26.3	31/118	
Agree	52.7	119/226	
Strongly agree	67.9	112/165	<0.001[b]
I am afraid of pain, needles, injection, and blood			
Strongly disagree	62.9	127/202	
Disagree	52.5	63/120	
Neither agree or disagree	44.2	19/43	
Agree	39.3	35/89	
Strongly agree	28.6	26/91	<0.001[b]
I am concerned about the loss of confidentiality by donating blood for genetic research			
Strongly disagree	65.3	109/167	
Disagree	58.5	86/147	
Neither agree or disagree	30.1	31/103	
Agree	39.2	31/79	
Strongly agree	28.9	13/45	<0.001[b]
I would participate in government organized studies about health			
No	37.1	127/342	
Yes	69.4	143/206	<0.001

[a]Non-Chinese includes Malays and Indians.
[b]χ^2 trend.
[c]Chronic illnesses refer to diabetes, hypertension, heart disease, stroke, and cancer.
[d]Excludes 23 missing responses.

research were belief in the benefit of genetic research; fear of pain, needles, injections, and blood; concern about the loss of confidentiality; and intention to participate in government organized studies (Table 2). Those who were afraid of pain, needles, injections, and blood and those who were concerned about the loss of confidentiality were significantly less likely to express willingness to give blood specimens. Race, educational level, housing type, family history of chronic illness, self-perceived health status, and awareness of genetic testing were no longer associated with the participants' willingness to give blood. Similar findings were found when the analysis was restricted to Chinese participants only and after stratifying by prior awareness of genetic testing.

Reasons for and against donating blood

The most common reasons reported for willingness to give blood were for medical advancement (81.9%), to benefit future generations (81.1%), and to create employment in life science research (40.4%). Reasons given by those who were unwilling to donate blood specimens were fear of pain, needles, injections, and blood (38.1%); no self-benefits (24.8%); fear of finding out that they have a disease (22.3%); and fear of discrimination by employers and insurance companies (18.7%). A small but significant proportion of respondents were concerned about adverse effects on their health such as becoming weak (15.1%) or gaining weight (9.4%) from giving blood specimens. As only half have heard about genetic testing before this survey, the reasons were analyzed after stratifying by their prior awareness of genetic testing to assess whether it has an effect on their reported reasons. The two groups did not differ in their reasons except for the reason on discrimination. About 26.5% of those who had prior knowledge of genetic testing did not want to give blood because of the fear of discrimination compared to 13.3% ($p < 0.05$) of those without prior knowledge of genetic testing.

Incentives and preferences

About half (40.9%) of the unwilling donors reported their intention to give blood, if incentives were provided. Health-care-related incentives, such as free medical check-ups, and treatment as well as priority in receiving health care, were most preferred. Money was least preferred with less than 20% opting for this incentive. Significantly, more people would donate blood, if the research was conducted by the government (64.5%) compared to the university (47.4%) or a private organization (14.7%).

Discussion

About half of adult Singaporeans in the sample were willing to donate blood samples for genetic research. Willingness to give blood showed a significant independent association with those who believed that genetic research would benefit people; who had intention to participate in government organized studies; who were not afraid of pain, needles, injections, and blood; and who were not concerned about the loss of confidentiality. The level of willingness in our study was much lower than that in the USA (7–9) and Europe (10), which reported levels from 60 to more than 90%. It was also lower than that reported in a study among ethnic

Table 2. Independent predictors of willingness to donate blood for genetic research among 548 adult Singaporeans, 2002

	Dependent variable: willing to donate blood [a]Adjusted prevalence ratio	
Predictor	(95% C1)	p value
Sociodemographic characteristics		
Non-Chinese *vs* Chinese[b]	1.11 (0.79–1.56)	0.557
Had received formal schooling (yes *vs* no)	1.10 (0.63–1.93)	0.730
Five-room/executive *vs* one to four room apartments	0.99 (0.75–1.31)	0.973
Family history of chronic illness (yes *vs* no)	1.13 (0.88–1.46)	0.341
Self-perceived health status (good *vs* no good)	1.22 (0.93–1.60)	0.157
Heard of genetic test (yes *vs* no)	1.01 (0.78–1.31)	0.945
Attitudinal and behavioral characteristics		
Believed that genetic research will benefit people (yes *vs* no)	1.92 (1.34–2.76)	<0.001
Afraid of pain, injections, needles, and blood (yes *vs* no)	0.70 (0.53–0.92)	<0.01
Concerned that personal information will leak out (yes *vs* no)	0.70 (0.53–0.93)	<0.05
Would participate in government organized studies (yes *vs* no)	1.59 (1.17–1.93)	<0.005

[a]Adjusted for other variables in the table, using the multivariable Cox regression model modified for cross-sectional data.
[b]The referent group is Chinese. This means that non-Chinese are 1.11 times more willing to donate blood compared to the Chinese, but the difference is not statistically significant.

minorities in the USA, where 56% African Americans indicated their willingness to participate in medical research studies (20).

Our findings were similar to Wang's study (7), in that willingness was associated with intention to participate in government studies. Other significantly associated factors reported in our study such as concern about the loss of confidentiality and belief in the benefits of genetic research were also reported in studies among the general population in Finland (5) and the USA (4, 9). However, a significant factor and an important reason associated with decreased willingness to donate blood specimens for genetic research, found in our study but not reported in studies in the USA or Europe, was the fear of needles, injections, and blood. This was found to be quite widespread with about half (40.6%) of the respondents expressing this fear. As this finding was not reported in other studies, it is unclear whether this reason was not important or was not assessed, as it was not specific to genetic research. The fear of injections and needles was reported in a focus group study (21) among racial minorities – the African Americans in the USA, but the extent of this concern was not assessed. Other reasons for not participating in genetic research reported in our study but not in other studies were no self-benefits and cultural beliefs of becoming weak and gaining weight from giving blood. The lower level of willingness to participate in genetic research in our study compared to other countries may be explained by differences in the above-mentioned reasons and factors as well as differences in awareness of genetic research. More than two-thirds of the respondents in the study in the USA (4) have heard of genetic testing compared to less than half of our respondents. We cannot rule out other factors that were not included in our study such as the participants' exposure to media reporting of genetic research and their perceptions of the harmful effects of genetic research.

This study has some limitations. The non-response rate of 25% may introduce some bias in the findings. This bias, however, is unlikely to be gross, as respondents did not differ from non-respondents in race, gender, and housing type. The findings should not be extrapolated to the entire population in Singapore, as the sample was taken from one constituency. Nevertheless, it provided useful findings, as all three major ethnic groups in Singapore were represented in this area. This study assessed intention to participate in research and hence may not reflect actual participation, which may be lower. We were also not able to assess a more comprehensive list of factors or psychological barriers affecting the public's willingness to donate blood for genetic research, as a high proportion had not heard about genes, and some respondents had difficulty understanding the questions especially the different hypothetical scenarios in which blood samples would be taken. Another limitation is that all respondents were asked to indicate their willingness based on a simple explanation of gene and genetic tests. Thus, for those who had no prior knowledge of genetic tests, their responses to our questions were probably based on this simple explanation. It is likely that some respondents might not have been able to differentiate between donating blood samples for general medical research and genetic research. Hence, we have compared our study findings with studies on participation in general medical research as well (20, 21). We also analyzed factors associated with willingness among the group who have heard of genetic testing prior to our study and compared them with the group with no prior information on genetic testing. The findings from both groups were very similar. The strengths of our study were the relatively high-response rate compared to other studies (6, 9) and the cultural relevance of the questions. Questions on concerns and reasons about participating in genetic research were generated from focus groups to ensure their appropriateness to the local population studied.

In conclusion, this study has identified informational needs and concerns to be addressed in planning programs to promote community participation in genetic research. Like Western populations, concern about confidentiality and belief in the benefits of genetic research were factors associated with willingness to donate blood specimens for research. Other important reasons against donating blood specimens found in our study but not reported in studies in other countries included the fear of blood, injection, and needles; no self-benefits; and the misconceptions of falling sick and gaining weight from giving blood. Although these reasons are not specific to genetic research and would apply to any general medical research study, strategies to recruit the public for genetic research in Singapore would still need to address these immediate barriers first before attending to other concerns specific to genetic research. This is particularly so in Singapore, whereby an alternative source like alcohol-containing mouthwash to obtain genomic DNA samples is not culturally acceptable to the Muslims. As about half had not heard about genetic testing, public education should provide more information on genetics and genetic testing. Simple and relevant messages could be disseminated through the mass media and incorporated into the school curriculum. Dialogue sessions with community members should be held concurrently to address their concerns. The community could be encouraged

to participate in genetic research by stressing its benefits, assuring confidentiality of the information, allaying misconceptions, offering incentives such as free medical check-ups, and providing alternative means of getting samples such as buccal swabs and mouthwash. The latter, however, should only be offered to non-Muslims because of its alcohol content.

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