Comparing Knowledge and Attitudes Towards Genetic Testing in Parkinson's Disease in an American and Asian Population

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INTRODUCTION

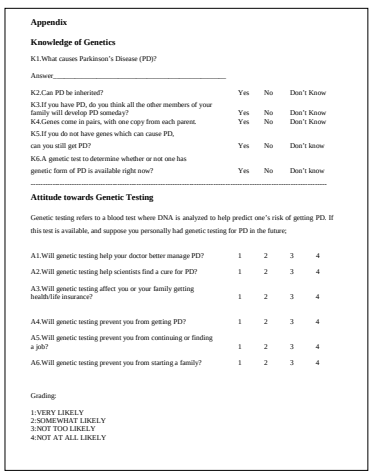
Recent discoveries of disease-causing genes in Parkinson's Disease (PD) have generated considerable interest regarding genetic testing in PD. Based on experience with hereditary cancers, the utilization of genetic testing by patients or asymptomatic subjects is largely influenced by knowledge and attitude towards testing. However, the exact relationship between knowledge and attitude has been debated. Prompted by the current paucity of information relating to attitudes towards genetic testing in PD and the increasing availability of genetic testing of this disease in both research and clinical setting, we conducted a study to evaluate the relationship between knowledge of PD genetics and attitude towards predictive genetic testing of PD in two independent centers in America and Asia involving PD patients and caregivers.

METHODS

This was a prospective study conducted concurrently at the movement disorders centers at Baylor College of Medicine, USA and Singapore General Hospital, Singapore. Patients diagnosed with idiopathic PD based on standardized criteria together with their caregivers and/or family members (all grouped as caregivers in this study) were included. A questionnaire survey on knowledge and attitudes towards genetics testing in PD was administered in the English language by a trained nurse or research assistant in a "face-to-face" interview. The demographics including age, gender, race, educational level, family history of PD and Hoehn & Yahr staging (for PD only) of all the study subjects were tabulated and analyzed.

Questionnaire

We utilized a 12-item questionnaire (6 items on genetic knowledge and 6 items on attitude towards genetic testing) The selection of the items on attitude towards testing was based on a preliminary survey on 50 of our PD patients and caregivers. These subjects have cited health effects, insurance and employment discrimination as their major concerns regarding genetic testing of PD. The first item in our knowledge section was an open ended and in the other five, choices of "agree", "disagree" and "don't know" were offered. Six items assessed attitude towards testing, with "agree" and "disagree" as choices.



Appendix

Knowledge of Genetics

K1.What causes Parkinson's Disease (PD)?

Answer_____

K2.Can PD be inherited? Yes No Don't Know

K3.If you have PD, do you think all the other members of your family will develop PD someday? Yes No Don't Know

K4.Genes come in pairs, with one copy from each parent. Yes No Don't Know

K5.If you do not have genes which can cause PD, can you still get PD? Yes No Don't know

K6.A genetic test to determine whether or not one has genetic form of PD is available right now? Yes No Don't know

Attitude towards Genetic Testing

Genetic testing refers to a blood test where DNA is analyzed to help predict one's risk of getting PD. If this test is available, and suppose you personally had genetic testing for PD in the future;

A1.Will genetic testing help your doctor better manage PD? 1 2 3 4

A2.Will genetic testing help scientists find a cure for PD? 1 2 3 4

A3.Will genetic testing affect you or your family getting health/life insurance? 1 2 3 4

A4.Will genetic testing prevent you from getting PD? 1 2 3 4

A5.Will genetic testing prevent you from continuing or finding a job? 1 2 3 4

A6.Will genetic testing prevent you from starting a family? 1 2 3 4

Grading:

1:VERY LIKELY
2:SOMEWHAT LIKELY
3:NOT TOO LIKELY
4:NOT AT ALL LIKELY

Table 1. Subject Demographics

Demographics			Singapore Study Group PD	Singapore Study Group Caregivers	USA Study Group PD	USA Study Group Caregiver s
Age	20-30	Count	-	15	-	5
		%	-	11.5	-	5.3
	31-40	Count	2	26	-	10
		%	1.1	20.0	-	10.5
	41-50	Count	20	41	11	23
		%	10.7	31.5	10.7	24.2
	51-60	Count	76	38	33	15
		%	40.6	29.2	32.0	15.8
	61-70	Count	50	5	37	28
		%	26.7	3.8	35.9	29.5
	71-80	Count	39	5	18	14
		%	20.9	3.8	17.5	14.7
	81-90	Count	-	-	4	-
		%	-	-	3.9	-
		Mean SD	61.3 10.1	45.5 10.0	62.8 9.8	55.4 14.7
Gender	Female	Count	127	78	37	69
		%	67.9	60.0	35.9	72.6
	Male	Count	60	52	66	26
		%	32.1	40.0	64.1	27.4
Education *	Primary / no education	Count	9	6	-	-
		%	4.8	4.6	-	-
	less than high school	Count	45	8	1	-
		%	24.1	6.2	1.0	-
	high school and above	Count	133	116	102	95
		%	71.1	89.2	99.0	100.0
Race for USA	Asian	Count	-	-	3	1
		%	-	-	2.9	1.1
	African-American	Count	-	-	-	5
		%	-	-	-	5.3
	Caucasian	Count	-	-	92	75
		%	-	-	89.3	78.9
	Hispanic	Count	-	-	8	14
		%	-	-	7.8	14.7
Race for Singapore	Chinese	Count	181	126	-	-
		%	97%	97%	-	-

* Education level significantly higher in USA study subjects than in Singapore study subjects, p < 0.00005

Statistical Analysis

Descriptive statistics, tabulation and univariate tests were done separately for the two study groups of PD and caregivers. The proportion of correct answers for items in the knowledge of genetics domain was calculated and tabulated. Responses for knowledge questions were categorized as correct or incorrect. "Don't know" was categorized as incorrect. Additionally, a total score was computed for overall knowledge by summing up the number of correct answers for questions 2 to 6 in that domain. Question 1 was not included in the calculation of the summative score as its answer was open-ended and not definite. A dichotomous variable was created for overall knowledge by classifying respondents with 3 or more correct answers as high knowledge and those with 2 or less correct answers as low knowledge. Similarly, dichotomous variables were created for each attitude item by categorizing a positive response as positive attitude and a negative response as negative attitude. Positive attitude consisted of "Very Likely" and "Somewhat Likely" for attitude items 1, 2 and 4 but for attitude items 3, 5 and 6, it consisted of "Not too likely" and "Unlikely". Association between knowledge and attitudes about genetic testing was assessed using chi-square test for dichotomous variables.

Separate multivariate tests using stepwise logistic regression to assess the effect of high/low knowledge on the outcome of each individual attitude, adjusting for demographics of age, gender, study group (PD or caregivers) and education were carried out. The variable entry and exit criteria for the model were $p < 0.05$ and $p > 0.10$, respectively. Data analysis was done using SPSS for Windows 10.0. All p-values were 2-sided and statistical significance was taken at $p < 0.05$.

RESULTS

A total of 545 subjects were initially screened for the study, out of which 515 comprising of 290 PD (187 from Singapore, 103 from USA) and 225 care givers (130 from Singapore and 95 from USA) satisfied the inclusion criteria and agreed to participate. The participation rate was 100% and 96.8% in the USA and Asian center, respectively. The age distribution in both the American and Asian cohort was similar (Table 1) and the mean age of PD in both centers was 62.8 ± 9.8 and 60.0 ± 14.7 years.

Assessment of Knowledge

American PD patients had higher knowledge of PD genetics than Asian PD (31.1% vs 12.3%, p=0.0002), and this was consistently observed for every item in the knowledge category (p value ranged from 0.0002 to <0.00005) (Table 2).

Assessment of attitude towards genetic testing

A greater number of American PD patients reported a positive attitude towards the potential medical benefits of genetic testing (help doctor to better manage PD and scientist to find a cure) compared to Asian PD (85.4% vs 42.2%, 92.2% vs 32.1%, p<0.00005). However, American PD were more likely to have a more negative attitude towards potential compromise in getting health and life insurance (43.7% vs 25.8%, p=0.0002). Similarly American caregivers generally also reported a more positive attitude towards potential medical benefits of genetic testing compared to their Asian counterparts (p<0.00005).

FIGURE 1. Knowledge of PD: Singapore Pts/Caregivers, USA Pts/Caregivers

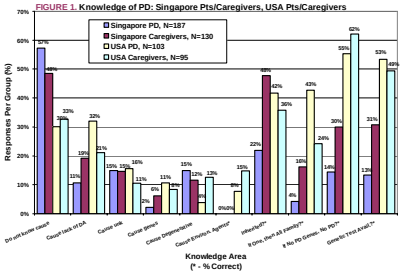


Table 2. Knowledge about genetic testing for PD.

Knowledge		Singapore Survey group PD N=187	Singapore Survey group Caregivers N=130	USA Survey group PD N=103	USA Survey group Caregivers N=95	Comparison Of knowledge between Singapore PD and USA PD (p-value)
K1:What is the cause of PD?	Do not know	107 57.2	63 48.5	31 30.1	31 32.6	
	Lack of dopamine	20 10.7	25 19.2	33 32.0	20 21.1	
	Unknown causes	28 15.0	19.0 14.6	16 15.5	10 10.5	< 0.00005 *
	Genetics	4 2.1	8 6.2	11 10.7	8 8.4	
	Degenerative	28 15.0	15 11.5	4 3.9	12 12.6	
	Environment agents	- -	- -	8 7.8	14 14.7	
K2:Can PD be inherited?	No. of correct answers	41	62	43	34	
	% correct	21.9	47.7	41.7	35.8	<0.0005 *
K3. If you have PD, all the other family members will develop PD someday?	No. of correct answers	8	21	44	23	
	% correct	4.3	16.2	42.7	24.2	< 0.00005 *
K4. Genes come in pairs, with one copy from each parent?	No. of correct answers	27	39	57	59	
	% correct	14.4	30.0	55.3	62.1	< 0.00005 *
K5. If you do not have genes which cause PD, can you still get PD?	No. of correct answers	25	40	55	47	
	% correct	13.4	30.8	53.4	49.5	< 0.00005 *
K6. A genetic test for PD is available right now?	No. of correct answers	24	44	32	28	
	% correct	12.8	33.8	31.1	29.5	0.0002 *
High Knowledge (>= 3 correct)	No.	23	36	32	28	
	%	12.3	27.7	31.1	29.5	0.0002 *

* Significantly higher rate of correct answers for knowledge by USA PD subjects as compared to Singapore PD subjects.

Univariate analysis correlating level of knowledge and attitude towards genetic testing

Amongst the Asian cohort, univariate analysis demonstrated that a statistically significant correlation between high knowledge of genetics with a positive attitude towards potential medical benefits of testing (help in management, prevention and finding a cure) but a negative attitude towards insurance and employment discrimination and starting a family. Amongst the American cohort, there was no significant correlation between level of PD genetic knowledge and attitude towards genetic testing. For those with high knowledge, the questions that produced the most negative response were those that suggested that testing could help in PD prevention (87.5% PD, 92.9% caregivers) and affected health and life insurance coverage (43.7% PD, 50% caregivers).

Multivariate analysis correlating level of knowledge and attitude towards genetic testing

For the Asian center, the multivariate analysis corroborated the findings in the univariate analysis. Independent of age, gender and education, a high knowledge was associated with a positive attitude response regarding the potential medical benefits of testing (p<0.0005) and a negative attitude towards compromises in healthcare and life insurance, getting a job and starting a family (p<0.0005). Asians with a high knowledge of PD genetics were 10 to 22 times more likely to perceive positively towards medical benefits of testing but 10 to 20 times more likely to perceive negatively towards health/life insurance, employment and starting a family. In the American center, multivariate analysis did not reveal any significant associations between level of genetic knowledge and attitudes towards testing, either in PD patients or caregivers (p>0.05).

DISCUSSION

Our study demonstrated that the relationship between level of genetic knowledge and attitude towards potential risks and benefits of predictive genetic testing in PD was distinctly different in two independent, racially and culturally different PD populations and caregivers. American PD and caregivers were generally more knowledgeable and more positive about the benefits of genetic testing. However, the level of genetic knowledge amongst Asian subjects seems to influence their perceptions about risks and benefits of testing more than their American counterparts. The appreciation of these factors and their interactions, such as differences in perception, cultural beliefs and practices amongst different races, and knowledge of healthcare systems and practices in individual countries should be taken into consideration in the development of PD genetic counseling programs.