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Knowledge of and interest in genetic results among Parkinson disease patients and caregivers

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Abstract

The purpose of the study is to investigate Parkinson disease (PD) patients' and caregivers' knowledge of and interest in genetic testing. Gaucher disease (GD) results from recessive mutations in glucocerebrosidase (*GBA*). Both heterozygote *GBA* carriers and GD patients are at greater risk for PD. Studies regarding knowledge of and interest in genetic testing have been limited and have not offered genetic results to participants. In this study, 353 PD patients and 180 caregivers were recruited to a PD genetic study. The association between GD, *GBA* mutations and PD was described to participants who reported their familiarity with genetic terms, answered questions on genetic concepts, and indicated their interest in knowing if they may have GD (two *GBA* mutations) and other genetic information that could impact their health. Ninety-three-percent of participants were interested in receiving *GBA* results; however, only 51.6% of PD participants and 55.6% of caregivers knew that "scientists have identified genes associated with a higher risk of developing PD." PD patients may benefit from education and genetic counseling on the implications of genetic testing.

Keywords

Parkinson's disease; Gaucher disease; glucocerebrosidase; genetics; counseling

Introduction

Background

For more than a decade, the genetic risk factors for Parkinson disease (PD) have been investigated with roughly a dozen genetic mutations implicated in the development of PD

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(McInerney-Leo, Hadley et al. 2005; Bekris, Mata et al. 2010). Interest in genetic testing has increased commensurately (Jacobs, Latza et al. 2001; Dahodwala, Connolly et al. 2007; Falcone, Wood et al. 2011); however, a range of studies have demonstrated a lack of general (Henneman, Timmermans et al. 2004; Catz, Green et al. 2005) or disease-specific genetic knowledge among various patient populations including PD patients (Falcone, Wood et al. 2011), breast cancer patients (Bluman, Rimer et al. 1999; Bluman, Rimer et al. 2003), and Huntington disease patients (Semaka, Balneaves et al. 2012).

PD is a complex disorder that may result from genetic and/or environmental contributions. Though a small percentage of PD cases is associated with a genetic mutation (Tan and Jankovic 2006), some ethnic groups with a high frequency of these mutations may be at higher risk for PD. One of the most common genetic risk factors for PD is carrying a mutation in the *glucocerebrosidase* gene (*GBA*) (Velayati, Yu et al. 2010; Anheim, Elbaz et al. 2012). Up to twenty percent of Ashkenazi Jewish PD patients and up to 7% of non-Ashkenazi Jewish PD patients carry a mutation in *GBA*, which is associated with a higher prevalence of PD (Sidransky, Nalls et al. 2009).

Two mutations in the *GBA* gene lead to Gaucher disease (GD), a rare, autosomal recessive disorder caused by lysosomal accumulation of glucocerebroside. In Type I GD, patients present with hepatosplenomegaly, thrombocytopenia, leukopenia, and bone disease. Some type I GD patients with mild symptoms are unaware of their GD status. In an Israeli Ashkenazi Jewish cohort, 1.4% of PD patients were identified as homozygous or compound heterozygous for *GBA* mutations, and therefore had GD (Gan-Or, Giladi et al. 2008). Intravenous enzyme replacement therapy is available for type I GD and may reverse many GD symptoms (Butters 2007). Identification of these GD cases may have therapeutic implications.

Attitudes towards Genetic Testing

Most PD patients do not seek genetic testing, and this may be a consequence of inadequate understanding of genetics or negative attitudes towards genetic testing results, including discrimination in the workplace or changes in insurance premiums or coverage (Tan, Lee et al. 2007). Additionally, patients considering genetic tests for HD (Quaid and Morris 1993) and PD (Dahodwala, Connolly et al. 2007) have cited low impact on clinical intervention as a reason for declining predictive testing.

While there are no interventions or preventative measures available for individuals considered high-risk for PD, there is treatment available for GD. We asked both PD patients and caregivers (jointly referred to as “participants” from this point forward) to indicate their interest in receiving biallelic (homozygous or compound heterozygous) *GBA* mutation results and other genetic results that may affect their health or the health of their family members. The Columbia University Institutional Review Board (IRB) committee approved sharing genetic results with study participants even if obtained from a non-CLIA (Clinical Laboratory Improvement Amendment) approved laboratory if treatment or intervention is available; therefore, we could not disclose information regarding *GBA* carrier status. Individuals with biallelic mutations in *GBA* were referred to genetic counseling and CLIA-certified laboratory testing.

Purpose of the Study

In the current study, we investigated the knowledge of and the interest in genetic testing results among PD patients and caregivers in a study exploring the association between *GBA* mutations, GD, and PD. The specific aims of this study are to: 1) measure and identify predictors of interest in *GBA* mutation results and other genetic results that may have

implications for one's health; 2) investigate knowledge of basic and PD-specific genetic concepts in PD patients and caregivers; and 3) examine the association between self-reported and actual knowledge of genetic concepts.

Methods

Participants

In this study, 533 participants, 353 PD patients and 180 non-blood-related caregivers who were predominately spouses, were recruited from the Center for Parkinson's Disease at Columbia University Medical Center in New York, NY. Considering caregivers often play an important role in patients' healthcare decisions, their knowledge of and interest in genetic testing results were also examined. PD patients were recruited in-person during regularly scheduled clinic appointments from September 2010 – October 2012, and caregivers (if present) were recruited simultaneously. The principal investigator, R.N.A. or study coordinator, K.S. explained the study background and purpose, obtained informed consent, administered a structured questionnaire, and collected a blood sample for DNA analysis from each participant (both PD patients and caregivers). All research-related activities were approved by the Columbia University Medical Center IRB.

Informed Consent

As part of the informed consent procedure, the study coordinator or principal investigator explained the association between *GBA* mutations, GD, and PD. Specifically, participants were told GD arises from two inherited mutations in the gene *GBA* (one copy from each parent), which leads to insufficient production of the enzyme glucocerebrosidase (GCase). The symptoms of GD were described, and study participants were told *GBA* mutations are a risk factor for PD that are present worldwide, but more common in the Ashkenazi Jewish population. Participants were informed of the primary and secondary study objectives: 1) to measure the GCase activity levels in PD patients and controls and 2) to investigate knowledge of and interest in genetic testing. The consent form and a member of the research team also explained DNA would be tested for genetic risk factors that may relate to an increased risk of developing PD in their offspring.

In the consent form, participants specified whether they would like to be notified of a possible GD diagnosis which would be indicated by two mutations in *GBA* and low GCase enzymatic activity. Additionally, they were asked to indicate their interest in receiving other genetic results that "may affect their health or their family's health."

Structured Interview

The same, standardized interview and assessments were conducted with PD patients and caregivers and included questions regarding demographics, medical history, family history of PD or other neurological disorders, and knowledge of genetics. The genetic knowledge questions were sampled from a questionnaire previously reported (Falcone, Wood et al. 2011). Participants reported their familiarity with the following terms: *gene*, *DNA*, *chromosome*, and *genetic testing* and answered six questions about genetics in general and PD specifically (Figure-1). Participants responded to these questions with "true," "false," or "don't know" responses. "Don't know" was scored as an incorrect response. Additionally, PD patients and caregivers were tested for cognitive functioning using the Montreal Cognitive Assessment (MoCA) (Nasreddine, Phillips et al. 2005) and for PD by the Unified Parkinson's Disease Rating Scale (UPDRS). PD patients and caregivers were generally consented and interviewed together, but separated during the MoCA exam.

Data Analysis

All data analysis was performed using SPSS for Windows V.19. An analysis of variance (ANOVA) and chi-square test (χ^2) were used as appropriate to compare demographic information, clinical characteristics, and knowledge of genetics between those interested in receiving genetic results and those not interested. Logistic regression models were used to assess the association between interest in receiving genetic information (outcome) and demographic data (predictors). A genetic knowledge score was calculated for each participant by summing the number of correct responses (out of six questions). Knowledge of genetics was tested in PD participants and caregivers. Pearson's correlation coefficient was used to examine associations between self-reported familiarity and genetic knowledge.

Results

A summary of demographic factors, clinical characteristics, knowledge of genetics, and interest in genetic results is presented in Table 1.

Interest in Genetic Results

Most PD participants were male (62.9%), non-Hispanic Caucasians (89.8%) with a mean age of 66.2 years (SD = 10.4), mean education of 16.7 years (SD = 2.8), mean MoCA score of 25.2 (SD = 3.7), and a mean knowledge score of 3.9 (SD = 1.5). Most caregivers were female (66.1%), non-Hispanic Caucasians (93.3%), with a mean age of 64.9 years (SD 9.5), mean education of 16.7 years (SD = 2.6), mean MoCA score of 27.1 (SD = 2.3), and a mean knowledge score of 4.4 (SD = 1.3). All participants were fluent English speakers. Out of 533 (353 PD and 180 caregiver) participants, 93.4% were interested in knowing if they may have GD. Additionally, 96.6% of participants were interested in knowing unspecified genetic information that may affect their health or their family's health that may be found in future studies.

Participants interested and not interested in receiving their genetic results were similar, except male caregivers were less interested in learning about their GD results $\chi^2(1, n = 180) = 9.70, p=0.002$ or other genetic results that could affect their health $\chi^2(1, n = 180) = 6.16, p = 0.013$ compared to female caregivers.

A multivariate logistic regression model ($n = 533$) testing the association between interest in genetic testing results with various predictors is summarized in Table 2. After adjusting for potential confounders, non-Jewish ancestry was the only factor associated with interest in receiving GD results (OR = 2.14; 95% CI 1.01 – 4.54; $p = 0.05$). Additionally, having PD was the only factor that predicted interest in receiving other genetic results (OR = 4.27; 95% CI 1.40 – 12.97; $p = 0.01$). Age, sex, education level, MoCA score, genetic knowledge score, family history of PD in a first-degree relative, and having children were not associated with interest in any genetic testing results.

Knowledge of Genetics

PD and caregiver participants differed in their genetic knowledge scores (PD mean = 3.9, SD = 1.5; caregivers mean = 4.4, SD = 1.3; $p < 0.001$) and MoCA scores (PD mean = 25.2, SD = 3.8; caregivers mean = 27.1, SD = 2.3; $p < 0.001$). Performance on the genetic knowledge questions between PD and caregiver participants are shown in Figure 1. The question with the lowest percentage of correct responses was: *scientists have identified genes that are associated with a higher risk of developing PD* (answer: true, PD 51.6%, caregivers 55.6%). Correctly answering this question was positively associated with Jewish ancestry (at least one Jewish grandparent) (OR=1.64; 95% CI 1.12–2.38; $p=0.01$) and

younger age (OR = 1.02; 95% CI 1.00–1.04; $p = 0.02$) after adjusting for potential confounders.

Self-Reported Familiarity with Genetic Terms

Most participants reported familiarity with at least three of the four genetic terms (PD 60.9%, Controls 72.8%). Self-reported familiarity with genetic terms was significantly and positively correlated with genetic knowledge (Pearson correlation coefficient $r = 0.26$, $p < 0.01$).

Discussion

This study provides further evidence that PD patients and caregivers are interested in genetic testing results that may have implications for their health or their children's health, but their knowledge of general and PD-specific genetics may be limited. Nearly half of the participants in this study were unaware that "scientists have identified genes that are associated with an increased risk for PD." This is a surprising result given the explanation they received during the informed consent process immediately prior to this question and their interest in receiving genetic results.

Two other PD studies have reported a lower percentage of correct responses (30–35%) for similar questions but did not include pretest discussion (although demographic characteristics may vary) (Tan, Lee et al. 2007; Falcone, Wood et al. 2011). The background information provided on *GBA*/GD and PD most likely increased participants' awareness of the role of genetics in PD in this particular study. This information was shared with participants because the study involves genetic biomarker testing; an explanation of the GD-PD relationship was necessary for full informed consent of the study.

Jewish ancestry predicted less interest in receiving GD results, but not in other genetic results compared to participants with non-Jewish ancestry. Given the increased incidence of GD in the Ashkenazi Jewish community, perhaps Ashkenazi Jewish participants are more hesitant about learning of a possible GD risk. Another possibility is that Ashkenazi Jewish participants may have already been tested for *GBA* mutations/GD risk and declined results for this reason. Jewish ancestry and younger age were positively associated with knowing that scientists have found genes linked to PD risk. Those with Ashkenazi Jewish ancestry are more likely to carry an identified genetic form of PD (Aharon-Peretz, Rosenbaum et al. 2004; Ozelius, Senthil et al. 2006; Sidransky, Nalls et al. 2009), and increased perceived risk may explain their increased awareness of PD-genetics. Also, Ashkenazi Jewish individuals are more likely to undergo preconception genetic testing, and they may be more familiar with genetic concepts from this experience.

The decreased interest in receiving genetic results among male caregivers is notable and surprising considering males are 1.5 times more likely to develop PD than females (Wooten, Currie et al. 2004). They may be aware of their increased risk for PD and decline testing to avoid additional anxiety. Retrospective studies have shown that women were also more likely to pursue predictive testing for HD than men (Harper, Lim et al. 2000; Creighton, Almqvist et al. 2003).

Study Limitations

The major limitation of our study is the brevity of our genetic questionnaire, which limits the conclusions that can be drawn about specific knowledge deficits in this population. Nonetheless, our results confirm previous findings (Tan, Lee et al. 2007; Falcone, Wood et al. 2011) that PD patients and caregivers are interested in learning about genetics and

receiving genetic testing results despite their limited understanding. In addition, while we tried to be consistent in the recruitment explanation of the link between *GBA* mutations and PD, we did not use a formal script.

All study participants were recruited from a tertiary center in New York, NY, and we do not know if these results are generalizable to PD patients and caregivers seen in primary/community settings. Most genetic counselors work in tertiary care centers and will likely encounter patients with similar demographic profiles. It is likely that individuals less interested in receiving genetic results did not participate in the study, and interest in genetic results among the general PD/caregiver population may be lower than our reported findings. Because potential research candidates were invited to participate in studies by their primary neurologist, we do not know how many patients refused the study and are unable to calculate a response rate. In contrast to most studies that rely on hypothetical scenarios of genetic testing, a major strength of our study is that actual genetic results were offered to participants. To our knowledge, no other study has examined interest in receiving *GBA* mutation results in this population.

Practice Implications

It may be important for providers to explore patients' understanding of genetic concepts through targeted knowledge questions. Although participants were provided an explanation of the association between *GBA* mutations, GD, and PD, this may have been difficult to comprehend without a working knowledge and foundation of basic genetic concepts, such as patterns of inheritance and the concept of penetrance.

Many participants did not know genetic risk factors for PD have been identified, and they may be unaware of genetic testing and counseling services available to them. With the increasing availability of direct to consumer genetic testing services, patients may pursue testing and receive genetic results without professional guidance and interpretation. To fully empower patients to make informed decisions, it is imperative that providers discuss the role of genetics in PD, explain the implications these results may have on family members, and consider including caregivers in this important conversation.

Caregivers themselves are an additional cohort of interest. They support probands in healthcare decisions, and their knowledge of and interest in genetic testing may be important to consider when counseling probands. Dementia and mild cognitive impairment (MCI) are common features of PD; it may be important for probands to include family members in the decision to receive genetic results so that their wishes are understood and a health care proxy may be available for probands with cognitive impairment.

Research Recommendations

Despite the explanation participants received about the association between *GBA* mutations, GD, and PD, almost half of all participants did not understand that *GBA* mutations were a genetic risk factor for PD. Considering the estimated risk of PD in *GBA* mutation carriers is 2.2% by age 65 and 10.9% by age 85, the associated PD-GD risk will need to be clearly explained to patients interested in counseling for either condition. (Rana, Balwani et al. 2013). Furthermore, when conducting informed consent sessions with participants for genetic studies, investigators should explore participants' understanding of genetic testing directly with knowledge questions.

We are aware of only one study that has examined specific genetic knowledge deficits among PD patients (Falcone, Wood et al. 2011), and further studies are necessary to evaluate caregivers' knowledge of genetics and their role in supporting probands' healthcare

decisions, especially in regards to genetic testing. It is not clear if participants expressed an interest in receiving biallelic *GBA* results because clinical intervention is available for GD or they wanted to assess the risk for PD in their family members and/or themselves (in the case of caregivers). Further studies that examine interest in actual genetic results (for which intervention may not be available) are also needed.

The decision of whether genetic research results should be returned to participants is continually debated. Many ethical considerations, including clinical utility and study context, have been explored (Knoppers, Joly et al. 2006; Ravitsky and Wilfond 2006). Participants' interest in genetic results and their baseline knowledge of genetics are key factors to consider in the decision to return genetic results, and these should be ascertained during the informed consent process.

Conclusion

In summary, we demonstrated the vast majority of participants were interested in receiving genetic testing results that may have implications for their health or their children's health. Given their limited understanding of genetics, we conclude further education of PD patients and family members is warranted to allow individuals to make informed decisions about genetic testing.

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Figure 1. Genetic knowledge performance in PD and caregivers

1. incorrect responses $n = 42$ (7.9%); don't know responses $n = 131$ (24.6%)
2. incorrect responses $n = 97$ (18.2%); don't know responses $n = 152$ (28.5%)
3. incorrect responses $n = 21$ (3.9%); don't know responses $n = 137$ (25.7%)
4. incorrect responses $n = 7$ (1.3%); don't know responses $n = 73$ (13.7%)
5. incorrect responses $n = 37$ (6.9%); don't know responses $n = 197$ (37.0%)
6. incorrect responses $n = 56$ (10.5%); don't know responses $n = 87$ (16.3%)

Table 1

Demographics, clinical characteristics, and genetics knowledge in participants interested or not interested in receiving GD genetic results

	PD		Caregivers		Total	
	Interested in GD (n=330, 93.4% of PD)	NOT Interested in GD (n=23, 6.5% of PD)	Interested in GD (n=168, 93.3% of caregivers)	NOT Interested in GD (n=12, 6.7% of caregivers)	Interested in GD (n=498, 93.4% of all participants)	NOT Interested in GD (n=35, 6.6% of all participants)
Percent male (n) ^a	63.0 (208)	60.9 (14)	31.0 (52)	75.0 (9)	52.2 (260)	65.7 (23)
Percent Non-Hispanic Caucasian (n)	89.7 (296)	100 (23)	92.9 (156)	100 (12)	84.8 (452)	6.6 (35)
Percent Hispanic (n)	5.5 (18)	0	3.0 (5)	0	4.3 (23)	0
Percent African American (n)	1.2 (4)	0	1.2 (2)	0	1.1 (6)	0
Percent Asian (n)	2.1 (7)	0	1.8 (3)	0	1.9 (10)	0
Percent Other race (n)	1.5 (5)	0	1.2 (2)	0	1.3 (7)	0
Age, yrs (SD)	66.2 (10.4)	66.7 (10.8)	64.9 (9.5)	68.0 (10.3)	65.7 (10.1)	67.2 (10.5)
Age-at-onset, yrs (SD)	59.3 (11.7)	59.1 (11.6)	N/A	N/A	N/A	N/A
PD duration, yrs (SD)	6.7 (6.3)	7.2 (4.9)	N/A	N/A	N/A	N/A
Education, yrs (SD)	16.6 (2.7)	17.7 (2.8)	16.6 (3.1)	16.7 (2.6)	16.6 (2.7)	17.3 (2.9)
MoCA ^b (SD)	25.2 (3.7)	24.7 (4.9)	27.1 (2.3)	27.4 (1.9)	25.8 (3.4)	25.7 (4.3)
GenKnow Score (SD)	3.9 (1.5)	4.3 (1.5)	4.4 (1.3)	4.1 (1.3)	4.1 (1.4)	4.3 (1.4)

^aThe percent of male caregivers interested in receiving genetic information was significantly lower than percent of male PD participants interested in receiving genetic information ($p < 0.05$)

^bMontreal Cognitive Assessment

Table 2

Multivariate logistic regression model of the association between genetic interest and demographics, clinical characteristics, and genetic knowledge score

	Interest in GD Results		Interest in Other Genetic Results	
	Adjusted OR ^a (95% CI)	p-Value	Adjusted OR ^a (95% CI)	p-value
Male gender	0.57 (0.26–1.2)	0.15	0.36 (0.11–1.1)	0.08
PD	1.28 (0.58–2.9)	0.54	4.27 (1.4–13)	0.01
Age	0.99 (0.95–1.0)	0.65	0.98 (0.93–1.0)	0.56
Education yrs	0.95 (0.81–1.1)	0.46	0.91 (0.73–1.1)	0.40
MoCA Score	0.99 (0.88–1.1)	0.83	0.98 (0.82–1.2)	0.78
GenKnow Score	0.89 (0.67–1.2)	0.43	1.04 (0.71–1.5)	0.85
Family History of PD	1.48 (0.57–3.9)	0.42	2.08 (0.53–8.1)	0.29
Non-Jewish Ancestry	2.14 (1.0–4.5)	0.05	1.96 (0.68–5.6)	0.21
Having children	0.68 (0.26–1.8)	0.43	2.26 (0.28–18)	0.44

^a Adjusted for all other variables in the table