Austin Alzheimer's and Parkinson's Disease

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Research Article

Nurses' Willingness to Refer First Degree Relatives to Genetic Testing for Alzheimer's Disease: Applying an Expanded Version of the Theory of Planned Behavior (TPB)

Goldstein D[1], Werner P[1]* and Mendelson G[2]

[1]Department of Community Mental Health, University of Haifa, Israel

[2]Netanya Governmental Geriatric Center, Israel

***Corresponding author:** Werner P, Department of Community Mental Health, Faculty of Social Welfare and Health Sciences, University of Haifa, Mt. Carmel, Haifa 31905, Israel

Received: November 04, 2014; **Accepted:** November 24, 2014; **Published:** November 25, 2014

Abstract

Using an expanded version of the Theory of Planned Behavior which incorporates the concept of Self-Efficacy (SE) as its conceptual framework, this study examined nurses' willingness to refer first-degree relatives for Genetic Testing (GT) for Alzheimer's disease (AD). A self-report structured questionnaire was completed by 120 certified nurses at two psycho-geriatric hospitals in Israel's major metropolitan area. Overall nurses' willingness to refer first-degree relatives to GT for AD was moderate. The elements of the theory explained 56% of nurses' willingness. Findings of this study may help identifying areas for potential intervention, such as increasing nurses' awareness about GT and their ability to explain the importance of GT to relatives with AD.

Keywords: Alzheimer's disease; Genetic testing; Theory of planned behavior

Introduction

Developments in the field of molecular genetics have led to the discovery of various genetic mutations, including mutations which cause the onset of Alzheimer's disease (AD) [1-3]. AD is a degenerative disease of the brain with far-reaching implications for the individual and his or her family, as well as for society. Although no effective prevention or treatment measures are available today, it is agreed that early diagnosis (including Genetic Testing - GT) of the disease should be emphasized [4-7]. GT may be accompanied by adverse psychological effects [8], especially in the case of AD since the existence of the E4 allele (an alternative form of a gene) in the gene Apolipoprotein E (ApoE) does not unequivocally point to certainty of onset, but rather constitutes an additional risk factor for the disease [9].

However, given the enormous advances in this area [10], GT for the diagnosis of AD will become available in the near future to millions of individuals who are at risk of developing the disease [11-13] and an increasing amount of research is being devoted to this topic in the last years. Several studies have discussed the advantages and disadvantages of GT for AD. The main advantages include the ability to plan the future on personal, familial, financial and health care aspects [11,14-16]; to contribute to research; to learn about one's own and children's risks [8,17-19]; to "feel in control" of one's own health [20] and the possibility to increase the awareness of early diagnosis and treatment [12,17,21]. The disadvantages include psychological adverse outcomes like stress [11,14,17] and depression [11,14], although it should be stated that these negative consequences have not been proven empirically. Indeed, a recent study has shown that both persons receiving a positive result for a deterministic mutation (e.g., presenilins) and persons receiving a genetic susceptibility testing (e.g., APOE) reported low levels of distress [22]. Moreover, it has been shown that people who learned they were genetically at risk of AD, were more likely to get involved in AD- specific health behavior changes [23-26], such as initiating a long-term care insurance program [25] or increasing the use of dietary supplements [26].

In sum, the experience gained in other diseases (like Huntington's disease) suggest that there are more benefits than limitations in GT, especially when it is done by a professional and multidisciplinary team [8,27-30]. Accordingly, several studies have concentrated on assessing and discussing the knowledge and preferences of physicians about GT for AD [31].

Although nurses have a comprehensive professional perspective that allows them to play a central role in genetic counseling, no studies have, to the best of our knowledge, concentrated on this professional group. The role of nurses on the genetic diagnostic process, which includes drawing blood samples and gathering information on the medical history of the patient's relatives [32], puts them in a sensitive and important position for influencing the process [33].

Therefore, the purpose of the present study was to explore nurses' willingness to refer first degree family members, who are at high risk for developing early onset AD [12,34,35] to perform a GT for the disease. While, several studies have examined willingness to undergo GT for AD among students [36], first degree family members of AD patients [14,16,37-39] and the general population, [11,40-42] no studies have examined this issue among nurses. This is the aim of the present study. An expanded model of the Theory of Planned Behavior (TPB) served as the conceptual framework of the study.

The TPB assumes that the best predictor for future behavior is behavioral intention [43]. Such intentions are affected by three main

Citation: Goldstein D, Werner P and Mendelson G. Nurses' Willingness to Refer First Degree Relatives to Genetic Testing for Alzheimer's Disease: Applying an Expanded Version of the Theory of Planned Behavior (TPB). Austin Alzheimers J Parkinsons Dis. 2014;1(3): 7.

factors: (1) Behavioral attitudes – which are defined as the individual's orientation toward objects in his or her environment, and which affect the performance or non-performance of the behavior [43]. Attitudes include emotional elements (e.g., agreeable/ disagreeable) and instrumental elements (e.g., effective/harmful) [44]; (2) Subjective norms – which are defined as the individual's perceptions or perceived pressure to perform or not perform the behavior, based on an evaluation of the preferences of significant others; and (3) Perceived behavioral control – which measures the individual's belief of his or her ability to perform a specific behavior based on internal factors (emotions, etc.) and external factors (dependency, etc.).

Lately, an expanded model of the TPB [43,45] was proposed to include also the concept of Self-Efficacy (SE). SE refers to the individual's beliefs about his or her ability to successfully perform various behaviors to achieve an expected outcome [46]. In accordance with the core assumptions of the TPB, it was hypothesized that attitudes, subjective norms and perceived behavioral control would be direct determinants of intentions to advise first degree relatives to perform GT for AD. The impact of self efficacy and knowledge were also explored. It was hypothesized that nurses would be more likely to advise GT to a first degree relative for AD if they believe they have the ability to perform the behavior and if they have greater knowledge about GT.

Methods

Participants

Participants included a convenience sample of 120 nurses, qualified to work with older adults, at two large psycho-geriatric government hospitals (of 740 beds and 364 beds, each) in Israel's major metropolitan area.

Instrument

A self-report structured questionnaire comprising 35 items was developed specifically for this study based on an extended model of the TPB [43].

The following variables were assessed:

Willingness to refer a first degree relative with AD to GT: Nurses were asked to report their willingness to refer a first degree relative to get GT for the disease in three hypothetical cases. Each case reflected a different degree of risk of developing the disease and a different level of test accuracy. The risk levels used were 18%, 28% and 57%, based on recommendations in the literature [8]. For example: "To what extent would you advice first degree relatives to perform a GT for AD, when hypothetically, he/she has a 28% risk of developing AD?" Each item was rated between 1 (*very low willingness*) to 7 (*very high willingness*). An overall index of the average of these three items was calculated. The internal reliability of this index was very high (Cronbach alpha=0.91).

The accuracy levels selected for the study were 60%, 80% and 100%, based on the literature [11]. Each item was rated between 1 (*very low willingness*) to 7 (*very high willingness*). An overall index of the average of the responses for accuracy was calculated, with a higher score reflecting greater willingness to refer relatives for GT. Internal reliability of the accuracy index was also very high (Cronbach alpha=0.93).

Based on Pearson correlation, we found a high association between the risk and accuracy indices ($r=0.74$, $p<0.01$), therefore a single index (i.e the mean of the six items) reflecting overall willingness to refer for GT was calculated. The internal reliability of this overall index was very high (Cronbach alpha=0.93).

Behavioral attitudes: Following Ajzen's statement [44], both emotional (e.g., frightening/not frightening etc.), and instrumental elements (e.g., effective/ harmful etc.) of attitudes were examined. Eight items were used to measure attitudes: five assessed instrumental elements and three assessed emotional elements. Items were rated on two 7 point semantic differential scales. For instance, "I think it is very effective/harmful to have a genetic test for early diagnosis of AD" - 1=effective; 7=very encouraging. Subsequently, two indices were constructed by averaging the items for both types of attitudes. The internal reliability of the instrumental index was very high (Cronbach alpha=0.92), while the internal reliability of the emotional index was low (Cronbach alpha=0.30) but improved when the item measuring attitudes as a function of fear was eliminated (Cronbach alpha=0.68). Consequently, the emotional attitude index used in the following analyses was comprised of only two items.

Subjective norms. Two items were used to assess participants' beliefs concerning nurses' attitudes regarding the referral of first-degree relatives for GT. Each item was rated on a Likert-type scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). For example: "I think most of the nurses around me whose professional opinion I appreciate support me referring a first-degree relative to GT for the disease". An overall index was calculated by averaging the items. The internal reliability of this index was high (Cronbach alpha=0.90).

Perceived behavioral control: Was assessed in two ways: First, SE was assessed using four items which evaluated nurses' perceptions of their ability to perform the assessed action (i.e. to refer for GT). For example: "I believe I am able to refer a first-degree relative for GT for early diagnosis of the disease." Each item was rated on a Likert-type scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). An overall index was constructed by averaging the items. The internal reliability of the SE index was high (Cronbach alpha=0.92).

Second, perceived behavioral control was also assessed through controllability: three items were used to assess nurses' perceptions of the degree to which they believed that the performance of the behavior (i.e. referring to GT) was dependent on external factors. For example: "The decision to refer a first-degree relative to GT for AD and early diagnosis of the disease depends mainly on me." Each item was rated on a Likert-type scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). An overall index was constructed by averaging the items. The internal reliability of this index was relatively low (Cronbach alpha=0.49), although when one item was eliminated, it increased (Cronbach alpha=0.80). Consequently, the final index of controllability used in the following analyses contains only two of the three items examined.

Knowledge about GT: This was measured using two items: the first, "How much have you heard about GT for AD?", and the second, "According to your knowledge, to what extent do first degree relatives of AD patients perform GT for the disease?". The items were rated on a 7-point Likert-type scale ranging from 1 (*low extent*) to 7 (*great extent*). A positive and statistically significant correlation was found

between these items (r=0.44, p<0.0001), therefore an overall index of the average of the responses was calculated, with a higher score reflecting greater knowledge about GT for AD.

Socio-economic and professional variables: These included age, country of birth, date of immigration, number of years of education, nursing training, and professional position.

Procedure

Nurses were recruited from two large psycho-geriatric hospitals in the central area of Israel and included registered nurses only because of the greater relevance of the topic to them. The study was approved by the ethics committee of the participating institutions. After a pre-test was completed with 15 nurses at one of the facilities for assessing the clarity of the questions, potential participants completed the questionnaire after signing an informed consent. Overall, 138 questionnaires were distributed and a total of 120 were returned, yielding a response rate of 87%. Data collection was performed during September and October 2005.

Data analysis

Data analysis was performed using SPSS. In order to describe the sample and the model's main variables, percentages, means, standard deviations and ranges were calculated. Pearson correlation coefficients were calculated to assess bivariate associations between the variables in the model. Finally, a hierarchical multiple regression was performed to find the best predictors of nurses' willingness to refer first-degree relatives to GT for AD. In the first step (block) the main TPB variables were included (i.e., instrumental and emotional attitudes, subjective norms and perceived behavioral control). In the second step, the variables in the expanded TPB model were added (i.e., SE and knowledge). Finally, background variables were included (i.e., socio-demographic and professional variables). In these equations the adjusted R^2 is reported due to the multiple steps.

Results

The majority of the participants (95%) were female, married (82.5%) and their household income was above average. Their average age was 42 (SD = 7.87; range was between 23 and 60 years). One half of the participants were born in Israel (50.8%), most had been living in Israel for many years (19.76 years on average; SD = 1.14 years; range between 7 and 55 years).

With regard to the participants' professional characteristics, less than half of the participants were registered nurses (40%), one third were graduates of an advanced training program (30%), one quarter had an undergraduate degree and a small percentage (5%) had a graduate degree. Participants had extensive experience in their profession (average of 17.93 years, SD = 7.46 years, range between 1 and 35 years), with slightly over one half (55.8%) working in managerial roles.

Willingness to refer for GT of AD

Means, standard deviations, and ranges of the items used to measure willingness to refer for GT of AD are presented in Table 1. As can be observed, overall participants showed a moderate level of willingness to refer relatives for AD testing. Repeated measures analysis of variance showed that participants' willingness was higher as the risk level was higher [$F_{(1,119)} = 71.69$, $p < 0.0001$] and as the test accuracy level was higher [$F_{(1,119)} = 70.69$, $p < 0.0001$].

Table 1: Means, SD, and ranges of items on willingness to refer for genetic testing (N=120).

When the risk of developing AD after the age of 65 is:	Mean	SD	Range
18%	3.81	1.89	7 - 1
38%	4.56	1.82	7 - 1
57%	5.21	1.86	7 - 1
When the accuracy of the test is:	**Mean**	**SD**	**Range**
60%	4.43	1.86	7 - 1
80%	5.09	1.82	7 - 1
100%	5.71	2.00	7 - 1
Overall willingness	4.80	1.62	7 - 1

1: very low willingness; 7: very high willingness

Attitudes: As can be observed in Table 2, participants reported moderate instrumental attitudes but low emotional attitudes toward GT ($t_{(119)} = 6.9$, $p < 0.0001$).

Subjective norms: Findings indicated that participants' subjective norms were neutral regarding the support of significant others for a decision to refer relatives to GT for AD.

Self-efficacy and controllability: In general, findings indicated that participants had a poor sense of control and SE regarding referral of first-degree relatives of AD patients to GT.

Knowledge: The average level of participants' knowledge on GT for AD was very low.

Bivariate associations: Pearson correlations were calculated among willingness to refer and the main variables in the extended TPB model. Particularly strong and statistically significant associations were found between willingness and instrumental attitudes ($r = 0.64$, $p < 0.0001$), and between willingness and subjective norms ($r = 0.63$, $p < 0.001$). Strong and statistically significant associations were found also between willingness and SE ($r = 0.48$, $p < 0.001$). A moderate but statistically significant association was found between willingness and emotional attitudes. Finally, a relatively weak association was found between willingness and controllability and between willingness and knowledge, with both associations being only marginally significant ($r = 0.18$, $p < 0.056$ and $r = 0.17$, $p < 0.057$ respectively).

Associations with socio-demographic and professional variables: According to the TPB, socio-demographic variables are external factors that affect model variables with the exception of behavioral intentions which are affected by attitudes, subjective norms, and perceptions of SE and controllability. Accordingly, the associations between continuous socio-demographic variables,

Table 2: Means, SD, and ranges of main variables in the TPB model (N=120).

Variable	Mean	SD	Range
Instrumental attitudes	4.60	1.61	7 - 1
Emotional attitudes	3.48	1.51	1-7
Subjective norms	4.29	1.70	7 - 1
Self-efficacy	4.67	1.61	7 - 1
Controllability	3.50	1.60	7 - 1
Knowledge	2.56	1.15	7 - 1

and instrumental attitudes, emotional attitudes, subjective norms, SE, controllability and knowledge were assessed using Pearson correlation coefficients. No statistically significant associations were found between these variables. The associations between model elements and categorical socio-demographic variables were examined using t-tests. The only association found was a statistically significant difference in the SE scores of nurses who had undergraduate degrees and those who did not have a similar academic background.

Testing the conceptual model

A hierarchical multiple regression analysis was performed to investigate the role of model variables. As stated, in the first step the main TPB variables were included (i.e., instrumental and emotional attitudes, subjective norms and perceived behavioral control). In the second step, variables in the expanded TPB model were added (i.e., SE and knowledge). Finally, background variables were included (i.e., socio-demographic and professional variables).

As can be seen in Table 3, the variables included in the first equation (i.e., the original TPB variables) significantly explained 51% of the variance in nurses' willingness- $F_{(4,119)} = 29.28$, $p < 0.0001$. Adding SE and knowledge increased slightly the prediction of willingness to refer to GT - $F_{(6,119)} = 24.20$, $p < 0.0001$; $R^2 = 0.56$. Finally, adding background variables increased the percentage of variance explained to 60% - $F_{(11,119)} = 14.45$, $p < 0.0001$. As could be expected based on the assumptions of the TPB, instrumental attitudes was the main predictor of willingness, followed by subjective norms.

Table 3: Hierarchical multiple regressions between model variables and nurses' willingness to refer to GT for AD overall index.

	Step 1	Step 2	Step 3
	β	β	β
TPB original variables			
Instrumental attitudes	.39**	.35**	.34**
Emotional attitudes	.04	.01	.01
Subjective norms	.37**	.30**	.29*
Perceived behavioral control	.03	-.09	-.09
Extended TPB model variables			
Self-efficacy		.21**	.19*
Knowledge		.14	.15
Socio-demographic and professional variables			
Sex			-.01
Age			-.20*
Seniority			.14
Income			-.06
Academic background			.13*
R^2	0.51**	0.56**	0.60
ΔR^2		0.05**	0.03

*Significance level: p<0.05
** Significance level: p<0.001

Discussion

The present study examined nurses' willingness to refer first degree relatives to GT for AD. Findings of the study showed that nurses' willingness to make such referrals was no more than moderate but increased as the risk of developing the disease as described in the hypothetical situations presented to the participants increased, and as the perceived accuracy of test results increased. These findings suggest that nurses are willing to make such referrals only in cases of high levels of certainty probably as a result of the absence of clear, mandatory guidelines regarding GT for the discovery of the genetic mutation in AD [16]. Another explanation to the moderate levels of willingness to refer for a GT might be related to nurses' knowledge that the test shows the presence of an additional risk factor rather than an unequivocal indication of the disease [16,47]. Consequently, nurses may view GT as adding to the stress and emotional burden of family members without offering any preventive contribution, and therefore they may wish to protect family members and prevent them to be exposed to information which could harm them. Finally, nurses' moderate levels of willingness may be related to instrumental reasons such as their concern about having either the time and/or the skills for that. Indeed, studies have found that nurses caring for AD patients did not provide guidance to family members due to the pressures of their routine work, lack of time for guidance and teaching [48] and lack of knowledge [48,49]. Similar to physicians who were found to prefer referring patients to a genetics professional because of the time needed to become familiar with the relevant aspects of the disorder, testing, management, and disease-specific psychosocial support services [50], nurses might be willing to defer this role to other professionals. Since in the present study participants were not requested to explain the reasons for their willingness or lack of willingness, future studies should explore in more depth the reasons for the moderate levels found.

Nurses in the present study reported relatively neutral attitudes toward GT, although nurses' instrumental attitudes towards the testing were more positive than their emotional ones. These findings suggest that nurses may feel anxious about the negative repercussions when relatives receive positive genetic test results, which may lead to frustration and discomfort.

An interesting finding relates to the relative low level found in nurses' evaluation of the support of their significant others (physicians or nurses) to refer relatives to GT. Indeed, there was no difference in the perceptions about the support of physicians or nurses. This raises the question of whose opinion is more important to nurses when deciding to refer relatives for GT- patients, relatives, social workers or others. Ambiguity on this point emphasizes the need to explore the issue of professional responsibility for initiating referrals for GT which may contribute to early diagnosis of AD. According to the guidelines of the American Nurses Association and the International Society of Nurses in Genetics [51], registered nurses (as members of health care teams) must be prepared to facilitate patients in the decision-making process inherent to genetic screening or genetic evaluation. Despite its low level, subjective norms were found to be significant predictors of nurses' willingness; suggesting that the referral decision involves both individual and social normative factors.

Nurses' perceived controllability over referral for GT, did not predict their willingness to refer relatives for GT. Several explanations can be provided for this lack of association. The first explanation relates to methodological reasons, and more specifically to the fact that nurses in this study were presented with hypothetical and brief cases, which did not stress the human complexities of the

process of referring to GT. The second explanation relates to the conceptualization of perceived behavioral control as including only external factors (e.g., time, opportunity and resources), and self efficacy as including internal factors (e.g., abilities' skills and compulsions) [52]. Consequently, nurses in our study might feel a poor sense of control regarding the external factors which are not in their hands. This is a significant finding mainly since SE was found to be a significant predictor of willingness, suggesting that nurses' moderate degree of SE might inhibit the delivery of secondary care to first degree relatives of AD patients which includes prevention based on early diagnosis of the disease. Moreover, nurses' low levels of SE are worrisome perceptions, mainly since in the last years the role of nurses in the process of GT is being stressed and widened. Indeed, the role of nurses in genetic counseling and genetic processes (i.e., genetic nursing) is defined as a holistic practice that includes assessing, planning, implementing, and evaluating the physical, spiritual, ethical, and psychosocial aspects of patients and families who have genetic concerns [53]. Undoubtedly, nurses have a role in the delivery of genetics services and the management of genetic information and the role has to be made clear first and foremost to nurses themselves.

Similarly, the low level of knowledge concerning GT for AD among nurses is worrying especially since it has been specifically stated that nurses need genetic knowledge to identify, refer, support, and care for persons affected by or at risk for genetic conditions [49,51]. However, it should be noted that the assessment of knowledge about GT in the present study was very limited as we used two items only – a fact that may explain the absence of an association. Future studies should explore this issue further by employing a more detailed research design.

Finally, no associations were found between model elements and external socio-demographic or professional variables, other than the statistically significant difference in the SE scores of nurses who had undergraduate degrees and those who did not have a similar academic background. It is possible that the acquisition of an academic degree by nurses confers a higher sense of confidence, self-worth and SE.

This model provided a suitable conceptual framework for understanding the research question and showed that the main factors influencing nurses' willingness were attitudes, subjective norms and SE. Understanding the factors associated with willingness to refer relatives for a genetic test of AD, may help to develop educational programs and other strategies aimed at changing attitudes and promoting behavioral change [54], as recommended by the American Nurses Association and International Society of Nurses in Genetics [51]. In the area of AD it has been suggested that educational programs about the benefits of GT might help prepare family members for one's potential illness [8]. Although, there is no cure for AD, scientific and clinical research indicated that there are prevention strategies that may slow the progression of the disease, mainly by decreasing risk factors like vascular risk factors (e.g., hypertension, high level of cholesterol, diabetes, atrial fibrillation and stroke) [55,56] or by making healthy lifestyle changes such as healthy diet [26,57] or stop smoking [58,59]. Therefore, referral to GT by clinicians at all and nurses in particular, may contribute to delay the onset of the disease in first degree relatives of AD patients.

Limitations of the study

The present study has several limitations. First, the study was based on a convenience sample conducted in two psycho-geriatric hospitals only, and therefore does not represent the full population of nurses in Israel. Furthermore, the sample comprised 95% female nurses. The gender ratio may have affected willingness. Additionally, encounters between nurses and elderly AD patients and their families also take place at other therapeutic settings including day care centers, memory clinics, neurological clinics in hospitals, and others. It is possible that in other settings, different factors will affect nurses' willingness to refer relatives for GT. It is therefore recommended to use larger and more representative samples in future studies.

Second, conclusions about the association between intentions to refer relatives to GT and behavior is limited because the present study assessed nurses' intentions in six hypothetical cases, from which conclusions concerning actual behavior cannot be made. Although Ajzen [43] claims that behavioral intentions predict actual behaviors, he also notes that to achieve a maximal prediction of behavior, intentions should be captured near in time to actual observed behaviors. Despite these limitations, the present study has important theoretical and practical implications.

Theoretical implications

The study proves that nurses' willingness to refer first-degree relatives of AD patients for GT is based primarily on cognitive and social factors - instrumental attitudes and subjective norms, and SE. These findings reinforce the recommendation to integrate the elements of the extended TPB model, including the concept of SE, into a theoretical model that explains the factors that affect nurses' willingness to refer first-degree relatives of AD patients for GT and early diagnosis.

Practical implications

The fact that the study showed that nurses' level of willingness is moderate indicates a need to develop training and study programs for nurses to increase their knowledge and awareness of GT for AD. Nursing programs at universities or continuing education courses should be adapted to include the most advanced medical and technological knowledge in the area of genetics and the human genome and discuss the role that nurses have in the implementation of this knowledge.

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Austin Alzheimers J Parkinsons Dis - Volume 1 Issue 3 - 2014
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Citation: Goldstein D, Werner P and Mendelson G. Nurses' Willingness to Refer First Degree Relatives to Genetic Testing for Alzheimer's Disease: Applying an Expanded Version of the Theory of Planned Behavior (TPB). Austin Alzheimers J Parkinsons Dis. 2014;1(3): 7.