Diagnostic Hesitancy of Primary Care Physicians in Puerto Rico Toward Alzheimer's Disease and Related Dementias: Opportunities for Transformation

Mirna L. Arroyo-Miranda, DrPH, JD*; Ernesto Rosario-Hernández, PhD†; Lillian Varcárcel, MSW‡; Brenda Soto-Torres, PhD, MPHE*; Jessica Irizarry-Ramos, PhD*

Objective: Migration of physicians in Puerto Rico makes it difficult to obtain specialized care for Alzheimer's disease and related dementias (ADRD). Primary care physicians (PCPs) can fill this gap, but there is limited information on how their beliefs and behaviors towards ADRD affect early diagnostic practices. Using the Theory of Planned Behavior (TPB), we addressed salient beliefs of PCPs that affect their intention to diagnose ADRD early, defined as "performing the recommended clinical testing to diagnose ADRD within 3 months from the patient's first subjective memory complaint".

Methods: This cross-sectional study included 103 Puerto Rican PCPs, surveyed at CME activities and online. We measured PCPs salient beliefs in terms of attitudes, pressure they feel from others, self-perception of ability to diagnose ADRD early, and intention to perform early diagnosis. Questionnaire measures were psychometrically acceptable.

Results: Structural equation modeling (PLS-SEM) analysis showed that, combined, framework constructs explained 35.7% of the variance, reflecting a moderate-to-strong intention of PCPs to diagnose early ($R^2 = 0.357$, p < 0.001). Self-perception of skills was the strongest predictor of intention (B = 0.378, p < 0.001). Hours in ADRD training and years of experience in medical practice were strongly correlated with the percentage of total diagnoses performed by PCPs.

Conclusion: Training and years of experience may be key for PCPs to have a positive outlook of their skills for early ADRD diagnosis. Findings could be useful to design interventions to dispel myths about ADRD, reduce stigma, and reduce diagnostic hesitancy toward ADRD among PCPs. [*P R Health Sci J 2023;42(3):212-218*]

Key words: Dementia, Early diagnosis and screening, Stigma reduction, Primary care physician practices

iagnostic hesitancy of Alzheimer's disease and related dementias (ADRD) among physicians is of critical concern. Early screening and diagnosis of ADRD are foundational to lessen disease impact, symptom reduction, and provide earlier access to healthcare services (1). It also allows patients a window of opportunity to make informed decisions about legal, financial, long-term housing and medical care, while they are competent (2).

Addressing diagnostic hesitancy in Primary Care Physicians (PCP) is of particular importance, since 1) they usually have a gatekeeping role within the healthcare system for patients (3, 4); and 2) the trusting nature of the relationship between the patient and PCP makes them better equipped to understand concerns and pick up on subtle changes in patient's cognitive function (5). Unfortunately, physicians delay diagnosis (6, 7), between 6 months to 2 years (8). Only about 50% of all ADRD cases

are diagnosed, and this typically occurs later in the cognitive spectrum (9). Physicians' misconceptions crucially contribute to this delay: they often 1) have negative beliefs about ADRD (10, 11); 2) ill-conceived notions that patients need shielding from diagnosis (12, 13); and 3) perceive themselves as lacking knowledge about diagnostic techniques (14-17). Studies also show PCPs often 1) feel sorry for patients and wait until the

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^{*}Ponce Health Sciences University, Public Health Program, Ponce, Puerto Rico; †Ponce Health Sciences University, Psychology Program, Ponce, Puerto Rico; ‡External Advisor

Address correspondence to: Jessica Irizarry-Ramos, PhD, Doctorate of Public Health in Epidemiology Program, Ponce Health Sciences University, Public Health Program. P.O. Box 7004, Ponce, PR 00732-7004. Email: jirizarry@psm.edu

last possible moment to diagnose (18, 19); or 2) would rather not diagnose at all, and refer the patient to a specialist so a third party will convey the bad news (20, 21).

ADRD is a major public health issue in Puerto Rico, as the fourth leading cause of death in Puerto Rico, with mortality rates doubling that of cardiovascular disease (22). Also, almost 50% of Puerto Rican physicians have migrated to the U.S. Mainland within the last 5 years (23, 24) which has limited patients' access to specialized dementia care (25). Therefore, as the first –or even maybe only– point of contact in the healthcare for most patients, PCPs who can effectively screen for, diagnose and manage ADRD are essential for the well-being of Puerto Rican AD/ADRD patients. There is little information to date, however, on how PCPs' perception of ADRD affects their screening, diagnosis, and management practices.

The current study sought to identify barriers and enablers among a Puerto Rican PCP sample for early diagnosis of ADRD, defined as "performing the recommended clinical testing to make an exclusion diagnosis of Alzheimer's disease within three months from patient's first subjective memory concern". Not only is there a critical need to address this phenomenon, but Puerto Rico serves as an example for medically underserved areas, where PCPs need to assume the lead role of diagnosing and caring for the ADRD patient with limited guidance or support of a specialist. Therefore, this research addresses a key gap in the existing literature.

The Theory of Planned Behavior (TPB) framework helps explain barriers and enablers of intention of PCPs to screen and diagnose ADRD early. TPB suggests individuals are rational actors influenced by beliefs in three major categories: Attitudes, Subjective Norm, and Perceived Behavioral Control. *Attitude* is the positive/negative assessment of the behavior. Subjective Norm refers to the pressure the person feels from society to perform the behavior, regardless of attitude. *Perceived Behavioral Control (PBC)* refers to the person's subjective evaluation of their skills, abilities, available

information, and willpower to perform the behavior; it is how confident they feel about what they know. The sum of those beliefs becomes *intention*, or likelihood that the individual will carry out the action, in this case, screening/ diagnose ADRD at an early stage (26). Figure 1 represents the relationship between theoretical constructs.

We hypothesized that, out of the three TPB constructs, attitude towards ADRD would have the largest effect on PCPs' intention to perform an early diagnosis of ADRD. As a secondary outcome, we sought to assess any correlation between sociodemographic variables of PCPs and their salient beliefs in each TPB construct.

Methods

Participants

This study included a cross-sectional sample of 103 PCPs, composed of general practitioners (n=65, 63.1%), family physicians (n=14; 13.6%), and internal medicine physicians (n=24; 23.3%). Exclusion criteria were PCPs who spent less than 50% of time in direct patient care. A priori sample size calculation estimated a minimum of 364 participants as sufficient to make inferences about the population, at a 95% confidence interval.

Data collection instrument

We designed a questionnaire for this study to: 1) describe PCPs' practices leading to underdiagnosis/ delayed diagnosis, 2) assess salient beliefs influencing PCPs' in each TPB construct and, 3) assess PCPs' level of intention to perform an early diagnosis of ADRD, and association of each construct with PCP intention.

The first part assessed sociodemographic variables (i.e. age, sex, education, etc.), as well as training and clinical practice description and referral variables. We developed TPB measures using content analysis of existing literature, and categorizing salient beliefs into one of the three TPB framework constructs with 7-point scale questions (26, 27). Content, convergent and discriminant validity, as well as internal consistency and reliability measures were all within adequate limits (Supplementary material 7). Instrument is included as Supplementary Material 5, and a list of variables per construct is appended as Supplementary material 6 (Supplementary material for this manuscript is available online, https://prhsj.rcm.upr.edu/).

Data collection

Data collection procedures occurred online and in paper formats during May and June of 2017. Three invitations to participate were sent via email through the Puerto Rico College of Physicians' system, to 6,634 registered PCPs, with a brief



Figure 1. Framework model: Theory of Planned Behavior (TPB) constructs.

explanation and link to the study. To maximize participation, we also conducted a paper-based collection at various Continuing Medical Education (CME) activities, and visits to primary care clinics and general hospitals across the island. Final response rate for both methods of data collection was 1.5%. A figure of our data collection strategy breakdown is included as Supplementary material 1.

Data management and quality control

We performed data quality control to remove incomplete/ missing data. In the online version, we excluded 50% of the reported questionnaires due to completely missing data, as the questionnaire would not allow PCPs to continue without consenting, many PCPs also opened the questionnaire link, filled out sociodemographic variables and closed before continuing to core questions. During data analysis we excluded 13 additional online questionnaires due to insufficient data. In the paper version we also performed quality control and only found 6 minor errors. Fifty-two percent of the questionnaires had some missing data, ranging from 14.7% to 25.9% in core model questions.

We performed Little's MCAR test to determine if data was missing completely at random (MCAR), in order to conduct multiple imputation (28). Little's null hypothesis is that data is not missing completely at random. In our case, we could not reject the null hypothesis and therefore, were able to assume data was MCAR (p = 0.208). We then ran multiple imputation with five iterations of parameter estimation to replace missing data, due to sample size and software issues.

Statistical analyses

Univariate analysis described socio-demographic characteristics of the population regarding age, sex, time spent in practice and number of years in practice, behaviors related to underdiagnosis (lack of screening, referral, non-disclosure), and salient beliefs for each TPB construct.

We conducted correlation analyses to determine if beliefs in each theoretical construct were associated with

sociodemographic variables, and Partial Least Squares Structural Equation Modeling (PLS-SEM) to determine associations between TPB constructs, controlling for sociodemographic covariates (29). We used effect size (f^2), predictive relevance (Q^2), and variance inflation factor (VIF) to verify potential multicollinearity issues. PLS-SEM allowed

for 1) simultaneous assessment of relationships between latent and observed variables, with specification of directional relationships among constructs (30, 31), and 2) study of a smaller-sized sample without losing statistical power (32).

Analyses were conducted with IBM SPSS Version 24.0 and SmartPLS 3.2.7 (29, 33). All participants consented to study procedures approved by Ponce Health Sciences University Institutional Review Board (Protocol 160809-BS).

Results

Primary Care Physician (PCP) sociodemographic, education, and practice characteristics

Sociodemographic characteristics are described in Table 1. Our PCPs were mostly experienced medical practitioners, and male and female PCPs spent a similar amount of their clinical practice time a week in direct patient contact. PCPs roughly estimated to have a large proportion of older adults among their clientele, but less than 50% of their patients had ADRD.

PCPs seemed equally divided on having received ADRD training throughout medical school and residency. We asked PCPs how many hours of training on Alzheimer's disease they had taken during their previous 3-year CME cycle, and they self-reported an average of 6.0 ± 0.2 hours. Cumulatively, 83.3% of all PCPs reported to have taken 12 hours or fewer of ADRD training in their last 3-year CME cycle.

Diagnosis, referral, and disclosure practices

PCPs diagnosed 22.6% \pm 31.4 of all ADRD cases themselves, but referred almost the same amount (23.1% \pm 31.02) to a specialist. PCPs also reported that about 1/3 of all ADRD cases already have a diagnosis upon their first visit. Among those who refer their patients to a specialist, the most cited reasons for referral were: 1) to rule out other conditions (52.5%); to ensure or begin ADRD treatment (47.6%); and 3) to obtain a second opinion (34.0%). Notably, 9.7% of all PCPs believed that referral is a medical requirement and 13.6% do not feel comfortable making the diagnosis independently.

There was a medium-sized association between the number of hours in ADRD training and the percentage of patients that PCPs diagnose, where the more hours in training, the more likely PCPs will perform the recommended clinical testing to diagnose ADRD themselves (r = 0.391, p < 0.001; Figure 2). Conversely, there was a negative, but non-significant correlation between a lower number of training hours, and more referrals to

 Table 1. Sample sociodemographic characteristics.

Characteristic	Total (n=103)	Male (n=51)	Female (n=52)	p†
Age	50.2±13.6 (27-78)	53.7±13.2 (27-78)	46.9±13.3 (27-72)	0.01*
Years of practice	20.25±12.7 (0-50)	23.0±13.5 (1-50)	17.5±11.3 (0-36)	0.03*
Hours of work per week	48.6±15.1 (18-80)	49.0±16.2 (0-60)	48.2±13.9 (18-80)	0.79

⁺Equal variances assumed; * Significant result

Table 2. Structural Equation Model summary.

Construct	R2	Adj. R2	F2	Q2	VIF
Attitude Subjective Norm Perceived Behavioral Control Intention	*** *** *** .350	*** *** .330	.022 .113 .195 ***	*** *** *** .268	1.074 1.173 1.126 ***

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specialists (r = -0.182, p = 0.08). We also found a statistically significant, positive correlation between the number of years in practice and the percentage of patients diagnosed by the PCP (r = 0.270, p = 0.006) (Figure 3).

Chi-square analysis showed most PCPs disclose the ADRD diagnosis to their patients. Female PCPs were 61% less likely to disclose the diagnosis to the patient, compared to male PCPs (p = 0.041). About 85% of all PCPs stated that they did not know of any support programs for ADRD patients. Eighty-seven percent did not know of any care centers for ADRD patients.

Primary outcome: Association between attitudes, subjective norm and perceived behavioral control constructs, and PCPs intention to diagnose early

We used PLS-SEM to determine if, combined, the TPB constructs (*Attitudes, Subjective Norm,* and *Perceived Behavioral Control*), as applied to early diagnosis of ADRD, were associated with PCPs' intention. To measure different psychological aspects of intention, we posed the same question with three different wordings: "hope," "wish," and "intend" (26, 27).

Table 3 shows the PLS-SEM analysis results. Combined, beliefs in the three constructs (*Attitudes, Subjective Norm*, and *Perceived Behavioral Control*) explained 35% of the variance in PCPs' intention to diagnose ADRD early ($R^2 = 0.350$, p < 0.001). Effect size values exceeded the

minimum threshold of 0.02 (34), and no multicollinearity issues were detected (VIF: 1.389 - 1.979). Adjusting for sex, specialty, years of practice, and number of hours in ADRD training did not yield statistically significant different results.

Path analysis shown on Figure 4 also shows the relationship of each independent construct with PCPs intention. The *Attitudes* construct was moderately, positively related to intention to make an early diagnosis of ADRD ($\beta = 0.123$, p = 0.234). *Subjective Norm* resulted in a slightly larger, statistically significant, positive relationship with intention to make an early diagnosis of ADRD ($\beta = 0.293$, p = 0.006). *Perceived Behavioral Control* showed an even higher, statistically significant association with PCPs' intention to diagnose ADRD early ($\beta = 0.378$, p < 0.01).



Figure 2. Correlation between number of hours spent by PCPs in AD management training and percentage of patients they diagnose.

Secondary outcome: Correlation between sociodemographic variables of PCPs and salient beliefs

Control beliefs in the *Perceived Behavioral Control* category were more strongly associated with sociodemographic characteristics than beliefs in the other two categories. Control belief 1, *"I feel confident in my clinical abilities to perform an early diagnosis of AD"*, had a mean score of 5.14 \pm 1.771 out of a possible 7 points, indicating a strong level of confidence. The number of hours PCPs spent in ADRD training the previous 3 years, demonstrated a moderate, statistically significant correlation with PCPs confidence levels (r= 0.299, p=0.003).



Figure 3. Correlation between number of years PCPs have been in medical practice and percentage of patients they diagnose

Table 3. Path coefficients for each independent TPB construct, in relation to intention to diagnose early.

	Original Sample	Sample Mean	Standard Deviation	t	p-value
Attitudes → Intention	0.123	0.133	0.103	1.191	0.234
PCB → Intention	0.378	0.372	0.091	4.133	<.001
Subjective Norms → Intention	0.293	0.304	0.106	2.771	0.006

Control belief 2, "I feel I have enough knowledge of sources of support for the patient", did not yield statistically significant correlation with age, sex, specialty, years in practice, years of education, or number of hours worked. However, it did show a positive, statistically significant correlation with number of hours PCPs spent in ADRD CME training in the previous 3 years (r = 0.267, p = 0.008).

In Subjective Norm, the normative belief that "[o]ther primary care physicians think I should not/ should perform an early diagnosis of AD to my patients", was only statistically significant by specialty; family practitioners believed more strongly than general practitioners (mean diff=-1.491, t=-2.686, p=0.009), or internal medicine specialists (mean diff. = -1.173, t =-2.099, p = 0.043), that other PCPs think they should perform an early diagnosis of AD. None of the behavioral beliefs in the Attitudes construct were significantly correlated to sociodemographic variables.

Discussion

Our core objective was to determine if PCPs' salient beliefs of each in the three theoretical constructs of the TBP framework influenced PCPs' decision-making to diagnose ADRD early, and we found that they do. Our findings suggest that, given their beliefs, 35% of our PCP sample intends to diagnose ADRD at an early stage of disease. Results from our study could help design medical training interventions for PCPs to improve clinical behaviors.

Contrary to our hypothesis, the most relevant predictor of Puerto Rican PCPs' intention to diagnose ADRD early was the *Perceived Behavioral Control (PBC)* construct. Existing literature on PBC suggests all medical graduates have enough training upon graduation to perform a diagnosis of ADRD, and that they search for information on the Internet and other sources (35). Yet, PCPs in the literature perceive themselves as not having sufficient knowledge or expertise to formulate a correct diagnosis of ADRD in the early stages. PCPs also cited their lack of knowledge about ADRD as one of the main reasons to refer or delay diagnosis; compared to specialists, PCPs seem to have more difficulty detecting ADRD or mild cognitive impairment than specialists (20), resulting in patient referral (9, 36). However, as more confidence is generated, PCPs will tend to refer less and evaluate more (37).

Our sample was consistent with this literature: despite having received ADRD training, lack of confidence in their skills to correctly diagnose, is their number 1 reason to not diagnose early. Notably, many PCPs also cannot even assist their patient in assessing other sources of support. On the other hand, our findings are further sustained when correlating sociodemographic variables: a higher number of hours the PCP spends in ADRD management training is associated with a greater likelihood that the PCP will perform a diagnosis. Female PCPs seem to

be especially vulnerable to ADRD training, as there seems to be a significant difference in disclosure practices between men and women. This is an issue never accounted for in the literature.

The role of actual control

We examined only intrapersonal factors that influence PCPs' behaviors in this study, as these can be modified via educational interventions. Even when our model explained 35% of the variance, anecdotal data from our paper-based participants suggested other external factors may also play a role in PCPs' hesitancy to diagnose ADRD early. Two of those were 1) the guidelines and policies of medical insurance companies regarding cost-effective diagnosis, and 2) the high cost of the medical tests involved (i.e., blood-based biomarkers, MRIs, PET Scans, etc.). One PCP noted that, if doctors feel they are being punished for doing what is right for the patient's well-being, they may have to make a choice about whether to incur in the expense or not do the diagnosis and refer the patient.

Strengths and Limitations

Our study has several strengths and limitations. Due to the relatively small size of our sample and limited participation rate, results may not be generalizable. PCP response rate was very low, given the number of attempts we made to obtain participation. This may be due in part to the questionnaire length, administered in an already difficult to recruit sample. The study also relied on self-report, associated with social desirability bias. We identified that weakly loading items in the Attitudes construct were aimed at obtaining a social judgment from PCPs; thus, these questions yielded extremely low mean values. Lastly, one major critique of the TPB framework has been the fact that intention does not necessarily translate into behavior modification (38). The process of diagnosing the patient is not a one-time event, and the decision to perform the diagnosis of ADRD may be conditioned by several factors, such as time, circumstances of the disease, patient resources, and even office-related settings (39).

Our study also has several strengths. To our knowledge, this is the first study to assess the beliefs and behaviors of PCPs in Puerto Rico about ADRD, and is also one of the first studies to apply the TPB framework to assess beliefs and behaviors on early diagnosis of ADRD. Sample size compares well to other studies in a population that is known to be especially difficult to capture, and a robust statistical method for this sample size was applied (32). Implications for Public health

Based on the results of our study, we suggest the following recommendations to reduce diagnostic hesitancy among PCPs:

- PCPs would benefit from learning experiences about attitudes and practices of physicians regarding AD, and dispel myths about the disease.
- Training in human behavior, community medicine, and social aspects of patient care, could help medical students and medical residence trainees understand the day-to-day complexities and reality of the ADRD patient and caregivers. Such training could include information on support and care programs for integration of PCPs into the multidisciplinary care of the patient.
- Data on screening/diagnosing practices of PCPs could be provided to patient advocacy groups to support their active roles in addressing negative beliefs of health care providers.

In sum, our results show regular and consistent training time on ADRD screening/diagnosing practices, plus information that dispels myths and reduces stigma about dementia, may be most effective to instill among PCPs a sense of mastery to screen and effectively diagnose ADRD at an earlier stage and move them towards early diagnosis. Any policies implemented to promote educational programs among PCPs on ADRD clinical practices should be geared towards adequate use and of screening tools, and management of screening results.

Resumen

Objetivos: La migración de médicos en Puerto Rico dificulta el obtener cuidado especializado para Alzheimer y demencias relacionadas (ADRD). Los médicos primarios (PCP) pueden llenar ese espacio, pero la información es limitada sobre cómo sus creencias y comportamiento hacia el ADRD afectan sus prácticas de diagnóstico temprano. Utilizando la Teoría del Comportamiento Planificado, (TPB) examinamos las creencias salientes de los PCP que afectan su intención de diagnosticar tempranamente el ADRD, definido como "realizar las pruebas clínicas recomendadas para diagnosticar ADRD dentro de 3 meses desde la primera queja subjetiva del paciente sobre memoria". Métodos: Este estudio transversal incluyó 103 PCPs puertorriqueños, encuestados en actividades de educación continua y en línea. Se midieron las creencias salientes sobre actitudes, la presión sentida de otros, auto-percepción de capacidad para diagnosticar el ADRD temprano, y su intención de hacer el diagnóstico temprano. Las medidas del cuestionario fueron psicométricamente aceptables. Resultados: Modelaje de ecuaciones estructurales (PLS-SEM) demostró que, combinados, los constructos del modelo TPB explicaron el 35.7% de la varianza, lo cual reflejó una intención moderada a fuerte de los PCP de hacer un diagnóstico temprano. ($R^2 =$ 0.357, p < 0.001). La auto-percepción de destrezas fue el mejor predictor de su intención ($\beta = 0.378$, p < 0.001). Las horas de entrenamiento en ADRD y años de experiencia en la práctica médica estuvieron fuertemente correlacionados con el porciento total de diagnósticos realizados por los PCP. Conclusión: El entrenamiento y los años de experiencia pueden ser clave para que los PCPs tengan una visión positiva de sus destrezas para diagnosticar el ADRD tempranamente. Los hallazgos podrían ser útiles para diseñar intervenciones que repelan los mitos sobre el ADRD, reduzcan el estigma y reduzcan la resistencia de los PCP al diagnóstico temprano.

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